

Original Article

Optimizing Patient Experiences and Outcomes: Proposal to Develop an Endometriosis Care Quality Collaborative in the United States

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ABSTRACT Endometriosis is a chronic disease that is characterized by pain, infertility, and reduced quality of life. Despite varied treatment modalities, a high proportion of individuals experience debilitating symptoms and develop comorbid pain conditions. In this manuscript, we describe the current state of endometriosis care in the United States and advocate for the establishment of an Endometriosis Care Quality Collaborative that would involve high-volume surgical management and multidisciplinary approaches to clinical care and research. We present quality and ethical arguments and outline a plan to design and implement accredited centers of expertise. This work was completed by members of the Endometriosis Care Quality Collaborative Taskforce and involved collaboration between members of multiple national societies, including the AAGL, the North American Society for Pediatric and Adolescent Gynecology, the Society of Gynecologic Surgeons, and the Society of Reproductive Surgeons. *Journal of Minimally Invasive Gynecology* (2026) 33, 141–146. © 2025 The Author(s). This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Key words: endometriosis; Laparoscopy; multidisciplinary care; health equity

Introduction

Endometriosis is a multi-system, chronic disease that affects an estimated 10% of reproductive-age women as well as an unknown number of gender diverse individuals and is characterized by pain, infertility, reduced quality of life, and rare end organ damage [1,2]. The impact of

endometriosis begins early in life, with two-thirds of adults diagnosed with endometriosis reporting their first pelvic symptoms prior to the age of 20 years, and 21% reporting pain prior to age 15 [3]. Individuals with endometriosis experience diagnostic delays of 7–10 years from symptom onset to diagnosis, presenting to their primary care physicians an average of 7 times before receiving an appropriate specialty referral [4–7]. Endometriosis has been associated with impairments in mental and emotional health, adverse effects on personal relationships, reductions in educational attainment, and alterations in career choices and successes [8]. The impacts of endometriosis over the course of an individual's lifespan can be significant and severe.

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Once disease-focused treatment is initiated for endometriosis, optimization of therapy can be difficult to achieve. Despite multiple varied treatment modalities, including anti-inflammatory medications, hormonal therapies to interrupt ovulation and suppress estrogen synthesis, and surgical intervention, a high proportion of individuals experience residual and recurrent symptoms [1,9,10]. Most people with endometriosis go on to develop one or more comorbid pain conditions, including irritable bowel syndrome, painful bladder syndrome, high tone pelvic floor dysfunction, and vulvodynia, which likely represent the progression of years of untreated pain and remodeling of the central nervous system [11,12]. Endometriosis is also a frequent contributor to infertility, which affects approximately 21-50% of women with the diagnosis [1]. Further compounding care inadequacies, people of color with endometriosis experience poorer clinical outcomes than their White counterparts, including reduced access to specialized surgery and higher rates of surgical complications [13,14]. Moreover, health care impacts associated with direct and indirect costs related to endometriosis, including delays in care and lost productivity, exceed \$60 billion per year [15].

The reasons underpinning the observed gaps in clinical care and research for such a severe and prevalent disease are complex. It is important to first call out widespread stigmas against menstruation and reproductive capacity, longstanding sex and gender discrimination within healthcare, oppression of female bodies, societal normalization of women's pain, and barriers to care for nonbinary and transmasculine patients who experience gynecologic disorders. These systemic ills prevent individuals from seeking care for abnormal pain and bleeding symptoms, hinder communication and trust between patients and their healthcare providers, and lead to devaluation of research and training related to endometriosis care [16]. In comparison, individuals with other chronic pain conditions and particularly those that can also impact men—such as inflammatory bowel disease, which affects only approximately 0.4–0.6% of the US population—benefit from shorter diagnostic delays, more effective treatment options, and higher amounts of national research funding [17–20]. These disparities between conditions highlight the need for significant reform to address the inequities in care for individuals with endometriosis.

European medical societies have long identified the need for disease-focused and specialized care for people living with endometriosis [21,22]. Centers of expertise for endometriosis have been developed to address this gap, and typically include high-volume surgical management and multidisciplinary approaches to clinical care and research [23,24]. At present, there are no metrics to identify or certify such centers in the United States. In this paper, we aim to describe the current state of endometriosis care in this country and to propose the establishment of an *Endometriosis Care Quality Collaborative (ECQC)* to improve clinical outcomes, optimize patient experiences, and promote

excellence in research and education. We hope this initiative will serve as a preliminary model that can be later refined and adapted on a multi-national scale. We present quality and ethical arguments in favor of the creation of an ECQC, and describe a multi-year plan to design and implement accredited centers of expertise.

