



## AMA Journal of Ethics®

February 2025, Volume 27, Number 2: E104-109

### HEALTH LAW: PEER-REVIEWED ARTICLE

#### Using Policy and Law to Help Reduce Endometriosis Diagnostic Delay

Annika J. Penzer and Scott J. Schweikart, JD, MBE

##### Abstract

Despite high incidence of endometriosis internationally and domestically, many patients wait a decade after symptom onset for an accurate diagnosis. This article suggests why diagnostic criteria should be clarified and why endometriosis screening should be incentivized among members of the public, clinicians, and health care organizations.

*The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the [AMA Ed Hub™](#). Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

##### Background

Up to 10% of American women aged 15 to 44 and roughly 176 million women worldwide suffer from endometriosis—a painful condition in which tissue, similar to that which lines the uterus, grows outside the uterine wall—making it one of the most common gynecological diseases.<sup>1,2,3</sup> Despite its high incidence, individuals on average wait 7 years after the initial onset of symptoms to receive an accurate endometriosis diagnosis, usually when they undergo surgery.<sup>4,5</sup> Many factors (eg, disease complexity, compromised access to health care, and insufficient research) likely fuel diagnostic delay and are exacerbated by lack of awareness among the public and clinicians.<sup>4,6,7</sup>

In individuals with the condition, endometrial lesions and scar tissue typically form in the pelvic area, affecting the pelvic peritoneum, ovaries, fallopian tubes, recto-vaginal septum, bladder, intestines, and surrounding organs.<sup>8,9</sup> When a person menstruates, misplaced endometrial tissue sheds, leaving blood trapped in the abdomen, and this build-up leads to inflammation, scarring, and adhesions that worsen over time.<sup>10</sup> Symptoms are sometimes serious and may include severe pain during menstruation and intercourse; chronic abdominal, pelvic, and lower back pain; excessive bleeding; gastrointestinal issues; and infertility.<sup>3,6,9</sup> Endometriosis symptoms are often debilitating, preventing women from attending school and work, damaging relationships, and leading to anxiety and depression.<sup>4</sup> Physicians do not know—and therefore cannot treat—the cause of endometriosis, although treating its symptoms can alleviate suffering.<sup>10</sup> Given that the cause cannot be treated, it is even more imperative that early diagnosis be successful and more widespread so that symptoms of endometriosis can be treated earlier.

## Diagnostic Delay

Several factors—financial, clinical, and social—contribute to diagnostic delay.

*Financial factors.* Endometriosis research is significantly underfunded in the United States. Although funding for endometriosis research in the United States has increased over the last few years, rising from \$13 million in 2019 to \$16 million by the National Institutes of Health in 2022,<sup>6,7</sup> this increase represents a rise from roughly \$1 to \$2 per diagnosed patient.<sup>6,7</sup> By comparison, Crohn's disease—which afflicts both men and women and affects only 0.21% of the US population—received \$90 million in funding in 2022, which amounts to \$130.07 per diagnosed patient in the United States—65 times more per patient than endometriosis received.<sup>6</sup> This disparity is consistent with findings that US research on diseases that primarily affect women is significantly underfunded compared to research on diseases that primarily affect men or that affect both men and women,<sup>11</sup> although there are some notable examples to the contrary, such as breast cancer.

While endometriosis' high incidence, severity, and diagnostic delays should alone inspire increased funding and public attention, there are also significant financial incentives to reduce diagnostic delays and improve treatment options for endometriosis. For example, those suffering from endometriosis typically have significantly higher health care utilization, with the annual economic burden of endometriosis in the United States being estimated to be between \$78 billion and \$119 billion.<sup>6</sup> During the lag time between symptom onset and accurate diagnosis, people with endometriosis might experience multiple emergency visits and hospitalizations, as well as undergo tests and treatments for conditions that they do not have. In addition, one study found that 75% to 84% of the annual endometriosis costs in Australia are due to productivity loss, as symptoms cause women to take sick days, quit, or be fired from their jobs at staggering rates.<sup>6</sup> Productivity costs are likely similar in the United States and other peer countries. All evidence suggests that the short-term costs of investing in endometriosis research would be greatly outweighed by the long-term benefits of reducing health care utilization and productivity losses.

