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Perceptions of endometriosis surgery on TikTok: quality and implications for patient counselling

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ABSTRACT

Background: TikTok is a popular platform for sharing health experiences, including those related to endometriosis. However, the quality and tone of the surgical information shared remain unclear.

Objectives: To characterise TikTok content regarding perceptions of surgical management for endometriosis and analyse content for information quality and differences between healthcare professionals and patients.

Methods: A cross-sectional analysis of the top 100 most-viewed TikTok videos under the search term "endometriosis surgery" was conducted on September 22, 2024. Videos were included if in English, referenced "endometriosis," and mentioned "surgery," "operation," or "laparoscopy." Two independent reviewers assessed creator identity, tone, and content. The brief DISCERN tool evaluated information quality.

Main Outcome Measures: Primary outcomes included the perceived benefits and drawbacks of surgery, tone towards surgical intervention, and thematic content. Secondary outcomes included DISCERN scores and comparison of content across creator identities.

Results: Of the included videos (2021-2024), 80% were created by patients. Most conveyed a neutral tone (41%) towards surgery. Perceived benefits included therapeutic effects (68%) and diagnostic clarity (61%). Reported drawbacks were postoperative recovery (58%) and symptom persistence (22%). Common themes among patients included barriers to surgery (35%), medical gaslighting (30%), delayed diagnosis/misdiagnosis (25%), and inadequate presurgical counselling (20%). Median DISCERN scores were significantly lower for patient videos (1.00) vs. healthcare professionals (1.96; $P<0.001$).

Conclusions: TikTok content on endometriosis surgery is largely driven by patient narratives that highlight both hope and frustration. The low quality of information underscores the need for accessible, evidence-based educational content. Our findings represent a cross-sectional snapshot subject to algorithmic ranking and platform dynamics.

What is New? This is the first study to systematically evaluate TikTok content focused on surgical management of endometriosis, demonstrating that patient-generated videos overwhelmingly drive the conversation. While patients frequently describe benefits such as diagnostic clarity and symptom relief, they also highlight barriers to surgery, postoperative challenges, recurrent symptoms, and experiences of medical gaslighting. Patient-created videos had significantly lower information quality than provider-generated content, underscoring a critical gap in evidence-based surgical education on social media and an opportunity for clinician engagement.

Keywords: Endometriosis, social media, TikTok, surgical resection, experience

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Introduction

TikTok, a short-form video-sharing platform with over 1 billion active users, is emerging as a significant medium for health communication.[1,2] In 2024, TikTok had more than 1.5 billion users across the globe.[1,2] Since 2021, there has been a 600% increase in health content, and over 3.8 million healthcare professionals are estimated to be actively generating content on this app.[1,2] Its unique algorithm and engaging formats allow for the rapid spread of user-generated information, often blending personal narratives with educational content. TikTok skews towards a younger audience, with a substantial proportion of users being women of reproductive age.[3] Endometriosis, a chronic gynaecological condition characterised by the presence of endometrial-like tissue outside the uterus, affects approximately 10% of women of reproductive age globally.[4] The condition is associated with a wide range of symptoms: chronic pelvic pain, dysmenorrhea, dyspareunia, and infertility.[5] Surgical management remains a cornerstone in definitive diagnosis and/or treatment of endometriosis.[5,6]

The diagnostic delays associated with endometriosis may drive patients to seek information and support through readily available resources such as TikTok.[7] Analysing TikTok content related to the surgical management of endometriosis may offer valuable insights into educational exposures that influence patient decision-making, treatment expectations, and satisfaction. Insights from existing content can, in turn, improve healthcare professionals' engagement with patients in digital spaces, address misconceptions, and improve shared decision-making in clinical settings.[1,3] There has yet to be an analysis on popular TikTok content around patients' perspectives on the surgical management of endometriosis. This is the first study to characterise TikTok content creator perceptions on surgical management for endometriosis and analyse content for information quality. Furthermore, we aim to assess differences in patient versus healthcare professional-created content.

