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Between Comments and Collective Action: The Potential of TikTok in Endometriosis Advocacy

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Scholars have been exploring the potential of TikTok in facilitating health communication and activism separately, leaving a gap in understanding the political implications of health communication on TikTok. Filling this gap is important because it matters whether and how the communication mediated by the platform can translate into collective action to address the underlying health inequality issues. In response, we conducted a case study of TikTok videos about endometriosis diagnosis and treatment. Particularly, we conducted a qualitative content analysis of 713 comments beneath 36 videos that share medical gaslighting experiences in endometriosis diagnosis and treatment. We identified that the comments mainly focused on (1) sharing lived experience, (2) extending affirmation, appreciation, and gratitude, and (3) critiquing the medical system. Our findings evidenced the potential of TikTok in endometriosis advocacy while also revealing the limitations of comments as spaces that can lead to collective action.

Keywords: TikTok, endometriosis, collective action

Media and communication scholars have long been interested in the sociopolitical implications of social media platforms, including TikTok. As one of the latest arrivals on the mainstream social media landscape, TikTok has gained a significant following since its launch in 2018. Media and communication scholarship on TikTok is in its infancy and has been gaining momentum since 2020 (Zeng, Abidin, & Schäfer, 2021). One of the main catalyzers of TikTok's commercial success is the COVID-19 pandemic, during which TikTok expanded its user base significantly and established itself as a platform for learning and entertainment (Zeng et al., 2021).

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The unique memetic logics of TikTok in driving content production and spread has drawn scholars' attention. Some scholars have been exploring the role of TikTok in health communication. A systematic review by McCashin and Murphy (2023) on studies that have examined TikTok for public health or mental health purposes shows that while existing studies identified the shortcomings, for example, disseminating videos of low informational quality, they also saw the positive potential of the platform in health communication, for example, better engagement with young users. Some scholars have identified the political potential of TikTok, especially in facilitating activism (e.g., Subramanian, 2021; Zulli & Zulli, 2022). However, the political implications of health communication on TikTok remain underexplored. This seems to be an issue with new media studies more generally as a systematic review by Hu (2015) revealed that no study had yet examined the use of new media for health policy advocacy.

As patients suffering from chronic pain from diseases like endometriosis turn more and more to social media platforms to share their experiences of medical disenfranchisement, this gap in the literature on social media and health advocacy has become ever more apparent. These experiences often include stories of dismissive and degrading responses from medical providers. Gonzalez-Polledo and Tarr (2016) called for research into how "making aspects of the pain experience visible or by networks of voices engaging and reinterpreting pain in networks of multimodal communications" (p. 1467) can bring up possibilities of health-related collective action to address the underlying health inequality issues. Echoing this call, we conducted a case study of videos about endometriosis circulating on TikTok ("EndoTikTok" thereafter for conciseness), identifying medical gaslighting experiences during endometriosis diagnosis and treatment and public responses to these videos. This is an early attempt to examine the political implications of using social media for health communication.

Social Media's Role in Collective Action

Researchers in different areas have been exploring how social media platforms can foster collective action. Studies on social media in general have identified a strong link between social media use and collective action. For example, Khalil and Storie (2021) found that social media platforms were used to expand Saudi women's campaign for the right to drive, Chan (2017) found that using social media for news can positively predict protest intention, and Seo, Houston, Knight, Kennedy, and Inglish (2014) identified a strong positive relationship between teens' YouTube use and their intention to participate in flash mobs. Recent feminist studies have acknowledged the facilitative functions of social media in, for example, making visible the emotional and physical costs of maintaining the work-life balance during the COVID-19 pandemic among academic mothers (Bauer & Ngondo, 2022) and challenging female genital normativity (Mowat, Dobson, McDonald, Fisher, & Kirkman, 2020). Social media has helped to challenge the status quo where women's voices are marginalized, stigmatized, or silenced.

Early evidence suggests that TikTok also facilitates activism (e.g., Subramanian, 2021; Zulli & Zulli, 2022). TikTok content relies on memetic logics to drive content production and spread. Consequently, posts generate relatability and collective sensibility (Schellewald, 2021). Zulli and Zulli (2022) therefore theorized TikTok users as "imitation publics" who are a collection of people whose digital connectivity is constituted through the shared ritual of content imitation and replication. Drawing from the features of the platform, Zulli and Zulli (2022) further predicted the potential of the platform in facilitating activism (e.g., users imitate and replicate civic-related videos if they are packaged as replicable challenges). Recent empirical studies supported TikTok's role in activism. For instance, the Asian community used TikTok to collectively combat anti-Asian racism by raising awareness of racism (Zhao & Abidin, 2023) and forming pan-Asian solidarity (Lee & Lee, 2023); girls from Bahujan communities in India identified themselves with the anti-caste movement by creating relevant assertions and expressions on TikTok (Subramanian, 2021); young, nonexpert users engage in climate activism on TikTok, using features like hashtags to unite their narratives (Hautea, Parks, Takahashi, & Zeng, 2021); and young people collectively expressed political stances via musical.ly, TikTok's predecessor that shares the same affordances, during the 2016 U.S. presidential election (Literat & Kligler-Vilenchik, 2019).

Health-Related Self-Disclosure on Social Media

Recent research into the interplay between social media and health-related self-disclosure has made two key findings. First, social media use by patients has brought visibility to and constructed meanings around ill-defined chronic illnesses, such as endometriosis on Instagram (Sendra & Farré, 2020) and Facebook (Gaybor, 2022) and fibromyalgia and lupus on Flickr and Tumblr (Gonzalez-Polledo & Tarr, 2016).

