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**Personal Accounts of  
Endometriosis:**

**Online Narratives of Lives  
Shaped by Pain**

**A Thesis Submitted to the  
Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Medicine**

**by**

**Véronique Anne Sabine Griffith**

**2009**

# PERSONAL ACCOUNTS OF ENDOMETRIOSIS: ONLINE NARRATIVES OF LIVES SHAPED BY PAIN.

Véronique Anne Sabine Griffith

Endometriosis is a chronic disease characterized by the presence of endometrial implants outside the endometrial cavity. Because of its chronicity and lack of cure, the experience of endometriosis goes well beyond physical symptoms and has a significant impact on the psychosocial aspects of affected patients' lives. Given this extensive impact on the patients' quality of life, it is surprising how little attention has been given by the medical profession to exploring the mechanisms used by endometriosis patients to cope with this disease. One such important mechanism is the use of online support groups.

This qualitative study focuses on the use of online support groups by patients afflicted with endometriosis. Two online groups were accessed, and a total of 28 posts from 27 patients were analyzed in detail in an attempt to understand how the patients used the groups and what matters they discussed. The following four major themes emerged from the analysis: (1) the quest to legitimize the endometriosis illness experience and the search for support, (2) the search for medical information, (3) descriptions of the effect the disease has on the patients' lives (known as the illness experience), and (4) efforts of group members to interact effectively with non-group members not suffering from the disease and therefore lacking this unique illness experience.

The results indicate that the patients were often dissatisfied with the treatment they had received from medical professionals who generally focused on the physical manifestations of the disease. The group's communications reflected a broader understanding of the illness experience that was frequently ignored by the medical profession. These results lead to the notion, deserving of further study, that the endometriosis peer groups may be an important adjunctive measure in the armamentarium of endometriosis treatment. In addition, the findings suggest that the training of physicians in the management of patients with endometriosis needs to be re-conceptualized to emphasize treatment of both the disease and its psychosocial impact on the patients.

## ACKNOWLEDGEMENTS

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In writing this acknowledgment, however, I cannot simply thank those individuals who had a direct impact on the creation of this manuscript. While this task has been demanding, it is merely a reflection of a history that has been written over many years. In thanking those who have helped to shape and direct this history, I begin with my family, the mother, father, and brother who have refused, sometimes even to my own chagrin, to let me go through this process alone. Through their love, this endeavor was possible, and I only hope that I can continue to make them proud.

To my brother, who from a distance has unwaveringly believed in my abilities to overcome adversity and find success, and more importantly, happiness.

To my mother, who through many conversations, arguments, and whisperings, has been a resolute and irreplaceable nurse, confidant, and rock for me. She has been there for every moment of this sometimes complicated journey, and I thank her for her constant devotion.

To my father, who has lived and died with my every moment of hope and pain throughout this difficult time. His intense commitment to my search for peace has been unbridled and only outdone by his dedication to the happiness of both his children.

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# I. INTRODUCTION

## A. General Comments

Endometriosis is a chronic disease characterized by the presence of implants of endometrial tissue outside the uterine cavity. When menstruation occurs, the ectopic endometrial implants bleed, thereby causing pain, dyspareunia, adhesions, and infertility (1, 2, 3). Because of its chronicity and lack of cure, the experience of endometriosis goes well beyond physical symptoms and has a significant impact on the quality of life of affected patients. Although the major themes identified as important by women with endometriosis have been previously described, little attention has been given to the emotional impact of the disease, and few papers have described mechanisms of adaptation that the women employ. Therefore, clinicians may have a skewed view of the true impact of this chronic disease. Online endometriosis support groups may be a useful tool to gain insight into this illness and to understand better how endometriosis patients employ this mechanism to cope with the impact of the disease. This is also in contrast to earlier qualitative studies done on endometriosis that have usually been investigator directed.

I examined concrete examples of patient experiences as described by individuals with endometriosis who employ internet support groups. I focused on describing and analyzing the matters women with endometriosis deemed most important and the problems they considered to have affected their lives most profoundly. I examined online narratives to determine what themes were most frequently discussed among patients. In

doing so, I hoped to shed light on this specific coping mechanism used by women with endometriosis to contend with their chronic illness.

