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THE INVISIBLE BURDEN OF ENDOMETRIOSIS: A REVIEW OF DIAGNOSTIC, TREATMENT, AND HEALTH POLICY CHALLENGES

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ABSTRACT

Background: Endometriosis is a chronic, estrogen-dependent inflammatory disease affecting approximately 6-13% of women worldwide, with estimates exceeding 100 million individuals. It presents with heterogeneous symptoms, including chronic pelvic pain, dysmenorrhea, dyspareunia, and infertility, significantly impairing quality of life. Despite its prevalence, endometriosis remains under-recognized and often inadequately addressed at clinical and policy levels.
Objective: This review aims to examine the multifaceted burden of endometriosis, including its epidemiology, impact on quality of life and productivity, diagnostic delays, treatment limitations, and health system and policy barriers.
Methods: A narrative review of the literature was conducted using major databases, including PubMed, Scopus, and Web of Science. Recent systematic reviews, meta-analyses, observational studies, and policy reports were analyzed to identify key themes and evidence gaps.
Results: Endometriosis is associated with substantial physical, psychological, and economic burden, including reduced work productivity and high healthcare costs. Diagnostic delay remains a major challenge due to factors at the patient, provider, and system levels. Current treatments are often limited in effectiveness and accessibility, with high recurrence rates. Fragmented healthcare systems, insufficient specialist training, and a lack of national policies further exacerbate inequalities in care.
Conclusions: Endometriosis represents a significant yet often invisible public health issue. Addressing its burden requires integrated care models, improved diagnostic strategies, increased research funding, and comprehensive policy action.

KEYWORDS

Endometriosis, Dysmenorrhea, Quality of Life, Diagnostic Delay, Healthcare Disparities

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Introduction

Endometriosis is a chronic, estrogen-dependent, inflammatory disease defined by the presence of endometrial-like tissue outside the uterus. This tissue is most commonly found on the ovaries, fallopian tubes, and peritoneal surfaces (As-Sanie et al., 2025). Endometriosis affects women and individuals assigned female at birth mainly during their reproductive years. It exhibits a wide range of clinical features, including chronic pelvic pain, dysmenorrhea, dyspareunia, and symptoms affecting the bowel and urinary systems, as well as infertility (As-Sanie et al., 2025; World Health Organization, 2025). Globally, endometriosis is estimated to affect approximately 10% of women, corresponding to 176 to 190 million affected individuals worldwide (Adamson et al., 2010; Nnoaham et al., 2011; Rogers et al., 2009). More recent evidence suggests that the prevalence may be as high as 18% among females aged 15 to 60 (Moradi et al., 2021). Symptoms are often non-specific and normalized, which has contributed to under-recognition of the condition despite its substantial impact on individuals and society.

Although there is no definitive cure, the focus is on managing symptoms and improving quality of life. Access to timely diagnoses and effective treatments remains limited in many regions, highlighting the complexity of this condition. Global health authorities now acknowledge endometriosis as a major women's health issue: the WHO notes its wide health, social, and economic implications, including pain, heavy bleeding, infertility, mental health burdens, work/school disability, and stigma (World Health Organization, 2025). Recent Lancet reviews emphasize significant inequities in recognition and care, as nearly half of all countries have no national policy or guidance on endometriosis diagnosis or management (Evans et al., 2025; Gibbons et al., 2025). In parallel, recent expert commentary underscores the urgency of moving from awareness to action by strengthening policy frameworks, clinical guidance, and service delivery (Mburu et al., 2025). In this context, endometriosis imposes a heavy public health burden that is often invisible.

The purpose of this review was to examine the multifaceted impact of endometriosis, from clinical presentation and diagnostic delays to treatment limitations and policy gaps, highlighting its hidden burden on individuals and society.

Material and Methods

This article is based on a narrative review of the available scientific literature. Relevant peer-reviewed publications were identified through searches in major academic databases, including PubMed, Scopus, and Web of Science. The search focused on studies addressing the epidemiology of endometriosis, diagnostic delay, treatment pathways, health system barriers, and policy responses, with particular attention to evidence from Europe. Priority was given to recent publications, particularly systematic reviews, meta-analyses, large observational studies, and policy reports published within the last decade, while earlier foundational studies were included when relevant. The selected literature was critically analyzed and synthesized to identify major themes, evidence gaps, and implications for healthcare systems and public health policy.