Second, studies found an exchange of social support afforded by social media. These studies largely built on the framework developed by Cutrona and Suhr (1992), who categorized social support into emotional (e.g., expressing empathy or providing encouragement), esteem (e.g., emphasizing recipient's abilities), network (e.g., reminding the person of the availability of companions), informational (e.g., providing detailed information about the situation), and tangible (e.g., expressing willingness to help) support. A meta-analytic review by Rains, Peterson, and Wright (2015) on content analyses examining computer-mediated social support messages among individuals coping with illness showed that informational, tangible, and network support were significantly more common among content analyses examining chronic health conditions in comparison with other health conditions. Recent empirical evidence showed that patients who had undergone a hysterectomy shared informational and emotional support through online social support groups (Parsons, 2019), breast cancer patients tended to receive socio-emotional support on Facebook (Mikal et al., 2021), and women who shared personal experiences of endometriosis received empathy, advice, and suggestions on Facebook (Gaybor, 2022).

Building illness worlds and extending support, as the above studies found, can have political implications. First, sharing disenfranchising experiences related to chronic diseases is linked to "a broader social critique that views structural inequalities and the uneven distribution of social power as responsible for the causes and/or triggers of the disease" (Brown et al., 2004, p. 60), which leads to the formulation of a politicized collective illness identity, scales up personal health issues to a social problem, and forms the basic mechanism of health-related social movements. Second, further to social support, Lee, Yuan, and Wohn (2021) found that participants who had seen a video streamer self-disclose mental health issues, compared with those who had not, had higher self-efficacy to seek help for depression. Third, emotional support can foster group-based emotions, for example, empathy toward the patient community and possibly anger toward the unequal social structure. According to established literature on collective action (van Zomeren, Postmes, & Spears, 2008), group-based social identification, efficacy, and emotion are strong predictors of collective action. However, while this is a pressing and timely political and social issue, studies have seldom taken a step further to examine the potential or impact of these self-disclosure practices on social media in health advocacy and mobilization, leaving a gap in studying the political implications of health communication on social media.

Gaybor's (2022) recent study explored how women used Facebook to cocreate knowledge and extend emotional support for each other in menstrual health. The study touched on the idea of how these practices might contribute to "defy[ing] the hegemonic knowledge and practices of menstrual bodies" (Gaybor, 2022, p. 909), a claim that could be strengthened with further research. In addition, the political implications of the discussions among the group members in a closed Facebook group need to be considered differently than those on public TikTok accounts.

Gendered Medical Gaslighting

Many patients, particularly women, report facing dismissive responses from medical providers when discussing pain. Symptoms and pains associated with female reproductive organs, like endometriosis, are stigmatized as being psychologically based or dismissed as "natural" parts of womanhood (Krebs & Schoenbauer, 2020; Wright, 2019). A meta-synthesis of qualitative research about the disenfranchising talk experienced by women with chronic overlapping pain conditions revealed that such talks discredited women's experiences, silenced their voices, and stereotyped their illness experiences (Hintz, 2023). This leads to damaged agency in future communications, decreasing self-perception of credibility and trust, reduced ability to seek care, support, and resources, and less confidence in patient-provider relationships (Hintz, 2023).

The prevalence of gendered medical disenfranchisement calls for urgent measures to address health inequalities and change unfair systems and policies (Hubinette, Dobson, Scott, & Sherbino, 2017; Zoller, 2005). In response, the World Health Organization and health advocacy groups have been drawing people's attention to the importance of menstrual health in recent years. Key demands include enabling patients to "access timely diagnosis, treatment and care for menstrual cycle-related discomforts and disorders," including "hav[ing] access to health services provided by competent health workers who operate in a system that is responsive to menstrual health needs" (Hennegan et al., 2021, pp. 32–34). Echoing this agenda, Hintz and Wilson (2021) urged researchers to explore "what individuals, groups, and communities *do* in efforts to enfranchise themselves again" (p. 245). Wright (2019) argued that "only through strong patient self-advocacy and knowledge can one rewrite the social scripts assigned to how women cope with menstrual pain" (p. 912).

Recently, patients with chronic pain have turned to social media to share experiences of medical disenfranchisement, including dismissive and degrading responses from medical providers. As argued by Hubinette and colleagues (2017), "Any discussion of social determinants of health, health inequities, or health care access necessarily invokes principles of fairness, the distribution of resources, systems-based practices and public policy—topics that are inherently political" (p. 128). To understand how such social media talks create spaces for collective action in relation to health advocacy, our study focused on EndoTikTok videos along with the comments on those videos related to medical gaslighting.

We chose endometriosis because it affects at least 10% of women and those assigned female at birth worldwide, including 1.5 million in the United Kingdom and 6.5 million in the United States (Ellis, Munro, & Clarke, 2022; Endometriosis UK, 2023). Endometriosis "is a condition where tissue similar to the lining of the womb grows in other places, such as the ovaries and fallopian tubes" (National Health Service, 2022). Despite being formally diagnosed more than 160 years ago, little is known about this illness, including its cause (Ellis et al., 2022). As diagnosis requires the cost and resource of laparoscopic surgery, the condition is often delayed or left undiagnosed, contributing to elongated periods of chronic pain and infertility rates (Ellis et al., 2022). In recent years, endometriosis has increased media attention and medical funding, due in part to social media's role in raising awareness of this illness. Yet endometriosis remains frequently undiagnosed or misdiagnosed—part of the larger dismissal and gaslighting of women's chronic pain (Graham, 2023).

Research Questions

Drawing from the above literature review, we asked the following research question:

RQ1: How do commenters respond to the EndoTikTok videos disclosing medical gaslighting experiences?

