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Research Article

"IT BURNS ME FROM THE INSIDE LIKE AN OPEN WOUND": A QUALITATIVE STUDY OF WOMEN'S ILLNESS EXPERIENCE WITH ENDOMETRIOSIS

Giulia Graziano[*] and Francesca Alby[*]

Endometriosis profoundly impacts public health, quality of life, and economic stability, causing severe pain, fatigue, and mental health issues, and impeding work and sexual health. Despite extensive research, diagnostic delays and treatment inefficacies persist, impacting quality of life and economic stability. This study aims to explore the personal experiences of women with endometriosis, focusing on symptomatology, treatment effectiveness, and the role of social support, using a qualitative methodology to enrich current understanding and guide future healthcare strategies. Interviews with nineteen women revealed diagnostic challenges, including delays and normalization of pain, unsatisfactory treatment outcomes, and substantial impacts on daily life and psychological well-being. The study identified a need for improved medical empathy, awareness, and support systems. The findings underscore the complexity of managing endometriosis. Women experienced isolation due to disbelief and lack of support, impacting familial, friendly, and intimate relationships. Positive healthcare experiences were characterized by empathy and active listening from professionals. However, the cost of treatments and hospitalizations often hindered access to medical care. Social support networks, including online communities, were crucial for comfort and infor-mation sharing. The study contributes to a deeper understanding of the profound impact of endometriosis on women's lives. It underscores the need for a multidisciplinary approach to treatment and prevention, including raising public awareness and early diagnosis. The research calls for destigmatizing menstrual education and improving healthcare literacy to challenge cultural norms around menstrual pain and endometriosis.

Keywords*: Endometriosis; diagnostic delays; treatment efficacy; quality of life; social support; thematic content analysis*

1. Introduction

Endometriosis is an inflammatory, chronic, and often painful disease characterized by the presence of ectopic endometrial tissue at extrauterine sites. Common symptoms include dysmenorrhea, chronic pelvic pain, dyspareunia, and, less frequently, dyschezia, dysuria, fatigue, and infertility (Bulletti et al., 2010). It is estimated to affect approximately 10% (190 million) of girls and women of reproductive age (WHO, 2023) and up to 50% of women with infertility (Becker et al., 2022). In Italy, at least 3 million women have been diagnosed with endometriosis (Ministry of Health, 2023). The exact causes of endometriosis, which include genetic

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[*] Sapienza University of Rome, Italy.

predisposition, immune system abnormalities, and environmental factors, are not fully understood (Giuliani et al., 2015). Currently, there is no cure for this condition, and its management focuses on preventing progression and alleviating symptoms through various treatments, such as analgesic drugs, hormone therapy, and minimally invasive or radical surgery (Culley et al., 2013). Despite significant investment in patient care, the current situation presents several challenges. To begin with, it takes too much time to diagnose the condition. In different countries, the estimated time interval between the onset of symptoms and a confirmed diagnosis ranges from 2 to 12 years (Ghai et al., 2019; Fryer et al., 2024). Throughout this extended period, women may endure ongoing symptoms that have a detrimental impact on their quality of life, productivity, and relationships, while the disease itself may continue to advance (Davenport et al., 2023).

At the individual level, diagnostic delay appears to be influenced by the inability to distinguish between normal and abnormal menstrual experiences. Often, early experiences of pain are not disclosed to friends or family members, either due to embarrassment or because women do not want to appear weak and unable to cope with menstruation (Laws, 1990; Kocas et al., 2023; Lindgren & Richardson, 2023).

On the medical level, several factors contribute to this delay, including the normalization of pain and devaluation of patients' symptoms, misdiagnosis often confused with conditions like irritable bowel syndrome (IBS) or pelvic inflammatory disease, lack of knowledge, awareness, and empathy, perpetuation of myths about endometriosis through attitudes, and the use of non-discriminatory investigations (Cox et al., 2003; Ballard et al., 2006; Culley et al., 2013). While medical and surgical therapies can provide relief from pain and address fertility issues, they are not always effective and may not target all the symptoms associated with endometriosis (Becker et al., 2017; As-Sanie et al., 2019; Singh et al., 2020).

Last, endometriosis can greatly impact an individual's ability to work or attend school, affecting their economic stability and productivity. Indeed, the financial burden of endometriosis is primarily driven by the indirect costs associated with productivity loss, followed by direct costs related to medical care and treatment (Simoens et al., 2012). Several studies have found the negative impact of endometriosis on health-related quality of life, focusing on multiple areas such as physical health, psychological well-being, daily activities, work productivity, fertility, social relationships, sex life, and economic burden (Gao et al., 2006; Moradi et al., 2014; Pope et al., 2015; Facchin et al., 2017; Soliman et al., 2017; Marinho et al., 2018; Márki et al., 2022; Van Niekerk et al., 2022).

Addressing endometriosis, therefore, not only involves medical treatment but also raising awareness, improving early diagnosis, and providing comprehensive care that includes psychological support and pain management. Given the above-mentioned challenges, the present study aimed to shed light on the personal experiences of women afflicted by endometriosis through a qualitative lens.

2. Materials and methods

2.1 Participants

Ethical approval for this study was obtained from the Sapienza University Ethics Board (CERT approval number 12/2022), and informed consent was obtained from all subjects involved in the study. The study was conducted between 2022 and 2023. Participants were recruited on social networks through groups/pages/accounts dealing with the topic of endometriosis. Twenty-four women diagnosed with endometriosis consented to participate in the research. However, five respondents dropped out by not taking part in the interview. The median age of the nineteen participants was 36.6 years. The most commonly reported symptoms were pelvic pain, dysmenorrhea, dyspareunia, and rectal discomfort, while rarer symptoms included pain during ovulation, leg pain, cystitis, nausea, difficulty sitting, chronic fatigue, urinary tract discomfort, vomiting, renal colic, hemorrhagic menstruation. Regarding treatment (either ongoing or terminated), most of the participants stated that they had undergone or were undergoing both medical and surgical therapy (N=13, 68.4%), followed by 26.3% undergoing medical therapy only (N=5), and 5.2% undergoing surgical therapy only (N=1).

