





Original Article

Endometriosis Influencers on Instagram: Who Are They and What Are They Posting?

Samantha N. Shiplo, MSc, MD, Mahsa Gholiof, MSc, Natasha Sarin, BSc, and Mathew Leonardi, MD, PhD

From the Department of Obstetrics and Gynecology, McMaster University (Shiplo and Gholiof), Hamilton, Ontario, Canada, Saba University School of Medicine (Sarin), The Bottom, Caribbean Netherlands, and Robinson Research Institute, University of Adelaide (Leonardi), North Adelaide, SA, Australia

ABSTRACT

Study Objective: To examine endometriosis-related content on Instagram, a platform increasingly used for health communication, to understand: 1) the identity of Instagram content creators; 2) themes, tones, and emotions evoked from posts; and 3) accuracy of educational information. The relevance of this study lies in its potential to inform healthcare providers on how to better engage with social media to support individuals with endometriosis.

Design: This mixed methods cross-sectional observational study was performed on June 6, 2021. Instagram content was collected via two approaches: 1) searching hashtags related to endometriosis from a list of 30 hashtags and analyzing the top 20 and 10 most recent posts and 2) searching endometriosis-related terms under accounts to examine the first 30 accounts retrieved. Posts were categorized into themes and evaluated for tone and emotion, with educational posts also evaluated for accuracy.

Setting: Publicly available data on Instagram.

Participants: None. **Interventions:** None.

Measurements and Main Results: The study analyzed 768 Instagram posts and 228 accounts. Of these, 59.9% of posts and 92.1% of accounts contained endometriosis-related content. Most posts (55.4%) and accounts (59.0%) were authored by people with endometriosis. Accounts owned by people with endometriosis were significantly more active and had more followers compared to those who identified as healthcare providers (mean difference of total # of posts = 714.4, p < .001, mean difference of total # of followers = 27,194.7, p < .001, respectively). Social support was the most common theme (67.2%). Many posts had a negative tone (43.7%) and evoked sadness (57.6%). Objective educational posts contained 85.0% accurate information. Allied healthcare providers were most likely to post accurate educational information compared to all other content creators (p < .001).

Conclusion: Instagram is widely used by people with endometriosis, with posts predominantly centered around social support and personal narratives. Healthcare providers can use this information better understand the experiences of people with endometriosis, and to engage more effectively on Instagram. Journal of Minimally Invasive Gynecology (2025) 32, 693 –700. © 2025 AAGL. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)

Keywords:

Pelvic pain; Social media; Education; Information sharing; Patient communities

Introduction

Endometriosis affects approximately 10% of individuals assigned female at birth [1]. Endometriosis is characterized by functional endometrial-like glands and stroma outside the uterus [1]. Despite the well-described symptoms of

Corresponding author: Samantha N. Shiplo, MSc, MD, McMaster University, 1200 Main St. West, Hamilton, Ontario L8S 4J9, Canada.

E-mail: sam_shiplo@hotmail.com

Submitted July 4, 2024, Revised January 28, 2025, Accepted for publication January 31, 2025.

Available at www.sciencedirect.com and www.jmig.org

endometriosis including dysmenorrhea, subfertility, and pelvic pain, diagnosis remains challenging due to variable presentations and limitation of non-invasive diagnostic tools [2–5].

Endometriosis is a difficult chronic disease to navigate [2,5]. Studies have shown that people with endometriosis want to learn more about endometriosis, however, information is often unreliable causing a sense of helplessness and distress [6,7]. Health professionals face difficulties in providing comprehensive information due to the disease's complexity and treatment controversies [1,5]. Given the variability in medical information, accurate dissemination

is crucial to further public and physician understanding of endometriosis.

Social media, notably Instagram, has revolutionized access to healthcare information. Studies have demonstrated the benefit of social media in improving patient health knowledge, communication, and empowerment, consequently enhancing the patient-physician relationship [8–10]. With 2.35 billion active accounts, Instagram is one of the most popular social media platforms that has seen rapid growth and engagement among individuals with endometriosis [11]. Its format allows sharing of content through images and captions, facilitated by hashtags for easy searchability.

