



Stigma and mental health in endometriosis

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ABSTRACT

This review provides an overview of patient experiences of endometriosis, endometriosis-related types and sources of stigma pertaining to menstruation, chronic pain, and infertility, and their impact on patients' mental health with particular implications for patient care. Because endometriosis is a complex disease with multifactorial etiology, complicated pathophysiology, and a spectrum of clinical features, diagnosis of endometriosis is typically a lengthy process, and many patients experience initial misdiagnosis. A hallmark symptom is severe menstrual pain with other symptoms including chronic pelvic pain, dysmenorrhea, and infertility. Prior research documents that the diagnostic odyssey, complex management, disabling and unpredictable nature of the disease, and painful symptom profile affect multiple life domains of patients, resulting in poor physical, social, and psychological functioning and clinically-significant rates of anxiety and depression for many. More recently, stigma has been recognized as a potent contributor to poor mental health in endometriosis patients, but existing research is limited and largely atheoretical. We identify major sources of stigma related to endometriosis, including menstrual stigma, chronic pain stigma, and infertility stigma, and their likely impact on patients and health care provision. An integrative theoretical approach is described to facilitate research on the prevalence and effects of endometriosis stigma and their explanatory mechanisms, highlighting specific well-validated psychological instruments to assess stigma. Implications for patient care are emphasized. Better understanding of stigma and mental health in people with endometriosis will enhance the standard of care for this patient population.

Introduction

1 in 10 individuals live with endometriosis, a chronic disease where tissue similar to the lining of the uterus, the endometrium, is found outside the womb [1]. Endometriosis affects the physical, social, and psychological functioning of patients and has long confounded clinicians and scientists due to its multifactorial etiology, complicated pathophysiology, spectrum of clinical features, and diverse routes of management [2]. Although a definitive etiology of endometriosis is unclear, it is generally accepted that hormonal, genetic, inflammatory, and immunologic processes contribute to manifestation of the disease [1]. Endometriosis patients have several treatment alternatives available, including surgical and pharmacological options. Individuals respond differently to these; some patients have well-controlled symptoms whereas others experience persistent or recurring symptoms.

Given the wide array of life domains that are affected, it is no surprise

that endometriosis is associated with mental distress [3–5]. A hallmark symptom of endometriosis is severe menstrual pain, which can be debilitating. Therefore, the majority of endometriosis-related psychological studies focus on the impact of menstrual pain in depression [6,7]. Recently, researchers have highlighted that psychosocial factors such as stigma also play a role in mental health distress among endometriosis patients [8]. In this review, we provide an overview of endometriosis and its impact on patients' mental health. We discuss stigma surrounding the condition, how stigma affects the care of patients, relevant types and sources of stigma, and highlight the need for further systematic research on endometriosis, stigma, and mental health.

Clinical features

Endometriosis is a complex disease and its presentation in patients is heterogeneous. Menstrual pain is its signature symptom [1]. Other

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common symptoms include chronic pelvic pain, dyspareunia, dysmenorrhea and abnormal menstruation, infertility, and gastrointestinal discomfort. Symptoms can start as early as menarche and last until menopause [2]. Yet the intensity of pain does not correlate with the severity of disease. Clinically, the severity of disease is determined based on number of endometrial lesions and their depth and classified from Stage I to Stage IV [1,2]. Some patients may have agonizing pain with mild disease, whereas others may experience mild discomfort with severe disease [1,9]. Others may become aware of endometriosis only after multiple attempts to conceive, when they seek fertility services.

Common comorbidities include migraine, irritable bowel syndrome (IBS), chronic fatigue syndrome, fibromyalgia, uterine fibroids, and ovarian cysts [1]. Endometriosis is characterized by a chronic inflammatory process primarily affecting pelvic tissues, involving the uterus, fallopian tubes, ovaries, peritoneum, and in the spaces between the bladder, uterus, and vagina [2], although the disease can also be found outside the pelvic cavity.

