

Evaluating quality, understandability, and actionability of YouTube content for gender-affirming surgery

Alexandra E. Hunter¹, Reade A. Otto-Moudry¹, Cynthia T. Yusuf², Rena D. Malik², Rachel A. Moses¹

¹Department of Surgery, Division of Urology, Geisel School of Medicine at Dartmouth, Hanover, NH, United States; ²Department of Surgery, Division of Urology, University of Maryland School of Medicine, Baltimore, MD, United States

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ABSTRACT

INTRODUCTION: The purpose of this study is to evaluate YouTube content about metoidioplasty on completeness of perioperative information, actionability, understandability, degree of misinformation, quality, and presence of commercial bias.

METHODS: A YouTube search for “Metoidioplasty” was conducted and the first 100 video results were watched by five independent reviewers. Videos in English, <30 minutes in length were included and videos primarily showing surgical footage were excluded. Videos were evaluated between January 2022 and June 2022. Each video was evaluated for presenter demographics, channel/video statistics, and whether it covered topics including anatomy, treatment options, outcomes, procedure risks, and misinformation, and whether it had a clickbait title. Calculated scores for validated DISCERN and patient education materials assessment tool (PEMAT) metrics were the primary outcome variables used to quantify quality, actionability, and understandability. For PEMAT, a cutoff of 75% was used to differentiate between “poor” vs. “good/sufficient.” Multivariate and univariate logistic regressions were performed to assess correlations among primary outcome variables and other variables.

RESULTS: Of the 79 videos analyzed, 24% (n=19) were of high quality; 99% (n=78) had poor understandability and 100% (n=79) had poor actionability. Patients/consumers were the most common publisher type (n=71, 90%).

CONCLUSIONS: This study demonstrates metoidioplasty content available on YouTube is not comprehensive and is of poor quality, and poor actionability and understandability, demonstrating a clear need for more relevant, accessible, comprehensible, and accurate content.

INTRODUCTION

Gender-affirming care is becoming increasingly accessible globally, which is associated with a proportional rise in demand for gender-affirming genital surgeries.¹⁻³ For transgender and gender-expansive individuals assigned female at birth, these include metoidioplasty and phalloplasty gender-affirming surgeries (MaPGAS). While access to these procedures has broadly improved in recent years, the healthcare landscape for transgender and gender-expansive Canadians remains complex.

All provinces and territories cover phalloplasty and hysterectomy, but metoidioplasty, testicular implants, vaginectomy, and scrotoplasty are only mentioned in about half of provincial health coverage plans. Furthermore, not all procedures covered by a province are offered within that province, meaning patients are faced with long wait lists and the need to travel to receive care.⁴ While for many these are necessary procedures to align their genitals with their affirmed gender, reduce gender dysphoria, and improve quality of life,^{5,6} they are also associated with high complication rates,⁷ can be cost-prohibitive, and require patients to make a plethora of complex decisions,⁸ especially in light of the challenging and inconsistent landscape of gender-affirming care in Canada.

Metoidioplasty and phalloplasty are both highly nuanced surgeries that can include or exclude several procedures to create a genital configuration best aligned with the individual patient's goals. Metoidioplasty, the focus of this study, involves the release and rear-

range of hypertrophic clitoral tissue to create a small neophallus. Metoidioplasty can also include vaginectomy, scrotoplasty, testicular implants, and urethral lengthening. Given the complexity of decisions that must be made by patients pursuing these procedures, it is imperative that there are accessible resources to aid patients in understanding their options, managing their expectations, and making informed decisions.⁹

In recent years, the accessibility and widespread use of the internet and social media has changed the way patients seek and access medical information.^{10,11} In 2009, it was estimated that eight out of 10 individuals in the U.S. pursue health information from online sources,^{7,8} and a study conducted in 2013 demonstrated that 32% of survey respondents relied on social media sites when seeking health-related information. Given the reliance on and growth of technology, it is reasonable to assume that the use of social media for health information has continued to increase.¹²