2.2 Interviews

Patients' narratives were collected through semi-structured interviews to explore in-depth experiences, as well as perceptions and opinions of respondents, and the meanings they attribute to these experiences. Such interview form is particularly useful in situations where the topic of interest is not well known and where the focus is on the variability rather than commonality of responses (Adams, 2010). Moreover, semi-structured interviews provide greater flexibility for the interviewer to: a) follow up on whatever angles are considered important by the interviewee; b) become more visible as a "knowledge-producing participant" (Brinkmann, 2014). The interview outline was developed based on an in-depth search of similar studies in the literature (Moradi et al., 2014; DiBenedetti et al., 2020; Guan et al., 2022; Ilschner et al., 2022). Additional insights were gathered through an interview conducted with a gynecologist experienced in endometriosis. The interview's structure involves questions on the following areas: the diagnostic pathway and treatment, the experience of illness, the impact of endometriosis on various areas of daily life, and perceived social support (see Appendix). The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist has been provided with the manuscript to ensure a comprehensive reporting of interviews (Tong et al., 2007; cf. Appendix).

All participants read, completed, and signed the informed consent for participating in the study and authorized the processing of their personal data. The one-on-one meeting with the participants took place remotely, via the teleconferencing application Google Meet, and included a short introductory phase aimed at explaining the study project. The interviews lasted an average of 45 minutes, were carried out by the first author of the article (female undergraduate student), and were audio and video recorded. The interviewer introduced herself to the participants as an undergraduate student of Psychology studying at Sapienza University of Rome and conducting this research for her Degree thesis.

2.3 Qualitative Analyses

The qualitative thematic analysis was conducted following a six-stage approach developed by Braun & Clarke (2006). After transcribing the interviews and checking against the tape, the authors familiarized with the dataset and started searching for patterns and meaning. Both first and second authors were involved in a comprehensive coding process and generated initial codes. The first author did all the coding and the second reviewed for accuracy. Consequently, together both authors created and named initial themes. Finally, a written report has been produced, developing a well-organized story about the data and the topic, and verbatim quotations of the selected interviews have been included to represent the identified categories. Each quote is followed by the initials of the interviewee (name and surname), the age at the time of the interview, and the year of diagnosis. Enough time has been allocated to complete all phases. The saturation level of the data was a matter of discussion and the data collected were considered sufficient for qualitative exploratory analysis.

3. Results

3.1 Results of the thematic analysis

Eleven main categories were identified through the thematic analysis of the interviews (refer to Table 1 for a summary).

Table 1. Qualitative analysis of patient experiences in endometriosis: Categories of lived challenges and coping mechanisms

Categories	Description of categories
	Diagnostic challenges
1. Tortuousness of the diagnostic pathway	The diagnostic delay characterizes the path of many participants, influenced by factors such as the normalization of menstrual pain, lack of knowledge about the disease, and poor communication skills in healthcare. The diagnosis may evoke relief or cause bewilderment and confusion.
2. Not being believed: the normalization of pain	Despite the intensity and disabling nature of endometriosis pain, it is often underestimated by health professionals, family members, friends, and colleagues.
3. The empathy of health professionals	Positive experiences with health professionals are characterized by their ability to actively listen to patients and adopt an empathetic attitude.
	Treatment and support challenges
4. Uncertainty	The experience of illness is marked by uncertainty regarding treatment and recurrence due to the limited and potential ineffective treatment options.

5. At war with endometriosis	Illness is often perceived as an external agent attacking the body; understanding the enemy is essential for reacting and defending oneself.
6. Barriers in access healthcare	The costs associated with medical examination, drug treatments, and hospitalizations, pose a major obstacle to the management of the disease.
	Impact on daily life and psychological well-being
7. Intolerable pain	Pain is described as a constant presence, using violent metaphors.
8. Limitations in daily life	Symptoms related to endometriosis, such as pelvic pain and chronic fatigue, have a significant impact on various areas of daily life, including school, work, and sports.
9. Isolation	The feeling of not being believed and understood and the lack of support and material assistance lead to the breakdown of various relationships, including family, friends, intimate connections.
10. Resignation, fear, hopelessness	The experience of illness may be characterized by negative moods related to the disease and its relapses.
11. Support network	Various sources of support, including finding comfort and avoiding isolation, gaining knowledge about endometriosis, and feeling the closeness of a community, play crucial roles.

3.2 Diagnostic challenges

3.2.1 Tortuousness of the diagnostic pathway

The diagnostic pathway for endometriosis exhibited significant variation in duration, with estimates ranging between 1 and 22 years, and an average of 7.3 years. This aligns with the national trend described by the Italian Ministry of Health (2023), which indicates a prolonged and complex diagnostic journey.

> *Here, doctors told me that I've had this disease for at least 6-7 years* (SS, 38, 2022).[1]

> *From the early years of high school, let's say around age 16, I received the diagnosis at 23* (SR, 32, 2013).

> *I discovered it [...] after six years of visits and check-ups, as I was experiencing difficulties conceiving* (DN, 38, 2019).

Even though many women in our study reported experiencing "painful periods" since menarche, which is the first menstruation, they had not delved into the causes of their pain until the appearance of other symptoms or a specific event, or until the pain became intolerable.

> *[The doctors] assume that the disease started to develop when I got my first period, because, especially during the first few years, the initial 4-5 years, I was continuously*

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[1] Each quote is followed by the initials (name and surname) of the participant, the age and the year of diagnosis.

> *returning home from either school or work due to vomiting and dysentery. The pain was so intense that it would cause me to double over* (DN, 38, 2019).