The study will provide clinicians with a better understanding of the personal experiences of those suffering from chronic endometriosis as well as unique insight into what issues patients discuss among themselves. This type of knowledge has the potential of improving the clinical management of individuals suffering from this disease.

## **B. Description of the Disease**

Endometriosis is a disease primarily affecting women, characterized by the presence of endometrial tissue outside of the uterine cavity. It affects approximately 10 percent of women and is considered to be an important cause of pelvic pain and infertility (1, 2, 3).

### **i. Historical Background**

A general history of endometriosis, as well as a biography of the “father of endometriosis,” has been described in great detail by Philip B. Clement, M.D. in his paper “History of Gynecological Pathology: IX. Dr. John Albertson Sampson” (4). Sampson published the first formal studies on endometriosis in 1921 (5), and he was the first to employ the term “endometriosis” in a 1925 publication (6). However, previous descriptions of endometriosis used other terminology to refer to this clinical entity. The first description of endometriosis is attributed to Rokitansky in 1860 with extraovarian endometriotic lesions referred to as adenomyomas (7). In addition, the invasive nature of the disease was already evident in the early descriptions of the late 19<sup>th</sup> century.

Adenomyomas were described as extraovarian, ovarian, and found in the round ligament and rectovaginal septum (4).

To this day, Sampson's terminology and theories of endometriosis permeate clinical discourse on endometriosis. His contributions have been seminal to our current understanding of the morphology and pathogenesis of endometriosis. He published 18 articles as a sole author on endometriosis which were remarkable for their length and the multiple gross and microscopic illustrations (4). Sampson is responsible for several major theories regarding the pathogenesis of endometriosis. The first, the theory of retrograde menstruation, states that retrograde menstrual flow through the fallopian tubes allows for endometrial tissue to find its way into the abdominal cavity and finally implant outside the uterus explaining the presence of ovarian endometriomas that Sampson had observed (3). However, retrograde menstruation is found among up to 90% of women implying that there are other factors involved in the formation of ectopic implants (8, 9). Two possible mechanisms have been suggested to explain the implantation of ectopic endometrium: molecular and immunologic abnormalities. These have been discussed in detail recently (10).

Sampson is also responsible for the second theory attempting to explain the pathogenesis of endometriosis: the Lymphovascular Metastasis Theory. In this theory endometrial cells are thought to be distributed through both lymphatic and hematogenous spread (6, 11). This, as well as the next two theories, may better explain the presence of endometriotic cells in the brain and lungs.

A third major theory, coelomic metaplasia, established by Gruenwald, suggests that endometriosis results from metaplastic change of mesothelial cells into endometrial

implants (12). This theory may help explain the case reports of cyclical hemoptysis, as well as the case reports of women with endometrial implants in their pituitary (3).

The fourth theory, the Embryonic Rest Theory hypothesizes that cells of mullerian origin could be induced to become endometrial tissue when subjected to certain stimuli (13).

Susceptibility to endometriosis has recently been linked to a complex combination of genetic, hormonal, immunologic and environmental factors (8). Moreover, altered angiogenesis and apoptosis have been considered relevant to the pathogenesis of endometriosis (10). Furthermore, there have been new suggestions that endometriotic tissue produces increased levels of Cox-2 as well as aromatase which in turn increases the level of prostaglandins as compared to normal endometrium (14).

To this day, the etiology and pathogenesis of endometriosis remain uncertain.

## **ii. Clinical Presentation**

The major symptoms of endometriosis are pelvic pain and infertility (3). Dysmenorrhea, intermenstrual pain and dyspareunia are quite common. The dysmenorrhea, a typical complaint of patients with endometriosis, begins before the onset of menses and continues until the end of flow. The pain is often diffuse, deep in the pelvis, dull and aching. The pain may radiate to the lower back and thighs. Patients may also complain of rectal pressure, nausea and episodic diarrhea.