YouTube, a public video social media platform that allows users to post and view video content, has been heavily used by the transgender and gender-expansive community as a means of information dissemination, personal documentation, and community-building.¹³ In our initial exploration, we found a variety of YouTube content focused on metoidioplasty, including patient experiences, physician-guided education, and academic university lectures. Given the impact patient information can have on shared decision-making, we feel it is important to evaluate the comprehensiveness, quality, actionability, and understandability of metoidioplasty YouTube content. Our primary outcomes measures included “quality,” “understandability,” and “actionability” of content, and our secondary outcomes measures included misinformation and commercial bias.

METHODS

Study design

To evaluate YouTube content about metoidioplasty, videos were examined independently by five independent reviewers (two medical students: RAM, AEH; one research fellow: CTY; and two physicians: RDM, RAM). Each reviewer was trained in the anatomy, treatment options, perioperative requirements, surgical outcomes, and risks associated with metoidioplasty. Reviewers were also trained in the use of the validated DISCERN tool and patient education materials assessment tool (PEMAT). Information on all DISCERN questions was collected, although only specific DISCERN metrics found to be relevant to the project were subsequently analyzed. A similar methodology was previously

used by Pace et al.¹² Discrepancies between reviewers were resolved by consensus.

The term “metoidioplasty” was searched in YouTube using an Incognito browser to avoid user search history impacting results, and the first 100 videos queried on January 1, 2022, were reviewed. Five reviewers individually rated the first selection of 10 videos with sequential answer comparison until consensus was reached. Videos that contained narration/text in a language other than English, contained primarily surgical footage, or were greater than 30 minutes in length were excluded. Videos were reviewed between January 2022 and June 2022. This study was determined to be exempt from institutional review board review and approval.

Objective data were collected for each video: date of upload, time since upload, and video duration, as well as data on narrator type and demographics. Primary outcomes of interest were content quality, understandability, and actionability. Comprehensiveness of video content was also evaluated according to whether the video discussed anatomy, treatment options, perioperative experience, surgical outcomes, and risks. Secondary outcomes included commercial bias, misinformation, and support for shared medical decision-making. The content was then evaluated qualitatively and for correlation between analyzed variables.

The utility and relevance of video content was assessed using DISCERN criteria and PEMAT. DISCERN criteria includes 16 questions addressing quality and can be used to help raters determine whether content is a useful and appropriate source of information. DISCERN questions 1–15 are scored as (yes, no, and partially) and focus on reliability, treatment choice, and shared decision-making. DISCERN 16 asks viewers to rate the overall quality of the publication (low, moderate, or high) based on individual judgement after scoring the first 15 DISCERN questions. This analysis uses DISCERN 15 to evaluate shared decision-making and DISCERN 16 to evaluate overall content quality. PEMAT assesses understandability and actionability of content and includes 26 questions scored “agree” or “disagree.” Of these, 17 were found to be relevant (13 on understandability and four on actionability).

Understandability and actionability totals were calculated using the percentage of “agrees” relative to the total possible score. A cutoff of 75% was chosen to differentiate “poor” vs. “good/sufficient” understandability and actionability.

Secondary outcome measurements were also collected. Misinformation was assessed using a Likert scale ranging from 1=no misinformation to 5=high

misinformation. The evaluation of misinformation was made comparing video content to accepted clinical guidelines and recommendations from scientific literature and professional opinion.^{14,15} Facilitation of shared decision-making with a physician was evaluated using DISCERN 15. Commercial bias was evaluated based on the presence of an endorsement for a product or service and/or link to a paid subscription option and excluded product placement for surgical practices if the content was from that practice. Clickbait was defined as videos having sensationalized titles whose main purpose was to draw viewers in with extravagant proclamations.

