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Diagnostic delay as structural injustice: Endometriosis, preventable suffering, and a human rights analysis

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ABSTRACT

Endometriosis affects millions worldwide, yet health systems continue to treat the condition as a biomedical puzzle rather than a contested site of structural neglect. This article offers a critical conceptual review and normative human rights analysis of diagnostic delay in endometriosis, with a primary focus on the United States and selected comparative policy developments. Drawing on interdisciplinary literature on endometriosis, feminist sociology of health, clinical guidelines, national policy developments, and international right-to-health standards, we examine how diagnostic delay is produced through institutional inaction, epistemic dismissal, and uneven accountability. We analyze diagnostic delay not as a passive waiting period, but as a product of three interrelated modes of injustice: *omissive nonrecognition*, where gendered norms render pain unintelligible to health systems; *commissive misrecognition*, where institutions deprioritize funding, education, and policy despite known disease burdens; and *epistemic blindspotting*, where diagnostic standards continue to marginalize patient narratives and functional impairment as evidence. We define "preventable suffering" as an analytical category encompassing harms arising not from endometriosis alone, but from foreseeable and modifiable failures in recognition, referral, research, education, and care. This suffering restricts central capabilities, resulting in cumulative losses in bodily health, autonomy, social participation, and life planning. Reframing diagnostic delay as a human rights problem requires rethinking accountability beyond state obligations alone. We conclude by outlining a rights-based reorientation of diagnostic pathways, participatory governance, and networked responsibility necessary to reduce preventable suffering and fulfill the right to health.

1. Introduction

Endometriosis is a common yet poorly understood condition characterized by the presence of endometrial-like tissue outside the uterus, affecting approximately 10% of reproductive-age women worldwide (around 190 million), as well as some trans men and non-binary people.[1] The scientific community has long regarded endometriosis as an enigma; to date, the exact cause remains unknown.[2] Historically, it has been labeled a "career woman's disease" or a "white woman's disease," contributing to its under-recognition among marginalized individuals, including those who do not identify as women, those living in low-resource settings, persons with disabilities, and racial and ethnic minorities, among other groups.[3]

Endometriosis may present with gastrointestinal and urinary symptoms, inflammatory processes, and fatigue, making the disease difficult to diagnose; however, its most commonly recognized symptom is severe pelvic pain. Gynecologists have historically prioritized the presence of endometrial lesions visualized during laparoscopic surgery to confirm the diagnosis.[4] Surgical diagnosis involves staging, a visual assessment of the depth, location, and invasiveness of lesions, as well as microscopic

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[1] Krina T. Zondervan et al., "Endometriosis," *New England Journal of Medicine* 382, no. 13 (2020): 1244–56, https://doi.org/10.1056/NEJMra1810764.

[2] Heather C. Guidone, "The Womb Wanders Not: Enhancing Endometriosis Education in a Culture of Menstrual Misinformation," in *The Palgrave Handbook of Critical Menstruation Studies*, ed. Chris Bobel et al. (Palgrave Macmillan, 2020), http://www.ncbi.nlm.nih.gov/books/NBK565622/.

[3] Guidone, "The Womb Wanders Not"; Kelechi E. Nnoaham et al., "Impact of Endometriosis on Quality of Life and Work Productivity: A Multicenter Study Across Ten Countries," *Fertility and Sterility* 96, no. 2 (2011): 366–73.e8, https://doi.org/10.1016/j.fertnstert.2011.05.090.

[4] Zondervan et al., "Endometriosis," 1251.

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analysis of lesions to confirm the presence of endometrial cells.[5] Laparoscopy has therefore long been treated as "the cornerstone" of accurate diagnosis.[6] However, this paradigm is increasingly being questioned, with some researchers and clinical guidelines calling for earlier clinical diagnosis and non-invasive diagnostic pathways.[7] Clinical diagnosis, based on symptoms and history, and emerging biomarker-based approaches, including saliva- or blood-based tests, may challenge the surgical paradigm[8]; however, their validation, availability, and implementation remain uneven. Despite these shifts, surgical confirmation continues to shape diagnostic norms across many practice settings, particularly among clinicians trained under the surgical paradigm. As a result, clinicians often continue to struggle to diagnose endometriosis in a timely manner.

The biomedical framing of endometriosis as a diagnostic puzzle can obscure the structural dimensions of the crisis. The average time from symptom onset to definitive diagnosis ranges from 6 to 11 years worldwide.[9] Despite recent changes in the diagnostic landscape, diagnostic delay remains a substantial public health issue. We argue that a delay of this magnitude cannot be understood solely as a technical challenge or a failure on the part of individual clinicians. Rather, it reflects systemic failures in knowledge production, medical training, resource allocation, and gendered norms of pain and credibility.[10] The persistence of diagnostic delay transforms endometriosis from a biological illness into a site of preventable suffering: harms arising not from the disease alone, but from modifiable institutional inaction, epistemic dismissal, and discriminatory health system arrangements.

This article is not a systematic review, scoping review, or empirical study; rather, it offers a critical conceptual review and a normative human rights analysis of diagnostic delay in endometriosis. We bring together interdisciplinary scholarship on endometriosis and women's pain, clinical and biomedical literature on diagnostic delay and diagnostic standards, selected national policy developments, and international right-to-health standards. These materials, not treated as a single empirical dataset, are read together to develop an analytical account of how diagnostic delay is structurally produced, epistemically maintained, and normatively actionable.

To understand diagnostic delay not merely as a clinical inefficiency but as a structural injustice, we draw on three bodies of theory that perform distinct analytical functions. Sociological theories of ignorance and non-knowledge explain how institutional inaction is produced and justified. The capability approach clarifies what is lost when diagnostic delay restricts bodily health, autonomy, social participation, and life planning. The right to health provides the normative language through which such harms can be understood as matters of obligation, accountability, and institutional responsibility. Together, these frameworks allow us to define "preventable suffering" as pain, uncertainty, functional loss, and social deprivation that are intensified or prolonged by foreseeable and modifiable failures in recognition, referral, research, education, and care.

The article proceeds as follows. We will first establish a normative-analytical framework for understanding preventable suffering. We then analyze diagnostic delay not as a passive waiting period but as a product of three interrelated modes of structural injustice: *omissive nonrecognition*, where gendered norms render pain unintelligible to health systems; *commissive misrecognition*, where institutions deprioritize funding, education, and policy despite known disease burdens; and *epistemic blindspotting*, where historical diagnostic standards devalue patient narratives and functional impairment as evidence. The article focuses primarily on the U.S. context, while drawing on selected international developments to show how improved policy and accountability mechanisms might be mobilized. We conclude by arguing that recasting diagnostic delay as a decentralized human rights problem requires moving beyond state-centered accountability toward a framework of networked responsibility, distributed across clinical, research, educational, policy, and everyday social actors.

2. Normative-analytical framework for preventable suffering

This article develops a conceptual reframing of diagnostic delay in endometriosis as a human rights concern. Rather than treating the right to health, the capability approach, and the sociology of ignorance as equivalent frameworks, we leverage them for distinct analytical purposes. First, the right to health provides a normative language for identifying obligations and accountability failures. Second, the capability approach reveals what is lost when diagnostic delay restricts bodily health, autonomy, social participation, and life planning, generating cumulative disadvantages that extend far beyond physical pain and alter life trajectories.[11] Finally, the sociology of ignorance, and specifically the sociology of "nothing," explains how institutional inaction and non-knowledge are produced, maintained, and justified. Articulated together, these frameworks allow us to analyze diagnostic delay as a structurally produced form of preventable suffering.

2.1. 3AQ assessment for the right to health

The relationship between human rights and biomedicine is ambiguous. We define "biomedicine" as the professional and institutional model of medical knowledge and practice centered on biological pathology, specialized expertise, technological verification, and disease-specific intervention. We furthermore recognize how biomedicine operates within broader health systems. Thus, our analysis focuses on how systemic arrangements can make gendered illness experiences less visible, measurable, and actionable.

Some critical human rights scholars have argued that "biological individualism" in medicine has often been inconsistent with structural

[5] Saima Rafique and Alan H DeCherney, "Medical Management of Endometriosis," *Clinical Obstetrics and Gynecology* 60, no. 3 (2017): 485–96, https://doi.org/10.1097/GRF.0000000000000292.

[6] Practice Committee of the American Society for Reproductive Medicine, "Treatment of Pelvic Pain Associated with Endometriosis: A Committee Opinion," *Fertility and Sterility* 101, no. 4 (2014): 927–35, https://doi.org/10.1016/j.fertnstert.2014.02.012.

[7] Sanjay K. Agarwal et al., "Clinical Diagnosis of Endometriosis: A Call to Action," *American Journal of Obstetrics and Gynecology* 220, no. 4 (2019): 354.e1-354.e12, https://doi.org/10.1016/j.ajog.2018.12.039.

[8] Andrew Spiers et al., "Clues to Revising the Conventional Diagnostic Algorithm for Endometriosis," *International Journal of Gynecology & Obstetrics* 168, no. 1 (2025): 101–11, https://doi.org/10.1002/ijgo.15840.

[9] Pauline De Corte et al., "Time to Diagnose Endometriosis: Current Status, Challenges and Regional Characteristics-A Systematic Literature Review," *BJOG: An International Journal of Obstetrics and Gynaecology* 132, no. 2 (2025): 118–30, https://doi.org/10.1111/1471-0528.17973; Karen Ballard et al., "What's the Delay? A Qualitative Study of Women's Experiences of Reaching a Diagnosis of Endometriosis," *Fertility and Sterility* 86, no. 5 (2006): 1296–301, https://doi.org/10.1016/j.fertnstert.2006.04.054; Boris Beloshevski et al., "Delayed Diagnosis and Treatment of Adolescents and Young Women with Suspected Endometriosis," *Journal of Gynecology Obstetrics and Human Reproduction* 53, no. 3 (2024): 102737, https://doi.org/10.1016/j.jogoh.2024.102737; Linda C. Giudice et al., "Time for Global Health Policy and Research Leaders to Prioritize Endometriosis," *Nature Communications* 14 (December 2023): 8028, https://doi.org/10.1038/s41467-023-43913-9.