Our research examines how Instagram's visual and narrative-driven content influences the discourse around endometriosis, unlike prior studies, which have primarily focused on other social media platforms or different conditions[12–17] Previous studies have provided foundational insights into the use of social media for health communication, but they have not thoroughly explored Instagram's role in shaping patient communities, the spread of medical information related to endometriosis, and accuracy of posts [15,17].

The objective of this study is to examine endometriosisrelated content on Instagram, including 1) identity of content creators; 2) themes, tones, and emotions evoked from Instagram posts; and 3) accuracy of educational posts. The aim of this study is to provide a comprehensive understanding of the landscape of endometriosis-related content on Instagram, offering new insights that can guide healthcare professionals in engaging with this medium.

Methods

A mixed methods cross-sectional observational study was conducted using publicly available Instagram data, following STROBE guidelines (Appendix A). A search of endometriosis-related hashtags and accounts was performed on June 6, 2021.

The study design was adapted from previous work on social media in healthcare [12–17]. A pilot was performed for the purpose of trialing data extraction and documentation. During the pilot study, hashtags associated with endometriosis were selected in an iterative process, with each search informing and expanding on the previous one, resulting in a comprehensive list of relevant hashtags (Appendixes B and C).

Instagram's search function allows filtering by "tags" (i. e., hashtags) or "accounts" (Supplementary Fig. 1). When using the "tags" option, Instagram displays results based on two criteria: top posts (i.e., most popular posts determined by the number of likes and interactions) and most recent posts in chronological order. The "accounts" search option presents a list of accounts, ranked by Instagram's internal algorithm.

A two-step approach was used. First, 30 predetermined hashtags associated with endometriosis (Appendix B) were searched under the "tags" category. From each hashtag, we recorded the content of the top 20 and 10 most recent posts, along with Instagram content creator information.

Next, 10 predetermined terms associated with endometriosis (Appendix C) were searched under "accounts" and the first 30 were examined. Due to time constraints, a subset of Instagram posts were analyzed, a method consistent with previous studies [12-17]. The study design methodology is further outlined in a flowchart in Supplementary Fig. 2.

Instagram posts included were in English or translated using the translation feature on Instagram. Multiple images posted in one post were examined together. Posts that were identified more than once in the hashtag searches were only counted once. Unrelated posts and videos, and private Instagram accounts, were not included in the analysis. To minimize search algorithm bias, a new Instagram account was activated and location services were disabled. Ethical approval was not required for this study as all data is publicly available on Instagram (McMaster University HiREB).

Study Outcomes

Instagram Descriptive Characteristics

Instagram accounts were reviewed to gather information about the content creator's geographic location and identity. Content creator identity was categorized as: medical healthcare providers (i.e., physicians, surgeons, physician assistants, and nurses); allied healthcare providers (i.e., occupational therapists, physiotherapists, and pelvic floor physiotherapists, nutritionists, dietitians); people with endometriosis; organizations; or other (i.e., journalist, life coach, retail or unknown).

Instagram Activity and Engagement

Activity level of an Instagram account was quantified using the total number of posts from initiation of the account until June 2021. A post's engagement level was quantified using the number of likes on that post and an account's engagement level was quantified using the number of followers of the account [18,19].

Posts' Characteristics

Discourse analysis was used in qualitative evaluation of the content, tone, and emotions evoked in the posts' text caption, emoticons, and images. Content themes were generated through an iterative process during analysis based on emerging themes to include: *education, social support, personal narrative, empowerment, and advertisement*. Tone of the posts were categorized as *positive, negative, or neutral*. Lastly, emotions evoked in the posts were categorized according to the emotion wheel as *sadness, anger, fear, compassion*,

p-value

<.001

-			
Table 1			
Activity and engagement level on Instagram			
Accounts		Engagement	
Author types	Accounts n (%)	Total # of followers Mean (SD)	p-valu
People with endometriosis	124 (59)	29 157.2 (16 689.1)	•
Healthcare providers (medical and allied)	6 (2.9)	1962.5 (516.2)	<.001
Organizations	20 (9.5)	7658 (2448.4)	
Other	60 (28.6)	4027.3 (1229.2)	
	. /	_ ` ′	

Posts n (%)

255 (55.4)

26 (5.7)

65 (14.1)

15 (3.3)

99 (21.5)

Engagement

491.4 (74.9)

432.3 (105.8)

587.7 (91.6) 209.8 (39.4)

206.3 (32.7)

Total # of likes Mean (SD)

happiness, or surprise (see Appendix D) [20]. Posts were categorized into one or more category if applicable.