Statistical analysis

Data was analyzed using STATA software (Stata SE 15.0, SPSS 28.0.1.0) to produce descriptive statistics and logistic regression functions assessing correlates. An independent t-test was used to compare the mean DISCERN score between patient- and physician/healthcare professional-created and published content ($p < 0.05$). Fischer's exact test was used to compare DISCERN scores for categories 1–15 between patient- and physician/healthcare professional-generated and published content ($p < 0.05$).

Univariate logistic regression was used to assess the impact of different variables on outcomes of interest: moderate to high levels of misinformation (≥ 3), videos that encourage shared medical decision-making (> 3), and poor understandability and actionability ($< 75\%$). Variables with univariate $p < 0.1$ were included in a multivariate regression to further characterize relationships. Independent variables that always yielded a "0" assignment in the dependent variable were dropped from univariate analysis, and variables found to be collinear were omitted from multivariate analysis by the software to minimize biasing odds ratios.

RESULTS

Creator characteristics

A total of 79 YouTube videos reviewed met the inclusion criteria. Most of the metoidioplasty content on YouTube (90%) was published by consumers or patients, followed by private hospitals or clinics and academic hospitals or clinics (8%) (Table 1). Patients were also the most common narrators (90%), followed by physicians (6%). The median number of YouTube creator subscribers was 1500 (interquartile range [IQR] 326–20900), the median number of views was 1362 (IQR 476.5–13895.5), the median number of likes was 25 (IQR 0–276.75), and the median number of comments posted on videos was five (IQR 1–54) (Table 2).

Content characteristics

Of the videos analyzed, only 51% of them discussed anatomy, 6% discussed treatment options, 37% discussed perioperative experiences, 54% discussed surgical outcomes, and 20% discussed risks. Of videos that addressed anatomy, the most common subtopic was the location and type of harvest (46%), followed by lengthening/releasing of the clitoris (38%). In videos addressing surgical options, metoidioplasty with urethral

Table 1. Characterization and analysis of metoidioplasty related content across YouTube

	Posts assessed
Publisher type	
Consumer/patient	71 (90%)
Private hospital/clinic	4 (5%)
Foundational/advocacy group	1 (1%)
Academic hospital/clinic	2 (3%)
Unknown/unclear	1 (1%)
Narrator type	
Patient	71 (90%)
Doctor	5 (6%)
Scientific group	1 (1%)
Other	2 (3%)
Commercial bias present	0 (0%)
Misinformation > 3	5 (6%)
Shared decision making > 3	59 (75%)
Quality score < 3	19 (24%)
PEMAT understandability $< 75\%$	78 (99%)
PEMAT actionability $< 75\%$	79 (100%)

PEMAT: patient education materials assessment tool.

Table 2. Video characteristics of metoidioplasty related content across YouTube

Quantitative video characteristics	Median (IQR)
Number of followers	1500 (336–20900)
Number of views	1362 (476.5–13895.5)
Number of likes	25 (10–376.75)
Number of comments	5 (1–54)

IQR: interquartile range.

Table 3. Content characterization of metoidioplasty content on YouTube

Topic	Posts assessed ¹
Anatomy	40 (51%)
Location of/type of harvest	36 (46%)
Lengthening/releasing the clitoris	30 (38%)
Treatment options	38 (48%)
No surgical intervention	5 (6%)
Hysterectomy/oophorectomy	23 (29%)
Vaginectomy	30 (38%)
Metoidioplasty with urethral lengthening	45 (57%)
Metoidioplasty without urethral lengthening	21 (27%)
Scrotoplasty	29 (38%)
Testes prosthesis	24 (30%)
Pre/post-op experience	29 (37%)
Genital exam	3 (4%)
Letters of support/referrals	6 (8%)
Fertility planning	0 (0%)
One year of continuous hormone therapy	10 (13%)
Vaginectomy needed for urethral lengthening	8 (10%)
Description of surgical procedure	18 (23%)
Need for suprapubic tube	14 (18%)
Length of time with suprapubic tube	11 (14%)
Need for Foley catheter	23 (29%)
Length of time with Foley catheter	16 (20%)
Length of hospital stay	18 (23%)
Need to stay near hospital for 4-6 weeks	5 (6%)
Length of home recover	15 (19%)
Followup appointments	19 (24%)
Procedure done in stages	30 (38%)

¹n=79 posts were assessed.

lengthening was the most discussed (37%), followed by vaginectomy (38%) and scrotoplasty (38%).

