

# Endometriosis – an enemy of quality of life

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## Abstract

Endometriosis is a chronic disease, very common among women of reproductive age, characterized by the presence of active endometrial tissue outside the uterine cavity. The patients with severe endometriosis have a complex of different symptoms, including painful menstruation, non-menstrual pelvic pain, dyspareunia and painful defecation. These symptoms cause profound distress and a significant reduction in their quality of life. The concept of quality of life is one of the most important directions in contemporary medicine. The interest shown in the medical world in quality-of-life issues for patients is demonstrated by the number of articles on quality-of-life issues published in prestigious journals and submitted to the PubMed database. Quality of life is represented by social, physical and mental well-being as well as by people's ability to carry out everyday activities. Completion of endometriosis symptom assessment questionnaires before surgery and at one year postoperatively may be useful to predict the degree of change in patients' perceived quality of life after endometriosis surgery.

**Keywords:** endometriosis, quality of life, assessment

## Rezumat

Endometrioza este o afecțiune cronică, foarte frecventă în rândul femeilor de vârstă reproductivă, caracterizată prin prezența țesutului endometrial activ în afara cavității uterine. Pacientele cu endometrioza severă prezintă un complex de simptome diferite, inclusiv menstruații dureroase, dureri pelviene nonmenstruale, dispareunie și scaune dureroase. Aceste simptome cauzează o suferință profundă și o reducere semnificativă a calității vieții. Conceptul de calitate a vieții reprezintă una dintre cele mai importante direcții în medicina contemporană. Interesul manifestat de lumea medicală față de aspectele legate de calitatea vieții pacienților este demonstrat de un număr impresionant de articole referitoare la această temă, publicate în reviste și introduse în baza de date PubMed. Calitatea vieții este reprezentată de bunăstarea socială, fizică și mentală, precum și de capacitatea oamenilor de a-și desfășura activitățile zilnice. Completarea chestionarelor de evaluare a simptomelor de endometrioza înainte de operație și la un an postoperatoriu poate fi utilă pentru a prezice gradul de schimbare a percepției calității vieții pacienților după intervenția chirurgicală pentru endometrioza.

**Cuvinte-cheie:** endometrioza, calitatea vieții, evaluare

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## Introduction

Endometriosis is defined by the presence of active endometrial tissue (endometrial glands and stroma) outside the uterine cavity. Adenomyosis is defined by the presence of active endometrial tissue in the myometrium.

Endometriosis is one of the most common benign gynecological pathologies, affecting approximately 6-15% of women of reproductive age<sup>(1)</sup> and its symptoms affect the quality of life. It is one of the main causes of female infertility<sup>(2)</sup>.

Endometriosis is an inexhaustible source of content for writing articles, book chapters and even entire treatises, because it is a vast field that seriously impacts the patient's quality of life.

## Etiology and pathogenesis

Endometriosis is known to be an estrogen-dependent condition, but the etiology and the etiopathogenic mechanisms are not fully understood<sup>(3)</sup>.

Several theories have been put forward which can be grouped into two broad categories: those that suggest that implants originate from the uterine endometrium

and those that consider that implants develop from tissues other than the uterine cavity<sup>(4)</sup>.

The theory of metaplasia of the coelomic epithelium is one of the theories supporting the non-uterine origin of the disease. This theory holds that normal parietal peritoneal tissue has the ability to transform into ectopic endometrial tissue. According to this theory, the parietal peritoneum is a pluripotent tissue that through metaplastic transformation becomes a tissue histologically indistinguishable from normal endometrium<sup>(5)</sup>. Inductive agents responsible for this transformation have not been identified, although endocrine disrupting chemicals (EDCs) could be candidates<sup>(4)</sup>.

The induction theory is a related theory based on the previously mentioned theory. According to this, there are endogenous inductive stimuli (hormonal or immunological factors). This theory holds that in peritoneum there are undifferentiated stem cells that under the influence of endogenous stimuli transform into endometrial cells<sup>(5)</sup>.

In recent years, another theory has emerged which supports the extrauterine origin of endometriosis. Thus, there are progenitor cells in the bone marrow that have

the ability to differentiate into endometriotic tissue. These cells include bone marrow mesenchymal stem progenitors and endothelial progenitors. This is a vast area of research and is currently being highlighted<sup>(4)</sup>.

The Halban theory states that ectopic endometriotic implants are the result of benign metastasis due to lymphatic or hematogenous dissemination of endometrial cells<sup>(6)</sup>. Microvascular studies have demonstrated lymph drainage from the uterus to the ovaries, making it plausible that the lymphatic system is involved in the etiopathogenesis of ovarian endometriosis<sup>(4)</sup>. The most important evidence in favor of the benign metastasis theory is the presence of histologically confirmed endometriotic lesions located distant from the uterus, for instance in the bones, lungs or brain<sup>(6)</sup>.