[10] Hugh S. Taylor et al., "Endometriosis Is a Chronic Systemic Disease: Clinical Challenges and Novel Innovations," *The Lancet* 397, no. 10276 (2021): 839–52, https://doi.org/10.1016/S0140-6736(21)00389-5.

[11] Stacey A Missmer et al., "Impact of Endometriosis on Life-Course Potential: A Narrative Review," *International Journal of General Medicine* 14 (January 2021): 9–25, https://doi.org/10.2147/IJGM.S261139.

approaches to illness and health inequalities (Fig. 3).[12] By implication, biomedicine may function as a power structure that perpetuates inequities. At the same time, such a view risks conflating biomedicine with structural power, thereby missing how biomedicine itself changes over time. Human rights have significantly contributed to the prioritization of women's sexual and reproductive health and rights (SRHR) and maternal morbidity and mortality, among other issues[13]; however, these contributions tend to be siloed from biomedicine.[14]

Human rights frameworks have also been critiqued for reflecting "distinctly Western and masculine values and ideals."[15] As Seear and Mulcahy argue, human rights may valorize rationality, autonomy, and propriety as qualities of the fully recognized human subject.[16] These are precisely the qualities from which menstruating, emotional, or "hysterical" women have historically been distanced. A human rights framework, therefore, may be inadequate for analyzing women's health, especially where women's pain has historically been treated as excessive, irrational, or less than fully credible. Nevertheless, human rights remain useful for understanding how health systems fail people with endometriosis, because they provide a language of obligation, accountability, and institutional responsibility.

The right to health is fundamental to human dignity. As defined by the World Health Organization (WHO) Constitution and the International Covenant on Economic, Social and Cultural Rights (ICESCR), it encompasses not merely the absence of disease but "the highest attainable standard of physical and mental health." This right is not an unlimited entitlement to health but rather an entitlement to the conditions that maximize the potential for health and well-being. In this sense, the right to health concerns the social, institutional, and clinical conditions that enable a livable life.[17] As Paul Hunt, the first United Nations Special Rapporteur on the right to health, argues, healthcare providers and professionals "make decisions in their daily practice which have profound human rights implications."[18]

To operationalize the right to health, we draw on the framework established in General Comments Nos. 14 and 22, often referred to as the 3AQ framework: availability, accessibility, acceptability, and quality.[19] This framework provides a diagnostic tool for assessing health system performance:

1. availability, which requires states to ensure sufficient functioning public health and healthcare facilities, goods, and services;
2. accessibility, for which health facilities must be accessible to everyone without discrimination, including physical accessibility, economic accessibility (affordability), and informational accessibility (the right to seek and receive information);
3. acceptability, indicating that all health facilities must be respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements; and
4. quality, for which health facilities must be scientifically and medically appropriate and of good quality.

Hence, diagnostic delay is not a biomedical shortcoming, but an outcome that implicates health systems across all four dimensions of 3AQ. For endometriosis, the right to health implies access to timely evaluation, appropriate referral, effective treatment, as well as accurate information, and care that takes gendered pain seriously. When diagnostic delay persists for a decade, it signals a systemic failure across these dimensions.[20] Yet because human rights discourse may reproduce narrow assumptions about who counts as a credible, rational, and fully recognized subject of rights, a rights-based framework is not comprehensive on its own.[21] It must be supplemented by an understanding of what delayed recognition does to a person's life, and how such delay is produced through institutional inaction.

2.2. A capability approach to a livable life

The capability approach, developed by Amartya Sen and Martha Nussbaum, provides the ethical metric for assessing the harms produced by diagnostic delay. This framework evaluates well-being not primarily by utility, income, or formal access to services, but by capabilities: the substantive freedoms and opportunities individuals have to "do and be" what they value. Namely, the capability approach asks not only whether a person receives treatment, but whether that person has genuine opportunities to live a life they have reason to value: to study, work, rest, participate socially, form relationships, make reproductive decisions, and plan a future.

The capability approach is a normative framework for assessing social justice and individual well-being.[22] It treats individual freedom as a central ethical rationale for social and economic organization. Sen distinguishes between basic capabilities, such as literacy and avoiding early mortality, and more complex capabilities, such as social participation

[12] Alicia Ely Yamin, *Power, Suffering, and the Struggle for Dignity: Human Rights Frameworks for Health and Why They Matter* (University of Pennsylvania Press, 2016), 6.

[13] Committee on Economic, Social and Cultural Rights, *General Comment No. 22: The Right to Sexual and Reproductive Health* (Article 12 of the International Covenant on Economic, Social and Cultural Rights) (United Nations Committee on Economic, Social and Cultural Rights, April 2, 2016), 22, https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-22-2016-right-sexual-and; Committee on the Elimination of Discrimination Against Women, *CEDAW General Recommendation No. 24: Article 12 of the Convention* (Women and Health) (United Nations Committee on the Elimination of Discrimination Against Women, July 2, 1999), https://www.refworld.org/legal/general/cedaw/1999/en/11953; Tlaleng Mofokeng, Sexual and Reproductive Health Rights: Challenges and Opportunities during the COVID-19 Pandemic, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, A/76/172 (United Nations General Assembly, July 19, 2021), https://undocs.org/A/76/172.

[14] Christina Zampas and Åsa Nihlén, "The State of International Human Rights Law on Sexual and Reproductive Health: An Overview," *Health and Human Rights* 27, no. 2 (2025): 291–304, https://www.hhrjournal.org/2025/11/24/the-state-of-international-human-rights-law-on-sexual-and-reproductive-health-an-overview/.

[15] Kate Seear and Sean Mulcahy, "Forging New Habits: Critical Drugs Scholarship as an Otherwise to Rights," *The International Journal of Human Rights* 28, nos. 8–9 (2024): 3, https://doi.org/10.1080/13642987.2023.2227104.

[16] Seear and Mulcahy, "Forging New Habits."

[17] Chong-Min Su and Po-Han Lee, "Activist Allyship, Unspoken Dilemma: Deconstructing the Tension between Reproductive Autonomy and Disability Justice," The International Journal of Human Rights 30, no. 5 (2026): 973–95. https://doi.org/10.1080/13642987.2025.2588184.

[18] Paul Hunt, *The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health A/60/348 (United Nations General Assembly, 2005), para. 9, https://digitallibrary.un.org/record/558962.

[19] Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (*Article 12 of the Covenant*)*, 11 August 2000, E/C.12/2000/4, https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WRGS/Health/GC14.pdf; *General Comment No. 22: The Right to Sexual and Reproductive Health (*Article 12 of the International Covenant on Economic, Social and Cultural Rights*)*, 22.

[20] Taylor et al., "Endometriosis Is a Chronic Systemic Disease."

[21] Seear and Mulcahy, "Forging New Habits."

[22] Diego Alveiro Restrepo-Ochoa, "La Salud Y La Vida Buena: Aportes Del Enfoque De Las Capacidades De Amartya Sen Para El Razonamiento Ético En Salud Pública," *Cadernos de Saúde Pública* 29, no. 12 (2013).

and civic engagement.[23] Nussbaum's version of the approach further identifies ten central capabilities essential for preserving human dignity, including, among others, good health, control over one's employment, and leisure activities.[24]

The idea that each person's unique perspective regarding the life they want to live — namely, the livability of the life they have — is a core concept of the capability approach.[25] Despite distinctions in their conceptual frameworks, both Sen and Nussbaum are ultimately concerned with the relational architecture of capabilities. Sen posits a hierarchical dependence in which elementary capabilities underpin complex ones[26]; Nussbaum, on the other hand, advances a model of reciprocal interconnection, wherein the deprivation of a single capability may simultaneously delimit multiple freedoms.[27]

From the perspective of the capability approach to health, endometriosis limits what Sen terms "complex capabilities," such as the ability to participate in social and community life,[28] plan a career,[29] or pursue education.[30] Nussbaum's list of central capabilities further illuminates these losses, particularly regarding bodily health (being able to have good health), bodily integrity (freedom from pain and violence),[31] and practical reason (being able to form a conception of the good and engage in critical reflection about the planning of one's life). Crucially, capability deprivation captures the cumulative nature of the losses associated with endometriosis, whereas diagnostic delay unnecessarily prolongs and intensifies them.

