

“Free butterflies will come out of these deep wounds”:

A grounded theory of how endometriosis affects women’s psychological health

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Abstract

This study aimed to develop a grounded theory of how endometriosis affects psychological health. Open interviews were conducted with 74 patients. The Hospital Anxiety and Depression Scale (HADS) was administered to all women, who were divided into distressed vs. non-distressed. At the core of our grounded theory was the notion of disruption due to the common features of living with endometriosis. Experiencing disruption (vs. restoring continuity) involved higher distress and was associated with a long pathway to diagnosis, bad doctor-patient relationships, poor physical health, lack of support, negative sense of female identity, and identification of life with endometriosis.

Keywords

Disruption, endometriosis, grounded theory, psychological distress, psychological health

Introduction

Endometriosis is a gynecological disease characterized by growth of endometrial tissue outside the uterus, with an estimated prevalence of 5-10% among women of reproductive age (Viganò et al. 2004). Endometriosis is a chronic disease associated with infertility and its treatment requires a long-term strategy aimed at managing symptoms. Endometriosis is painful in most women (up to 80%; Bulletti et al. 2010), who may experience different types of pain, such as dysmenorrhea (pain at menstruation), dyspareunia (pain at intercourse), dyschezia (pain at defecation), and chronic pelvic pain. Painful endometriosis is associated with depression, anxiety, and impaired quality of life (Facchin et al. 2015; Pope et al. 2015). Endometriosis is also an inflammatory disease, because the presence of endometrial tissue outside the uterine cavity causes an inflammatory response (Luisi et al. 2015). Several studies have demonstrated that inflammatory diseases such as endometriosis may be associated with mood disorders due to the interaction between the immune system and the neural central system (Nasyrova et al. 2011). Qualitative research has described the negative impact of the disease and pelvic pain on several dimensions, such as everyday activities, social and work functioning, family and intimate relationships, plans for the future (including having children), and psychological wellbeing (Denny 2009; Roomaney and Kagee 2015, 2016). However, these studies examined the psychosocial impact of endometriosis without addressing any specific research question focused on individual differences, which seem to play an important role among women with this disease (Facchin et al. 2016). For example, no studies have systematically investigated how and why endometriosis differently affects women, such that not all of them are distressed. It is known that women with painful endometriosis may have poorer mental health and quality of life as compared with those who do not have pain (Facchin et al. 2015; Pope et al. 2015). However, more research is needed to develop a comprehensive explanatory theory of the psychological impact of endometriosis.

Thus, we conducted a grounded theory study aimed at providing a broader understanding of how endometriosis affects women's psychological health.

Methods

Procedures and participants

This study was conducted between 2014 and 2015 into an Italian tertiary-level referral center for the treatment of endometriosis with the approval of the local Ethics Committee and aimed at developing a dynamic theory to: (a) describe the common characteristics of living with endometriosis; (b) explain why some women have clinically significant distress, while some others do not, although affected by the same disease. Consistent with a grounded theory approach (Corbin and Strauss 2008), we used theoretical sampling, a recursive process in which data collection and analysis occur simultaneously. Because effort was made to account for the most variability in women's experience of endometriosis, data collection was expanded to the point of reaching a number of participants ($N = 74$) that is uncommon for grounded theory studies, in which sample size usually ranges from 10 to 60 persons (Starks and Trinidad 2007).

Eligible participants were women consecutively self-referring to our endometriosis center, who had surgical diagnosis of endometriosis and fluency in Italian. Data collection began with purposive recruitment of patients who met the inclusion criteria and suffered from different forms of endometriosis, and proceeded until theoretical saturation was reached (Morse et al. 2002), i.e., the emergent theory was fully represented by the data collected. At the end of their gynecological visit, eligible women were invited to participate in a study that involved an open interview focused on living with endometriosis. A story-telling approach was used to encourage women narrate their personal experience with endometriosis ('Can you tell us your endometriosis history?'). All patients received complete information about

the research goals and procedures (including privacy protection), were aware that participation was voluntary and without any type of reward, and that they were free to interrupt the interview and leave the study at any time. Written informed consent was provided by all participants. None of the women recruited withdrew from the study or asked to interrupt the interview. Individual interviews took place in a private room into the dedicated center and were tape-recorded (and subsequently transcribed) with permission. The interviews lasted 45 minutes on average and were conducted by trained psychologists, including the first author; field notes were taken during the interviews.