Methods

Search Strategy

This study was considered IRB exempt by the Massachusetts General Brigham Institutional Review Board. The search term "endometriosis surgery" was entered into the TikTok search bar on September 22, 2024, to retrieve relevant content. The inclusion criteria for videos were: 1) in English, 2) inclusion of the word "endometriosis," and 3) mention of the terms "surgery," "operation," or "laparoscopy." Duplicate, irrelevant, or promotional videos (e.g., advertisements or unrelated medical topics) were excluded. The top 100 most-viewed videos, based on TikTok's ranking algorithm, that met the inclusion criteria were selected for analysis. The "top 100 most-viewed" reflects TikTok's engagement-weighted ranking at a single time point, prioritising popularity rather than representativeness. Although only the single most-used term was applied for uniformity, we pilot-tested related hashtags to confirm content overlap.

Data Extraction

Data were extracted from each video. User demographics focused on information about the content creator (e.g., healthcare provider, patient, or organisation). The primary outcome was the content creator's perception of surgical management of endometriosis. Content creator perspectives considered personal narratives shared in the video, including reasons for undergoing surgery, expectations, and emotional responses. User perspectives considered personal narratives shared in the video, including reasons for undergoing surgery, expectations, and emotional responses. Clinical content involved key topics such as symptoms leading to surgery, the type of surgical procedure discussed, and postoperative outcomes. Healthcare experiences were identified as descriptions of interactions with healthcare providers, challenges in accessing care, and satisfaction with surgical outcomes. The overall tone of the videos was also evaluated as a subjective assessment agreed upon by researchers and grouped into either negative, neutral, or positive. These data were assessed via reviewer judgement.

The secondary outcome focused on information quality, which was assessed using the brief DISCERN questionnaire, a reliable and valid instrument for judging the quality of consumer health information.[8] The DISCERN scale was developed by an expert panel comprised of health information providers, patients, and self-help groups. Its reliability has been assessed across multiple studies,[9,10] and the DISCERN scale has been implemented in prior social media studies examining the content quality of TikTok videos regarding various health conditions.[11-13]

Each video was rated using the Brief DISCERN instrument,[8] a six-item, five-point scale (1: very poor reliability, 5: high reliability). As DISCERN was originally

validated for written content, it was applied here as an adapted metric for video-based health information following prior TikTok studies.[11-13] To ensure accuracy and reliability, two reviewers (JP, ATL) independently analysed the demographic and content data extracted from each video. Discrepancies in video selection, tone, or categorisation were discussed between the two reviewers and subsequently resolved. As codes were finalised by consensus rather than retained as independent ratings, a kappa statistic was not calculated.

Statistical Analysis

Descriptive statistics were used to summarise the demographic and content variables. Qualitative analysis was used to identify subthemes of the major categories that had been identified prior to the data collection step. Subthemes in user perspectives and healthcare experiences were identified by both reviewers, and final themes were mutually agreed upon. Median and interquartile range (IQR) were reported for the Global DISCERN scores. Chi-squared and Wilcoxon rank sum tests were used to test differences between content creator groups. Statistical significance was defined as $P<0.05$.

Results

In total, the TikTok videos analysed within our study generated over 36.2 million views. Of the 100 TikTok videos analysed, 80% (80/100) were created by patients, while 15% (15/100) were generated by healthcare professionals or organisations. The remaining videos (5/100) were not included as they included medical procedure descriptions and were made by organisations without human portrayal. All included videos incorporated at least one of the following overlying themes: surgery benefits, surgery drawbacks, recommendations, and prior healthcare experiences (Table 1). Through our study, we evaluated patient-created versus healthcare professional-created TikTok videos and overall found significant differences. Table 2 demonstrates differences between themes derived from patient-created versus provider-created videos.

Surgical Benefits and Drawbacks

Of the 80 videos identifying specific surgical procedures, 50% (40/80) mentioned laparoscopic resection or excision, 34% referenced general laparoscopic surgery (27/80), and 9% (7/80) discussed hysterectomy. Overall, 13% (10/80) of videos noted other procedures: cystectomy, bowel resection, and salpingo-oophorectomy. The benefits of surgery, as reported in 33 videos, included symptom relief (79%, 26/33), diagnostic clarity (48%, 16/33), and improved fertility (9%, 3/33). Drawbacks were noted in 52 videos, with postoperative pain being the most cited issue (58%, 30/52), followed by postoperative bloating (29%, 15/52), surgical complications (21%, 11/52), recurrent or residual symptoms (15%, 8/52), irregular vaginal bleeding (6%, 3/52), and financial costs (6%). A total of 17% of all videos analysed in this study (17/100) mentioned alternatives to surgical management, such as hormonal suppression and alternative medicine strategies.