A decade of undiagnosed pain does not just hurt the body; it erodes the life one values. Pelvic pain, which may occur with the menstrual cycle or outside of it, is a distinct symptom of endometriosis. One patient describes the intensity of pain, "sometimes it was so bad I couldn't move. I was paralysed with pain."[32] Peterson et al. illustrate how unmanaged pain regularly renders women bedbound, their immobility leading to a profound loss of liberty.[33] Due to the unpredictability of symptoms, people are often forced to withdraw from social, community, and family lives, becoming "disconnected from themselves and the course of their lives."[34]

Some capability losses arise from endometriosis itself. However, diagnostic delay and medical dismissal intensify these losses by prolonging unmanaged pain, delaying access to treatment, and leaving patients without the clinical, social, and occupational recognition needed to make sense of their condition. Because of the intense and chronic nature of pain, endometriosis can diminish multiple central capabilities, including the freedom to complete education, seek employment, control one's environment, and participate in social life. These losses are particularly significant because they may begin at a young age: endometriosis symptoms may begin with menarche, which typically occurs between the ages of 12 and 13, but may occur earlier.[35] As a major cause of infertility, endometriosis may also restrict the ability to plan for relationships and reproduction. Without intervention, chronically diminished capabilities may force people to silently downgrade their expectations of a full life, "making allies out of the deprived."[36]

2.3. A sociological perspective on ignorance

The right to health and the capability approach help identify obligations and harms, but both have limitations. In both models, rights and capabilities are often evaluated against thresholds of a dignified or flourishing life. This makes them powerful tools for naming deprivation, but less able on their own to explain how some harms become invisible before they can be counted, evidenced, or recognized as violations. A sociological perspective is therefore essential to politicize this silence. By shifting the analytical focus from individual outcomes to structural and epistemological processes, we can examine how illness and health inequalities are not merely accidental gaps in care but are actively constituted by what health systems choose to know, measure, validate, and ignore. This shift enables us to examine the void of diagnosis not as an absence of activity but as a manifestation of structural neglect.[37]

Our analysis builds on Hudson's account of endometriosis as an example of "undone science" through willful ignorance, where the absence of knowledge is not a neutral gap but a product of institutional priorities, gendered assumptions, and uneven research agendas.[38] We extend this argument by asking how such undone science becomes normatively actionable. When the absence of knowledge produces preventable suffering, the right to health, capability deprivation, and networked responsibility may serve as frameworks for identifying opportunities for action at the levels of practice and policy.

To explain how a health system fails to fulfill rights and protect capabilities, we turn to the sociology of ignorance, specifically the "sociology of nothing." Institutional inaction is often framed as a passive void: a simple lack of evidence, resources, or consensus. However, sociological analysis suggests that "nothing" (e.g., silence, inaction, absence, and non-events) is socially produced (Fig. 1).[39]

We distinguish between two modes of producing this "nothingness" in the context of endometriosis. *Commissive misrecognition* (making something not happen) refers to active forms of "doing nothing," where institutions recognize that a problem exists but decide not to prioritize, fund, or respond to it. This includes suspending agenda items, declining to fund research, or failing to develop policy despite known disease

[23] Jennifer Prah Ruger, "Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements," *Yale Journal of Law & the Humanities* 18, no. 2 (2006): 3.

[24] Martha Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard University Press, 2011).

[25] Su and Lee, "Activist Allyship, Unspoken Dilemma (2026)."

[26] Amartya Sen, "Human Rights and Capabilities," *Journal of Human Development* 6, no. 2 (2005): 151–66, https://doi.org/10.1080/14649880500120491.

[27] Martha Nussbaum, "Capabilities as Fundamental Entitlements: Sen and Social Justice," *Feminist Economics* 9, nos. 2–3 (2003): 33–59, https://doi.org/10.1080/1354570022000077926.

[28] Brianna Peterson et al., "'It Just Stops Me from Living': A Qualitative Study of Losses Experienced by Women with Self-Reported Endometriosis," *Journal of Advanced Nursing* 79, no. 10 (2023): 3892, https://doi.org/10.1111/jan.15745.

[29] Stacey A. Missmer et al., "Impact of Endometriosis on Life-Course Potential: A Narrative Review," *International Journal of General Medicine* 14 (January 2021): 13, https://doi.org/10.2147/IJGM.S261139.

[30] Mary Lou Ballweg, "Endometriosis: The Patient Perspective," in *Infertility and Reproductive Medicine Clinics of North America*, vol. 3 (W.B. Saunders Company, 1992), https://www.researchgate.net/publication/259558426_Endometriosis_the_patient_perspective_from_Infertility_and_Reproductive_Medicine_Clinics_of_North_America.

[31] Peterson et al., "'It Just Stops Me from Living,'" 3892.

[32] Elaine Denny, "Women's Experience of Endometriosis," *Journal of Advanced Nursing* 46, no. 6 (2004): 644, https://doi.org/10.1111/j.1365-2648.2004.03055.x.

[33] Peterson et al., "'It Just Stops Me from Living,'" 3890.

[34] Peterson et al., "'It Just Stops Me from Living,'" 3894.

[35] Committee on Adolescent Health Care, *Menstruation in Girls and Adolescents: Using the Menstrual Cycle as a Vital Sign*, ACOG Committee Opinion No. 651 (American College of Obstetricians and Gynecologists, 2015), https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2015/12/menstruation-in-girls-and-adolescents-using-the-menstrual-cycle-as-a-vital-sign.

[36] Amartya Sen, "Positional Objectivity," *Philosophy & Public Affairs* 22, no. 2 (1993): 136.

[37] Susie Scott, "Social Nothingness: A Phenomenological Investigation," *European Journal of Social Theory* 25, no. 2 (2022): 197–216, https://doi.org/10.1177/1368431020958899.

[38] Nicky Hudson, "The missed disease? Endometriosis as an example of 'undone science'," Reproductive Biomedicine & Society Online 14 (2021): 20–27. https://doi.org/10.1016/j.rbms.2021.07.003.

[39] Susie Scott, "A Sociology of Nothing: Understanding the Unmarked," *Sociology* 52, no. 1 (2018): 3–19, https://doi.org/10.1177/0038038517690681.

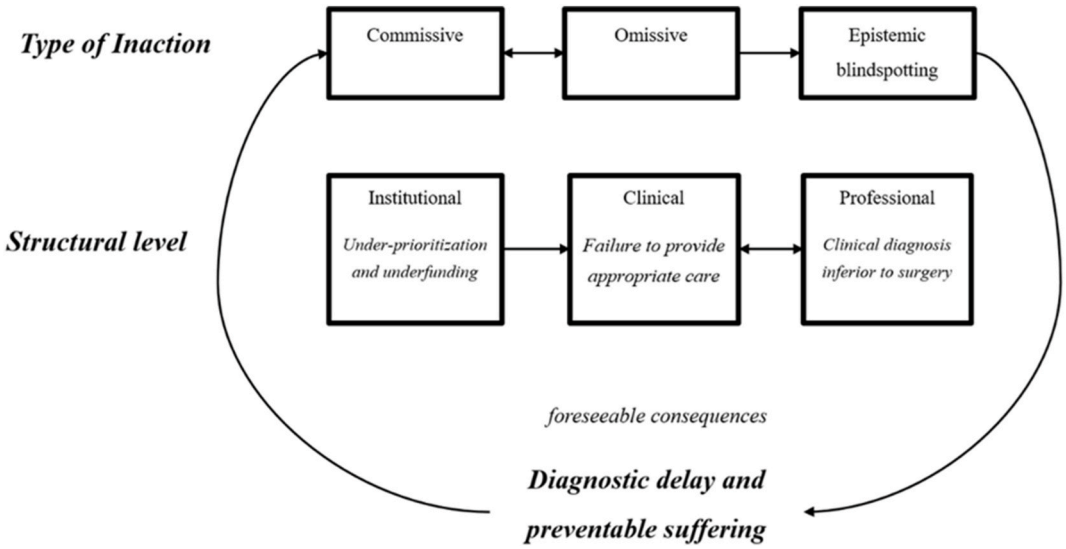

Fig. 1. The production of structural injustice: commissive, omissive, and epistemic modes of inaction mapped to levels of the health system. The cycle illustrates how a "lack of evidence" is not a neutral gap but a self-perpetuating outcome of these systemic failures.

burdens. *Omissive nonrecognition* (allowing nothing to happen), by contrast, refers to passive default, where a subject remains unmarked, unintelligible, or unaccounted for within existing systems of knowledge and care. In this case, the sufferer's needs are overlooked not necessarily through conscious malice, but because they do not fit the normative medical model.[40]

By "normative medical model," we mean a model of clinical reasoning organized around acute, visible, localizable, and objectively verifiable pathology, often calibrated against male bodies and linear disease trajectories. Endometriosis troubles this model because its symptoms may be cyclical, diffuse, chronic, multi-systemic, difficult to visualize, and poorly correlated with lesion stage. The patient may therefore appear not as someone with a recognizable disease, but as someone whose pain is excessive, vague, emotional, or difficult to classify.

Building on this perspective, we argue that the "lack of evidence" regarding endometriosis is not a neutral scientific gap.[41] Rather, it is a symptom of commissive decisions to underfund women's health and omissive failures to recognize pain that falls outside androcentric norms. The resulting preventable suffering is produced through these forms of constructed ignorance: suffering made possible by what health systems do as well as by what they repeatedly fail to know, count, hear, and act upon (Fig. 1).[42]

3. Production of preventable endometriosis-related suffering

The normative-analytical framework developed above allows us to move beyond describing diagnostic delay solely as a matter of delayed recognition.[43] In this section, we examine how specific modes of institutional failure — omissive, commissive, and epistemic — coalesce to produce preventable suffering among people with endometriosis. Categorizing diagnostic delay merely as "wait time" obscures the mechanisms through which delay is produced, normalized, and justified. Drawing on the sociology of ignorance, we analyze diagnostic delay as the product of three interrelated modes of failure: omissive nonrecognition (what the system fails to see), commissive misrecognition (what institutions choose not to prioritize despite knowing), and epistemic blindspotting (what evidentiary paradigms count as clinically meaningful).

3.1. Gendered exclusions as omissive nonrecognition

Omissive nonrecognition occurs through "passive default," in which a subject's needs are overlooked because they do not fit the dominant normative framework. In the context of endometriosis, this operates through the rendering of pain as unintelligible, especially when symptoms are filtered through historical, gendered, racialized, and biomedical assumptions.