All participants also completed the Italian version of the Hospital Anxiety and Depression Scale (HADS; Costantini et al. 1999; Zigmond and Snaith 1983), a self-report questionnaire that we administer to endometriosis patients in our routine clinical practice to assess psychological health. The HADS provides scores for two 7-item subscales (HADS-Anxiety and HADS-Depression) and a full scale score (HADS-Total; scores ranging from 0 to 42). In this study, the HADS total scores were used to compare distressed versus non-distressed patients, with scores ≥ 15 indicating clinically significant distress (Grassi et al. 2013).

Data analysis

Data analysis was performed independently by three of the authors throughout data collection using a constant comparative method (Corbin and Strauss 2008). Initial line-by-line textual analysis (*open coding*) of all transcripts (282 pages) was conducted to develop preliminary theory concepts (open codes); in the second analytic phase (*axial coding*), the open codes were condensed into conceptual categories, and in the third phase (*selective coding*) the final explanatory theory was constructed through the identification of the category that accounted for most of the variation in the data and articulated the relationships among categories, i.e.,

the core category (Draucker et al. 2007). We examined the field notes taken during the interviews and the memos written throughout the research process to create an audit trail aimed at providing clear description of the steps taken. All emerging themes were constantly discussed by the research team and feedbacks about the final theoretical construction were asked to expert gynecologists, as well as to women members of a non-profit endometriosis association. All discrepancies were discussed until full consensus was reached.

Results

Living with endometriosis: common themes

Participants were 74 Caucasian women aged from 24 to 50 (see Supplemental Table 1). Four categories emerged from the analyses of almost all interviews and therefore can be considered as common aspects of living with endometriosis (see Supplemental Table 2): (a) experiencing pain; (b) having a chronic disease; (c) dealing with anticipated or ascertained infertility; (d) needing specialized and multidisciplinary care.

Experiencing pain. Although several women (37.8%) were not currently suffering from persistent pelvic pain, almost all participants stated that symptom onset was characterized by intense pelvic pain, especially dysmenorrhea and non-menstrual pelvic pain: “[...] This pain involves your back, the rectum, your legs, your head. It drives you crazy” (35-year-old woman). Overall, patients displayed a tendency to normalize their period pain. Normalization was enforced by doctors, who were often unable to understand women’s complaints, as well as by participants’ significant others, including women’s mothers and girlfriends. Due to normalization, many participants ignored their pain or tried to relieve it with a huge amount of over-the-counter analgesics, to the point of seeking help only when their sufferance was extremely high and endometriosis had already caused damages.

Having a chronic disease. For almost all women, the main struggle was to accept having a disease for which there is no definitive cure. This emerging category involved two subthemes:

Endometriosis and everyday life. Endometriosis interfered with multiple aspects of women lives, for instance in terms of difficulties in finding an effective way to explain their disease to friends and coworkers. Many women felt like their friends and colleagues thought they were constantly in a bad mood, while they were actually in pain, with remarkable limitations in social and work functioning due to endometriosis symptoms, including heavy bleeding during period and chronic fatigue. In many cases, living with endometriosis meant not feeling understood by others.

Endometriosis and intimate relationships. Almost all women talked about the way in which endometriosis affected their actual or potential intimate relationships. Infertility represented a primary concern, followed by poor sexuality due to pain at intercourse, but also to an overall lack of desire caused by pharmacological treatments.

Dealing with anticipated or ascertained infertility. Being diagnosed with endometriosis involves becoming aware that conceiving may be impossible, or at least very difficult. Considering that all participants were diagnosed in reproductive age, it is not surprising that almost all of them felt threatened by infertility.