*Clinical factors.* While additional research funding would help close the endometriosis information gap, underfunding alone cannot account for the current significant diagnostic delays patients experience. Symptom variation can mean that endometriosis is **hard to diagnose**; there are a long list of gynecologic, gastrointestinal, and other conditions that present similarly to endometriosis.<sup>9</sup> Hence, no 2 patients with endometriosis are the same, and symptoms and pain levels vary widely. Identifying Patient A and Patient B as suffering from the same condition is often not intuitive, especially when one presents with acute pelvic pain during urination and another presents with mild, chronic lower back pain, for example. Lengthy diagnostic delay might also occur because physicians may be inclined to rule out a long list of other conditions before they consider endometriosis, especially as diagnosing the condition requires surgery,<sup>5</sup> usually a laparoscopic procedure in which “the surgeon can look inside the pelvic cavity.”<sup>12</sup> For these reasons, no policy change can ensure that endometriosis patients will be diagnosed during their first hospital or obstetricians and gynecologist (OB/GYN) visit. However, it is likely that these medical realities—that endometriosis symptoms are easy to mistake for other conditions and that securing a diagnosis requires laparoscopic surgery—do not fully account for diagnostic delays.

*Social factors.* Social factors also contribute to the staggering diagnostic delays. First,

gender bias renders women more likely than men to have their pain and symptoms dismissed as psychological by their clinicians,<sup>13,14,15,16,17</sup> and Black people face this sort of implicit bias at higher rates than White people.<sup>18</sup> If not **dismissed as psychological**, severe pelvic pain is often written off as a “normal” effect of menstruation.<sup>19</sup>

Another social factor that contributes to diagnostic delays is lack of awareness about endometriosis among health care professionals in training. While medical students and OB/GYN residents learn about endometriosis in their education, greater emphasis on this topic might be needed to improve diagnosis and treatment.<sup>20,21</sup> As mentioned above, mistaking symptoms of endometriosis for those of another condition is reasonable, given their similarity, but failing to consider endometriosis at all in the diagnostic process when relevant symptoms arise is not. Ensuring that all health care professionals—not only specialists—actively consider the possibility of endometriosis when patients present with relevant symptoms would likely drastically reduce diagnostic wait times.

A final social factor is cost, as the cost of accessing specialized care for diagnosis and treatment is disproportionately prohibitive for those belonging to marginalized groups who have lower access to health care.<sup>22</sup> More research is needed, however, to determine how socioeconomic factors impact treatment disparities.<sup>23</sup>

### **Policy Improvement**

We propose incentivizing hospitals and other health care facilities to ask all female patients routine screening questions related to endometriosis during intake. Patients whose answers indicate symptoms associated with endometriosis should have a note in their file flagging the possible diagnosis. Although screening questions will not be able to confirm or deny the presence of endometriosis, employing them will ensure that health care practitioners consider endometriosis among other possible diagnoses. Such a screening tool would be ideal for a wide range of clinicians to use as a basis for referral to specialists like OB/GYNs or radiologists who could then make more timely diagnoses. Indeed, recent clinical research has validated a questionnaire devised to identify patients at high risk of endometriosis.<sup>24</sup> Such tools, when clinically validated, should be incentivized for broader use, with accumulated data being used to further refine the screening tools.

Once an endometriosis screening tool has been clinically validated and medically accepted, one way to ensure that it is broadly implemented in health care facilities is to mandate its use by law. However, a direct legal mandate forcing physicians to use a particular screening tool is problematic, in that it would promote government intervention directly in the practice of medicine when malpractice law and state medical boards already serve to enforce standard of care.

Instead of mandating endometriosis screening, incentivizing it with a financial reward may be more successful in encouraging clinicians to implement such screening quickly. A reward for participating could come directly from the government or from **insurance companies**. While it is in insurance companies' best interest to shorten the endometriosis diagnostic wait time and reduce health care utilization costs, the federal government can also require insurance companies to provide this reward to participating health care providers.

## Conclusion

Ensuring that every health care practitioner—not just OB/GYNs—properly considers endometriosis as a potential cause of relevant symptoms can play a role in decreasing the average diagnostic wait time for patients. Promising screening tools have been developed, and we call for continued research to further refine the tools and for government or insurance provider incentivization of their use. The use of validated screening tools could potentially alleviate pain and improve the lives of millions of women, as well as reduce health care utilization costs and productivity losses. Furthermore, raising awareness about endometriosis among nonspecialist health care professionals and the general public by implementing routine screening could promote greater interest in research and subsequently more funding for it. Given the high incidence, severity, and costs of endometriosis, improving the standard of care for endometriosis diagnosis is well past due.

