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Endometriosis as a Chronic Disease - Impact on Patients Quality of Life

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ABSTRACT

Endometriosis is a chronic gynecological condition marked by the presence of endometrial-like cells outside the uterine cavity, most commonly affecting the ovaries, fallopian tubes, and peritoneum. Despite an estimated prevalence of 10% among women of reproductive age, the condition is often underdiagnosed and underrecognized. Many women endure years of symptoms before receiving an accurate diagnosis, resulting in prolonged physical suffering and significant disruption to daily life. Common symptoms include severe menstrual pain, dyspareunia, chronic pelvic pain, fatigue, and infertility. Due to their cyclical and persistent nature, these symptoms negatively affect women's physical and mental health, social functioning, relationships, and professional life. As there is no definitive cure and symptoms often recur, endometriosis is classified as a chronic illness requiring a comprehensive care approach. This paper explores the multifaceted impact of endometriosis on quality of life and examines key assessment tools such as SF-36, WHOQOL-BREF, and EHP-30. It also includes an overview of current treatment strategies - both pharmacological and surgical - as well as supportive and non-pharmacological approaches. The need for an individualized and multidisciplinary model of care is emphasized to improve outcomes and support the overall well-being of affected women.

Keywords: endometriosis, chronic disease, quality of life, women's health, pelvic pain, fertility, social functioning, treatment, multidisciplinary care.

INTRODUCTION

Endometriosis is a chronic gynecological condition characterized by the presence of endometrial-like cells outside the uterine cavity, commonly affecting the ovaries, fallopian tubes, and peritoneum. Although its prevalence is estimated at around 10% among women of reproductive age, the condition remains frequently underrecognized in both healthcare systems and public discourse [1]. Many women endure years of painful symptoms before receiving an accurate diagnosis, which not only results in prolonged physical suffering but also significantly disrupts various aspects of daily life and overall functioning.

Common symptoms of endometriosis include severe menstrual pain, pain during intercourse, chronic pelvic pain, fatigue, and fertility issues [2]. The persistent and cyclical nature of these symptoms can significantly reduce overall well-being, limiting both social interactions and professional engagement. Due to the challenges in diagnosis, the tendency for recurrence, and the absence of a definitive cure, endometriosis is classified as a chronic condition.

As a result, treatment should not focus solely on medical interventions, but also embrace a comprehensive, holistic approach that addresses the quality of life for women living with this disease.

The concept of quality of life refers to an individual's overall well-being—encompassing physical, mental, and social dimensions. In the context of chronic illnesses, this notion is particularly significant, as it captures how the disease affects daily life beyond what clinical indicators alone can show [3]. When it comes to endometriosis, research shows that the condition has a substantial negative impact on women's quality of life—not only due to physical symptoms, but also because of persistent stress, emotional frustration, diminished self-esteem, and difficulties in interpersonal relationships [4].

The aim of this paper is to present endometriosis as a chronic condition and explore how it affects various aspects of women's lives—including physical health, psychological well-being, social relationships, sexuality, and professional activity. It will also examine the available tools for assessing quality of life, as well as the need for multidisciplinary care approaches that go beyond symptom management to support patients' overall functioning and well-being.

CHARACTERISTICS OF ENDOMETRIOSIS

Endometriosis is a chronic estrogen-dependent gynecological disorder characterized by the presence of endometrium-like cells outside the uterine cavity. These lesions are most commonly found on the ovaries, peritoneum, uterosacral ligaments, intestines, or bladder [1]. The condition typically presents in three main forms: peritoneal endometriosis, ovarian (endometriotic cysts), and deep infiltrating endometriosis (DIE) [5]. One of the most widely used classification systems is that of the American Society for Reproductive Medicine (ASRM), which categorizes endometriosis into four stages—from minimal (Stage I) to severe (Stage IV) based on lesion size and the presence of adhesions [6]. However, due to its limitations in reflecting the actual impact of the disease on patients' daily lives, alternative classification

systems have been developed, including the ENZIAN system and the Endometriosis Fertility Index (EFI).

