

Protean Symptoms and Reductive Diagnosis

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Abstract

Endometriosis is a common, but difficult to diagnose and manage, condition for women of reproductive age. Published studies have shown that healthcare providers and women comprehend endometriosis from different perspectives. To identify the notions behind the discrepancies between the descriptions of women with endometriosis and healthcare professionals, we explored the reported impacts and manifestations described for endometriosis. Two branches regarding the impact of endometriosis on women were categorized as follows: disability and isolation, as well as pain and intimacy. In contrast, the features of the symptoms were characterized as protean and diffusing symptoms that were simplified to obtain reductive diagnosis, and anchor versus relief. To promote healthcare for women with endometriosis, researchers must embrace a broader and more holistic approach to the investigation of emic knowledge of women with endometriosis.

Introduction

Endometriosis is a common, but difficult to diagnose and manage, condition for women of reproductive age [1]. Given that the physical manifestations of endometriosis cause women to suffer from potential impacts on fertility, intimate relationships, and social psychological distress [1-3], endometriosis has been described to cause disruptions in daily life [1,4].

Oral or written descriptions about an illness and the effect of an illness are termed illness narratives [5]. People describe an illness within the frame of particular types of illnesses and the typical forms of their appearance but also with a practical or instrumental attitude regarding the illness [6]. Written narratives about illnesses and the effects on the lives of affected people do not merely reflect the experience of symptoms and suffering [7], but also contributes to understand narrators' knowledge and ideas about illness.

Published studies have shown significant gaps between the descriptions of the symptoms of endometriosis provided by women and gynaecologists [3,8,9]. To identify the notions behind the discrepancies between the descriptions of women with endometriosis and healthcare professionals, we review the published literatures concerning the effects and symptoms related to endometriosis, to provide insights regarding the current discourses on endometriosis as well as a deeper reflection on the clinical practice.

Women with Endometriosis

Consequent to fluctuations in hormones, the endometrial tissue outside of the uterine cavity swells, bleeds and releases inflammatory substances into the surrounding tissue of different parts of the body. The symptoms of endometriosis are diverse and include heavy menstrual bleeding, pain, fatigue, malaise, abdomen distention, diarrhoea, alginuresis, dyspareunia, insomnia and depression, which are experienced monthly [1,10,11]. Treatments for endometriosis, including analgesics, gonadotropin-releasing hormone agonist (GnRH), oral contraceptives, laparoscopy and radical surgery, cannot cure the illness and instead focus on symptom relief [1]. The symptoms and treatment of endometriosis have been revealed to cause impacts on women's daily life.

Studies have shown that the experience of living with endometriosis can be represented by narratives from women diagnosed with this condition. Qualitative studies investigating endometriosis have

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revealed that the two branches of the illness experience are 1) disability and isolation and 2) pain and intimacy.

Disability and Isolation

To examine the psychosocial impact of endometriosis, Culley et al. reviewed 42 peer-reviewed, English-language journal articles, which included 23 quantitative, 16 qualitative and 3 mixed-methods studies. These selected studies have demonstrated that endometriosis harmfully and substantively impairs women's health and daily life. The majority of women in those studies reported noticeable impairments in quality of life and everyday activities due to endometriosis-related as well as coexisting symptoms. These impairments may persist over time. The long-term effects of treatments are unknown, and there is no cure. A decrease in energy and vitality has been mentioned [1]. A recent qualitative study focusing on descriptions of the "occurrence and diagnosis" of endometriosis by 6 gynaecologists and 12 patients also demonstrated that the women experienced different feelings that interfere with their wellbeing and lives, and sometimes were disabling [8].

Fourquet, Gao, Zavala, Orengo, Abac, Ruiz, Laboy and Flores noted that the severe and chronic pain has a negative impact on work performance, on family relationships and self-esteem, and on all aspects of life [10]. Since biomedicine can not improve the intense pain, many women are unable to handle daily affairs of life and daily activities during their menstrual period, especially when their pain is most severe. These disruptions lead to feelings of fatigue, sadness, fear, hopelessness, powerlessness, alienation and depression [3, 12]. The feelings are accompanied by a condition that is chronic, of an uncertain etiology, or fail to improve [12]. Hence, women with endometriosis have experienced physical limitations in conducting daily tasks such as domestic tasks, as well as disturbances in their social life resulting in isolation [13].