Medical Training

Barriers to effective care for endometriosis start with insufficient healthcare provider education and training. A survey of primary care physicians found that over 60% reported feeling uncomfortable in the diagnosis and management of people with endometriosis [25]. Chronic pelvic pain is also within the realm of Pediatrics, and in particular Adolescent Medicine, however, diagnosis of endometriosis is not uniformly incorporated into trainee curricula. Inadequate training and low confidence among primary care physicians, pediatricians, and adolescent medicine physicians, has direct adverse effects on patients' diagnostic experiences, often resulting in multiple medical visits before gynecologic referral is initiated [6]. Furthermore, despite affecting over 176 million persons of reproductive age worldwide [26], and thus being a central disease process within Obstetrics and Gynecology, management of endometriosis, chronic pelvic pain, and infertility is largely absent from formal residency curricula. The Accreditation Council for Graduate Medical Education (ACGME) has not labeled medical and surgical treatment for endometriosis as a residency graduation requirement, in contrast to other surgical disciplines, in which specific surgical procedures are listed [27,28]. In addition, while residency programs are required to provide residents with minimum procedural experiences in several procedures such as minimally invasive hysterectomy and incontinence and pelvic floor procedures, there are no requirements related to fertility-sparing surgical treatment of endometriosis and pelvic pain [29]. As such, Obstetrics and Gynecology residents may graduate from accredited residency programs with minimal exposure to endometriosis care and limited opportunities to rectify this deficit after graduation.

The AAGL Fellowship in Minimally Invasive Gynecologic Surgery (FMIGS), the ACGME-accredited fellowship in Reproductive Endocrinology and Infertility (REI), and the North American Society for Pediatric and Adolescent Gynecology (NASPAG) Fellowship for Pediatric and Adolescent Gynecology (PAG) provide examples of training programs that specifically incorporate the management of endometriosis and pelvic pain as dedicated fellowship curriculum objectives [30]. As trends in REI practice have changed in favor of assisted reproductive technologies such as IVF, there is significant heterogeneity in REI fellowship training in reproductive surgery, including endometriosis diagnosis and management [31]. The American Society for Reproductive Medicine (ASRM) and its affiliate, the Society for Reproductive Surgeons (SRS), have developed a Surgical Scholars Track to provide specialized reproductive

surgical training for select REI fellows who would like to develop advanced reproductive surgery skills, and this training includes endometriosis surgery. A recent survey of FMIGS fellows demonstrated that the majority of participants rated their experience as “good” or “extensive” in managing superficial and deep endometriosis [32]. However, even among FMIGS fellows, exposure to advanced surgical techniques for treating severe endometriosis and experience with addressing complex pelvic pain is heterogeneous. The same study found marked variation in feelings of satisfaction and preparedness related to training in pelvic pain [32], showing that even those who receive the most dedicated training in endometriosis and chronic pelvic pain may still feel unprepared to provide high-quality care.

Research

Lack of available knowledge is another important contributor to inadequate endometriosis treatment options and care deficits. Large studies to date have shown that no available medical or surgical treatment options are definitive [33]. Moreover, current medical therapies function by suppressing ovulation and menstruation, forcing individuals to stop treatment while trying to conceive, leading to worsening of pain and other symptoms during this time [34]. With many individuals receiving intermittent and time-limited relief from symptoms, it is imperative to search for more effective disease-focused treatments for this chronic condition.

Although funding from the National Institutes of Health (NIH) to study endometriosis has been rising steadily since 2018 [20], there remains a significant gap in research funding. Annual research dollars allocated by the NIH for endometriosis in 2022 were approximately \$27 million, which represents 15% of the research dollars allocated for inflammatory bowel disease, 7% for sexually transmitted infections, and 4% for urologic diseases [20]. Taking the population prevalence of endometriosis into account, NIH funding provides approximately \$2 per patient per year, compared to over \$130 per patient per year for Crohn's disease [17]. Notably, the NIH Office of Research on Women's Health (ORWH) emphasized endometriosis as a specific area of research and funding priority in its 2023 funding opportunity announcement (RFA-OD-23-014), which may help address this disparity moving forward.

