



Article

Endometriosis Awareness Month on Social Media: A Content Analysis of Images and Captions on Instagram

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Abstract: Endometriosis Awareness Month (EAM) is a global movement that seeks to increase awareness of endometriosis. There is a paucity of peer-reviewed research that explores the social media activity of EAM, making it difficult to draw conclusions about what information is being shared. To address this gap, we performed inductive thematic analysis to investigate the visual and written content of images ($n = 879$ images), as well as post captions of $N = 600$ posts that contained the hashtag “#endometriosisawarenessmonth”. Results show that written content within the images most frequently contained features of the disease. Caption content featured general/vague knowledge about the disease and general awareness of endometriosis, such as ‘pain (general/unspecified)’. The mental health impact of the disease was underrepresented in Instagram posts. Moving forward, the #endometriosisawarenessmonth campaign could be strengthened by communicating specific diagnostic and prevalence information, and harnessing conversations about the impact of the disease on mental health.

Keywords: instagram analysis; endometriosis; endometriosis awareness; content analysis; women’s health



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1. Introduction

Endometriosis is a chronic, inflammatory, estrogen-dependent disease characterised by endometrium-like tissue located outside of the uterus [1]. The disease affects at least 10% of people assigned female at birth [1,2]. However, accurate prevalence data is difficult to obtain because a reliable diagnosis requires surgery and given the current paucity of empirical prevalence studies in broader general populations [3]. Common physical symptoms include chronic pelvic pain and abdominal bloating [4,5]. Infertility is another outcome associated with the disease, with 30–50% of women with endometriosis experiencing infertility [6]. Given that endometriosis is associated with reduced quality of life [7], it is unsurprising that symptoms of depression and anxiety co-occur frequently in endometriosis patients [8]. This disease has economic impacts too, with pain severity strongly related to productivity costs [4]. A diagnosis of endometriosis is often delayed owing to a scarcity of definitive, non-invasive diagnostic options, and reliable biomarkers [9]. Moreover, pain severity does not represent the severity of the disease [10], which means that endometriosis can often be asymptomatic and undetected, leading to a delayed diagnosis [9,11–13]. Further, the exact aetiology and risk factors of endometriosis are not well understood [14]. There is currently no cure for endometriosis [4], and while a variety of treatment options exist (e.g., medications, surgery, and natural lifestyle approaches [15]), all have varying success [16]. Further, due to limited research, there are no studies to identify if early diagnosis of endometriosis may lead to relieved pain or prevention of infertility [3].

Addressing these challenges requires a multidisciplinary approach to endometriosis research [17]. Indeed, medical research recommendations aimed at improving the detection and diagnosis of endometriosis exist [17], as well as core outcome sets to facilitate quality treatment outcome evaluations [18]. Psychology also has an important role to play, given the potential influence that greater public knowledge and awareness about the symptoms

of endometriosis could have on decreasing diagnostic delays [19,20], reducing societal stigma about chronic pelvic pain [21], and influencing policy change [22].

One way to raise awareness is via social media. A review exploring social media and broader chronic disease management found that such strategies were linked to improved health outcomes, increased social support and interaction, as well as improved disease-specific knowledge [23]. An Instagram analysis of posts tagged with the hashtag “#chronicpain” found that endometriosis was the second most discussed pain condition, after fibromyalgia [24]. Research examining the features of social media activity for endometriosis specifically has focused on user characteristics, as well as reasons for, and benefits of, an online support group. For example, Carneiro et al. [25] reveal that women aged between 25 and 44 were the predominant users of a Facebook “fan page” designed to provide educational information regarding endometriosis. Carlson et al. [26] analysed Instagram hashtags and found that posts by patients typically comprised less educational content than information shared by health professionals. Koller and Bullo [27] analysed social media images that include endometriosis-themed tattoos (i.e., the yellow ribbon), and concluded that tattoos are a tool to increase endometriosis awareness and were often posted alongside content referring to “fighting” endometriosis (e.g., “warrior”). Wilson et al. [28] showed that members of the Facebook group “MyEndosis” believed that the continuous dialogue about endometriosis facilitated feelings of empowerment. Group members also believed that they were not receiving satisfactory information from medical professionals, and therefore joined the group to receive information from other patients [28].

