

**Navigating Endometriosis Care: A Content Analysis of Women's Online Accounts of
Doctor-Patient Relationships**



The University of Adelaide

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(Honours)*

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Abstract

Endometriosis is a chronic condition experienced by women of reproductive age, where endometrial-like tissue grows outside the uterus. Women's experiences of their interactions with doctors about endometriosis are under-researched. Online discussion forums provide an opportunity to conduct naturalistic observations of how women describe doctor-patient relationships in the context of endometriosis without researchers' influence. Therefore, the current study aimed to explore how women with endometriosis (suspected or confirmed) describe doctor-patient relationships in online accounts. One hundred and seventy-six opening posts made during March 2023, Endometriosis Awareness Month, by 160 posters to a Reddit endometriosis Subreddit, identified through a systematic search, were analysed using conventional qualitative content analysis. Five overarching categories were generated to summarise posters' doctor-patient relationships: 'Communication', 'Accessing care', 'Negative healthcare experiences', 'Invalidation and dismissal', and 'Positive healthcare experiences'. Findings provide insight into how women with endometriosis interact with doctors and the difficulties they report encountering, such as doctors not being specialised in endometriosis, normalisation of pain, invalidation and dismissal, long delays, and challenges obtaining referrals and accessing appropriate care. Communication between doctors and patients must be improved to decrease long diagnostic delays and maximise patient satisfaction. Further research, including more naturalistic studies, about doctor-patient interactions for endometriosis would be beneficial and should include doctors' perspectives. Enhanced health professional training may also aid in optimising endometriosis care.

Keywords: endometriosis; women; online accounts; doctor-patient relationships; conventional content analysis

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made.

I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

██████████

September 2023

Contributor Roles

ROLE	ROLE DESCRIPTION	STUDENT	SUPERVISOR
CONCEPTUALISATION	Ideas; formulation or evolution of overarching research goals and aims.	X	X
METHODOLOGY	Development or design of methodology; creation of models.	X	X
PROJECT ADMINISTRATION	Management and coordination responsibility for the research activity planning and execution.	X	
SUPERVISION	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team.		X
RESOURCES	Provision of study materials, laboratory samples, instrumentation, computing resources, or other analysis tools.	N/A	N/A
SOFTWARE	Programming, software development; designing computer programs; implementation of the computer code and supporting algorithms; testing of existing code.	X	
INVESTIGATION	Conducting research - specifically performing experiments, or data/evidence collection.	X	
VALIDATION	Verification of the overall replication/reproducibility of results/experiments.		X
DATA CURATION	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later re-use.	X	
FORMAL ANALYSIS	Application of statistical, mathematical, computational, or other formal techniques to analyse or synthesise study data.	X	X
VISUALISATION	Visualisation/data presentation of the results.	X	
WRITING – ORIGINAL DRAFT	Specifically writing the initial draft.	X	
WRITING – REVIEW & EDITING	Critical review, commentary or revision of original draft	X	X

A colleague with expertise in computer technology assisted by developing the programming script and running the initial searches. I used Grammarly to help detect minor grammatical errors on the final draft of my thesis.

**Navigating Endometriosis Care: A Content Analysis of Women's Online Accounts of
Doctor-Patient Relationships**

Endometriosis is a chronic inflammatory reaction that occurs when endometrial-like tissue forms outside the uterus lining and is found elsewhere in the body (i.e., in the pelvic organ region, brain, kidney, lung, or bladder) (Konrad et al., 2019). Each month, during a woman's menstrual cycle, the blood gets trapped inside instead of leaving the body (Bedaiwy et al., 2017; Bullo, 2018; Márki et al., 2022; Metzemaekers et al., 2021; Olive & Pritts, 2001). While estimates vary, endometriosis is a significant health issue, said to affect 2% - 10% of the general population, 50% of people with infertility (Bullo, 2018; Márki et al., 2022; Metzemaekers et al., 2021), and more than 60% of people with chronic pelvic pain (Bedaiwy et al., 2017). It affects around 700,000 women in Australia (Fernley, 2021) and an estimated 190 million women worldwide (Horne & Missmer, 2022). Endometriosis is a chronic, painful, recurrent condition that can be highly debilitating (Bedaiwy et al., 2017). As a result, women with endometriosis report multiple adverse consequences that can significantly reduce their quality of life). In recognition of the debilitating nature of endometriosis and the need to improve care, The Australian Government has developed a National Action Plan for Endometriosis (Department of Health, 2018) to raise community and health professional awareness, increase early diagnosis and intervention, ensure access to appropriate care and encourage further research.

Endometrial inflammation can cause scarring, cysts, and adhesions, which result in significant pain (Bedaiwy et al., 2017; Bullo, 2018). Women may experience dysmenorrhea (pain before and/or during menstruation), with the pain being particularly incapacitating during ovulation and menstruation (Bullo, 2018; Bullo, 2020). Additionally, endometriosis symptoms include pelvic pain, dyspareunia (pain during intimacy), constipation, urinary tract

infections, fatigue, and infertility (Bullo, 2018; Márki et al., 2022; Metzemaekers et al., 2021; Olive & Pritts, 2001). Symptoms may result in insomnia and poor sleep quality (Facchin et al., 2021). Moreover, endometriosis significantly affects sexual health, intimate relationships, social involvement, and quality of life (Casalechi et al., 2021; Della Corte et al., 2020; Facchin et al., 2021; Metzemaekers et al., 2021). Indeed, women diagnosed with endometriosis have a higher prevalence of psychological disorders, such as anxiety and depression (Casalechi et al., 2021). A systematic review and meta-analysis containing 49 studies reported that the prevalence of anxiety and depressive symptoms was 31.8% and 28.9%, respectively; with anxiety 2.8 times more common in women with endometriosis (Delanerolle et al., 2021).

Women's physical and psychological health can also be impacted by endometriosis treatments such as pain medications, and hormonal and surgical treatments that have limitations, including cost, adverse side effects, and risk of recurrence (Bedaiwy et al., 2017; Metzemaekers et al., 2021). Due to intense pain, women are often prescribed pain medications long-term, which can result in addiction, including opioid addiction (Guan et al., 2023; Nezhat, 2020). Also, while surgery can effectively treat endometriosis pain, potential complications can include damage to the urinary tract, and temporary or permanent stoma (Metzemaekers et al., 2021). Surgery may also result in weight gain, mood swings, decreased libido, headaches, and medication addiction (Metzemaekers et al., 2021; Nezhat, 2020).

Adding to the complexity of endometriosis is the challenge of obtaining a diagnosis, which, on average, takes 7.5 to 10 years (Bedaiwy et al., 2017; Bullo, 2018; Bullo, 2020; Márki et al., 2022). Diagnosis often occurs in the context of exploring infertility rather than pain complaints (Bullo, 2018). Given women's symptoms, long delays in obtaining a diagnosis, and treatment needs and side effects, they have frequent contact with doctors. Therefore, it is essential to understand women's experiences of interactions with doctors.

WOMEN'S ACCOUNTS OF DOCTOR-PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

Much research has been conducted on doctor-patient relationships. Such relationships are an important aspect of health care, as a good doctor-patient relationship improves the quality of health services and patient satisfaction (Langberg et al., 2019). Additionally, trust in doctors is valuable in helping patients feel understood and obtain the correct diagnosis (Harbishettar et al., 2019), and in promoting treatment adherence and recovery (Barbara et al., 2021).

The potential importance of doctor-patient relationships and communication was first considered in the 1950s and 1960s. Szasz and Hollander (1956) proposed three basic models of the doctor-patient relationship: (1) Activity-Passivity, (2) Guidance-Cooperation, and (3) Mutual-Participation (Szasz & Hollander, 1956). The Model of Activity-Passivity involves the doctor being active and in total control and the patient being the passive recipient of care (Szasz & Hollander, 1956). The Model of Guidance-Cooperation involves the doctor giving instructions and the patient obeying, but both parties actively contribute to the relationship and its outcomes. The Model of Mutual-Participation involves the doctor and patient working in partnership, with the doctor helping the patient to help themselves (Szasz & Hollander, 1956). The Model of Mutual-Participation is considered the most appropriate form of doctor-patient relationship when caring for people with chronic illness (Szasz & Hollander, 1956). However, each model is appropriate under different circumstances. Doctors may need to use the models of care interchangeably at different stages when working with the patient to maximise positive outcomes (Szasz & Hollander, 1956).