The symptoms of endometriosis are highly variable and do not always correspond to the extent of the lesions. Common complaints include chronic pelvic pain, dysmenorrhea (painful menstruation), dyspareunia (pain during intercourse), and infertility, which affects approximately up to 50% of individuals with the condition [7]. However, the disease can also present with mild or no symptoms at all, which significantly complicates timely diagnosis.

The exact pathogenesis of endometriosis remains unclear, although several key hypotheses have been proposed to explain its development. One of the earliest and most widely accepted is the retrograde menstruation theory, which suggests that endometrial fragments flow backward through the fallopian tubes into the peritoneal cavity, where they implant and proliferate [8]. The metaplastic theory proposes that mesothelial cells can transform into endometrial-like cells under the influence of hormonal and inflammatory stimuli [9]. Another explanation is the genetic hypothesis, based on familial clustering of cases, which points to a possible hereditary component [10]. The immunological theory suggests that dysfunctions in the immune system may impair the clearance of ectopic endometrial cells, allowing them to persist and grow outside the uterus [11]. Currently, it is widely accepted that endometriosis is a multifactorial condition, involving complex interactions between genetic, hormonal, environmental, and immune-related factors.

The diagnostic process for endometriosis is often complex and prolonged, with an average delay of 7 to 10 years from the onset of symptoms to a confirmed diagnosis [12].

Initial assessment typically includes a detailed clinical history, pelvic examination, and imaging studies such as transvaginal ultrasound or magnetic resonance imaging (MRI).

However, the gold standard for definitive diagnosis remains diagnostic laparoscopy, which allows for direct visualization of lesions and biopsy for histopathological confirmation [13].

The treatment of endometriosis is tailored to each patient, taking into account factors such as age, symptom severity, lesion location, and reproductive plans. Pharmacological therapy primarily involves hormonal treatments aimed at suppressing the menstrual cycle, reducing lesion activity, and alleviating symptoms. Common options include oral contraceptives, gonadotropin-releasing hormone (GnRH) analogs, and progestins. Surgical intervention, typically performed via laparoscopy, focuses on the removal of endometriotic lesions, cysts, and adhesions. Additionally, non-pharmacological approaches are increasingly used as

supportive therapies. These include dietary modifications, pelvic physiotherapy, and psychotherapy, all of which contribute to pain management and improved quality of life [14].

Endometriosis is a chronic and often recurrent condition, which presents one of the greatest therapeutic challenges. Even after successful surgical treatment, symptoms may recur, with the risk of recurrence within five years ranging from 20% to 40% [15]. Recurrent pain, the need for prolonged treatment, and the impact of the disease on various aspects of life make endometriosis not only a medical issue but also a social and psychological problem.

ENDOMETRIOSIS AS A CHRONIC DISEASE

According to the World Health Organization (WHO), a chronic disease is characterized by a long duration and typically slow progression, often requiring continuous treatment, monitoring, and lifestyle adjustments by the patient. Common features of chronic diseases include incurability, recurrence, therapeutic challenges, and a significant impact on various aspects of daily life, including social, professional, and psychological functioning [3].

In the context of this definition, endometriosis meets all the criteria of a chronic condition. Despite the available pharmacological and surgical treatments, there is currently no therapy that leads to a complete cure of the disease. The treatment primarily aims to alleviate symptoms, limit progression, and improve the quality of life for patients. In many cases, symptoms recur after hormonal therapy or surgery, necessitating continuous monitoring and often requiring modifications to the therapeutic strategy [2].

Endometriosis affects not only physical health but also mental and emotional well-being. Chronic pain, limitations in physical activity, sexual difficulties, and fertility issues contribute to mood disturbances, anxiety, and even depression. The condition also makes it difficult to carry out daily tasks, negatively impacts interpersonal relationships, and decreases professional productivity, significantly reducing overall quality of life [12].

Due to the complex and multidimensional nature of endometriosis, a multidisciplinary approach to treatment is recommended. Effective management of the disease should include not only gynecological care but also support from other specialists. A psychologist can help patients cope with chronic pain, stress, and emotional disturbances. A dietitian can provide personalized dietary therapy to assist in managing chronic inflammation and alleviating gastrointestinal symptoms. Additionally, a urogynecological physiotherapist can support pelvic pain therapy and improve comfort in daily life [14].