Posts' Accuracy

Posts

Author types

Other

Organizations

People with endometriosis

Medical healthcare providers

Allied healthcare providers

Posts categorized as educational in the posts' content assessment were then further reviewed for accuracy. Two reviewers, MG and NS, independently evaluated each educational post, and their classifications were kept confidential from each other. Each educational post was categorized as subjective (i.e., personal narratives, experiences, perspectives, and statements based on personal feelings or opinions) or objective claims (i.e., substantiated based on data). The objective educational posts were evaluated for accuracy by cross-referencing peer-reviewed publications. Discrepancies were reviewed by a third evaluator (S.S.).

Statistical Analysis

Analyses were conducted using IBM SPSS version. Descriptive statistics were reported for primary outcomes. Author activity and engagement were assessed using a one-way ANOVA and Tukey's test. Post content, tone, emotion, and accuracy were compared using Chi-Square tests with Bonferroni adjustment. Statistical significance was set at p-value <.05.

Results

In total, there were 1.5 million posts using the *endometriosis* hashtag on Instagram at the time the search was performed.

Instagram Descriptive Characteristics

A total of 768 posts and 228 accounts were identified. Of those identified, 59.9% (460/768) of posts and 92.1% (210/228) of accounts had endometriosis-related content and were included in the analysis. People with endometriosis

authored 55.4% (255/460) and 59.0% (124/210) of endometriosis-related posts and accounts, respectively (Table 1). Most of the posts originated in the United States of America (20.9%, n = 96) and the United Kingdom (20.7%, n = 95), followed by Australia (12.0%, n = 55), Canada (8.0%, n = 37), Germany (5.4%, n = 25), while the remainder originated from various other countries (33.0%, n = 152). Regarding account origins, the majority were not specified or were from other countries (i.e. South Africa, Ireland) (78.0%, n = 164), followed by the United Kingdom (9.1%, n = 19), Australia (6.2%, n = 13), the United States of America (5.2%, n = 11), Germany (1.0%, n = 2) and Canada (0.5%, n = 1).

Activity

Total # of posts Mean (SD)

812.2 (470.2) 97.8 (17.2)

536.1 (141.6) 193.8 (73.9)

p-value

.19

Instagram Accounts' Activity and Engagement

Accounts authored by people with endometriosis were significantly more active, posting more than healthcare providers (mean difference [MD] of total # of posts = 714.4, p < .001) and others (MD of total # of posts = 618.4, p = .005). Moreover, accounts created by organizations were significantly more active than healthcare providers (MD of total # of posts = 438.3, p < .001) and other users (MD = 342.3, p = .012) (Table 1). Accounts authored by people with endometriosis had the greatest number of followers, which was significantly higher than healthcare providers (MD of total # of followers = 27 194.7, p < .001), organizations (MD of total # of followers = 21 499.2, p < .001), and others (MD of total # of followers = 25 129.9, p < .001).

Instagram Posts' Engagement

Posts were authored as follows: people with endometriosis (55.4%), allied healthcare providers (14.1%), others (21.5%), medical healthcare providers (5.7%), and organizations (3.3%) (Table 1). Posts by allied healthcare providers received the highest average likes (mean 491.4,

SD 74.9), though not statistically significant (p = .19) (Table 1).

Posts' Characteristics: Content Themes

The most common theme to emerge from endometriosis-related posts was social support (67.2%, 309/460), followed by personal narrative (47.6%, 219/460), education (31.3%, 144/460), empowerment (21.1%, 97/460), and advertisement (9.6%, 44/460). Allied healthcare providers (56.9%, 37/65) and medical healthcare providers (53.8%, 14/26) contributed significantly more to educational posts compared to people with endometriosis (24.3%, 62/255) (p < .001 and p = .01, respectively). Additionally, allied healthcare providers (20%, 13/65) posted significantly more advertisement-related content than people with endometriosis (5.9%, 15/255) (p = .002). People with endometriosis (54.1%, 138/255) contributed significantly more to personal narrative content than medical healthcare providers (23.1%, 6/26) and allied healthcare providers (33.8%, 22/65) (p = .002) (Fig. 1).