There is no clear correlation between the extent of involvement of the organs with endometriosis and the severity of pain. There is, however, a correlation between dyspareunia and involvement of the cul-de-sac (3).

Endometriosis can involve any organ system including pituitary, lungs, umbilicus, sciatic nerve, bladder, and intestines. Extrapelvic endometriosis therefore is associated with a wide array of often cyclical symptoms associated with the involved organ (3).

### **iii. Diagnosis**

The only pathognomic way to diagnose endometriosis is through surgical visualization, most commonly laparoscopy. MRI, X-Ray and ultrasound do not have strong diagnostic accuracy for endometriosis. Similarly, pelvic exams are also notoriously unreliable at measuring the extent of the disease process (15, 16). It is important, however, to note that a good history and physical examination are essential in leading the clinician towards sharpening his or her suspicion of the correct diagnosis, since the gold standard of diagnosis is invasive. On physical examination, signs may be tender nodules located in the posterior vaginal fornix, uterine motion tenderness, or tender adnexal masses. Endometriosis may also present without any of these signs detectable at examination.

Unfortunately, the differential diagnosis of chronic pelvic pain is quite extensive, which therefore makes it difficult to reach a diagnosis of endometriosis. The differential diagnosis includes adenomyosis, pelvic inflammatory disease, congenital anomalies of the reproductive tract as well as disorders in the gastrointestinal, neurological, urinary or musculoskeletal systems. Patients should be evaluated thoroughly before treatment is initiated and should be re-assessed in cases of treatment failure (15, 16).

## **iv. Treatment**

### **1. Established Medical Treatments**

The current medical treatments for endometriosis are based on Sampson's theory of the disease process. In thinking that ectopic endometrium came out of the uterus through retrograde flow, Sampson assumed that the ectopic implants behave similarly to eutopic endometrium. Therefore, the treatments are meant to decrease cyclic menstruation in an effort to reduce peritoneal seeding, halt the growth and activity of the eutopic endometrium, and therefore result in a decrease in ectopic implants (3, 17). Additionally, the mainstays of current treatment for endometriosis are also based on two additional observations allowing for a potential link of endometriosis to hormonal influences. The first observation was that endometriosis is more frequently found in the nulliparous woman, suggesting a protective effect of pregnancy. The second observation was that endometriosis occurs almost exclusively in reproductive age women, i.e. menstruating women. Therefore, the mainstay of medical treatment for endometriosis remains centered on hormonal therapy to alter the normal menstrual cycle during reproductive years (3).

The main hormonal treatments currently available for endometriosis are oral contraceptives, progestins, GnRH –agonists and androgenic agents (18). There has been no superior benefit shown of one hormonal therapy over another. However, a more useful point of comparison is between side effect profiles. For all these medical agents, the effect seems to last only through administration, with high recurrence rates after stopping the treatment (18).

NSAIDs (nonsteroidal anti-inflammatory drugs) have been used in the treatment of chronic pelvic pain associated with endometriosis (19, 20). Unfortunately, NSAIDs provide only partial benefit (21). It has, however, been found that use of amitriptyline and gabapentin may be helpful (22).

Recently, pilot studies have shown aromatase inhibitors to be effective in the treatment of endometriosis. However, their use is still considered investigational, as they have not been approved by the FDA for this indication (15, 16).

## **2. Infertility Treatment**

The treatment of infertility due to endometriosis has been reviewed recently (18). Hormonal therapy has not been shown to increase fertility rates, although there have been a few studies showing that laparoscopy with removal of implants does improve fertility rates among stage I and stage II patients. Ovarian stimulation with or without Intrauterine Insemination (IUI) has been recommended after laparoscopy in patients in the early stages of the disease. If this approach fails or in cases of severe disease affecting the ovaries or the fallopian tubes, the use of In Vitro Fertilization (IVF) has been suggested (18).

## **3. Surgical Treatment**

Generally, the surgical treatment of endometriosis falls into two categories: that affecting the actual endometriotic implants, and that targeting pain specifically (2). The first class involves laparoscopy or hysterectomy. Generally laparoscopy is considered to be first line relative to hysterectomy, which is considered to be far more serious an intervention. The second class involves LUNA and Presacral neurectomy.