Historically, endometriosis was conceptualized as a "career woman's disease," a label rooted in early twentieth-century assumptions that linked the condition to delayed childbearing among upper-class white women.[44] This stereotype was extended in the 1930s and 1940s by research attributing the disease to contraception and delayed childbearing.[45] The effects of the career-woman stereotype have persisted. As one Kenyan woman recalled in a 2023 study, "My doctor told me I could not have endometriosis because endometriosis is a 'disease of the affluent'."[46] Such stereotypes create epistemic distortion by shaping an imagined profile of the endometriosis patient, where those who do not match this profile are often overlooked. Black women, for instance, have historically been, and continue to be, misdiagnosed with pelvic inflammatory disease rather than endometriosis, despite the absence of

[40] Scott, "A Sociology of Nothing: Understanding the Unmarked."

[41] Po-Han Lee, "Un(Ac)Countable No-Bodies: The Politics of Ignorance in Global Health Policymaking," *Critical Public Health* 33, no. 1 (2023): 48–59, https://doi.org/10.1080/09581596.2022.2025578.

[42] Nicky Hudson, "The missed disease? Endometriosis as an example of 'undone science'".

[43] Zondervan et al., "Endometriosis," 1252.

[44] Lisa Michelle Sanmiguel, "From 'Career Woman's' Disease to 'an Epidemic Ignored': Endometriosis in United States Culture since 1948" (Ph.D. dissertation, University of Illinois at Urbana-Champaign, 2000), https://www.proquest.com/docview/304598081/abstract/747ECAC818594FB8PQ/1.

[45] Sanmiguel, "From "Career Woman's" Disease to "an Epidemic Ignored": Endometriosis in the United States Culture since 1948."

[46] Sadie Bergen et al., "Living with Endometriosis: A Narrative Analysis of the Experiences of Kenyan Women," *International Journal of Environmental Research and Public Health* 20, no. 5 (2023): 4125, https://doi.org/10.3390/ijerph20054125.

biological evidence supporting such racial differences.[47]

The normalization of menstrual pain forms the basis of nonrecognition. When professional norms treat severe pain as "normal" or presume patients may be exaggerating their symptoms, suffering becomes difficult for clinicians to recognize as pathological.[48] The patient exists, but their pain is interpreted as a natural feature of womanhood rather than as a sign requiring clinical attention. This nonrecognition is compounded by the tendency to psychologize women's suffering.

Psychologization refers to the attribution of physical pain to emotional or psychological causes. The inadequate treatment of women's pain is well documented.[49] Women are more likely to experience pain disorders, yet their pain is also more likely to be dismissed as emotional in origin.[50] When presenting with the same pain symptoms as men, women are more likely to receive sedatives or antidepressants than analgesics.[51] This reflects a persistent bias in which women's pain is attributed to emotional excess, anxiety, or heightened sensitivity, rendering physical pathology less visible. As Samulowitz et al. argue, women are often positioned as "more sensitive to" pain and "more willing to show and to report pain" than men.[52] Importantly, these patterns do not reflect individual malice on the part of clinicians but rather the constraints of training, time pressure, and gender norms that shape clinical reasoning within contemporary health systems.

Normalization and psychologization also shape how symptoms are disclosed before people enter clinical encounters. Drawing on Seear's work on menstrual concealment, we can see how stigma discourages women from naming or making their suffering visible. Seear describes Janine, who "pass[ed] out regularly" while menstruating, yet concealed what was happening because she felt "ashamed and embarrassed" about her periods.[53] Such concealment reflects a social environment in which menstruation is stigmatized and disclosure risks shame, disbelief, or discreditation. In this sense, concealment is not the cause of nonrecognition, but part of the social conditions through which nonrecognition is sustained.

These gendered and racialized biases are further complicated by uncertainty within biomedical assessment. As Denny argues, endometriosis symptoms do not easily match biomedical expectations of clear criteria and predictability.[54] Symptoms may be cyclical or acyclic; they may or may not correlate with menstruation, and non-menstrual pain may overlap with several other possible diagnoses. As a result, endometriosis produces a "tension between women's experience of symptoms and the doctors' interpretation of them."[55] This tension helps explain why endometriosis becomes unintelligible within clinical systems that prioritize clear diagnostic boundaries, linear symptom patterns, and predictable disease trajectories.

Sometimes, symptoms are recognized as problematic, but uncertainty dissuades clinicians from providing appropriate and timely referrals to specialty care.[56] When clinicians repeatedly fail to refer, patients enter what Cox et al. call a "medical merry-go-round," a cycle of omission and delay.[57] Referral time is therefore a substantial contributor to diagnostic delay.[58] Uncertainty about when a referral is warranted is partly due to unclear guidelines and insufficient training, making it an issue of information accessibility as well as clinical judgment.[59] Omission by referral may take the form of untimely referral, incorrect referral, or no referral at all.

This omission is exacerbated by the medical system's failure to recognize Chronic Overlapping Pain Conditions (COPCs). Endometriosis frequently co-occurs with other conditions such as migraines, fibromyalgia, irritable bowel syndrome, and other chronic pain conditions. Multi-systemic pain syndromes more commonly affect women, in part due to their increased risk of autoimmune processes.[60] Yet because medical specialization is siloed, a person presenting with multi-systemic pain may be treated as having "medically unexplained symptoms" rather than a cohesive physiological condition.[61] Under these conditions, women with endometriosis are commonly misdiagnosed with mental health disorders.[62]

Women with COPCs may become difficult for siloed systems of care to recognize, especially where clinical reasoning is organized around

[47] O. Bougie et al., "Influence of Race/Ethnicity on Prevalence and Presentation of Endometriosis: A Systematic Review and Meta-Analysis," *BJOG: An International Journal of Obstetrics and Gynaecology* 126, no. 9 (2019): 1104–15, https://doi.org/10.1111/1471-0528.15692; Donald L. Chatman, "Endometriosis in the Black Woman," *American Journal of Obstetrics and Gynecology* 125, no. 7 (1976): 987–89, https://www.ajog.org/article/0002-9378(76)90502-0/abstract; Olga Bougie et al., "Revisiting the Impact of Race/Ethnicity in Endometriosis," *Reproduction and Fertility* 3, no. 2 (2022): R34–41, https://doi.org/10.1530/RAF-21-0106.

[48] Maryam Moradi et al., "Impact of Endometriosis on Women's Lives: A Qualitative Study," *BMC Women's Health* 14, no. 1 (2014): 5, https://doi.org/10.1186/1472-6874-14-123.

[49] D. E. Hoffmann and A. J. Tarzian, "The Girl Who Cried Pain: A Bias against Women in the Treatment of Pain," *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics* 29, no. 1 (2001): 13–27, https://doi.org/10.1111/j.1748-720x.2001.tb00037.x.

[50] Anke Samulowitz et al., "'Brave Men' and 'Emotional Women': A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain," Pain Research and Management 2018 (2018): 1–14, https://doi.org/10.1155/2018/6358624.

[51] Diane E. Hoffmann et al., "The Woman Who Cried Pain: Do Sex-Based Disparities Still Exist in the Experience and Treatment of Pain?," *The Journal of Law, Medicine & Ethics* 50, no. 3 (2022): 519–41, https://doi.org/10.1017/jme.2022.91.

[52] Samulowitz et al., "'Brave Men' and 'Emotional Women,'" 9.

[53] Kate Seear, "The Etiquette of Endometriosis: Stigmatisation, Menstrual Concealment and the Diagnostic Delay," *Social Science & Medicine* 69, no. 8 (2009): 1225, https://doi.org/10.1016/j.socscimed.2009.07.023.

[54] Elaine Denny, "'I Never Know From One Day to Another How I Will Feel': Pain and Uncertainty in Women With Endometriosis," *Qualitative Health Research* 19, no. 7 (2009): 992, https://doi.org/10.1177/1049732309338725.

[55] Denny, "'I Never Know From One Day to Another How I Will Feel,'" 989.

[56] Sharon Dixon et al., "Navigating Possible Endometriosis in Primary Care: A Qualitative Study of GP Perspectives," *The British Journal of General Practice: The Journal of the Royal College of General Practitioners* 71, no. 710 (2021): e668–76, https://doi.org/10.3399/BJGP.2021.0030.

[57] Helen Cox et al., "Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go-Round," *International Journal of Nursing Practice* 9, no. 1 (2003): 2–9, https://doi.org/10.1046/j.1440-172X.2003.00396.x.

[58] Ballard et al., "What's the Delay?," 1298; Lenore Manderson et al., "Circuit Breaking: Pathways of Treatment Seeking for Women with Endometriosis in Australia," *Qualitative Health Research* 18, no. 4 (2008): 532, https://doi.org/10.1177/1049732308315432.

[59] Moniek van der Zanden et al., "Barriers and Facilitators to the Timely Diagnosis of Endometriosis in Primary Care in the Netherlands," *Family Practice* 37, no. 1 (2020): 131–36, https://doi.org/10.1093/fampra/cmz041; Dixon et al., "Navigating Possible Endometriosis in Primary Care," 672; Sophie Davenport et al., "Barriers to a Timely Diagnosis of Endometriosis: A Qualitative Systematic Review," *Obstetrics and Gynecology* 142, no. 3 (2023): 580, https://doi.org/10.1097/AOG.0000000000005255.

[60] Michael J. Lacagnina et al., "Autoimmune Regulation of Chronic Pain," *Pain Reports* 6, no. 1 (2021): e905, https://doi.org/10.1097/PR9.0000000000000905.

[61] Hoffmann et al., "The Woman Who Cried Pain: Do Sex-Based Disparities Still Exist in the Experience and Treatment of Pain?"