Results

In the Results section, the challenges related to the burden of endometriosis identified through this review are presented both visually and descriptively. Specifically, the key dimensions of this burden have been synthesized and illustrated in the form of a graph (Figure 1) to provide an integrated overview. In addition, each of these aspects is discussed in detail in the following subsections to allow for a more comprehensive interpretation of the findings.

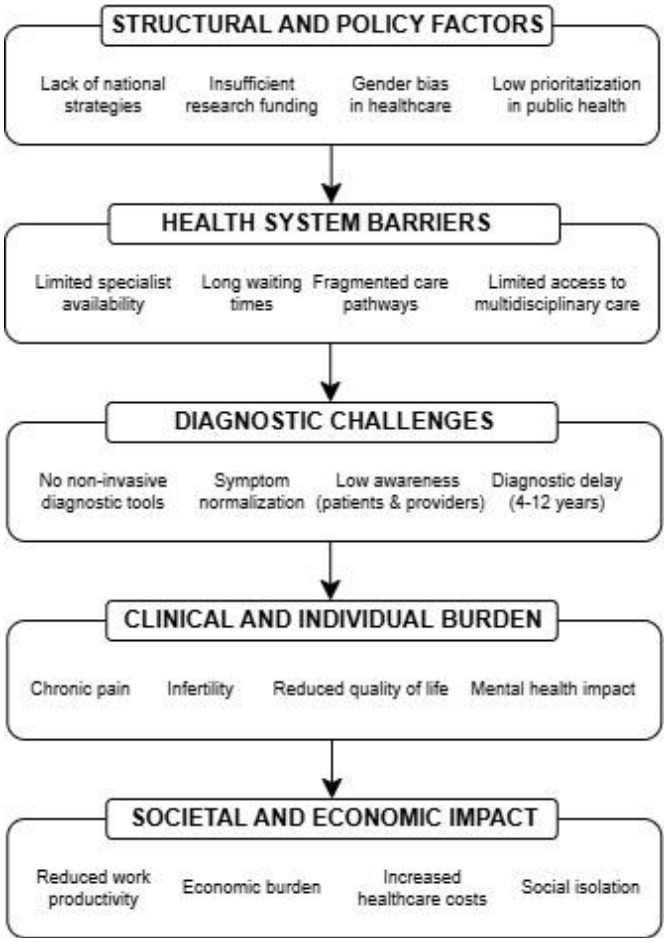

Fig. 1. *The invisible burden of endometriosis: multilevel determinants and consequences*

The framework illustrates the relationships among structural and health system barriers, diagnostic delays, treatment limitations, and their consequences for individuals and society.

Global prevalence

Reliable estimates of endometriosis prevalence remain difficult to determine, as the gold standard for diagnosis has traditionally been surgical visualization of lesions during diagnostic laparoscopy (Hudson et al., 2020; Rahmioglu & Zondervan, 2024). Overall, estimates generally range from approximately 6% to 13% of women affected worldwide, corresponding to 114–247 million individuals. Meta-analyses suggest that around 5% of women are affected by endometriosis, with prevalence reaching 30–50% among women who are symptomatic or experiencing infertility (Rogers et al., 2009; Sarria-Santamera et al., 2020; Wang et al., 2025). Thus, endometriosis likely affects well over 100 million women worldwide. However, these estimates vary depending on study design and the population studied. Community-based studies may miss asymptomatic or undiagnosed cases, whereas studies conducted in specialized clinics may report higher prevalence. While endometriosis prevalence appears similar across regions, research is concentrated in high-income countries. Estimates of prevalence are usually based on women of reproductive age. Nevertheless, even conservative estimates indicate that tens of millions of women worldwide are affected by the condition.

Quality of life and economic impact of endometriosis

Endometriosis substantially affects patients' quality of life, including physical, emotional, and social well-being. Women with the condition consistently report poorer physical and mental health compared to healthy women or those with similar symptoms but without endometriosis (Nnoaham et al., 2011; Szypłowska et al., 2023). Pain, fatigue, and bleeding frequently interfere with daily activities, relationships, social life, and career. A systematic review found high rates of depression and anxiety and reduced health-related quality of life (HRQoL) (Szypłowska et al., 2023). Even mild forms can significantly affect daily functioning, with symptoms such as severe dysmenorrhea and dyspareunia disrupting sexual activity and social participation (World Health Organization, 2025).