**a. Laparoscopy**

The surgical options for treatment of endometriosis laparoscopically are use of unipolar or bipolar cautery, laser ablation using various chemicals and excision techniques. There is a lack of randomized trials comparing the various techniques in laparoscopy and their efficacies (16).

**b. Hysterectomy (TAH-BSO)**

A total abdominal hysterectomy with bilateral salpingo-oophorectomy (TAH-BSO) is usually reserved for women with severe symptoms attributed to endometriosis who have finished childbearing and in whom other therapies have not worked. The TAH without bilateral salpingo-oophorectomy is less effective with more recurrence (16).

**c. Laparoscopic Uterosacral Nerve Ablation (LUNA)**

LUNA is a procedure that disrupts the efferent nerve fibers in the uterosacral ligaments in order to decrease uterine pain. However, the results show that LUNA does not give added benefits compared to conservative surgery alone (16).

**d. Presacral Neurectomy**

Presacral neurectomy disrupts the sympathetic innervation of the uterus at the level of the hypogastric plexus (16). This procedure has been suggested for use to treat midline pelvic pain. Its effects on dyspareunia and lateral pelvic pain have been inconsistent. Furthermore, this surgery is technically difficult and is associated with a risk of hemorrhage from the adjacent venous plexus (16).

## **C. Literature Review of Previous Qualitative Studies and Personal Illness Narratives**

There are very few papers that discuss the patient's experience of endometriosis. Those papers that do exist have been generally published outside the United States, and written by non-physicians. Studies focused specifically on endometriosis online support groups have been limited (23-25).

In one of the studies, Denny asked women identified through the message board of an online endometriosis support group to describe their endometriosis story and then conducted a semi-focused interview of fifteen women (23). The major themes that were identified as important were the following: "delay in the diagnosis of endometriosis, pain, dyspareunia, treatment, work and social relationships, the workplace, and the future." She reported mixed positive and negative responses in relation to work, social relationships and the future (23).

In her qualitative study, Whelan (24) combined thematic results from a focus group of six women in Winnipeg, Canada on the experience of GnRH-agonist use in endometriosis and the results of 18 responses to an online survey on "WITSEND0," an online endometriosis support group. Whelan concluded that the illness experience creates a basis for solidarity among members of the endometriosis community, allowing them to define themselves as insiders in contrast to the outsiders who are those without the endometriosis illness experience. Whelan stated that the illness experience is considered a type of knowledge that only the members can know, making all outsiders, including the medical community, at best "pseudo-experts" on endometriosis. Whelan did not address

the endometriosis illness experience itself, but instead discussed the use of the online support group as a method for gaining both medical and what she called “experiential” knowledge in response to clinician’s “unwillingness to share information with patients.”

Finally, Whitney (25) looked at the responses of 46 participants of an endometriosis online support group to a questionnaire exploring their social support experiences. The questionnaire focused on “four relationship categories: spouse/partner, friends/extended family, others with endometriosis and health care providers.” The following themes emerged from the responses: The participants were seeking validation of their experiences with the disease and wished to be believed by those hearing their reports. They wished their support system to be knowledgeable about the disease as well as to understand the symptoms of endometriosis. Finally, the participants wanted those in their support network to share their knowledge of endometriosis. Whitney concluded that the participants valued interactions with other endometriosis patients and that the subjects were looking for more medical information on endometriosis from both their clinicians and others in their support system.

However, there have been several other types of qualitative studies focused on patients’ experiences of endometriosis (26-30). Huntington audio-taped 18 interviews of endometriosis patients, who were part of the same support group (26). The interviews were then analyzed for common themes. The major theme resulting from the study was the experience of severe, chronic pain. This theme was further subdivided into four categories: “manifestations of pain, the pain trajectory, intractable pain, and controlling pain.” This paper did not address the illness experience associated with the pain itself (26).