Emanuel and Emanuel (1992) have also theorised about doctor-patient relationships, suggesting four models that determine the goals of the interaction, doctors' obligations, patients' values, and patient autonomy. The four models are: (1) Paternalistic, (2) Informative, (3) Interpretive, and (4) Deliberative (Emanuel & Emanuel, 1992). The Paternalistic Model indicates a relationship where the doctor acts as the patient's guardian, is assumed to know what is best, and determines the course of action, presenting patients with

select information to encourage them to follow their recommendation, although sometimes using this model doctors may act more authoritatively (Emanuel & Emanuel, 1992). In the Informative Model, the doctor provides the patient with all the available information, the patient chooses the best intervention, and the doctor enacts the patient's wishes (Emanuel & Emanuel, 1992). Similarly, in the Interpretive Model, the doctor provides information about all intervention options but assumes more of a 'counsellor' or 'advisor' role, assisting the patient to identify their values and choose interventions that best align with them (Emanuel & Emanuel, 1992). In the Deliberative Model, the doctor acts as a friend or teacher, helping the patient to choose the best health-related values to guide intervention choices; they may deliberate and discuss together, but coercion is avoided (Emanuel & Emanuel, 1992).

Overall, according to Emanuel and Emanuel (1992), the Deliberative Model is the preferred doctor-patient relationship, as it embodies autonomy, involves meaningful discussion, assists patients in identifying and considering health-related values and is not camouflaged paternalism (Emanuel & Emanuel, 1992). While there may be preferred models of doctor-patient relationships, each model described above can be appropriate at different times in medical care (Emanuel & Emanuel, 1992; Szasz & Hollender, 1956). Such models may offer important insights when seeking to understand doctor-patient relationships in the context of endometriosis.

While some models of doctor-patient relationships may benefit women with endometriosis, women often report challenges in their interactions with doctors. Doctors' insufficient awareness of, or expertise with, endometriosis and the normalisation of menstruation-related pain pose significant challenges that contribute to prolonged diagnostic delays (Bullo, 2020; Márki et al., 2022; Metzemaekers et al., 2021). Women are often dissatisfied with the information and support they receive from doctors, reporting that their symptoms are normalised as common among women of reproductive age or dismissed

(Bullo, 2018). Women have also reported a lack of control and disempowerment in their interactions with doctors (Bullo, 2018; Bullo, 2021). Additionally, not having a good doctor-patient relationship can lead to fear, depression, and 'doctor shopping' (moving from one doctor to the next), resulting from mistrust and increased fear due to insufficient professional knowledge and diagnostic delays (Márki et al., 2022). Previous research has acknowledged a lack of care and understanding from doctors, resulting in poor communication from a doctor-patient perspective (Márki et al., 2022). Indeed, Márki et al. (2022) reported that most women stated that one of the most crucial elements in managing endometriosis is having a trustworthy doctor with specialist knowledge in endometriosis.

Most research exploring doctor-patient relationships in endometriosis has been cross-sectional, meaning causal conclusions cannot be drawn (Spector, 2019). Quantitative research typically focuses on associations between women's characteristics and their symptoms. It uses quality-of-life measures whose psychometric properties are not fully established in endometriosis, especially when exploring women's satisfaction with doctor-patient relationships regarding diagnosis and treatment (Culley et al., 2013).

In previous qualitative research, women have described adverse impacts associated with long diagnostic delays and a lack of identity due to poor relationships with their doctors (Facchin et al., 2018; Márki et al., 2022). Additionally, women have reported issues with communication, where building a doctor-patient alliance is hampered by a level of disempowerment due to doctors' insufficient knowledge about endometriosis and failure to consider women's experiential knowledge (Bullo, 2018; Márki et al., 2022).

Further, reviews have examined doctor-patient relationships among women with endometriosis. For example, Culley et al. (2013), in a narrative review of 42 studies, identified that diagnostic delay and uncertainty, followed by medical and self-management, were key factors impacting women's psychological and social health. Additionally, in a

systematic review of 27 studies, O'Hara et al. (2019) identified positive doctor-patient relationships as important components of endometriosis self-management.

While it is positive to see quantitative, qualitative and review research examining doctor-patient relationships in endometriosis, further research is warranted. Although cross-sectional data, in-depth, rich data from qualitative studies and reviews offer valuable insights, causal inferences cannot be made (Spector, 2019), and the information gained may be impacted by researchers' influence (i.e., study design, research questions, sampling, data collection, analysis and interpretation; Johnson et al., 2020; Márki et al., 2022; Metzemaekers et al., 2022) or review quality or publication bias (Jerrim & de Vries, 2017).

Therefore, there is a need to examine more naturalistic data, which enables researchers to collect rich, detailed qualitative data with reduced influence from researchers and their interactions with women with endometriosis. Naturalistic data may reduce social desirability, enabling women to speak freely (Karavadra et al., 2019), and naturalistic data, such as posts in online discussion forums, enable exploration of how unsolicited conversation manifests in certain social contexts (Jowett, 2015). For other health conditions, using online forums has resulted in more active involvement in diagnosis and confidence to question medical professionals' judgments (Drioli-Phillips et al., 2020; Seymour-Smith, 2013).

Very few studies have implemented naturalistic study designs when exploring endometriosis. Grundstrom et al. (2020) examined Swedish blog posts about the healthcare experiences of women with endometriosis. In this study, women reported concerns about the normalisation of pain, trivialisation, distrust, health professionals' lack of knowledge, and their concerns not being taken seriously (Grundstrom et al., 2020).

Given the clear importance of doctor-patient relationships for women with endometriosis, the limitations in past research, and the National Action Plan for Endometriosis (Department of Health, 2018), further research to understand women's

experiences is needed. The current study aims to use naturalistic qualitative data from a Reddit endometriosis Subreddit forum where women with endometriosis (suspected or confirmed) communicate with others with similar experiences, to increase understanding of doctor-patient relationships in endometriosis. Specifically, this study aims to explore how women with endometriosis describe their relationships with doctors in an online forum.

Method

Design

This study employed a naturalistic qualitative design, gathering data from a publicly available online forum (Reddit). The researcher had no interaction with participants, but rather used a Reddit Subreddit (a user-created and moderated online community that focuses on a specific topic or interest) to conduct naturalistic observations (Gough, 2016; Seymour-Smith, 2013) where women's accounts were not produced by researcher activity (Speer, 2002). This design enabled women to speak freely about doctor-patient relationships, producing rich and naturalistic data while limiting bias (Seymour-Smith, 2015). The current study adopted a critical realist perspective, recognising that what participants say is their truth, but their experiences and sociocultural environment also shape knowledge and experiences (Clark et al., 2008; Clarke & Braun, 2021).

Even though naturalistic designs minimise researchers' influence, researchers may still influence data analysis and interpretation. Therefore, the researcher considered positionality and engaged in self-reflexivity throughout the research (Braun & Clarke, 2013; Cain et al., 2019). The researcher is a young, Caucasian, female diagnosed with likely endometriosis who has experienced negative doctor-patient relationships. Therefore, she may be considered an "insider researcher" as she has a direct identity or shared experience with the population and/or topic of interest (Sanghera & Thapar-Björkert, 2008). Although being an "insider" can confer benefits such as being knowledgeable about the area of interest,

efforts should be made to avoid potential researcher bias. In the current study, the potential impact of the researcher's positionality was minimised by having no interaction with participants (O'Connor & Joffe, 2020) and regular discussions with the research supervisor about the research, data analysis, and interpretation.

Ethical Considerations Associated with Using Social Media Data

Ethical considerations, particularly regarding participant consent, arise when using social media for research (British Psychological Society [BPS], 2021). This study examined opening posts (asynchronous message posts under a particular topic title that is the start of all other discussion in that thread) made to a publicly available Subreddit. As the opening posts were shared 'publicly', they are considered public information (BPS, 2021). Public posts are considered textual documents that do not need consent from the poster if the data is collected passively, and no harm is likely to arise (Smedley & Coulson, 2021). Although Subreddits are open pages, many have rules about research, with some prohibiting research. The Subreddit used did not prohibit research.

