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Pain Associated with Endometriosis. A Review of Quality of Life. Psychological Aspects, Career Development, Sexual Health, and Intimate Partner Relationships

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ABSTRACT

Introduction: Endometriosis is a chronic estrogen-dependent inflammatory disease characterized by the presence of tissue resembling the endometrium outside the uterine cavity. It affects approximately 10% of women of reproductive age. The main symptoms include severe pain, reduced fertility, and sexual dysfunction. Treatment includes pharmacotherapy and surgical interventions, depending on the severity of symptoms, the location of lesions, and their extent.

Study Objective: The aim of the study was to assess quality of life, as well as the impact of dyspareunia and other endometriosis-related symptoms on sexual health and intimate partner relationships.

Materials and Methods: Over 60 scientific articles addressing this issue were analyzed. The studies were retrieved from the PubMed platform, spanning the years 2004 to 2024.

Conclusions: The symptoms of endometriosis, along with limited therapeutic options, significantly affect overall quality of life, sexual health, and partner relationships. Based on the available literature and current knowledge, it can be concluded that it is crucial to provide not only medical treatment but also sexological and psychological support.

Keywords: endometriosis, pain, dyspareunia, infertility, quality of life, sexuality, intimate partner relationships

INTRODUCTION

Endometriosis is a chronic estrogen-dependent inflammatory disease characterized by the presence of tissue resembling the endometrium outside the uterine cavity.

Ectopic endometrial tissue causes immune system dysfunction, triggering a localized immune and inflammatory response, which is associated with the production of cytokines, chemokines, and prostaglandins (1).

The presence of ectopic endometrial tissue induces a chronic estrogen-dependent inflammatory response. Pain results from elevated prostaglandin levels, pressure, and/or infiltration of adjacent nerves and can initially be understood as inflammatory nociceptive pain. Over time, increased expression of nerve growth factors, heightened nerve fiber density, and angiogenesis stimulate peripheral nerve sensitization.

These factors activate visceral and peritoneal nerve fibers, leading to increased pain sensitivity. Consequently, pain mechanisms develop that may be activated independently of hormonal stimuli (2).

Endometriosis affects approximately 10% of women of reproductive age (3).

Studies indicate that the highest prevalence of endometriosis is observed between the ages of 25 and 29 (4). Due to nonspecific symptoms, delayed diagnosis is common. In the United States, the average time from the onset of symptoms to diagnosis is about 4.4 years, whereas in Germany, it can be as long as 10.4 years (5, 6). The delay in diagnosis is also influenced by self-medication with over-the-counter painkillers, the use of hormonal contraception, and misdiagnosis.

An increasing number of studies (both quantitative and qualitative) document the negative impact of endometriosis on women's quality of life (7).

Pain, in many cases, leads to impaired sleep quality, increased stress, reduced activity levels, and higher rates of coexisting mental health disorders such as depression and anxiety.

Chronic pain, fatigue, and dyspareunia have been shown to negatively affect sexual life (8), and in some relationships, these symptoms have led to relationship breakdowns (9). However, many women emphasize how supportive their partner is during the course of the disease (10). Most studies focus primarily on women's perspectives, while the views of their partners remain largely absent from widely available literature (8).

Another aspect impacting quality of life is professional life. Symptoms of endometriosis, such as pain, chronic fatigue, and heavy menstrual bleeding, contribute to work absenteeism or the need to shorten working hours (11). The inability to fully engage in professional life not only negatively affects the women concerned but also their families, with broader economic implications for society.

Endometriosis is a condition that affects all aspects of life, with economic implications both at the individual and societal levels (12).

SYMPTOMS

The symptoms of endometriosis depend on the extent and location of the endometrial lesions. Typical symptoms include dysmenorrhea, dyspareunia, dysuria, dyschezia, and infertility. In patients where endometrial tissue is located within the gastrointestinal tract, symptoms may include rectal bleeding, painful bowel movements, diarrhea, constipation, and intestinal obstruction.

A unique form of endometriosis is umbilical endometriosis, also known as Villard's nodule (13). Umbilical endometriosis manifests as pain and bleeding from the umbilicus during the menstrual cycle (13).