Women with endometriosis also experience substantial work loss. In the Global Study of Women's Health (GSWH), patients lost an average of 10.8 work hours per week due to reduced productivity (presenteeism). Absenteeism and presenteeism contribute to high indirect costs, with weekly productivity losses ranging from $4 per woman in Nigeria to $456 in Italy (Nnoaham et al., 2011). In the United States, claims data show that patients with endometriosis have substantially higher healthcare utilization and costs than matched controls (12-month costs approximately $16,500 versus $4,700), as well as more work absences (31 versus 24 days per year) and short-term disability days (14 versus 3). Chronic pain and repeated medical interventions further negatively affect mental well-being and personal and professional relationships (Soliman et al., 2018).

The annual economic burden per woman is substantial and appears to be increasing. Direct healthcare costs range from US$1,100 in Canada to $12,100 in the United States, while indirect costs from lost work range from $3,300 in Austria to $15,700 in the United States per year (Soliman et al., 2016). Although these figures predate the introduction of newer treatments, more recent claims data confirm the overall pattern. In a US cohort, total 1-year all-cause costs were approximately $16,573 per patient, compared with $4,733 for matched controls, while endometriosis-specific costs (procedures and medications) averaged around $6,498 per patient-year (Soliman et al., 2018). Overall, estimated annual costs per patient may reach approximately €9,500, comparable to other chronic conditions such as diabetes (Kirk et al., 2024).

Underdiagnosis and diagnostic delay

One of the characteristic problems with endometriosis is the long delay in diagnosis. In practice, most patients wait several years from the onset of symptoms to receive a definitive diagnosis. According to the WHO fact sheet, the average time to diagnosis ranges from 4 to 12 years (World Health Organization, 2025). n the United Kingdom, an expert panel reported a mean delay of 9 years, while in New Zealand, patients report an average of approximately 8.6 years (Ellis et al., 2022; Karavadra et al., 2025). Diagnostic delays occur at every income level and health system, but can be especially long where access to specialists or laparoscopy is limited. The GSWH study further found that delays were shorter in private compared with state-funded healthcare (5.5 vs 8.3 years), highlighting the influence of system-level barriers (Nnoaham et al., 2011).

Factors contributing to delay are multi-level. Patient-related factors include lack of awareness and normalization of symptoms. Many young women and even some physicians consider dysmenorrhea and pelvic pain to be normal menstrual discomfort. In a 2004 North American study, 47% of women with endometriosis had consulted at least five doctors before receiving a diagnosis or referral (Ballweg, 2004). In Poland, only around 4% of surveyed women reported having very good knowledge of endometriosis (Szymańska & Dąbrowska-Galas, 2021). Taboo around menstruation and scant sex education mean early symptoms are often ignored.

Provider-related factors include insufficient training and gender bias. Primary care doctors and general gynecologists may lack familiarity with endometriosis signs. Studies suggest that physicians recognize the condition is often overlooked during routine consultations, and that advocacy by patients, sometimes supported by a partner, can be crucial for obtaining referrals (Karavadra et al., 2025). Women commonly report that their symptoms are dismissed as typical menstrual discomfort or being misdiagnosed with ordinary cramps (Ellis et al., 2023). Indeed, one US review found that Black women were significantly less likely to receive an endometriosis diagnosis than White women (OR≈0.49), pointing to provider/systemic biases and disparities in care access (Rahmioglu & Zondervan, 2024). Disease-related factors further complicate diagnosis, as symptoms are highly heterogeneous and can resemble other conditions such as irritable bowel syndrome or urinary disorders. No reliable non-invasive biomarkers currently exist, and definitive diagnosis generally requires laparoscopic visualization. This procedure is time-consuming and costly, which contributes to many cases remaining unrecognized for years (Hudson et al., 2020).

The consequences of delayed diagnosis are serious. Prolonged under-treatment allows the disease to progress and spread, often leading to more severe pain and organ damage including advanced lesions and adhesions (Kirk et al., 2024). Fertility may also be affected, as up to 30–50% of women experiencing infertility have undiagnosed endometriosis, and earlier intervention could improve reproductive outcomes (World Health Organization, 2025). Patients with chronically delayed diagnoses frequently undergo repeated consultations and multiple surgical procedures, which can contribute to declining mental health due to ongoing pain and frustration. As a result, quality of life and work productivity are significantly impaired. Overall, diagnostic delays magnify the hidden burden of endometriosis, prolonging suffering and increasing both personal and societal costs. Table 1 summarizes the key indicators of the global epidemiology and burden of endometriosis.