Each username was replaced with a poster number, names and identifying information provided by posters, and the Subreddit name was removed to protect posters' privacy and identity (BPS, 2021). Additionally, to further protect posters, only extracts, rather than full posts, were included (BPS, 2021). This strategy is consistent with previous studies examining online posts (Drioli-Phillips et al., 2020; Gough, 2016; Hanna & Gough, 2016; Kaufman & Whitehead, 2018). Additionally, this study followed the Standards for Reporting Qualitative Research (SRQR) guidelines, a 21-item checklist for reporting qualitative research (O'Brien et al., 2014; see Appendix A), and was approved by the University of Adelaide School of Psychology Human Research Ethics Sub-committee (23/16).

Participants

Participants were 160 users of a Reddit Subreddit for endometriosis who made opening posts within the chosen Subreddit during March 2023. Consistent with other naturalistic research using online forums (i.e., Gough, 2016; Hanna & Gough, 2016; Seymour-Smith, 2013), participants' demographic information was collated by examining information provided in opening posts (i.e., use of gendered tags (e.g., explicit references to being female) or roles (i.e., girlfriend, wife, daughter, sister); age; residence; endometriosis symptoms and diagnosis); as this is reliant on what women chose to share, demographic and endometriosis data are not available for all participants. Eleven posters explicitly indicated they were female, and ages ranged from 16-44 years (for the 49 posters who indicated age). The 16 posters that stated their residence were located in Australia, Canada, India, Los Angeles, Louisiana, Pennsylvania, Richmond, Scotland, the United Kingdom, and the United States. Fifty-six posters had experienced endometriosis symptoms for years, with 36 having suspected and 43 confirmed endometriosis. Forty-two posters were on birth control, 10 had an intrauterine device (IUD), 39 had received an ultrasound, and 55 reported having surgery or laparoscopy.

Data Collection

Data were collected from a publicly available endometriosis Subreddit, open to people experiencing symptoms of endometriosis or related conditions to receive support or advice about their experiences. The Subreddit name has been excluded to protect its users.

For this study, only opening posts made during March 2023 were collected because it was anticipated that a sufficient number of posts would be made as it was Endometriosis Awareness Month (Gochi et al., 2020). The dataset comprises opening posts to the chosen Subreddit during March 2023 about members' doctor-patient relationships. Opening posts were selected using a script that was created using Python (version 3.9.7) and PRAW

WOMEN'S ACCOUNTS OF DOCTOR-PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

(version 7.5.0) (Boe, 2021; see Appendix B). Access was granted to use Reddit's official Application Programming Interface (API), which is consistent with the terms of service for the platform to gather posts from Subreddits (Proferes et al., 2021). The API allows access to publicly available data and Reddit functions. The researcher created a Reddit account and agreed to the terms of the service to use the API (Reddit, 2021). The researcher registered through the Reddit developer application portal, agreed to the API terms of service, and was assigned relevant authorisation to gain access to the API to enable the creation of a programming script to collect data from Reddit for research purposes.

A list of search terms was developed to capture relevant opening posts (see Appendix C). The search terms included: "health professional", "healthcare professional", "gynaecologist", "doctor", "clinician", "specialist" and other relevant alternatives, abbreviations (i.e., "dr") and colloquial terms (i.e., "doc"). The research supervisor also reviewed and cross-checked the search terms to maximise accuracy. A colleague with expertise in computer technology assisted the researcher by developing the programming script and running the initial searches.

The Reddit API system was used to search each search term. The script collected every publicly available post made in the last year, including the textual content, title, author, date of creation, and URL. All opening posts were reviewed and manually reduced to include only posts made in March 2023, as it was impossible to limit posts to one month through the API system. All opening posts were collated in Excel, reviewed to identify, and remove duplicate posts that may have resulted from being relevant to multiple search terms, and then screened against the inclusion/exclusion criteria.

Opening posts were included if they (i) contained symptoms of endometriosis (self-identified, diagnosed by exclusion or medical examination), and (ii) content describing

doctor-patient relationships. Opening posts containing content about topics other than doctor-patient relationships or advertising products were excluded.

Data Analysis

Conventional qualitative content analysis, using the approach of Hsieh and Shannon (2005), was employed to classify posts into codes, subcategories and categories relevant to the research aim. An inductive approach was employed, as the researcher was not searching for preconceived categories of information posters may share on the Subreddit about their doctor-patient relationships (Braun & Clarke, 2013; Smith, 2008).

Analysis was undertaken using the following steps (Hsieh & Shannon (2005). First, the researcher and the research supervisor co-screened a proportion of opening posts against the inclusion criteria to reduce selection bias, with any discrepancies resolved by consensus discussion. Next, the researcher immersed themselves in the data with repeated reading of all eligible posts. Exact words were highlighted to capture key thoughts, and the researcher's thoughts were noted to create codes. Additionally, the researcher and research supervisor co-coded a proportion of posts to ensure agreement on the coding structure. The codes were then compared for similar content or meaning and developed into larger categories and subcategories to generate meaningful clusters. The unit of analysis was the number of posters who created textual data for each category and subcategory. Example posts were selected to illustrate the findings.

