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Online video resources pertaining to cerebral palsy: A YouTube-based quality control study

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Abstract

Aim: To assess the content and quality of YouTube videos related to cerebral palsy to provide insights into the online video resources available for individuals affected by cerebral palsy and suggest strategies for improvement.

Methods: YouTube videos were analyzed based on interaction parameters, content characteristics/category, and video source. Video reliability and quality were assessed using the Journal of American Medical Association benchmark, Global Quality Scale, and cerebral palsy-specific score. Statistical analyses examined associations between video characteristics and reliability/quality scores.

Results: The average video ($n = 48$) length was 6.8 min, with 29 informational and 19 experiential videos. The mean Journal of American Medical Association score was 2.0, indicating moderate reliability. The Global Quality Scale suggested good quality content (average: 3.5), but only 14% were rated as good via cerebral palsy-specific score. Higher views were associated with higher Journal of American Medical Association score and cerebral palsy-specific score ($p = 0.002$ and $p = 0.006$), and nonphysician medical expert videos had lower Journal of American Medical Association scores than academic videos ($p = 0.042$). Video content was not significantly associated with either score.

Conclusion: YouTube provides moderate to good quality information on cerebral palsy. Critical evaluation of video sources and content is essential. Findings can guide strategies to enhance the quality of cerebral palsy-related YouTube content, benefiting individuals with cerebral palsy, health care providers, and caregivers.

Keywords: Cerebral palsy, YouTube, resources, patient education

Introduction

Cerebral palsy (CP) is a neurological disorder that affects movement and posture, resulting in a wide range of physical and cognitive impairments. This lifelong condition affects both children and adults and has an estimated prevalence of 2.1–2.5 per 1000 live births, according to the Centers for Disease Control and Prevention.[1,2] CP can significantly impact an individual's physical, cognitive, and social development and is a common cause of physical disability in children.

One of the significant challenges for those affected by CP and their families is accessing accurate and up-to-date information about the disorder. Traditional sources of information, like health care providers, may not always be readily available or provide the level of detail and support that patients and families need.[3] Prior studies show that 74% of all US adults use the Internet, with 61% having searched for medical or health-related information on the Internet.[4,5] Social media has also become an alternative source of information and support for

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individuals with CP and their families.[6,7] CP manifests in various forms, and the appropriate care plan varies among patients. Consequently, caregivers may find value in viewing videos featuring individuals with CP or informative content about the condition.[8,9]

YouTube has become a popular platform for disseminating health-related information, with patients and families turning to Internet-based sources to seek information and support.[10] However, the quality of videos on this platform pertaining to CP needs to be adequately assessed, and it is essential to understand the ways in which YouTube is used by those with CP and their families.

This study aims to explore the content and quality of YouTube videos related to CP and to assess the reliability and quality of information presented in these videos, based on the video source. The results of this study will provide essential insights into the quality of online video resources available to those affected by CP and will inform future efforts to improve the accessibility and quality of such resources.

Methods

The study was conducted between October and November 2022 by two independent examiners who queried YouTube using the keyword "Cerebral Palsy." The first 100 videos were evaluated for eligibility, excluding videos not related to CP, duplicates, and videos in languages other than English. Forty-eight videos were extracted for analysis after applying the eligibility criteria. "Relevance" was the only search filter used to sort results similar to how a typical user would see them. Incognito mode was used to avoid skewed results from the search algorithm within YouTube's platform. In doing so, location, watch history, and demographics did not influence the queried results.[10]

The extracted videos were categorized based on interaction parameters and content characteristics: video title, duration (min), number of views, days since upload, view ratio (views/day), number of likes, and number of comments. The video sources were categorized into seven different groups. These categories encompassed: academic sources, which involved uploads associated with research groups or universities; physician sources, including independent physicians not directly affiliated with research or university groups; nonphysician medical providers like physical therapists; medical sources, which encompassed animations or content from health education websites; and patient experiences. In addition, the content was further sorted into five distinct categories: (1) pathophysiology, (2) surgical/nonsurgical management, (3) types of CP, (4) patient experience, and (5) advertisement. Each video was classified into source and category type by two co-authors. Video analysis was also performed by a combination of two co-authors using three separate scoring systems, and their scores were averaged. The scoring systems that were chosen have been used in similar, prior studies to evaluate for reliability and quality of videos.[8,11,12,13]

Video reliability and quality

The evaluation of video reliability involved applying the *Journal of American Medical Association* (JAMA) benchmark criteria, as outlined in Table 1. This evaluation assessed whether the videos met specific criteria related to authorship, attribution, currency, and disclosure. Each criterion was rated on a binary scale, with a maximum score of 4 indicating highly reliable information. In addition, two other scoring systems were employed to gauge video quality.