> *I started feeling unwell from the very first menstruation, even before it, during the preparatory phase. I consistently experienced stomach and intestinal problems, struggled with digestion, and was hospitalized due to abdominal pains before the onset of menstruation. Yet no one understood what it was (EB, 29, 2019).*

The diagnostic path is often challenging and involves in-depth diagnostics and numerous medical examinations.

> *I discovered I had endometriosis through a coded diagnosis in my medical records in November 2012. The diagnosis was confirmed via a diagnostic laparoscopy, a procedure decided upon after a series of, quite literally, catastrophic events* (AB, 42, 2012).

> *I had undergone numerous tests, eliminating all other possible pathologies except for endometriosis (FB, 29, 2018).*

Participants shared both positive and negative experiences with health professionals, although the latter were more prevalent.

> *[Endometriosis] was not explained to me correctly… The gynecologist… I only remember him saying to me: – You must immediately get pregnant –. He didn't elaborate on the fact that this is a disease that can cause infertility. If he had said just a few more words, maybe I would have led my life differently* (TV, 49, 1997).

When the diagnosis of endometriosis was revealed, the interviewees had varied reactions. Many participants expressed feeling relief, happiness, joy.

> *Giving a name [to the disease] was the turning point for me. It was fundamental, and it also reignited my desire to fight and move forward...* (CC, 42, 2017).

> *I was very happy, extremely happy, to have understood what the problem was, I mean, where my pain comes from* (MG, 30, 2020).

At the time of diagnosis, some women reported feeling dazed, confused, lost, and disoriented. Some of them had limited knowledge about the disease or its severity, while others experienced fear and discouragement.

> *I had no idea at all, so the moment I was diagnosed, it felt like an entire building had collapsed on me* (IC, 42, 2009).

> *I felt totally lost because I didn't understand what it was [...]. At the time, I didn't grasp the extent of this problem, that is, I didn't... I didn't realize* (SR, 32, 2013).

3.2.2 Not being believed: the normalization of pain

Most negative experiences with health professionals were linked to the downplaying and normalization of pain.

> *The gynecologists I consulted told me that it was completely normal, but I knew that there was something wrong* (LC, 42, 2002).

> *[A doctor] didn't make me feel understood in my pain at all [...] And I felt like she was belittling my experience a lot* (MC, 29, 2020).

> *I lost trust in the doctors because they didn't believe me* (SC, 36, 2019).

Other women reported being recommended for psychological therapy by health professionals, as their words were not trusted, and their painful symptoms were underestimated.

> *Sometimes, someone who prevents you from reaching the diagnosis makes you think that it's all in your head, and that, therefore, leads you to believe that you are crazy* (DG, 46, 2003).

> *The very fact of being told: "No, well, it's nothing" [...] puts a worm in your head, and anything else you do in life or say becomes: "Is it true? Am I making something up?* (EB, 29, 2019).

In some cases, dysmenorrhea has manifested as early as menarche. Despite this, the culturally and socially widespread and consolidated belief that menstrual pain is normal has led many participants not to seek the cause through gynecological and instrumental examinations, or not to be believed by family, friends, or health professionals.

> *Since my first menstrual cycle, I have always had a very, very painful period. As a child, I was told that it was completely normal* (IC, 42, 2009).

> *Not being believed in pain, especially because an invisible pain is not seen, being underestimated in the things I expressed, and just not being believed is what distinguishes women with endometriosis until they find someone who will... who will help them* (SC, 36, 2019).

3.2.3 The empathy of health professionals

When positive experiences were reported, they were related to health professionals' ability to listen to the patient, believe the painful symptoms that were reported, and show empathy.

> *I was fortunate to have doctors who listened to me, with whom I had a good relationship, you know... no one minimized my pain; on the contrary, they were interested in understanding my daily life, the impact of such heavy bleeding, the pain, so no one minimized. I was lucky* (FS, 45, 2000).

> *[The obstetrician] asked for my consent, so every time she touched me, even on the knee, she would ask: - Can I touch you here? -. So, for everything, there was consent, and it's something that has never happened to me, so I felt very welcomed, listened to* (ST, 27, 2022).

3.3 Treatment and support challenges

3.3.1 Uncertainty

Another characteristic of endometriosis highlighted by the participants was the uncertainty related to both the outcome of treatment and the recurrence of symptoms. Participants mentioned undergoing various medical and surgical treatments.

> *Now I hope I won't... I won't become ill, but we know it… it's a condition that can change at any moment, a condition that doesn't heal. So, I don't know how it will go... who knows!* (SR, 32, 2013).

> *The real problem with endometriosis is experiencing this pain, not understanding its origin, not finding answers, and thinking that you are inventing everything or somatizing something due to stress, believing you have created it yourself* (MG, 30, 2020).

3.3.2 At war with endometriosis

Endometriosis is frequently described as an external and hostile agent that invades the body violently and without legitimacy.

> *The disease had completely eaten away the vagina* (EB, 29, 2019).

> *It's something that can spread, it persists if they don't... if they don't remove it. I mean, nothing is spared* (SS, 38, 2022).

As a result, the woman's role was often passive: illness was endured, akin to the attack of an enemy from which it was not possible to defend oneself.

> *Sometimes, unfortunately, you can't... you can't predict or manage [the symptoms], so you are knocked out, and [the disease] doesn't relent until it has finished its outburst* (DN, 38, 2019).

Images related to death and cancer frequently emerged.

> [Endometriosis] had completely, exactly as the doctor said, affected one of the tubes to the ovaries, which were practically dead. (AB, 42, 2012)

> It's like having a tumor inside you that slowly consumes you. […] Something inside me is slowly dying, slowly consuming me, and I can't do anything about it (IC, 42, 2009)

> At that time, [the doctor] had told me: - Endometriosis takes a similar course as a tumor -. That was the first thing he told me. (LC, 42, 2002)

Taking up the metaphor of war, understanding the enemy allowed one to "fight" it and regain a sense of agency and hope to improve one's health and living conditions.

