MEGA JOURNAL OF CASE REPORTS

OPEN ACCESS

Brief Review

Compiled Date: September 10, 2026

# The Diagnostic Odyssey of Endometriosis: Why Timely Diagnosis Remains Elusive

**Tobi Ash, PhD**

World Research Organization, Cape Coral, FL 33914, USA, Tel: +1 3052182121

## Introduction

Endometriosis is a chronic, estrogen-dependent inflammatory disease defined by the presence of endometrial-like tissue outside the uterine cavity, most commonly on the pelvic peritoneum, ovaries, and rectovaginal septum [1]. It affects an estimated 10% of women and girls of reproductive age worldwide and is strongly associated with dysmenorrhea, chronic pelvic pain, dyspareunia, and infertility [1,2]. Despite its high prevalence and substantial impact on quality of life and work productivity [3], endometriosis remains one of the most poorly and slowly diagnosed conditions in gynecology. Multiple international studies converge on a strikingly consistent finding: patients typically wait several years, often the better part of a decade, between the onset of symptoms and a confirmed diagnosis [3-8]. This delay is not attributable to any single cause but instead reflects an interlocking set of patient-level, clinician-level, and health-system-level barriers, compounded by the biological ambiguity of the disease itself. This review synthesizes the current evidence on the scope of diagnostic delay in endometriosis and examines the factors that make the condition so difficult to identify in a timely manner.

## The Scope of the Problem

Estimates of diagnostic delay vary considerably by country and by methodology, but the overall picture is remarkably consistent. In a landmark multicenter study spanning ten countries, Nnoaham and colleagues found that women experienced significant, multi-year gaps between symptom onset and diagnosis, with delay compounded by repeated visits to multiple providers before a diagnosis was reached [3]. A more recent scoping review estimated an average global diagnostic delay of approximately 6.6 years, with substantial geographic variation from roughly six months in some cohorts to over two decades in others, reflecting differences in healthcare system structure, awareness, and access [7]. That review further decomposed the delay into discrete

intervals: roughly two years elapse between symptom onset and a first primary-care consultation, followed by an additional two to three years before referral to gynecology, and a further two to three years before a definitive diagnosis is reached [7]. Similar multi-year delays have been documented in Austria and Germany [6] and in numerous single-country cohorts summarized in a 2025 systematic literature review of regional diagnostic patterns [8]. A companion systematic review and meta-analysis quantified the relative contribution of different factors, finding that delays attributable to patients' own care-seeking behavior and delays attributable to clinician misdiagnosis or reliance on non-specific diagnostic strategies each carried a large, statistically robust effect on overall time to diagnosis [4].

## Why Endometriosis Is So Difficult to Diagnose

### Symptom normalization and non-specific presentation

A central and recurring theme across qualitative and quantitative studies alike is the normalization of menstrual pain. Ballard, Lowton, and Wright's qualitative study of women's diagnostic journeys found that many patients and, critically, many of the clinicians they consulted, initially interpreted severe dysmenorrhea as a normal, if unpleasant, feature of menstruation rather than a sign of underlying pathology [5]. Because pelvic pain, heavy bleeding, and fatigue are common and nonspecific complaints with a broad differential diagnosis, early symptoms are frequently attributed to primary dysmenorrhea, irritable bowel syndrome, interstitial cystitis, or psychosomatic causes rather than to endometriosis [1,7]. This diagnostic ambiguity is compounded by the disease's heterogeneous presentation: symptom severity correlates poorly with the extent or stage of visible disease, so a patient with extensive endometriosis may report modest pain, while a patient with minimal lesions may experience debilitating symptoms [1,2]. This mismatch undermines the intuitive clinical assumption that symptom severity should track disease burden and makes triage by symptom presentation alone unreliable.

### Limitations of clinical examination and imaging

Endometriosis also resists straightforward physical and radiological confirmation. The 2022 ESHRE guideline notes that pelvic examination has low diagnostic accuracy for identifying endometriotic lesions and that further diagnostic evaluation is warranted even when examination findings are normal [2]. Imaging modalities such as transvaginal ultrasound and pelvic MRI are recommended as part of the diagnostic work-up and can reliably detect ovarian endometriomas and some deep infiltrating disease, but both modalities are substantially less sensitive for superficial peritoneal implants, which represent a common and clinically significant disease phenotype [1,2]. Consequently, a negative imaging study does not exclude endometriosis, yet in practice it is frequently and inappropriately treated as reassuring, delaying further work-up [2]. Historically, definitive diagnosis has depended on direct visualization of lesions at laparoscopy, ideally with histological confirmation [1,2]. Because laparoscopy is an invasive surgical procedure carrying its own risks and costs, clinicians are understandably reluctant to proceed to surgery on the basis of symptoms and imaging alone, particularly early in a patient's symptom course. This creates a structural bottleneck: the gold-standard diagnostic test is one that most patients will not undergo until other

explanations have been exhausted and symptoms have persisted for years.

