Overview

In 2019 the Society for Women's Health Research conducted a roundtable meeting to discuss the scientific state of endometriosis, highlight areas requiring improvement and enhance diagnosis and treatment through interdisciplinary approaches, education, disease management, and patient awareness.

It is estimated that 10% of women of reproductive age are affected by endometriosis, a chronic condition characterized by the growth of endometrial-like tissue outside of the uterus[1]. Symptoms may include dysmenorrhea, chronic pelvic pain, infertility, and dyspareunia. It is associated with a variety of comorbid conditions and an increased risk of developing several types of cancer. In addition to negatively impacting daily life, endometriosis carries a substantial financial burden, with average annual healthcare costs that are three times higher for women with endometriosis compared to those without.[2]

Diagnostic

Laparoscopy is the gold standard for diagnosing endometriosis, though an invasive, risky, and costly procedure.

Social barriers

The delay in diagnosis is around 7-12 years due to the stigma of menstruation, the taboo of painful sex, and the normalization of women's pain.[3] The diagnosis takes longer when prompted by pelvic pain compared to infertility. A deferred diagnosis leads to an impaired quality of life, and social costs other than physical and emotional damage.[4,5]

All together these factors act as barriers, preventing women from pursuing an early diagnosis and delaying effective treatment.

Barriers due to uncertain etiology

Endometriosis arises from a complex interplay of genetic, hormonal, and environmental factors. Symptoms in common with other disorders, and diseases coexisting with endometriosis (fibroids, adenomyosis, IBS, and others) can potentially complicate the diagnostic process.[6]

Health Care Professionals (HCPs) Barriers

It typically takes around seven visits for patients to be referred to a specialist, contributing to misdiagnosis and prolonged time to diagnosis.

Healthcare providers also face challenges and gaps in knowledge. The absence of standardized screening tools and diagnostic questionnaires along with the insufficient training of healthcare providers present considerable obstacles to diagnosing endometriosis.[7]

Diagnostic tools barriers

The current diagnostic landscape is characterized by a lack of noninvasive techniques, resulting in delays in diagnosis, especially for young women not sexually active.[8] The current approach does not take into account the inflammatory and systemic nature of the disease. Moreover, invasive approaches, such as laparoscopy, can also prevent women from participating in scientific research.

Future perspective on diagnosis

It would be beneficial to identify non-invasive diagnostic tools. Transvaginal ultrasounds and magnetic resonance imaging represent the main alternatives. The first approach showed a high specificity and sensitivity to detect ovarian endometriosis, but it is not reliable for peritoneal disease and inadequate operator training can affect accuracy and sensitivity. An additional non-invasive methodology is represented by biomarkers. The limitation lies in the endometriosis heterogeneity: the several pathways involved require a combination of multiple biomarkers. To overcome diagnostic delay and errors, it becomes necessary to collect information about symptoms, severity and associated comorbidities from a highly phenotyped population.[9,10]

Treatment

Comprehensive Approaches to Managing Endometriosis

There is no cure for endometriosis. Management strategies, including surgical options, are used to control symptoms and address infertility. The first-line treatment -low cost, well tolerated, easily accessible- includes: anti-inflammatory drugs and estrogen-progestin hormonal therapy. Second-line treatments include gonadotropin-releasing hormone agonists, antagonists, and androgenic steroids, which are more expensive and may cause side-effects, therefore representing a higher risk-benefit ratio. In terms of surgical approach, laparoscopy can be considered as a first- or second-line surgical approach, while neurectomy and hysterectomy are considered as third- or fourth-line options. It is essential to adopt a comprehensive strategy that includes non-drug therapies such as pelvic floor physiotherapy, acupuncture, and yoga. Mental health professionals can also play an important role.[11,12]

Barriers to the effectiveness of treatment

Despite treatment options, many patients with endometriosis continue to face challenges, including persistent pain, the need for further surgeries, and barriers related to healthcare access and understanding. After medical treatment, 11-19% of patients experience no improvement in pain, while 5-59% report persistent pain despite treatment. Side effects cause 5-16% of patients to discontinue treatment, often followed by a recurrence of pain once treatment is stopped. Following laparoscopy, 55% of patients require further surgical intervention within seven years, and in 20% of cases, initial surgery is unsuccessful in achieving the desired outcome. The data indicates that 7.3% of patients who had a hysterectomy with ovarian preservation required reoperation within two years, rising to 21.6% within seven years. In cases of hysterectomy with bilateral oophorectomy, the reoperation rates were 4% within two years and 8.3% by seven years. The reasons for reoperation may include incomplete excision of lesions and the coexistence of unidentified or untreated comorbid conditions. A poor understanding of endometriosis by employers can lead to an unsupportive working environment. The uneven distribution of gynecologists in the US results in some women being prevented from accessing an obstetrician-gynecologist locally. In addition, some healthcare providers recommend hysterectomy as a first- or second-line treatment for endometriosis, despite the lack of guaranteed efficacy.

Future perspective for treatments

It is essential to allocate additional funds to collect more comprehensive and reliable data and enhance knowledge in this field. Presently, approaches are centered on lesion suppression, despite the unclear relationship between lesions and symptoms. A patient-centered approach with a multidisciplinary strategy is essential to focus care on the person as a whole, rather than addressing one symptom at a time.[13,14,15]

Conclusion

Endometriosis has a significant impact on women's life, their families, and society as a whole. To address this, we need to change how we perceive and talk about female pain. We need to move away from relying on invasive, expensive diagnostic methods, replacing them with non-invasive, interdisciplinary tools that focus on improving women's quality of life. It is crucial to raise awareness, improve diagnostic accuracy, and enhance patient well-being through continued research, education, and comprehensive training for healthcare professionals. Working together it is possible to drive the change needed to improve care and outcomes for women with endometriosis.

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