We were also interested in exploring the nuances of the responses as per different content creators, practices, and narrative styles; hence the next question:

RQ2: How are the type of content creator, the style of the video, and the content of the video related to the kinds of comments left below the video?

Method

Data Collection

This study is part of a broader project on endometriosis self-disclosure on TikTok. We first assembled a sample of TikTok videos using Web scraping. Although widely used in studies on social media content, Web scraping has been picked up by researchers of TikTok only recently (e.g., Kaye, Rodriguez, Langton, & Wikström, 2021) and has not received explicit and reflexive discussion on its application (Kanthawala, Cotter, Foyle, & DeCook, 2022). Our study used a reflexive four-step Web-scraping process. First, we had an initial exploratory hashtag run. It allowed us to get an overview of what was shared under the individual hashtag #endometriosis. We used the free version of Octoparse, a Web-scraping app that enables users to automatically retrieve video data from the Web browser version of TikTok without coding (Ahamad, Mahmoud, & Akhtar, 2017). Second, we aggregated returned videos to further investigate hashtags, keywords, user profiles, and user post frequency. Recent research suggests that looking beyond individual hashtags can help counter filtering biases, consider collocated hashtags, and "draw on contextual cues in the interplay between posts' visual content, captions and profile management" (McCosker & Gerrard, 2021, p. 1900). The third step drew from these data insights to create a refined Web scrape, that is, incorporating additional hashtags and video data. Our final step involved qualitative coding to determine which videos met our inclusion criteria, that is, videos that explicitly mention endometriosis in the video narrative itself instead of only using a related hashtag in the caption. We excluded those that (i) focused on peripheral issues (e.g., period pain and cramps), (ii) used non-English-language captions or speech, (iii) referred to irrelevant topics, or (iv) were unavailable. This resulted in a final sample of 139 videos for the broader project. For all the retrieved videos, we recorded (1) basic information (username, video URL, video length, caption, and hashtags), (2) engagement metrics (number of likes, comments, and shares), (3) technical and stylistic features, and (4) thematic and narrative elements.

We then subsampled videos with a thematic focus on medical gaslighting—experiences of inadequate medical advice or treatment and/or dismissal by health-care professionals in dealing with endometriosis. This resulted in 39 videos for our comments analysis. We further removed three due to comment retrieval restrictions, obtaining a final subsample of 36 videos. We labeled these 36 videos from 1 to 36 for convenience and clarity in presenting findings. We collected the first 20 comments shown under each video or all comments if the total number of the comments was less than 20. This resulted in a total sample of 713 comments.

Data Analysis

We used qualitative content analysis to analyze the comments. Qualitative content analysis refers to "the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). The method combines the strengths of qualitative methods (i.e., considering the specialty of data when generating the codebook and contextualizing the data in data interpretation) with those of the quantitative methods (i.e., quantifying the categories; Kracauer, 1952).

We combined deductive and inductive approaches when designing the codebook (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). The overall structure of the codebook was guided by the notion of health literacy (see Table 1). People's responses to health-related information, the medical gaslighting experiences shared on EndoTikTok in our case, reflect viewers' health literacy (Nutbeam, 2000; Sykes, Wills, Rowlands, & Popple, 2013). Health literacy refers to an individual's motivation and ability to access, comprehend, interact with, critique, and use health-related information for the purpose of maintaining good health (Frisch, Camerini, Diviani, & Schulz, 2012). The concept can be further categorized as functional health literacy, which concerns the basic understanding of health-related information, interactive health literacy, which refers to people's engagement with the information, and critical health literacy, which refers to people getting involved in health-related interventions and policies (Nutbeam, 2000). The three categories exist on a continuum, and greater autonomy is needed to achieve a higher level of literacy (Nutbeam, 2000). The above definition and categorization have proved useful in understanding and interpreting public's reactions to health-related materials (e.g., Fogg-Rogers, Bay, Burgess, & Purdy, 2015).

We further matched each of the three categories, that is, functional, interactive, and critical literacy, with specific codes. Three codes were inspired by previous literature on how social media users engage with comments to (i) construct illness world (our code "sharing lived experience") and (ii) extend social support (our codes "affirmation, appreciation, and gratitude" and "informational support"). References for these three codes have been provided in the "Operational Definition" column in Table 1. The remaining codes were inductively generated. Overall, we ensured that the codes were "internally as homogeneous as possible and externally as heterogeneous as possible" (Lincoln & Guba, 1985, p. 349).

To answer RQ1, we qualitatively assigned each comment to all relevant codes (Graneheim & Lundman, 2004; Tesch, 1990). It is common for some comments to reflect different codes at the same time. For example, we applied two codes, "affirmation, appreciation, and gratitude" and "sharing lived experience" to the comment "So true I'm a living testimony. I use celery juice to help with the pain." We also ranked the frequencies of the application of all codes to quantify comment patterns (Hsieh & Shannon, 2005).

Table 1. Codebook for Comments.

