DIAGNOSTIC DELAYS IN ENDOMETRIOSIS

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Endometriosis is a chronic inflammatory disease characterized by the presence of endometrium-like tissue outside the uterine cavity. It affects approximately 5-10% of women in their reproductive years, affecting an estimated 176 million women worldwide and is associated with pelvic pain and infertility (Zondervan et al., 2018). Despite its high prevalence and substantial impact on physical, psychological and reproductive health, endometriosis is still diagnosed much later than many other chronic gynecological conditions.

Diagnostic delay is the interval between the onset of symptoms and confirmation of diagnosis. In endometriosis, studies report delays of up to 7-10 years (De Corte et al., 2025). This prolonged delay is multifactorial and can negatively affect quality of life and reproductive outcomes (Becker et al., 2022; Li et al., 2025).According to Dr Pooya Beigi, who coined the term "mismedicine", it is a broad umbrella term used to describe any medical action, decision or systemic process that misses the standard of care and results in patient harm, inefficiency or confusion (Beigi, 2023). In essence, mismedicine refers to failures in healthcare that results in preventable patient harm or care that falls below the accepted standard of care. Diagnostic delays in endometriosis represent an important example of mismedicine because patients often experience prolonged suffering before receiving proper evaluation and treatment. This article examines the causes, consequences, and potential approaches for reducing the diagnostic delay in endometriosis.

Why Does Diagnosis of Endometriosis Take So Long?

Diagnostic delay of endometriosis is multifactorial, involving normalization of menstrual pain, nonspecific and overlapping symptoms, limited awareness among healthcare professionals and healthcare-system barriers. These can contribute to mismedicine, as delayed recognition may prolong suffering and delay appropriate treatment (Beigi, 2023).

Normalization of dysmenorrhea along with the social taboos that accompany the discussion on menstruation is one of the causes of delayed diagnosis (Li et al., 2025). Girls may be taught from adolescence that menstrual pain is normal, leading to some of them tolerating symptoms rather than seeking medical attention. In addition, some healthcare professionals may underestimate or dismiss reports of severe menstrual pain, particularly when symptoms are considered consistent with normal menstruation. The normalization of menstrual pain among families, communities, and healthcare providers reinforces delayed diagnosis and represents a form of mismedicine through missed opportunities for early recognition (Becker et al., 2022).

Another challenge is variable and non-specific clinical presentation of endometriosis which may mimic other medical conditions such as irritable bowel syndrome, pelvic inflammatory disease, ovarian cysts, interstitial cystitis (Li et al., 2025). Symptoms including chronic pelvic pain, dysmenorrhea, dyschezia and fatigue are not unique to endometriosis, and this may result in alternative diagnosis, repeated lab investigations and prolonged delays to accurate diagnosis (Becker et al., 2022).

Limited awareness among healthcare professionals can further contribute to diagnostic delay. The diverse presentation of endometriosis may make recognition difficult, particularly in primary healthcare settings where the symptoms could be attributed to normal menstruation or other medical conditions. Inadequate recognition of atypical presentations can delay referral to gynecologists and prolong patient suffering, representing yet another potential form of mismedicine (Li et al., 2025; Winter et al., 2026).

Healthcare system barriers are another vital cause of delayed diagnosis. Limited access to specialist gynecological services and diagnostic imaging particularly in low and middle income countries can delay appropriate evaluation and management (Becker et al., 2022). Multiple primary care consultations and lengthy referral pathways may further prolong the time to diagnosis. These systemic barriers can very much contribute to mismedicine by delaying appropriate assessment and allowing symptoms to remain untreated.

Consequences of Diagnostic Delay

Delayed diagnosis of endometriosis could impact both short and long term health. Ongoing disease activity worsens chronic pelvic pain and other symptoms which could impair quality of life. In some patients, delayed diagnosis may be associated with disease progression that could lead to clinical complications like adhesion formation, ovarian endometriomas and infertility (Becker et al., 2022). This emphasizes the importance of early diagnosis and treatment of disease so as to improve quality of life and also reproductive outcomes.

Delayed diagnosis also has psychological and social consequences. Chronic pelvic pain that patients experience may interfere with education, employment, intimate relationships and overall quality of life while years of unexplained symptoms and dismissal of pain may contribute to anxiety, depression and frustration (Li et al., 2025).

Strategies for Reducing Diagnostic Delays

Reducing diagnostic delays requires intervention at the patient, clinician and healthcare system levels. Public awareness campaigns should challenge misconceptions about menstruation and encourage earlier help seeking.

Continuing medical education is important in improving health care professional's awareness of diverse presentations of endometriosis and encouraging consideration of endometriosis in patients with chronic pelvic pain, dysmenorrhea, dyspareunia, infertility, with timely referral when suspected.

At the healthcare level, streamlined referral pathways and improved access to gynecologists and increasing investment in women's health can help shorten time between symptom onset and disease diagnosis.

Development of novel, affordable, non-invasive diagnostic methods for endometriosis has the potential to improve the diagnostic accuracy and reduce delays, especially in low and middle income countries where shortages of skilled personnel, limited healthcare facilities continue to pose challenges (Li et al., 2025; Becker et al., 2022).

Conclusion

Diagnostic delay remains one of the greatest challenges in the management of endometriosis and represents an important example of mismedicine (Beigi, 2023). Normalization of menstrual pain, nonspecific symptoms, limited clinical awareness and healthcare system barriers can delay appropriate diagnosis and treatment. These delays have significant clinical, psychological, social, and economic consequences that adversely affect patients' quality of life. Strengthening public and professional awareness, improving referral pathways, and developing accessible diagnostic methods are essential to reducing delays and improving patients' quality of life and reproductive outcomes. Future research should evaluate the effectiveness of targeted education and streamlined referral pathways in reducing time to diagnosis, particularly in low and middle income countries.

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