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REVIEW ARTICLE

Impact of endometriosis on quality of life

Nathalia Melissa Simbaña-Cola[1], **Génesis Samantha Torres-Núñez**[1], **José David López-Núñez**[1], **Sylvia del Pilar Núñez-Arroba**[1]

[1]Autonomous Regional University of the Andes. Ambato, Ecuador.

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ABSTRACT

Introduction: endometriosis is a chronic gynecological disease affecting women of reproductive age, deteriorating multiple dimensions of their quality of life.
Objective: to analyze, through a literature review, the impact of endometriosis on women's physical, emotional, social, and functional well-being.
Methods: a systematic review of the scientific literature was conducted across multiple databases. The search employed an algorithm combining keywords and Boolean operators to identify relevant sources. Selected studies, after applying inclusion and exclusion criteria, were critically analyzed considering recency, methodological quality, and thematic relevance, and integrated into the final synthesis of the review.
Development: endometriosis is characterized by chronic pelvic pain, dysmenorrhea, dyspareunia, and infertility, with an estimated prevalence of 10–15 % among fertile women. These symptoms impair work productivity, interpersonal relationships, and mental health, increasing anxiety and depression. Diagnosis is often delayed by more than seven years, primarily due to clinical variability, with laparoscopy as the confirmatory method. Treatment combines pharmacological options (NSAIDs, hormonal contraceptives) and surgical approaches (laparoscopic resection, hysterectomy), tailored to disease severity and reproductive expectations.
Conclusions: endometriosis profoundly affects women's physical, emotional, and social health, causing significant limitations in daily and reproductive life. Early diagnosis and comprehensive management are essential to reduce suffering and improve quality of life. Strengthening research and clinical awareness is needed to optimize diagnostic and therapeutic strategies in this population.

Keywords: Quality of Life; Endometriosis; Mental Health.

INTRODUCTION

Chronic diseases currently represent a major public health challenge worldwide, negatively affecting the quality of life of hundreds of millions of people. Among the most common are cardiovascular, metabolic, respiratory diseases, and cancer. However, less prevalent conditions are also considered chronic due to their progression and duration—such as certain gynecological disorders like endometriosis, which affects women of reproductive age.(1)

Endometriosis is defined as the presence of endometrial stroma and glands outside the uterine cavity—in locations where this tissue does not normally exist. It is a chronic, inflammatory, estrogen-dependent disease that causes pelvic pain and infertility. Common sites include the ovaries, fallopian tubes, bladder, and rectum. By 2010, global prevalence among women aged 15–45 was estimated at 1,7 million; however, current prevalence has increased, though exact figures remain unknown due to ongoing research and etiological complexity.(2,3)

This disease significantly impacts the quality of life of affected women, primarily due to chronic pelvic pain—which directly interferes with social, occupational, and psychological functioning by limiting daily activities. Additionally, it affects sexual and reproductive health through dyspareunia and infertility, leading to emotional and psychological distress from uncertainty about symptom relief.(4)

The impact of endometriosis on quality of life in women of reproductive age must be studied and managed through a multidisciplinary approach, analyzing physical, social, and emotional dimensions—with emphasis on pain intensity and its direct relationship to the ability to perform daily activities.(5) Given these considerations, this study was conducted to analyze, through a literature review, the impact of endometriosis on women's physical, emotional, social, and functional well-being.

METHODS

A systematic bibliographic review was conducted following PRISMA guidelines to evaluate the impact of endometriosis on quality of life in women of reproductive age. The search period spanned from 2019 to 2024.

Databases included PubMed, SciELO, Cochrane Library, and Google Scholar, supplemented with grey literature (theses, clinical guidelines, institutional reports). Secondary references from selected articles were also reviewed. Search terms included “endometriosis,” “quality of life,” “chronic pelvic pain,” and “fertility,” combined with Boolean operators (AND, OR). Articles in Spanish, English, and Portuguese were considered.

Inclusion and exclusion criteria

Included studies were human-based, published within the defined timeframe, with full access and direct relevance to the topic. Excluded were animal studies, duplicates, methodologically weak articles, and publications outside the period. The initial search identified 50 articles; after applying exclusion criteria, 22 studies were retained for final analysis.

Data extraction and analysis

Variables extracted included author, year, study design, sample size, clinical manifestations, and quality-of-life impacts. A qualitative synthesis was performed, and findings were integrated into comparative tables.