[62] Allyson C. Bontempo and Lisa Mikesell, "Patient Perceptions of Misdiagnosis of Endometriosis: Results from an Online National Survey," *Diagnosis* 7, no. 2 (2020): 97–106, https://doi.org/10.1515/dx-2019-0020; Allyson C Bontempo and Gordon D Schiff, "Diagnosing Diagnostic Error of Endometriosis: A Secondary Analysis of Patient Experiences from a Mixed-Methods Survey," *BMJ Open Quality* 14, no. 1 (2025): e003121,6, https://doi.org/10.1136/bmjoq-2024-003121.

singular, acute, localizable complaints. Rather than being understood as evidence of complex embodied suffering, multi-systemic symptoms are often met with dismissal, negative attitudes, and unnecessary or inappropriate treatment.[63] The complexity of the presentation does not make suffering less real. It makes suffering less legible to a system organized around narrower diagnostic expectations.

The historical omission of endometriosis symptomatology further illustrates how medicine has long ignored women's pain while questioning women's mental stability. For centuries, symptoms resembling endometriosis were often interpreted through the frame of *hysteria*, a disorder defined by its supposed mysteriousness and uterine or psycho-neurological origins. Reflecting on this history, Nezhat et al. describe pelvic pain in women as "a rather elusive [subject], one curiously and consistently neglected in the archives of history."[64] Endometriosis was not identified as a distinct disease for centuries, despite the prevalence of its symptoms. While hysteria is no longer a legitimate medical diagnosis, similar patterns persist through the normalization, dismissal, and psychologization of women's physical symptoms. Omissive nonrecognition, therefore, does not mean that nothing happens. It means that suffering is repeatedly made invisible through ordinary clinical, social, and epistemic routines.

3.2. Structural injustice as commissive misrecognition

If omissive nonrecognition refers to passive failures to see or register suffering, commissive misrecognition refers to institutional forms of "doing nothing" despite knowledge that a problem exists.[65] The process of commissive misrecognition does not necessarily reflect individual malice or explicit intent. Rather, it captures situations in which institutions have sufficient evidence of disease burden, diagnostic delay, and unmet need, yet continue to deprioritize research, education, policy reform, or resource allocation. In the context of endometriosis, commissive misrecognition is most visible in the organization of research funding, medical education, and national policy agendas.

This is evident in the allocation of research resources in the U.S. Despite affecting approximately 190 million people globally — a burden comparable to diabetes — endometriosis has historically suffered from chronic underfunding.[66] In the U.S., women's health research at the National Institutes of Health comprised only 8.8% of total NIH spending between 2013 and 2023. When adjusted for disease burden, endometriosis remains disproportionately underfunded compared to male-dominated conditions.[67] Since the early 1990s, qualitative researchers, patient advocates, and clinicians have called for greater attention and funding for endometriosis, repeatedly showing that a lack of knowledge about the disease contributes to diagnostic delay and worsened outcomes.[68] Despite these longstanding calls, the status quo of deprioritizing endometriosis largely persists in the U.S.

Disproportionate resource allocation is not simply a matter of isolated funding decisions. It also reflects upstream institutional priorities and classificatory systems that make some conditions easier to fund than others. The National Academies have found that women's health conditions, including endometriosis, fibroids, polycystic ovarian disease, and myalgic encephalomyelitis/chronic fatigue syndrome, often misalign with existing organizational categories and priorities.[69] In other words, chronic, multisystemic women's health conditions do not fit easily into funding structures organized around more conventional disease categories. This leaves conditions such as endometriosis to fall through the cracks of categories such as non-communicable disease, reproductive health, chronic pain, and cancer. The continued underfunding of endometriosis thus contributes to a self-reinforcing cycle in which limited research investment sustains limited knowledge, which in turn becomes a rationale for further inaction.

This pattern of active neglect in research is reinforced through medical education. Curricular design represents an institutional decision about what knowledge is deemed essential for future clinicians. As Loeser et al. note, negative attitudes toward chronic pain patients can originate early in medical training. Yet pain management often lacks structured curricula or explicit learning objectives in medical education.[70] A survey of medical schools found that 96% of those in the U.S. and the U.K., and nearly 80% in Europe, did not include dedicated pain education, with many U.S. schools requiring only 5 or fewer hours on the subject across 4 years of training. As a result, primary care physicians frequently report inadequate education in chronic pain management; they may lack the background needed to diagnose or manage complex chronic pain conditions such as endometriosis.[71] This is not merely a passive oversight. It is an institutional pattern that reproduces professional ignorance across generations of clinicians.

International developments further demonstrate that endometriosis-related neglect is not inevitable. States and public institutions outside the U.S. have increasingly recognized historical failures in relation to endometriosis and women's pain. The Victorian Government's *Inquiry into Women's Pain* report, for instance, describes a health system in which men's health claims are often treated as the default, while girls' and women's claims are viewed as atypical, exaggerated, or fabricated.[72] Similarly, a member of the U.K. Parliament stated during a debate on endometriosis workplace support, "we must recognise that we have failed to act to date, and that we now have an opportunity and a responsibility to take decisive action."[73] Such statements do not mean that these jurisdictions have fully resolved diagnostic delay or gendered pain dismissal. Rather, they show that public acknowledgment of structural failure is a necessary first step toward institutional accountability.

Australia offers one example of translating recognition into policy action. In 2018, Australia introduced its *National Action Plan for Endometriosis.* Subsequent investment has directed substantial public funding toward research, education, and improved diagnostic pathways. These

[63] John D. Loeser and Michael E. Schatman, "Chronic Pain Management in Medical Education: A Disastrous Omission," *Postgraduate Medicine* 129, no. 3 (2017): 332–35, https://doi.org/10.1080/00325481.2017.1297668.

[64] Camran Nezhat et al., "Endometriosis: Ancient Disease, Ancient Treatments," *Fertility and Sterility* 98, no. 6 (2012): S2, https://doi.org/10.1016/j.fertnstert.2012.08.001.

[65] Susie Scott, *The Social Life of Nothing: Silence, Invisibility and Emptiness in Tales of Lost Experience* (Routledge, 2019), https://doi.org/10.4324/9781315098906.

[66] Zondervan et al., "Endometriosis."

[67] Arthur A. Mirin, "Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health," *Journal of Women's Health* 30, no. 7 (2021): 956–63, https://doi.org/10.1089/jwh.2020.8682.

[68] Elaine Denny, "Women's Experience of Endometriosis," *Journal of Advanced Nursing* 46, no. 6 (2004): 641–48, https://doi.org/10.1111/j.1365-2648.2004.03055.x; Emma Whelan, "Negotiating Science and Experience in Medical Knowledge: Gynaecologists on Endometriosis," *Social Science & Medicine* 68, no. 8 (2009): 1489–97, https://doi.org/10.1016/j.socscimed.2009.01.032; Ballweg, "Endometriosis: The Patient Perspective."

[69] Committee on the Assessment of NIH Research on Women's Health et al., *A New Vision for Women's Health Research: Transformative Change at the National Institutes of Health*, ed. Sheila P. Burke et al. (National Academies Press, 2025), https://doi.org/10.17226/28586.

[70] Loeser and Schatman, "Chronic Pain Management in Medical Education," 332.

[71] Elspeth E. Shipton et al., "Systematic Review of Pain Medicine Content, Teaching, and Assessment in Medical School Curricula Internationally," *Pain and Therapy* 7, no. 2 (2018): 139–61, https://doi.org/10.1007/s40122-018-0103-z.

[72] Department of Health, State of Victoria, Australia, *Bridging the Gender Pain Gap: The Inquiry into Women's Pain Report 2025* (Melbourne, 2025).

[73] Ivan Lewis,"Endometriosis Workplace Support" Hansard UK Parliament, Volume 667: debated on Tuesday 29 October 2019, https://hansard.parliament.uk/commons/2019-10-29/debates/69A9E721-DD86-4583-9872-78719B8FBC15/EndometriosisWorkplaceSupport.

developments indicate that governments can treat endometriosis not merely as an individual clinical issue, but as a public health and policy concern requiring coordinated action. By contrast, the U.S. has not adopted a comparable national strategy, despite evidence of diagnostic delays, chronic underfunding, and gaps in medical education. This contrast illustrates commissive misrecognition: the failure to mobilize known evidence, available policy models, and institutional resources to better fulfill the right to health for people with endometriosis.

This underfunding and educational neglect are not accidental. They constitute a form of structural violence. The "lack of evidence" regarding endometriosis is often used as a rationale for inaction in policy (Fig. 2). However, as Lee argues in the context of global health governance, lack of evidence is frequently self-perpetuating: states and institutions decline to act because there is insufficient data, while insufficient data persists because they have not funded the research necessary to produce it. In this cycle, ignorance is not simply an absence of knowledge.[74] It is maintained through institutional decisions about what to fund, teach, measure, and prioritize. Hence, commissive misrecognition names the active maintenance of ignorance through patterned non-prioritization.