Needing specialized and multidisciplinary care. Our study was conducted in a specialized center, but most patients had previous experiences of general care. For many women, moving from general to specialized care involved a positive change because they felt reassured by the fact of being cured by doctors who had a specific expertise in endometriosis. Several women

reported negative experiences with doctors who were unable to diagnose endometriosis, or to provide adequate information. Endometriosis is a complex disease that affects multiple parts of the body (such as bladder and intestines). Thus, many women underlined the importance of a multidisciplinary team approach that should include different medical professionals, as well as psychologists and psychotherapists.

How endometriosis affects psychological health: experiencing disruption vs. restoring continuity

The differences between distressed and non-distressed women were explained by a superordinate theme entitled *experiencing disruption vs. restoring continuity*, which is at the core of our grounded theory (see Figure 1). In this context, the notion of disruption is referred to as an interruption of women's regular lives due to endometriosis. One may say that all women who are affected by the disease may experience a certain degree of disruption due to the common features of living with endometriosis, a challenge for any woman. However, the endometriosis histories of our distressed participants were characterized by an intense experience of disruption that involved a dramatic rupture in multiple domains of their lives: everyday normal activities, including work; plans for the future; intimate and interpersonal relationships; sense of identity.

Some distressed participants felt 'devastated' by endometriosis. These women seemed extremely overwhelmed or even dominated by the disease, to the point of organizing their entire existence around it. On the other hand, non-distressed participants expressed how endometriosis may have caused initial disruption, but these women seemed more able to adjust to their illness and to find their individual way to live with it, which led to a restored sense of continuity in their personal experience.

The process of *experiencing disruption vs. restoring continuity*, which was at the core of our participants' endometriosis experience, was affected by six factors (see Table 1): (a) pathway to diagnosis, which included a subtheme entitled *communication of the diagnosis*; (b) quality of doctor-patient relationship; (c) current presence of symptoms; (d) support, which included two subthemes: *intimate relationships* and *financial support*; (e) female identity, which involved *impact of infertility, body image, and sexuality*; (f) meaning of life with endometriosis.

Pathway to diagnosis. All women talked about their pathway to diagnosis. The stories of distressed women were characterized by a slow track to diagnosis (up to 12 years from symptom onset to diagnosis). Normalization was the major cause of delayed diagnosis. Some women felt treated like they were insane, especially by doctors, as pointed out by this 32-year-old woman: "They thought I was crazy [...] and I felt so disheartened". For distressed women, the long pathway to diagnosis involved intense physical and emotional suffering ("panic", "terror"), traumatizing hospitalizations, and negative experiences with doctors. On the other hand, almost all non-distressed women reported a fast track to diagnosis, since endometriosis was discovered a short time after symptom onset. These women may have had even severe physical pain, but their pathway to diagnosis did not involve the devaluation and the overall emotional upheaval that emerged from the stories of distressed patients.

Communication of the diagnosis. Many women felt relieved on receiving the diagnosis, which involved a final legitimization of their pain as real. However, the way in which the diagnosis of endometriosis was communicated differed between distressed and non-distressed women. The experiences reported by distressed women were characterized by bad doctor-patient communications, with poor or confused information, lack of empathy and support, with dramatic feelings of loneliness and helplessness, fear and loss of control. When

the doctor-patient communication was poor, women were more likely to use the internet to retrieve information, which led to increased stress and wrong self-treatment as that material was general and not specifically focused on the individual case. Non-distressed women reported positive experiences with doctors who provided complete information regarding endometriosis and its treatment. These women described the communication of the diagnosis as “open”, “clear”, “transparent”, “honest”. For women with the lowest levels of anxiety, which was predominant among distressed women relative to depression, choices regarding treatment options, including surgery when necessary, were effectively shaped by the complete and consistent information received.

Quality of doctor-patient relationship. Distressed participants reported remarkable difficulties in the doctor-patient relationship, with an overall lack of trust, as well as intense anger towards doctors who did not believe their sufferance was real, or provided incorrect diagnosis. For many years these patients visited different doctors without having one they could trust, to the point that a 42-year-old woman said: “I felt like a laboratory rat!”. On the other hand, non-distressed patients reported very positive relationships with gynecologists, using words like “faith”, “professionalism”, “competence”, “understanding”, “empathy”. Non-distressed women felt sustained and guided by their doctors, who not only provided information and tools to manage the disease, but also made women feel listened to and understood. Several non-distressed women claimed they believed in the importance of clinical research to increase knowledge about endometriosis and some of them had already participated in clinical trials.