Table 1. Global epidemiology and burden of endometriosis

INDICATOR	ESTIMATE
Global prevalence	6–13%
Total affected worldwide	114–190 million
Diagnostic delay	4–12 years
Productivity loss	10.8 hours/week
Annual cost per patient	€9,500
Infertility association	30–50%

Undertreatment and gaps in clinical management

Many patients face suboptimal treatment even after diagnosis. Endometriosis has no cure; current therapies are mainly hormonal suppression and surgical excision, both of which have limitations. According to the WHO, available medical treatments, including NSAIDs, combined hormonal contraceptives, progestins, and GnRH analogues, can alleviate symptoms but often cause side effects and do not address infertility. Surgical removal of lesions can improve pain and fertility in experienced hands, yet invasive procedures are not always available, and benefits may be temporary due to high recurrence rates (World Health Organization, 2025). In practice, many women rely long-term on analgesics or hormonal therapy with incomplete symptom relief, and traditional stepwise treatment approaches often fail to restore autonomy or prevent disease recurrence (Mick et al., 2024).

Barriers to effective care are numerous. Access to minimally invasive surgery depends on the availability of specialists, leaving women in rural areas or resource-limited settings at a disadvantage, sometimes waiting years for referrals or being offered only extensive surgery as a last resort. Advanced pharmaceuticals, such as GnRH antagonists, can be expensive or not reimbursed, resulting in high out-of-pocket costs for patients. Surveys in New Zealand highlighted that timely access to surgical or hormonal therapy was often impossible without private insurance, creating a sense of injustice among affected women (Ellis et al., 2023). Multidisciplinary care involving physiotherapy, pain management, and mental health support is considered ideal but remains largely unavailable due to cost, time constraints, and fragmented healthcare systems (Mick et al., 2024). Care pathways are frequently disjointed, with patients seeing multiple specialists independently without coordinated management.

Inequalities in care persist even within high-income countries. Specialized endometriosis centers are emerging in some regions of Europe and Australia, providing expert surgery and research opportunities, yet many areas, including much of Eastern Europe, lack such services. In Poland, for example, national programs

have only recently begun to emerge, but there are still very few specialized centers, long waiting lists, and a shortage of trained endometriosis specialists. Within countries, racial and socioeconomic disparities further affect treatment: in the United States, White women are more likely to receive minimally invasive surgery, whereas Black women experience higher complication rates and longer perioperative stays.

Overall, many women with endometriosis face unmet treatment needs. Patient surveys consistently highlight gaps in affordable and timely access to diagnostics and surgery, better pain management, and increased research and education (Martínez-Zamora et al., 2025). Patients call for subsidized care programs and greater investment in research, reflecting frustration with current services. Clinical management remains limited by both the nature of the disease and by health system constraints, leaving many women undertreated.

Health system and structural barriers

Specialist training in endometriosis is largely concentrated within gynecology, and even experienced gynecologists may feel unprepared to manage the full spectrum of the disease, particularly when bowel or bladder surgery is required (Mick et al., 2024). Limited hospital budgets and long waiting lists can delay imaging and surgical interventions. The Global Study of Women's Health (GSWH) found that women relying on public healthcare experienced longer waits for diagnostic laparoscopy compared with those in private care (Nnoaham et al., 2011). Reimbursement policies often do not cover multidisciplinary therapies, such as physiotherapy or cognitive behavioral therapy for chronic pain, which are frequently needed. In low-income countries, necessary infrastructure for laparoscopy or advanced imaging may be lacking entirely.

Menstrual pain is still commonly normalized by clinicians, and the World Health Organization highlights that this widespread stigmatization adversely affects mental health and well-being. tructural neglect follows, as menstrual health rarely receives priority in medical curricula or public health programs, leading to underdeveloped referral pathways and limited funding for essential services. Care is frequently fragmented, with endometriosis managed only in the context of infertility or symptom relief rather than through comprehensive chronic disease management. Some experts describe this as a missed opportunity to address a prevalent and impactful condition in a coordinated way.

Health policy and institutional gaps

At the policy level, endometriosis remains under-prioritized in most countries. Scoping reviews show that only about 7% of countries have official clinical guidelines endorsed by the government, while around half of the nations lack any policies or strategies addressing the disease (Evans et al., 2025; Gibbons et al., 2025). Where guidelines exist, they are often informal or inconsistent. High-income regions, especially Europe, have more published guidance, while most other countries have no endometriosis-specific strategy. Some exceptions demonstrate the impact of focused policy. Australia launched a National Action Plan for Endometriosis (2020–25), and France has implemented a multi-year endometriosis plan to improve care and research. By 2025, however, only about twelve countries worldwide had adopted any national endometriosis strategy (Gibbons et al., 2025). In most health ministries, endometriosis remains embedded within general gynecology or menstrual health programs, with limited dedicated funding or oversight.