Healthcare Experiences

Both patients and professionals provided general recommendations for endometriosis management. Of the 30 videos with this content, 63% (19/30) emphasised preparation for postsurgical recovery, 23% (7/30) advocated for patient self-advocacy, and 17% (5/30) highlighted the importance of finding

Table 1. Thematic analysis of included TikTok videos.

Surgery benefits	**n=33**
Symptom relief	79% (26)
Diagnostic clarity	48% (16)
Improved fertility	9% (3)
Surgery drawbacks	**n=52**
Postoperative pain	58% (30)
Postoperative bloating	29% (15)
Surgical complications	21% (11)
Recurrent/residual symptoms	15% (8)
Irregular vaginal bleeding	6% (3)
Financial costs	6% (3)
Recommendations	**n=30**
Post-surgical recovery preparation	63% (19)
Patient self-advocacy	23% (7)
Identifying experienced healthcare professionals	17% (5)
Prior healthcare experiences	**n=20**
Barriers to surgery	35% (7)
Medical gaslighting	30% (6)
Delayed diagnosis/misdiagnosis	25% (5)
Inaccurate surgery counselling	20% (4)

*Remaining videos (n=5) were not included in Table 1 as they included medical procedure descriptions and were made by an organisation without human portrayal.

experienced healthcare professionals. Lastly, prior healthcare experiences were discussed in 20 videos by patients. Patient-generated videos regarding prior personal healthcare experiences frequently highlighted barriers to surgical care (35% 7/20), experiences of medical gaslighting (30%, 6/20), delayed diagnoses or misdiagnoses (25%, 5/20), and inadequate presurgical counselling (20%, 4/20). The term medical gaslighting was included if used specifically by the TikTok video creator and often referred to as manipulation by healthcare providers who minimised patients' clinical concerns. Importantly, though medical gaslighting was frequently tied to delayed diagnosis and management, it specifically referred to the act of providers invalidating symptoms and pain.

Information Quality and Engagement

Overall DISCERN scores for patient videos were low, with a median of 1 (IQR 1-1). However, healthcare professional-created videos had significantly higher DISCERN scores, suggesting better quality health information (median: 2 vs. 1; $P<0.001$) (Table 3). Engagement, measured by likes, was similar between healthcare professional- and patient-generated videos (median: 1,921 vs. 1,622; $P=0.756$) and not significantly influenced by tone or video type. Regarding tone, overall, 41% (38/93) of the videos were neutral, 32% (30/93) were positive, and 27% (25/93) were negative. Healthcare professional-created videos were predominantly neutral in tone (92.9%, 13/15). Patients were significantly more likely than healthcare professionals to have a negative tone towards surgical management (33.3%, 25/80 versus 0%, 0/15, $P<0.001$).

Table 2. Differences in themes generated by patient-generated vs. provider-generated content.

	Overall	Patient (n, %)	Provider (n, %)	*P* value
Pros of surgery	32 (32.0)	25 (31.3)	7 (46.7)	0.246
Cons of surgery	50 (50.0)	44 (55.0)	6 (40.0)	0.286
Recommendations	29 (29.0)	23 (28.8)	6 (40.0)	0.385
Prior healthcare experiences	19 (19.0)	19 (23.8)	0 (0)	0.036

Table 3. Quality of content, tones, and types of included TikTok videos created by healthcare professionals vs. patients.