Cox et al. published two separate qualitative studies out of Australia (27, 28). The first paper reported the results of focus groups of 61 women found through the Endometriosis Association (Vic) Inc. membership and the Epworth Endometriosis Centre database (27). The results can be divided into three categories: first, difficult access to information regarding endometriosis and the need for this information not only for the patients but also for significant others, co-workers and others; second, “lack of knowledge and negative attitudes of GPs and non-specialist gynaecologists, and the resultant trauma and depression experienced by the women”; and third, “[t]he difficulty of learning to take control of their lives and be assertive in relation to communicating with health care professionals.”

The second paper by Cox et al. (28) studied 61 women with endometriosis through focus groups in Australia. The themes that emerged were: “the struggle of living with the disease; the eventual need to become assertive; and the ways in which use of complementary, or in some instances alternative, therapies allowed these women to take control of their lives and of their health.”

Gilmour et al. (29) found three major themes when they interviewed 18 women with endometriosis. The first theme was endometriosis as a private affair. The authors found that the patients were uncomfortable speaking with male employers about endometriosis due to its status as a reproductive disease associated with menstruation. The second theme, life interrupted by endometriosis, spoke to the issue of disruption of education, work and personal relationships due to the disease. The third theme addressed strategies women developed to manage both the symptoms and the impact of endometriosis in their lives (29).

Jones et al. (30) found 15 themes when they interviewed 24 women with a laparoscopic diagnosis of endometriosis. The themes were: “pain, physical functioning, role performance, social functioning, emotional well-being, relationship with the medical profession, treatment, sexual intercourse, energy and vitality, employment, infertility, physical appearance, lack of control and powerlessness, feelings of social isolation and concerns that their daughters might develop endometriosis.”

Finally, a personal illness narrative of endometriosis was published in the *Lancet* by Wang (31). Wang succeeded in painting a picture of the relief she felt in finally receiving a diagnosis, a name for an unknown disease she feels she had for many years; she thought her symptoms were a ‘normal’ part of menstruation. In speaking of endometriosis, Wang noted “it drains our confidence, leading us to hate our bodies. It boldly steals from us our dreams, career, relationships, friends, and the right to a decent life” (31).

All of these studies have been investigator directed with the exception of Wang’s personal narrative. The present work extends the qualitative studies on endometriosis to analyzing the matters chosen by women afflicted with endometriosis.

## II. STATEMENT OF PURPOSE / SPECIFIC AIMS

In this study, I examined patient experiences as described by individuals with endometriosis who employ internet support groups. This forum provided an account of patient concerns unbiased by clinician input. As no questions were asked of the patients, the forum remained a reflection of the issues the patients themselves chose to address.

This project was formulated as a qualitative study focused on describing and analyzing the matters women with endometriosis deem most important and the problems they consider to have affected their lives most profoundly. I examined online narratives to determine what themes are most frequently discussed by these patients.

It is hoped that this study will provide clinicians with a better understanding of the personal experiences of those suffering from chronic endometriosis and with unique insights into what issues patients discuss among themselves. This type of knowledge has the potential to improve the clinical management of endometriosis and help narrow the distance between healthcare professionals and patients with endometriosis. The results from this qualitative study should also lead to the articulation of hypotheses that could be the basis of future empirical research.

The specific aims are:

1. To identify themes discussed by women on online endometriosis support groups.
2. To discuss potential clinical implications of women's online narratives and identify strategies deemed to be helpful for coping with the illness.
3. To identify ways, from the narratives, that medical professionals might address shortcomings in the care of endometriosis patients.

### III. METHODS

Information was collected from the internet through endometriosis online support groups whose written products belong to the public domain. Access is limited to individuals with endometriosis. The author was allowed access to the online sites because of her status as a patient with endometriosis. The project was reviewed by the Yale University School of Medicine Human Investigations Committee and the project was found to be exempt from review because the patients had already given the information in a public forum, and the information was therefore no longer deemed confidential.

The following two online groups were accessed: the Endometriosis Research Center (ERC) and the Goddesses of Endometriosis. A total of 1735 posts were initially printed and evaluated in an attempt to understand how the groups were used and the major issues discussed. Twenty eight online posts from 27 patients were selected because of their clarity and expressiveness to illustrate the four themes identified in the initial review.