Diagnosis and clinical management

On average, patients spend 7–10 years searching for a diagnosis, and 75% experience initial misdiagnosis [10,11]. Misdiagnosis is a result of low awareness among the public and medical community [12]. Some patients delay medical care as they are unaware of endometriosis and believe their painful menstrual periods are normal [12,13]. For patients that do seek medical care, an abundance of research indicates that they are often dismissed by medical providers, who may normalize their pain and attribute their symptoms to psychological causes [12,14].

A definitive endometriosis diagnosis can only be confirmed through biopsy [1]. Receiving a pathology-confirmed diagnosis of endometriosis is a turning point for all patients, but is particularly validating for those who have been dismissed by medical professionals [12,14]. Seeing a photo or video of their lesions confirms the reality of patients' pain. That said, the invasive nature of a biopsy and its cost are prohibitive for some patients.

Strategies to manage endometriosis include medical treatments such as non-steroidal anti-inflammatory drugs, combined estrogen-progestin hormonal contraceptives, progestins, and other hormone treatments, as well as laparoscopic excision surgery, which must be performed by a physician specialist [1]. While the majority of patients obtain pain relief through these treatments, others continue to experience some level of pain. For those using medical therapies, 11–19% report no pain relief and 5–59% report that they continue to experience some degree of persistent pain after they have terminated treatment [15]. Patients who opt for laparoscopic excision surgery have disease recurrence rates as high as 30–50% [16]. It is believed that several factors contribute to chronic pain despite treatment, including 1) incomplete excision of endometriosis lesions during surgery, resulting in post-surgical accumulation of endometrial tissue, 2) central sensitization, and 3) other comorbid conditions [1].

Endometriosis and psychological distress

The endometriosis disease trajectory can be extremely taxing – both physically and mentally. While each patient experience is unique, the time and energy spent searching for a diagnosis, along with the disabling and unpredictable nature of the disease, generally lead to significant disruptions in multiple domains of life [11,17]. Disturbances to relationships with friends, families, and partners are common. For example, 50–56% of women report that endometriosis affected their intimate relationships, with 8–10% cases resulting in a break-up [18,19]. Many individuals also experience substantial interference with their education and jobs, as they must cease working, take sick leave, or are unable to perform their jobs or school work adequately [18,20]. One study revealed that on average, every week, each person with endometriosis loses 6 h of productivity at work [21]. Difficulties at work are

complicated by employers and colleagues who do not understand the disease and by workplace policies that do not provide necessary sick leave [20]. Disruption to employment, coupled with the cost of treatment of endometriosis also result in financial burden for some patients [13].

Given the wide array of life domains that are affected, it is unsurprising that endometriosis can greatly affect mental health. Rates of anxiety and depression among endometriosis patients are consistently higher when compared to healthy controls [3–5]. Women have described feeling miserable, angry, frustrated, helpless, hopeless, and defeated [13], with some even contemplating suicide [18]. The mental health consequences are in part due to the physical effect of the disease but also by the ways in which patients are treated by others with respect to their condition [22], including dismissal, diagnostic delay, and ineffective treatment. Many are concerned about their future ability to cope with the disease as the recurrence of symptoms is unpredictable [12,13].

Pain resulting from endometriosis is a key driver of disruptions to quality of life [23] and mental health [4,5,7]. Women with endometriosis and chronic pelvic pain (CPP) have higher rates of mental distress when compared to women with endometriosis with no CPP [24]. Additionally, higher pain intensity is associated with higher levels of mental distress [7]. The temporal relationship between chronic pain and mental health distress is likely bidirectional. That is, while depression and anxiety increase the risk of developing chronic pain, chronic pain also increases the risk of depression and anxiety [25].