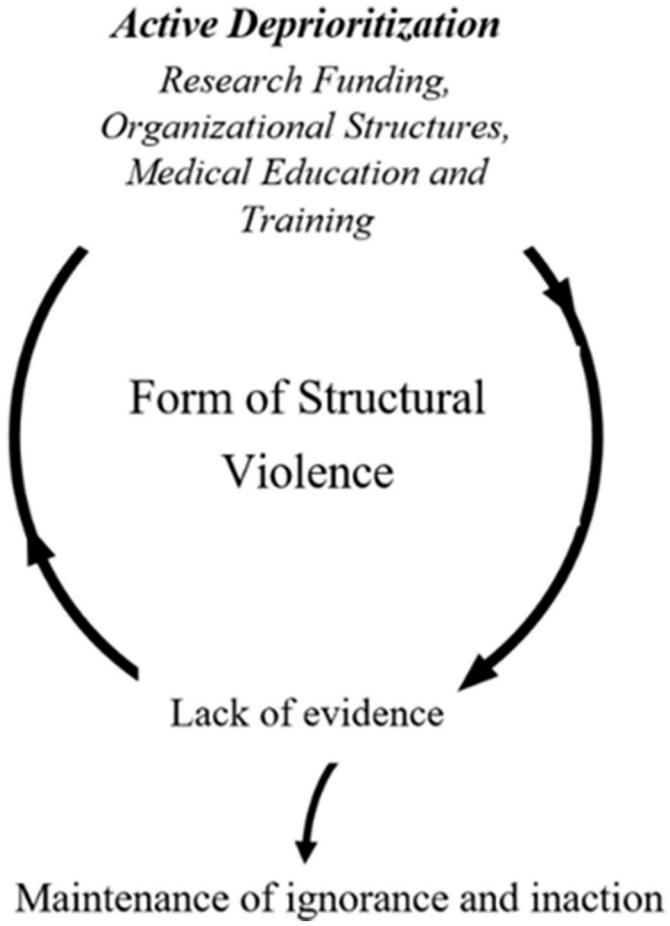

Fig. 2. Commissive misrecognition of endometriosis across multiple institutional levels constitutes a form of structural violence against people suffering from the disease. The cycle begets continued ignorance, passed down from one generation to the next.

3.3. Diagnostic validation and epistemic blindspotting

The third mode of failure is epistemic blindspotting, which refers to the exclusion of evidence that does not meet a specific, often arbitrary, professional standard.[75] Since its identification as a distinct condition, endometriosis has been shrouded in mystery: its pathogenesis remains uncertain, its cure remains elusive, and some have even debated whether it should be understood as a disease at all.[76] As Seear argues, the persistent framing of endometriosis as enigmatic and uncertain shapes how the disease is understood and treated, creating epistemic conditions in which only a narrowed range of evidence is recognized as valid.[77] Historically, these conditions have centered on the surgical paradigm. Although emerging biomarker tests challenge this paradigm by expanding the range of diagnostic evidence, they do not necessarily disrupt the epistemic deprioritization of patient narratives and lived experience. As the diagnostic environment shifts, the role of symptom narratives, functional impairment, and experiential knowledge remains marginalized.

For decades, the surgical paradigm relied on laparoscopic visualization and histological verification to confirm the disease and validate symptoms. This is illustrated by one general practitioner's account:

> There was this lady who had a wide range of complaints, very diffuse. And to be honest, she came up with the diagnosis [endometriosis] herself. Actually, I didn't much agree with her. But then the gynecologist did a laparoscopy, and *it appeared to be endometriosis after all* (emphasis added).[78]

The patient's account of her symptoms was insufficient or unauthoritative to support a diagnosis. Only in surgical retrospect was her account recognized as clinically meaningful. Within the surgical paradigm, visualization is prioritized,[79] subordinating narrative history as a valid and meaningful form of evidence.[80] This subordination is often gendered. Women tend to use more descriptive, graphic, or metaphorical language to describe pain than men. Endometriosis pain has been described as "knifelike"[81] or like "shards of glass."[82] Rather than being interpreted as a detailed clinical history, such a communication style is frequently misread by providers as "emotional" or "exaggerated," leading to lower estimates of pain severity.[83] Patient testimony is thus downgraded as less valid than the surgeon's gaze or other forms of

[74] Po-Han Lee, "The Demagogies of 'Lack': The WHO's Ambivalence to the Right to Health of LGBT People," *Global Health Governance* XII, no. 1 (2018): 17–21; Nicky Hudson, "The missed disease? Endometriosis as an example of 'undone science'".

[75] Lee, "Un(Ac)Countable No-Bodies: The Politics of Ignorance in Global Health Policymaking."

[76] J. L. Evers, "Endometriosis Does Not Exist; All Women Have Endometriosis," *Human Reproduction* (Oxford, England) 9, no. 12 (1994): 2206–9, https://doi.org/10.1093/oxfordjournals.humrep.a138421.

[77] Kate Seear, *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics* (Routledge, 2016), https://doi.org/10.4324/9781315555782.

[78] van der Zanden et al., "Barriers and Facilitators to the Timely Diagnosis of Endometriosis in Primary Care in the Netherlands," 135.

[79] Mathew Leonardi et al., "When to Do Surgery and When Not to Do Surgery for Endometriosis: A Systematic Review and Meta-Analysis," *Journal of Minimally Invasive Gynecology* 27, no. 2 (2020): 405, https://doi.org/10.1016/j.jmig.2019.10.014.

[80] Sanjay K. Agarwal et al., "Clinical Diagnosis of Endometriosis: A Call to Action," *American Journal of Obstetrics and Gynecology* 220, no. 4 (2019): 354.e1–54.e12, https://doi.org/10.1016/j.ajog.2018.12.039; Mee-Ran Kim et al., "Clinical Diagnosis and Early Medical Management for Endometriosis: Consensus from Asian Expert Group," *Healthcare* 10, no. 12 (2022): 2515, https://doi.org/10.3390/healthcare10122515.

[81] Moradi et al., "Impact of Endometriosis on Women's Lives," 4.

[82] Cara E. Jones, "The Pain of Endo Existence: Toward a Feminist Disability Studies Reading of Endometriosis," *Hypatia* 31, no. 3 (2016): 555, https://doi.org/10.1111/hypa.12248.

[83] Hoffmann et al., "The Woman Who Cried Pain: Do Sex-Based Disparities Still Exist in the Experience and Treatment of Pain?"

technically mediated evidence.[84] This paradigm creates a "blind spot,"[85] behind which the system cannot "see" the disease until it is objectively validated, even when patients have reported classic symptoms for years.

This blindspotting is particularly problematic because endometriosis produces profound functional disruption (Fig. 3). The primary clinical distinction between endometriosis and primary dysmenorrhea — a more "normal," self-resolving cause of menstrual pain — lies in the persistence, severity, and unmanageability of pain. Inquiring about functional impact, such as recurrent absenteeism, mobility restriction, or inability to carry out everyday activities, can help clinicians assess which aspects of pain are manageable and to what degree.[86] Despite this, women with endometriosis repeatedly describe how providers did not ask about, or did not appreciate, the severity of their symptoms and the capabilities they had lost.[87] Because diagnostic systems prioritize technical proof of disease, whether through surgery, imaging, or biomarker testing, functional impairment may remain epistemically devalued. Consequently, the prevailing episteme of validation discounts the authority of clinical diagnosis, risking the de-prioritization of descriptions of suffering. This creates a *blind spot* in which functional impairment is overlooked in the absence of technical proof.

The risks of surgery are especially consequential for adolescents and young people with suspected endometriosis. As stated by the American College of Obstetricians and Gynecologists, "The benefits of laparoscopy include confirmation of the presence or absence of endometriosis or other causes of chronic pain such as adhesive disease." While surgery can be therapeutic, its risks, including anesthesia complications and potential injury, mean that many adolescents and their families may reasonably decide to forgo it. Moreover, adolescents with endometriosis often have early-stage disease, which can be more difficult to detect using imaging or other diagnostic tools. When proof is required, but difficult or risky to obtain, young people may be left in diagnostic limbo, creating another profound epistemic blind spot.[88]

Although the diagnostic paradigm is shifting, the surgical stage remains a dominant framework for communicating disease severity for patients with surgically confirmed endometriosis. Surgical stage is defined by the depth, extent, and visual severity of lesions, yet it is poorly correlated with symptom severity.[89] A patient with extensive stage IV lesions may be asymptomatic, while a patient with minimal stage I lesions may experience severe, disabling pain.[90] Despite this mismatch, surgical staging continues to categorize disease as "mild" or "severe" in ways that may fail to incorporate patient narratives, functional impairment, or quality of life. In this sense, staging can communicate anatomical findings while marginalizing lived severity.

Reliance on costly diagnostic methods, such as surgical visualization, advanced imaging, or biomarker detection, can disadvantage patients who cannot access specialized care because of cost, geography, or insurance barriers.[91] Even as biomarker-based diagnostic tools emerge, access to them is likely to be uneven in rural, lower-resourced, or financially constrained contexts. In the context of migraine, Kempner shows how insurance systems may institutionalize inequity by organizing coverage around biologically "legitimate" diagnoses.[92] A similar logic can affect people with suspected or clinically diagnosed endometriosis. In a circular process, undiagnosed patients may not qualify for medical intervention because they lack the diagnosis needed for that. As a result, patients may be denied coverage for medications or procedures or forced to pay out of pocket while continuing to experience symptoms.[93]

When surgery is available, health systems and insurance-related factors often force patients to pay out of pocket and endure excessive wait times while they are still experiencing symptoms.[94] By privileging evidence from surgery, imaging, or biomarker validation over patient narratives and functional impairment, insurance systems contribute to diagnostic delays of 6–11 years.[95] In many practice settings, the continued requirement for technical proof transforms a clinical diagnosis into a forensic process, leaving patients in preventable suffering while they wait for the system to validate their reality. Even where medical management is offered without a definitive diagnosis, the absence of epistemic recognition shapes how patients' symptoms are interpreted, reassessed, escalated, and legitimized over time.

4. Networked responsibility for protecting the right to health

If the suffering associated with endometriosis is structurally produced through omission, commission, and epistemic blindspotting, then accountability cannot be understood only as a matter of individual clinical error. Nor can it be addressed solely through formal state obligations in a narrow sense. While international human rights law primarily focuses on state duties, the harms associated with diagnostic delay emerge within a decentralized ecosystem of clinical associations, research bodies, insurers, medical educators, employers, schools, families, and everyday social relations. Addressing these harms, therefore, requires a framework of networked responsibility that extends, rather than replaces, state accountability.