> *You must try to take hold of your life a bit; it won't be the life of normal people, but it's still life, and you must live it, you have to live it [...]. I will never give in to this cursed illness; I will never give in as long as I have strength* (TV, 49, 1997).

> *Let's say that, once you know what you have to fight against, it opens up a different perspective [...]. You are no longer resigned to the pain, but you see how the heck you have to do to overcome it. There is a chance to get better even if it's a long journey, even if the surgery is not easy[...]* (SS, 38, 2022).

3.3.3 Barriers in accessing healthcare

The costs of medical examinations and pharmacological treatments were significant obstacles in managing the disease. The inequity that characterized access to care and the need to ensure it for all women suffering from endometriosis was often emphasized.

> *I can't afford to take a job where they pay me less because I wouldn't cover the medical expenses* (FB, 29, 2018).

> *At that time, I lived in a family where there wasn't much money... my mom had tried to have me undergo some examinations, but, well, nothing special came out, nothing specific emerged* (TV, 49, 1997).

3.4 Impact on daily life and psychological well-being

3.4.1 Intolerable pain

The interviewees employed various metaphors to underscore the violence and the intensity of the pain associated with endometriosis.

> *It's like someone sticking a hand in and turning me inside out* (AB, 42, 2012).

> *I have a pain like a pin stuck in my stomach, as if someone keeps turning it continuously* (DG, 46, 2003).

I feel the uterus... as if it's on fire... and these flames rise upwards, so it's like they're practically burning everything (EB, 29, 2019).

It's like putting a band-aid on living tissues, and every now and then, someone suddenly tears it off. I mean, endometriosis pain is a burning, a real pain... it burns me from the inside like an open wound, and every now and then, someone blows on it suddenly (MM, 44, 2021).

Many women emphasized the disabling and limiting nature of pain.

It's definitely a constant and strong pain, kind of... that somewhat immobilizes, okay? So, it's a pain in which... it makes everything seem static to me (MC, 29, 2020).

Sometimes it's a pain that... that doesn't let you be clear-headed, and all you feel is pain (SR, 32, 2013).

The image of childbirth was also evoked, drawing parallels between the intolerable labor pain and current abdominal cramps.

I had cramps... well, I don't know what it means, I don't know what it's like to have contractions, labor pains, childbirth, I don't know because I've never given birth, but I think it was very close (AB, 42, 2012).

Exactly like childbirth pain, as if I were supposed to give birth, so I felt a strong... I mean, everything was pulling, and I had to push something, I don't really know... as if I had to give birth continuously, all day long (SS, 38, 2022).

Ultimately, pain was described as a constant presence, to which women have grown accustomed and with which they coexist.

It's not just one pain; practically, it's a mix of pain, so practically... so at a certain point, it's as if you don't feel it anymore (MG, 30, 2020).

It almost becomes like your... almost a friend, almost a travelling companion, this pain [...] that's the feeling, like having an inconvenient friend, but it's there, always there, you know? (TV, 49, 1997).

3.4.2 Limitations in daily life

Chronic fatigue was one of the most debilitating manifestations of endometriosis. Many women reported feeling low and fatigued, unable to keep up with others.

I also had something that made me feel guilty... a chronic fatigue that never... never went away. I felt terribly guilty, because you feel inadequate compared to others, right? (CC, 42, 2017).

> *You feel like a kind of mollusk that... that just vegetates because then you can't do much, it drains your energy, leaving you constantly tired* (MM, 44, 2021).

> *Sometimes I don't recognize myself, meaning that at times I feel like a walking corpse* (DN, 38, 2019).

> *The most annoying thing is that you realize that... I mean, it's as if you see someone else's life* (SS, 38, 2022).

Another topic concerned the lack of control: endometriosis pain could occur suddenly, without warning. The strategies used to alleviate it were sometimes unsuccessful, which could lead to anger and resignation.

> *This life is a bit like this... always suspended, always with the fear that tomorrow you wake up, you have another attack... because they are real attacks (TV, 49, 1997).*

> *Firstly, there's this resignation to always feeling unwell, and then the thing that bothered me the most [...] is that I couldn't... I no longer had control over my life* (AB, 42, 2012).

In many cases, the onset of endometriosis symptoms occurred while the participants were adolescents and attending school or during their academic careers.

> *I have always been stronger, despite the pain. If I had to take an exam, I would sit down and study, even if it meant... breaking my stomach with Aulin* (AB, 42, 2012).

> *If I had, um, a school trip or something, I was terrified because I already knew that, one way or an-other, I had to give up* (DN, 38, 2019).

In many cases, sports activities and fitness became impractical due to the limitations imposed by some symptoms of endometriosis, such as chronic fatigue.

> *After a day of work, I'm ready to drop, I mean, I'm really exhausted. Sometimes, I can't even make dinner* (FB, 29, 2018).

The working environment, along with the possibility to adapt work to one's own health needs, significantly influenced the experience of the participants.

> *[My colleagues] always somewhat pointed at me as someone who was, so to speak, favored or given special treatment* (TV, 49, 1997).

> *I had a fixed-term contract, so I couldn't afford to take sick days, and I went to work stuffed with medication, painkillers... yes, it was very exhausting* (SC, 36, 2019)

3.4.3 Isolation

The impact of endometriosis on social relationships, especially friendships, was described by many women as devastating. In numerous cases, the participants felt compelled to end several relationships and isolate themselves.

> *I completely cut off relationships; I no longer go out with the people I knew, because maybe they say: - Yes, okay, we'll meet, let's plan for the day after tomorrow - and on that day, you have the famous gnome in your belly scratching you with sandpaper* (MM, 44, 2021).

