QAULITY OF LIFE IN ENDOMETRIOSIS PATIENTS

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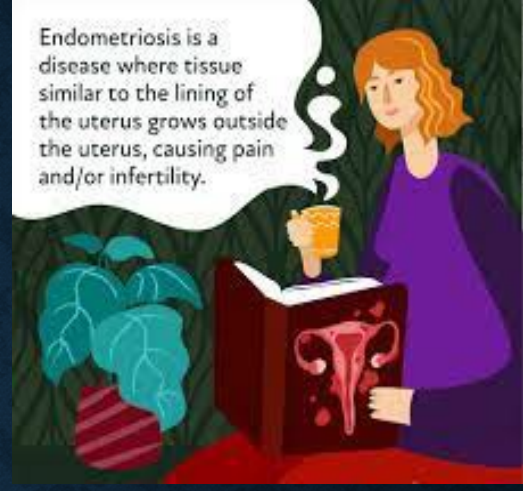
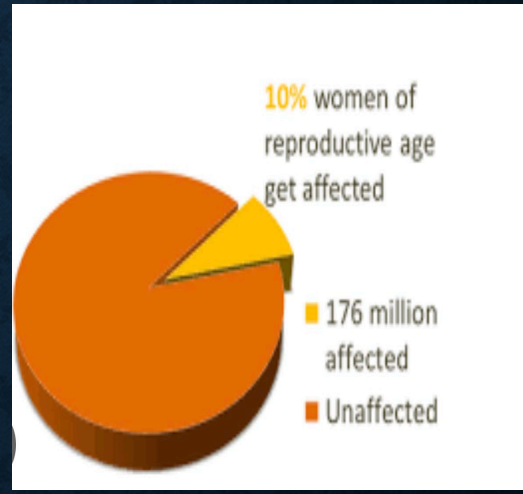
- **Endometriosis** is a benign chronic disease affecting **10%** of women of reproductive age and is characterized by the presence of endometriotic tissue beyond the uterine cavity, mainly in the ovaries and other pelvic organs.
- Endometrial-like tissue thriving outside the uterus leads to local and systemic inflammation that can result in a wide range of life-impacting effects, including pelvic pain, dysmenorrhea, dyspareunia and infertility
- The causes of endometriosis have not yet been determined .



- Women with endometriosis may be **asymptomatic** or may report symptoms of dysmenorrhea; deep dyspareunia; chronic pelvic pain; urinary pain or intestinal pain; & has a major impact on **infertility** & impact on a **patient's quality of life** and **overall well-being**



Three types of pain are generally associated with endometriosis:

- Dysmenorrhea
- Deep dyspareunia
- Non-menstrual chronic pelvic pain
- Dyschezia
- Lower back pain
- Urinary symptoms

- Infertility itself may also induce psychological stress, low self-esteem, depression
- **Endometriosis** as a disabling condition that may affect the social relationships, mental health, & sexual activity of women .

There are several factors that can complicate the diagnosis:

- Asymptomatic cases
- The late appearance of symptoms
- Increased presence of comorbidities with similar symptoms to endometriosis

- Symptoms begin during adolescence; thus, treatment is often started several years after use of NSAIDs medica and psychosocial factors contribute to a delayed diagnosis.

- Women with endometriosis experience a range of **nonclinical symptoms** including depression, feelings of isolation, fatigue , lack of energy.

- Endometriosis is reported to have an adverse impact on physical, mental, social wellbeing and a negative effect on health-related quality of life (HRQoL), psychological health, strain social, intimate relationships and lead to losses in productivity, both at home and in the workplace. However, with surgical and/or medical treatment, QOL is improved.