The most popular theory is that of retrograde menstruation. Described by Sampson in 1921, the theory of retrograde menstruation is attractive and supported by multiple scientific evidence<sup>(7)</sup>. According to this theory, a retrograde flow occurs during menstruation in which fragments of endometrial tissue spill into the peritoneal cavity through the fallopian tubes. These fragments of ectopic endometrial tissue implant in sloping areas and, under hormonal stimulation, develop in a similar way to the endometrium.

## Clinical manifestations

Endometriosis may be asymptomatic or may be associated with pain and/or infertility<sup>(8)</sup>.

Cyclic bleeding from endometriotic implants causes inflammation with scar tissue formation and adhesions that generate disabling symptoms such as pain in various forms, infertility, metrorrhagia and fatigue<sup>(9)</sup>. A variety of painful symptoms are associated with endometriosis, namely dysmenorrhea, dyspareunia, dysuria, dyschezia and chronic pelvic pain. However, a clear characterization of the typology and topology of pain in endometriosis is lacking<sup>(10)</sup>.

Recent clinical studies have correlated dyspareunia with posterior fundus and uterosacral ligament lesions, dysmenorrhea with ovarian or peritoneal lesions, dysuria with bladder or peritoneal lesions, and dyschezia with deeply infiltrative lesions of the vagina<sup>(11)</sup>. In addition, the depth of lesions has been correlated with the presence of chronic pelvic pain, but not with cyclic pain<sup>(12)</sup>.

Menstrual cycle disturbances in the form of spotting and/or menometrorrhagia may be present<sup>(7)</sup>.

Rectal mucosal involvement may result in rectorrhagia, and the presence of bladder lesions may be accompanied by hematuria.

## Quality of life (QOL)

Endometriosis is a benign condition but, due to its impact on quality of life, it behaves like a malignant condition.

Due to chronic disabling pelvic pain, endometriosis negatively affects the quality of life by impairing the daily life of patients who are prevented from participating in daily and social activities, their physical and

sexual functioning, intimate and peer relationships, work productivity, mental and emotional health and well-being being affected.

The aim of endometriosis surgery is to improve the quality of life. However, because deeply infiltrative endometriosis requires extensive, sometimes debilitating surgery with organ resection, and having a risk of postoperative complications, patients sometimes need months of recovery time, and this worsens the patient's already weak psychological status.

The concept of quality of life is one of the most important directions in contemporary medicine. The interest shown in the medical world in quality-of-life issues for patients is demonstrated by the number of articles on quality-of-life issues published in prestigious journals and submitted to the PubMed database. At present, when discussing quality of life in endometriosis, we have to take into account a cross-sectional analysis of methods of diagnosis, treatment and prophylaxis. Quality of life assessment is a valuable, informative, economical and efficient method of assessing a patient's condition, sometimes the only criterion by which the effectiveness of a new treatment method can be evaluated. It has been shown that the patient's subjective opinion is as valuable as the results of instrumental and laboratory research.

Quality of life is an integral indicator that includes physical, psychological, emotional and social characteristics of the patient, based on subjective perception, which reflects the human capacity for adaptation towards his disease and allows to perform deep multilateral analysis of the evolution of the disease and recovery on the basis of treatment. In contemporary medicine, the term "health-related quality of life" is widely used<sup>(13)</sup>.

The definition of quality of life is logically and structurally related to the definition of health proposed by the World Health Organization in 1946: "Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity". The concept of quality of life is volumetric in its basis<sup>(14)</sup> and includes: psychologically favorable state, socially favorable state, physically favorable state, spiritually favorable state.

It represents a multidimensional concept that assesses individuals' perception of their physical and psychological state.

It is well known that individual's perception of quality of life is not just about the medical condition, but is the effect of the medical condition in conjunction with the patient's whole environment, including social and family determinants.

The delay in diagnosis has a negative impact on health-related quality of life. It has a profound negative effect on patients' personal lives and relationships.

Patients with severe endometriosis have a complex of different symptoms, including painful menstruation, non-menstrual pelvic pain, dyspareunia and painful defecation. These symptoms cause profound distress and a significant reduction in their quality of life.

The negative impact on quality of life is due to the following: intensity and frequency of symptoms and

their association, concurrent infertility, adverse effects of medical and surgical treatments, persistence of symptoms after treatment, recurrence of the disease, and the need for continued long-term therapy. Chronic pain can lead to social isolation and negatively affects the emotional well-being<sup>(15)</sup>.

The main goal of endometriosis management can be stated simply, in one sentence: to improve the patient's overall quality of life.

Numerous researchers have worked on summarizing tools designed to assess the quality of life in medical practice. Global quality of life assessment tools measure personal satisfaction in 15 distinct areas of life, including financial security, health, relationships with family and friends, learning, work, creativity, socializing and personal independence. Generic tools apply to several groups of patients, for the assessment of all types of pathologies or conditions, applicable in any medical unit or even in the general population.