Stigma and endometriosis

Although there is an abundance of research examining the impact of endometriosis symptoms, pain, and physical functioning on mental health and quality of life, less attention has been paid to the social factors that contribute to wellbeing in endometriosis patients, particularly stigma. Recently, scholars have highlighted that stigma plays an important role in the mental health of endometriosis patients and have called for more research [8].

Goffman's early work remains highly influential in defining stigma [26]; he describes stigma as a "deeply discrediting" and socially undesirable attribute. It is a stain or mark that sets people apart from others and labels them as having a defect of body or character that spoils their appearance or identity. Conceptualization of stigma has evolved somewhat over time, informed by Goffman's foundational work [27–29]. For example, in a particularly well-articulated, integrative approach, Brohan et al. [27] suggest that stigma has three elements: *perceived stigma*, *experienced stigma*, and *self-stigma*. *Perceived stigma* is what an individual believes "most people think about the stigmatized group in general" and "how each individual believes society views him or her personally because he or she is a member of the stigmatized group" [28] (p. 414). Thus, perceived stigma also includes fear of discrimination and unfair treatment [29]. In contrast, *experienced stigma* includes "actual instances of stigmatization and discrimination due to one's status as a member of a stigmatized group" [28] (p. 414). *Self-stigma* involves the negative consequences of perceived and experienced stigma. It occurs when members of a stigmatized group accept and internalize the negative attitudes and stereotypes towards their group and themselves. Self-stigma often manifests in emotions such as shame, blame, hopelessness, and guilt [30].

These levels of stigma have been studied in multiple chronic health conditions, including human-immunodeficiency virus (HIV), hepatitis C, serious mental illness, substance use, obesity, and diabetes. In these conditions, stigma has been shown to be associated with numerous constructs important for mental health, including hopelessness, depression, suicidal ideation, weak social support/integration, and low self-esteem, self-efficacy, and life dissatisfaction [31].

Only a handful of studies have been conducted on stigma in endometriosis, and most of these focus on stigma associated with menstrual pain or menstruation itself. There is a long-standing history of menstrual

stigma across cultures [32,33]. Thanks to initiatives that challenge menstrual stigma, attitudes are changing; however, negative depictions of menstruation have not disappeared completely [34]. Laws [35] noted that negative portrayals of menstruation have influenced individuals who menstruate to develop “menstrual etiquette” – rules around the management of menstruation – because of a fear of discrimination. In other words, the stigma surrounding menstruation leads individuals to develop rules which govern what is and what is not discussed about menstruation, and where it is acceptable to discuss: in physician offices, among female friends and family, or in health education classes. Evidence shows that these rules persist in society; a recent editorial in *The Lancet* notes: “In the UK, nearly 80% of adolescent girls have experienced concerning menstrual symptoms (such as unusually heavy or irregular bleeding) but hadn’t consulted a health professional; 27% of those said they were too embarrassed to discuss the topic” [36] (p. 1). Experimental studies corroborate that menstruating individuals can experience discrimination [37] and internalize stigma, leading to feelings of powerlessness [38].

In Sear’s [39] interviews with 20 endometriosis patients in Australia, participants faced discrimination for revealing menstrual symptoms. After disclosing their menstrual symptoms to family members, romantic partners, friends, employers, and medical providers, their pain was normalized or trivialized. Some were accused of malingering, for example, to avoid work or sex with their partners, and their abilities to perform their jobs effectively were questioned. Sear [39] suggests that stigmatization of menstruation plays a critical role in the stigmatization of endometriosis. Similar results were observed in a study [40] involving focus groups in Puerto Rico. Patients disclosed feeling that others did not view endometriosis as a serious health condition, expressing that their menstrual symptoms were normalized and invalidated. People viewed them as “changuería”, a term used to label someone as a whiner or complainer without an apparent reason. Matías-González and colleagues [41] sought to understand stigma in endometriosis quantitatively and found that endometriosis stigma was associated with higher endometriosis symptomatology, as well as lower quality of life and lower self-esteem in Latin American and Caribbean patients.

