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Celiac Disease in Children and YouTube: Do the Videos Contain Accurate Information?

Abdulkerim Elmas, Mustafa Akcam

Division of Pediatric Gastroenterology, Department of Pediatrics, Hepatology and Nutrition, Süleyman Demirel University School of Medicine, Isparta, Türkiye

What is already known?

- *Today, the internet and social media have replaced the books used in the past to access information. YouTube, the world's most popular video application, is a social media platform that users frequently use to obtain information. However, the accuracy and reliability of the information shared are debated. In many studies, the reliability of health-related information on YouTube has been found to be low.*

What this study adds?

- *Our study is unique in that it shows how much reliable information parents researching their children's illnesses can find on social media platforms such as YouTube.*

ABSTRACT

Objective: Celiac disease (CD) is a gluten-associated enteropathy whose incidence has been increasing in recent years. Parents whose children are diagnosed with CD search for information about the disease via the internet. YouTube is one of the most frequently used platforms to access information due to the number of users and ease of access.

This study aims to investigate how much quality and reliable information the most frequently viewed videos contain for families seeking information about celiac disease in children via YouTube.

Materials and Methods: On November 13, 2023, a global search for "Celiac in Children" was conducted on YouTube. The first 150 videos were evaluated using the most frequently watched video filter, and 86 eligible videos were included in the study. *Journal of the American Medical Association* (*JAMA*), Global Quality Scale (GQS), and modified DISCERN (ModDISCERN) scoring were performed for quality and reliability of the videos.

Results: Thirty-five of the videos (40.7%) were related to childhood CD. When analyzed according to the upload source, 67 (77.9%) were created by healthcare professionals (doctors, nurses, dietitians, etc.) and 19 (22.1%) by independent users. Of all videos, 62% were of very poor and poor quality (1 and 2 points). Videos created by healthcare professionals had higher *JAMA* scores, GQS scores, and ModDISCERN scores (P = < .001/P =< .001/P =< .001/P =< .001/P =< .001, respectively).

Conclusion: The quality and reliability of the most frequently watched YouTube videos about CD in children were generally low. At this point, analyzing videos on medical topics by experts and adding them to the search algorithm according to the scores will help users access reliable information.

Keywords:: Celiac disease, children, online education, online videos, social media, YouTube

INTRODUCTION

Celiac disease (CD) is a systemic, immune-mediated disease associated with gluten consumption that can also affect extra-intestinal organs. The disease is triggered by gluten intake in individuals with a genetic predisposition.[1] A gluten-free diet should be continued for life. Intestinal damage normalizes as long as the diet is adhered to.

The prevalence of the disease has been increasing in recent years. In addition to new diagnostic methods and easier access to health care, increased health literacy is an important factor. Individuals receive information and awareness about the findings and the disease through the internet and social media.[2,3]

Corresponding author:
Abdulkerim Elmas
✉ akelmas@gmail.com
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Today, YouTube ranks first among popular online video sources, with over 2 billion users and over 1 billion hours of video views daily.[4] Especially during the pandemic period we have experienced, individuals have increasingly used YouTube to get information about their symptoms and diseases.[5,6] However, there are no guidelines to check the reliability of the information provided on YouTube, which is used as a source of information. Medical videos are sometimes used to advertise hospitals, physicians, and medicines.

YouTube's algorithm is designed based on popularity, relevance, and view history rather than quality of content.[7] A study found that 25% of the most-watched YouTube videos on COVID-19 contained misleading information.[8] Videos need to improve in expert evaluation, content, language, and topics. For this reason, the accuracy, quality, and content of the information presented must be evaluated by experts in the field.[4,9] To the best of our knowledge, there are no studies on YouTube content evaluation of CD in children. With this study, we aimed to evaluate the quality and reliability of the content of "Celiac Disease in Children" informational videos on YouTube by experts in the field.

MATERIALS AND METHODS

Search

A cross-sectional analysis was conducted on November 13, 2023, reviewing the first 150 relevant YouTube videos with the search terms "Celiac in children." The search was carried out with the "most viewed" criteria. The most viewed filter was developed to examine videos with a larger audience. The first 150 videos were evaluated according to the results suggested by the YouTube algorithm (Figure 1). The first 150 videos were saved as a list to avoid being affected by YouTube's algorithm changes. After excluding those deemed unsuitable for the study, the videos were scored by 2 Pediatric Gastroenterology experts (authors of the article) according to the scoring systems specified.

