

Patients' perspective on barriers related to delayed diagnosis of endometriosis: A systematic review of qualitative studies

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Background

- Endometriosis is a common, disabling, and painful chronic disease that has a severe negative impact on women's daily life activities and mental and sexual health. It affects approximately 190 million people who menstruate globally, regardless of ethnic origin or social status.¹
- It arises from an inflammatory reaction in the endometrium that provokes the presence of endometrial-type tissue outside the uterus.¹
- The condition varies in severity and can cause various gynecological symptoms such as dysmenorrhea, dyspareunia, chronic pelvic pain, excessive or irregular menstrual bleeding, and associated fatigue.^{2,3} In advanced cases, endometrial tissue can be found within the abdominal cavity, affecting the bowels, appendix, bladder, and rectum and causing urological or gastrointestinal symptoms. In rare cases, growth is detected in the lungs, diaphragm, and brain. Endometriosis may also interfere with fertility.
- Diagnosing endometriosis can be challenging because pain and bleeding can be attributed to other conditions. Laparoscopy is considered to be the gold standard for diagnosis, followed by histology evaluation and magnetic resonance imaging. Other less accurate methods used in the diagnosis include pelvic exams, CA-125 blood tests, and ultrasounds.
- There is no definitive cure for endometriosis; available treatments are intended to manage the symptoms and slow down disease progression (Table 1).

Table 1. Available treatments for endometriosis

Oral medications
Pain medication (mainly NSAIDs like ibuprofen and naproxen)
Hormonal supplements to help slow down the growth of the endometrial tissue (hormonal contraceptives, GnRH agonists and antagonists, progestins, aromatase inhibitors)
Medication to reduce the bleeding (tranexamic acid, NSAIDs)
Surgical interventions
Conservative excision surgery to remove the endometriosis implants if preservation of fertility is desired
Hysterectomy with or without oophorectomy

Key: GnRH – gonadotropin-releasing hormone; NSAID – nonsteroidal anti-inflammatory drug.

- Although the condition is very common among women, the time from symptom onset to diagnosis is prolonged and can take between 4 and 10 years due, partly, to the lack of affordable, accurate, and noninvasive diagnostic tools.
- Delays in diagnosis have a significant impact on the disease course, with most patients being diagnosed after they have already reached the more severe stages of the disease.^{4,5}
- The impact of endometriosis-associated symptoms is multidimensional. They can negatively and substantially affect quality of life and daily activities such as household tasks, energy, vitality, and socializing, as well as physical functioning. The symptoms also interfere greatly with patients' working lives or schooling, and patients experience difficulties in disclosing health information to employers, teachers, or peers.⁶
- Endometriosis represents a high economic burden before and after diagnosis, with associated increased healthcare resource utilization and excess costs.⁷
- There is little research focused on patients' own experiences to achieve diagnosis, and similar previous systematic literature reviews (SLRs) only included data published up to 2018.⁸⁻¹⁰

Objective

- This SLR aimed to identify the barriers to timely diagnosis of endometriosis from the patient perspective as reported in qualitative studies.

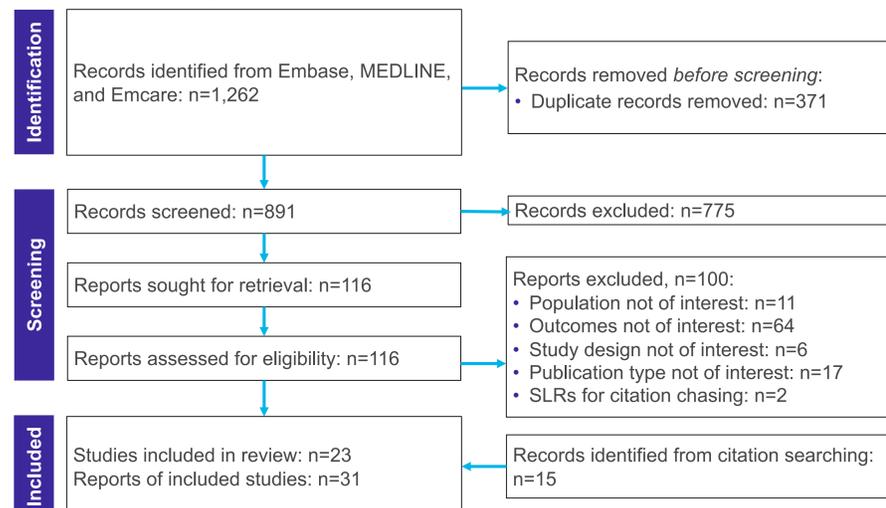
Methods

- Searches were run in Embase, MEDLINE, and Emcare (via Ovid) on June 20, 2022, following PRISMA guidelines.
- Studies were included if they were in English language; were qualitative studies reporting women's journeys to endometriosis diagnosis; and were conducted in Australia, Canada, New Zealand, the United States, and Western Europe.