	Overall (n=100)	Healthcare professionals (n=15)	Patient (n=80)	*P* value
Likes (median, IQR^)	1691 (438-4495)	1921 (733-2236)	1622 (336-1622)	0.756
DISCERN score (median, IQR)	1 (1-1)	2 (2-2)	1 (1-1)	$P<0.001$
Tone of video (n, %)				
Positive	30 (32.3)	1 (7.1)	28 (37.3)	
Neutral	38 (40.9)	13 (92.9)	22 (29.3)	
Negative	25 (26.9)	0 (0.0)	25 (33.3)	$P<0.001$
Type of video (n, %)				
Educational/advising (didactic content presenting information or guidance)	28 (28.0)	14 (93.3)	11 (13.8)	$P<0.001$
Preoperative experiences (anticipatory content prior to surgery)	7 (7.0)	0 (0.0)	7 (8.9)	0.592
Postoperative experiences (recovery narratives or symptom updates following surgery)	35 (35.0)	0 (0.0)	35 (43.8)	0.001
Humorous (comedic pieces based on experiences or opinion)	11 (11.0)	0 (0.0)	11 (13.8)	0.203
Personal reaction (spontaneous emotional responses or opinion pieces)	19 (19.0)	1 (6.7)	16 (20.0)	0.216

^ IQR refers to interquartile range, *Remaining videos (n=5) were not included in Table 3 as they included medical procedure descriptions and were made by an organisation without human portrayal.

Discussion

Principal Findings

This study provides valuable insights into how TikTok functions as a major platform for disseminating information and sharing personal experiences related to surgical management of endometriosis. Content was overwhelmingly patient generated, reflecting a growing reliance on social media to share personal health journeys, seek validation, and bridge perceived gaps in traditional healthcare communication. Patient videos most often described postoperative pain, recovery challenges, and mixed satisfaction with surgical outcomes, while healthcare professional videos focused on procedural explanations and educational messaging. Despite clear differences in tone and content, engagement levels -measured by likes- were similar between groups, suggesting that emotionally resonant and professionally informative content can achieve comparable visibility. However, information quality was low, particularly among patient-generated videos, as indicated by markedly lower DISCERN scores compared with healthcare professionals. These findings underscore a critical disconnect between the content most visible to patients and the standards of evidence-based surgical education, raising concerns about misinformation, unmet information needs, and the influence of digital narratives on patient expectations and decision-making.

Results in Context of What is Known

The volume of patient-generated content highlights the power of relatable and emotional narratives in resonating with audiences. Personal stories of postoperative recovery, struggles with symptoms, and humour in navigating endometriosis resonate deeply with viewers, potentially offering a sense of solidarity and validation.[14,15] However, these narratives often lack the nuance and evidence-based guidance necessary for informed decision-making, underscoring a missed opportunity for healthcare professionals to engage audiences with both relatable and accurate content.[16,17] While DISCERN scores were higher for healthcare professionals' generated videos, even clinician-generated videos achieved a median DISCERN score of 2/5, underscoring that high-quality educational material remains scarce on the platform. Healthcare professionals may consider using the DISCERN criteria while making content and focusing on providing balanced information, acknowledging uncertainty, and citing sources in their captions.[7] Additionally, the predominantly neutral tone of healthcare professional videos may come across as impersonal or overly clinical, potentially reducing their appeal to TikTok users.[18] This finding suggests a need for healthcare professionals to adopt more patient-centred communication strategies, such as incorporating storytelling, addressing common fears and misconceptions, and using an empathetic tone to connect with viewers on a personal level. The variability in tone and content reflects the multifaceted -and often intertwined- challenges faced by individuals with endometriosis, including delayed diagnoses, medical gaslighting, and limited access to experienced healthcare professionals.[19,20] The popularity of videos discussing these topics indicates that social media platforms are not only sources of information but also spaces for advocacy and community building. Collaborations between patients and healthcare professionals may be an opportunity for accurate information that leverages the compelling nature of narrative and personal experiences.[21] For example, co-created content featuring patient testimonials alongside expert commentary could combine the authenticity

Table 4. Optimising TikTok content for endometriosis surgery.

Video structure	Inclusion of both patient and healthcare professional
	Empathetic tone
	Incorporate a narrative
	Ensure video objectives/aims are focused and clearly communicated
Video information	Provide accurate, unbiased, and balanced information
	Avoid absolute statements of management that do not reflect areas of uncertainty
Video themes	Include reliable references and link to cited sources, and more patient information
	Guidance to optimise care (symptom timeline, treatment timeline, seek multiple opinions, bring a support person to appointments, prepare questions to ask)
	Misconceptions and/or misinformation topics
	Preoperative and postoperative expectations/guidance

of lived experiences with the reliability of professional guidance. We offer suggestions for generating social media content that can help inform patients about the surgical management of endometriosis in Table 4.

