Psychosocial impact of endometriosis: From co-morbidity to intervention

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Abstract
Endometriosis-associated pelvic pain is a major health concern in women of childbearing age. Controlled studies have shown that endometriosis can adversely affect women and their partners’ general psychological well-being, relationship adjustment, and overall quality of life. Furthermore, women with endometriosis report significantly more sexual dysfunctions compared to healthy women. Empirical studies indicate that specific psychosocial factors may modulate pain experience, pain-related distress, and treatment outcome. Research on psychosexual interventions in endometriosis treatment is limited but shows to be effective in reducing endometriosis-related pain and associated psychosexual outcomes. An individualized, couple-centered, multimodal approach to care, integrating psychosexual and medical management for endometriosis, is thought to be optimal.

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Introduction

Chronic pain problems involving the female reproductive system are major health concerns in women of all ages. A case in point is chronic genital pain because of endometriosis. A population-based study suggests that endometriosis affects 5–10% of the general female population in their reproductive years [1]. As a condition that is often misdiagnosed, mismanaged, trivialized, or ignored [2],...
endometriosis entails a great personal cost to patients and their partners and a significant financial cost to society, due to both direct and indirect costs [4].

The experience of cyclic and chronic pain, combined with a lack of proper recognition by health professionals [5] may generate varying degrees of psychological and interpersonal impairments, which are as much a source of distress for the patient and her partner as the pain itself. Furthermore, pain problems of the reproductive tract may carry an even heavier psychosocial burden in comparison to other chronic pain problems common in women because of their deleterious effect on fertility, sexuality, and romantic relationships [6].

Indeed, controlled studies in women with vulvodynia have shown that chronic genital pain can adversely affect women and their partners’ general psychological well-being, relationship adjustment, and overall quality of life [7,8]. Many patients report feelings of shame, inadequacy, low self-esteem, and body image concerns [9]. Compared to healthy women, women with chronic genital pain report more state and trait anxiety [10] and higher depression scores [11]. Further, women with chronic genital pain report more catastrophizing about their pain (i.e., an exaggerated and pessimistic perspective with magnification, rumination, and feelings of helplessness) [12], higher levels of hypervigilance toward the pain, more fear of pain, and lower levels of self-efficacy (i.e., the belief in one’s capacity to meet the challenges of managing pain) [13] compared to healthy women. In addition, previous research has shown that the experience of chronic genital pain may disrupt all aspects of sexual function [14] including sexual desire, arousal, orgasm, and sexual satisfaction. Moreover, chronic genital pain may have consequences for the partners’ psychological and sexual well-being [8,15], and it may have a negative effect on the partner relationship and the couple’s social well-being [16]. Finally, cognitive (e.g., attributions or beliefs about the pain), behavioral, affective, and interpersonal factors may modulate the pain experience and associated negative sequelae [14] and thus play a role in pain modulation, management, and compliance to treatment.

However, psychosocial and sexual impairments associated with chronic genital pain have been mainly assessed in patients with vulvodynia. Vulvodynia is characterized by superficial dyspareunia, whereas endometriosis-associated pain is classically deep dyspareunia. Therefore, the findings cannot be directly translated into the clinical setting of patients with endometriosis. Pain in endometriosis may be nociceptive (including inflammatory), neuropathic, or a combination of both. It shares features of other chronic pain syndrome such as hyperalgesia, allodynia, and central sensitization. Furthermore, specific characteristics of endometriosis, such as being diagnosed with a chronic disease, the evolution of disease/symptoms over time, the presence of chronic pelvic pain, long-term hormonal treatment, fertility concerns, extensive pelvic surgery at a young age, and risk of recurrence, might exacerbate the emotional/cognitive, sexual, and interpersonal elaboration of pain. Therefore, the aim of this review is to outline the consequences of endometriosis on the psychological, sexual, and interpersonal functioning of both patients and their partners. Second, treatment approaches from medical, psychosocial, and integrated perspectives will be suggested, and recommendations for future research will be formulated.

Psychological consequences and associated difficulties

Women with endometriosis may suffer from a wide range of pelvic pain. Nevertheless, pain and pain-related distress seem to be independent of the stage of endometriosis [17], suggesting that psychosocial factors may be involved in pain experience in women with endometriosis. In particular, controlled cross-sectional studies showed that women with endometriosis report heightened psychological distress including guilt toward their partner, lower feelings of femininity, alteration of body image, feelings of loss of control over one’s own body, worthlessness, hopelessness, and alexithymia [18–21]. Compared to healthy women, women with endometriosis reported significantly higher levels of pain catastrophizing [22], stress [23,24] and more depression, and anxiety [23–27] with prevalence rates up to 87% [25]. In a cohort of patients with chronic pelvic pain due to endometriosis, pain catastrophizing played a pivotal role in pain experience, severity, and recurrence [28]. Catastrophizing was found to predict poorer response to surgery [29] and persistent pain after 1-year follow-up [28]. Furthermore, a cross-sectional study of 236 women with endometriosis showed that higher pain catastrophizing was associated with reduced quality of life, independent of other psychological

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