For most advocacy groups, social media is one component of a targeted campaign, such as a public health awareness initiative, aimed at facilitating public awareness of a condition. This goal is an important first step to raise the public profile of a disease such as endometriosis, where symptoms have historically had limited community awareness [20,29,30]. One such campaign, Endometriosis Awareness Month (EAM), has occurred annually in March since 1993 [31]. The organisers describe EAM as a global movement that seeks to increase awareness of endometriosis, to improve diagnosis and treatment (through fundraising activities), and to facilitate policy changes [32]. Despite its long history, there is a paucity of peer-reviewed research specifically exploring the social media activity of EAM, which makes it difficult to draw conclusions about what information is being shared because of this campaign. Of the scholarly work that does explore the social media activity, search terms were narrow, research purposes differed, and, at the time of writing, both projects were published as conference abstracts [30,33]. Gochi et al.’s [33] analysis of the top Instagram posts published during EAM 2020 found that Instagram accounts were more active during EAM, and content that was posted during EAM included posts that were more emotional and more educational than posts shared prior to EAM [30]. Meanwhile, Coen and colleagues [34] analysed associations between features of the Instagram handle name and type of content. Both analyses focused on content posted under the hashtag “#endometriosisurgery”, and Coen et al. [34] further focused on content posted only by accounts that had “endo” in the Instagram handle. Given these narrow methodological approaches, a broader analysis of EAM content is warranted to comprehensively understand how this initiative is being used to raise awareness online, and to explore what type of content is shared. To address this gap, the current study sought to analyse the visual and written content of Instagram posts during EAM. The aim of this research is to determine the features of image content and caption content of Instagram posts published with the hashtag “#endometriosisawarenessmonth”.

2. Method

2.1. Selection of Instagram Posts

We searched the hashtag “#endometriosisawarenessmonth” while logged into the primary researcher’s (B.L.) Instagram profile. Consistent with previous Instagram analysis post-selection methods [35,36], we coded the last 600 public posts shared during Endometriosis Awareness Month 2021 (March 2021). Video posts were not included in

this analysis, owing to a different analysis method necessary for this media type. Posts were identified in one sitting in May 2021. Three duplicate posts were identified and replaced with the next three public posts. Posts were removed from the analysis if captions only linked to information in a bio or image (5%), had no captions (3%), captions and/or images were not in English (4%), and captions and/or images were unrelated to endometriosis (4%). Posts that were removed based on these caption and image features were replaced with the next available post. Where a single post contained more than one image (i.e., a carousel post; $n = 92$), all images were included in the analysis. The final sample comprised 600 posts that contained 879 images and 600 captions.

2.2. Reflexive Thematic Analysis of Visual, Written, and Caption Features of Posts

We performed reflexive thematic analysis [37] to identify and interpret patterns in three components of a single post: (1) visual features of the image, (2) written features within the image (where applicable), and (3) post caption text. First, we familiarised ourselves with the data by reviewing post features, to gain a preliminary understanding of the whole post. During this time, the authors made brief notes about common features. As this was the first comprehensive Instagram analysis of EAM, an inductive approach to identifying initial codes from the raw data was utilised, such that initial code production was guided by the content of the post features and not a pre-existing theory or framework [37]. Initial codes for the visual features of the image and caption text were first developed by B.L. Initial codes for the written features within the image were developed by S.M. and were refined through discussions amongst both authors. In the final stages, a table was developed to cluster codes into broader themes. Consistent with typical practice guidelines [38], 10% ($n = 87$) of the images were coded independently by a second coder, to gauge consistency of identifying patterns within these data. Where discrepancies emerged, this was discussed to reach a consensus. Inter-coder agreement ranged between 87 and 100% across analyses. Miles and Huberman [39] propose a standard of 80% agreement on 95% of the codes, reflecting an adequately consistent interpretation of the codes across raters in this research.

3. Results

3.1. Image Analysis: Visual Content

We identified 11 categories that represented key features of the post content. The category labels were: text, people, yellow, endometriosis ribbon, books, uterus, miscellaneous object, abdomen, animal, cartoon drawing, and other. Over half of the posts (58%, $n = 348$) included text, and over a third (34%, $n = 204$) included images of people. Yellow, the colour associated with endometriosis [27], was evident in over a third of the images (34%, $n = 204$). The endometriosis ribbon was represented in 9% ($n = 55$) of the images. See Table 1 for an overview of the category features and frequency of image content.