Pulmonary endometriosis is very rare. When endometrial tissue is located in the lungs, characteristic symptoms include pneumothorax, chest pain radiating to the shoulders and arms, and dyspnea. Episodes of hemoptysis may also occur during the menstrual cycle, resolving after menstruation ceases (14). However, there is a reported case of a woman who experienced hemoptysis related to endometriosis that was not linked to the menstrual cycle. In this case, a chest CT scan revealed multiple pseudocavities and numerous nodules located in the lower lung lobes. Histopathological examination confirmed pulmonary endometriosis (15).

Abdominal wall endometriosis can occur following surgical procedures, primarily cesarean sections, but also laparoscopic surgeries, amniocentesis, or hysterectomy. It typically presents as cyclical pain at the site of the surgical scar, with a palpable mass or nodule (16).

The most severe form of endometriosis is deep infiltrating endometriosis, which is characterized by endometrial lesions penetrating more than 5 mm beneath the peritoneal surface (17).

DIAGNOSTIC TOOLS

Diagnosing endometriosis is a challenging task. The foundation of diagnosis should be a detailed medical history and physical examination. Through palpation, the physician can detect nodules in the vaginal fornix and rectal area. During a gynecological examination, the gynecologist can assess the ovaries. Even if no abnormalities suggestive of endometriosis are observed during the physical exam, the condition cannot be ruled out. In such cases, additional diagnostic tests should be considered. Examples of such tests include imaging studies. The primary imaging modalities are transvaginal ultrasound (TVUS) and magnetic resonance imaging (MRI). Both methods have high sensitivity (18). However, other factors should also be considered. Ultrasound is a significantly cheaper, more accessible, and better-tolerated method by patients, which makes it the first choice for imaging studies (19).

The highest diagnostic sensitivity is achieved through a combination of medical history, physical examination, transvaginal ultrasound, and MRI imaging (20). Currently, diagnostic laparoscopy and laparotomy are being phased out. While effective, these methods are too invasive and costly (21).

In clinical practice, there is currently no non-invasive diagnostic test to detect endometriosis. However, there is growing interest in hematological parameters. A study published in the Bratislava Medical Journal confirmed that women with endometriosis have a higher neutrophil-to-lymphocyte ratio, increased mean platelet volume, and a lower lymphocyte-to-monocyte ratio compared to a control group (22). Similarly, regarding cytokines, specifically interleukin-6, monocyte chemoattractant protein-1, and interferon-gamma, their levels are higher in the serum of women with endometriosis compared to healthy women (21). Further studies are needed to assess the clinical utility and effectiveness of this marker panel in the standard diagnosis of endometriosis.

TREATMENT

Endometriosis is a chronic condition and thus requires appropriate management. Treatment can be divided into two aspects: pharmacotherapy and surgical treatment. The cornerstone of treatment is hormonal therapy, which should be initiated as early as possible. The aim of hormonal therapy is to block the menstrual cycle—inducing a pseudopregnancy state and/or reducing estrogen secretion by the ovaries through inhibition of the hypothalamic-pituitary-ovarian axis, thereby alleviating endometriosis symptoms.

First-line therapy involves the combination of estrogen and progestin or progestin monotherapy (23). Progestins act by binding to progesterone receptors, reducing the secretion of follicle-stimulating hormone (FSH) and luteinizing hormone (LH), and inducing anovulation (24). A study conducted by Francesco La Torre and colleagues confirmed that progestin therapy significantly reduces dysmenorrhea, dyspareunia, dyschezia, dysuria, and chronic pelvic pain (25).

In cases of poor tolerance to first-line therapy, gonadotropin-releasing hormone (GnRH) agonists and antagonists are used as second-line treatment. This therapeutic approach is in accordance with the current ESHRE guidelines (23). GnRH agonists and antagonists may be more effective in relieving pain and suppressing menstruation. These agents inhibit ovarian function, induce a hypoestrogenic environment, and thus mimic the menopausal state. Unfortunately, due to side effects such as bone mass reduction, which may lead to future osteoporotic fractures (26), and vascular dysregulation, their use is limited to a maximum of six months of therapy (27).