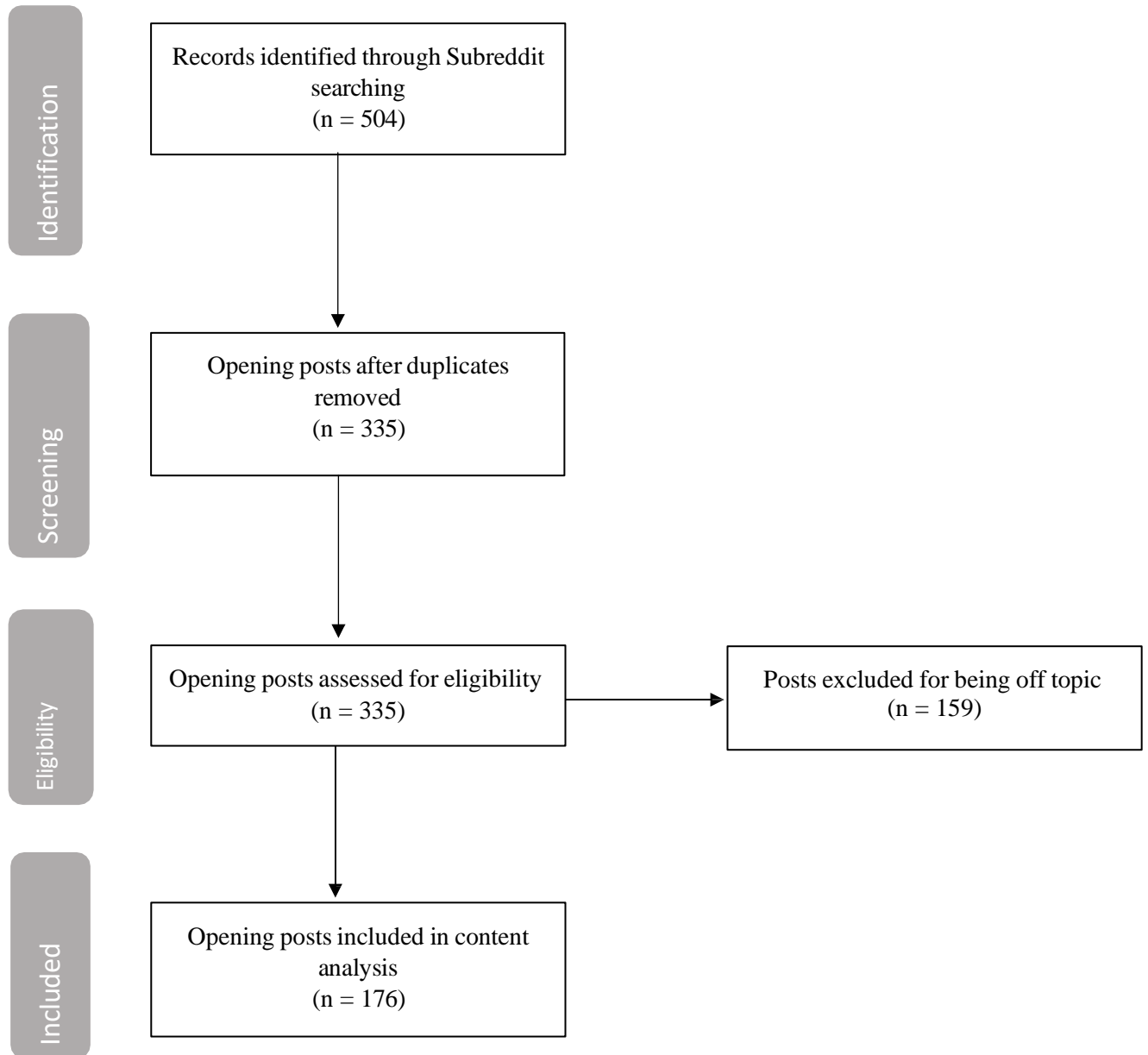
Results

Selection of Opening Posts

The Subreddit search yielded 504 opening posts (See Figure 1). The removal of 169 duplicate posts resulted in 335 posts remaining. These posts were assessed for eligibility, with 159 posts excluded as off-topic. Therefore, the final data set comprised 176 posts made by 160 posters.

Figure 1

Flowchart Illustrating Opening Post Selection Process

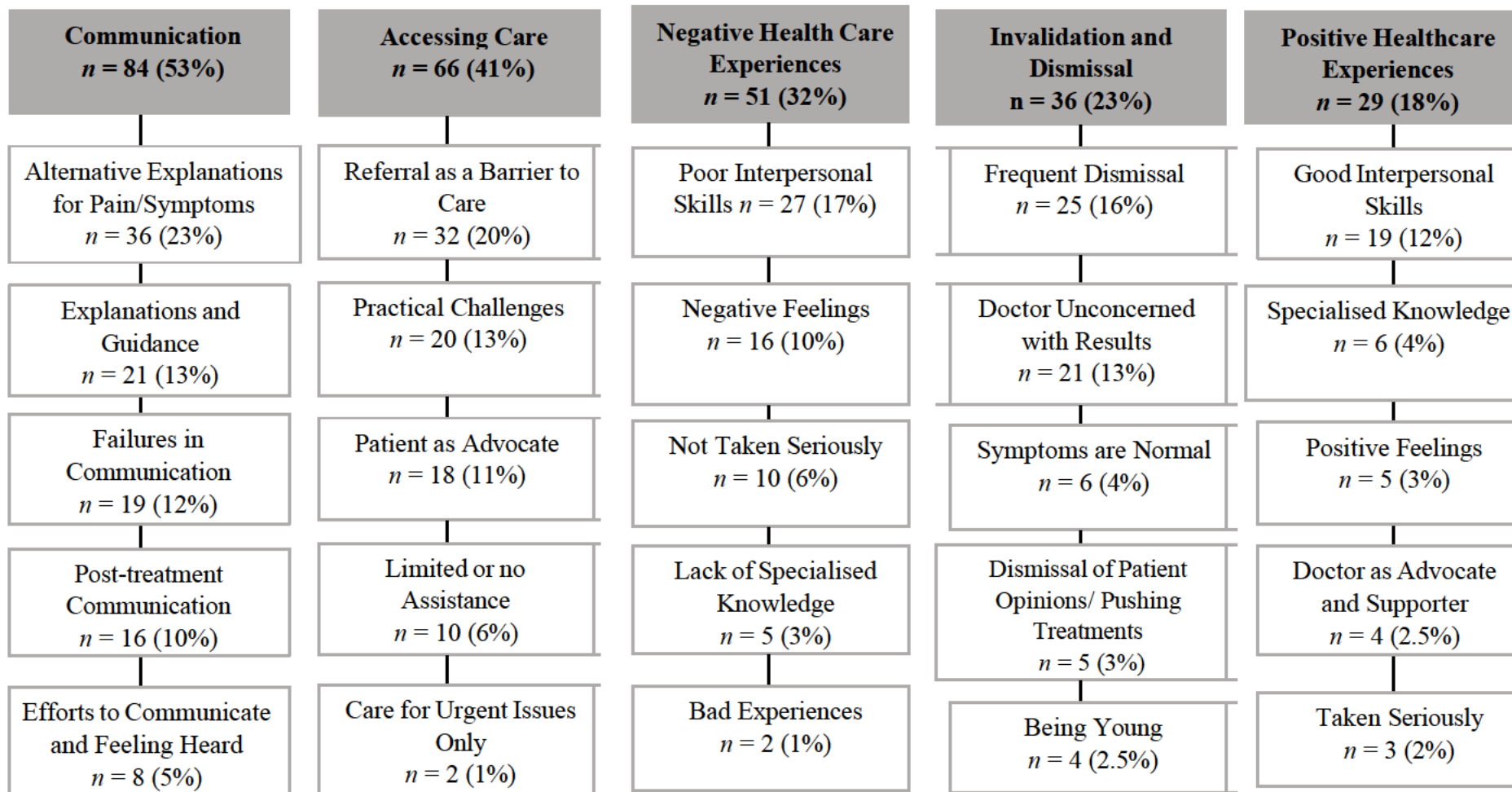


Codes, Categories and Subcategories

Five overarching categories and 25 subcategories were established by analysing the relevant Subreddit posts using conventional qualitative content analysis (Hsieh & Shannon, 2005) (see Appendix D for the full analysis structure). Figure 2 shows the five major categories, subcategories, and percentages of the unit of analysis. The number of

Figure 2

Overarching Categories (grey) and Accompanying Subcategories with Occurrence Frequencies



Note. Percentages are calculated based on the total number of posters (N = 160).

posters who created textual data for each category and subcategory served as the analysis's unit of analysis. For example, 84 posters shared content about "Communication".

Communication

The most endorsed category noted in the data was "Communication", which consisted of five subcategories, capturing doctor-poster communication. The subcategory "Alternative explanations for pain/symptoms", summarised communication where posters' doctors suggested explanations other than endometriosis for their pain and symptoms. Common explanations included other physical health issues and medication side effects ($n = 22$): *"I'm not getting anywhere with my OBGYN [obstetrician gynaecologist] and was already in the ER [emergency room] last week for suspected appendicitis (negative)"* (Poster 146). Posters also reported symptoms being attributed to mental health, including stress and low mood ($n = 8$): *"As most other women, I got told by my doctor it's probably just stress"* (Poster 133), or resulting from infection ($n = 4$): *"I was constantly told. I have UTI [urinary tract infection] symptoms. However, the majority of the time I didn't actually have a UTI [urinary tract infection]"* (Poster 11). A small number of posters reported doctors making no mention of endometriosis ($n = 2$): *"I've been to doctors before to talk about my IBS [irritable bowel syndrome] and PMDD [pre-menstrual dysphoric disorder] and they've never brought up endometriosis"* (Poster 136). Additionally, one poster stated their doctor attributed their symptoms to their weight ($n = 1$): *"My doctor said my pain is cause I'm chubby and excess fat causes more estrogen which can make the lining of uterus thicker"* (Poster 12).

The second subcategory, "Explanations and guidance", described communication where doctors provided information and instructions ($n = 10$): *"So many nurses and doctors coming in and telling me what they are going to do. The risks."* (Poster 15), and advice and guidance ($n = 5$): *"the very sweet practitioner mentioned that I should probably look into some mental health care around all the trauma I've experienced from endometriosis and"*

PCOS and medical gaslighting etc” (Poster 128). Additionally, some doctors explained the locations of the endometriosis ($n = 3$): *“She said that it is covering large areas of my abdominal wall, and there are some growths on my bowels and bladder”* (Poster 43).

