Original Research Article

A cross-sectional study to evaluate uploader-based quality and reliability of content on YouTube about endometriosis

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ABSTRACT

Background: Endometriosis is characterized by the development and presence of endometrial glands and stroma outside of the uterine cavity. Reflux of endometrial tissue fragments, cells, and protein-rich fluid into the pelvis during menstruation is considered the most important mechanism for the development of endometriosis, which is termed reflux menstruation. This study aims to assess quality and reliability of information on YouTube related to endometriosis.
Methods: A cross-sectional observational study of YouTube videos was conducted in April 2023. Videos related to endometriosis were searched by six authors, easy using one search term. Relevant videos in English or Hindi language of duration 1-20 minutes were included in the study. These were evaluated for type of uploader, popularity, type of content and lastly quality and reliability using global quality score (GQS) and DISCERN scores respectively.
Results: The 67 relevant videos conveying Endometriosis related information had 21,620,808 views, 120,830 likes and 11,655 comments. Around 31 (46.3%) of videos uploaded were by doctors and health care organizations, outnumbering those uploaded by news channels 14 (20.9%), patients 5 (7.5%), and others 17 (25.4%). 59 (88.06%) of these videos described symptoms of endometriosis, and 67.1% presented the cause or etiology. A total of 47 (70.1%) of videos discussed information regarding treatment options.
Conclusions: YouTube videos have a wide reach among audience. In this study it was found that there was no significant difference in the quality, reliability or video power index (VPI) of videos uploaded by different types of uploaders. It is important to ensure that content with high quality and reliability is available from qualified medical professionals and organizations; for viewers to understand their disease and take treatment decisions.

Keywords: Endometriosis, Infertility, YouTube, Global quality score, Reliability score, Video power index, Fertility, Educational content online

INTRODUCTION

Endometriosis is characterized by the development and presence of endometrial glands and stroma outside of the uterine cavity. The important clinical manifestations are chronic pelvic pain and impaired fertility.[1] Reflux of endometrial tissue fragments, cells, and protein-rich fluid into the pelvis during menstruation is considered the most important mechanism for the development of endometriosis, which is termed reflux menstruation.[2] 70–90% of clinically abnormal pelvic examinations correlate

with endometriosis; however, a normal examination doesn't exclude the diagnosis, as 50% of women with normal examinations have been laparoscopically proven to have the disease. The main non-invasive diagnostic modalities revolve around pelvic imaging, blood, peritoneal, and urinary markers, and the characteristics of abnormal endometrium, although their diagnostic value is yet to be evaluated. Surgical diagnostic procedures include laparotomy and laparoscopy, and the latter is the most commonly used in recent times.[3]

YouTube is a tool for self-education, and one study has shown that it is the most common source of videos for surgical laparoscopy trainees. Although there can be a tad bit of inaccurate information here and there, owing to the level of credibility of the author and other factors, which is inevitable, it also serves as a source of basic medical information to the general public, raises awareness about a particular medical condition that they are concerned about, and helps in forming motivational self-help groups among those affected by a similar condition.[4]

The number of views about endometriosis on YouTube has crossed 20 million, most of which were uploaded by doctors and medical professionals and mostly included describing the symptoms and/or treatment, as these are the two main concerns for both the doctors and patients. Non-medical information about endometriosis, that is, relating to patients sharing their experiences or doctors addressing the general population, is less popular than that relating to sharing medical or surgical information.[5] YouTube is not an appropriate source to get adequate information on endometriosis. YouTube staff should work on using more filters to improve the stratification of information.[5] Additionally, misinformation and unsuitable remedies could mislead patients seeking medical advice online and can potentially affect their view of the management of endometriosis as well as their prognosis.[6] It is essential that professional advice and guidance be provided while producing and consulting YouTube as a source for endometriosis information.

YouTube is also not an appropriate source of information on the surgical treatment of endometriosis, particularly a hysterectomy. The videos made by patients were negatively biased towards the surgery.[7]

This cross-sectional observational study is aimed at evaluating the type of content, quality and reliability of content on YouTube about endometriosis using global quality score (GQS).

METHODS

A cross-sectional observational study was conducted in the month of April 2023; utilizing YouTube as the source of data collection. Due to the absence of human subjects in the study, ethics committee approval is deemed exempt.