Multiple clinical societies and international consensus groups have outlined research priorities for endometriosis on a global scale. These include noninvasive diagnostics, multi- and interdisciplinary approaches that recognize the common co-occurrence of other chronic pain conditions, and underlying epigenetics and disease biology [16,35]. We hope that as endometriosis research progresses, this will translate to improved diagnostic and treatment modalities and greater focus during medical education. We argue that equitable focus on female anatomy and physiology is critical in medical education and research spending. The

proposed ECQC model would involve disease-focused research through a national registry database and nationwide dissemination of information and education related to endometriosis, chronic pelvic pain, infertility, fertility preservation, and mental health.

Infertility Care

Given the significant overlap between endometriosis with infertility, multidisciplinary and collaborative care between surgical and fertility treatment teams is essential. Although it is established that endometrioma surgery decreases ovarian reserve, it is unclear whether the observed post-surgical changes in anti-mullerian hormone (AMH) levels are clinically significant for women attempting conception or undergoing fertility treatments [36]. Other unresolved areas relevant to the infertile patient with endometriosis include the impact of endometriosis surgery on reproductive outcomes (especially in the setting of assisted reproductive technology) and the ideal sequencing of planned endometriosis surgeries in relation to fertility treatments [1]. Lastly, it is unclear when fertility preserving techniques such as egg or embryo freezing are indicated in women with advanced disease. Currently, there are no society recommendations to guide referral for fertility preservation in the setting of endometriosis. Multi-center registry data can provide insights into these and other essential questions related to the management of endometriosis and infertility. Additionally, 19 states in the U.S. mandate insurance coverage for fertility preservation for individuals receiving cancer treatments and other medical therapies that are harmful to ovarian reserve and future fertility [37]. However, many state mandates are not applicable to patients with endometriosis, despite associations with decreased ovarian reserve and the frequent need for surgical treatment that can further harm fertility [1]. Currently, the out-of-pocket expenses for egg and/or embryo cryopreservation cycles are cost-prohibitive to many patients with endometriosis who have often faced disproportionate medical costs for years due to their disease. Moreover, their burdens are often amplified through having lower yield in the context of lower oocyte quantity and quality.

Physician Reimbursement

Inequitable reimbursement for endometriosis surgery is a meaningful contributor to decreased availability and quality of care. There are marked differences in compensation rates between gynecologic and urologic procedures such that female-specific procedures are valued lower than anatomically and technically comparable male-specific procedures [38]. This reimbursement structure perpetuates hospital- and institutional-level financial incentives to undervalue the impacts of endometriosis. In addition, poor reimbursement for gynecologic surgery drives many physicians to forego building a practice with a high volume of complex and

high-risk procedures in favor of performing obstetric services [39]. It is well-established that procedures performed by high-volume surgeons are associated with reduced intra-operative complications and perioperative morbidity compared to procedures performed by low-volume surgeons [40,41]. Furthermore, access to high-quality care is often hindered by health inequities, as underinsured patients lack access to specialized centers and experienced surgeons. This disparity exacerbates existing gaps in safety and quality for individuals undergoing gynecologic surgery.

Regarding surgical management of endometriosis specifically, the International Classification of Diseases (ICD) coding related to endometriosis was updated in 2022 after many years of extensive effort by advocates. The recently modified coding framework will allow physicians to better describe the location and severity of endometriotic lesions and thereby demonstrate the severity of advanced endometriosis. Unfortunately, there remains only one surgical Current Procedural Terminology (CPT) code to bill for endometriosis surgical care, regardless of the severity of the disease and the complexity of the surgical procedure. Although excision of endometriosis is associated with improved reductions in pain symptoms compared with ablation or fulguration of endometriotic lesions [42], there is no way to meaningfully distinguish between these techniques when billing for services. Therefore, surgeons are unable to receive appropriate compensation for the additional time, skill, and effort involved in comprehensive surgical excision of endometriosis within the current reimbursement structures. Some surgeons require patients to pay out-of-pocket for endometriosis surgery, thereby limiting access to individuals with significant financial resources. It is ethically unacceptable that current national billing structures encourage patients to seek care at costs of \$20,000 or more out-of-pocket when insurance should be responsible for these payments. Efforts by national gynecologic societies are underway to correct these billing inequities and ensure that endometriosis is adequately funded and reimbursed on a national level. The establishment of an ECQC could assist in these efforts by elevating the quality of surgical care and collecting data to allow for meaningful research and advocacy.

Vision for Endometriosis Care Quality Collaborative

Through collaboration between healthcare providers, institutions, patient representatives, and professional societies devoted to advancing evidence-based surgical gynecologic care, we can uphold our professional and ethical duty to advance knowledge and skills in comprehensive endometriosis care. The creation of an ECQC would define and elevate expert-level endometriosis care for patients worldwide and compel surgeons, providers, researchers, and educators to advance the science and clinical outcomes related to this complex condition.