3.2. Image Analysis: Written Content

Written content in the images was represented by seven themes: feature of the campaign, feature of the disease, feature of the delivery style, message tone, impact of the disease, further education and learning, and other (see Table 2). The three most frequently identified subthemes fell in the 'feature of the disease' theme, and included: symptomatology (21.6%), treatment/symptom management (21.3%), and diagnostic information/prevalence (15.2%). Other common aspects of the written content included text delivered as a single endometriosis-related title, phrase, or word (10.6%) such as "endo", and text that encompassed a message tone that reflected support and empowerment (10.6%), such as "how has the endo community helped you?".

Table 1. Features and frequencies of visual image content in posts with the hashtag “#endometriosis-awarenessmonth”.

Theme	Description ^a	Frequency % (n)
Text	Posts that included text (e.g., infographics or quotes)	58.0 (348)
People	Posts that included people (excluding photos of only the abdomen and animations/drawings)	34.0 (204)
Yellow	Posts that included the colour yellow anywhere in the image	34.0 (204)
Endometriosis ribbon	Posts that included the endometriosis ribbon	9.1 (55)
Miscellaneous object	Posts that only include a miscellaneous object (i.e., as the only feature in the image)	5.8 (35)
Abdomen	Posts that included a human abdomen with adhesions, scars, bruises, and/or bandages	5.5 (33)
Uterus	Posts that included features of a uterus	4.8 (29)
Books	Posts that included book(s)	4.5 (27)
Animal	Posts that included features of an animal	3.0 (18)
Other	Posts that included content that was undistinguishable	2.6 (16)
Cartoon/drawing	Posts that included a cartoon/drawing (including cartoon figures of humans) with no words	1.5 (9)

^a Example coded images are presented in Supplementary Materials. Note. Instagram images were exhaustively coded, therefore cumulative percentages exceed 100.

Table 2. Features and frequencies of written text in images of posts with the hashtag “#endometriosis-awarenessmonth”.

Subtheme	Theme	Definition	Examples/Descriptions of Text	Frequency % (n)
Symptomatology	Feature of the disease	Written text refers to symptoms of endometriosis	“almost 30–50% of patients with endometriosis also suffer from infertility”, “83% of people with endo say their first symptom was bloating”, tips on identifying warning signs for endometriosis, ways to improve bloating	21.6 (75)
Treatment	Feature of the disease	Written text refers to endometriosis treatment or symptom management.	“stent removal”, infographic with tips to improve bloating, surgical preparation vlog advertisement, infographic about treatment options	21.3 (74)
Diagnostic information/prevalence	Feature of the disease	Written text refers to aspects of endometriosis diagnosis and/or its prevalence.	“68% of women with endometriosis were initially misdiagnosed with another condition”, “200 million women suffer from endometriosis”, “1 in 10”, reference to diagnostic delay	15.2 (53)
Single endometriosis-related title, phrase, or word	Feature of the delivery style	Written text encompasses a word or phrase that is related to endometriosis. No additional information about features of EAM or endometriosis is included.	“endometriosis”, “endometriosis awareness month”, “the endo diaries”, “end endo”, “#EndoTheStigma”	10.6 (37)
Support and empowerment	Message tone	Written text that represents a feeling of empowerment or community support	Invitations to join support groups, reference to the positive impact of the support from the online endometriosis community, “Endometriosis is knowing that I am not alone”, “you can do everything right and still have a flare up”	10.6 (37)

Table 2. Cont.