Strengths and Limitations

This study is among the first to analyse TikTok content related to the surgical management of endometriosis, addressing an important gap in digital health communication research. The mixed-methods design, combining quantitative analysis of engagement and DISCERN scoring with qualitative thematic coding, provides both breadth and depth of insight into how surgical information is framed and perceived online. The inclusion of dual independent reviewers enhanced analytic rigour and minimised individual bias in video selection, coding, and tone classification. The use of a validated information-quality tool, adapted transparently for short-form media, allowed structured comparison between patient- and clinician-generated content. By focusing on a highly visible sample of the most-viewed videos, the study also captures the messages most likely to shape public understanding and discourse around endometriosis surgery.

Limitations include reliance on algorithm-driven, cross-sectional sampling at a single time point, restriction to English-language content, and lack of adjustment for confounders such as follower count or video length. The DISCERN tool, while validated for written health information, may not fully capture the narrative, visual, or emotional elements that influence short-form video communication. Finally, although we performed a preliminary patient versus provider analysis based on the content that met inclusion criteria for our study, this analysis is certainly limited by the discrepant sample sizes, as only 15% of videos were generated by providers compared to the 80% generated by patients. These limitations notwithstanding, the findings provide an informative snapshot of current digital discourse and a foundation for future longitudinal and multilingual studies of social-media-based gynaecological education.

Implications for Practice and Future Research

Healthcare professionals, national women's health organisations, and healthcare systems should note that common themes on TikTok reflect longstanding gaps and systemic issues in endometriosis care. Addressing these barriers through improved training, earlier diagnosis, and accessible care options could have a significant impact on patient outcomes and satisfaction. Educational campaigns led by national organisations tailored to social media that emphasise preparation for surgery, recovery tips, and dispelling myths may also help bridge the information gap.[22,23]

Future research should explore how TikTok content evolves over time, the role of platform algorithms in shaping public discourse, and the real-world impact of this content on patient decision-making, health literacy, as well as care-seeking behaviour. Future studies should also employ multi-keyword, multilingual, and longitudinal designs to assess how algorithmic changes shape the visibility of endometriosis content. Complementary tools beyond DISCERN could capture narrative accuracy, empathy, and influence on patient decision-making. Given the exploratory aim and cross-sectional design, we report unadjusted comparisons and recommend adjusted modelling in future work.

The findings from our study additionally have important implications for both patients and healthcare providers. For patients seeking information about endometriosis surgery, the dominance of low-quality, patient-generated TikTok content may shape expectations and decisions based on anecdotal, emotionally resonant -but often incomplete- information. For healthcare providers, the study underscores an urgent need to engage with social media platforms more actively and empathetically. As summarised in Table 4, effective TikTok communication around endometriosis surgery should combine authentic narrative with clinical accuracy. Recommended strategies include structuring videos with clear objectives, using empathetic and accessible language, presenting balanced and referenced information, and addressing common misconceptions or postoperative expectations. Such approaches can help healthcare professionals produce content that is both engaging and evidence-based, ultimately fostering more informed and empowered patient communities. This dual insight highlights both the power and pitfalls of digital health narratives and calls for collaborative, patient-centred communication to improve education, trust, and shared decision-making.

Conclusion

TikTok offers a unique blend of opportunities and challenges in health communication for endometriosis. Our study found that videos related to the surgical

management of endometriosis discussed surgical benefits, surgery drawbacks, recommendations, and prior healthcare experiences. While the majority of endometriosis patient-created videos are patient-generated, the healthcare professionals-created content illustrated higher, yet still low, levels of reliability and quality. Our study highlights the critical need for improved patient education. Given the utilisation of TikTok content by patients, social media content produced by healthcare professionals, particularly minimally invasive gynaecological surgeons, may be an opportunity to improve understanding of surgical approaches for endometriosis.

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Transparency: This manuscript is an honest, accurate, and transparent account of the study being reported. No important aspects of the study have been omitted.

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