Furthermore, some posters expressed that doctors debated whether endometriosis was a cause of disability ($n = 3$):

No doctors I've seen believe it's cause for disability. But now I'm needing it [Family and Medical Leave Act] again, so I don't lose my new job, but I'm feeling hopeless that I'll be met with the same attitude of doctors in my new state. (Poster 26)

The third subcategory, “Failures in communication”, reflected posts that suggested doctors failed to communicate appropriately. Posters expressed concerns about receiving inadequate explanation or guidance ($n = 9$): *“He never came and explained to me what was done, what he removed, what it looked like, or even if the diagnosis was confirmed”* (Poster 108). They also described not receiving answers to their questions ($n = 6$):

“My surgeon was vague when I followed up about it (the usual "bodies are mysterious and periods are usually delayed after surgery")” (Poster 155). Some posters explicitly reported feeling unheard by doctors ($n = 4$): *“I'm going to find a second opinion, it's just hard where I am to find good doctors that listen. It's just a reminder to me how hard it is for us to be heard”* (Poster 37). Additionally, one poster knowledgeable about their health conveyed being questioned by their doctor ($n = 1$): *“The doctor asked me if I was a medical professional, I guess he didn't expect me to know so much about it”* (Poster 35). There was also one instance where a poster's healthcare was not approved due to the doctor failing to send the correct documents ($n = 1$): *“They never sent the correct documentation to my health insurance company, so it was never approved”* (Poster 2).

The fourth subcategory, “Post-treatment communication”, summarised doctor-poster communication post-treatment, which varied widely. Many posters reported a lack of communication with doctors’ post-treatment ($n = 8$): *“She never did a follow up with me with any additional tests. I even messaged her to follow up with my test results and they claimed that they never received it [the message]”* (Poster 47). In contrast, some posters reported clear post-treatment communication ($n = 5$): *“The doctor briefly popped up after I woke up and said that I had no endo [endometriosis] at all but that they removed quite a bit of adhesions”* (Poster 145). However, at times, doctors communicated with posters’ carers post-treatment rather than with posters ($n = 5$): *“When my husband told me the results that my surgeon texted him, I cried tears of relief for hours”* (Poster 121). Also, one poster reported their doctor not taking accountability ($n = 1$): *“I tried to ask my surgeon/gynaecologist if it was related to the surgery and everything that happened, but they said no which I’m not surprised at as they took no accountability with my infection and everything”* (Poster 159). In another instance, a poster reported their doctor explained that their post-treatment symptoms were not normal ($n = 1$): *“It’s not normal to have so many blood clots and heavy amounts of blood this late while being on Mirena from what I discussed with my gynaecologist”* (Poster 86).

The fifth subcategory, “Efforts to communicate and feeling heard”, contained posts where posters expressed making a conscious effort to be heard by their doctor. Posters appreciated doctors who listened to them but noted that they could be difficult to find ($n = 6$): *“She is the first doctor who stopped when I explained the surgery to them and went wait, that’s not right. No one has ever tried to figure out why”* (Poster 44). One poster expressed the need to have frequent conversations with doctors to be heard ($n = 1$): *“I’ve tried talking to my doctor multiple times”* (Poster 10). Further, one poster reported concern about seeing a male doctor and their surprise about the outcome of feeling truly heard ($n = 1$):

I was very worried when I noticed it was a male dr [doctor] (since it was hard enough to get a woman to listen to me) but he really truly listened to me... I was in utter shock when the first doctor to truly listen to me was a MAN. (Poster 125)

Accessing Care

The second most predominant category noted in the data, “Accessing care”, consisted of five subcategories that illustrated difficulties accessing care. The subcategory “Referral as a barrier to care”, summarises the challenges in obtaining a referral to a specialist. Despite difficulties, some posters reported eventually receiving a referral ($n = 27$): *“They ended up giving me my referral and telling me they hope that I get the answers I need. I finally got in to see the OBGYN [obstetrician gynaecologist] specialist here in my town”* (Poster 125). For others though, no referrals or further testing were offered ($n = 3$): *“Sorry I can't help you over and over, with no further investigation or referrals”* (Poster 36) or were very difficult to obtain ($n = 2$): *“I moved to Canada and thought the doctors here would be more compassionate. But it's so hard to get them to give you a referral”* (Poster 74).

The second subcategory, “Practical challenges”, emphasised posters’ practical challenges in accessing care and results. While a few posters reported frequent appointments ($n = 7$): *“After multiple doctor appointments and ER [emergency room] visits, the consensus was that I probably had endometriosis (although we don't know for sure since I haven't gotten the surgery diagnosis)”* (Poster 62), others reported appointments being cancelled and rescheduled ($n = 6$): *“Apparently they moved my appt to next Monday, farther than my original appt and said there was nothing they could do”* (Poster 144). A smaller number indicated long waits for appointments ($n = 2$): *“After over a year's wait for the gynaecologist”* (Poster 80), and delays in receiving results ($n = 2$): *“I have my diagnostic laparoscopy on Wednesday, but my doctor won't tell me my results until two weeks*

later" (Poster 59). Additionally, some posters were unable to book post-treatment follow-up appointments ($n = 2$): *"I tried to call the clinic to talk to the doctor, but I was told that if the doctor hadn't requested a follow-up appointment, I couldn't book one myself"* (Poster 145). Furthermore, one poster reported issues with their health insurance due to their doctor's billing practices ($n = 1$): *"got recommended a new gyno [gynaecologist] since the last one was trying to bill my insurance with out-of-pocket costs"* (Poster 47).

The third subcategory, "Patient as advocate", reflected posters' accounts of self-advocacy. Posters reported pushing and being persistent ($n = 12$) and begging doctors for answers ($n = 7$): *"I have been complaining about heavy periods, painful bowel movements, ovarian cysts, and begging drs [doctors] to check me for endometriosis for almost 20 years now"* (Poster 120).

The fourth subcategory, "Limited or no assistance", focused on the instances where doctors were offered posters no or limited assistance with their care. Many posters described only being given one treatment option ($n = 7$): *"We left off with well you might have endometriosis, you might not, but you don't want to do birth control so I can't really do anything, peace out"* (Poster 32). Whereas some explained that doctors could not assist them ($n = 3$): *"I woke up and my doctor said she couldn't insert it because I had way too much scar tissue in the area and there was too much risk involved"* (Poster 122).

The fifth subcategory, "Care for urgent issues only", described occasions where posters could only access care in an emergency. In two instances, posters reported that doctors would not speak to them or operate unless it was urgent ($n = 2$): *"I cannot get a doctor's appointment, my doctor will not speak to me unless it's urgent"* (Poster 104).

Negative Healthcare Experiences

The third category, "Negative healthcare experiences", consisted of five subcategories, that described posters' negative experiences with doctors. The subcategory

“Poor interpersonal skills” encompassed instances where posters described their doctor as unhelpful ($n = 9$), gaslighting ($n = 6$), not understanding ($n = 4$), unsupportive ($n = 3$), rude ($n = 2$), fighting/combatative ($n = 2$), and judgemental ($n = 1$):

But my concerns regard 1. her abrasive and apathetic behaviour, and 2. she does NOT understand what Endometriosis is. She genuinely believes that my hysterectomy "healed me" and that it's impossible to grow back. So, she had 0 interest in looking into my pelvic pains, assuming it to just be scar tissue discomfort... (Poster 92)

Additionally, a small number of posters reported needing to battle with doctors they perceived as incompetent and health insurance companies to access specialist care ($n = 2$): *“I have an appointment with a specialist after a long road of fighting insurance and incompetent doctors and surgeons”* (Poster 18). Further, one poster described being treated as if they were their disease and not a person ($n = 1$):

*I've had my fair share of 'doctor shopping' and horrible appointments - walking out holding back tears all the way to the car only to break down as soon as I got there, fighting tears in the office so they don't mark my medical chart as 'mentally unsound', being treated like I AM my disease, not like I HAVE my disease... Did I find doctors who had knowledge? Yes, but they didn't treat me like a ****human****. (Poster 88)*

The second subcategory, “Negative feelings”, comprised posts where posters’ described their feelings during or after interactions with doctors. Posters expressed frustration ($n = 6$): *“I was frustrated and tried to politely voice concerns in class or offer an alternative experience as a chronic pain patient and wound up having an argument with her that's left me feeling really upset and frustrated basically”* (Poster 142). Additionally, posters expressed feeling upset ($n = 3$), mad ($n = 3$), and tired and exhausted ($n = 2$):

This is not the first time something like this has been done to me by a doctor, so it's dug up a lot of trauma for me... I feel angry, but I mostly feel exhausted. I'm so tired of fighting this. (Poster 91)

Furthermore, posters conveyed feeling bad ($n = 1$) and disappointed with their treatment ($n = 1$): *"I'm honestly left feeling a bit disappointed in the way I was spoken to"* (Poster 99).