The topic of perioperative experiences contained 15 subtopics, with procedural staging discussed the most frequently (38%), followed by need for Foley catheter (29%), followup appointments (24%), and length of hospital stay (23%). The subtopics least frequently discussed were fertility planning (0%), clinical genital exam (4%), length of required stay near hospital (6%), need

Table 3 (cont'd). Content characterization of metoidioplasty content on YouTube

Topic	Posts assessed ¹
Surgical outcomes	43 (54%)
Regret	20 (25%)
Standing to pee	29 (37%)
Define standing to pee	6 (8%)
Urinating from tip of penis	18 (23%)
Length of penis	30 (38%)
Phallus sensation	11 (14%)
Tactile sensation	4 (5%)
Erotic sensation	9 (11%)
Unassisted erection	14 (18%)
Penetrative sex	10 (13%)
Prosthetic for sex	2 (3%)
Buccal graft scar	11 (14%)
Resolution of gender dysphoria	40 (51%)
Risks	16 (20%)
Stricture	11 (14%)
Fistula	18 (23%)
Wound complications	13 (16%)
Loss of sensation	2 (3%)
Positioning injuries	4 (5%)
Urinary retention	0 (0%)
Urinary leakage	2 (3%)
Pelvic pain	9 (11%)
Mucocele	1 (1%)

¹n=79 posts were assessed.

for letters of support (8%), and recommendation for vaginectomy prior to urethral lengthening (10%).

In videos covering surgical outcomes, the most discussed topics included resolution of gender dysphoria (51%), length of penis (38%), standing to pee (37%), and regret (25%). The least common subtopics discussed were the need for a prosthetic for sex (3%), tactile sensation (5%), and providing an explicit definition of standing to pee (8%).

Lastly, in videos addressing risk, nine subtopics were discussed, with fistula being the most common (23%), followed by wound complications (16%), stricture (14%), and pelvic pain (11%). The least common sub-

topics discussed were urinary retention (0%) and loss of sensation (0%). This data is summarized in Table 3.

Primary outcomes

As seen in Figure 1, DISCERN 1, “Are the aims clear?” had 56 (71%) yes responses; 2, “Does it achieve its aims?” had 58 (73%); and 3, “Is it relevant?” had 62 (78%). DISCERN 4, “Is it clear what sources of information were used to compile the publication?” had 12 (15%) yes responses, while 5, “Is it clear when the information used or reported in the publication was produced?” had two (15%). DISCERN 6, “Is it balanced and unbiased?” had 41 (52%) yes responses. DISCERN 7, “Does it provide additional sources of support and information?” had 26 (33%) yes responses, while 8, “Does it refer to areas of uncertainty?” had 22 (28%). DISCERN 9, “Does it describe how each treatment works?” had 20 (25%) yes responses. DISCERN 10, “Does it describe the benefits of each treatment?” had 31 (39%) yes responses, while 11, “Does it describe the risks of each treatment?” had 12 (15%). DISCERN 12, “Does it describe what would happen if no treatment is used?” had 34 (44%) yes responses, and 13, “Does it describe how the treatment choices affect overall quality of life?” had 35 (48%). DISCERN 14, “Is it clear that there may be more than one possible treatment choice?” had 36 (46%) yes responses. DISCERN 15, “Does it provide support for shared decision-making” had 41 (52%) yes responses.