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Symptoms of endometriosis

Women with endometriosis experience incapacitating pain and dyspareunia, which negatively affects their sex lives and intimate relationships [1, 10]. Pelvic pain associated with a lack of sexual desire, and impaired sexual function has been reported by women [14]. A number of articles report that women with dyspareunia avoid or limit sexual intercourse or endure intercourse due to a desire for pregnancy, maintaining a normal life and closeness with a partner [1, 3, 15]. All of these result in feelings of inadequacy and guilt, and they also have a negative impact on intimacy, that contributes, in some cases, to relationship breakdown [1]. Some women experience both dyspareunia and infertility, causing them to feel like they have lost their female role [3]. However, some women and their spouse become a unity to struggle and seek resources together [15].

Qualitative studies have reported that women with endometriosis are reluctant to discuss their intercourse pain with healthcare professionals, or anyone, and healthcare professionals do not question women about sexuality [1, 4, 13]. Emad investigated women's sexuality and found that several women felt free to discuss the painful sex in an online discussion, but this issue was seldom discussed in medical care [13]. Taken together, the sexual issue is seldom discussed by either physicians or women, but it is an important factor affecting intimate relationships [16].

Pain and Intimacy

Most of the women participating in the studies were symptomatic; 72% reported having more than 8 endometriosis-related or coexisting symptoms [10]. Dysmenorrhea, incapacitating pain, and intercourse pain were the most common symptoms [10]. A ignoring and neglecting of women's illness has been reported which cause women with endometriosis to experience a range of problems without adequate support [4]. A systematic review and integration of the findings of qualitative research indicated that the symptom descriptions provided by physicians were less severe than those described by the women [8]. Cox, Henderson, Andersen, Cagliarini and Ski [4] designed five focus groups to explore the informational need of women with endometriosis. They found that the worst experiences described by these women were their encounters with health professionals, and the trivialization and dismissal on their complains. Riazi, Tehranian, Ziaei, Mohammadi, Hajizadeh and Montazeri [3] explored the perception and experiences of patients and physicians regarding the occurrence and diagnosis of endometriosis. They reported that some women are misdiagnosed with recurrent pelvic infections or chronic infections, and are treated for these diagnoses for many years. To provide insights regarding current discourses on the symptoms of endometriosis, the features of the reported manifestations are described below.

Protean and diffusing symptoms

Qualitative studies have shown that women describe their experiences with endometriosis based on the sensations in their body [3,9,11,17]. Pain is the most common complain of women with endometriosis. The majority of the narratives provided by women surround the nature of the pain, such as the severity, quality, temporality, location, and impacts. The pain is described as crippling, disabling, insides coming out of my body, lower back, on the rack, constant ache, legs as lumps of iron, not often free of it, worse during menstruation, a gnawing pain that keeps awake, and sitting on a

knitting needle [11]. Emad used an online public space for women with endometriosis to write daily and voice their experiences concerning their illness. Among the words which women used to describe their pain, terms such as the alienating intractability of the pain, rein habiting pain, engulfing pain; the pain occurs before and during menstrual periods, during and after sexual activity, often during and after bowel movements [13]. Pain also causes various problems in different parts of the body, such as abdominal pain, headache, lower back pain, anal pain, mastalgia and lower limb pain [3].

Denny [15] also described the experiences of women with endometriosis and found that during occurrence of the worst pain, the women were vomiting or dizzy, and some women experienced severe pain around the time of ovulation that was almost constant [16]. The severity of the pain fluctuates in a wavelike manner according to menstruation or treatment and is considered to impair function. Pain increases in severity and duration over the years for most of women with endometriosis, at times almost disappearing in response to treatment but usually re-occurring with renewed intensity [11].

The symptoms of endometriosis are always chronic and an intense presence in everyday reality. Pain and other symptoms are consistently and repeatedly expressed by affected women. Sometimes the women could not verbalize the unpredictable and equivocal sensation, but it was a reality in their bodies.

Simplified and reductive diagnosis

For some of the women with endometriosis, painful symptoms started during adolescence (11-19 years old) [10]. Some women visited with five or more physicians before being diagnosed [10]. Ultrasonography, CA125, family history, and laparoscopy are usually employed to determine the diagnosis. Family history has been considered as a key factor leading to the diagnosis of endometriosis by the physician [3]. However, laparoscopy remains the gold standard for the diagnosis of endometriosis.