Social/emotional impact of the disease	Impact of the disease	Written text refers to the social/emotional impacts of the disease	"How am I feeling now? Forgotten. Giving up hope of surgery. Struggling day to day. Resentful of others getting surgery. Shame for feeling resentful. Neglected. Scored of the damage." "1 in 4 women with endometriosis have contemplated suicide"	9.7 (34)
Aetiology information	Feature of the disease	Written text refers to the course and/or cause of endometriosis	"Does endometriosis grow or spread? There is no evidence to support this at present", "there are many areas of the body endometriosis can affect including your ovaries, uterus, bladder, large and small bowels, lungs, cervix, diaphragm, liver, gallbladder, the list goes on" "is endometriosis an autoimmune disease? As of now, no. But it causes autoimmune inflammation that weakens immune response"	8.9 (31)
Inspirational quote	Feature of the delivery style	Written text is a quote with inspirational sentiment	"endometriosis doesn't define me", "you are worthy of love exactly as you are", "you are beautiful", "maybe you've been assigned this challenge so you can show others how to fix it"	7.2 (25)
Seminar, podcast, webinar, channel, live talk, blog/article advertisement	Further education and learning	Written text advertises an opportunity for additional learning about endometriosis.	Advertisement of a seminar, podcast, blog post, channel, webinar, live talk, non-peer reviewed article or blog related to endometriosis	6.0 (21)
Information about/characteristics of EAM	Feature of the campaign	Written text describes features of EAM	"March is endometriosis awareness month" "endometriosis awareness month might be coming to an end, but the conversation is not over"	5.5 (19)
Humour	Feature of the delivery style	Written text aimed to provoke laughter and provide amusement	"here come the cramps, do do do" text with the Beatles <i>Abby Road</i> album cover image, picture of a cartoon uterus holding a knife with the text "let's get this party started, b**ch", picture of Bob the Builder with the text "not even Bob the Builder can fix this"	4.6 (16)
Disempowerment	Message tone	Written text relates to the feeling of disempowerment resulting from living with endometriosis	"When your oppressor is your doctor and propaganda is the doctrine, your perception of reality is forever altered", negative hospital experience review, negative treatment experience, "it's not just a bad period!", online censorship of endometriosis content, "do you believe me now?"	3.2 (11)
Endometriosis research	Further education and learning	Written text that links to peer-reviewed research, or refers to an issue related to peer-reviewed research	Screenshot of a peer-reviewed research article, calls for more research funding, "In July of 2020, the United States doubled its research funding for endo"	2.6 (9)
Fundraising	Feature of the campaign	Written text describes fundraising initiative	Calls to donate, total summaries (e.g., "total raised so far, \$400")	2.3 (8)

Table 2. *Cont.*

Metaphor	Feature of the delivery style	Written text is a metaphor	“my body is a haunted house”, “my silence is just another word for pain”, “the wound is the place where the light enters”	1.7 (6)
Consumer engagement strategies	Feature of the campaign	Written text refers to an Instagram challenge, giveaway or competition	“March into awareness video challenge for endometriosis awareness month”, a makeup voucher winner announcement, tens machine giveaway competition	1.4 (5)
Other			“trans and queer deserve the whole world”, “did you know”, posts about general women’s health	4.3 (15)

3.3. Post Caption Analysis

Five themes were identified in the caption content: knowledge and awareness of endometriosis symptomatology, assessment and diagnosis, treatment and management, and support (Table 3).

Table 3. Features and frequencies of caption text of posts with the hashtag “#endometriosisawarenessmonth”.

Subtheme	Theme	Description	Frequency % (n)
#EndometriosisAwarenessMonth	Knowledge and awareness	Mention of Endometriosis Awareness Month	30.0 (180)
Pain: general/unspecified	Symptomatology	Discussion of pain (generally) being a symptom of endometriosis	26.0 (156)
Medical intervention/support: surgery	Treatment and management	Discussion of how surgery (e.g., laparoscopy and hysterectomy) is used to diagnose and/or manage endometriosis	16.0 (96)
Calls to raise awareness about endometriosis	Knowledge and awareness	Encourage others to raise/continue to raise awareness about endometriosis	15.0 (90)
1 in 10	Assessment and diagnosis	Discussion of how 1 in 10 of people with a uterus have endometriosis at reproductive age	13.0 (78)
Diagnostic delay	Assessment and diagnosis	Discussion of challenges regarding diagnosing endometriosis and the typically long process	12.2 (73)
Issues with health care system	Assessment and diagnosis	Discuss issues with the healthcare system (e.g., medical gaslighting, lack of funding)	9.8 (59)
Infertility challenges	Symptomatology	Discussion of challenges conceiving and having a full-term pregnancy, including the use of interventions (e.g., IVF)	9.0 (54)
Fundraising	Knowledge and Awareness	Caption relates to fundraising activities for endometriosis	7.8 (47)
Irregular menstrual cycle	Symptomatology	Discussion of oligomenorrhoea (irregular menstrual cycle) as a symptom of endometriosis	7.7 (46)
Online support	Support	Discussion of the supportive community for endometriosis on social media and other online mediums	7.5 (45)

Table 3. Cont.