Each of the 6 authors were assigned one search term out of the following: that were used in "endometriosis," "endometriosis causes," "endometriosis pain," "endometriosis treatment," "endometriosis and pregnancy," and "endometriosis and infertility." Each author analyzed top 15 videos under the search term allotted to them. Videos that were relevant to the topic "endometriosis"; in English or Hindi language; and video length between one to 20 minutes were included in the study Videos that did not contain any information about endometriosis; were in a different language than Hindi or English; and video length less than one minute (too short to convey information) or more than 20 minutes (too long to hold attention of viewers) were excluded from the study.

Videos included in this study were analyzed for: baseline characteristics (type of uploader, time since uploaded and popularity); type of content (symptoms, diagnosis, and treatment); and quality and reliability of content using GQS and reliability score - DISCERN, respectively.[8,9] Data collected was entered in Microsoft excel sheet.

Statistical analysis was performed using statistical package for the social sciences (SPSS) software (IBM Corp. SPSS Statistics for Windows Version 21.0, Released 2012. Armonk, NY). Kruskal-Walli's test was used to assess difference in quality and reliability of content on YouTube among different types of uploaders.

RESULTS

A total of 90 YouTube videos were evaluated for this study. However, after applying the inclusion/exclusion criteria and after deleting repeated videos, a total of 67 videos were used.

Table 1 highlights the characteristics of the YouTube videos that were analyzed. The total number of views was 21,620,808, the total number of likes was 120,830, and the total number of comments was 11,655. Moreover, 53 (79.1%) of the videos were uploaded after a year with no updates, with 31 (46.3%) being uploaded by doctors and health care organizations, outnumbering those uploaded by news channels 14 (20.9%), 5 patients (7.5%), and others 17 (25.4%).

Table 2 highlights the type of the content about endometriosis on YouTube videos. A total of 59 (88.06%) videos described symptoms; 45 (67.1%) described cause or etiology and; 47 (70.1%) of videos discussed information on endometriosis regarding treatment options. Information about support groups and patient sharing experiences with family members were the least discussed in the videos with both having a cumulative score of 8.96%.

In addition, only 4 (5.97%) of these videos conveyed promotional content by doctors and pharmaceutical companies.

Table 1: Characteristics of YouTube videos analysed.

Time since uploaded	N (%)
More than a week to six months (7-180 days old)	08 (11.9)
More than six months to last one year (180-365 days)	06 (09.0)
More than one year (>365 days)	53 (79.1)
Popularity	
Total no. of views	21620808
Total no. of likes	120830
Total no. of dislikes	4375
Total no. of comments	11655
Type of uploader	
Doctor	20 (29.9)
Hospital and healthcare organization	11 (16.4)
News channel	14 (20.9)
Patient	05 (07.5)
Other	17 (25.4)

Comparisons of the GQS, reliability score, and video power index (VPI) were made based on the type of uploader, as shown in Table 3. The Kruskal-Wallis test was used to analyze the medians for each category. There was no significant difference in the quality, reliability or VPI of videos uploaded by different types of uploaders.

Table 2: Information being "disease" by the YouTube videos.

Information	N (%)
Description of symptoms	59 (88.06)
Information about cause/etiology?	45 (67.16)
Info about investigations/test to diagnose	36 (53.73)
Info about prevention	11 (16.42)
Info about treatment	47 (70.15)
Info about complications	51 (76.12)
Info about endometriosis and pregnancy	39 (58.21)
Info about endometriosis and infertility	41 (61.19)
Info about mortality	07 (10.45)
Info about support groups	03 (4.48)
Info about people/patient's sharing their own experience	24 (35.82)
Info about parent sharing their experience with their family members	03 (4.48)
The post has a promotional content by pharmaceutical company or by doctors?	04 (5.97)
Is this video suitable for doctor/patient/both?	00 (00)

Table 3: Comparison of GQS, reliability score and VPI based on type of uploader.

Score	Doctors (n=20)	Hospital and healthcare organization (n=11)	News channel (n=14)	Patient (n=5)	Others (n=20)	P value and test used Kruskal-Wallis test
	Median (IQ1, IQ3)					
VPI	47.96 (2.64, 115.10)	15.73 (2.94, 30.95)	20.735 (7.28, 44.89)	21.71 (11.49, 59.01)	45.46 (15.44, 117.40)	0.492
GQS	4 (4, 4.75)	3 (3, 4)	4 (2.75, 4)	3 (3, 3)	4 (3, 4.5)	0.074
Reliability score	4 (3, 4)	3 (2, 4)	4 (2.75, 4)	3 (2.5, 3)	4 (3, 4)	0.357

DISCUSSION

There were many important findings in this study. About 53 (79.1%) of the videos in this study were uploaded more than a year ago. The videos analyzed had a huge reach, with views of 21,620,808 and likes of 120,830. The most common topic discussed was the description of symptoms of endometriosis, which was present in 59 (88.06%) of the videos analyzed. Only 04 (5.97%) of the videos had promotional content by pharmaceutical companies or by doctors. There was no significant difference in the quality or reliability of content based on type of uploader.