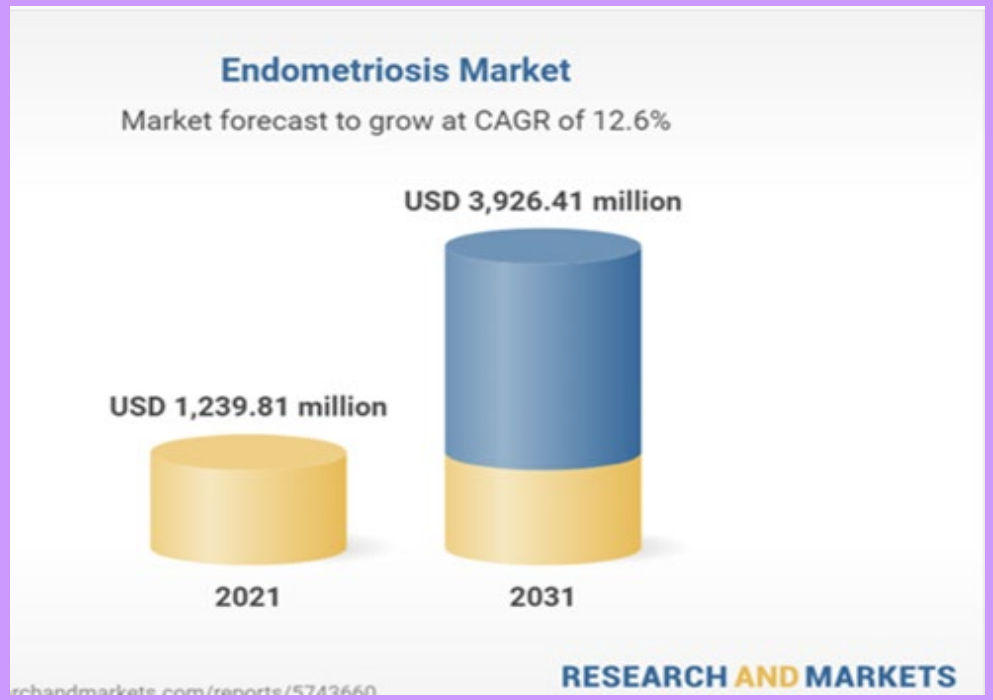
- [Health-related quality of life is a multidimensional concept encompassing physical, psychological and social aspects associated with a particular disease or its treatment.

- These issues have been further exacerbated by the **COVID-19 pandemic**, which has led to reduced access to medical care, delayed treatments, increased stress, loss of work productivity and mandated self-isolation.

- Reduction in 38%of the work productivity of these women, mainly attributed to pelvic pain
- **88%** of these women had anxiety disorders or depression
- **50%** of patients diagnosed with endometriosis had some **fertility disorder**, due to chronic inflammation and the formation of pelvic adhesions.
- Women with chronic pain have a lower QOL due to both physical and psychological factors.
- Pain reduction is generally not related to the improvement of psychological disturbances.

Endometriosis can negatively affect on QOL, particularly in more advanced stages,

- Outside the physical and emotional toll, the collective symptoms of endometriosis are also associated with direct and indirect costs that are burdensome to patients.



- Visits to physicians and emergency departments, pharmacyclaims and other direct expenses are estimated to cost between $12000 and $15000 per patient per year in the USA, and the loss of work and productivity may amount to additional losses of thousands of dollars per patient.

- Understanding life-course impairment, as opposed to focusing on the symptoms of the disease (pain or infertility, is vital because of the complicated inter-relationship among symptoms and their downstream effects.
- **Individual symptoms** can influence critical life decisions (eg, work, education or personal relationships) in ways that are interrelated and can impact other areas of a patient's life.
- **Chronic pain** may influence the **type** and **amount of work performed** or whether a patient decides to work at all, which, in turn, can have financial implications on the patient's lifestyle, family, relationships or sense of personal fulfilment.
- **Dyspareunia** related to endometriosis may lead some **women to avoid intimate relationships, which may have downstream implications for marriage, family planning , mental and emotional health**.
- Persistent symptoms of endometriosis and their impact on daily activities and family and intimate relationships can **negatively impact** the trajectory of women's lives and are **profound** and **far-reaching**.

- Insights into a patient's complete experience with endometriosis are needed to develop and provide access to effective treatments to reduce the negative impacts of endometriosis on a woman's life course.

- Greater awareness of the potential negative life-course impacts of endometriosis is important for **helping physicians** to identify and understand patients' needs and improve the long-term management of endometriosis.

- It is difficult to characterize the quality of life (QOL) among specific patient groups because it is a broad concept that includes life satisfaction, good health, education, personal and family safety, adequate housing, employment, interrelationships.
- QOL is evaluated using a multitude of validated and non-validated questionnaires, such as the **36-item survey generic questionnaire (SF-36)**. (before and 12 months after the surgery)

It includes eight (8) conceptual health domains:

- General Health (GH), Physical Functioning (PF), Bodily Pain (BP), Role Physical (RP), Vitality (VT), Social Functioning (SF), Mental Health (MH), Role Emotional (RE);
- These are summarized in the **physical (PCS)** and **mental (MCS) component scores** .

- Interviews of patients both before and after surgical or medical endometriosis treatment

- The 36-item survey generic questionnaire, **SF-36**, seems to represent an efficient/valid method for assessing the QOL of patients with endometriosis who are undergoing surgical or hormonal treatments.

- The **EHP-30 questionnaire** measures the unique impact of endometriosis on HRQoL in patients with this disabling disorder and, importantly, scoring might be unaffected by the cyclical/menstrual symptoms characteristic of endometriosis.

- The questionnaire contains 30 questions that women with endometriosis themselves find important to their quality of life.
- The questions can be divided into **five subscales** covering 'pain 'control and powerlessness', 'social support', 'emotional wellbeing' and 'self-image'.