Medical intervention/support: other	Treatment and management	Discussion of other medical interventions to manage endometriosis (e.g., hormone treatments)	7.2 (43)
No prevention or cure	Treatment and management	Discussion of how there are no cures or preventions for endometriosis	6.7 (40)
Impact of endometriosis on the body	Assessment and diagnosis	Explanation of how endometriosis affects the body	6.5 (39)
Dysmenorrhea	Symptom recognition	Discussion of how severe pain during menstruation is a symptom of endometriosis	5.8 (35)
Instagram challenge	Knowledge and awareness	Post was part of an Instagram challenge (e.g., “stack for a cause”)	5.2 (31)
Lack of public understanding about endometriosis	Knowledge and awareness	Discussion regarding how the public have a lack of knowledge of endometriosis	5.2 (31)
Mental illness	Symptomatology	Discussion about how endometriosis can lead to mental health concerns (e.g., depression and/or anxiety)	5.2 (31)
Diet modification	Treatment and management	Discussion of how diet modifications (e.g., gluten-free or LowFODMAP) can be used to manage endometriosis	5.0 (30)
Gastrointestinal symptoms	Symptomatology	Discussion of how gastrointestinal symptoms (e.g., constipation and diarrhea) are a symptom of endometriosis	4.3 (26)
Exhaustion/fatigue	Symptomatology	Discussion of how exhaustion and/or fatigue are a symptom of endometriosis	4.2 (25)
Impaired quality of life	Symptomatology	Discussion of how endometriosis can impair people’s quality of life (e.g., ability to go to work or socialize)	3.8 (23)
Dyspareunia	Symptomatology	Discussion of how pain during intercourse is a symptom of endometriosis	3.7 (22)
Abdominal bloating	Symptomatology	Discussion of how abdominal bloating is a symptom of endometriosis	3.5 (21)

3.3.1. Knowledge and Awareness of Endometriosis

Within the Instagram captions that discussed content related to the theme of knowledge and awareness of endometriosis, content most frequently contained discussions about how EAM is a tool for spreading awareness and sharing personal endometriosis stories (30%; e.g., “My Endo Story, just in time before the end of #endometriosisawareness-month”). A further 15% of posts within this theme called for the need to be more aware of endometriosis, as there is “a lack of knowledge of endometriosis”.

3.3.2. Symptomatology

The most frequent symptom discussed in the posts was general pain (evident in 26% of posts); for example, “endometriosis is one of the most painful conditions”. Pain specifically related to menstruation (dysmenorrhea), “excruciating cramps”, and dyspareunia, “pain during or after sex”, was discussed in 65.8% and 3.7% of posts, respectively. A further 9% of posts discussed how infertility is a common symptom of endometriosis; “it is one of the top 3 causes of infertility”, “there is a chance I won’t be able to fall pregnant or carry a baby until full term”. Other common symptoms discussed included: abdominal bloating, colloquially known as “endo belly”, oligomenorrhoea (irregular menstrual cycles) or “very heavy bleeding”, and various mental health symptoms “[endometriosis] pushed me down to deep dark holes” and “crippling anxiety”.

3.3.3. Assessment and Diagnosis

Caption text contained information about delays in diagnosis: “it takes an average of 7–10 years to receive an endometriosis diagnosis” (evident in 12.2% of captions). Instagram captions also discussed the physical aspects of endometriosis, such as how endometriosis impacts the uterus, and how endometriosis is not only found in the uterus: “I have endometriosis in the bowel” (evident in 6.5% of captions). Thirteen percent of posts discussed how endometriosis is a condition that affects “one in ten”.

3.3.4. Treatment and Management

The most frequent treatment and management strategy discussed in the captions was surgical/medical interventions (16% of captions), where both laparoscopy and hysterectomy were discussed. Other medical interventions, such as birth control (e.g., the pill or IUD), were discussed in 7.2% of captions. Diet modification as a management strategy was evident in 5% of the captions (e.g., “choosing gluten-free options”, “eating lots of fibrous meals”). A total 6.7% of the captions contained information that stated there is no cure or prevention for endometriosis.