Most measures of QOL are psychosocially oriented structured questionnaires that contain scores that can be summed and quantified. However, QOL has multiple other dimensions which include pain, mobility and the ability to have sexual or social interaction, among others.

The following questionnaires are available as tools to quantify the perception of quality of life: Short Form 36 (SF-36), KESS and GIQLI. It is necessary that these questionnaires are completed by patients preoperatively and one year after surgery.

### Short Form 36 (SF-36)

This is the short, commercial version of a much larger study (MOS; Medical Outcome Study). It is a generic quality of life assessment instrument consisting of 36 questions grouped into eight domains, summarizing the patient's self-perceived physical and mental state<sup>(16)</sup>.

Basically, the questionnaire has 11 items with sub-items, 36 questions in total (this is why it is called SF-36), and is divided into eight domains. All these items are scored from 0 to 100, with 0 being a poor perception of quality of life and 100 being a perfect perception. Thus, the higher the score, the better the perception of quality of life<sup>(17)</sup>.

First field assesses physical functioning. It contains 10 items, scored 0, 50 or 100. Basically, it covers the sub-items of question number 3 and represents the respondent's perception of her quality of life as influenced by physical activity. Both physically demanding activities, such as running, lifting weights, strenuous sports, climbing several flights of stairs and walking distances greater than 1 km, and activities requiring moderate physical exertion such as bending, kneeling or stooping or self-bending and dressing, are assessed.

The second field refers to the physical role. It contains four elements, scored 0, 25, 50, 75 or 100. This domain relates to the performance of duties in daily activities (work or routine) and how these are affected by physical health.

The third area deals with the emotional role. It contains three items scored 0/25/50/75/100. Assesses the extent to which the respondent's emotional state (for example feeling depressed or anxious) limits her daily functioning and her ability to fulfil her roles, which is targeted by reducing the time spent at work or in other activities and, consequently, reducing her achievements relative to her desires.

The fourth domain, vitality, contains four elements, scored 100/75/50/25/0 or 0/25/50/75/100. It refers to the respondent's experience of feeling energetic and full of life/energy/energy, or "worn out" and tired.

The fifth domain, mental health, contains five items, scored 0/25/50/75/100. It determines the extent to which the respondent feels, among other things, lively, happy, calm and peaceful, or "worn out" and tired.

The sixth area concerns on social functioning and contains two elements, scored 0/25/50/75/100. It refers to the respondent's social activities and interaction with important people in her life, such as family members, friends, neighbors and other social relations.

The seventh domain, body pain, has two items, scored 100/80/60/40/20/0 or 100/75/50/25/0. The scores for the questions in this domain indicate the extent to which the respondent's body pain makes it difficult for her to carry out daily activities, including both work-related duties in the public environment and tasks in the family environment.

Last area, the eighth domain, is the general health, and contains five items, scored 0/25/50/75/100. Respondent's perception of general health is measured in conceptual terms, such as excellent, very good, good, average, poor, getting sick more easily compared to other people, as healthy as anyone she knows.

In addition to the **SF-36**, there should be considered the KESS (Knowles Eccersley Scott Symptom Score) and GIQLI (Gastrointestinal Quality of Life Index) questionnaires. These are questionnaires that assess the quality of life correlated with digestive symptoms, as all forms of endometriosis need to be assessed, including those with deeply infiltrative endometriosis, particularly as intestinal endometriosis greatly impacts quality of life.

**Knowles Eccersley Scott Symptom Score (KESS)** comprises 11 questions aimed at establishing the diagnosis of constipation. It has the advantage that it also differentiates subtypes of constipation. The total score can range from 0 (no symptoms) to 39 (severe symptoms)<sup>(18)</sup>.

**Gastrointestinal Quality of Life Index (GIQLI)** is a highly sensitive questionnaire for assessing the quality of life in patients with various gastrointestinal diseases, including those undergoing surgical treatment. It contains 36 questions regarding physical state, emotional state, social activity and typical gastrointestinal symptoms, which are rated according to a 5-point score. The total amount can be from 0 to 176. This questionnaire is widely used for comparative analysis of different surgical treatment methods in

gastrointestinal pathology. The survey can be completed in 10-15 minutes<sup>(19)</sup>.

These three questionnaires are valid tools useful for demonstrating the improvement of the overall quality of life in women undergoing surgery for endometriosis.

## Conclusions

Why is it important to improve people's quality of life by implementing intervention programs based on data obtained with measurement tools such as the SF-36, KESS and GIQLI questionnaires? Because the presence of sick individuals is dysfunctional for society.

It is dysfunctional to the extent that it creates a disruption of the social environment: the person is unable to perform his duties and responsibilities to the expected level; the person is unable to maintain his mental health and emotional well-being, which manifests itself in depression, excessive irritability, unhappiness or anxiety; the person finds it difficult to maintain activities and social interactions with significant others, such as family members and friends. ■

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