Surgical treatment should be combined with hormonal therapy both preoperatively and postoperatively. In women who undergo surgical treatment followed by postoperative hormonal therapy, pain reduction, including pelvic pain, dysmenorrhea, and dyspareunia, has been observed, as measured by the visual analog scale. Furthermore, in cases of disease recurrence, the recurrence rate 12 months post-surgery decreased from 17% to 3%-9%. After 24 months, the disease recurrence rate decreased from 25% (without postoperative hormonal therapy) to 6%-14% (in patients receiving postoperative hormonal therapy) (28).

However, hormonal treatment is not always feasible. Some women cannot tolerate hormonal medications due to side effects, others undergoing fertility treatments may need to discontinue hormonal therapy, and some women may refuse pharmacotherapy due to health-related beliefs. Although the results of the study (28) show a clear benefit of postoperative hormonal therapy, it is crucial to adopt a holistic approach to treatment and tailor the therapy to the individual woman's needs.

DIETARY AND NUTRITIONAL INTERVENTIONS

There is increasing recognition that diet and nutritional components may significantly modulate the pathophysiological processes underlying endometriosis. Some women opt for dietary interventions instead of hormonal therapy (29). However, to date, there is limited evidence supporting the positive effects of dietary and nutritional interventions on the progression of endometriosis due to the small number of studies conducted (30).

A gluten-free diet has shown potential in reducing pelvic pain and gastrointestinal symptoms (31). In a retrospective cohort analysis of 363 women with endometriosis, it was demonstrated that removing wheat and gluten from the diet reduced pain, and upon reintroducing wheat, symptoms such as pain, bloating, diarrhea, constipation, headaches, and chronic fatigue returned (32).

A high-fiber diet, which primarily includes vegetables, fruits, whole grains, legumes, and nuts, has also been explored (33). A large study by Parazzini et al. indicated that the consumption of fruits and vegetables reduces the risk of endometriosis. However, as this was a case-control study, the collected data may not be fully accurate (34). The development of endometriotic tissue, inflammation, and pain are, among other factors, regulated by estrogen. It has been proven that a fiber-rich diet significantly reduces serum estrogen levels (35). A plant-based diet, high in fiber and supporting a diverse microbiome, aids in the binding and excretion of sex hormones from the body. Additionally, it has been suggested that a fiber-rich diet, high in fruits and vegetables, decreases oxidative stress and inflammation (35).

An anti-inflammatory diet includes high amounts of fatty fish and lean animal proteins, with reduced carbohydrate intake. It is also rich in fiber, olive oil, and anti-inflammatory spices such as ginger and turmeric (36). A 2021 study (37) by Japanese researchers assessed the relationship between an anti-inflammatory diet and the risk of preterm birth in women with endometriosis.

The study, which included 3,249 participants, demonstrated a significant reduction in preterm births and an overall improvement in well-being. The role of an anti-inflammatory diet as a necessary dietary approach for women with endometriosis was further confirmed in a 2023 study with 3,410 participants. The study showed a correlation between pro-inflammatory foods and the risk of endometriosis. In this research, the levels of inflammatory biomarkers such as C-reactive protein, IL-6, and TNF-α, which all significantly increase in endometriosis, were analyzed (38).

The Mediterranean diet, which is rich in vegetables (including leafy greens), fruits, grains, nuts, legumes, and olive oil, is characterized by moderate consumption of fish, poultry, and dairy products, and low consumption of eggs, red meat, and sweets (39). A study by Ashrafi et al. involving 413 women found that a higher intake of fresh fruits, leafy vegetables, dairy products, cheese, and legumes was associated with a lower risk of endometriosis (40).

There is no definitive answer as to which diet is the most suitable for women with endometriosis. Each woman should receive a personalized approach to selecting the appropriate dietary and nutritional intervention, one that takes into account her comprehensive clinical history and lifestyle.

PSYCHOLOGICAL ASPECTS

Approximately 80% of women with endometriosis experience pain (41). The intensity of pain is not always proportional to the extent of the disease, and the location of the pain does not always correlate with the location of endometrial lesions. Non-specific symptoms, including pain, significantly delay diagnosis, reducing quality of life and impacting mental health (42).