Current presence of symptoms. Although almost all women had experienced severe pelvic pain, many of them were currently pain-free due to medical treatment. However, several

distressed women were still suffering from pelvic pain, especially those who were not under hormonal therapy, or from other types of pain related to other diseases. Some women had abdominal pain caused by problems other than endometriosis, such as Chron's disease or irritable colon syndrome. Some others stopped taking hormonal therapy due to migraine headache. Many distressed patients complained of chronic fatigue, which is a common endometriosis symptom: "Fatigue is something that belongs to endometriosis. It really wears you out" (43-year-old woman). Among non-distressed patients, those with symptomatic endometriosis had an overall better physical health relative to distressed participants and had found their own personal effective way for managing endometriosis symptoms.

Support. Although almost all participants had to alter their everyday life due to endometriosis, distressed participants felt like they were alone in their struggle with endometriosis. Many distressed women described how they had been and still were suffering from a general lack of support and understanding in different settings: family, work, doctor-patient relationships, intimate relationships, interpersonal relationships: "I can't count on anyone but myself" (43-year-old woman). Non-distressed women revealed that endometriosis had unexpectedly helped them identify who their real friends were, i.e., people who remained on their side through the good and bad times. Non-distressed participants emphasized how they felt "loved", "sustained", "supported", "accompanied" by their significant others, including doctors. These women had positive feelings towards the others, such as trust and closeness, and felt like endometriosis made them more connected to the other people and more empathic. This was an important difference between non-distressed and distressed women, who seemed to be alienated from social life by endometriosis.

Intimate relationships. For non-distressed participants who were in a relationship, the intimate partner represented an important source of love and support. Distressed women told

different stories characterized by relationship breakups due to endometriosis, and/or by negative feelings toward partners, such as anger, sense of guilt, shame: “For a long time I’ve been asking myself, maybe he would fit better with someone else, someone who doesn’t have my problems. I feel guilty” (38-year-old woman).

Financial support. The need for financial support represented another source of stress for our endometriosis participants. The economic burden of endometriosis was due to the costs of pharmacological therapy, specialist care, hospitalizations, and transfers to reach specialized centers.

Female identity. Endometriosis negatively affected women’s female identity and this led to high levels of distress. Although almost all participants talked about the many struggles and frustrations due to endometriosis, distressed women showed an extremely negative sense of their female identity, with low self-esteem and low perception of their own value: “I am only half a woman” (28-year-old woman).

Impact of infertility. Most women in our sample had a wish to conceive, but had not tried yet. These women, as well as those who were trying to get pregnant without success (a few participants were trying in vitro fertilization), had to deal with the threat of infertility. Other women had ascertained infertility, due for instance to radical surgery. However, not all these women were distressed. Why? Non-distressed women had to deal with a huge amount of struggles and frustrations related to actual or anticipated infertility, but fertility problems did not destroy their female identity and self-esteem. These women recounted hard times and sadness, but they currently showed full acceptance of their situation and were still able to see themselves as valuable women, who deserved love and appreciation. Other women stated they were stressed because they were not currently willing to have a child (for instance because they were too young, or were not in a stable relationship), but they felt pressured by

doctors who had strongly advised them to conceive as soon as they could to avoid future problems. Many women whose female identity was very negatively affected by infertility reported specific anxiety disorders, such as recurring panic attacks that started after the diagnosis of endometriosis and were connected to the fear of infertility. These women also displayed from moderate to severe depression, but only a few had sought professional psychological help.

Body image. Almost all participants had a negative body image, mostly characterized by seeing themselves as overweight as a consequence of hormonal therapy. However, distressed women described the relationship with their body as a constant struggle to control its tendency to gain weight, or to manage the physical symptoms caused by induced menopause (tiredness, hot flashes, vaginal dryness, poor libido). Body image influenced choices regarding what to wear (for instance, large clothes to hide bloated belly), to the point that a 42 year-old woman claimed: "The more my body is covered up, the better it is!". The scars left by surgical interventions represented another concern for many participants.