The Global Quality Scale (GQS), presented in Table 2, is a widely used 5-point rating system designed to assess the general educational value of the content. A score of 5 represents high-quality content, while a score of 1 indicates poor quality.

For a more targeted assessment of informational content about CP, a "cerebral palsy-specific score" (CPSS) was devised. This CPSS consisted of eight items, as described in Table 3, and was used to evaluate the presence of specific information in the videos. Each item presented in the video contributed one point, with a maximum possible score of 8. A higher score indicated a better educational quality regarding CP from a clinical perspective. A score of 6 or higher signified that the video content offered a comprehensive and valuable educational resource on CP. A score of 4–5 suggested that the video contained some educational value but might lack important information, while a score of 3 or lower indicated that the video might not be very informative from a clinical perspective. This approach was adapted from other specific scores, like the

Table 1. JAMA criteria.

Authorship	Authors and contributors, their affiliations, and relevant credentials should be provided.
Attribution	References and sources for all content should be listed clearly, and all relevant copyright information noted.
Disclosure	Web site "ownership" should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or 16 support, or potential conflicts of interest. This includes arrangements in which links to other sites are posted because of financial considerations. Similar standards should hold in discussion forums.
Currency	Dates that content was posted and updated should be indicated.

Table 2. GQS criteria.

Score	Global score description
1	Poor quality, poor flow of the site, most information missing, not at all useful for patients
2	Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients
3	Moderate quality, suboptimal flow, some important information is adequately discussed but others poorly discussed, somewhat useful for patients
4	Good quality and generally good flow, most of the relevant information is listed, but some topics not covered, useful for patients
5	Excellent quality and excellent flow, very useful for patients

Table 3. CPSS criteria.

1	Overview the pathophysiology of CP
2	Explain the potential causes or risk factors for CP, including prenatal, perinatal, and postnatal factors
3	Discuss the different types of CP
4	Describe the clinical presentation of CP
5	Explain any associated illnesses or co-morbidities that can occur with CP
6	Detail the nonoperative and/or operative management of CP (i.e. strategies for improving mobility, communication, and daily living skills)
7	Provide information on the long-term outlook for individuals with CP (i.e. potential complications and health concerns)
8	Discuss the role of caregivers and family members in the care and management of individuals with CP?

CP: cerebral palsy.

modified meniscus-specific score (MSS) employed by Kunze et al.,[11] which has been demonstrated to be effective in various quality control studies in the literature.[14,12]

To ensure consistency, each video was evaluated by two out of five raters (NT, RG, JM, RC, and SR) using both the JAMA benchmark and CPSS tools. Subsequently, the intraclass correlation coefficient (ICC) was employed to measure the reliability of the assessments. The scores from the two raters were averaged, and no significant differences were observed between them. ICC estimates, along with their 95% confidence intervals, were calculated using SPSS version 27. An ICC value below 0.50 is considered poor, while 0.50–0.75 indicates moderate reliability, 0.75–0.90 reflects good reliability, and an ICC greater than 0.90 is regarded as excellent.

Statistical analysis

The collected data were analyzed using descriptive statistics to summarize the video's reliability, quality scores, and characteristics. To evaluate the difference in video quality and reliability based on video content and source, one-way analysis of variance tests was used for normally distributed data, and Kruskal–Wallis tests were used for non-normally distributed data. The influence of specific video characteristics on video quality and reliability was determined through multivariate linear regression analyses. All statistical tests were performed using SPSS V26.0 (IBM Corporation, Armonk, NY), and a p value of less than 0.05 was considered to indicate statistical significance.

Results

Of the 48 videos that met the inclusion criteria and were analyzed, the average video length was 6.8 ($\pm$7.2) min with 29 classified as informational and 19 as experiential videos. In total, 13 of the 29 informative videos (45%) provided information about the pathophysiology. Of these videos, most sources were nonphysician (as shown in Table 4). The comments on the videos were predominantly supportive, with viewers expressing gratitude for the information and encouragement provided by the videos. Several viewers also commented on their own experiences and offered support to others with CP. Interaction parameters and content characteristics are outlined in Table 5.

The average CPSS, JAMA score, and GQS score were determined only for informational videos. The mean JAMA score was 2.0 $\pm$ 1.1, indicating moderate reliability. The quality of the content was deemed to be good via GQS with an average of 3.5 $\pm$ 1.3; however, only 14% of the videos were rated as good ($\geq$6) based on the CP-directed CPSS scale.

Multivariable regression models were created for individual analysis, aiming to assess the influence of video content, video attributes, and the source of video uploads on both JAMA score and CPSS. In these models, negative predictors signified a decrease in the score, while positive predictors indicated an increase in the score, in relation to specific video characteristics or types. A higher number of views was associated with higher JAMA scores ($\beta = 0.02$ per 10,000 views, $p = 0.002$) and CPSS ($\beta = 0.03$ per 10,000 views, $p = 0.006$). Video duration was not associated with either score. Videos by nonphysician medical

Table 4. Descriptive statistics.