Perceiving endometriosis as a chronic disease is essential for understanding the needs of patients and implementing appropriate therapeutic strategies. This enables a holistic approach to treatment, aimed not only at symptom control but also at improving the overall quality of life and functioning of women affected by this condition.

QUALITY OF LIFE - CONCEPT AND MEASUREMENT

Quality of Life (QoL) is a complex and multidimensional concept that encompasses the evaluation of an individual's physical, mental, social, and functional well-being. According to the World Health Organization (WHO) definition, quality of life is "an individual's perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns" [3]. WHO also developed a dedicated tool for measuring quality of life—the WHOQOL-BREF questionnaire, which allows for the assessment of four key domains: physical health, psychological health, social relationships, and the environment [3].

Another commonly used tool is the SF-36 (Short Form Health Survey), which assesses eight domains of functioning, including physical and emotional limitations, pain, general health, vitality, social functioning, mental health, and health perception [16]. Both of these tools have been adapted for studies on the quality of life in women suffering from endometriosis.

In the context of this disease, assessing quality of life becomes particularly important, as its symptoms – such as chronic pain, painful menstruation, dyspareunia, and fertility issues – negatively impact various aspects of daily functioning. The literature identifies five key dimensions of quality of life affected in women with endometriosis: physical, psychological, social, sexual, and professional [4]. Chronic pain and physical limitations affect daily activity and physical well-being. The psychological sphere suffers from frustration, anxiety, and a lowered mood related to the disease. Social functioning may be disrupted by isolation and limitations in relationships and social activities. Issues in intimate relationships, especially painful intercourse (dyspareunia), lower the quality of sexual life. Meanwhile, chronic absenteeism from work and decreased productivity affect professional functioning [12].

In addition to general tools like SF-36 or WHOQOL-BREF, a specialized instrument specifically designed to assess quality of life in women with endometriosis has been developed – the Endometriosis Health Profile-30 (EHP-30). This is a comprehensive questionnaire that takes into account both physical symptoms and the impact of the disease on emotions, interpersonal relationships, sexual relations, work, and social interactions [17]. Due to its

specificity, EHP-30 is currently considered one of the most accurate and sensitive tools for assessing quality of life in this patient group.

Considering a multidimensional assessment of quality of life is crucial not only for diagnosing and monitoring the effectiveness of endometriosis treatment but also for planning individualized and holistic care for the patient.

THE IMPACT OF ENDOMETRIOSIS ON PATIENTS LIVES

Physical Aspect

Endometriosis is a condition where the most common and severe symptom is chronic pain. Menstrual pain (dysmenorrhea) often reaches a level that impairs daily functioning, and some women also experience ovulation-related pain, resulting in almost continuous symptoms throughout the month [7]. Additionally, many patients suffer from pain during urination (dysuria) and defecation (dyschezia), particularly when endometrial lesions affect the bladder and intestines [5]. These symptoms not only cause physical suffering but also significantly limit mobility and physical activity. Endometriosis is also associated with chronic fatigue that persists even after rest. Studies show that fatigue may be a consequence of chronic inflammation and sleepless nights due to pain [4]. Sleep disturbances, frequently reported by patients, further contribute to decreased physical performance and exacerbate depressive symptoms. The mobility limitations caused by pain and weakness hinder participation in sports and the ability to carry out basic daily activities.

Psychological Aspect

The chronic nature of the disease, recurring symptoms, difficulties with conception, and the absence of a definitive cure significantly impact the mental health of women with endometriosis. Many patients experience an increased risk of anxiety disorders, depression, and a general lowering of mood [12]. Due to a lack of understanding from their surroundings and the trivialization of their symptoms by healthcare professionals, women often feel isolated and alone. Untreated chronic pain can lead to emotional burnout and a decreased ability to cope with stress. Patients frequently describe feelings of injustice and frustration related to prolonged diagnosis and the need for long-term therapy with no guarantee of success [14]. All these factors can contribute to reduced self-esteem, lack of motivation, and difficulty in making everyday decisions.