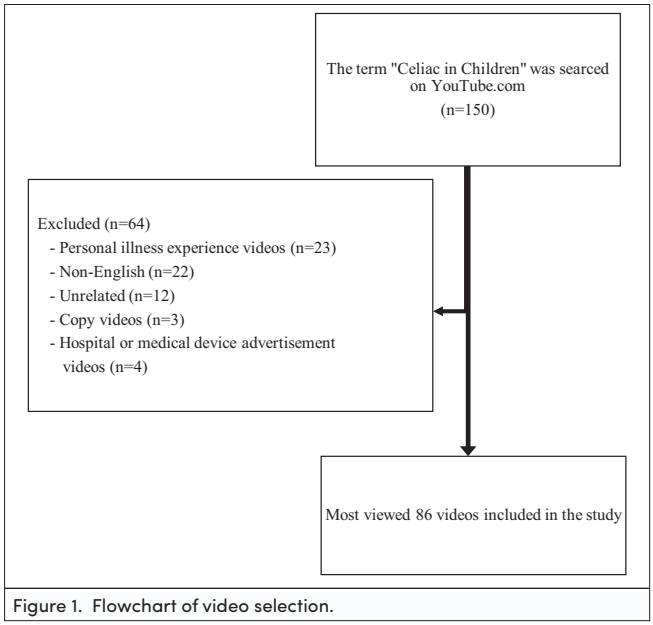

Figure 1. Flowchart of video selection.

Video Selection

Non-English videos, hospital and medical device advertising videos, copied videos, videos describing personal illness experiences, unrelated videos, and videos with only audio and no information were excluded from the study (Figure 1). Different videos uploaded from the same source were considered separate videos. Videos included the following information: URL, channel name, views, target audience, length of video (seconds), number of likes, time elapsed since upload (days), view rate (number of views divided by the number of days since upload), number of comments, and daily comment rate (number of comments divided by the number of days since upload).

Video Sources

As indicated in the description and video content of the "About" section of the channel, the videos were classified into 2 categories based on their source: independent users and healthcare professionals (such as doctors, nutritionists, biologists, and pharmacists).[10,11]

Video Reliability and Content Quality

We employed a video engagement index (VEI) along with 3 industry-standard scales for content evaluation to assess the videos.[4] The videos featured the patient's perspective and asked the following questions: what is CD, how does it show up in kids, how is a diagnosis made, and what considerations need to be made while utilizing diet therapy?

For video reliability, the 4-criteria *Journal of American Medical Association* (*JAMA*) criteria were applied. The following components receive 1 point each from the *JAMA* score: authorship (author and contributor credentials and their affiliations should be provided), attribution (all copyright information should be clearly listed, and references and sources for content should be stated), currency (initial date of posted content and subsequent updates to content should be provided), and disclosures (conflicts of interest, funding, sponsorship, advertising, support, and video ownership should be fully disclosed). The *Journal of American Medical Association* criteria is a binary (yes or no) rating table, on a scale from 0 (poor reliability) to 4 (highest level of reliability).[12,13]

The video's instructional content was evaluated using the Global Quality Scale (GQS).[14,15] Global Quality Scale criteria were utilized to assess the richness and validity of video information. These scores range from 1 (poor quality) to 5 (excellent flow and quality).

The videos were examined for dependability and quality using the Modified DISCERN (modDISCERN) score.[16,17] Five questions ("Are aims clear and achieved?", "Are reliable sources of information used?", "Is the information provided balanced and unbiased?", "Are additional sources of information listed for patient reference?", "Are any areas of uncertainty/controversy mentioned?") make up the modDISCERN score; each question has a yes (1 score)/no (0 score) response option.

Higher scores, as in earlier publications, correspond to increased reliability. In addition, a simple formula, which is not available in the literature, was applied to calculate how much interaction (number of views, likes, and comments) the videos received from the community since the day they were

uploaded. Accordingly, the VEI was calculated using the formula: number of views+number of comments+number of likes / number of days since upload. The average of the ratings provided by 2 authors for each video was used to determine the video's GQS, *JAMA*, and modDISCERN scores.

Statistical Analysis

Statistical analysis was performed using SPSS, version 27.0 for Windows (IBM Corp.; Armonk, NY, USA). Descriptive data were presented as frequency, percentage, and median (25th-75th percentiles and min-max) values. For the intergroup analysis, the arithmetic mean of the scores assigned by the authors was used. Additionally, correlations between individual scores were evaluated.