We propose that the process of developing an ECQC integrates two major principles that are well-established in literature across surgical specialties: 1) high surgical volume and technical expertise are critical for achieving excellent surgical outcomes, and 2) multidisciplinary care is associated with improved outcomes for complex disease states. Data from colorectal surgery, minimally invasive gynecologic surgery, and ophthalmology show that care through high-volume surgeons result in shorter hospital stays, reduced complication rates, decreased mortality, and lower healthcare costs [41,43–45]. Procedural volume is often used as a proxy for surgical skill; however, the importance and utility of video review has become increasingly significant for understanding the technical aspects of surgery. Studies in bariatric and colorectal surgery have demonstrated that surgical skill can be measured on video review and correlated with clinical outcomes [46–48]. Video review can also provide insight into technical variation to the surgical approach and assist in identifying critical steps with the goal of providing objective data to support a standardized approach and best practices [49]. Other surgical disciplines, including colorectal surgery and gynecologic oncology have utilized modified Delphi approaches to gather consensus regarding surgical core outcomes and quality indicators [50–52]. Furthermore, multidisciplinary care teams have been called “essential” within colorectal surgery to facilitate education and patient care pathways [53]. Multidisciplinary care models support early diagnosis and treatment, advanced decision-making, team communication, increased efficiency, enhanced patient safety, and improved patient experiences [42,53,54]. Equally important is the integration of patient-reported outcomes to ensure that the patient experience and voice remains central to endometriosis care. This approach enhances a holistic, patient-centered model that aligns both clinical outcomes and patient-defined metrics of success and well-being.

With these data-driven principles in mind, we propose a multi-year effort to design and implement a national ECQC that involves:

1. Provision of high-quality care to individuals with endometriosis, with a particular focus on historically marginalized groups such as Black, Indigenous and Persons of Color, gender-diverse individuals, adolescents, and people who live in underserved areas.
2. Creation of partnerships and engagement of key stakeholders, including national societies, endometriosis foundations, and industry to align resources and ensure diverse representation.
3. Development of a robust patient registry to allow for data collection and outcomes reporting, including patients from adolescence through menopause to capture long-term effects of early treatment on prognosis and outcomes.

4. Establishment of evidence-based best practices for non-surgical and surgical endometriosis care using a Delphi approach, with specific focus on best surgical techniques, long-term surgical complications, and core outcomes for hysterectomy and uterine-preserving surgery in cases of advanced disease.
5. Establishment of evidence-based best practices for fertility-preserving and promoting endometriosis surgery, with a specific focus on reproductive outcomes and indications for referral for assisted reproductive technologies, including in vitro fertilization and egg/embryo cryopreservation in at-risk individuals.
6. Incorporation of technology platforms to map critical surgical steps, foster transparency, and aid in teaching of endometriosis surgery.
7. Expansion of continuous professional development opportunities, including surgical coaching for lifelong learning and advancement.
8. Continuous evaluation of initiatives to allow for improvement and refinement based on research and experience.

We aim to engage patient representatives, physicians, and providers across the country to refine and carry out the steps required to launch this quality collaborative, including members of the AAGL, NASPAG, the Society of Gynecologic Surgeons, the American Society for Reproductive Medicine (and its affiliate, the Society of Reproductive Surgeons), and the American College of Obstetricians and Gynecologists. We envision members of this ECQC to serve as proponents and leaders of education and legislative reform related to endometriosis care.

Once the above preliminary plans are in place, we intend to open the quality collaborative to select pilot centers within one year. This will allow for testing and modification before wider dissemination along a 5- to 7-year time frame. Subsequent publications at select time points will describe the experience of the original pilot programs, propose evidence-based changes, and share plans for wider adoption nationally.

Once established, we aim to promote an inclusive Endometriosis Care Quality Collaborative that increases surgical access and multidisciplinary care across the United States, provides guidance for metrics related to surgical and reproductive outcomes and quality of life, improves medical, surgical, and fertility-related endometriosis education, and creates a community of practice that offers surgeons opportunities for continuous improvement. We believe this ECQC can serve as a template that can be continually refined and expanded on an international scale. Only through such a concerted and collaborative effort can we achieve meaningful change for this complex patient population.

Summation

This manuscript outlines the urgent need for the establishment of multidisciplinary centers of expertise through an Endometriosis Care Quality Collaborative to improve outcomes and equity in endometriosis care across the U.S.

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