Social Aspect

Endometriosis also significantly affects the social functioning of patients. Due to frequent pain symptoms, women often limit their participation in social and family life, leading to social isolation and deterioration of interpersonal relationships [4]. Sometimes, they have to cancel plans, meetings, or activities, which can be misunderstood by their surroundings and may lead to conflicts. Partner relationships can also be problematic. The constant presence of symptoms and the frustration associated with a lack of improvement often impact the quality of the relationship, communication within the partnership, and the sense of togetherness. Partners do not always understand the nature of the disease and its impact on daily life, which can deepen emotional distance.

Sexual Aspect

One of the more common symptoms of endometriosis is dyspareunia, or pain during sexual intercourse. This symptom is particularly prevalent during deep penetration and is associated with the location of endometrial lesions in the rectovaginal septum or uterosacral ligaments [15]. The pain leads to the avoidance of sexual activity, which, in turn, negatively impacts intimate relationships and the sense of closeness within the partnership. Furthermore, chronic stress, fear of pain, and low self-esteem related to somatic symptoms result in a decrease in libido. Sexual dysfunction can intensify tensions between partners, leading to frustration, conflicts, and even the breakdown of the relationship.

Professional Aspect

Endometriosis also significantly affects the professional life of women. Key limiting factors include workplace absences caused by pain, hospitalizations, and the need for frequent medical consultations. Patients often experience decreased productivity, difficulty concentrating, and reduced efficiency [12]. A lack of understanding from employers and colleagues leads to frustration and guilt among women who cannot fulfill their professional duties to the same extent as healthy individuals. In some cases, this results in difficulties maintaining employment or a shift to a less physically demanding career path. Endometriosis, in each of the mentioned aspects, causes a substantial decline in the quality of life for patients. Its comprehensive impact on health and functioning requires an integrated therapeutic approach, considering not only the treatment of physical symptoms but also psychological, social, and professional support.

TREATMENT OF ENDOMETRIOSIS

The treatment of endometriosis poses a challenge due to the chronic nature of the disease, the variety of symptoms, and the individual needs of patients. The choice of therapeutic strategy depends on several factors, such as age, the severity of pain symptoms, the desire for pregnancy, the location of endometrial lesions, and the response to previous treatments.

Pharmacological Treatment

The foundation of pharmacotherapy involves medications aimed at inhibiting the menstrual cycle, which reduces the stimulation of ectopic endometrium. The most commonly used treatments include combined oral contraceptives, progestins (e.g., dienogest), gonadotropin-releasing hormone (GnRH) analogs, and aromatase inhibitors [7,13]. These medications help reduce pain symptoms but do not lead to a complete cure of the disease, and symptoms often return after discontinuation [1].

GnRH analogs, although effective in suppressing ovarian activity and reducing lesion size, can cause menopausal-like symptoms. Therefore, their long-term use requires add-back therapy, designed to protect bone health and improve overall quality of life [14]. New pharmacological approaches include selective progesterone receptor modulators (SPRMs) and kinase inhibitors, though these are still in the research phase [22].

Surgical Treatment

The goal of surgery is to remove endometrial lesions, ovarian cysts, and adhesions, which can provide pain relief and improve fertility [5]. The most commonly used surgical method is laparoscopy, which allows for precise removal of lesions with minimal invasiveness [15]. In cases of deep infiltrating endometriosis, more advanced surgical treatment may be required, involving a multidisciplinary team [2]. Despite its effectiveness, surgical treatment carries the risk of disease recurrence – it is estimated that 20-40% of patients experience a return of symptoms within five years.

Supportive and Non-Pharmacological Treatment

Increasing importance is being placed on supportive treatment, which includes lifestyle modifications, dietary therapy, pain management, and psychological support. Regular physical activity, an anti-inflammatory diet, and relaxation techniques can help alleviate symptoms and improve quality of life [21]. Methods such as urogynecological physiotherapy, acupuncture, and yoga are also gaining popularity as part of comprehensive care.