The chi-square test was used to compare the frequency of categorical variables between different groups. Kolmogorov–Smirnov and Shapiro–Wilk tests were used to assess the normality of the quantitative data. The Mann–Whitney *U* test for non-normally distributed data was used to compare 2 groups. The Spearman correlation coefficients were as follows: low (rho: < 0.40), moderate (rho: 0.40-0.59), and high (rho: > 0.60). Intraclass correlation analysis was used to examine agreement between pediatric gastroenterology experts. A probability (*P*) less than .05 was considered significant for all tests.

RESULTS

Of the 150 videos pre-screened, 64 were deemed unsuitable for the study. The study was completed with 86 videos. A flowchart of the video selection process is provided in Figure 1. The total duration of the included videos was 1067.35 minutes, and the total number of views was 6 087 624. Thirty-five videos (40.7%) were related to childhood CD. The remaining videos pertained to CD and were deemed to be of interest to the general patient population. However, they did not meet the exclusion criteria in terms of content. The median video duration was 355 seconds (142-690). When analyzed according to the upload source, 67 (77.9%) were prepared by healthcare professionals (physicians, nurses, dietitians, etc.) and 19 (22.1%) by independent users. When the videos were analyzed according to their topics, 74 (86%), 6 (7%), 3 (3.5%), and 3 (3.5%) were found to be about the disease in its totality, only about diet, only about treatment, and only about diagnosis, respectively. The characteristics of the videos are presented in Table 1.

The videos were divided into 2 categories: videos produced by healthcare professionals and videos produced by independent users (Table 2). Thirty (44.8%) of the healthcare professionals' videos and 5 (26.3%) of the independent user-generated videos were especially related to children. The number of views and likes was significantly lower for the videos from healthcare professionals (*P* = .009 and *P* = .016, respectively). However, the VEI score, *JAMA* score, GQS score, and ModDISCERN score were significantly higher (*P* = .03/*P* =< .001/*P* =< .001/*P* =< .001/*P* =< .001, respectively). No significant difference was found in video duration and number of comments. The videos prepared by health professionals provide a comprehensive examination of the disease, encompassing all relevant aspects. In contrast, the videos prepared by independent users tend to focus on specific aspects such as diet or diagnosis. Upon analysis of the video topics, a statistically significant difference was identified (*P* = .038).

Table 1. Characteristics of YouTube Videos Related to the Search "Celiac in Children"

	Total (n = 86)
Videos about CD in children	35 (40.7)
Video duration (s)	355 (142-690) (38-5282)
Number of views	12,855 (4325-42 818) (1559-986 561)
Likes	214 (36-804) (1-20 000)
Comments	12 (1-56) (1-2821)
Time elapsed since the video (d)	1640 (952-3025) (32-5258)
VEI score	10.57 (1.8-55.1)
Video source; n (%) Healthcare professionals Independent users	 67 (77.9) 19 (22.1)
Video topic; n (%) The disease in its totality Only about diet Only about treatment Only about diagnosis	 74 (86) 6 (7) 3 (3.5) 3 (3.5)

Categorical data are presented as n (%). Continuous data are presented as median (25th-75th percentiles), including (minimum–maximum) for some.

A correlation analysis was performed between video characteristics (Table 3). A strong correlation was found between *JAMA* and DISCERN (rho = 0.758, *P* < .001), *JAMA* and GQS (rho = 0.666, *P* < .001), and modDISCERN and GQS (rho = 0.733, *P* < .001).

Additionally, positive significant correlations were observed between views and likes (rho = 0.889, *P* < .001), views and VEI score (rho = 0.878, *P* < .001), and likes and VEI score (rho = 0.906, *P* < .001). When examining the correlation between VEI score and video quality scores, only VEI and GQS scores showed a statistically significant positive correlation (rho = 0.215, *P* = .047). Interestingly, video duration was positively correlated with *JAMA*, GQS, and modDISCERN scores (rho = 0.295, *P* = .006; rho = 0.514, *P* < .001; rho = 0.388, *P* < .001, respectively).

Finally, the intraclass correlation analysis (ICC) performed for JAMA, GQS, and modDISCERN scores demonstrated a high level of agreement among the experts (ICC = 0.92, *P* < .001; ICC = 0.77, *P* < .001; ICC = 0.85, *P* < .001).

The scores of the scoring systems (*JAMA*, GQS, and ModDISCERN) based on video sources are presented in Figure 2. Accordingly, 62% of the videos were of very poor and poor quality (1 and 2 points), while 15.2% of the videos were of good and excellent quality (4 and 5 points).