Funding shortfalls exacerbate these challenges. Endometriosis research receives a disproportionately small share of biomedical resources. A Danish study reported that only 27 of approximately 146,000 EU framework projects addressed endometriosis, representing 0.02% of grants. In the United States, the NIH allocated just $16 million to endometriosis research in 2022, equivalent to about $2 per patient per year, far below funding for other diseases of similar prevalence (Kirk et al., 2024). Chronic underinvestment limits clinical trials, slows drug development, and constrains understanding of disease mechanisms. Health services are also affected by shortages of trained specialists, inadequate reimbursement for essential care, and poor integration of services. Key challenges, consequences, and recommended actions are summarized in Table 2.

Table 2. Summary of key challenges, consequences, and recommended actions in endometriosis care.

DOMAIN	KEY CHALLENGES	CONSEQUENCES	RECOMMENDED ACTIONS
Diagnosis	Lack of awareness, normalization of pain, and no biomarkers	Diagnostic delay (4–12 years), disease progression	Education, screening tools, biomarker research
Treatment	Limited specialists, high cost, recurrence	Persistent symptoms, infertility, poor QoL	Multidisciplinary care, improve access to surgery
Health system	Fragmented care, long waiting times	Inefficient management, inequity	Integrated care pathways, specialist centers
Policy	Lack of national strategies, low funding	Underprioritization, poor outcomes	National action plans, increased research funding
Society	Stigma, poor menstrual health literacy	Delayed help-seeking, psychological burden	Public awareness campaigns, school education

Discussion

Despite increasing recognition of endometriosis in recent years, this review demonstrates that the condition remains insufficiently understood, underdiagnosed, and inadequately addressed across clinical practice, health systems, and policy. Although it affects a substantial proportion of women globally and has profound consequences for quality of life, productivity, and mental health, it continues to be treated as a secondary issue rather than a major public health concern (World Health Organization, 2025). One of the most consistent findings is the persistence of major epidemiological gaps. Although data on the prevalence of endometriosis are available, they remain limited in quality, as they are largely based on models or clinical populations rather than robust population-based studies. Furthermore, research is heavily concentrated in high-income countries, which limits the generalizability of findings and obscures the true global burden of disease. This uneven evidence base reflects structural inequalities in research funding and prioritization more broadly.

At the clinical level, the absence of a validated non-invasive diagnostic method remains a central challenge. Current diagnostic pathways often rely on laparoscopic confirmation, which is invasive, costly, and not universally accessible (Mick et al., 2024; Rahmioglu & Zondervan, 2024). As a result, diagnostic delays are still widely reported across healthcare systems (World Health Organization, 2025). These delays are not solely due to technological limitations, but also arise from a combination of factors at the patient, provider, and system levels. The normalization of menstrual pain, low patient awareness, and insufficient healthcare provider training contribute to delayed recognition (Karavadra et al., 2025). In addition, symptom heterogeneity and overlap with other conditions further complicate diagnosis. Importantly, disparities in diagnosis, such as lower rates among Black women in the United States, highlight the role of systemic and provider-level biases in shaping access to care (Rahmioglu & Zondervan, 2024). The consequences of delayed diagnosis are substantial. Prolonged under-recognition allows disease progression, leading to more severe symptoms, increased risk of infertility, and cumulative physical and psychological burden (2,14). These findings highlight the need to reconsider endometriosis as a chronic condition that requires early diagnosis as well as long-term, comprehensive management.

Even after diagnosis, a significant number of patients continue to receive suboptimal care. Current therapeutic strategies, including hormonal treatments and surgical interventions, are often limited by adverse effects, high recurrence rates, and restricted accessibility, and remain largely symptom-oriented. In practice, many women remain reliant on long-term pharmacological management with incomplete symptom control. Access to advanced treatments, including minimally invasive surgery or newer pharmacological options, is frequently constrained by cost, availability of specialists, and reimbursement policies. These barriers are particularly evident in publicly funded healthcare systems and in regions with limited specialist infrastructure (5,22,23).