> *Going out with friends isn't... isn't... you're always the party pooper of the group, essentially, the one who always has some issue, right? And I have to be careful about what I eat, I can't drink, and I can't go far because if I feel unwell, if something happens, I have to go to the hospital* (SS, 38, 2022)

Many women reported that they were not believed by their families, especially before receiving the diagnosis, and that they did not feel understood or listened to.

> What I suffered the most was the lack of understanding from my mother, who never understood me. (TV, 49, 1997)

Several participants reported that they did not receive the necessary help, including material assistance, from parents and friends, and that they felt misunderstood and abandoned in their pain.

> *I never have the feeling that if I collapse, someone will catch me, and that's something that makes me suffer a lot. I mean, I know that if I don't do things for myself, no one else will do them for me* (FB, 29, 2018).

> *Regarding interpersonal relationships, like family, friends, I have distanced some people over time, because they haven't been close to me* (VD, 28, 2016).

3.4.4 Resignation, fear, hopelessness

Feelings of despair, lack of hope, and a sense of downheartedness, as well as sadness, characterized women's experiences of illness.

> *I don’t feel like I can be light-hearted as a 27-year-old, because everything, anyway, is connected to the illness to some extent* (ST, 27, 2022).

> *Thinking about spending your whole life like this makes you want to throw yourself under a train, and I understand it* (SS, 38, 2022).

> *I really had the feeling of wanting to fall asleep and never wake up again; […] and I was very de-pressed during that period because this pain really took away any desire to live* (SC, 36, 2019).

> *Psychologically, then, you feel knocked down, you feel inadequate, you don't feel suitable, you don't feel like a woman, you don't feel... you don't feel anything anymore* (IC, 42, 2009).

> *Before the surgery, I had hope, I thought: - Oh, I would like to go to Japan […]- now I no longer have these thoughts, and this is a bit sad, I mean... hope is something that often lifts your spirits* (FB, 29, 2018).

Many women expressed strong concern about reduced fertility, which, in some cases, contributed to the onset of negative emotional states marked by anger, fear, frustration, hopelessness, and sadness.

> *If there was a friend of mine getting pregnant or my sister-in-law, etc., I would cry for two, three days, I mean... why them? why not me? why are they fortunate? why am I not?* (DN, 38, 2019).

> *Regarding the disease itself, endometriosis, I have to tell you the truth: the biggest concern I've had is about a possible, let's say, impact on fertility because... that's still the thing that I admit concerns me the most* (MC, 29, 2020).

Some participants mentioned that they had undergone psychological therapy in the past and/or were currently undergoing it to accept endometriosis, cope with bodily changes, address reduced fertility, manage anxiety and depressive symptoms, and navigate the stressful conditions experienced during the diagnostic pathway.

> *I needed someone to help me become aware of something that was happening to me on a physical level* (AB, 42, 2012).

> *After the surgery, when I discovered this whole mess, yes, I sought the help of a counselor specialized in this type of distress, because I had to recover from all the aftermath of the years, as I had a breakdown. I went into menopause; I had a collapse in every sense; I didn't feel like a woman any-more. I certainly needed support...* (SC, 36, 2019).

3.4.5 A support network

Many women reported finding comfort and support in numerous online groups on various platforms, primarily Facebook. Associations of patients with endometriosis and professionals involved in its treatment often played a supportive and helpful role.

> *Since 2021, a thousand social media profiles of individuals or associations have emerged […] talking about endometriosis... mmm, it was a very nice thing to feel understood, of course, to be able to connect with someone* (FB, 29, 2018).

> *When you hear that actually many other girls have managed to... to be well nonetheless, then you already feel psychologically reassured; you say: -Well, it's not really all that negative, I can do it –* (IC, 42, 2009).

Family members, partners, and friends were another valuable source of support.

> *In the family context, for sure, my parents and my husband help me, yes, let's say, to accept this new... this new lifestyle* (AP, 29, 2022).

> *Everyone, especially my friends in high school, was quite understanding; I mean, they didn't make me feel like a person with a problem. They understood that I was actually not well and tried to meet me halfway* (MG, 30, 2022).

The partners' reactions played a significant role in shaping women's responses to the pain experienced during sexual intercourse.

> *To the partners I've had, boyfriends, casual relationships... even before having the diagnosis, I would say: - Look, I might experience pain during intimacy - and I've never met anyone who made me feel wrong* (EB, 29, 2019).

4. Discussion

The present study used qualitative thematic analysis to bridge the gap in understanding the multifaceted impacts of endometriosis on women's lives, with a specific focus on the economic, psychological, and social dimensions. Given the significant burden of endometriosis revealed by previous research (Simoens et al., 2012; Soliman et al., 2016; Malik et al., 2022), and the challenges associated with delayed diagnosis and treatment inefficacies (Surrey et al., 2020; Fritzer et al., 2012; Ghai et al., 2019; Hadfield et al., 1996), our study sought to offer novel insights into the lived experiences of women with endometriosis.

4.1 Diagnostic challenges

One of the key areas our study investigated was the diagnostic challenges faced by women with endometriosis. The diagnostic pathway described by the participants, in most cases, was troubled, confirming findings from other studies (Cox et al., 2003). Consistent with Bontempo and Mikesell (2020), many participants in our study consulted several specialists, predominantly general practitioners, and gynecologists, and either did not receive any diagnosis or received a misdiagnosis. Therefore, in line with Culley et al. (2013), the lack of knowledge about the clinical picture of endometriosis among health professionals played a significant role in perpetuating diagnostic delays.