Chronic fatigue, sleep disturbances, and insomnia (43) are significantly more common in women with endometriosis compared to healthy controls. The difficulty in obtaining a diagnosis, managing treatment, and the lack of a definitive cure can contribute to the development of depressive and anxiety symptoms. Moreover, poor sleep quality further exacerbates anxiety and depression (44). It is estimated that up to 1 in 5 patients will develop depressive disorders, while anxiety disorders may affect approximately 10-21% of patients (45). In another study (46) conducted on a Brazilian population, 103 women aged 15–49 were evaluated: 53 patients with endometriosis formed the study group, and 50 formed the control group. Depression levels were assessed using the Beck Depression Inventory, which measured depression from mild to moderate, moderate to severe, and severe. Symptoms were observed in 35 women with endometriosis (66%), of whom 20 (37.7%) exhibited mild depression, 4 (7.5%) mild to moderate, 6 (11.3%) moderate to severe, and 5 (9.4%) had severe depression. In the control group, depression symptoms were observed in 29 women (58%), with 7 (14%) showing mild depression, 2 (4%) mild to moderate, 10 (20%) moderate to severe, and 10 (20%) severe depression. However, according to Fisher's test, no significant association was found between endometriosis and depressive symptoms (p = 0.423).

Another study concluded that women with endometriosis exhibit significantly more severe symptoms of depression and anxiety. This suggests a strong link between pain and psychological distress (47). It has been hypothesized that both pain and depressive symptoms may stem from dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis (48), significantly weakened immune function (49), and exacerbated inflammatory processes (50). However, simply alleviating pain does not lead to a reduction in depressive symptoms, suggesting a complex interaction with emotional and social factors that affect the perception of pain and psychological suffering.

Interestingly, a study conducted by Reis et al. (51) demonstrated that experiencing stress or depression in early life may be a contributing factor to the development of endometriosis. Additionally, other research has indicated that children who were victims of physical or sexual abuse were at an increased risk of developing endometriosis (52).

Based on these findings, it can be concluded that post-traumatic stress disorder (PTSD) and depression are significant risk factors for the development of endometriosis. Likewise, endometriosis and its associated chronic pain can contribute to mental health disorders, creating a vicious cycle that exacerbates the disease (53).

PROFESSIONAL LIFE

The quality of professional life is a crucial aspect of overall quality of life. The costs associated with endometriosis are not solely related to the direct expenses of medical treatment; a significant portion is attributable to reduced professional activity, accounting for up to 75% of the total costs of endometriosis (54). The ability to engage in one's desired profession not only significantly impacts financial well-being but is also an important health factor.

In 2019, a study was conducted focusing on the evaluation of professional life among women with endometriosis (11). The study yielded the following results: 10.3% of women with endometriosis reported working part-time or had completely stopped working (5.8%) due to the disease. Among women who remained professionally active, a portion was forced to take sick leave due to their condition, with 13.1% of patients utilizing sick leave within a year.

Furthermore, 75.5% of women with endometriosis reported going to work in the previous month despite experiencing severe pain. Among women diagnosed with endometriosis, 89.8% reported a loss of work productivity due to the condition, with 65.1% reporting severe or very severe limitations on days when symptoms of endometriosis were particularly debilitating. On days with minimal symptoms, 75.3% still experienced some degree of work productivity loss (11).

In another study (55) conducted by Fourquet et al., 43% of participants confirmed that pain significantly or moderately interfered with their work over the past month. Additionally, 66.2% reported that their physical health condition had limited their choice of occupation, resulting in them performing jobs that did not align with their ambitions. A similar finding was observed by 45.4% of women, who indicated that emotional health issues also contributed to their dissatisfaction with their professional roles.

In the context of professional life, early diagnosis of endometriosis is also critically important. The prompt initiation of treatment significantly improves both the physical and psychological comfort of life, thereby positively impacting professional life and self-fulfillment.