Variable	*N*	%
Type		
Informational	29	60
Experiential	19	40
Content		
Pathology/Pathophysiology	13	27
Operative/Nonoperative management	7	15
Types	5	10
Patient experience	16	33
Advertisement	7	15
Source		
Academic	7	15
Physician	3	6
Nonphysician	11	23
Medical source	9	19
Patient experience	18	38

Table 5. Interaction parameters and content characteristics.

Variable	Mean	*SD*	Range
Views	353,435.8	1,708,228.2	2520–11.8 m
Likes	5457.7	27,309.2	6–184,904
Comments	838.5	4893.2	0–32,492
Video length (min)	6.8	7.2	0.6–78.6
JAMA	2	1.1	0.5–4
GQS	3.5	1.3	1–5
CPSS	3.1	2.2	0–7

SD: standard deviation; JAMA: Journal of American Medical Association; GQS: Global Quality Scale; CPSS: cerebral palsy-specific score.

experts were associated with lower JAMA scores than videos from academic institutions ($\beta = -1.06$, $p = 0.042$; $\beta = -1.69$, $p = 0.011$). Adjusting for all other factors, video content was not significantly associated with either score (Table 6).

The experiential videos varied in their findings and motives, with most of them being inspirational in nature. Many of these videos contained a firsthand perspective of someone affected with CP. Common themes included the struggles these individuals faced and their positive experiences and impressive accomplishments. Other videos discussed overcoming obstacles and how these individuals are now helping others do the same. Some of the videos were experiential from the perspective of the caregiver.

Discussion

The use of social media platforms like YouTube to access health-related content is becoming increasingly common. However, insufficiencies remain for information about content characteristics on CP and other childhood disabilities. Our study evaluated the overall quality of YouTube videos related to CP and found that most of these resources

Table 6. Linear regression analyses.

	Effect on JAMA				Effect on CPSS			
Variable	Estimate	Lower 95%	Upper 95%	*p*	Estimate	Lower 95%	Upper 95%	*p*
Views (×10,000)	0.02	0.01	0.04	0.002*	0.03	0.01	0.06	0.006*
Length (min)	0.02	−0.03	0.08	0.515	0.09	−0.001	0.17	0.052
Source								
Physician versus academic	−0.81	−2.16	0.54	0.227	−1.10	−3.41	1.20	0.330
Nonphysician versus academic	−1.06	−2.07	−0.04	0.042*	−1.25	−2.97	0.48	0.147
Medical source versus academic	−0.19	−1.18	0.80	0.688	−0.01	−1.70	1.67	0.990
Content								
Pathology/Pathophysiology versus advertisement	−0.54	−1.66	0.58	0.324	1.19	−0.71	3.10	0.206
Operative/Nonoperative management versus advertisement	−0.58	−1.79	0.63	0.328	0.56	−1.51	2.62	0.580
Types versus advertisement	0.02	−0.03	0.08	0.515	0.09	−0.001	0.17	0.052

JAMA: *Journal of American Medical Association*; CPSS: cerebral palsy-specific score.
*$p < 0.05$.

offer moderate to good quality information, with 60% categorized as informational and the remaining as experiential. This finding holds significant implications for patients, health care providers, and caregivers involved in the CP community, suggesting YouTube's potential as a tool for patient education and support.

In this study, higher views were associated with higher JAMA score and CPSS ($p=0.006$), identifying a correlation between videos with higher views and higher quality scores. Videos created by nonphysician medical experts had lower JAMA scores compared with videos from academic institutions ($p=0.042$). This suggests that videos from scholarly sources were generally of higher quality and provided more reliable information.

For patients with CP and their caregivers, these results demonstrate that YouTube can be a valuable source of accessible information. Most of the videos analyzed in this study were informational, indicating that users can gain insights into various aspects of the condition, including symptoms, treatment options, and research developments. In addition, several videos were experiential, allowing CP patients and their families to share personal experiences. This facilitates networking and support and provides a platform for patients to be heard, express their thoughts and feelings, and foster a sense of community among viewers. Furtado et al.[8] similarly assessed the content of CP presented in Brazilian-Portuguese YouTube Videos and found that the majority of videos similarly had moderate trustworthiness but contrarily were mostly experiential.