In the third subcategory, "Not taken seriously", posters articulated concerns about their interactions with doctors. Specifically, posters described experiences of their pain or other health concerns not being taken seriously ($n = 10$): *"I've not had a great experience with the hospital or doctors, I just don't feel like I'm being taken seriously"* (Poster 11).

The fourth subcategory, "Lack of specialised knowledge", involved posters discussing doctors' expertise. Posters described doctors lacking knowledge or not being specialised in endometriosis ($n = 5$): *"But in my mind, she just might not be understanding enough to reason with me, or she might not have enough medical knowledge on this disease [endometriosis]- I wanted to find someone who was a 'specialist'"* (Poster 88).

The fifth subcategory, "Bad experiences", encompassed posts describing experiences with doctors that posters perceived to be 'bad'. Posters expressed having multiple bad experiences with multiple doctors ($n = 2$): *"I have had shit experiences with the majority of doctors I've had to see about my endometriosis"* (Poster 128). One poster described their doctor treating them as a drug-seeker ($n = 1$):

*asked for Tramadol [pain medication], as my previous gynaecologist was prescribing it to me and I only take it **as needed.** I hate medications, but I do not abuse them, but I was immediately treated like I was drug-seeking.*
(Poster 88)

Invalidation and Dismissal

The category “Invalidation and dismissal” consisted of five subcategories, where posters described feeling invalidated and dismissed by doctors. The subcategory “Frequent dismissal”, conveys moments where posters expressed apprehension when doctors frequently dismissed their concerns, symptoms, and pain ($n = 25$):

I went through at least 30 pads and tampons a day. It was really bad. I had clots the size of my fist. I ended up taking myself to the ER [emergency room] a couple of times & was continuously put down and dismissed about my concerns and pain. I even went as far as to refuse any pain medicine in fear they thought I was seeking drugs and that's why they ignored me. (Poster 125)

Additionally, some posters were cautious about how they presented themselves to doctors in the hopes of getting the assistance they needed, and others emphasised their pain to enhance believability. However, even then, sometimes these concerns were dismissed.

Right away when I told her my issues, she said well it's only a 3cm cyst... She said and I quote if your cyst was at the size to remove, you'd be shooting off the table right now. She basically completely shut down my theory of endo [endometriosis] and told me that excision is essentially pointless. She said it will just come back, yet refused to say I have endo[endometriosis]. (Poster 37)

The second subcategory, “Doctor unconcerned with results”, summarised posters' accounts of doctors seeming unconcerned about posters' test results. Posters wanted action after tests but reported doctors told them not to worry ($n = 8$):

When I asked for the next steps, she insisted I don't worry about it and that I could probably just take Orilissa [birth control] for 2 years and just be fine afterwards, no surgery needed. And all of this is based on those ultrasounds

which showed nothing! but you can't see endo [endometriosis] on ultrasounds right?! (Poster 77)

Instead, posters stated that doctors advised a 'wait and see' approach, preferring to monitor symptoms ($n = 7$): *"he said since my cyst is still relatively small (~4cm) he wants to take the wait and see approach while I stay on BC [birth control]"* (Poster 139). Posters reported doctors told them there was nothing wrong ($n = 4$): *"She said it's pointless as in her words 'there's nothing wrong'"* (Poster 60) or that they had found no other health issues ($n = 2$): *"She saw no other issues except maybe bowel blocking the view"* (Poster 60). One poster shared an example of when their doctor did not act on test results ($n = 1$): *"My GP basically ignored the clinical pathway and decided to do nothing about my two ultrasound scans indicating an endometrioma"* (Poster 35).

In the third subcategory, "Symptoms are normal", posters' expressed doctors telling them their symptoms were normal. Symptoms dismissed as normal included pain and vomiting ($n = 6$):

I had all of this to discuss with my doctor and she said: 1. Throwing up on period is normal, 2. Even if I wake up every day with stomach pain because it goes away it's normal, 3. My urine test came back normal so no issue with me peeing constantly, 4. I took a pelvic ultrasound 2 years ago and it came back normal so I'm fine (even though pelvic ultrasounds don't always show everything). (Poster 95)

The fourth subcategory, "Dismissal of patient opinions/pushing treatments", captured posters' accounts of doctors dismissing their opinions and 'pushing' treatment options onto them ($n = 5$): *"And they kept trying to push me into getting an IUD [intrauterine device] when birth control pills proved useless against my cramps"* (Poster 74).

The fifth subcategory, “Being young”, summarised instances where posters reported being dismissed due to their age. Posters discussed being dismissed and refused specific interventions as they were young ($n = 4$): *“You're too young for a hysterectomy (27) and the ovaries still provide cardiac health, and it's not worth it to risk it. “You're too young to decide that you don't want children” (Poster 88).*

Positive Healthcare Experiences

The last category, “Positive healthcare experiences”, consisted of five subcategories, where posters had positive experiences with doctors. The subcategory “Good interpersonal skills” depicted doctors’ interpersonal skills as positive when they were helpful ($n = 6$), kind ($n = 6$), understanding ($n = 5$), supportive ($n = 3$), and trusted ($n = 2$):

When we got to the part of rating my pain on a scale, I rated conservatively. My past doctor said my pain being at an 8 or a 9 is impossible, that'd it would be comparable to labour pains in that case.. A 7 seems too light for what you are describing here. I literally couldn't compute in that moment that a doctor thought I was for once understating my pain. (Poster 96)

The second subcategory, “Specialised knowledge”, described posters’ discussions of doctors’ knowledge and expertise. Posters described doctors as having considerable knowledge and/or skill ($n = 4$): *“My specialist seems very knowledgeable, and endo [endometriosis] is the focus of her practice” (Poster 8).* Furthermore, some posters described doctors as specialised in endometriosis ($n = 2$): *“I just had my consultation with an Endometriosis specialist at [hospital name] in Los Angeles last week. He is considered one of the best” (Poster 139).*

The third subcategory, “Positive feelings”, encompassed posters’ positive feelings during or after interactions with doctors. Posters described feeling hopeful ($n = 2$): *“I know it'll be hard but want to hope for a good outcome” (Poster 8)* and feeling grateful that doctors

took action to assist them ($n = 2$): *“They put me on the waiting list for a laparoscopy so I suppose I shouldn't feel too bad about the experience”* (Poster 99). Additionally, posters reported feeling good when doctors were kind and empathetic ($n = 1$): *“I always end up crying at any doctor appointment, especially more so if they are kind and empathetic and actually listen!”* (Poster 75).

The fourth subcategory, “Doctor as advocate and supporter”, comprised codes where posters spoke highly about doctors. Posters recalled interactions where doctors were concerned about their results ($n = 3$):

She was concerned about removing the Nexplanon [birth control implant] and the bleeding becoming major again. I am too, but I explained to her that I feel like I need to go through a neutral phase with my hormones to see if the depression goes away. (Poster 74)

Posters also discussed interactions where doctors advocated for or supported them ($n = 2$): *My nurse was urging her to prescribe Percocet [pain medication] or something because she's had it [surgery] done and says it really does hurt, but that didn't work”* (Poster 59).

The fifth subcategory, “Taken seriously”, represents posters' accounts of their concerns being taken seriously ($n = 3$): *“My usual gynaecologist is on maternity leave, so I saw her colleague. She was nice and took me seriously”* (Poster 87).

Discussion

Overview of Findings

The present study employed conventional qualitative content analysis to explore how women with endometriosis (suspected or confirmed) describe doctor-patient relationships in online accounts on a Subreddit forum. Five overarching categories were produced to summarise eligible opening posts. These categories captured the communication between posters and their doctors, barriers to accessing care, negative healthcare experiences,

invalidation and dismissal, and positive healthcare experiences. The findings are discussed in more detail below.