The subjects were a self-selected population of patients who had joined the endometriosis online support groups voluntarily. The subjects were mostly women of reproductive age with endometriosis (or chronic pelvic pain); only a few of the subjects were teenagers or post-menopausal women. In general, the authors of the online posts identified themselves as (1) having an established diagnosis of endometriosis, (2) having been recently diagnosed with endometriosis and looking for information, or (3) believing that they may have endometriosis because of their histories of chronic pelvic pain or severe pain with their menstrual cycle.

The table below lists the personal information provided by the 27 subjects who were the authors of the 28 selected illness narratives.

**Information provided by the 27 subjects<sup>A</sup> in the 28 selected online postings**

<b>Category of information provided</b>	<b>Number of subjects who provided information</b>	<b>Detail of information provided</b>
Age	5	All were < 24 years of age
Marital status	5	4 were married 1 was engaged
Education	3	2 had graduate degrees 1 was a high school student
Children	8	5 had no children 3 had children
Time since diagnosis of endometriosis	4	1 was newly diagnosed 3 had a diagnosis 3, 11, and 15 years ago, respectively

<sup>A</sup> Two of the subjects said there were new to the group at the time they posted their narratives.

The project employed a qualitative approach by analyzing first-person, subjective narratives of women suffering from endometriosis. The data collected were evaluated using a thematic analysis approach. The qualitative nature of this study allowed for an emphasis on the narratives told by the research subjects. The accounts given by the participants reflected experiences that they considered to have significantly shaped their lives. This type of qualitative study allows researchers to pinpoint issues that studied subjects themselves consider important, with no influence from project researchers (32, 33).

## IV. RESULTS

In reading the online posts four overarching themes became clear. The first common element in many posts addressed the reason for joining an online support group: the search to legitimize an illness experience. The second major theme was the search for medical information. The third element exhibited by many posts online was that group members did not discuss physical symptoms as much as they tended to focus on the illness experience as a whole, with some emphasis on the disease's impact on quality of life. Finally, the fourth major theme discussed how best to interact with individuals not within the online community, those deemed to be not ill with endometriosis, and therefore likely lacking a clear understanding of the illness experience elucidated in the posts.

It was very rare to find one post that explicitly addressed only one theme. Rather, a single post regularly described multiple themes. Some posts described themes other than the four major ones already noted.

### **A. Theme One: Legitimizing the Disease and Seeking Support**

A common reason for joining given by the members of the support group was to seek a connection to individuals with the endometriosis illness experience. The first message posted by new group users usually looked for an affirmation that both the physical symptoms and emotional feelings related to endometriosis were appropriate and legitimate. Joining the support group seemed to be a search for social legitimization of

the individual's complaints that had not been found elsewhere. The legitimization of this illness was mentioned over and over in subsequent posts as lacking within the doctor-patient relationship, which appeared to heighten the importance of seeking legitimization elsewhere. Social legitimization of the disease is essential for the patient to be considered ill by those around her and for the patient to envisage healing within the social and healthcare systems (34).

This following example illustrates the two main components of this theme: the quest to legitimize the disease and the search for support.

*"I do like this group because I don't feel like I am alone and completely crazy....my pain is real and I really feel like finally someone believes me."- T*

The conviction that someone finally believes her legitimizes this woman's illness experience and also decreases the social isolation she feels. The author of this post suggests that the online group functions as a social network that decreases the feeling of being on society's fringe.

The next post is by an author whose symptoms may not be explained by a diagnosis of endometriosis. She has had a laparoscopy where very few implants were seen, and she was told that the relatively few implants could not explain the pain she has. As a result, she is wondering whether she in fact has endometriosis, and whether she has exaggerated the extent of her pain. She is questioning herself rather than her doctor, a common reaction to the lack of an official diagnosis. She appears therefore to be looking for acknowledgement that she is not making up her symptoms, that she is suffering from a true disease.