Posts' Characteristics: Tone

Among assessed posts, 43.7% (201/460) portrayed a negative tone, 37.8% (174/460) were positive, and 18.5% (85/460) were neutral. Posts created by allied healthcare

providers (18.5%, 12/65) contributed less significantly to negative tone compared to the others (50.5%, 50/99) (p < .001) and more significantly to neutral tone (33.8%, 22/65) compared to people with endometriosis (12.2%, 31/255) (p-value <.001). Medical healthcare providers (50%, 13/26) had a significantly more neutral tone compared to people with endometriosis (12.2%, 31/255) and others (15.2%, 15/99) (p < .001). Positive tone differences across author types were not significant (p = .07) (Fig. 2).

Posts' Characteristics: Emotions

The most common emotion conveyed through endometriosis-related posts was sadness (57.6%, 265/460), followed by compassion (50.2%, 231/460), anger (39.3%, 181/460), happiness (36.3%, 167/460), fear (26.5%, 122/460), and surprise (5.9%, 27/460). People with endometriosis posts portrayed significantly more anger (44.7% (114/255) vs 16.9% (11/65), p = .009) and sadness (64.3% (164/255) vs 32.3% (21/65), p = .001) compared to allied healthcare providers (Fig. 3). Posts created by allied healthcare providers (73.8%, 48/65) contributed more significantly to compassion (p < .001) compared to people with endometriosis (47.5%, 121/255) and others (35.4%, 35/99).



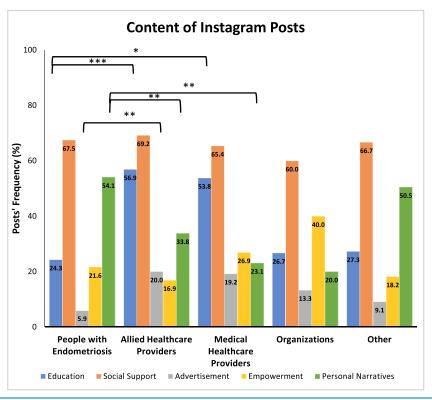
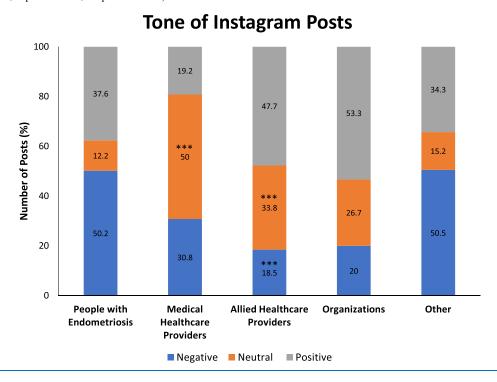


Fig. 2

Tone of Instagram posts. This figure shows the frequency of Instagram posts with positive, neutral, and negative tone (%) posted by different author types: people with endometriosis, medical healthcare providers, allied healthcare providers, organizations, and others. Asterisks show significant difference (*p-value <.05, **p-value <.01, ***p-value <.001).



Posts' Accuracy

Of 144 educational posts, 55.6% (80/144) were objective and 44.4% (64/144) were subjective. Of the objective posts, 85.0% (68/80) contained accurate scientific information while 15.0% (12/80) did not. Most of the inaccurate objective educational posts provided incorrect facts or statistics about endometriosis (58.3%, 7/12), or made unsupported dietary recommendations (41.7%, 5/12) (Supplementary Table 1). Allied healthcare providers posted more accurate posts (73.7% (28/38), p < .001) and fewer subjective posts (13.1% (5/38), p < .001) (Fig. 4). There was no significant difference in number of inaccurate posts by author type (p = .35) (Fig. 4).