Sexuality. Many women told they were feeling older than they actually were due to pharmacological therapy, which caused an overall loss of libido, as well as other types of sexual dysfunctions. However, non-distressed women, especially those who were in a stable relationship, had been able to find a way to have sexual intercourses with their partner (by choosing the right position in order to avoid too much pressure or deep penetration; by planning sex around endometriosis acute symptoms and/or menstrual periods; by finding other ways to please themselves and their partners when vaginal intercourse was too painful) and were still enjoying their sexual life despite endometriosis. In contrast, many distressed women said they completely lost interest in sex, to the point that they were totally avoiding it. These participants were overwhelmed by negative thoughts and feelings related to infertility, and were convinced that endometriosis had made them irremediably flawed. They perceived

endometriosis as ‘their own problem’ and were not likely to consider that it could be shared and discussed with their actual or potential partner to find a way to deal with it as a couple, rather than as an isolated individual.

Meaning of life with endometriosis. Distressed women seemed mortified by the certainty of being a failure as women and perceived their femininity as a conviction. Their female identity was reduced to the disease and it seemed as though endometriosis had pervaded their entire existence. Many distressed women described themselves as pessimist and anxious, while non-distressed participants displayed a positive orientation towards life, acceptance of the disease, as well as sense of humor and spiritual resources (which involved religious faith, but also life dreams, interests, and aspirations). Non-distressed women were able to identify sources of growth in the challenge of endometriosis, such as the chance to discover unknown positive aspects of their personality, strength, and courage. Other participants described an increased feeling of connectedness with others, as well as an improved ability to acknowledge that life does have a meaning and may be pleasant despite endometriosis:

I realized that I didn’t want to be my disease, I just wanted to be myself. I didn’t want my endometriosis to destroy my projects and objectives. I wanted to deal with it and integrate it into my life. It doesn’t come naturally, it takes effort, but it’s important.

(47-year-old woman)

Discussion

We conducted a large grounded theory study aimed to understand how and why endometriosis affects women’s psychological health overall, as well as by comparing distressed vs. non-distressed participants. The 74 interviews analyzed allowed to examine different situations in terms of type and severity of endometriosis, presence of symptoms,

including pelvic pain, fertility status, and psychological health conditions, which we assessed using the HADS.

At the core of our theoretical construction is the process of *experiencing disruption vs. restoring continuity*. Disruption, which is a key concept in the research on chronic illness (see Aasbø et al. 2016; Larsson and Grassman 2012), is experienced by all women with endometriosis, to some extent. The stressful nature of endometriosis as a painful, cyclical, unpredictable disease, has been widely acknowledged by the literature (see Culley et al. 2013). Most of our participants recounted difficulties with doctors, friends, and families who normalized or even trivialized their pain. Several studies underlined how dangerous it may be to underestimate period pain complaints (Manderson et al. 2008). Our findings confirm that normalization of pain can lead to diagnostic delays, which represent a major source of distress for women. Normalization of period pain may depend on a culturally determined gender belief according to which femininity equals pain. Because all women have menstruations, pain is considered as normal and those who complain are labeled as weak, or even pretenders. These labels stick to women's identity, especially when put by their significant others.

Although the common components of living with endometriosis have been identified by other studies, the original contribution of our article is a dynamic theory that explains why some women are distressed, while others are not. According to our theoretical construction, endometriosis may cause a huge amount of distress when the women affected experience their disease as an irremediably disruptive event that involves a definitive rupture in their lives (i.e., *experiencing disruption*). The impact of life disruption due to endometriosis has been underlined by other studies. Guilmour et al. (2008) found that disruption represented a crucial theme in the interviews of 18 women with endometriosis, for which the disease entailed an interruption of the regular flow of their existence (i.e., going to university,

working, playing sports, attending social events), with anger, depression, and lack of enthusiasm. Hudson et al. (2016) explored the notion of biographical disruption as used in sociological research (Bury 1982) on the lived experience of chronic illness in couples dealing with endometriosis. The authors demonstrated how endometriosis leads to biographical disruption on an individual and a relational level by affecting key aspects of couple relationships (sexuality, planning for and having children, working and social lives).