DEVELOPMENT

Endometriosis is a chronic, inflammatory, estrogen-dependent gynecological condition in which functional endometrial glands and stroma proliferate outside the uterine cavity. This ectopic tissue induces bleeding, fibrosis, and endometrial nodules.(6) It is defined as the presence of endometrium-like tissue outside the uterine cavity—in organs and structures where endometrial glands or stroma are not normally found. As a chronic, estrogen-dependent disease, it remains active and may worsen during a woman's reproductive years. Implants most commonly occur in the ovaries—the most frequent site—as well as the pelvic peritoneum, pouch of Douglas, uterosacral ligaments, and rectovaginal septum. In approximately 8–12 % of cases, extra-genital involvement occurs in the gastrointestinal tract, urinary system, liver, pancreas, spleen, lungs, extremities, skin, and nervous system.(7)

Globally, endometriosis affects 10–15 % of reproductive-age women, with peak incidence between 25–35 years—though it also affects younger and postmenopausal women. Risk increases in nulliparous women with early menarche, late menopause, dysmenorrhea, and high alcohol consumption.(8,9)

The exact cause remains unknown but likely involves multiple factors. Leading theories include retrograde menstruation (menstrual flow entering the pelvic cavity), vascular dissemination, coelomic metaplasia (transformation of pelvic cells into endometrial-like cells), and genetic predisposition. Immune and hormonal dysregulation are also under investigation. Recent research suggests environmental factors—such as exposure to dioxins and other endocrine-disrupting compounds—may play a significant role.(10)

The primary symptom is pelvic pain, often linked to menstrual cycles. While many women experience menstrual cramps, those with endometriosis report significantly more intense pain, which may worsen over time—even in girls under 17.(11)

Symptoms include chronic pelvic pain (cyclic and non-cyclic), painful periods (dysmenorrhea), painful intercourse (dyspareunia), painful defecation (dyschezia), and painful urination (dysuria). Symptom severity ranges from mild to debilitating. Some women are asymptomatic, while others experience sporadic or constant pain in multiple body areas. Notably, some progress from episodic, localized pain to complex, chronic pain that is harder to treat. Women with severe anatomical disease may have minimal symptoms, while those with minimal disease may suffer severe, life-disrupting symptoms.(11)

As with other chronic pain conditions, women with endometriosis commonly experience fatigue and depression. Infertility risk is doubled compared to unaffected women. Endometriosis is diagnosed in 30–50 % of women seeking assisted reproductive treatment.(12) It is also associated with infertility and subfertility in 20–50 % of affected patients. Deep infiltrating endometriosis—extending below the peritoneal surface—is the most severe form.(13)

Patients with endometriosis have increased risk of other chronic pain disorders—fibromyalgia, migraines, rheumatoid arthritis, psoriatic arthritis, and osteoarthritis. Back, bladder, and intestinal pain are common. They also face higher risks of benign gynecological conditions (uterine fibroids, adenomyosis), subsequent malignancies, autoimmune diseases, premature natural menopause, and cerebrovascular and cardiovascular conditions.(14)

Diagnosis is confirmed via laparoscopy—the first-choice method—which allows evaluation of retroperitoneal structures and visualization of organ-involving lesions. Affected tissues are excised, and biopsy samples are taken for histological analysis. Visual identification by a technician has limited value, with sensitivity averaging 95 % and specificity ranging from 77 % to 85 %.(12)

Classic endometriosis lesions appear as red-burn-like spots, often with additional anatomical distortions, whitish opacities, yellow-brown discoloration, and blue-brown lesions. Plaques and nodules may also be present.(15) Diagnosis is often delayed because women do not recognize or take their symptoms seriously—leading to misdiagnoses and empirical treatments that temporarily alleviate symptoms.(16)

On average, diagnosis is delayed by 7,5 years from symptom onset to definitive identification. Staging by the American Society for Reproductive Medicine classifies disease severity as follows:(9,12)

- Stage I (Minimal): Isolated superficial implants without significant adhesions.
- Stage II (Mild): Superficial implants <5 cm scattered on peritoneum and ovaries, without significant adhesions.
- Stage III (Moderate): Ovarian endometrioma alone or with multiple superficial/deep implants and dense peritubal/periovarian adhesions.
- Stage IV (Severe): Multiple superficial and deep implants, large ovarian endometrioma, and dense adhesions partially or fully obstructing the pelvis.

Management must be individualized based on disease extent, location, symptom severity, clinical history, reproductive status, and treatment side effects. It is approached as a chronic condition requiring personalized care.(17)

Pharmacological treatment

The primary goal is pain control and reduced need for surgery. Options include:(18–20)

- Nonsteroidal anti-inflammatory drugs (NSAIDs): First-line for mild-to-moderate pain without endometrioma. Well-tolerated and effective, though COX-2 inhibitors are avoided in women seeking pregnancy due to ovulation interference.
- Combined hormonal contraceptives: Effective for endometriosis-related pain and suitable for long-term use. They suppress ovarian function, reduce ectopic endometrial activity, and lower endometrial and ovarian cancer risk.
- Progestins: Indicated for women who cannot use estrogens. They inhibit metalloproteinases and angiogenesis—critical for ectopic endometrial growth.
- GnRH agonists: Used in severe, refractory cases. They induce hypoestrogenism by blocking gonadotropin secretion, causing menopausal-like side effects mitigated with norethindrone acetate add-back therapy.
- Aromatase inhibitors: For persistent symptoms despite GnRH agonist therapy. Anastrozole suppresses local estrogen production in endometriotic lesions.
- Danazol: Rarely used due to side effects. It inhibits steroidogenesis and may relieve symptoms in rectovaginal endometriosis.

