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Q8 Psychosocial impact of endometriosis: From co-morbidity to intervention

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A B S T R A C T

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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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Q1 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],

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1 endometriosis entails a great personal cost to patients and their partners and a significant financial cost
2 to society, due to both direct and indirect costs [4].

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

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

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

39 **Psychological consequences and associated difficulties**

40 Women with endometriosis may suffer from a wide range of pelvic pain. Nevertheless, pain and
41 pain-related distress seem to be independent of the stage of endometriosis [17], suggesting that
42 psychosocial factors may be involved in pain experience in women with endometriosis. In particular,
43 controlled cross-sectional studies showed that women with endometriosis report heightened psy-
44 chological distress including guilt toward their partner, lower feelings of femininity, alteration of body
45 image, feelings of loss of control over one's own body, worthlessness, hopelessness, and alexithymia
46 [18–21]. Compared to healthy women, women with endometriosis reported significantly higher levels
47 of pain catastrophizing [22], stress [23,24] and more depression, and anxiety [23–27] with prevalence
48 rates up to 87% [25]. In a cohort of patients with chronic pelvic pain due to endometriosis, pain cata-
49 strophizing played a pivotal role in pain experience, severity, and recurrence [28]. Catastrophizing was
50 found to predict poorer response to surgery [29] and persistent pain after 1-year follow-up [28].
51 Furthermore, a cross-sectional study of 236 women with endometriosis showed that higher pain
52 catastrophizing was associated with reduced quality of life, independent of other psychological
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