Of all the 79 posts analyzed from the YouTube social media platform, 19 (24%) were of high quality (DISCERN >16) and 60 (76%) were of low-moderate quality (DISCERN 16 ≤3). According to PEMAT scores, 78 of the posts (99%) had poor understandability (≤75%), and 79 posts (100%) had poor actionability (≤75%) (Table 1).

Secondary outcomes

None of the 79 posts (0%) showed commercial bias. A total of four of the 79 (5%) posts were found to contain a moderate to high level of misinformation compared to the standard clinical practices for metoidioplasty gender-affirming surgery; 59 (75%) posts provided support for shared decision-making with a physician or healthcare provider (DISCERN 15 >3).

DISCUSSION

To our knowledge, this is the first study to comprehensively assess the quality of metoidioplasty content on YouTube using validated measures (DISCERN and PEMAT). We found most of the metoidioplasty con-

tent on YouTube was of low-to-moderate quality and had poor understandability and actionability. Further, most of the content did not provide viewers with a comprehensive summary of surgical options, requirements, outcomes, and risks.

In analyzing the metoidioplasty content on YouTube, we found that over 90% of the videos were published and produced by patients, with only a small proportion of videos produced by physicians or healthcare institutions. This differs from content on other genitourinary subjects, such as prostatitis, where the most common producers and publishers of YouTube content are physicians.¹⁶ While there is undeniable value in patient testimonials, our findings highlight the need for physicians and healthcare institutions to create evidence-based metoidioplasty content.

Of the videos produced by physicians or healthcare groups, the majority focus on technical descriptions of the procedure, occasionally containing demonstrations of operative procedures, rather than serving as a patient education resource.

We also found that over 75% of metoidioplasty content on YouTube was of poor quality (DISCERN 16 ≤3). These findings are consistent with studies evaluating the quality of YouTube content on other genitourinary subjects, such as overactive bladder and pelvic organ prolapse, in which 65%¹⁷ and 74%¹², respectively, were found to be of poor-moderate quality. While our analysis did not demonstrate a significant quality difference between patient- and physician-produced content, we were not powered appropriately to do so.

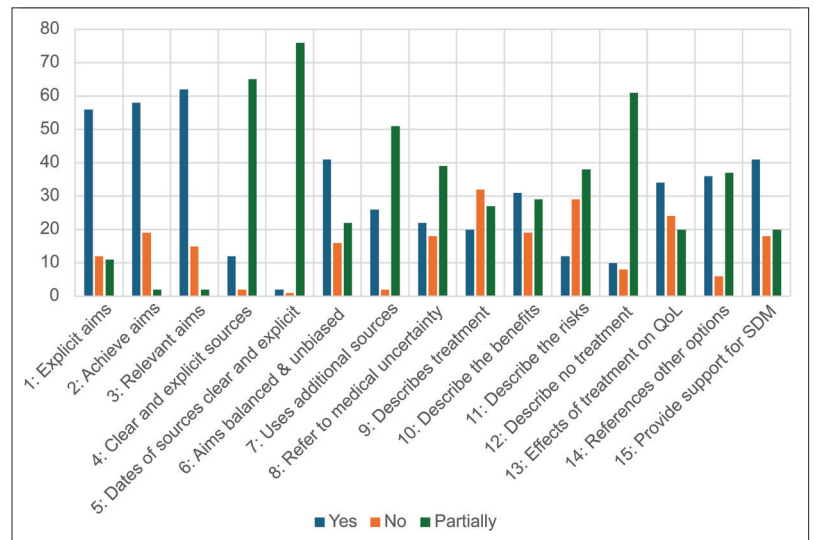


Figure 1. DISCERN responses: Questions 1–15.