Surgical treatment

Surgery is an option for medically refractory cases. Laparoscopy is preferred, ranging from conservative lesion resection to hysterectomy and visible implant removal.(18)
- Conservative surgery: Ablation or resection of lesions.
- Definitive surgery: Hysterectomy with or without oophorectomy.
- Radical surgery: Removal of all visible implants.

Surgery provides histological diagnosis and pain relief by eliminating ectopic implants. However, it carries risks—including organ damage, reduced ovarian reserve, and postoperative complications. Postoperative hormonal suppression with continuous oral contraceptives is recommended to prevent symptom recurrence.(21)

Impact on quality of life

Endometriosis significantly impairs women's health—particularly mental well-being—affecting all life domains. Symptoms and treatment side effects diminish quality of life. Although global data are limited, the Global Study of Women's Health (GSWH, 2008–2010) showed pelvic pain and disease severity are primary drivers of reduced work productivity. Women with chronic pelvic pain and dyspareunia report higher anxiety and depression levels, further diminishing quality of life.(22)

Healthcare professionals focus on preserving quality of life through prevention and treatment. Patients require ongoing assessment of functional status and well-being. Validated tools evaluate anxiety and depression, enabling measurement of disease impact and treatment response. Primary care should prioritize early diagnosis to reduce suffering and improve work productivity. Endometriosis negatively affects intimate and sexual relationships—dyspareunia being a key factor. Pain, sexual dysfunction, comorbidities, and frequent medical visits/surgeries influence health perception.(23)

Each woman experiences endometriosis uniquely, influenced by disease severity, diagnostic delay, treatment type, and available support. Most affected areas include work, career development, finances, leisure, partnerships, motherhood, and sexuality.(24) Dyspareunia impacts sexual life and self-esteem, sometimes straining relationships. Fertility challenges introduce uncertainty filled with physical, mental, and emotional stress—for both the woman and her partner.

In summary, endometriosis profoundly affects women's quality of life, interfering with social, emotional, and spiritual functioning. Factors like income, education, pain impact on work/study, and partnership correlate with better quality of life. Chronic pelvic pain can disrupt all aspects of sexual function—from desire to satisfaction—replacing desire with fear and avoidance.(25)

Finally, endometriosis may impair ovarian reserve and ovulation, contributing to infertility. The World Health Organization (WHO) reports tubal factors (including endometriosis) and ovulatory disorders as leading causes of infertility. Overall, endometriosis negatively affects multiple life domains—some difficult to identify due to their intimate nature.(26)

Endometriosis is a complex gynecological disease significantly affecting many women, characterized by endometrial tissue outside the uterine cavity. It causes chronic pelvic pain and multiple complications that deteriorate quality of life. Pain—often severe and debilitating—disrupts daily life and relationships. Infertility adds considerable emotional burden. Symptom variability complicates early diagnosis, which is frequently delayed.(27)

Treatment must be personalized based on disease characteristics and individual patient needs. Medical therapies—NSAIDs and hormonal contraceptives—effectively control pain and suppress endometrial activity. However, treatment selection requires comprehensive symptom assessment and individual response evaluation. Surgical interventions—from lesion resection to hysterectomy—can provide durable pain relief and precise diagnosis but carry risks of postoperative complications and potential ovarian reserve reduction.(18,20)

Endometriosis broadly impacts quality of life across multiple domains. Beyond physical pain, many women experience anxiety and depression, affecting work performance and personal relationships. Infertility—present in a significant proportion—adds further stress. Thus, management must address not only physical symptoms but also provide emotional support to improve overall quality of life.(28)

Diagnosis is often slow, with delays exceeding 7 years from symptom onset. This stems from low awareness and clinical variability. Laparoscopy remains the diagnostic gold standard, though visual examination sensitivity is limited. Improving education and awareness is crucial for earlier diagnosis, reduced suffering, and better long-term outcomes.(29,30)

CONCLUSIONS

Endometriosis significantly affects the quality of life of women of reproductive age, impacting their physical, emotional, social, and functional well-being. Diagnostic delays—due to symptom variability and complexity—not only postpone treatment but also amplify patient difficulties. Management must be highly individualized, addressing both physical and psychological aspects of the disease. Treatment options range from medical therapies for pain control to surgical interventions offering more durable relief—albeit with certain risks. It is essential that healthcare professionals adopt a comprehensive approach that considers not only disease extent but also the overall impact on the patient's life.

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