Several participants reported experiencing "painful periods" since menarche but did not investigate or consider this symptom problematic, assuming their experience was normal. Moreover, the relationship with health professionals was often described in negative terms, particularly when the woman's pain was normalized and underestimated. If the participant felt unheard, misunderstood, or not believed, and perceived a lack of empathy and consideration by the doctor, the doctor-patient relationship was characterized by anger and mistrust (Facchin et al., 2018). Conversely, participants who perceived health professionals as empathetic, professional, respectful, understanding, and interested in the impact of endometriosis on their daily lives described positive experiences.

4.2 Treatment and support challenges

One of the most common reactions exhibited by the participants at the time of diagnosis was relief. This aligned with Ellis et al. (2022), who suggested that relief might appear as a paradoxical emotion considering that endometriosis is a chronic, inflammatory, and currently untreatable disease. The relief experienced by women could be understood in the context of the prolonged diagnostic pathways described and the encountered lack of trust and support in relationships with family, friends, and health professionals. However, in this study, relief was frequently accompanied by, and in some cases completely replaced with, worry, confusion, and sadness, especially when the pathology was unknown. Many participants reported uncertainty related to both the outcome of treatment and the recurrence of symptoms. In most cases, they had never heard of endometriosis before the diagnosis or had very vague and general knowledge about the condition. Several studies have highlighted the complexity of endometriosis-related pain, which often hinders the recognition of the disease. Considering that pain is invisible to external observers, can manifest itself physically in multiple ways, and its experience is inherently subjective, women with endometriosis frequently use metaphorical language to communicate their painful symptoms (Bully, 2020; Abraham & Rajasekaran, 2023).

In our study, the experience of endometriosis was likened to "warfare" and "invasion". These metaphors captured the sense of intrusion that the condition imposed on the body, disrupting normalcy, and introducing pain and suffering. Emerging literature suggests that individuals living with endometriosis tend to report more negative body image (Sayer-Jones & Sherman, 2023), since the relationship with their own body is described as a constant struggle. Consistently with Facchin et al. (2018), some participants negatively refer to their bodies because of the presence of scars left by surgical interventions, the tendency to gain weight, and the physical symptoms caused by the hormonal therapies. The costs associated with medical examinations, drug treatments, and hospitalizations posed a major obstacle to the management of the disease. In our study, this theme frequently emerged from the interviews. Many participants mentioned resorting to private healthcare due to long waiting times in the public health system and facing challenges in accessing medical care due to extremely high costs. This economic burden aligns with findings from the study conducted in Italy by Facchin et al. (2018) with a sample of Italian women, as well as with international literature (Malik et al., 2022).

4.3 Impact on daily life and psychological well-being

The symptoms most frequently reported in the present study (pelvic pain, dysmenorrhea, dyspareunia, and rectal discomfort) aligned with those seen in the general population of women with endometriosis (Bulletti et al., 2010). Among these symptoms, Culley and colleagues (2013) identified pain as the most pervasive and disabling one, significantly impacting various aspects of individuals' lives. Patients' narratives depicted physical pain, either triggered by certain actions (e.g., "It feels like someone is sticking a hand in and turning me inside out") or attributed to an object (e.g., "like a pin stuck in my stomach"). Additionally, metaphorical expressions were used to describe sensations of heat and pressure, sometimes likened to the experience of childbirth. Equally intriguing was the portrayal of pain as a constant companion, to which the woman had grown accustomed over time, eventually becoming an "unwelcome friend". In this regard, it is worth mentioning that some participants found that accepting the disease and its symptoms allowed them to consider endometriosis as an integrated part of their life history ("restoring continuity") (Facchin et al., 2018).

Indeed, some women identified opportunities for personal growth through endometriosis, such as developing greater sensitivity, fostering meaningful social relationships, or taking part in projects to educate the general population about endometriosis. Conversely, it was observed that the diagnosis of endometriosis was met with anger, sadness, and resignation, and was considered an "unfair" event ("experiencing disruption"), especially when characterized by diagnostic delay and negative experiences with health professionals (Facchin et al., 2018). This disruption may also concern the sense of personal identity, especially gender identity and body image (Cole et al., 2021). Indeed, Facchin et al. (2018) suggest that endometriosis may negatively affect women's female identity, leading to high levels of distress, low self-esteem and low perception of their own value.

In line with Moradi and colleagues (2014), some participants described experiencing painful periods throughout their education, impacting their school and university life variably. While some women employed painkillers to manage and persisted in their activities, others had to skip school trips and frequently missed classes due to intense pain. In terms of physical activity, the impact of endometriosis varied: some were hindered by pain, whereas others reported that moderate exercise improved their well-being. However, the scientific literature on the relationship between physical activity and endometriosis is scarce, with few systematic reviews suggesting that current studies are too limited to conclusively determine the effects of exercise on endometriosis symptoms (Bonocher et al., 2014).

Regarding work environment, most research participants reported experiencing absences, requesting sick days from their employers, missing opportunities for promotion, and feeling uncomfortable explaining their illness to colleagues. Previous research (Simoens et al., 2012) underscored the significant indirect costs associated with the condition, particularly those stemming from diminished work and academic participation. The same study delineated how endometriosis adversely affected individuals' capacity to maintain regular employment or educational pursuits, thereby exacerbating the financial strain attributed to the disease. Building upon this literature, our study highlights the role of workplace dynamics. The accounts gathered from interviews with affected women revealed that the absence of empathy and comprehension within professional environments amplified the economic burden borne by individuals. Conversely, narratives depicting positive workplace interactions underscore the value of employer and colleague support, including the provision of flexible work arrangements.

Lack of understanding and support from others led women with endometriosis to avoid discussing their health with friends, family, and colleagues, resulting in feelings of isolation (Cole et al., 2021). Similar experiences were reported by our participants: the termination of friendships was often linked to the difficulty of sharing one's painful symptoms and the feeling of "being a burden" to others or making them uncomfortable because of one's health condition. Regarding family relationships, the interviews revealed contrasting experiences: some women received support throughout the diagnostic and treatment pathway (e.g., from their mother and/or father), while others received such support only after diagnosis. Some women perceived that they were never believed or helped by their family members. Others reported difficulties in intimate relationships, as well as guilt and fear of feeling "wrong" and misunderstood by their partner, particularly in cases where dyspareunia made sexual intercourse impossible or very painful. In this regard, many women emphasized the importance of having a patient and understanding partner by their side, with whom the relationship can also be strengthened and consolidated following the diagnosis.