Furthermore, Gupta et al. [42] conducted focus group discussions with adolescents in the general population in New York City to understand their attitudes and reactions to people with endometriosis symptoms. Participants were presented with a variety of vignettes, each highlighting different symptoms suggestive of endometriosis. Across groups, there was consensus that such symptoms, such as debilitating menstrual cramps, were stigmatized. The authors discuss how stigma leads to isolation and lack of social support, either because others fail to provide support as they normalize and invalidate endometriosis patients’ symptoms, or because patients choose not to disclose symptoms. They argue that normalization and invalidation can lead patients to doubt their own symptoms, and discourage patients from seeking medical attention. In fact, a UK-based, patient-focused endometriosis charity recently reported that 62% of women with endometriosis delayed seeking medical advice for fear of being dismissed, invalidated, or embarrassed, or because they felt their symptoms were normal [43]. 47% of respondents were concerned about telling their employer that they needed sick leave due to endometriosis.

Although many of the existing studies on endometriosis stigma described above focus on menstrual pain and menstrual stigma, chronic pain is also stigmatized. Given that endometriosis is associated with chronically painful menstruation, sex, and pelvic symptoms, pain stigma can contribute to endometriosis stigma and poorer mental health as well. Chronic pain is well documented within the endometriosis literature, and while the stigma of chronic pain is implied, it is often not explicitly discussed. Scholars have argued that pain is frequently stigmatized and dismissed because it is subjective, invisible, and often not measured using standardized procedures [44]. The subjectivity leads to doubt, which is intensified when pain reports are unaccompanied by

medical findings. De Ruddere et al. [45] demonstrated that pain patients with medically unexplained symptoms are more likely to be socially excluded – people are less sympathetic, are less likely to offer help, and less willing to interact with them than with patients who have medically explained symptoms. Moreover, women’s pain is more likely to be dismissed than men’s pain [46]. Pain associated with sex is particularly vulnerable to stigma given the private nature of this topic [47]. Pain stigma has been linked to anxiety and depression [48]; thus, it is likely that stigma associated with the chronic pain experienced by many women with endometriosis also contributes to stigmatization of the disease and suboptimal mental health.

Additionally, infertility stigma is a likely contributor to endometriosis stigma and poorer mental health in people with endometriosis, as up to half of endometriosis patients experience infertility [49]. While it is generally accepted that more advanced stages of the disease, Stages III and IV, cause infertility, the connection between endometriosis and infertility is less clear in Stages I and II [50].

Although the experience of infertility differs cross culturally and is related to differences in gender norms [51], infertility stigma appears to be a universal experience as the norm across cultures is for humans to reproduce. Regardless of the primary source of infertility, the female partner is often perceived to have fertility problems [52]. Women that deviate from the gendered role of motherhood may be labeled as deficient and defective. Participants in Taebi et al.’s [53] qualitative study in Iran discussed how a common belief is that a childless house is “cold and spiritless” (p. 191). Participants expressed feeling humiliated due to degrading looks and comments from others, primarily other women. In Ghana, women described being called a “witch,” “barren,” and as possessing “spirits,” sometimes leading to exclusion from important events [52] (p. 7). Some of them also experienced intimate partner violence in the form of verbal abuse and physical abuse. In the U.S., women have described receiving “unnecessary attention” [54] for not having children, unsolicited advice such as herbal remedies and sex positions to facilitate conception, and being told they need “only relax” to become pregnant, originating from the mistaken belief that infertility is caused by a woman’s emotional state [55]. Infertility stigma has been linked with depression and anxiety [51,56]. While research on the role of infertility stigma in endometriosis is lacking, given the prevalence of infertility in endometriosis patients and findings from infertility studies, infertility stigma is a likely contributor to stigma and poor mental health in endometriosis.