Health Literacy	Code	Operational Definition	Example
Functional	Affirmation, appreciation, and gratitude	Affirming the statements or information given in the video, and/or showing appreciation or gratitude for the content creator and the information or experience shared (Cutrona & Suhr, 1992; Zhao, Feigenbaum, & McDavitt, 2022)	"This is the first time I fully understood this condition. Thank you for explaining it so well!"
Interactive	Sharing lived experience (an insider perspective)	Sharing experience from one's own life (Cutrona & Suhr, 1992; Zhao, Abrahamson, Anderson, Ha, & Widdows, 2013)	"It took me years to convince a doctor that I needed more help. Then I was getting 'when was your last period' 🤦‍♀️🙄"
	Sharing vicarious experience (an outsider perspective)	Sharing testimony/witnessing of another's life	"My sister finally had hers removed in 2016 after almost bleeding to death! She couldn't have kids because of her endo and they wouldn't remove her uterus."
	Informational support (both insider and outsider perspectives)	Helping the recipient navigate their situation by giving advice, offering detailed information, facts or news, and/or referring the recipient to other sources of information or help (Cutrona & Suhr, 1992; Yip, 2020)	"In 2020 (I think) the universities in Australia got a couple of million dollars to research it. Hopefully something good comes from it."
	Information seeking	Asking a question to the creator or the community reading comments	"Is feeling like you are about to throw up when you are on your period normal?"
Critical	Critique of medical system	Critiquing the medical establishment, including doctors, hospitals, diagnostics, or treatments, in terms of finance, insurance, resource distribution, and/or normalization of pain, etc., as being structurally problematic, oppressive, and/or wrong	"Even worse when what all doctors suggest is chemicals from birth control instead of looking into the root of the cause."

	Critique of patriarchy	Critiquing misogyny, patriarchy, and/or normalization of women’s period pain and other reproductive issues	“It’s sexism in medicine. If endo affects men the way it does women, there would be a way better treatment and screening.”
	Call for structural change	Proposing structural change by protest, legal intervention, and other measures, as well as changes to norms and perspectives on a societal level	“We must stop normalizing debilitating periods.”

To answer RQ2, we categorized the sampled 36 videos as per their user information. This included two categories based on information in the user's profile bio: "Primary user type" and "influencer." We also categorized the videos as per the style of the video ("delivery style") and the content of the video (whether the video contained messages regarding "solidarity" and "collective experience"). Each of the categories contained several options. See Table 2 for detailed explanations. As for the analysis, we used the results from RQ1 against the options developed for RQ2, that is, calculating the frequencies of the application of the codes for comments in Table 1 against each of the options in Table 2.

Table 2. Categorization of Videos.

Category	Description	Options
Primary user type	The primary way the content creator describes themselves in the bio, caption, or video	• Diagnosed: Creator has an endometriosis diagnosis (i.e., patient or person living with the illness) • Entrepreneur/business owner • Health professional (including, but not limited to, obstetrician-gynecologist, endometriosis specialist, general practitioners, and nurses) • Wellness/nutrition specialist (e.g., dietician, nutritionist, or yoga- or fitness-related wellness specialist) • Advocate: Creator does not have endometriosis or symptoms but is advocating for a related cause
Influencer	Anyone who has more than 30,000 followers according to the Advertising Standards Authority	• Yes • No
Delivery style	The overall tone and style of the content being delivered in the video	• Sharing information • Sharing life story • Venting/catharsis • Humor • Other
Solidarity	Discussion about a loved one or others with endometriosis where the person speaking does not have endometriosis or any symptoms	• Yes • No
Collective experience	Transformation of any related illness narratives from the personal to the collective or broader political realm, proposing interventions that go beyond the individual level but consider policy or structural changes (Sendra & Farré, 2020)	• Yes • No

Throughout the codebook design and coding process, all three authors engaged in reflexive dialogues to ensure the trustworthiness of data analysis (Graneheim & Lundman, 2004).

Ethical Considerations

Ethics approval for this research was obtained from Bournemouth University's research ethics panel. Our ethical considerations echo those of recent scholarship. In line with best practice, this study only included videos created on public accounts. We also checked the content of the videos to ensure that they were intended for public viewership. These practices are consistent with those applied by recent TikTok studies focusing on health communication (Southerton, 2021; Southerton & Clark, 2023). As some of the sample videos (especially those created by users who were diagnosed with endometriosis) may still reveal personal information, we chose not to identify the creators when presenting our findings but still thank them for their contribution. In relation to our sample of comments, we also only included those that were publicly available. To eliminate the risks of any reader tracing the commenters or the corresponding videos, we did not reproduce the comments included in this article verbatim, following the practice by Southerton (2021) and McCosker and Gerrard (2021). Instead, we made minor adjustments to most of the examples, such as correcting grammar and removing redundant emojis, for ethical and accurate presentation. The comments presented verbatim were unlikely to be unique on social media (e.g., "Thank you for understanding").

Findings

Figure 1 captures our answer to RQ1. Commenters responding to the self-disclosure of medical gaslighting experiences on EndoTikTok overwhelmingly shared their personal experiences with the illness, with the category "sharing lived experience" appearing 460 times in the sampled 713 comments. The category "affirmation, appreciation, and gratitude" ranked second but with a much lower frequency (N = 255). The third most frequently applied category, "critique of medical system," was expressed by 183 comments. All the other categories appeared in less than 100 of the sampled comments, with only eight comments that explicitly "call for structural change."