Additionally, educating patients and enabling them to actively participate in therapeutic decision-making positively influences treatment effectiveness and their satisfaction [3].

Treatment and Fertility

For women planning to conceive, the treatment of endometriosis focuses on improving fertility. Early stages of the disease can be treated surgically, which increases the chances of spontaneous conception. In more advanced cases, assisted reproductive techniques such as intrauterine insemination (IUI) or in vitro fertilization (IVF) are used [7].

REVIEW OF SCIENTIFIC RESEARCH RESULTS

Recent scientific research has clearly shown that endometriosis significantly reduces the quality of life of patients, regardless of their age, the location of lesions, or the stage of disease progression. To assess the quality of life of women with endometriosis, standardized tools are most commonly used, such as SF-36 (Short Form-36), WHOQOL-BREF (World Health Organization Quality of Life - BREF), and EHP-30 (Endometriosis Health Profile-30) [18,19].

A multicenter study conducted by Nnoaham and colleagues in 2011 using the SF-36 questionnaire showed that patients with endometriosis scored significantly lower across all dimensions of quality of life, especially in the areas of physical health, vitality, mental health, and social functioning [12]. Pain symptoms, particularly their chronic nature, had a particularly strong impact. The more intense the pain—whether menstrual, ovulatory, or related to urination and defecation—the more significantly the perceived quality of life was reduced [4]. This relationship was also confirmed in studies using the EHP-30, which provides a detailed assessment of how the disease affects daily functioning, social relationships, emotional health, and professional activity [20].

Analyses using the WHOQOL-BREF tool have shown that women with endometriosis experience significant reductions in quality of life in the areas of physical and mental well-being, as well as social relationships [21]. Endometriosis often leads to chronic stress, depression, and anxiety disorders, which further exacerbate the negative feelings associated with the disease. A 2019 study by Armour and colleagues highlighted a significant correlation between the intensity of pain symptoms and the severity of depressive and anxiety symptoms, emphasizing the need for a holistic approach to treatment [14].

Moreover, it has been shown that patients with more severe forms of the disease (e.g., deep infiltrating endometriosis) report greater limitations in their professional, sexual, and social lives, as reflected in the results of tools such as the EHP-30 and SF-36 [22]. This indicates a direct correlation between the extent of symptoms and the degree of deterioration in quality of life.

In conclusion, the review of the scientific literature clearly shows that endometriosis significantly affects all key dimensions of women's quality of life. The severity of symptoms correlates with a decline in physical, mental, and social functioning, and the multidimensional impact of the disease underscores the necessity for an individualized and interdisciplinary therapeutic approach.

SUMMARY

Endometriosis, being a complex, chronic disease that is still often underestimated by both society and the healthcare system, requires a comprehensive diagnostic and therapeutic approach. Despite its relatively high prevalence, many women struggle with undiagnosed symptoms for years, which not only prolongs their physical suffering but also leads to serious psychological and social consequences. Delayed diagnosis and lack of proper psychological support can result in a diminished quality of life, feelings of isolation, frustration, and the deepening of anxiety and depressive symptoms. Therefore, it is crucial not only to shorten the time to diagnosis but also to implement continuous, empathetic psychological care.

The implementation of an interdisciplinary treatment model is also of fundamental importance, which involves cooperation between gynecologists, psychologists, physiotherapists, dietitians, and sexologists. Only such an approach can bring about a real improvement in the functioning of women affected by endometriosis. Equally important is widespread social education – both among potential patients and medical personnel – to increase awareness of the symptoms,

progression, and consequences of the disease. This education can also help reduce stigmatization and contribute to earlier diagnostic and therapeutic interventions.

It is also important to emphasize the necessity of individualizing therapy – both pharmacological, surgical, and psychophysical. Every patient experiences the disease in a unique way, so it is essential to consider her needs, preferences, and lifestyle when choosing therapeutic methods. Such an individualized approach not only helps alleviate symptoms more effectively but also has a real impact on improving the quality of life and mental well-being of women suffering from endometriosis.

Disclosure

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