3.3.5. Support

Seven percent of captions contained information highlighted that the online endometriosis community provides support, e.g., “the support I’ve seen online has been staggering”. This included reference to specific endometriosis accounts, e.g., “amazing support can be found at @endometriosis.uk for anyone who thinks they may have endometriosis”.

4. Discussion

We analysed visual and written features of the images and captions of 600 Instagram posts that contained the hashtag “#endometriosisawarenessmonth”. Broadly, we found consistency between the information contained in the Instagram posts and information featured in empirical evidence. For example, the ‘1 in 10’ prevalence statistic, which represents current available research that suggests endometriosis impacts at least 10% of people with a uterus at reproductive age [1,2], was frequently shared in Instagram posts. This consistency suggests that EAM is facilitating the sharing of scientifically supported knowledge related to the symptoms of, and treatment for, endometriosis via written content in images on Instagram.

In contrast, our thematic analysis of caption text revealed that information most frequently related to unspecified/vague mentions of knowledge and awareness about endometriosis. That is, the level of detail differed markedly between information featured in image and caption texts, such that image text was more detailed. We offer two points for discussion regarding this finding. First, this result could reflect the use of Instagram as a predominantly photo-based social media platform, where users can include a caption up to 2200 characters long to add context to their image [40]. This format allows for images and captions to be interpreted together, which has been hypothesised to facilitate meaning multiplication, i.e., image and content details interpreted together provide a meaning that is more complex than the literal meaning of the text and image content individually [41]. A second point for discussion is whether the level of detail featured in the caption text is inconsequential. This point is supported by Brown and Tiggeman’s [40] finding that caption content did not influence self-reported body dissatisfaction and lower body appreciation scores among females aged 18–30. Further research is required to understand if, how, and to what extent, the level of detail in caption content influences the way an Instagram post is interpreted.

We identified a lack of specificity in detail pertaining to symptoms. Principally, “pain (general/unspecified)” was the most frequently identified symptom theme in the captions. In contrast, specific symptoms (e.g., dysmenorrhea, abdominal bloating, gastrointestinal symptoms, exhaustion/fatigue, impaired quality of life, infertility challenges) were

each represented in <10% of the captions. The prevalence of general/nonspecific pain as a symptom is consistent with previous research that found Instagram posts with the hashtag “#chronicpain” commonly discussed endometriosis [24]. The emphasis on general/unspecified pain could reflect how unspecified pain is often emphasised as the most common symptom of endometriosis [3,42]. Although infertility is another commonly listed outcome in medical research [42], it was infrequently featured in Instagram posts identified in this research. This absence could be explained by the young Instagram demographic, i.e., 39% of users are aged between 13 and 24 [43], such that topics of conception and fertility are not a priority for this user group. Alternatively, the absence could reflect a lack of awareness of the breadth of endometriosis symptoms. Given the lack of specificity in the Instagram posts, and the limited empirical data regarding endometriosis aetiology, symptomology, and treatment [3,14,16] from this study, it cannot be determined if misinformation regarding endometriosis is shared on Instagram.

We also found that branding features of endometriosis, such as yellow and the yellow ribbon, were uncommonly represented in content. This result might highlight that EAM is not strongly associated with the other marketing elements of endometriosis (e.g., the yellow ribbon), compared to other hashtags, e.g., “#endotattoo” [27]. Consistent branding strategies have been successful in other health awareness campaigns; for example, the widely recognised pink ribbon for breast cancer [44]. The ribbons use and popularity are argued to be a key reason that discourse around breast cancer shifted from stigmatised, to enriching and affirming [44]. There is a Breast Cancer Awareness Month (October) that is marked by companies and events embracing and promoting pink, which continues to generate large donations and shifts in awareness [45]. Clearly, there is benefit to a consistent branding strategy when attempting to raise awareness of, and promote knowledge about, a health concern. Nonetheless, there does appear to be some cohesion globally regarding what features of endometriosis should be targeted. Governments around the world, including Australia, Canada and England have implemented National Action Plans for Endometriosis, which include awareness of and education about endometriosis as a key priority [46–48]. Social media can play a meaningful role in achieving the goals listed in these national plans, by serving as a platform to communicate messages in a cohesive and branded way (i.e., be part of EAM and be linked to the yellow ribbon). Last, despite research outcomes that indicate significantly more people with endometriosis experience symptoms of anxiety and depression compared to healthy populations [8], we found that content related to mental health was scarce. This finding indicates an opportunity for social media to promote discussions about the mental health implications of living with endometriosis.