To provide social support to individuals who lacked this resource in their informal network is vital fostering connections with others who could empathize with their situation and share positive experiences. In a sustainability perspective, virtual support groups can reduce the need for travel, which can be helpful for women with chronic pain or fatigue. Many participants reported joining groups, mostly online, or associations consisting of other women with endometriosis. These interactions were predominantly described as positive, as they allowed participants to share their experiences and fears, feel understood, find comfort, and learn more about the condition. Whelan (2007) extensively studied support groups and defined them as "epistemological communities" since, in addition to providing mutual support in accepting and managing the disease, the exchange of information among members facilitated the development of shared knowledge.

Among the factors strongly influencing psychological well-being, infertility, normalization of pain, and disability have been identified. Infertility, along with pain, is a primary reason why women with endometriosis seek treatment (As-Sanie et al., 2019). During the interviews, this topic often proved delicate, particularly for participants with a strong desire for motherhood. Consistently with Sayer-Jones & Sherman (2023), in some cases loss of body functionality impacted gender identity and ability to fulfill life choices. Some women defined the risk of infertility as the most worrisome aspect of endometriosis. Others highlighted the stress and pressure resulting from professionals advising them to conceive as soon as possible to avoid future complications. This advice often did not consider the woman's willingness to conceive and her circumstances (e.g., young age and/or unemployment).

Most studies agree that depressive disorders, anxiety disorders, and emotional distress are more prevalent in women with endometriosis compared to the healthy population. Although the origin of this correlation is not yet clear, some authors attribute it to the experience of pelvic pain itself (Della Corte et al., 2020). In the present study, participants frequently reported experiencing negative emotions, such as hopelessness, anger, guilt, inadequacy, and sadness. As reported by Facchin et al. (2018), distressed women with endometriosis may consider themselves worthless and reduce their female identity to the disease. Some women described developing "negative thoughts," at times so distressing that they evoked the image of death. Many participants reported benefiting from psychotherapy or other psychological interventions aimed at increasing awareness of endometriosis, accepting it, and coping with its consequences. Some emphasized the need to complement the support of a mental health professional with that of the gynecologist treating them, starting from the time of diagnosis.

A systematic review (Van Niekerk et al., 2019) concluded that evidence-based psychological interventions are effective in reducing anxiety and depressive symptoms in women with endometriosis. Mindfulness, psychoeducation, and individual psychotherapy based on cognitive-behavioral therapy have been found to be promising for enhancing health-related quality of life and pain-related coping strategies (Evans et al., 2019).

5. Conclusion

Medicine has for a long time underestimated some pathologies that affect the woman's body, including endometriosis. Our study contributes to calling attention to this topic and invites future psychosocial research. By providing a patient-centered view of the challenges and coping strategies of women with endometriosis, this study contributed to the existing literature by highlighting areas for improvement in healthcare policy, patient support services, and public awareness initiatives. The findings are expected to inform multi-disciplinary strategies to enhance the quality of life for individuals affected by endometriosis and to guide future research focusing on sustainable healthcare solutions.

To begin with, improving healthcare professionals' awareness and understanding of endometriosis, and fostering empathy, active listening, and communication skills can help speed up the diagnostic process for individuals with endometriosis, ensure timely access to effective treatments that can improve health outcomes, and reduce the economic burden of the disease. In addition, improving education and raising awareness about endometriosis among women and girls, as well as within the broader community, can empower those affected to seek care and advocate for their health needs. Empowerment also involves addressing stigma and myths surrounding menstruation and the normalization of pain, which can deter individuals from seeking help. Clearing menstrual education of taboos and false myths is essential for individuals to distinguish between normal and abnormal experiences, care for their bodies, and understand when, how, and where to seek medical help. Menstrual health should be promoted through education programs in schools and communities, rather than relying solely on the role of mothers, grandmothers, sisters or friends (Guidone, 2020). Poor health literacy perpetuates menstrual shaming and significantly contributes to the diagnostic delay and treatment ineffectiveness. Therefore, alongside scientific advancements, there is a need for a systematic deconstruction of cultural norms surrounding menstruation and related pain. From a psychological perspective, further research is needed to better understand the dimensions related to the female body, blood, and fertility image representation and (own-other) perception.

Furthermore, special attention should be directed towards understanding the role of comorbidities, as nearly 95% of women with endometriosis report one or more additional disorders (As-Sanie et al., 2019). As no treatment is currently definitive, there might be disparities in access to allied health disciplines and complementary treatments that are not covered by the health system or private insurance. Ensuring equitable access to healthcare services for endometriosis is essential. Last, recognizing the interconnectedness of physical, mental, and social factors calls for adopting a comprehensive care model that includes medical, psychological, and social support services. This can improve the quality of life for individuals with endometriosis. In summary, patients' narratives underscored the need for an integrated approach to managing endometriosis, aligning with several key sustainability goals, including good health and well-being, gender equality, and reduced inequalities.