Our study found that the most frequently addressed subtopics included surgical outcomes, anatomy, and treatment options. Despite this, many important topics were not addressed. For example, only 5% of videos mentioned tactile sensation and as few as 11% of videos mentioned erotic sensation when evaluating outcomes. Less than half of the videos reviewed provided a summary of perioperative requirements and experiences. An even smaller proportion discussed surgical risks and none of the reviewed videos discussed fertility planning or urinary retention. Prior work demonstrates the importance of factors, such as the probability of maintaining tactile and erogenous sensation, perioperative requirements, and surgical risks for individuals considering MaPGAS, and reveals additional YouTube metoidioplasty content areas lacking comprehensive coverage.⁶

While most YouTube metoidioplasty content we evaluated did not contain moderate or high degrees of misinformation when compared to standard clinical practice, the five videos that did contain significant misinformation were all patient-generated. The current literature has established that while there is a large volume of social media content focused on urologic healthcare issues, the majority has not been evaluated for accuracy.¹⁸ This aligns with our findings concerning metoidioplasty and demonstrates the importance of platforms like YouTube verifying and recommending high-quality, reputable health information to prevent the dissemination of misinformation.

We found many of the videos to be characterized by poor understandability, which differs from content created about other genitourinary topics, including erectile dysfunction,¹⁷ overactive bladder syndrome,¹⁸ and varicocele treatment.¹⁹ While other genitourinary content might generally demonstrate good understandability, prior studies have shown that online resources pertaining to gender-affirming surgical care present information significantly above the proficiency level of their intended audience.²⁰

Similarly, while YouTube content on other genitourinary topics, such as erectile dysfunction or overactive bladder syndrome, tend to have high actionability,^{21,22} the MaPGAS content we reviewed on YouTube did not. We believe this may be due to the high proportion of patient-produced content, which is generally intended to share personal experiences rather than aid others in making healthcare decisions.

While we recognize much of this content was likely not intended to serve as a medical resource, many patients seeking information about MaPGAS likely use it as such.²³ With the increasing use of social media for health information, verified resources for metoid-

ioplasty are crucial to promote high-quality content for patients. This is especially important for metoidioplasty YouTube content, given a lack of MaPGAS support resources outside of social media, with only one patient decision aid developed for transmasculine genital reconstruction as recently as 2021.⁶

Furthermore, the transgender/gender-expansive population is disproportionately affected by health disparities related to access to care.²⁴ In many communities, transgender/gender-expansive healthcare specialists may be geographically distant,²² making the use of online resources for information about gender-affirming surgery — and the associated risks, requirements, and complications — of particular importance.

Limitations

While our study sought to characterize the metoidioplasty content available on YouTube, it is important to recognize that our study did not analyze all potentially relevant content. YouTube also uses a proprietary search algorithm, and the platform allows patients to navigate through content in multiple ways, such as seeking creator-specific content or clicking through a series of recommended videos. Patients can also receive health information through other platforms, making a more comprehensive review necessary to evaluate and assess patients' future access to metoidioplasty information. Additionally, it is possible that these reviews may have been biased based on each independent reviewer's beliefs and medical background. To mitigate this potential bias, each reviewer independently evaluated the first 10 videos and then joined a sequential answer comparison discussion with the other reviewers until consensus was achieved. After consensus was reached, the videos were assessed.

CONCLUSIONS

To the best of our knowledge, this study was the first to analyze metoidioplasty content on YouTube using validated DISCERN and PEMAT variables, while also evaluating the presence of commercial bias and of misinformation. In using these metrics, we found that most videos contain low-moderate-quality content and lack understandability and actionability. We also found that most videos were created and produced by patients and have incomplete perioperative information on surgical risks and perioperative requirements. Given that gender-affirming surgical care is becoming increasingly available to transgender/gender-expansive individuals, this demonstrates a clear need for more relevant, accessible, comprehensible, and accurate metoidioplasty information on social medial platforms like YouTube.

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CORRESPONDENCE: Dr. Rachel A. Moses, Department of Surgery, Division of Urology, Geisel School of Medicine at Dartmouth, Hanover, NH, United States; rachel.a.moses@dartmouth.edu