DISCUSSION

To the best of our knowledge, this is the first study to evaluate videos about CD in children on YouTube. In today's world of increasing health literacy and access to information, parents increasingly use the internet to learn about their children's symptoms and diseases. YouTube is one of the most popular open-access video sites, with more than 100 million views per

Table 2. Characteristics and Scores of YouTube Videos by Video Source

	Healthcare Professionals (n = 67)	Independent Users (n = 19)	*P*
Videos about CD in children; n (%)	30 (44.8)	5 (26.3)	.148**
Video duration (s)	382 (158-758)	254 (98-519)	.082
Number of views	8040 (3888-28,095)	31,194 (9533-55,338)	**.009**
Likes	121 (29-552)	472 (225-1900)	**.016**
Comments	11 (1-55)	33 (1-138)	.435
Time elapsed since the video (d)	1640 (977-3305)	1471 (811-2240)	.281
VEI score	6.7 (1.6-45.8)	30.7 (9.2-104.04)	**.03**
Video topic:			**.038****
The disease in its totality	60 (89.6)	14 (73.7)	
Only about diet	2 (3)	4 (21.1)	
Only about treatment	2 (3)	1 (5.3)	
Only about diagnosis	3 (4.5)	–	
JAMA score*	2.17 (1-4)	1.21 (1-2)	**< .001**
1 and 2 points	50 (74)	19 (100)	
3 points	12 (17)	–	
4 points	5 (7)	–	
GQS*	3.13 (1-5)	1.89 (1-4)	**< .001**
1 and 2 points	17 (26)	15 (79)	
3 points	25 (37)	3 (16)	
4 and 5 points	25 (37)	1 (5)	
ModDISCERN score*	2.41 (1-5)	1.36 (1-3)	**< .001**
1 and 2 points	42 (63)	17 (89)	
3 points	17 (25)	2 (11)	
4 and 5 points	8 (12)	–	

Values in bold indicate statistical significance. Categorical data are presented as n (%). Continuous data are presented as median (25th-75th percentiles).
*Scoring systems with asymmetric distribution are presented with mean (min-max). Mann–Whitney *U* test was used.
**Chi-square test was used.

day.[16,18] At this point, videos whose content is unreliable and not prepared by health professionals delay the diagnosis of the disease, sometimes causing unnecessary anxiety and inappropriate demands from families.[19,20]

Studies evaluating the quality and reliability of health-related videos on YouTube were analyzed. It was observed that these studies were conducted in the adult age group. In our study, only 35 (40.7%) of the 86 videos analyzed were related to CD in children. The remaining videos addressed features of the disease across all age groups, as well as topics related to diet, diagnosis, and treatment.

JAMA, GQS, and DISCERN are widely used scoring systems for evaluating the quality and reliability of video content. Studies conducted using these scoring systems are generally focused on adults. In a study on insulin resistance in adults, the same scoring systems were used and the video content was found to be 54% very poor and poor, and 11% good and excellent.[14] In our study, overall, 62% of the videos were evaluated as very poor or poor quality, while 15.2% were evaluated as good or excellent quality. The videos in our study were analyzed by dividing them into 2 groups based on their sources. It was observed that the quality scores of the videos prepared by healthcare professionals were higher. Similar to our findings, previous studies have also shown that videos prepared by doctors or hospital accounts had better quality scores.[10,21-24] More research is needed to identify common features to be used in evaluating the quality of health-related videos. Identifying these characteristics and scoring videos according to these criteria will help users access quality and reliable content.

The number of views and likes of videos produced by healthcare professionals was significantly lower; however, their reliability and content scores were higher. These results were consistent with other studies evaluating patient information videos on YouTube.[9,23,21,25] The videos prepared by health professionals provided comprehensive coverage of the subject matter, and this approach was found to be statistically significant.

In this study, no significant relationship was found between video popularity (VEI score) and higher quality scores, except for the statistically significant positive correlation between VEI and GQS scores. This result is consistent with previous studies.[2,4,22,26]

A meta-analysis of 202 publications on the same subject was published in 2022.[4] The study found that YouTube is an unreliable source of health and medical information, and it was recommended that the number of views or likes on a video should not be used to determine its quality. In this study, similar to previous studies, a positive significant correlation was found between video duration and quality scores.[14,27] Videos with longer durations may be more reliable in terms of content and quality. It was recommended that YouTube change its recommendation and ranking algorithm to provide quality content, provide expert moderation for medical and health-related content, and add the moderation score to the ranking algorithm.