*Hi guys, I'm new to the group but I'd really appreciate some advice. I'm also new to having endometriosis, and I really need some assurance that I'm not crazy!!!*

*When you have endo, can it also cause pain in the hip/leg sort of connected to the pelvic pain?*

*Does your pain get worse with activity, walking, standing lifting etc?*

*Is it possible to NOT have periods, or skip many periods and still have endo?? When I started having severe pain last year, I missed my period for 8 months in a row. I thought endo was heavier periods??*

*Is it possible to have endo that is not seen during pelvic laparoscopy? I had a lap back in Dec; they found a small amount of endo and a growth/adhesion thing, but I still have severe pain. Could they have missed it?*

*I just need to know if anyone else can identify or has had similar issues. I don't quite believe this even endometriosis...Please help!!*

*-M.*

This post demonstrates a need to find someone else who has experienced the same thing that the author, M., has experienced. It is almost as if her symptoms cannot be real unless another has lived through it too. This is, par excellence, the phenomenon of legitimization.

The next post is a response to M.

*Hi Dear,*

*You are not crazy... just suffering with endo... yes, to all that you have written. It is possible, if an ob/gyn did your surgery (not an RE/Endo specialist) endo was missed and if it was burned off (not excision) as a means of removal, then you would most likely have continued severe pain. I am so very sorry for your suffering as I have lived endo "full circle". Please visit our personal website to learn of letrozole as a possible positive treatment, my daughter, [K], is doing wonderfully after using letrozole.*

*I hope this is helpful, please write with any questions. I am here to assist if I can. God Bless.*

*T.*

Such a response may support the recipient, M., in believing in her symptoms and in considering the possibility for her pain to be due to endometriosis, even if there is still a question as to the cause of her symptoms. It may also help to deepen her conviction that she is not alone and that her pain is real and her symptoms are due to endometriosis. T. acknowledges the suffering that endometriosis entails. She also offers her assistance, in effect saying that M. is not alone but rather now part of a community in place to support its members.

T.'s post is one of the few that mention an endometriosis patient in recovery, doing well. By saying that there is a possibility of truly living with endometriosis, she may provide hope to others who read her post.

The experience of M. regarding the length of time to diagnosis is not uncommon within the endometriosis patient group, as the average length of time to diagnosis is 7 to 10 years (2). This next post is written by a woman who has been looking for a diagnosis of her symptoms for 10 years.

*My name is [L]. I am 24 years old, married with no children (not for lack of trying!!!) and I recently found out I have endometriosis. I've been treated like a gyno's science project for almost ten years... doctors telling me to just take birth control pills to get rid of the pain and not to worry about the clots, or that the severe pain was all in my head. One doctor from [Jersey] even told me I had PCOS and put me on metformin BEFORE testing me (tests finally proved I did not have PCOS). It wasn't until I got married last year and chose a new doctor in Florida that I've been correctly diagnosed with Endometriosis. The pain gets ssooooo bad some days that I have to call out of work and stay in bed in a fetal position. I've never had a "normal" period. I'd go 4-6 months without a cycle, then I'd bleed HEAVYYYYYYY for up to 19 weeks!*

*Being diagnosed was a relief, but now I have to research how to cope with what I have. I've been looking for a support group for two months now, and this is the first one I've joined. I need to know I'm not the only one out there that has pain, that was lied to by doctors in the past, etc. My husband and I have been trying to conceive for a long time (since before we got married, actually) and I cry every time I think about being infertile.*

*This June I go on Clomid and Metformin to try and conceive again, but until then I'm on birth control pills to clean my lining. Talk about PAIN!*

*If there's anyone out there who was told they couldn't have children, or someone who waited years for the truth about their condition PLEASE respond. I'd love to hear your story! I look forward to being a part of this group's family.*

*Sincerely,  
L.*

This post also reflects the theme of legitimization. The author was looking to validate the reality of her symptoms. Like many other women in the online support groups, until recently, she felt she has been treated poorly by physicians who did not believe that her symptoms were real, since they could not establish the link between her complaints and a disease process. A common sentiment found within the posts was that clinicians often made the members “feel like ... a hypochondriac making [their] symptoms up.” Lacking a diagnosis interfered with L's ability to speak clearly about her experience of her disease. It is noteworthy that while receiving a diagnosis, she still has a need to recognize that her own illness experience is similar to that of other members of the online community. This need for her symptoms to be acknowledged by others is not uncommon within the online support groups with many women stating the need for support to counteract a feeling that “I am not important to these doctors and I am just being a pain.”