Drawing on the "rights-and-responsibilities" framework, we argue that realizing the right to health in complex health systems requires coordinated action across multiple institutional and social actors. In the context of endometriosis, this network includes (1) professional societies, responsible for advancing clinical guidelines to fully recognize

[84] Manderson et al., "Circuit Breaking," 531.

[85] Scott, "A Sociology of Nothing: Understanding the Unmarked."

[86] Committee on Adolescent Health Care, *Dysmenorrhea and Endometriosis in the Adolescent*, ACOG Committee Opinion No. 760 (American College of Obstetricians and Gynecologists, 2025), https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/12/dysmenorrhea-and-endometriosis-in-the-adolescent.

[87] Bontempo and Schiff, "Diagnosing Diagnostic Error of Endometriosis," 6; Cox et al., "Focus Group Study of Endometriosis," 6.

[88] Committee on Adolescent Health Care, *Dysmenorrhea and Endometriosis in the Adolescent*.

[89] Omar T. Sims et al., "Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay," *International Journal of Environmental Research and Public Health* 18, no. 15 (2021): 8210, 3, 15, https://doi.org/10.3390/ijerph18158210.

[90] American Society For Reproductive Medicine, "Revised American Society for Reproductive Medicine Classification of Endometriosis: 1996," *Fertility and Sterility* 67, no. 5 (1997): 817–21, https://doi.org/10.1016/S0015-0282(97)81391-X.

[91] Gunilla Backman et al., "Health Systems and the Right to Health: An Assessment of 194 Countries," *The Lancet* 372, no. 9655 (2008): 2047–85, https://doi.org/10.1016/S0140-6736(08)61781-X; Christopher P. Childers and Melinda Maggard-Gibbons, "Understanding Costs of Care in the Operating Room," *JAMA Surgery* 153, no. 4 (2018): e176233, https://doi.org/10.1001/jamasurg.2017.6233; Melissa Schwartz et al., "Laparoscopic Surgery for Gynecologic Cancer in Low- and Middle-Income Countries (LMICs): An Area of Need," *Gynecologic Oncology Reports* 20 (May 2017): 100–2, https://doi.org/10.1016/j.gore.2017.03.016.

[92] Joanna Kempner, *Not Tonight: Migraine and the Politics of Gender and Health* (University of Chicago Press, 2014).

[93] Madalene Zale et al., "Shedding Light on Endometriosis: Patient and Provider Perspectives on a Challenging Disease," *Journal of Endometriosis and Pelvic Pain Disorders* 12, no. 2 (2020): 69–76, https://doi.org/10.1177/2284026520905239.

[94] Bergen et al., "Living with Endometriosis"; Madalene Zale et al., "Shedding Light on Endometriosis: Patient and Provider Perspectives on a Challenging Disease," *Journal of Endometriosis and Pelvic Pain Disorders* 12, no. 2 (2020): 69–76, https://doi.org/10.1177/2284026520905239; Moradi et al., "Impact of Endometriosis on Women's Lives," 5; Jennifer Makin et al., "Cost of Gynecologic Laparoscopy in Rural Western Kenya [21D]," *Obstetrics & Gynecology* 129, no. 1 (2017): 47S, https://doi.org/10.1097/01.AOG.0000514367.99362.0b.

[95] Beloshevski et al., "Delayed Diagnosis and Treatment of Adolescents and Young Women with Suspected Endometriosis."

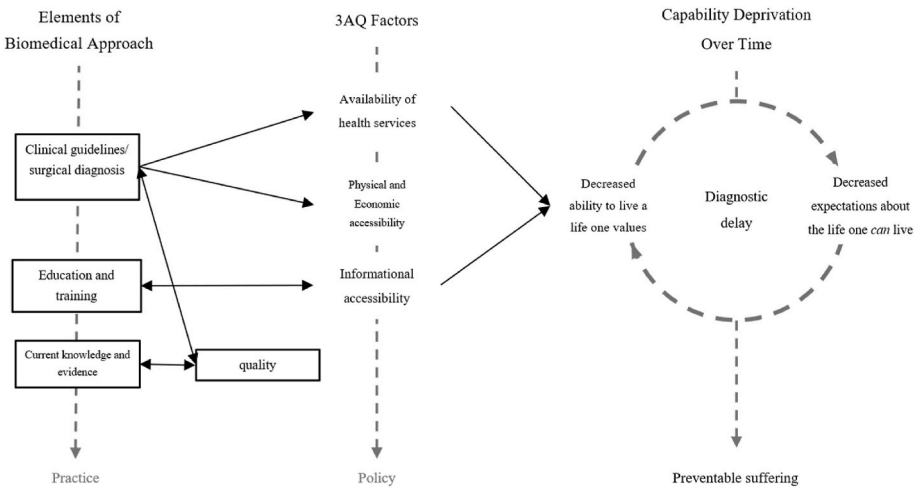

Fig. 3. Elements of the biomedical approach mapped to 3AQ. These elements form the structural basis of diagnostic delay, contributing to cumulative capability deprivation over time (adapted from Thaddeus & Maine, 1994; and Yamin, 2016).

patient narratives and clinical diagnoses, (2) research institutions, responsible for rectifying commissive misrecognition by prioritizing funding proportionate to disease burden rather than maintaining the status quo of neglect; (3) medical educators, responsible for addressing omissive nonrecognition by integrating sex-specific pain education into curricula across specialties, ensuring providers can "see" the disease outside of gynecology; and (4) actors responsible for recognizing and prioritizing suffering related to endometriosis, including peers, colleagues, and family members, before women even reach the health system.

This distributed responsibility does not absolve states; rather, it highlights that the state's duty to protect and fulfill the right to health involves regulating, incentivizing, funding, and coordinating these non-state actors. A primary function of the networked approach is to dismantle the "lack of evidence" defense. As established in our sociological analysis, the lack of evidence is often cited by policymakers as a rationale for inaction. However, within a human rights framework, this absence is not a defense but a symptom of the violation itself. When "not knowing" results from commissive choices to underfund research — as seen in the disproportionately low NIH funding for endometriosis relative to its burden — the "lack of evidence" becomes a form of structural violence (Fig. 2). A rights-based approach calls for actors to be held accountable for what they do and for what they choose not to know.

To dismantle the structures of preventable suffering, we propose a human rights-based reorientation of practice and policy based on three interrelated pillars:

1. *Epistemic accountability through legitimizing clinical diagnosis*: To counter epistemic blindspotting, health systems must legitimize clinical diagnosis, based on history, symptoms, examination, and functional impairment, as a valid pathway to diagnosis. Professional societies should adopt standardized terminology for non-surgically confirmed disease, such as "suspected," "clinical," or "probable" endometriosis, to ensure that people can access treatment, referral pathways, and insurance coverage without undergoing invasive surgery. Diagnosis should also be supported by coding systems that recognize endometriosis symptomatology, functional impairment, and non-surgically confirmed diagnoses, rather than relying solely on lesion validation.[96]
2. *Structural justice through equitable resource allocation*: To address commissive misrecognition, funding bodies should adopt equity-oriented allocation models. This requires transparent tracking of disease burden relative to funding levels,[97] accountability for internal decisions on categorical funding priorities,[98] and targeted legislative or policy action. Measures such as the U.S. Endometriosis CARE Act, which mandates research on disparities (see Appendix 1), indicate one possible pathway, but broader structural reforms are needed to ensure that endometriosis is not repeatedly deprioritized by organizational categories that fail to capture chronic, gendered, and multisystemic conditions.
3. *Participatory governance through patient expertise*: Overcoming omissive nonrecognition requires the active participation of those living with endometriosis. We recommend adapting the principle of Greater Involvement of People Living with HIV/AIDS, or GIPA, to endometriosis governance.[99] Just as GIPA helped transform HIV care by recognizing affected people as experts rather than passive recipients of intervention, endometriosis guidelines, research agendas, and policy reforms should be co-developed with patients and advocacy organizations. While the World Endometriosis Society has begun this process,[100] participatory governance should become standard across national and clinical guideline development so that pain and functional loss are not merely heard anecdotally but incorporated into the evidentiary and institutional design of care.

5. Conclusion and recommendations

Endometriosis offers a paradigmatic case of how suffering is produced not solely by biological disease, but by what we term the "politics of nothing" — the active and passive failures of health systems to recognize, record, and respond to gendered pain. Focusing primarily on the U.S. context, this article has argued that diagnostic delay in

[96] American Medical Association, *ICD*-10-CM *2025 the Complete Official Codebook* (American Medical Association, 2024), N80.0–N80.9.

[97] Mirin, "Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health."

[98] Committee on the Assessment of NIH Research on Women's Health et al., *A New Vision for Women's Health Research,* 390.

[99] John Tobin and Damon Barrett, "The Right to Health and Health-Related Human Rights," in *Foundations of Global Health & Human Rights*, ed. Lawrence O. Gostin and Benjamin Mason Meier (Oxford University Press, 2020), https://doi.org/10.1093/oso/9780197528297.003.0004.

[100] Neil P. Johnson et al., "Consensus on Current Management of Endometriosis," *Human Reproduction* 28, no. 6 (2013): 1552–68, https://doi.org/10.1093/humrep/det050.

endometriosis cannot be dismissed as a biomedical inevitability or an individual clinical error. Rather, prolonged delay constitutes a form of structural injustice embedded within contemporary health systems and sustained by three interrelated mechanisms of ignorance.