In our study, we found that videos produced by healthcare professionals were mostly about children and had longer video durations. However, the number of views and likes was

Table 3. Correlation Table

		Views	Duration	Likes	Time Since Video Upload	Comments	VEI Score	JAMA	GQS	modDISCERN
Views	Spearman's rho *P*	– –								
Duration	Spearman's rho *P*	0.209 .053	– –							
Likes	Spearman's rho *P*	0.889** **< .001**	0.441* **< .001**	– –						
Time since video upload	Spearman's rho *P*	−0.220 **.042**	−0.504 **< .001**	−0.452 **< .001**	– –					
Comments	Spearman's rho *P*	0.519* **< .001**	0.388 **< .001**	0.607** **< .001**	−0.447 **< .001**	– –				
VEI score	Spearman's rho *P*	0.878** **< .001**	0.385 **< .001**	0.906** **< .001**	−0.613 **< .001**	0.603** **< .001**	– –			
JAMA	Spearman's rho *P*	−0.140 .200	0.295 **.006**	−0.088 .419	−0.078 .474	−0.014 .895	−0.095 .386	– –		
GQS	Spearman's rho *P*	0.201 .064	0.514* **< .001**	0.243 **.024**	−0.117 .283	0.148 .173	0.215 **.047**	0.666** **< .001**	– –	
modDISCERN	Spearman's rho *P*	0.014 .897	0.388 < .001	0.042 .700	−0.092 .399	0.081 .460	0.056 .607	0.758** < .001	0.733** < .001	– –

Values in bols indicate statistical significance. The Spearman test was used.
*rho 0.40-0.59.
**rho > 0.60.
GQS, Global Quality Scale; JAMA, Journal of the American Medical Association benchmarks criteria; VEI, Video Engagement Index.

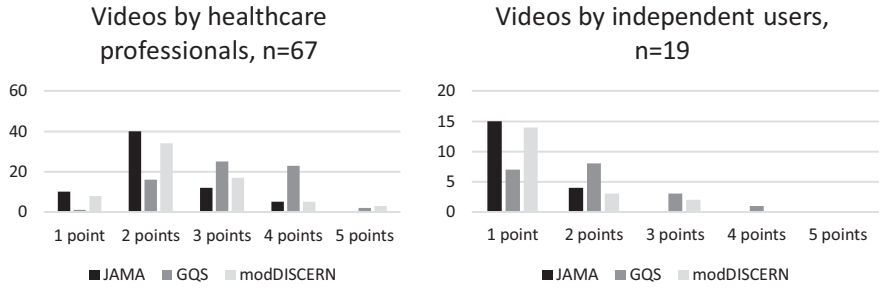

Figure 2. Results of scoring systems by video source.

significantly lower. At this point, we think that the YouTube algorithm emphasizes shorter videos in search suggestions. We believe the shorter duration of videos prepared by healthcare professionals is necessary to deliver the correct information to more users.

Our study has some limitations. Since there is not yet a proven method for scoring videos, the evaluation may be limited. Our study was limited because the search was conducted worldwide and only English-language videos were included. In addition, health websites and other videos posted on these websites were not analyzed. Users may not use the "search by viewing frequency" filter when searching on YouTube. Each user may encounter different videos the algorithm suggests according to their interest level. Therefore, this cross-sectional study cannot be generalized to all users.

CONCLUSION

The quality and reliability of YouTube videos on celiac in children varied according to the source of the video but were generally found to be low. At this point, we recommend videos prepared by health professionals to access reliable and up-to-date information. In addition, we believe that designing health-related videos according to established criteria before they are uploaded to YouTube will increase content quality and reliability. YouTube should consider the evaluations made by experts on videos uploaded on health-related and specialized topics and adjust its ranking algorithm accordingly.

When obtaining health information online, users should pay attention not to the number of views and likes, but to the source and reference of the video, the credentials of the creators, and details such as sponsorship and advertising features.

Availability of Data and Materials: The data that support the findings of this study are available on request from the corresponding author.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept – A.E., M.A.; Design – A.E., M.A.; Supervision – A.E., M.A.; Resources – A.E., M.A.; Materials – A.E., M.A.; Data Collection and/or Processing – A.E., M.A.; Analysis and/or Interpretation – A.E., M.A.; Literature Search – A.E., M.A.; Writing – A.E., M.A.; Critical Review – A.E., M.A.

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