### Clinician-level and health-system barriers

Beyond the biology of the disease, evidence points to substantial gaps in clinician awareness and to structural inefficiencies in referral pathways. The scoping review by Fryer and colleagues, using a social-ecological framework, found that patients consulted an average of four or more different physicians before receiving a diagnosis, with many reporting that they felt "unheard" and that their recurrent presentations were misattributed to somatization rather than recognized as a signal of unresolved underlying pathology [7]. The same review identified a general lack of endometriosis-specific knowledge among both patients and primary care providers as a key driver of delay, alongside health-system factors such as long waits for specialist gynecological referral and disparities in delay associated with access to private versus public care [7]. The 2025 systematic review and meta-analysis similarly identified misdiagnosis and over-reliance on nonspecific diagnostic strategies as a major, quantifiable contributor to delay, on par with delays originating from patients' own care-seeking behavior [4]. Regional variation in delay, documented across multiple health systems [6,8], further suggests that structural features of care delivery — availability of specialist gynecologic services, standardization of diagnostic pathways, and clinical education — meaningfully shape how quickly patients are diagnosed, independent of the disease's inherent biological ambiguity.

## Discussion and Implications

Taken together, the evidence indicates that diagnostic delay in endometriosis arises from the convergence of three distinct problems: a disease whose symptoms are common, nonspecific, and poorly correlated with objective disease burden; diagnostic tools whose noninvasive forms (history, examination, and imaging) cannot reliably rule the condition in or out, while the historically definitive tool (laparoscopy) is invasive enough to be reserved for later in the diagnostic pathway; and a healthcare system in which limited clinician awareness and normalization of menstrual pain cause early symptomatic presentations to be dismissed or misattributed. Recent guideline revisions have begun to address the second problem directly: the 2022 ESHRE guideline explicitly permits empirical medical treatment to proceed in parallel with, or even prior to, definitive laparoscopic diagnosis in appropriately selected patients, reflecting a shift away from treating laparoscopy as a mandatory diagnostic gatekeeper [2]. Addressing the first and third problems — biological ambiguity and clinician/system-level barriers — will likely require continued investment in noninvasive diagnostic biomarkers, structured clinical education about the variable presentation of endometriosis, and streamlined referral pathways that shorten the interval between symptom onset and specialist evaluation. Until these gaps are closed, the multi-year diagnostic odyssey documented across the literature is likely to persist as a defining, and largely preventable, feature of the endometriosis patient experience.

## References


1. Zondervan KT, Becker CM, Missmer SA. Endometriosis. N Engl J Med. 2020;382(13):1244-56.
2. Becker CM, Bokor A, Heikinheimo O, et al. ESHRE Endometriosis Guideline

Development Group. ESHRE guideline: endometriosis. Hum Reprod Open. 2022;2022(2):hoac009.

3. Nnoaham KE, Hummelshoj L, Webster P, et al. World Endometriosis Research Foundation Global Study of Women's Health Consortium. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. Fertil Steril. 2011;96(2):366-373.
4. Li W, Feng H, Ye Q. Factors contributing to the delayed diagnosis of endometriosis—a systematic review and meta-analysis. Front Med (Lausanne). 2025;12:1576490.
5. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. Fertil Steril. 2006;86(5):1296-1301.
6. Hudelist G, Fritzer N, Thomas A, et al. Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. Hum Reprod. 2012;27(12):3412-16.
7. Fryer J, Mason-Jones AJ, Woodward A. Understanding diagnostic delay for endometriosis: a scoping review using the social-ecological framework. Health Care Women Int. 2024;46(3).
8. De Corte I, et al. Time to Diagnose Endometriosis: Current Status, Challenges and Regional Characteristics—A Systematic Literature Review. BJOG. 2025.

## Citation of this Article

Ash T. The Diagnostic Odyssey of Endometriosis: Why Timely Diagnosis Remains Elusive. Mega J Case Rep. 2026;9(9):2001-2004.

## Copyright