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Appendix

Interview outline

Area	Topic	Questions
Anamnestic and socio-demographic information	• Age • Email • Year of diagnosis of endometriosis • Symptoms • Treatment (ongoing or terminated)	
Diagnosis and treatment pathway	Experience with endometriosis/diagnosis pathway	Share the narrative of your experience with endometriosis: How did you first become aware of it? What was the diagnostic process like, and what treatments have you pursued thus far? Provide a brief overview of your journey. Additional prompts: What diagnostic tests were conducted? Who diagnosed you, and when and how was the diagnosis made? How many years passed before you received the diagnosis?
	Awareness of the condition	Were you familiar with endometriosis before receiving your diagnosis? If yes, where did you gather information about this condition?
	Pain	Can you provide more details about the pain associated with endometriosis that you have experienced or are currently experiencing? Please describe the type of pain and how you would explain it to someone unfamiliar with this condition.
	Reaction to the diagnosis of endometriosis	Can you share your initial reaction to the diagnosis of endometriosis? Additionally, have your feelings or attitudes changed over time, and if so, how?

	Experiences with health professionals	Reflecting on the health professionals you encountered, were there specific individuals who played a positive or negative role in managing your endometriosis? If so, could you elaborate on the experiences that influenced your perception?
	Treatment	What treatment are you currently undergoing for endometriosis? On a scale from 1 to 4, with 1 being minimal and 4 being significant, how would you rate the effectiveness of the treatment in reducing symptoms and improving your quality of life? Could you share the reasons behind your rating? Additionally, are you undergoing any other treatments aside from medical interventions?
Illness experience	The impact of endometriosis on various areas of life	Can you describe how endometriosis has impacted and continues to affect various aspects of your life, especially in terms of work or school, relationships, private life, and sports or physical activities? If possible, share a specific episode or example. Additionally, do you believe that this disease can have an impact on the psychological health of patients? If so, in what ways? For instance, what kind of impact or disturbances could it create?
	Coping strategies and support	In comparison to your experience with the illness, what strategies or support mechanisms have helped you cope with endometriosis? Have there been specific individuals, groups, or initiatives that provided support or assistance during your journey?
Do you have anything else to add?		

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

No. Item	**Guide questions/description**	**Remarks**	**Reported on**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1. Inter viewer/facilitator	Which author/s conducted the interview?	The first author (GG) conducted the interviews.	2.2 Interviews
2. Credentials	What were the researcher's credentials?	GG: undergraduate student FA: PhD, Associate professor	2.2 Interviews
3. Occupation	What was their occupation at the time of the study?	GG was attending a master's degree in psychology at Sapienza University of Rome. FA is an Associate Professor of Social Psychology at Sapienza University of Rome.	2.2 Interviews
4. Gender	Was the researcher male or female?	Female	2.2 Interviews
5. Experience and training	What experience or training did the researcher have?	GG attended courses on qualitative research methods and read several articles on qualitative thematic analysis. FA is an experienced researcher in qualitative studies and has published numerous qualitative research articles.	N/A
Relationship with participants			
6. Relationship established	Was a relationship established prior to study commencement?	Only for the purposes of this research.	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g.	The interviewer introduced herself to the participants as an undergraduate	2.2 Interviews

	personal goals, reasons for doing the research	student of Psychology studying at Sapienza University of Rome and conducting this research for her Degree thesis.	
8. Interviewer characteristics	What characteristics were reported about the interviewer? e.g. Bias, assumptions, reasons and interests in the research topic	None	N/A
Domain 2: study design			
Theoretical framework			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was applied to the interviews.	2.3 Qualitative Analyses
Participant selection			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience sampling	2.1 Participants
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Participants were recruited on social networks (Facebook and Instagram) through groups/pages/accounts dealing with the topic of endometriosis, where the first author posted an invitation. Those who expressed interest to participate received an email with additional information on the study and informed consent.	2.1 Participants

12. Sample size	How many participants were in the study?	19 women with endometriosis.	2.1 Participants
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Out of the 24 women approached, 5 did not reply to invitation email to the interview. Reasons are unknown.	2.1 Participants
Setting			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data were collected at first author 's (GG) home. The one-on-one meeting with the interviewee took place remotely, via the teleconferencing application Google Meet	2.2 Interviews
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No-one else was present besides the participants and the researchers.	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	All the participants were female, the median age was 36.6 years.	2.1 Participants
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The interview structure is reported in Appendix. The interview was tested by the first author with 3 university colleagues.	Appendix
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were carried out.	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Interviews were audio and video recorded.	2.2 Interviews
20. Field notes	Were field notes made during and/or after the interview?	No field notes were made.	N/A
21. Duration			

	What was the duration of the interviews or focus group?	The interview lasted an average of 45 minutes (ranging from 20 to 100 minutes).	2.2 Interviews
22. Data saturation	Was data saturation discussed?	Data saturation was a matter of discussion and the data collected were considered sufficient for qualitative exploratory analysis.	2.3 Qualitative Analyses
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	The transcripts were not returned to participants for comment or correction.	N/A
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	The first author (GG) did all the coding and the second (FA) reviewed for accuracy.	2.3 Qualitative Analyses
25. Description of the coding tree	Did authors provide a description of the coding tree?	Categories identified through the thematic analysis of the interviews are provided in Table 1	Table 1
26. Derivation of themes	Were themes identified in advance or derived from the data?	Following an inductive approach, themes were derived from the data during the analysis.	2.3 Qualitative Analyses
27. Software	What software, if applicable, was used to manage the data?	N/A	N/A
28. Participant checking	Did participants provide feedback on the findings?	No, participants did not provide any feedback on the findings.	N\A
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation	Each quote is followed by the initials of the interviewee (name and surname), the age at the	2.3 Qualitative Analyses

	identified? e.g. participant number	time of the interview, and the year of diagnosis.	
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, there was consistency between the data presented and the findings	3. Results
31. Clarity of major themes	Were major themes clearly presented in the findings?	"Diagnostic challenges", "Treatment and support challenges", and "Impact on daily life and psychological well-being" have been identified as major themes and are clearly presented in the findings.	3.1 Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes are presented and discussed in Table 1 and in the Results' section.	3.1 Results; Table 1

Developed from:
Tong, A, Sainsbury, P., Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,19*(6), 349 – 357.