- **EHP-30** appears to be a valid, stable & specific measure of HRQoL in women with endometriosis, and the finding of a five-factor model across several countries supports the cross cultural validity of the EHP-30.

- The EHP-30 questionnaire shows a good overall performance in measuring HRQoL. The present work underlines, that the surgical treatment of endometriosis has a positive effect on all well-being parameters measure by the EHP-30.

- Significant improvement of EHP-30 was achieved in all endometriosis groups, except peritoneal endometriosis.

- Especially women with DIE—with or without ovarian endometrioma -show a pronounced benefit from surgery compared to peritoneal and ovarian endometrioma without DIE.

- Routine evaluation of HRQOL in women who suffer from endometriosis is essential both for the health-care provider and the patient .

- Ideally studies should measure HRQoL at least one calendar month before treatment and at 3, 6 and 12 months there after, continuing evaluation on an annual basis for as long a period as possible.
- The SF-36 scale is the most commonly used scale in endometriosis studies.

- **EHP-30** and **SF-36 questionnaires** are **sensitive** to changes related to endometriosis, especially correlations between increased pressure pain sensitivity and hyperalgesia and the impairment of QOL parameters.

- The pharmacological treatment for endometriosis-related pain may be necessary **for decades**, or **at least until** there is a **desire for pregnancy** or **physiologic menopause occurs**.

- **Clinicians** should consider **not only the efficacy**, but also **side effects**, **tolerability**, and **costs**, along with women's preferences toward different treatments.

- Several medical options are available to manage symptomatic endometriosis, a chronic inflammatory estrogen-dependent disease characterized by the presence and proliferation of endometrium outside the uterine cavity.

- Medical therapy for endometriosis is **symptomatic** and **not curative**, as the pharmacological approach is not cytoreductive and the hypo-estrogenic milieu determined by the **hormonal suppressio**n is **temporary** .

- Oral very-low-dose monophasic estrogen-progestin combinations may be considered for women with **peritoneal lesions** and **endometriomas**

- Whereas **progestins** should be favored for those with **deep infiltrating lesions**.

- The rationale that should guide the clinicians in the management of women with endometriosis, as stated by the Practice Committee of the American Society of Reproductive Medicine (ASRM) , is the maximization of the use of medical therapies for long periods of time:
- To achieve adequate control of pain symptoms
- Amelioration of quality of life
- To minimize the use of repeated surgery

- To improve these women's lives, care should also respond to the social, emotional, and sexual issues resulting from the illness. Such interventions will contribute to improved comfort and QoL among these women.

- **Variability in factors**, indicating the need for a **multidisciplinary, individual approach** to a patient. As stressed by Rowe et al., patient-oriented care, characterized by continuity, respect, and provision of information, may improve HRQoL in women with endometriosis.

Factors that affect the perceived QoL in women with endometriosis include:

- Acceptance of illness (AIS score)
- Pain intensity
- BMI
- Negative impact of symptoms on the relationship with the partner
- Dyspareunia
- Expensive endometriosis treatment
- Age
- Pain experienced during menstrual periods
- Family health
- Education

- Raising awareness on endometriosis in the society
- Distributing reliable knowledge on its symptoms impact on the daily lives of affected women

- This could help in early diagnosis and treatment, and prevent misunderstanding associated with prolonged diagnostics.

- To improve these women's lives, care should go beyond focusing on symptoms and their impact on daily life, and respond to the social, emotional, and sexual issues resulting from the illness.

- Such interventions will contribute to improved comfort and QoL among women with endometriosis.

- Endometriosis related pain, but not the disease itself, seems to increase the prevalence of depression.
- Reduced physical and sexual activity due to the symptoms related to the underlying disease are observed in the majority of affected women.

- On the basis of the available evidence, there is no significant correlation between the severity of endometriosis and the incidence of different types of pain.

- Symptoms related to endometriosis poorly predict its stage.
- The stage of endometriosis is significantly related to the prevalence of infertility, which seems not to correlate with the incidence of depression in those women.

- **Morbidity** and **mortality alone** are not comprehensive measures of evaluating the benefits of surgical interventions in endometriosis patients, thus, subjective patient-reported instruments are required.

- **SF-36** is a valid and reliable survey instrument for endometriosis patients' QoL.

❖ Improvement in the overall HRQoL & improvement in digestive function in women who undergo surgery for colorectal DE.

❖ Surgically-treated colorectal endometriosis associates with better HRQoL and improvement in digestive function, as evaluated with SF-36, GIQLI, KESS and VAS questionnaires.

❖ The decision to perform a surgical procedure should be a consideration in symptomatic patients with colorectal DE.