SEXUAL ASPECTS

Sexual function is a crucial component of overall well-being. Among women with endometriosis, approximately 61% report experiencing issues related to their sexual life (56). Pain during intercourse is one of the primary symptoms of endometriosis. Dyspareunia affects up to 75.7% of women with endometriosis (57). Dyspareunia associated with endometriosis is often described as deep pain resulting from contact with sensitive pelvic structures such as the rectouterine pouch (Douglas' pouch), cervix, uterus, pelvic floor, and the base of the bladder during deep penetration (58). Superficial dyspareunia, pain occurring at the vaginal entry, often correlates with deep dyspareunia and may arise from hypersensitization of the nervous system. Chronic pain states can lead to regional allodynia and hyperalgesia (59). The relationship between pain during intercourse and sexual dysfunction arises from recurrent experiences of painful sex and fear of pain. Consequently, this fear negatively impacts vaginal lubrication, increases pelvic floor muscle tension, diminishes sexual desire and arousal, and decreases sexual satisfaction (60). Up to 40% of women with endometriosis may report dissatisfaction with their sexual life due to a reduced frequency of intercourse, vaginismus, and decreased sexual drive (61).

The perception of pain by the female partner during intercourse also affects the initiation of sex by men, with around 20% of men expressing reluctance to initiate sex (62).

Despite its high prevalence, dyspareunia remains an overlooked and neglected symptom of endometriosis due to stigmatization, embarrassment, and normalization by patients (63).

Quality of life is significantly lower in women who are sexually inactive, highlighting the pivotal role of sexual health in the overall quality of life (64).

PARTNER RELATIONSHIPS

Chronic diseases, such as endometriosis, can pose significant challenges in partner relationships. Not only does dyspareunia contribute to misunderstandings between partners, but infertility can also play a role. A study published in 2017 revealed that 80% of couples reported that endometriosis affected their plans for having children, 40% of couples were forced to undergo infertility testing and treatment, and 40% confirmed that the disease influenced their decisions regarding whether, how many, and when to have children. One in ten couples decided to attempt conception earlier than they otherwise would have if the female partner did not have endometriosis (62). In a study by Moradi et al. (65), it was concluded that concerns about infertility increased the burden of endometriosis and negatively affected marital relationships, among other aspects.

Around 40–50% of both women and men affected by endometriosis perceive the disease as a burden on their relationship (66).

A 2024 study by Shinan-Altman et al. (67) highlighted the significant role of the partner in the diagnostic process. The involvement of the partner allowed both individuals to offer mutual support and helped the partner understand the significance and consequences of the disease. This finding was also supported by research conducted by Margatho et al. (68), which emphasized that endometriosis not only affects the woman but also has an impact on the partner, especially in terms of intimacy, fertility, and overall quality of life.

Positive effects of endometriosis on partner relationships have also been observed. After receiving the diagnosis, the ability to communicate between partners significantly improved, as did the relationship itself (62, 65). Researchers emphasized that the development of a supportive approach from the partner significantly strengthened the relationship, making the partners feel closer. However, in the same study, it was also noted that 30% of men in relationships with women suffering from endometriosis considered ending the relationship due to the disease (62).

All of the studies reviewed focused on heterosexual couples and were conducted on small populations, so the limitations of these studies should be considered when interpreting the results.

CONCLUSIONS

The aim of this article was to assess the impact of pain on the quality of life of women with endometriosis, as well as the effects of pain on psychological aspects, professional life, sexual health, and partner relationships. The main goal was to identify which aspects of quality of life are most affected by endometriosis. After analyzing the collected studies, it can be concluded that endometriosis significantly reduces the quality of life in women. The pain that accompanies women on a daily basis limits their developmental potential in the context of professional life. In partner relationships, both dyspareunia and infertility pose challenges for the partners. It is important to emphasize that endometriosis impacts both the affected woman and her partner by diminishing their quality of life.

Sexual health is also a crucial component of quality of life. The majority of women highlight the link between the disease and sexual difficulties, namely the reduced frequency of sexual intercourse and decreased libido. Pain, lack of understanding from the external environment, and a diminished quality of life directly affect the mental health of patients, often leading to anxiety and depression.

In the treatment of endometriosis, a holistic approach to the patient is essential. In addition to pharmacological therapy and surgical treatment, an appropriate nutritional regimen can significantly influence the course of the disease. Women with endometriosis should be surrounded by understanding and support. Standard treatment should be complemented by psychotherapy and sexological support. Such an approach would undoubtedly improve the quality of life for women with endometriosis.

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