Throughout the study, the most predominant and significant issue raised was communication. The current study found communication failures where many posters reported that when they voiced their concerns, they often felt that they were not listened to, and their doctor did not guide or explain anything to them. Consistent with the current study's findings, previous literature has acknowledged the lack of concern and understanding on the part of health professionals, leading to poor communication between physicians and their patients (Grundstrom et al., 2020; Márki et al., 2022; Pettersson & Berterö, 2020; Young et al., 2020). Failures in communication, including a lack of understanding, can often cause a woman to feel dismissed. Another overarching category was invalidation and dismissal, where some posters reported that their symptoms were normalised and they were often dismissed because they were too young. Previous literature has focused on the dissatisfaction with the support that is provided to them by their doctors due to a high reporting of their symptoms being normal because of their age or being dismissed, leading to a lack of guidance and effort to communicate (Bullo, 2018; Ghai et al., 2020; Grundstrom et al., 2020; Hawkey et al., 2022; Van Der Zanden et al., 2020). Communication issues, making posters feel invalidated and dismissed may contribute to higher reports of negative experiences. A few posters reported issues with uncertainty and mistrust about a lack of professional knowledge and neglectful attitudes towards women's symptoms. The findings are consistent with previous literature concerning disempowerment and dismissing women's experiential knowledge (Bullo, 2018). Previous literature has emphasised the lack of knowledge about the disease that women are receiving, where doctors are not providing them with the knowledge or skills to cope with the disease (Bullo, 2018; Pettersson & Berterö, 2020), making it difficult for doctors to understand which can lead to the normalisation of menstruation

cramps, resulting in a negative experience and longer diagnostic delays (Grundstrom et al., 2020; O'Hara et al., 2019; Pettersson & Berterö, 2020). Other literature consistent with the current study found that some healthcare providers did not take women seriously, doubting women's symptoms, and being dismissive (Grundstrom et al., 2020; Márki et al., 2022; O'Hara et al., 2019; Pettersson & Berterö, 2020).

Communication affects negative experiences and impacts the ability to access care. The current study found concerns about accessing care, particularly issues with long delays and receiving referrals. A few posters reported practical challenges, such as long waits, delays in receiving their results, issues with insurance and costs, and frequent appointments. Both Culley et al. (2013) and Márki et al. (2022) found that long diagnostic delays provided the biggest impact on a woman's psychological and social health. Although a few reported having practical challenges, only a couple reported having delays when receiving their results, leading to longer diagnostic delays, consistent with Pettersson and Berterö (2020). However, other research has suggested that it is the normalisation of women's symptoms that contributes the most to long diagnostic delays (Bullo, 2020; Ghai et al., 2020; Grundstrom et al., 2020; Metzemaekers et al., 2021). A few posters reported that their doctor stated their symptoms were normal when brought up in appointments. However, other literature suggests differently. Márki et al. (2022) suggest uncertainty and a lack of knowledge about endometriosis that causes long diagnostic delays, consistent with relevant findings stated earlier with regard to communicating with a doctor who is specialised and skilled in endometriosis. Only a handful of posters reported interacting with a specialised doctor. Regarding such low consistencies, the real effect of diagnostic delays cannot be determined.

Concerning difficulties obtaining a referral, O'Hara et al. (2019) conducted a systematic review of women's self-management regarding endometriosis, where they found related experiences. They reported that women had positive and negative experiences when

interacting with their doctors. Much of the research that was collated regarded referrals to see a specialised doctor. O'Hara et al. (2019) found that, in some studies, women described positive experiences when referred to a specialist, although they found negative experiences were encountered more commonly. In the current study, most reported having difficulties with getting a referral. These findings are consistent with the findings of Ellis et al. (2023) and O'Hara et al. (2019), indicating more of a reluctance to refer or provide access to specialised doctors (Ellis et al., 2023; O'Hara et al., 2019; Van Der Zanden et al., 2020). More communication failures and lack of understanding may be highly caused by a lack of specialised doctors, contributing to the number of negative experiences reported.

Although most posters reported negative experiences when communicating with their doctors and the difficulties they encountered when accessing care, consistent with previous literature, a small minority posted positive healthcare experiences, though it is not universal (Grundstrom et al., 2020; Márki et al., 2022; O'Hara et al., 2019; Pettersson & Berterö, 2020). Although only a few reported positive healthcare experiences, it is important to note to increase doctor-patient satisfaction. A few indicated that their doctor was kind, trusting, and specialised. In the current study, some have emphasised the importance of positive healthcare experiences when suffering from endometriosis where their specialist acts as trustworthy, skilled, and specialises in the disease to decrease long diagnostic delays, which is consistent with previous literature (Márki et al., 2022; O'Hara et al., 2019). Other literature has expressed the importance of building rapport and communication between the doctor and patient to increase satisfaction (Grundstrom et al., 2020; Márki et al., 2022; Young et al., 2020). By taking good communication into account and doing it well, it can lead to more positive experiences.

Models of Doctor-Patient Relationships

The current results can also be understood in terms of the previous models of doctor-patient relationships. Considering the doctor-patient relationship models, most posts defined Szasz and Hollender's (1956) Model of Activity-Passivity, where the doctor is in total control, and the patient acts as a passive recipient of care. Posters often felt that they were not listened to or understood as their doctor did not work collaboratively with them, and they were not able to access the appropriate care. In terms of this model, posters' opinions and values were often not considered. Another model that posters described was Emanuel and Emanuel's (1992) Paternalistic Model, where the doctor acts as a 'guardian', but may act more authoritatively at times, while providing the patient with information and encouraging them to follow through, as it is assumed that they know what is best. Posters often reported a lack of specialisation and understanding and were often provided with information on treatment options, but were pushed onto a certain one that was not always the best course of action for their situation. These two models were often described when posters reported negative experiences that they had encountered when interacting with their doctors.

However, when posters reported more positive healthcare experiences, they often described Szasz and Hollender's (1956) Model of Mutual-Participation. The Model of Mutual-Participation occurs when the doctor and patient work collaboratively, and the doctor helps the patient help themselves (Szasz & Hollender, 1956). It is considered the most appropriate model of care for individuals suffering from chronic illness (Szasz & Hollender, 1956). Another model defined, closely related to Szasz and Hollender's (1956) Model of Mutual-Participation, is Emanuel and Emanuel's (1992) Deliberative Model, where the doctor acts as a friend or teacher and helps the patient to choose the best course of action considering their values, enabling a safe space for discussion without coercion (Emanuel & Emanuel, 1992). These two models were illustrated when posters reported positive experiences by describing their doctors as kind and helpful, and listened and provided them

with all the available information. Posters reported when their doctors advocated for them and were specialised and fully understood the suffering women were experiencing.

Although all models can be flexible and no one model fits every situation, Emanuel and Emanuel (1992) suggest that the Deliberative Model should be implemented most often as it enables patients to make their own decisions, while allowing room for discussion and considers patients' values (Emanuel & Emanuel, 1992). Therefore, Emanuel and Emanuel's (1992) Deliberative Model should be considered a priority when implementing training for doctors to better improve awareness and appropriate care.

Strengths and Limitations

To the researcher's knowledge, this is the first study that has explored doctor-patient relationships in online accounts in a naturalistic setting. Very few naturalistic studies have been previously conducted. By collecting naturalistic data, it was possible to collect accounts of women's doctor-patient relationships using a robust systematic method for post-selection without the influence or biases of the researcher. However, data was only collected from a singular Subreddit. It is unknowable whether it is the first or only Subreddit to which women post, and whether women talk about similar doctor-patient relationships in other Subreddits. It may be beneficial to explore other Subreddits in case the Subreddit analysed attracts certain women. While some demographic information could be gleaned from the opening posts (i.e., age, gender), this data was not available for all posters, so it was not possible to explore whether doctor-patient relationships vary according to demographics. Lastly, the study focused on women's perspectives of doctor-patient relationships. However, relationships are reciprocal; doctors may have different perspectives concerning doctor-patient relationships with women with endometriosis. Therefore, the findings may not represent the experiences of all women with endometriosis or be unique to women with endometriosis.