In summary, research demonstrates that stigma influences mental wellbeing and that it deserves more attention in endometriosis, given that mental distress is common among endometriosis patients. Stigma at all levels – including perceived stigma, experienced stigma, and self-stigma – has been found to influence wellbeing in a variety of chronic illnesses. Although research on stigma in endometriosis is sparse, it already shows that stigma is prevalent. Existing studies focus on stigma surrounding menstruation, yet research on the experience of endometriosis shows that chronic pain and infertility – conditions that are frequently stigmatized – are also common among patients. Therefore, in addition to menstrual stigma, it is likely that chronic pain and infertility stigma are contributors to the overall stigma experienced by individuals with endometriosis. However, the prevalence of these types of stigma and their particular impact on mental health in endometriosis patients is presently unknown. Patient stigma and poor mental health can be serious impediments to health care. Clearly, more work is needed to elucidate the relationship between stigma and mental health in endometriosis; the next section focuses on future directions for research.

Future directions

Existing studies of endometriosis-related stigma have made important contributions to a field where rigorous research is lacking. However, there remains much room for improvement. First, a better understanding of endometriosis stigma, and how stigma associated with

menstruation, chronic pain, and infertility independently and jointly influence endometriosis stigma, is needed. Expanding research on endometriosis stigma beyond its prior focus on menstrual pain will allow for a deeper appreciation of stigma in endometriosis and its impact on mental health. This type of research can be enhanced by incorporating clearer, theoretically-based definitions of stigma, including differentiating perceived, experienced, and self-stigma. Applying stigma theory to research will help identify the mechanisms through which stigma acts to influence mental health. Studies can be designed to understand how the different levels (perceived, experienced, and self-stigma) or types (menstrual, chronic pain, and infertility stigma) of stigma produce poorer mental health. Endometriosis-specific stigma scales would be especially valuable to conduct such research. The Stigma Scale for Chronic Illness (SSCI) [57], for example, is a validated, 24-item scale to measure experienced stigma and self-stigma in individuals with chronic illness. Respondents rate their agreement with statements such as “Because of my illness, some people avoided me,” on a Likert scale. Matías-González and colleagues used the 8-item short form of this scale and adapted it to the endometriosis population [41]. Adapting the full version of the SSCI to the endometriosis population will allow for a more nuanced understanding of how the different levels of stigma affect patients. Such an endometriosis-specific stigma scale can then be used together with scales that examine menstrual, chronic pain, and infertility stigma, to better understand how they contribute to the experience of endometriosis. Several validated scales already exist; the Menstrual Self-Evaluation Scale (MSES) [58], Chronic Pain Stigma Scale (CPSS) [59], and Infertility Stigma Scale (ISS) [60] are excellent options that can be adapted to study endometriosis.

There is evidence that endometriosis patients delay seeking medical care due to the stigma associated with their symptoms [43]. For those who do visit a care professional, it is common for their symptoms to be normalized and invalidated [12,14]. Thus, endometriosis stigma interferes with patient care-seeking and the quality of care that they receive. Better understanding of stigma and mental health in people with endometriosis will enhance the standard of care for this patient population. Additionally, physicians can help to raise awareness of endometriosis among the general public to help reduce stigma, and can discuss the influence of stigma on mental health with patients and guide them, when needed, to seek appropriate mental health services and support. Elucidating the sources of stigma that endometriosis patients experience and the mechanisms through which stigma influences their mental health can also be used to improve interventions focused at individual, community, and societal levels.

Conclusion

The present article provides an overview of existing research examining how stigma influences the mental health of individuals living with endometriosis, and identifies gaps in current knowledge. Stigma is an important, but under-studied dimension of the experience of endometriosis, and an important target to improve the wellbeing of patients and the clinical care provided to them. In order to achieve this, research must be expanded to obtain a fine-tuned understanding of how stigma influences patients' experience. The standard of care can only be improved when addressed at multiple layers – including the medical as well as the psychosocial.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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