Our study emphasizes the importance of disruption in women with endometriosis as the major source of distress. Factors related to medical professionals have a remarkable influence on the process of *experiencing disruption vs. restoring continuity* and thus on women's psychological health. The time to diagnosis, the way in which the diagnosis is communicated, and the overall quality of doctor-patient relationships are pivotal, and negative experiences with doctors represent a major risk factor for these patients. On one hand, there is still a lack of knowledge about endometriosis, especially among general practitioners; thus, we agree with our participants who underlined the importance of seeking specialized care. On the other hand, women with endometriosis, who may also have different physical symptoms due to multiple pathologies, need different types of professional support, i.e., not only medical, but also specialized psychological support, for which doctors are not trained. This is even more evident considering how the sense of female identity of our distressed participants had been dramatically affected by endometriosis, to the point that they were likely to perceive themselves as worthless women; they also had a negative body image and were unable to experience pleasure from their sexuality. Such an intense psychological pain requires specialized psychological treatment, especially if one considers that the most distressed women in our sample reported important depressive and anxiety symptoms, such as panic attacks.

Although almost all participants experienced a certain degree of life disruption, some of them were able to effectively reorganize their everyday life and identity by accepting the disease as an integrated part of their life history (i.e., *restoring continuity*), which led to lower distress. *Restoring continuity* is an integrative process that promotes a sense of biographical continuity, which involves maintaining identity and life meaning, revising life histories, reorganizing everyday activities, and dealing with uncertainty (Aasbø et al. 2016). Our findings reveal that this reintegration occurs *after* as well as *through* disruption, since non-distressed participants were able to identify or strengthen protective factors and resilient qualities (Richardson 2002) as opportunities for growth through endometriosis.

Overall, *experiencing disruption vs. restoring continuity* should be conceptualized as a complex (rather than linear) dynamic process that involves a constant interaction between psychological, physical, social, and spiritual dimensions. Our findings suggest that personality (anxiety and pessimism vs. positive orientation towards life) may affect this process. A study by Facchin et al. (2016) showed that a tendency to experience anxiety and pessimistic worries (i.e., Harm Avoidance) was associated with more severe chronic pelvic pain due to endometriosis. More studies are needed to investigate whether individual characteristics (personality, self-efficacy, self-esteem, coping strategies) may moderate the psychological impact of endometriosis.

Positive family, social, and intimate relationships also represent an important protective factor for women with endometriosis, whose mental health is negatively affected by a general lack of support, including financial support. Endometriosis patients experience a high economic burden both before and after diagnosis (Fuldeore et al. 2015) and this should be considered in order to develop effective social policies. A multidisciplinary team approach may be a good answer to our patients' needs, although the paucity of financial resources still represents a major problem. Gynecologists and psychologists should work

together to improve doctor-patient communication. All women with endometriosis need extensive, clear information that should be provided in a sensitive manner. Having effective tools for managing the disease in the everyday life is essential for all patients with chronic illness. A constant dialogue between professionals and patient associations is pivotal to develop research and treatment programs, as well as to promote early detection of endometriosis by increasing young women's knowledge of this disease. This is key if one considers that, as confirmed by our study, delayed diagnosis is a major source of distress for women. Patient associations play a fundamental role since they launch important national awareness campaigns using effective information sources (such as Facebook, blogs, and the Internet in general, but also schools) that young women easily access (Shadbolt et al. 2013).

Although in this study we provide a grounded theory of how endometriosis affects psychological health, our sample was culturally homogenous. This should be acknowledged as a limitation, as the important role played by cultural beliefs may have been underestimated. Moreover, all patients were referring to the same institution, i.e., a specialized endometriosis center located in Northern Italy, which may limit the generalizability of our findings (although we included patients coming from different areas of Italy, who reported previous experiences in other types of clinics, either public or private). Gender issues may also have a remarkable influence on women's meaning-making processes of endometriosis and its implications, especially with regard to anticipated or actual infertility. This may represent an interesting avenue for future research.

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