Discussion

This study provides valuable insights into the nature of endometriosis-related content on Instagram, highlighting the significant role of social media in shaping public discourse around this chronic condition. Our findings showed that most endometriosis-related posts and accounts on Instagram were created by people with endometriosis, who demonstrated higher post frequency and follower counts compared to healthcare providers. This underscores the importance of patient voices in the digital

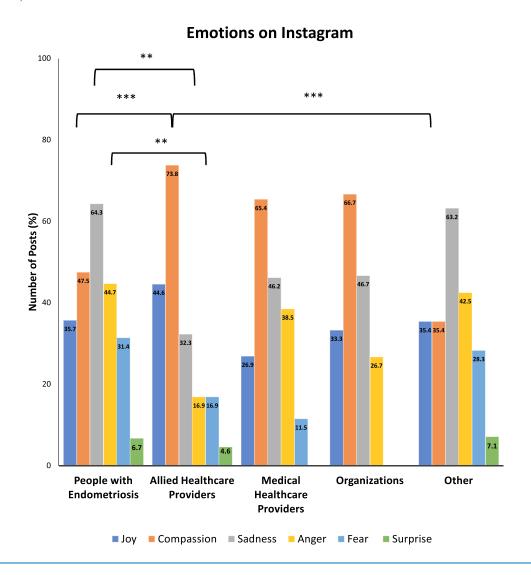
space, particularly in communities discussing chronic pain conditions.

Themes emerging from our analysis centered on social support and personal narratives, with many posts conveying negative emotions such as sadness and anger. These findings reflect the emotional burden carried by individuals with endometriosis and the reliance on Instagram as a platform for sharing personal experiences and seeking support [14–17,21,22]. The frequent expression of negative emotions highlights unmet needs within this patient population, including the desire for treatments, timely diagnoses, and empathetic healthcare providers. People with endometriosis may experience more post-operative pain, especially when diagnosis is delayed, potentially leading to central sensitization, altering a patient's pain phenotypes. This persistent negativity correlates to worsened clinical outcomes and reduces quality of life [22–26].

While healthcare providers contributed educational content on Instagram, their presence was significantly less prominent compared to individuals with endometriosis. Educational posts authored by healthcare providers were generally more accurate, indicating their potential to play a crucial role in disseminating evidence-based information. However, lower engagement levels suggest that healthcare providers may need to adjust their communication strategies to connect effectively with this audience. Social media



Emotions evoked on Instagram. This figure shows the emotions evoked by Instagram posts with the following authors: people with endometriosis, medical healthcare providers, allied healthcare providers, organizations, and others. Asterisks show significant difference (*p-value <.05, **p-value <.01, ***p-value <.001).



offers an opportunity for healthcare providers to bridge the information gap by engaging empathetically and resonating with the lived experiences of individuals with endometriosis.

Our findings align with previous research indicating that people with endometriosis post the most endometriosis-related information on Instagram [12,15]. This contrasts with other medical specialties, where healthcare providers have a more dominant social media presence [11,13] This difference may be due to the deeply personal, stigmatized, and emotionally distressing nature of endometriosis, which might deter healthcare providers from engaging publicly [11,20,21]. Nonetheless, Grajales et al. [8] demonstrated that healthcare providers on social media can significantly enhance patient experiences by offering accurate,

supportive, and compassionate content. Their research found that social media improves patient engagement and education in chronic disease management through peer support and expert advice, reinforcing the importance of accurate and compassionate social media communication [8].

In contrast to earlier research by Sinha et al. [17], which found no educational posts authored by healthcare providers on Instagram, our study reveals an increase in such posts. This indicates a growing trend of healthcare provider involvement on social media, which is crucial given the variability in the accuracy of medical information online [16,27,28]. The inconsistency inaccurate information poses challenges for individuals trying to discern reliable sources. While the data highlights the benefits of healthcare providers' involvement on social media, further

Fig. 4 Accuracy of Instagram Posts. This figure shows the accuracy of posts by different author types. Asterisks show significant difference (*p-value <.05, **pvalue <.01, ***p-value <.001). **Instagram Posts Accuracy** 100 25 36.8 80 41 2 Number of Posts (%) *** 11.8 59.7 53.6 50 20 People with Medical Allied Healthcare Organizations Other **Endometriosis** Healthcare **Providers Providers**

■ Subjective Inaccurate Accurate

investigation is needed to assess patient outcomes and the patient-physician relationship.