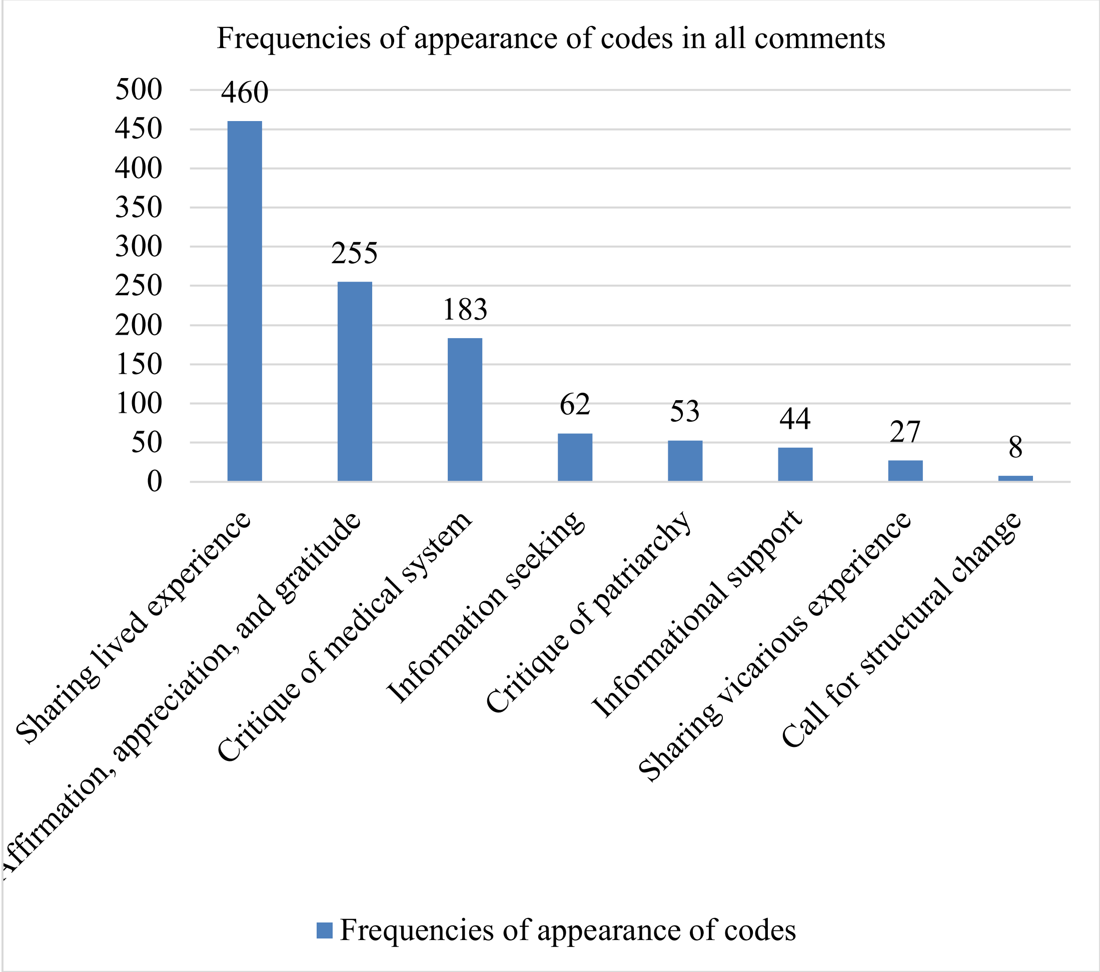

Figure 1. Comments on medical gaslighting experiences on EndoTikTok.

Table 3 answers RQ2. Echoing our finding to RQ1, the three categories of comments, that is, "sharing lived experience," "affirmation, appreciation, and gratitude," and "critique of medical system," consistently appeared more frequently across almost all the options within each category of the videos. Possibly corresponding to a larger proportion per category, seven types of videos resonated with more engagement from users who echoed the videos with "sharing lived experience," "affirmation, appreciation, and gratitude," and "critique of medical system." They were videos that were created by those who were (1) "diagnosed," (2) "health professional," or (3) "influencer," or were using the delivery style of (4) "sharing life story" or (5) "sharing information," or not containing messages regarding (6) "solidarity" or (7) "collective experience."

Table 3. Comments As Per the Different Categories of the Videos.

Category	Options	*N* of Videos	*N* of Comments	Affirmation, Appreciation, and Gratitude	Sharing Lived Experience	Sharing Vicarious Experience	Informational Support	Information Seeking	Critique of Medical System	Critique of Patriarchy	Call for Structural Change
Primary user type	Advocate	4	80	20	47	5	6	2	29	14	0
	Diagnosed	18	353	143	223	17	22	29	74	14	3
	Entrepreneur/business owner	2	40	10	23	1	4	7	12	7	1
	Health professional	11	220	82	151	4	10	22	67	17	4
	Wellness/nutrition specialist	1	20	0	16	0	2	2	1	1	0
	Total	36	713	255	460	27	44	62	183	53	8
Influencer	Yes	23	460	148	302	16	32	51	93	32	6
	No	13	253	107	158	11	12	11	90	21	2
	Total	36	713	255	460	27	44	62	183	53	8
Delivery style	Sharing information	10	200	66	144	2	11	19	53	17	4
	Sharing life story	14	273	115	172	12	22	25	62	11	3
	Venting/catharsis	8	160	45	88	11	8	14	42	17	0
	Humor	3	60	24	40	2	1	1	21	6	0
	Other	1	20	5	16	0	2	3	5	2	1
	Total	36	713	255	460	27	44	62	183	53	8
Solidarity	Yes	13	260	96	165	7	16	20	86	33	5
	No	23	453	159	295	20	28	42	97	20	3
	Total	36	713	255	460	27	44	62	183	53	8
Collective experience	Yes	9	180	60	94	13	13	15	60	22	3
	No	27	533	195	366	14	31	47	123	31	5
	Total	36	713	255	460	27	44	62	183	53	8

For example, under the category "primary user type," beneath video 16, whose creator was diagnosed with endometriosis, comments such as "I feel this" (personal communication, February 4, 2022), "You're so brave" (personal communication, September 7, 2022), "Bless you and thank you for sharing something so raw and true" (personal communication, July 23, 2022), and "I 100% feel your pain" (personal communication, March 5, 2022) showed "affirmation, appreciation, and gratitude." Viewers were also active in "sharing lived experience" under video 16, with examples such as the following: "I got ignored for two years. I ended up getting pregnant but not knowing until I was 32 weeks" (personal communication, February 4, 2022); "I'm on an endo journey myself searching for answers the last year. I have my first appointment in December" (personal communication, September 7, 2022); and "I had my first laparoscopy yesterday. I need to go back in 8 weeks for a more invasive surgery to remove the endometriosis" (personal communication, February 4, 2022).