- **Which treatment best improves QoL in patients with endometriosis?**
- There is **no clear answer** because therapy must be personalized for each patient and depends on the woman's goals.

- Particular attention must be paid to the management of the patient with DIE, trying to take into account the natural history of the disease and book the surgery at the right time that matches the needs and desires of the woman, always following the guidelines provided by scientific societies.

- Women should be **educated about endometriosis** and given easily accessible **information to improve treatment adherence** and, consequently, the QoL of patients with endometriosis.

- we consider the period between the onset of endometriosis symptoms and diagnosis as "Duration Untreated Endometriosis (DUE)". Among current management approaches, surgery and hormonal drugs are considered as primary treatment to reduce recurrences and to improve the QoL in women suffering from endometriosis

- **Longer period of DUE** was related both to worst HRQoL and Physical QoL.

- **Duration Untreated Endometriosis (DUE)** and **pain** are important variables related to psychological aspects of women with endometriosis.

- Diagnostic delay and pain are related to worsening of different component of both QoL and HRQoL of women with endometriosis.

- **DNG** seems to have a **greater effect than EE/DNG** on **dyspareunia reduction** over time. Improvement in pain symptom and QoL is the central goal in the treatment of endometriosis toward a global management of the disease.

- Women with endometriosis show both poor physical and mental components of QoL.

- Pain perception is associated with worsening of different components of generic QoL, specific HRQoL and sexual problems DUE is related to worsening of different component of both QoL and HRQoL.

- Need for multidisciplinary approach and clinician education to decrease the effect of endometriosis on women's QoL and to reduce the duration of untreated endometriosis.

- Higher pain level was related to poorer quality of life, emphasizing both physical and psychological aspect of the disease also for treatment project .A key factor correlated with disease and QoL is the available treatment method.

- Severe endometriosis-related pain and the presence of psychiatric disorder were associated with lower quality of life.

- Comprehensive management of endometriosis is crucial to improve patients' quality of life.

- The lowest quality of life belonged to the **infertile pateint**, followed by the endometriosis.

- Endometriotic patients' treatment I terms of improvement of quality of life should be considered by all professional health care teams.

- Surgical or medical treatment improves the QOL and choosing the best strategy out of these two methods, depends on the patient's conditions.

- Laparoscopic excision of DIE lesions significantly improves general health and psycho-emotional status at six months from surgery without differences between patients submitted to intestinal segmental resection or intestinal nodule shaving.

- Minimally invasive surgery for patients with pain and deep infiltrating endometriosis after the **failure of medical treatment** led to an **improved quality of life** and a significant decrease in dysmenorrhea and dyspareunia 2 years after surgery.

- Conservative surgery showed comparable results to total surgery.

- The optimal route for surgery as regards to robotic and classic laparoscopy remains unclear and needs to be assessed with a larger sample and in a prospective way.

- Drugs for endometriosis-relate pain should have a high safety profile, be well-tolerated have few side effects, and have reasonable costs
- Pharmacological therapies for endometriosis **prevent pregnancies during their use and do not increase the likelihood of conception after their discontinuation.**

- **Medical therapy for endometriosis** should be proposed to **women with endometriosis-related pain with no wish for pregnancy an without surgical indications**.

- **According to several guidelines** on endometriosis management released by the most authoritative gynecological societies, hormonal contraceptives, progestins, antiprogestogens GnRH agonists, and GnRH antagonists should be used for the management of endometriosis-related pain.

- A pragmatic and reasonable approach to medical treatment for endometriosis-related pain should involve a realistic balance with a long-term view between efficacy (in terms of improvement of the overall quality of life of women affected by the disease) safety, tolerability, and costs, considering women's treatment preferences and their wish for pregnancy.

Absolute indications for surgery:

- Presence of large endometriomas
- Adnexal masses
- Uncertain appearance at diagnostic imaging procedures
- Ureteral stenosis causing hydronephrosis
- Bowel stenosis associate with sub-occlusive symptoms

- When choosing medical treatments for endometriosis-related pain, clinicians should consider no only the efficacy, but also side effects, tolerability, adherence to treatment, costs and women's preferences

- One considers the chronic nature of the disease potentially determining a long-term impairment of women's overall quality of life, mental health, social activities, work, sexual and intimate relationships.

- Oral very-low-dose monophasic estrogen-progestin combinations may be considered for women with peritoneal lesions and endometriomas, whereas **progestin** should be favored for those with **deep infiltrating lesions .**

- Endometriosis is a condition associated with pelvic pain, infertility, and possibly with decreased quality of life as well as psychiatric disorder.

- We conclude that severe endometriosis-related pain and the presence of psychiatric disorder were associated with **lower quality of life**.

- As well as improvement in pain symptoms, an improvement in QoL is a crucial aspect in endometriosis toward a global management of the disease.