Social media provides healthcare providers a platform to improve patient outcomes by actively engaging with patient communities, sharing accurate, evidence-based information, and correcting misinformation. Such engagement can build trust, enhance health literacy, and equip patients with the resources to manage their conditions more effectively [10]. Although our study found accurate endometriosis content on Instagram, individuals must critically evaluate its objectivity and accuracy. Healthcare providers' presence on social media is crucial for identifying and addressing knowledge gaps and guiding the development of educational materials to raise awareness about endometriosis.

Active social media users with endometriosis often trust information from peers more than healthcare professionals, potentially straining these relationships [29,30]. It's important for healthcare providers to engage on social media, offering support, accurate information, and building trust. While social media has the potential to enhance patient-physician relationships by facilitating communication, further research is needed to understand its impact fully. Additionally, interdisciplinary collaboration facilitated by social media in managing complex conditions like endometriosis warrants further investigation.

Strengths of our study include a large sample size encompassing both posts and accounts, detailed discourse analysis of the posts based on author types, and evaluation of educational post accuracy, a method previously used for online

resources [27,28]. However, the cross-sectional nature of the study limits the generalizability of the findings. Challenges accessing certain Instagram data due to privacy settings and the exclusion of Instagram Stories may have excluded alternate perspectives. Despite these limitations, the study highlights the critical role that social media plays in the lives of individuals with endometriosis and its potential for healthcare providers to engage meaningfully. Future studies should consider longitudinal analyses to capture the evolving role of healthcare providers and to assess the long-term impact of their engagement on patient outcomes.

In conclusion, while Instagram serves as a powerful platform for individuals with endometriosis to share their experiences and seek support, there is a clear need for more active participation from healthcare providers. By engaging empathetically and providing accurate information, healthcare providers can improve patient-physician relationships, enhance patient outcomes, and contribute to a more informed and supportive online community.

Conflict of Interest

Mathew Leonardi reports grants from Australian MRFF, AbbVie, CanSAGE, Hamilton Health Sciences, Hyivy Health; honoraria for lectures/writing from AIUM, GE Healthcare, Bayer, AbbVie, TerSera, consultancy work with Hologic, Chugai, affiliations with Imagendo, outside the submitted work. The remaining authors report no conflict of interest.

Prior Presentation

RT Weaver Scientific Day, April 6, 2022, Hamilton, Ontario, Canada (oral), AAGL Global Conference, December 2, 2022. Aurora, Colorado, USA (oral), 8th Congress of the Society of Endometriosis and Uterine Disorders, May 18 to 21, 2022, Athens Greece (poster).

Summation

People with endometriosis frequently use Instagram for social support and healthcare providers should join, providing compassionate and accurate healthcare information.

Ethics Approval

Ethics was applied for via McMaster University Hireb and was granted not necessary as Instagram is available publicly and therefore, consent is assumed.

Data Availability Statement

Data is available from the authors upon reasonable request.

Acknowledgments

Mehak Behal, Vidhi Bhatt, Jashnoor Chhina, and Kyobin Hwang, students, no funding.

References

- Zondervan KT, Becker CM, Missmer SA. Endometriosis. N Engl J Med. 2020;382:1244–1256.
- Hudelist G, Fritzer N, Thomas A, et al. Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. Hum Reprod. 2012;27:3412–3416.
- Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. Fertil Steril. 2006;86:1296–1301.
- Leonardi M, Robledo KP, Goldstein SR, Benacerraf BR, Condous G. International survey finds majority of gynecologists are not aware of and do not utilize ultrasound techniques to diagnose and map endometriosis. *Ultrasound Obstet Gynecol*. 2020;56:324–328.
- Duffy JMN, Arambage K, Correa FJS, et al. Laparoscopic surgery for endometriosis. Cochrane Database Syst Rev. 2014.
- Canis M, Bourdel N, Houlle C, Gremeau AS, Botchorishvili R, Matsuzaki S. Endometriosis may not be a chronic disease: an alternative theory offering more optimistic prospects for our patients. *Fertil Steril*. 2016;105:32–34.
- Shadbolt NA, Parker MA, Orthia LA. Communicating endometriosis with young women to decrease diagnosis time. *Heal Promot J Aust*. 2013;24:151–154.
- Grajales FJ III, Sheps S, Ho K, Novak-Lauscher H, Eysenbach G. Social media: a review and tutorial of applications in medicine and health care. J Med Internet Res. 2014;16:e2912.
- Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *J Med Internet Res.* 2013;15:e1933.