4.1. Limitations

Results should be interpreted in the context of the study’s limitations. Our sample did not include posts published on private Instagram accounts. Private posts may portray endometriosis differently, resulting in under- or over- representation of themes. For example, some Instagram users may not be comfortable posting pictures of their body/abdomen publicly. Case in point, McCosker and Gerrard [49] noted in their analysis of the hashtag “#depressed” that public posts featured stigmatised signs of depression (e.g., cut marks), whereas private posts featured intimate, confessional captions. We excluded posts that featured non-English languages, which may indicate that our results primarily represent the shared content of people with a Western country of origin. Consistent with existing work that references differences of experiences within minority groups living with endometriosis, e.g., [50], content related to endometriosis awareness may be different among Instagram users of non-Western origin. We must also consider the potential implications of collecting these data during COVID-19; it is possible that the proportion of certain themes (e.g., support/empowerment) could be influenced by features of the pandemic (e.g., lockdowns, physical distancing). Last, we acknowledge that it is challenging to

generalise what content is viewed by an individual Instagram user, thus threatening generalisability of results.

4.2. Implications and Directions for Future Research

While results provide preliminary evidence that the hashtag “#endometriosisawarenessmonth” is promoting empirically supported information, it is widely acknowledged that knowledge is a necessary, but not sufficient step, to change behaviours, policies, and societal views [51]. Consistent with psychological theory (e.g., theory of planned behaviour and its extensions), attitudes, norms, expectations, and self-efficacy (among other factors), are integral to successfully fostering change at an individual, community, and population level. From an intervention perspective, these active ingredients to change could be tapped into via the increased social media presence of key endometriosis organisations to more explicitly guide what content is shared (e.g., identifying a content ‘theme’ for the awareness month), as well as integrating calls to action. For example, a content theme that focuses on mental health and endometriosis, with a call to start a conversation about endometriosis. Starting a conversation has been used in other initiatives, such as Australia’s R U OK day, which encourages people to ask others “are you okay?” to promote discussion about mental illness. The R U OK initiative has been found to increase behavioural intentions to engage in helping actions [52] and these findings may be transferable to the endometriosis context. From a research perspective, scientific exploration of other active ingredients to change (beyond awareness, e.g., attitudes, public opinion, and social norms concerning the disease, and concerning social media communication about the disease specifically), could shed further light on barriers and enablers of change.

There is a scope for future scholarly work to analyse content shared on other social media platforms, such as Facebook, Tik-Tok, and Tumblr, to compare the nature of the content shared on these platforms with Instagram. Research has found that social media users engage with platforms differently regarding their posting behaviours, depending on whether they typically use the platform for social, entertainment, or informative purposes [53]. Finally, while social media data are useful for providing preliminary understanding of the content being shared about Endometriosis Awareness Month, the interpretation of these data is typically more comprehensive when analysis methods are triangulated (e.g., interpreted alongside survey and interview data) [54]. Therefore, future research could triangulate data methods.

5. Conclusions

This content analysis provides preliminary evidence that the Instagram hashtag “#endometriosisawarenessmonth” is a meaningful conduit for communicating evidence-based information about, and experiences of, endometriosis. This outcome is important, given that stronger awareness, acknowledgement, and education about endometriosis among the general public have been coined the “bedrock of an improved response” (Commonwealth of Australia, pp. 10; 46), and an important circuit-breaker for diagnostic delay, under-recognition, and ultimately, prolonged human suffering [46]. Importantly, results underscore which features of endometriosis are commonly shared on Instagram, such as the ‘1 in 10’ prevalence statistic, and the diagnostic delay time-period. Results also highlight features shared less frequently, such as specific endometriosis symptoms (i.e., beyond general/unspecified pain), as well as related mental health impacts of the disease. Understanding what is currently shared on Instagram via “#endometriosisawarenessmonth” can inform the focus of future campaigns, as well as guide direction for future research to address the remaining scholarly gaps pertaining to the use of social media for communicating about endometriosis.

Supplementary Materials: The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/women3010007/s1>, Table S1: Examples of Instagram posts.

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