Results

- Out of 891 unique records identified, 16 met all the inclusion criteria. Fifteen additional studies were included via manual checks of included publications and systematic reviews. The 31 publications reported data from 23 unique studies. Figure 1 presents the literature screening process.

Figure 1. PRISMA diagram



Key: SLR – systematic literature review.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. doi:10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

Results (cont.)

Search results

- The evidence published between 2003 and 2022 reported on 7,188 patients with endometriosis in total, but most studies included small samples of 12 to 74 participants (n=20 studies). Most studies were carried out in English-speaking countries including the United Kingdom (n=7), Australia (n=6), the United States (n=3), New Zealand (n=2), and Canada (n=2). There were also accounts reported from patients in the Netherlands, Italy, France, and Sweden.
- The methods of data collection for these qualitative studies varied. More studies used semi-structured interviews to capture patients' perceptions of the disease (n=8 studies), followed by focus groups (n=5), open interviews and online surveys (n=4 each), and in-depth interviews (n=3).
- When reported, the age of patients ranged from 16 to 78 years, with averages ranging from 30.6 to 45.5 years. Eleven studies reported the average time to diagnosis within a range of 1 to 18 years, and 2 studies reported that patients experienced symptoms for 1.5 to 30 years before being diagnosed with endometriosis.

Barriers to timely diagnosis

- Evidence from the literature suggests that the first barrier to timely diagnosis from symptom onset begins with delaying seeking medical advice due to "normalization" of women's own symptoms.¹¹⁻¹⁵ A tendency to avoid disclosing and discussing their symptoms with other women due to embarrassment further contributes to reduced awareness of how the symptoms of endometriosis are abnormal and what warrants further investigation.^{11,12,16,17}
- Women convince themselves that they are weak and unable to deal with a normal body function,¹¹ while feelings of helplessness and vulnerability have a significant impact on patients' self-esteem.^{16,18} Women report that they frequently have to adapt their schedule and decline attendance to social events due to their fear of not being able to manage the pain and other debilitating symptoms of their condition.^{18,19}
- According to patients' perspectives, normalization of symptoms, trivialization of women's experiences, and lack of awareness and sympathy from clinicians further complicate the provision of appropriate care and cause further distress.^{11,12,14,20} Another important factor highlighted by women is the intermittent suppression of symptoms using hormonal medication.¹¹ These issues seem to be experienced mainly in the primary care setting, with general practitioners delaying the referral to specialists.
- Women highlighted that the encounters with medical professionals have often left them feeling disbelieved, dismissed, and ignored, leading to mistrust and the erosion of the patient-clinician relationship.^{11,12,14,16,19,21-25,27,29-32}

Barriers to accurate diagnosis

- In the absence of cheap and accurate noninvasive diagnostic tools, misdiagnosis is quite common. Approximately 75% of women have reported that based on their presenting symptoms, they have been misdiagnosed with bowel diseases, sexually transmitted diseases, ovarian cysts, appendicitis, pelvic inflammatory disease, and other conditions with similar symptoms.^{5,15,22-26}
- Interestingly, the diagnosis of mental health-related conditions including anxiety or depression usually preceded the diagnosis of endometriosis²⁴; it is, however, unclear whether these comorbidities contributed further to delayed diagnosis or developed as a result of the untreated endometriosis.

Conclusions

- The barriers to the diagnostic journey of patients with endometriosis are similar among most patients; these barriers seem to promote the delayed or missed diagnosis of endometriosis regardless of geography, which is mainly fed by a profound lack of awareness of the presentation of endometriosis from women and clinicians alike.
- A strategy to address the challenges associated with the diagnostic process of endometriosis should include efforts to increase awareness of symptomatology by clinicians and the general public to facilitate early recognition of endometriosis.¹²
- Other barriers such as lack of cheap and accurate noninvasive diagnostic methods need to be addressed to radically reduce diagnostic delay. In the absence of these methods, experienced clinicians can predict the presence of endometriosis based on patients' history and symptomatology. It has been suggested that available treatments can be offered before definitive diagnosis is received to alleviate the burden of disease.
- A patient-centered approach that involves cooperation between disciplines,^{11,12} including gynecologists, sexologists, and psychotherapists, could significantly improve patients' quality of life.
- Receiving a diagnosis is life-changing for women, who feel validated and relieved that their symptoms are not related to cancer.^{11,14,17,23,25-27,30} There is hope that after diagnosis, appropriate treatment, follow-up, and support can be provided.

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