- Househ M. The use of social media in healthcare: organizational, clinical, and patient perspectives. Stud Health Technol Inform. 2013; 183:244–248.
- Bizcognia. Instagram statistics. https://bizcognia.com/instagram-statistics/. Accessed September 18, 2024.
- 12. Qin LA, El-Neemany D, Winkler H, Shalom D. #Urogyn. Female Pelvic Med Reconstr Surg. 2020;26:283–286.
- Park JH, Christman MP, Linos E, Rieder EA. Dermatology on instagram: an analysis of hashtags. J Drugs Dermatol. 2018;17:482–484.
- Gochi MS AM, Coen NB, Ge S, Stuparich MA, Nahas S, Behbehani S. Instagram users' content on endometriosis—does endometriosis awareness month make a difference? Fertil Steril. 2020;114:e213–e214.
- Carlson S, Coyne K, El-Nashar S, Billow M. Analysis of endometriosis related hashtags on Instagram. *J Minim Invasive Gynecol*. 2020; 27:S141–S142.
- Towne J, Suliman Y, Russell KA, et al. Health information in the era
 of social media: an analysis of the nature and accuracy of posts made
 by public Facebook pages for patients with endometriosis. *J Minim Invasive Gynecol*. 2021;28:1637–1642.
- Sinha R, Shibata R, Patel A SJ. Social media in minimally invasive gynecologic surgery: what is #trending on Instagram? *J Minim Inva*sive Gynecol. 2021;28:1730–1734. https://doi.org/10.1016/j.jmig. 2021.02.011.
- HubSpot. How to use Instagram insights (in 9 easy steps). https://blog. hubspot.com/marketing/how-to-use-instagram-insights. 2022. Accessed September 22, 2023
- Demeku A. The ultimate guide to Instagram analytics in 2023. https://later.com/blog/instagram-analytics/. 2023. Accessed September 22, 2023.
- Mohsin MA, Beltiukov A. Summarizing emotions from text using Plutchik's wheel of emotions. Adv Intell Syst Resaerch. 2019;166:291–294.
- Melander I. Multimodal illness narratives on Instagram: sharing the experience of endometriosis. *Interdiscip E-J Narrat Res.* 2019;8:68–90.
- Holowka EM. Mediating pain: navigating endometriosis on social media. Front Pain Res. 2022;3:889990.
- Gambadauro P, Carli V, Hadlaczky G. Depressive symptoms among women with endometriosis: a systematic review and meta-analysis. *Am J Obstet Gynecol*. 2019;220:230–241.
- Zarbo C, Brugnera A, Dessi V, et al. Cognitive and personality factors implicated in pain experience in women with endometriosis: a mixedmethod study. *Clin J Pain*. 2019;35:948–957.
- Van Niekerk L, Johnstone L, Matthewson M. Predictors of self-compassion in endometriosis: the role of psychological health and endometriosis symptom burden. *Human Reprod.* 2022;37:264–273.
- McPeak AE, Allaire C, Williams C, Albert A, Lisonkova S YP. Pain catastrophizing and pain health-related quality-of-life in endometriosis. Clin J Pain. 2018;34:349–356.
- Arena A, Degli Esposti E, Orsini B, et al. The social media effect: the impact of fake news on women affected by endometriosis. A prospective observational study. Eur J Obstet Gynecol Reprod Biol. 2022;274:101–105.
- 28. Hirsch M, Aggarwal S, Barker C, Davis CJ DJ. Googling endometriosis: a systematic review of information available on the internet. *Am J Obstet Gynecol*. 2017;216:451–458.e1.
- Benetoli A, Chen TF, Aslani P. How patients' use of social media impacts their interactions with healthcare professionals. *Patient Educ Couns*. 2018;101:439–444.
- **30.** Piszczek CC, Foley CE, Farag S, et al. Social media utilization, preferences, and patterns of behavior in patients with gynecologic pelvic pain. *Am J Obstet Gynecol*. 2022;226:547.e1–547.e14.

Supplementary materials

Supplementary material associated with this article can be found in the online version at https://doi.org/10.1016/j.jmig.2025.01.018.