Moreover, comments showing "critique of medical system" were found under videos created by those who were "diagnosed," such as the following: "Why won't the doctors listen to me" (video 16; personal communication, February 15, 2022); "Nowadays a lot of doctors just want the money, and don't actually want to help people. Sad. Not everyone, but a lot of them" (video 32; personal communication, June 24, 2021); and "It's shocking that how many doctors shouldn't be doctors" (video 36; personal communication, February 5, 2021).

Under video 10 created by a "health professional" explaining "women and girls at the GP" (content in caption), the comment "Thank you! This is 100% accurate! I'm too frightened to see my GP about anything anymore because I'm scared that they'll act like I'm wasting their time" (personal communication, November 23, 2020) echoed all the three categories, that is, "sharing lived experience," "affirmation, appreciation, and gratitude," and "critique of medical system." Similarly, the three categories were also manifested in the comment "Thank you for understanding! I have had many doctors who have treated me unfairly because they don't want to understand! So Thank you" (personal communication, August 26, 2021) under video 25 created by a "health professional."

Moreover, under the category "delivery style," videos that used the style of "sharing life story" also attracted viewers who were engaging in "sharing lived experience," "affirmation, appreciation, and gratitude," and "critique of medical system." Examples include "I can wholeheartedly relate! I just got diagnosed with endometriosis and a fibroid that has the size of an orange after years of being told that I just had bad periods" (video 2; personal communication, March 31, 2021) and "Are we living the same life?? I was also gaslighted and told it was in my head. I have gone to five different doctors for a diagnosis for about 5–6 years" (video 4; personal communication, November 17, 2021).

All other categories only appeared occasionally in the 713 comments. For example, comments to "influencer" videos reflected an expansion of knowledge of endometriosis, that is, offered "informational support" (*N* = 32) and "information seeking" (*N* = 51). Comments such as "try a cooling pad" (video 17; personal communication, June 18, 2021) and "If you haven't already looked Nancy's endometriosis nook has a ton of resources and education articles including a list of surgeons who do excision" (video 4; personal communication, November 17, 2021) showed "informational support" to the patient community. On the other hand, comments such as "What do we have to ask a doctor to get us checked for that? Which keyword should we use?" (video 9; personal communication, February 24, 2021) and "Is pain during ovulation a sign?" (video 28; personal communication, February 22, 2021) demonstrated "information seeking." Videos that contained a narrative regarding “solidarity” attracted comments that engaged in “critique of patriarchy” (*N* = 33); for example, “It’s women that are dismissed by doctors ALL THE TIME” (video 3; personal communication, January 31, 2022) and “Women just don’t get listened to about their health” (video 7; personal communication, July 9, 2021).

Discussion

Overall, our study found that comments on self-disclosed medical gaslighting experiences on EndoTikTok primarily helped to construct the illness world, affectively shared solidarity and support, and critiqued the medical system. We unpack our findings below.

First, in answering RQ1, we found that the comments overwhelmingly focused on “sharing lived experience,” helping build medical knowledge about endometriosis, a poorly defined and underdiagnosed chronic disease. This aligns with studies showing that social media help construct the illness world of chronic diseases (Gaybor, 2022; Gonzalez-Polledo & Tarr, 2016; Sendra & Farré, 2020). Collective sharing can foster a politicized collective illness identity, a strong predictor of collective action (Brown et al., 2004).

The political implications of “sharing lived experience” can also be reflected in the nuances of comments as per different video categories. In answering RQ2, we found that videos by those who were “diagnosed” or a “health professional” or an “influencer” or using the delivery style of “sharing life story” or “sharing information” frequently received comments from other users “sharing lived experience.” These videos create spaces for meaning making. They have transgressive power as they help diagnosed and undiagnosed patients to make sense of their experiences by engaging with the experiences and information shared in the videos. This testimony from others would likely be unavailable otherwise. Comments “sharing lived experience” also legitimize the content creators’ messages. They add qualitative depth to the original videos, confirm the prevalence of endometriosis experiences, and turn individual occurrences into a collective phenomenon. This resonance between comments and videos lays the groundwork for further political claims or movements.

While EndoTikTok discussions can benefit engaged users, they can create echo chambers with limited reach. On the one hand, since the videos focused on self-disclosure of illness experiences rather than public education about endometriosis, they may not engage members of the broader public who do not have the disease. On the other hand, as these videos centered on the patient community, they did not focus on drawing medical professionals into the conversation. Advocacy requires combining patient and medical voices to provide scientific and educational information about endometriosis. More dialogues between medical professionals and patients on social media could validate the experiences expressed in these videos and viewers’ responses in comments. As tackling medical disenfranchisement is a wider societal and structural issue that goes beyond the patient community, for EndoTikTok videos to have a greater political impact, content would need to include more public education narratives and dialogues with medical professionals.

Second, about one-third of the responses expressed “affirmation, appreciation, and gratitude” for the video creators, consistent with the works by Mikal and colleagues (2021), Gaybor (2022), and Zhao and colleagues (2022). These supportive comments came from both the endometriosis community and those who learned about the disease via these videos. This can help form group-based emotion, which can facilitate the initiation of relevant collective action.