From a health care provider's perspective, this study reinforces the potential of integrating YouTube as an auxiliary tool in patient education strategies.[15] Videos can complement traditional patient education methods by offering visual demonstrations and real-life examples, enhancing understanding and retention. Providers can recommend curated lists of high-quality videos, utilizing the platform's popularity to disseminate accurate and comprehensive information.[16] Health care organizations or patient groups could host regular live-streamed Q&A sessions, interactive discussions, or webinars on YouTube to address common concerns and provide advice in real time.[17] Experiential videos could be highlighted in support group settings to facilitate discussion and empathy.[18]

However, it is essential to acknowledge the potential pitfalls of using YouTube as an information source. Not all content on YouTube is reliable or of high quality, and there can be significant variability in video quality.[18,13] As noted in this study, while most of the analyzed videos were of moderate to good quality, low-quality or misleading content still exists. Therefore, continual quality control studies like this one are crucial to monitor and evaluate the reliability of online video resources. In addition, video content is mainly geared for a specific type of user: someone merely seeking information about CP, patient-to-patient advice from personal experience, or suggestions for treatment from medically educated and nonmedically educated persons. Obtaining information from personnel without proper medical training is the more potentially dangerous part of YouTube-based content. Users should be encouraged to approach online information critically and discuss online resources, including YouTube, with their physician to better understand the source and accuracy of information, and how to incorporate that into the patient's care.

The following recommendations may allow patients and families to make more informed decisions when utilizing YouTube as an educational resource for CP:

1. Seek videos from reputable sources: Videos created by academic institutions were found to have higher quality scores. Therefore, it is advisable to prioritize videos from recognized medical institutions, universities, or organizations specializing in CP. These sources are more likely to provide reliable and accurate information.
2. Consider videos with higher views: The number of views significantly impacted both the JAMA score and CPSS. Videos with more views might indicate that they are more informative or have been vetted by a larger audience. However, it is important to critically evaluate the content regardless of the view count.
3. Be cautious with nonphysician medical expert videos: The study found that videos created by nonphysician medical experts had lower quality scores. While this does not mean that all videos from nonphysician experts are unreliable, it suggests that extra scrutiny should be applied. Look for videos that feature qualified health care professionals or experts with specific expertise in CP.
4. Diversify the content: While video content was not significantly associated with either quality measurement, it may be beneficial to explore videos that cover a variety of topics related to CP, including different types, causes, symptoms, treatment options, and management techniques to provide a more comprehensive understanding of the condition.
5. Be critical and engage with health care professionals: Remember that YouTube videos should not be a substitute for professional medical advice. Always consult with health care professionals, such as doctors, therapists, or support groups, to validate the information obtained from YouTube. They can provide personalized guidance and ensure that the information aligns with the patient's specific needs.
6. Use YouTube as a starting point: YouTube can be a valuable resource for gaining general awareness and understanding of CP. However, it should be complemented with information from reliable medical websites, scientific journals, and trusted health care professionals. Use YouTube as a starting point to familiarize yourself with the topic, but rely on something other than it for making important decisions about diagnosis, treatment, or management.

Limitations

When interpreting the results, it is essential to acknowledge the limitations of this study. First, the video sample was limited to the top 100 videos, which may not accurately reflect all CP-related videos on YouTube. Second, the video sample was restricted to only those in English and may not fully represent videos in other languages. Finally, the results should be considered taking into account the content analysis methodology used, which has its limitations and restrictions. Despite these limitations, YouTube plays an important role as a source of information and support for people with CP and their families and should be further considered.

Conclusion

In conclusion, our study indicates that YouTube holds promise as a valuable source of information and support for the CP community. With how easily information is accessed and distributed across the Internet, it is important for physicians to be informed on where and what information their patients may be accessing. Patients and caregivers can benefit from the diverse range of informational and experiential videos on the platform, while physicians may use this as an additional resource for patient education. Most of the videos were informational in nature and provided moderately reliable information about the condition. YouTube can be used to provide information about the causes, symptoms, and treatment of CP and to provide social support and encouragement to individuals with CP and their families. Further research is needed to verify the credible use of YouTube for CP-related content. However, as with any online resource, a mindful and critical approach is necessary to ensure that the information obtained is accurate, reliable, and beneficial for the patients. Future studies may wish to explore strategies for improving the accessibility and reliability of YouTube content on CP and other health-related topics.

Author contributions

N.D.T. is the lead author, and performed study design, data gathering, and manuscript preparation. J.M. performed data gathering, study design, and manuscript preparation. R.C. performed data gathering, study design, and manuscript preparation. S.R. performed data gathering, study design, and manuscript preparation. N.P. performed statistical analysis, data interpretation study design, and manuscript preparation. R.G. performed data gathering, study design, and manuscript preparation. N.T. performed study design, data interpretation, and manuscript preparation. R.M.T. performed study design, data interpretation, and manuscript preparation. D.S. performed study design, data interpretation, and manuscript preparation. H.C. performed study design, data interpretation, and manuscript preparation.

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Ethical statement

This study does not involve any human participants and/or animals. No Institution Review Board/Ethics committee approval required. No informed consent required as no subjects were included in the study.

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