Although various symptoms occurred concomitantly, the symptoms were not integrated into any pattern but rather were considered to be different problems for many years [11]. Pain has been described as a crucial and destructive feature of endometriosis. Pain has been documented according to different characteristics and impacts various parts of body, according to the physiology of pain [18]. Health professionals usually ask women to describe the intensity of their pain based on the assessment tools used in western medicine, such as a pain scale of 1-10, but they rarely consider the quality and temporality of the pain [11,13,16]. The symptoms and signs corresponded to a specific body part or function, e.g., the pelvis, bladder, bowel, menstruation, intercourse, and fertility, among others [1,4,9]. Conventional treatments only provided temporary palliation for months or a few years [1,3]. Health professionals have seldom considered the complaints related to recurrence and the accumulation of pain [11,13]. Some physicians have recognized periodic symptoms as typical manifestations of normal menstruation [3,9].

The clinical reasoning for differentiating the manifestations of endometriosis is centered upon a specific biomedical model which break human's body into fragments. This model assumes that the pain, a symptom of endometriosis, can be reliably quantified using one-dimensional tools and can be reduced into pieces and eliminated piece by piece. However, chronic pain requires a multidimensional qualitative assessment and holistic intervention [19]. A lack of

concern regarding the nature of pain can result in a delayed diagnosis and overlook the women in difficulty [4].

Anchor and Relief

Diagnostic delay is a common experience for women with endometriosis. The diagnostic process typically takes 3-10 years, and women with endometriosis endure cruel symptoms for years without being diagnosed [1,10,11]. The main causes of the delayed diagnosis are as follows: analgesic and hormonal formulations complicate the manifestation of endometriosis during early stages of disease [3]; a lack of endometriosis awareness [1, 9]; and the complaints of women being attributed to a psychosomatic disorder or being normalized [8, 9].

After the diagnosis was made, treatment only relieves symptoms for a period of time, and is not helpful for some women who eventually undergo multiple laparoscopies [4]. Some women seek help from alternative medicine [20] and attempt to change their activity and dietary habits to control their symptoms [11]. However, women and professionals both are engaged in the search for a reliable diagnostic indicator [3]. Receiving a definite diagnosis of endometriosis has been defined as a critical stage of a women's illness trajectory [11].

A diagnosis of endometriosis provides women with the name of a physiologic disorder, which results in access to both biomedical managements and to the knowledge offered by groups of women with the same diagnosis. It also frees patients from the stigma associated with having a disability or a psychosomatic disorder [1, 3]. Thus, the diagnosis of endometriosis provides an anchor for the long-term illness and relief from psychosocial suffering.

Conclusions and Suggestions

There are no abnormalities in the appearance of women with endometriosis, but they suffer from their condition. Under the impact of protean symptoms, women experience considerable disability in performing daily life tasks, going to social activities and maintaining intimate relationships. In published articles, the individual illness experience and clinicians' efforts in the diagnostic process all are presented in the context of western medicine. However, there is a significant discrepancy between the descriptions of endometriosis provided by affected women compared with the descriptions provided by gynecologists. The main feature of this gap is that women describe endometriosis as a chronic, complicated, and disabling condition, but primary healthcare practitioners diagnose and treat each symptom as capable of being located, cured and present as an independently occurring problem.

Published studies have shown that healthcare providers and women comprehend endometriosis from different perspectives [3, 9]. By enduring a chronic, mysterious pain with an unknown cause for a long time, women develop their knowledge of endometriosis based on the sensations in their body, information from others and interactions with physicians. Conversely, primary healthcare professionals, e.g., physicians and nurses, learn the schemas and techniques to approach women from textbooks [11, 20]. To promote healthcare for women with endometriosis, researchers need to regard the women as experts on endometriosis, and embrace a broader and more holistic approach to investigate women's descriptions of their symptoms. Women's emic knowledge of their body on endometriosis can provide a valid supplement for the healthcare of women with endometriosis.

Because the majority of women with endometriosis present various symptoms concurrently, researchers should consider the holistic impact of a group of symptoms rather than a specific problem. Some researchers have mentioned that lifestyle changes and alternative therapies are helpful to relieve suffering. Few studies have focused on the relationships between symptoms and complementary and alternative medicine (CAM). Given the impact of endometriosis, further researches should consider the common compositions of symptoms and the effects of CAM.

Competing Interests

The authors declare that they have no competing interests.

Authors' Contributions

Study conception, design and coordination: HCC, HLL, and SMW; performed literature search, selection, final review of results and findings, wrote the manuscript: HCC and SMW; revise the manuscript: HCC. All authors read and approved the final manuscript.

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