As seen in Table 3, “affirmation, appreciation, and gratitude” responses were more frequent for videos by those who were “diagnosed” or “health professional” than those by “advocate,” “entrepreneur/business owners,” or “wellness/nutrition specialist.” There were more affective responses to “influencer” than non-influencer videos. Videos using the delivery style of “sharing information” or “sharing life story” received more affective responses than those using “humor” or “venting/catharsis.” This result might not be a surprise as the proportions of the videos, and hence the sampled comments, falling in the former types are larger than the latter. Nevertheless, viewing the comments from an aggregated perspective can illuminate the nature of the spaces that the comments created. The spaces were largely constructed by comments in response to videos that were created by content creators with, to a certain extent, credibility and authenticity in message delivery. However, the voices of the content creators delivered in the latter types of videos found fewer responses from viewers, squeezing out the communicative spaces for content creators who communicated the medical gaslighting issue surrounding endometriosis from the perspective of, for example, politics (“advocate”), commerce (“entrepreneur/business owner”), demonstration of anger (“venting/catharsis”), or humorous response to the disenfranchisement experience (“humor”). This indicates the limitation of the spaces generated by the interactions between videos and viewers in generating wider and more diverse affective discussions.

Third, about one-fourth of comments expressed “critique of medical system,” exposing reasons for medical gaslighting in endometriosis diagnosis and treatment. This indicates user engagement with relevant political discussions (Hubinette et al., 2017). Table 3 shows that such critiques resonated with videos by those who were “diagnosed” or “health professional” or who used the delivery style of “sharing life story” or “sharing information.” This resonance helps legitimize the need to change the status quo of medical gaslighting in endometriosis care.

Of note, Figure 1 shows a stark contrast between the frequency of “critique of medical system” ($N = 183$) and “critique of patriarchy” ($N = 53$). Unlike patriarchy, the medical system presents a more tangible and immediate target for critique. It is one in which enacting change and influencing practice can be more easily attainable than addressing the all-encompassing magnitude of the guiding patriarchal thoughts and systems in our society. Therefore, while medical gaslighting in endometriosis diagnosis and treatment is a feminist issue, users blame the underlying patriarchal culture less often. This might limit the implications of the political discussion on changing the status quo where women and others with uteruses face challenges in chronic illness diagnosis and treatment.

Fourth, while viewer interactions with the videos created spaces for discussions on disease experiences, affectively validating content creators, and critiquing the medical system as outlined earlier, the spaces were largely occupied by comments on videos that did not explicitly address themes of “solidarity” or “collective experience.” This does not diminish the value of the spaces in fostering a supportive environment for sharing illness experiences, which directly aids viewers in managing their health conditions. However, as the videos that address the disease on a systematic or structural level showed less viewer engagement, the impact of the spaces in bringing to the fore the underlying sociopolitical issues surrounding the disease and its diagnosis and treatment might be weakened.

Fifth, all other categories of the comments appeared much less frequently. For instance, “informational support” appeared in only 44 comments. This aligns with the findings by Mikal and colleagues (2021), who found that while breast cancer patients mainly sought support for resources on Facebook, they tended to receive socio-emotional support, which requires less commitment and engagement from the audience. Moreover, while previous studies evidenced TikTok's role in fostering collective action (e.g., Hautea et al., 2021; Literat & Kligler-Vilenchik, 2019; Subramanian, 2021), our study found that only eight comments directly mentioned "call for structural change."

Overall, our analysis identified three patterns in the comments: constructing the illness world, affectively sharing solidarity and support, and critiquing the medical system. These comments collectively aimed to solve the same issue, that is, the illness and the surrounding medical gaslighting issues, and fell within the realm of social media activism (Chon & Park, 2020; Nekmat, Gower, Zhou, & Metzger, 2019). They contribute to endometriosis advocacy by building a politicized collective illness identity, forming group-based emotion, and scrutinizing the medical system. Therefore, theoretically, this study evidenced the political implications of health communication on TikTok. While our identified limitations prevent definitive claims about whether the comments will eventually amount to collective action, their role in empowering the public to assert agency and drive change cannot be overlooked.

Theoretical Implications

This study contributes to understanding the political implications of health communication on social media. Medical gaslighting issues in the treatment of women with chronic diseases reflect those related to the "principles of fairness, the distribution of resources, systems-based practices and public policy" (Hubinette et al., 2017, p. 128). These are health-care issues that are underscored by power imbalances in the medical system and its embedded patriarchal culture. While existing research has importantly examined how social media users construct the illness world and exchange social support, our study extends this scholarship by exploring the role of self-disclosure on social media in facilitating collective action and health advocacy.

Based on previous research and this case study, we propose the following typology to map how self-disclosure on social media spans from raising awareness to calling for structural change. This typology can help health communication researchers understand how content and engagement on social media spaces can transition between support-oriented spaces and platforms for public advocacy and collective action. In the typology, we treat the political aspects, that is, structural critique and call for action, as an integral element of the whole map, echoing existing scholarship that understands health literacy as a continuum, progressing from functional to interactive to critical literacy (Nutbeam, 2000). By demonstrating the trajectory of self-disclosure on TikTok from a support community to spaces for collective action, we emphasize that issue publics formed around chronic illness do not "emerge, exist for varying durations, and then eventually dissolve" (Dahlgren, 2009, p. 74). Instead, they create hybrid spaces where long-term support and kinship evolve into discourses of collective action and dissent. The visualization of this typology is given in Figure 2. Here we specify categories for grouping comments (middle row) and their implications for collective action (upper row). The continual efforts in raising awareness and constructing and expanding knowledge are necessary to generate structural critique and social change. Integrating this typology into comment codebooks allows scholars studying health communication on social media, particularly TikTok, to better grasp its potential for patient advocacy and policy change.