Another critical gap is the organization of care. Although multidisciplinary approaches integrating gynecology, pain management, physiotherapy, and psychological support are increasingly recommended, such models are implemented inconsistently (23). Care pathways are often fragmented, leaving patients to navigate multiple providers without coordinated management. There is limited evidence on the effectiveness and cost-efficiency of multidisciplinary care, highlighting an important area for future health services research. Inequities in access to diagnosis and treatment further compound these challenges. Differences between public

and private healthcare systems, as well as regional disparities within countries, significantly influence waiting times, access to specialists, and treatment options (5). In Europe, including Poland, emerging national initiatives represent important progress, yet access to specialized care remains uneven, with long waiting times and limited availability of expert centers. Socioeconomic and racial disparities observed in other contexts further illustrate how structural factors shape patient outcomes.

At the system level, endometriosis is still shaped by a broader lack of prioritization within healthcare. Menstrual pain is frequently treated as something normal, and menstrual health is not sufficiently included in routine clinical practice or medical education. As a result, referrals are often delayed, care pathways remain poorly developed, and investment in services is limited. Fragmented care, together with insufficient reimbursement for multidisciplinary approaches, further reduces the effectiveness of current healthcare responses. Policy gaps represent a major barrier to progress. Despite growing awareness, only a small proportion of countries have implemented formal strategies or guidelines for endometriosis (7,8). While national action plans in countries such as Australia and France demonstrate the potential of coordinated approaches, these remain exceptions rather than the norm. In most settings, endometriosis is not treated as a distinct public health priority, resulting in limited funding, weak policy frameworks, and insufficient integration into broader health strategies. Underinvestment in research further exacerbates these challenges. Compared with other chronic conditions of similar prevalence, endometriosis receives disproportionately low levels of funding, which limits advances in diagnostics, treatment, and understanding of disease mechanisms (14). As a result, fundamental questions regarding etiology, including the roles of immunological, genetic, and environmental factors, remain unresolved. In addition, there is a lack of research on health service organization, policy effectiveness, and cost-efficient care models.

Taken together, the data collected in this review underscore the need for a coordinated, multi-level response. Clinically, there is an urgent need to improve early recognition, including treating menstrual health as a routine component of assessment and implementing simple screening tools in primary care. Expanding access to multidisciplinary care and reducing fragmentation should be key priorities. At the policy level, governments should adopt comprehensive national strategies that integrate public awareness, professional training, and dedicated funding for services and research.

Limitations and Future Directions

This narrative review covers multiple aspects of endometriosis, from epidemiology and diagnosis to treatment and health system responses, but it has several limitations. This review is based on a selection of the most relevant and influential publications and does not represent a systematic review of the literature. Its purpose is to provide a broad overview of key issues across multiple areas rather than an exhaustive synthesis of all available evidence. The synthesis relies heavily on heterogeneous studies of varying quality, and many areas, such as long-term outcomes, patient-reported experiences, and health service effectiveness, remain underexplored. Evidence from low- and middle-income countries is scarce, which limits the global applicability of the conclusions.

Future research should aim to address these gaps. First, developing non-invasive diagnostic tools, including biomarkers and advanced imaging techniques, could reduce dependence on surgical confirmation and improve early detection. Large-scale epidemiological studies in underrepresented regions are needed to better estimate the true disease burden. Evaluations of health service interventions and policy initiatives must be more rigorous, incorporating quantitative and qualitative data. Finally, integrating patient perspectives into study design and policy planning is essential to ensuring that research translates into interventions that address real-world needs, from system-level care pathways to individual clinical management.

Conclusions

Endometriosis continues to place a significant yet often overlooked burden on individuals and healthcare systems. Persistent delays in diagnosis, limited treatment options, fragmented care, and systemic inequities highlight a broader failure to adequately prioritize this condition. There are research gaps, particularly regarding the global prevalence, long-term outcomes, and lived experiences of patients with endometriosis. This underscores the need for more inclusive and comprehensive studies. Addressing these challenges requires shifting from awareness to decisive action. Clinically, this means integrating menstrual health into routine assessments, expanding access to multidisciplinary care, and developing tools for earlier and more accurate diagnoses. At the policy level, governments and healthcare organizations must implement strategies that combine professional training, public education, and dedicated funding for services and research. Patient

perspectives must be central to these efforts to ensure that interventions are meaningful and effective in real-world settings. Most importantly, stakeholders across the healthcare spectrum, including clinicians, researchers, policymakers, and patient advocates, must collaborate to prioritize endometriosis. Only through coordinated action, sustained investment, and systemic change can we reduce the burden of this condition and ensure that all those affected receive timely, comprehensive, and compassionate care.

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