## References

1. Endometriosis. Johns Hopkins Medicine. Accessed August 14, 2024. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/endometriosis>
2. Endometriosis. Yale Medicine. Accessed August 14, 2024. <https://www.yalemedicine.org/conditions/endometriosis#:~:text=One%20of%20the%20most%20common>
3. Nuffield Department of Women's and Reproductive Health. What is endometriosis? University of Oxford. Accessed August 14, 2024. <https://www.wrh.ox.ac.uk/research/endometriosis-care-what-is-endo>
4. BMC Medicine. Shining a light on endometriosis: time to listen and take action. *BMC Med*. 2023;21(1):107.
5. National Institute of Child Health and Human Development. How do healthcare providers diagnose endometriosis? National Institutes of Health. Reviewed February 21, 2020. Accessed August 14, 2024. <https://www.nichd.nih.gov/health/topics/endometri/conditioninfo/diagnose#:~:text=Surgeries%20is%20currently%20the%20only>
6. Ellis K, Munro D, Clarke J. Endometriosis is undervalued: a call to action. *Front Glob Womens Health*. 2022;3:902371.
7. Our commitment to research. Endometriosis Foundation of America. Accessed September 3, 2024. <https://www.endofound.org/research>
8. Endometriosis. World Health Organization. March 24, 2023. Accessed August 14, 2024. <https://www.who.int/news-room/fact-sheets/detail/endometriosis>
9. Sinrich J. 14 conditions endometriosis is mistaken with the most. CCRM Fertility. Accessed January 15, 2025. <https://www.ccrmivf.com/news-events/endometriosis-conditions-mistaken/>
10. Endometriosis. UCLA Health. Accessed January 15, 2025. <https://www.uclahealth.org/medical-services/obgyn/conditions-treated/endometriosis>
11. Mirin AA. Gender disparity in the funding of diseases by the US National Institutes of Health. *J Womens Health (Larchmt)*. 2021;30(7):956-963.
12. Endometriosis symptoms, diagnosis and treatment. Brigham and Women's Hospital. Accessed September 3, 2024. <https://www.brighamandwomens.org/obgyn/infertility-reproductive-surgery/endometriosis/endometriosis-guide-for-women>
13. Gaslighting in women's health: no, it's not just in your head. Northwell Health. Accessed August 14, 2024. <https://www.northwell.edu/katz-institute-for->



womens-health/articles/gaslighting-in-womens-health

14. Analysis: women's pain is routinely underestimated, and gender stereotypes are to blame. *UCL News*. April 9, 2021. Accessed August 14, 2024. <https://www.ucl.ac.uk/news/2021/apr/analysis-womens-pain-routinely-underestimated-and-gender-stereotypes-are-blame>
15. Women and pain: disparities in experience and treatment. *Harvard Health Blog*. October 9, 2017. Accessed August 14, 2024. <https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562>
16. Maserejian NN, Link CL, Lutfey KL, Marceau LD, McKinlay JB. Disparities in physicians' interpretations of heart disease symptoms by patient gender: results of a video vignette factorial experiment. *J Womens Health (Larchmt)*. 2009;18(10):1661-1667.
17. Banco D, Chang J, Talmor N, et al. Sex and race differences in the evaluation and treatment of young adults presenting to the emergency department with chest pain. *J Am Heart Assoc*. 2022;11(10):e024199.
18. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci U S A*. 2016;113(16):4296-4301.
19. Doleeb Z, McCoy LG, Dada J, Allaire C. Underrecognition of dysmenorrhea is an iatrogenic harm. *AMA J Ethics*. 2022;24(8):E740-E747.
20. Sullender RT, Jacobs MB, Sandhu MS, et al. Perception and comfort with endometriosis management among OB/GYN residents. *Int J Womens Health*. 2023;15:1801-1809.
21. Lefton M. Elevating endometriosis to a public health crisis: a two-part blog. Society for Women's Health Research. October 30, 2023. Accessed September 9, 2024. <https://swhr.org/illuminating-the-endometriosis-experience-to-improve-care/>
22. Committee on Community-Based Solutions to Promote Health Equity in the United States. The state of health disparities in the United States. In: Weinstein JN, Geller A, Negussie Y, Baciu A, eds. *Communities in Action: Pathways to Health Equity*. National Academies Press; 2017:57-97.
23. Westwood S, Fannin M, Ali F, et al. Disparities in women with endometriosis regarding access to care, diagnosis, treatment, and management in the United States: a scoping review. *Cureus*. 2023;15(5):e38765.
24. Chapron C, Lafay-Pillet MC, Santulli P, et al. A new validated screening method for endometriosis diagnosis based on patient questionnaires. *EClinicalMedicine*. 2022;44:101263.

**Annika J. Penzer** is a fourth-year undergraduate student at Stanford University in Stanford, California, majoring in philosophy with minors in biology, archaeology, and human rights. Her research focuses on topics such as organ transplantation, gestational surrogacy, and physician-assisted death.

**Scott J. Schweikart, JD, MBE** is a senior policy analyst at the American Medical Association in Chicago, Illinois, where he is also a contributing editor for the *AMA Journal of Ethics*. Mr Schweikart earned his MBE from the University of Pennsylvania, his JD from Case Western Reserve University, and his BA from Washington University in St Louis. He has research interests in health law, health policy, and bioethics.

**Citation**

*AMA J Ethics.* 2025;27(2):E104-109.

**DOI**

10.1001/amajethics.2025.104.

**Conflict of Interest Disclosure**

Authors disclosed no conflicts of interest.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*