Future Research and Practical Implications

Based on the current findings and existing literature, further research regarding endometriosis and doctor-patient relationships is needed. Future research should explore further naturalistic studies, other Subreddits, and doctors' perspectives on doctor-patient relationships. There is also a need to look at different variations in demographics if they are available.

A key finding in the study is the need to increase awareness and patient satisfaction. In South Australia, only two endometriosis specialist clinics exist; one being in rural South Australia, and a second recently announced to open in metropolitan Adelaide. The Australian government acknowledges that endometriosis is a major public health issue and is seeking to improve awareness, diagnosis, and care through the National Endometriosis Action Plan (Department of Health, 2018).

The results from the current study support and are consistent with the plan. Women are reporting that their doctors lack knowledge or are not specialised in endometriosis and are very appreciative when their doctors are. Therefore, to enhance doctor-patient relationships, there is a need for the government to continue to expand health promotion awareness campaigns and to implement consumer-informed training highly focusing on Emanuel and Emanuel's (1992) Deliberative Model and enabling women affected by endometriosis to help guide healthier doctor-patient relationships, in turn, increasing satisfaction and improving outcomes (Arena et al., 2022; Grundstrom et al., 2020; Márki et al., 2022; Metzemaekers et al., 2022). If actioned, the National Action Plan (Department of Health, 2018) may succeed in raising community and health professional awareness and providing access to specialised care through opening further specialist endometriosis clinics.

Conclusion

In online accounts, most women reported poor doctor-patient relationships. Communication regarding endometriosis between doctors and patients must be improved to increase access to care, decrease long diagnostic delays, and maximise patient care and satisfaction. More needs to be done to increase community awareness and provide doctors with specialised training in endometriosis and its care. Additionally, improved doctor-patient relationships and health outcomes are likely to result from increasing the number of specialist endometriosis clinics.

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Appendix A

Standards for Reporting Qualitative Research Checklist

Item	Page no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1, 8
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	5
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	8-13
Purpose or research question - Purpose of the study and specific objectives or questions	13-14
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended	14
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	14-15
Context - Setting/site and salient contextual factors	14
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation)	16-18
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	15

WOMEN'S ACCOUNTS OF DOCTOR PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings	16-18
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	16-18
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	18-19, 21
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	16-18
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach	18
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation)	16

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	18-31
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	18-31

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	31-38
Limitations - Trustworthiness and limitations of findings	36

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14-15
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	N/A

Appendix B

Data Collection Script

''' This script take a list of key words, searches the [REDACTED] subreddit.

It then saves all the results to csv file'''

```
import praw
```

```
import pandas as pd
```

```
word_list = [ "OB", "GP", "gyno","gynae", "gynaecologist", "gynecologist", "doctor",\
              "dr", "doc", "physician", "consultant", "nurse","surgeon", "endocrinologist", "gastroenterologist",\
              'Health professional', 'Health care professional', 'Healthcare professional',\
              'Medical professional', 'Medical practitioner', 'Health practitioner', 'Specialist',\
              'Obstetrician', 'Obstetrician-gynaecologist', 'General practitioner', 'Clinician', 'Psychologist' ]
```

```
reddit = praw.Reddit(client_id='jh5mABBvxvDdtTpSHOjYzA',
                    client_secret=[REDACTED] user_agent='webscrap')
```

```
for search_term in word_list:
```

```
    posts = []
```

```
    ml_subreddit = [REDACTED]
```

```
    for post in ml_subreddit.search(search_term, time_filter="year", limit=1000):
```

```
        posts.append([post.title, post.subreddit, post.url, post.selftext, post.created, post.author])
```

```
posts = pd.DataFrame(posts, columns=['title', 'subreddit', 'url', 'body', 'created', 'author'])
```

```
posts['created'] = pd.to_datetime(posts['created'], unit='s')
```

```
posts.to_csv("new_batch/endometriosis_"+search_term.replace("/","_") + "_year.csv")
```

Appendix C

List of Search Terms

Consultant	Health care professional
Clinician	Health practitioner
Doc	Health professional
Doctor	Medical practitioner
Dr	Medical professional
Endocrinologist	Nurse
Gastroenterologist	OB
General practitioner	Obstetrician
GP	Obstetrician-gynaecologist
Gynae	Physician
Gynaecologist	Psychologist
Gynecologist	Specialist
Gyno	Surgeon
Healthcare professional	

Appendix D

Full Analysis Structure (N = 160)

Category	Subcategory	Codes	n	% of N
Communication	Alternative explanations for pain/symptoms	Other physical health conditions and medications	22	14%
		Mental health	8	5%
		Not mentioning endometriosis	2	1%
		Being overweight	1	.01%
	Explanations and guidance	Providing instructions	10	6.5%
		Providing advice and guidance	5	3%
		Explaining location of endometriosis	3	2%
		Endometriosis as cause of disability	3	2%
	Failures in communication	Inadequate explanation and guidance	9	6%
		Questions remain	6	4%
		Not listening/hearing	4	2.5%
		Doctor questioning patient	1	.01%
		Not sending correct document	1	.01%
	Post-treatment communication	No communication with doctor post-treatment	8	5%
		Communication with doctor post-treatment	5	3%
		Doctor communicating with carer	5	3%
		Symptoms not normal	1	.01%
		Lack of accountability	1	.01%
	Efforts to communicate and feeling heard	Listening/hearing	6	4%

WOMEN'S ACCOUNTS OF DOCTOR PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

		Frequent conversations/trying to communicate	1	.01%
		Male doctor listened	1	.01%
Accessing Care	Referral as a barrier to care	Referral to specialist care	27	17%
		No referrals/further testing	3	2%
		Difficulties getting a referral	2	1%
	Practical challenges	Frequent appointments	7	4.5%
		Appointments being cancelled/rescheduled	6	4%
		Long waits	2	1%
		Delay in receiving results	2	1%
		Lack of follow-up care	2	1%
		Cost/billing insurance	1	.01%
	Patient as advocate	Pushing and being persistent	12	8%
		Begging for Answers	7	4.5%
	Limited or no assistance	Only one option	7	4.5%
		Could not assist	3	2%
	Care for urgent issues only		2	1%
Negative Healthcare Experiences	Poor interpersonal skills	Unhelpful	9	6%
		Gaslighting	6	4%
		Not understanding	4	2.5%
		Unsupportive	3	2%
		Rude	2	1%

WOMEN'S ACCOUNTS OF DOCTOR PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

		Fighting/combative	2	1%
		Judgemental	1	.01%
		Not treated as person/treated as my disease	1	.01%
	Negative feelings	Frustrated	6	4%
		Upset	3	2%
		Mad	3	2%
		Tired/exhausted	2	1%
		Disappointed	1	.01%
		Bad	1	.01%
	Not taken seriously		10	6.5%
	Lack of specialised knowledge	Lacking endometriosis knowledge/not specialised	5	3%
	Bad experiences	Multiple bad experiences	2	1%
		Drug seeking	1	.01%
Invalidation and Dismissal	Frequent dismissal		25	16%
	Doctor unconcerned with results	Not to worry	8	5%
		Symptom monitoring	7	4.5%
		Nothing wrong	4	2.5%
		Found no other issues	2	1%
		Not taking action	1	.01%
	Symptoms are normal		6	4%

WOMEN'S ACCOUNTS OF DOCTOR PATIENT RELATIONSHIPS IN ENDOMETRIOSIS

	Dismissal of patient opinions/pushing treatments		5	3%	
	Being Young		4	2.5%	
Positive Healthcare Experiences	Good Interpersonal Skills	Kind	6	4%	
		Helpful	6	4%	
		Understanding	5	3%	
		Supportive	3	2%	
		Trusted	2	1%	
	Specialised Knowledge	Having knowledge and/or skills	4	2.5%	
		Specialised in endometriosis	2	1%	
	Positive Feelings	Grateful	2	1%	
Hopeful		2	1%		
Good		1	.01%		
Doctor as advocate and supporter					
	Doctor concerned about results	3	2%		
	Doctor advocating/supporting	2	1%		
	Taken Seriously		3	2%	