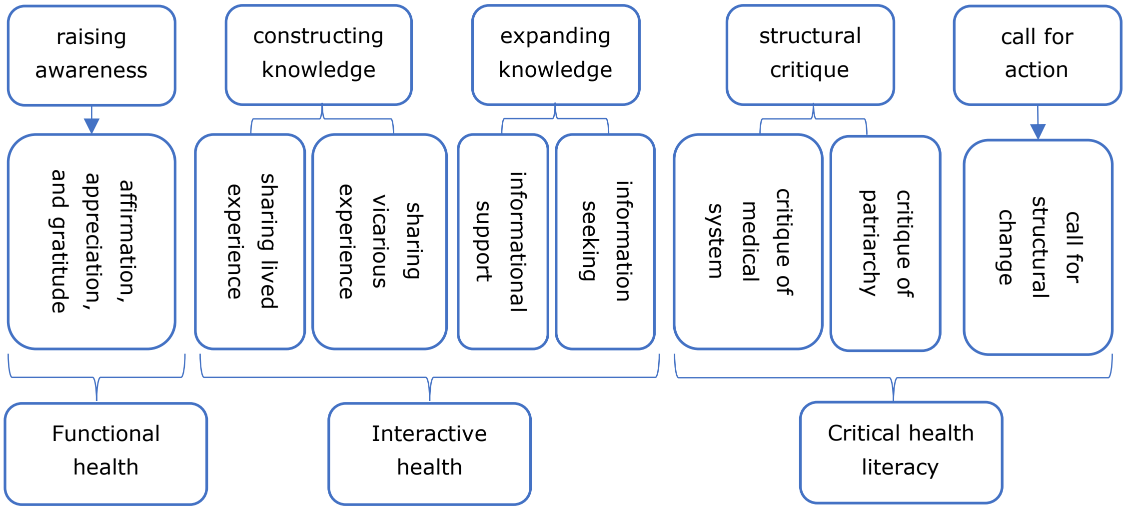

Figure 2. Typology of public responses to health-related self-disclosure.

Practical Implications

Responding to the call by Hintz and Wilson (2021), our findings offer empirical insights for developing health advocacy and patient support strategies on TikTok. As suggested by Besley and Dudo (2022), effective science communication tactics should be goal oriented. Therefore, to raise awareness of endometriosis and the related medical gaslighting issues, collectively build knowledge of the poorly defined disease, or encourage structural critique, one can use the communicative spaces created by the interactions between video content creators and viewers focusing on the medical gaslighting issues on EndoTikTok.

Given that the disease and the related gaslighting issues have been brought to the public attention only recently, it is reasonable and understandable to leverage the types of videos that primarily focus on the disease itself and/or have a certain level of trustworthiness to achieve either of the above three objectives. These include videos that are created by individuals who are (1) "diagnosed," (2) "health professional," or (3) "influencer," or those using the delivery style of (4) "sharing life story" or (5) "sharing information," or those devoid of messages regarding (6) "solidarity" or (7) "collective experience."

Limitations and Future Directions

Our study has several limitations. First, our sampling method for the broader project was constrained by the software used, which returned only the top 900 videos by likes. This limitation is common in social media analyses that rely on Web scraping. Such methods potentially exclude smaller accounts, videos with low engagement metrics, and content creators less adept at leveraging platform algorithms. While focusing on the most liked videos aligns with platform algorithms and our focus on collective action, it is important to acknowledge that this approach may overlook voices crucial to health policy advocacy, both in videos and their corresponding comments.

Second, the codebook for comments may be applicable only to medical cases that are ill-defined. For cases that are extensively studied and have established treatment, viewers may be less likely to ask questions regarding the illness (i.e., "information seeking") or critique the medical system for inadequate diagnosis and treatment. These two limitations underscore a common challenge in research at the intersection of health communication and social media. A well-rounded research team for such studies should ideally include experts in the specific medical field under investigation, health communication, social media, and computer science. We hope our study stimulates discussions on forming effective interdisciplinary teams.

Third, this small-scale study using qualitative content analysis has inherent limitations in data analysis and results reporting. Our sample size was not large enough to be validated with quantitative reliability procedures, and we were unable to draw inferential conclusions. This limits our understanding of the relationships between comment categories and video types. Moreover, we did not explore the qualitative relationships between responses and videos that were produced by "influencer" who might also fit into one of the "primary user type" options, which might have yielded additional insights into the relationship between a content creator's popularity, identity, and viewer responses.

Conclusion

This study examined comments on self-disclosed experiences of medical gaslighting on EndoTikTok. It analyzed the nuances in comments in relation to the type of the content creator, the delivery style and the content of the video. We found that the comments mainly focused on "sharing lived experience," "affirmation, appreciation, and gratitude," and "critique of medical system." These comments are helpful in building a politicized collective illness identity, forming group-based emotion, and scrutinizing the medical system, respectively, evidencing the political implications of health communication on TikTok. Our findings also revealed the limitations of video comments as spaces that can lead to collective action, as the spaces are limited in, for example, generating wider affective responses or critiquing the underlying patriarchal culture within the society. However, rather than seeing these support spaces fostered by content creators and their viewers as apolitical or apathetic, we argue that they form a supportive community where a movement can gather momentum. Understanding this momentum's development and its implications for health advocacy strategies warrants ongoing scholarly attention.

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