First, through omissive nonrecognition, gendered norms surrounding the presumed "naturalness" of menstrual pain render patients' experiences unintelligible to the medical gaze, leading symptoms to be overlooked by passive default. Second, through commissive misrecognition, U.S. institutions continue to deprioritize endometriosis within research funding, medical education, and policy agendas, transforming lack of evidence from a scientific gap into a form of structural violence. Third, through epistemic blindspotting, diagnostic standards have historically privileged surgical visualization and other forms of technical proof over patient narratives, clinical histories, and functional impairment. The result is that many people endure years of preventable suffering while awaiting professional validation of their pain.

By reframing diagnostic delay through the combined lenses of the right to health, the capability approach, and the sociology of ignorance, we have shown that this suffering is not only clinically significant but also legally and ethically actionable. Diagnostic delay restricts central capabilities — including bodily health, social participation, and life planning — producing cumulative disadvantages that erode human dignity well before a formal diagnosis is ever reached. Crucially, these harms arise not from the absence of treatment per se but from failures of recognition that shape how care is delivered, evaluated, and escalated over time.

Addressing this diagnostic crisis, therefore, requires more than technical innovation or further improvements in biomedical tools. It calls for a human rights-based reorientation of the health system. This includes moving beyond strictly state-centric models of accountability toward a framework of networked responsibility, in which professional societies, research institutions, educators, funding bodies, insurers, policymakers, employers, schools, families, and other social actors are collectively implicated in dismantling the conditions that sustain preventable suffering. In practice, this requires legitimizing clinical diagnosis — grounded in symptom persistence, functional impairment, and patient-reported experience — as a valid pathway to care alongside biomedical evidence. In the U.S., it also necessitates equity-oriented research funding proportional to disease burden, following the example of intentional prioritization in countries such as Australia and the U.K. Participatory forms of governance will position patients as epistemic agents with expertise in their own conditions rather than just as recipients of care.

These recommendations build on longstanding calls for reform in endometriosis care. Patient advocates, feminist scholars, nursing professionals, medical sociologists, clinicians, and endometriosis organizations have called for improved recognition, education, referral, funding, and participatory care for decades; our contribution is to reinterpret the repeated failure to implement these reforms as evidence of structural ignorance and preventable suffering. Ultimately, preventable suffering is not merely a descriptive concern but a normative imperative. The continued marginalization of endometriosis reflects a series of institutional choices about what counts as knowledge, whose pain is credible, and which forms of suffering warrant systemic response. Recognizing diagnostic delay as a potential violation of the right to health is a necessary first step toward making different — and more just — choices.

Data availability statement

Data sharing does not apply to this article, as no data were produced through this study.

Declaration of generative AI and AI-assisted technologies in the manuscript preparation process

During the preparation of this work, the authors used Grammarly to proofread the text and enhance readability. After using this tool, we reviewed and edited the content as needed and take full responsibility for the content of the published article.

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CRediT authorship contribution statement

Emily Shi: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing. **Po-Han Lee:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix 1

Selected national legislative and policy documents are outlined below, including how they implicitly or explicitly respond to different modes of neglect. Their analytical features are mapped onto policy operationalization and persistent challenges.

Policy/Legislation (Country, Year)	Analytic Categories of Neglect and/or Suffering[a]	Policy Description	Operationalization	Challenges
National Action Plan for Endometriosis	Refers to *commissive failures*, including inadequate recognition and funding.	Allocates more than AUD 87 million for research and education.	Addresses the disease in proportion to its burden.	No specific recommendations regarding how **awareness** will translate into **accountability and**

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(*continued*)

Policy/Legislation (Country, Year)	Analytic Categories of Neglect and/or Suffering[a]	Policy Description	Operationalization	Challenges
(Commonwealth of Australia, 2018)[b]	Emphasizes *capability deprivation.*	The main goal of the plan is a *"tangible improvement in the quality of life* for individuals living with endometriosis" (p. 7). Action is justified by its *potential to restore complex capabilities.*	Particularly aims for an "increase in social and economic participation" (p. iii).	**responsibility** among diverse actors, including the public.
	Recognizes *commissive failures* at the medical educational level in relation to pain management.	Explicitly bridges clinical competency with the resilience of capabilities, providing "clinicians with specific pain management skills to reduce day-to-day impact on personal life."	Increased **informational accessibility** for healthcare providers aims to bridge the gap in capability loss.	
	Emphasizes that vulnerable groups are likely to "fall through the gaps" of clinical assessment (p. 16).	States that underrecognized groups require increased attention. These groups include "Aboriginal and Torres Strait Islander people, culturally and linguistically diverse populations, people with disabilities, people in rural and remote settings, adolescents, transgender men, and non-binary people" (p. 16).	Non-discrimination in healthcare services requires increased **informational accessibility** for healthcare professionals.	
Gender Equality in Employment Act (The Republic of China (Taiwan), 2002)[c]	Addresses *omissive nonrecognition* of dysmenorrhea as a valid symptom, which may result in difficulty performing work.	Menstruation is recognized as a regularly occurring physiological event that should not impact gender equality in employment.	Protects the **right to the freedom from non-discriminatory treatment** in the workplace, contributing to the **construction of new norms** around acceptable accommodations.	Since its enactment in 2002, there have been numerous reported instances ofwomen being denied leave, discouraged or coerced from taking it, or subjected to discriminatory treatment after doing so.
Endometriosis CARE Act (*Not enacted,* United States, 2022)[d]	Counters *commissive misrecognition* and the resulting lack of evidence.	Calls for the completion of a study on populations who lack available or physically accessible healthcare (p. 2, line 24).	Applies to individuals living in underserved and/or rural areas, as well as those without access to transportation for services.	The Bill did not attempt to address the limitations of the current biomedical approach or the health system structure, potentially due to the complexity of private/public insurance schemes.
	Emphasizes the lack of disease awareness, including the provision of appropriate public information.	Aims to raise awareness of endometriosis among the public.	Focusing on **informational accessibility** for racial and ethnic minority and other underserved groups (p. 4, line 21), further exemplifies the principle of non-discrimination.	The Bill strongly implies that increased evidence is needed to inform further intervention, especially for vulnerable groups. As such, it focuses heavily on funding research to address health disparities.
	Brings attention to the lack of evidence focusing on vulnerable groups.	Aims to elucidate further endometriosis outcome disparities by "race, ethnicity, geography, primary language, sexual orientation, gender identity, disability status, and insurance status" (p. 6, line 23). Conceptualizes and funds a study to understand these disparities.	Findings would most likely challenge prevailing discriminatory stereotypes.	While the Bill proposed allocating USD 50 million to fund endometriosis research, the national funding structures that currently limit such research would remain unchanged.
Act Concerning Endometriosis, 2023 (State of Connecticut, 2023)[e]	Addresses *commissive failure* to fund robust scientific research. The Act implies that the current lack of understanding (and cure) is the result of such failures.	Mandates the creation of an endometriosis biorepository that links patient DNA to phenotypic data.	Biorepository creation is primarily focused on developing a non-invasive, non-surgical diagnostic test.	The Act is limited in scope. However, its swift passage (from introduction on February 9, 2023, to passage on June 26, 2023) suggests that these specific aims are likely to garner sufficient bipartisan support.
	Recognizes adolescents as an often-overlooked population (this provision appeared in earlier but not final versions).	Requires endometriosis education for school nurses.	Increased **informational accessibility** aims to identify the disease earlier.	
National Plan to Combat Endometriosis (France, 2022)[f]	Explicitly addresses capability losses in multiple domains of life.	Considers "all dimensions of the disease," including "its consequences on school life, professional life, sports, sexual life, and fertility" (p. 15).	Capability losses are addressed through a multisectoral response.	The Plan allocates extensive resources to research and innovation. However, vulnerable groups, such as racial and ethnic minorities and those with lower education levels, are not mentioned.
	Explicitly states that diagnostic delay is unacceptable.	Elaborates on the primary drivers of unacceptability: the length of delay and the high prevalence and morbidity of the disease.	Responses are designed to **reduce diagnostic delay.**	
	Recognizes and illuminates the *decentralized network of responsibility.*	Elaborates on "all actors likely to detect endometriosis," including "school nurses, occupational physicians, sports physicians, and human resources managers [in companies]" (p. 15).	Requires informational accessibility for all actors in all relevant settings.	

[a] Such categories may be addressed either implicitly or explicitly.

[b] Commonwealth of Australia, *National Action Plan for Endometriosis* (Department of Health, 2018), https://www.health.gov.au/sites/default/files/national-actio

n-plan-for-endometriosis.pdf.

[c] Gender Equality in Employment Act - Chapter - Laws & Regulations Database of The Republic of China (Taiwan) (2023), https://law.moj.gov.tw/ENG/LawClass/LawParaDeatil.aspx?pcode=N0030014&bp=4.

[d] Rep. Underwood, Lauren [D-IL-14], "H.R.7974 - 117th Congress (2021–2022): Endometriosis CARE Act of 2022," legislation, June 7, 2022, 2022-06-07, https://www.congress.gov/bill/117th-congress/house-bill/7974 U.S. Congress, 2022; "H.R.8565 - 118th Congress (2023–2024): Endometriosis CARE Act" legislation, 2024, https://www.congress.gov/bill/118th-congress/house-bill/8565/text U.S. Congress, 2024.

[e] Connecticut HB06672 | 2023 | General Assembly, HB 6672 (2023), https://legiscan.com/CT/bill/HB06672/2023.

[f] *Stratégie nationale de lutte contre l'endométriose* (Ministère des Solidarités et de la Santé, 2022), 33, https://sante.gouv.fr/IMG/pdf/strategie-endometriose.pdf.

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