In this study 24 (35.82%) of people shared their personal experience. A study by Holowka had 32.4% of people sharing their personal experience.[10] A similar study was performed by Lee, which analyzed videos having a greater reach with views of 35,220,141.[5] The study by Lee had 96% of people sharing their personal experience, in contrast to this current study having 35.82% of people. This showed that our study had a blend of personal and professional individuals sharing their views and opinions regarding endometriosis.

Moreover, 47 videos (70.15%) in this study gave information regarding treatment, while a study by Kaya et al showed only 21%.[11] A similar study by Van revealed that respondents reported overall positive impacts on psychological, social, and cognitive health outcomes (76%) from social media use.[12] This was a positive aspect, as we were looking for videos that gave correct medical information regarding endometriosis and also included some information regarding the different treatment modalities. In this study, the most common uploaders were doctors, which were about 29.9%, whereas a study by Sinha showed 97.3% of videos uploaded by healthcare authors.[13] The fewest videos uploaded in our study were by the patients, which was about 7.5%. News channels and

hospitals were other important contributors, contributing 20.9% and 16.4%, respectively.

In this study, 45 (67.16%) videos discussed the cause and etiology, 41 (61.19%) were about endometriosis and infertility, 39 (58.21%) were about endometriosis and pregnancy, 36 (53.73%) discussed investigations for diagnosis, and about 7 (10.45%) covered mortality. Information about prevention and support groups covered 11 (16.41%) and 3 (4.48%), respectively. A study by Carnerio showed that 80% of patients searched for health-related information but did not categorize it under separate headings.[14] Our study included all the possible relationships between endometriosis and different medical outcomes in order to check the reliability of these videos and the information they conveyed.

Upon statistical analysis, it was found that the quality of videos posted by doctors, hospitals, or news channels is nearly the same. There is no alarming difference between these groups. A similar study by Goel supported our findings, indicating that healthcare professionals should pay more attention to the symptoms and diagnosis of endometriosis, discuss these topics with patients to reduce their dissatisfaction with doctors, and contribute more to the overall well-being of women with endometriosis.[15] The reliability score of each of these groups is also equal. Considering that there is no difference in scores between the groups, this can be interpreted as YouTube becoming more popular and allowing laypeople to easily access and produce content.

Limitations

This study had several limitations since the source of the videos is information available online. The first limitation was the date of the uploads. Approximately 79% of the videos available were uploaded more than a year ago. Since clinical research gets published daily, a significant portion of the information in the videos would become outdated. Furthermore, only about 45% of the information was uploaded by a doctor or someone associated with a medical office or hospital. Approximately 7% of the videos were made by patients themselves, talking about the condition and their own experience. The remaining percentage was made up of other people who did not have the qualifications or experience to fully discuss endometriosis. The number of videos analyzed was limited, and the sample size was smaller since there is a human tendency to scroll only a limited number of videos. However, with time, there can be an increase in the number of videos posted and an increase in the interaction with the videos so as to better understand the reach these videos have.

Some inter observer differences could have also led to certain discrepancies in our findings. For example, the reliability score and GQS could have varied from observer to observer. Despite these limitations, healthcare authors provided most of the information and gave a detailed description of the symptoms.

CONCLUSION

From this study we concluded that there is a variety of information being provided regarding endometriosis, with a myriad of sources behind it. While some information is verified, scientific, and comes from healthcare authors or organizations, other information was from third-party uploaders who did not have the proper qualifications to discuss such an important disease. As noted in the total percentage of videos, those done on the basis of medical knowledge and authority made up less than half of the videos found. This means patients are not getting information first hand from a verified medical professional, but rather from those talking about the condition from personal experience or anecdotes. Healthcare providers need to be aware of the information being given online, as it gives room for misinformation and a lack of complete understanding of endometriosis, especially for the patients affected.

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