In Western culture, validation of an individual's symptoms, the disease, comes about by physician establishment of a diagnosis (34). Ideally, this then facilitates the legitimization of the illness experience, the psychosocial impact of the disease, by friends and family (35). When the doctor does not fulfill his role of legitimizing the disease, as in the case where he provides no diagnosis or where he finds it difficult to link symptoms

to a disease process, then the role of a proxy for friends and family (such as the online group) to legitimize both the disease and the illness experience becomes more important as the friends and family at home cannot provide the legitimization needed.

In the next post, the author refers to the online support group as a pseudo-family.

*I have heard but don't think that it's true...that once the Lupron starts wearing off the pain comes back with a vengeance? I am so confused and so scared that my life is going to go back to what it was... confined to the 4 walls of my house : ( Thank you ladies...in advance for listening to me ramble and advice would be helpful. This group gives a whole new meaning to the word support... You are more than a forum you truly are FAMILY!!!!*

The writer uses the forum as a place to share her thoughts and her fears regarding the illness. It is notable that she does so without judgment or ridicule. In general, responses to messages are not confrontational as there seems to be an understanding that posts are to remain supportive. The notion of viewing the online support group as a family was quite strong among the posts I reviewed. This concept, assuming a close-knit, well-functioning family, suggests at least two separate questions: whether the user feels closer to other members of the online group than to her own family; and whether the user interacts with other members of the online community as family members, telling them both good and bad news.

In contrast, I found few posts that discussed endometriosis in a positive light. One of the few examples we saw before was from T who told us of her daughter's recovery. There could be two reasons for this finding. First, it appears that most members of the online group have a severe form of endometriosis. The authors of the posts appear to have exhausted many of the standard therapeutic modalities, thereby requiring more support. The second reason could be that there are likely few women who

remain in the support group once they are feeling better. Regarding the second point, the author of this next post admits that when she was feeling well, she did not use the online support group. Now that she is feeling ill again, she is back. She trusts the group, even as she is angry with her physician.

*Hi everyone I have been gone for a while.  
I had a lap 1 and ½ years ago and was doing very well.  
I just had a lap 6/20 with a new doctor and everything is terrible.*

*Only a few days after surgery, my leg started feeling numb.  
My ob/gyn could not explain what was going on and referred me to a neurologist.*

*I really need support right now. I am very depressed and find myself crying multiple times a day.*

*I have not felt like this in a long time. I went into surgery to fix a problem and now I have another problem. I am upset with the doctor whom I believe messed up. My back hurts so bad right now.*

*I am confused trying to understand why this is happening and hoping God has a better plan for my life and this is a blessing in disguise. I only wish that I could be in a better mood. I don't understand how this happened! I don't understand why we go through so much.*

*It's hard not to cry and feel sorry for yourself. It's hard to find people who understand your pain. Needing words of encouragement!!!!*

The endometriosis illness narrative is commonly a story of chronicity and lack of cure. When the author states that “it is hard to find people who understand your pain,” she is implying that few are equipped to grasp the complexity of the endometriosis illness experience. It is likely for this reason that this post and others look for support and acknowledgement from others with the same physical symptoms that she has. This group of people can acknowledge and validate the extent of the endometriosis illness experience because they have lived through it too.

## **B. Theme Two: The Search for Medical Information**

The members of the online support group often present their medical histories to the group with the intention of asking for a medical opinion. This search for medical information seems to be used to decrease their fear of endometriosis and the illness experience that it represents. Their posts often reflect a distrust of information that their clinicians have provided them, especially when the information has not led to improvement of their symptoms.

The search for medical information from the online support group is a search for medical information from people who are not medical professionals, and it may lead to changes in medication and medical decisions made as a result of information provided by these non-medical personnel. The search may also contribute to social legitimization of the illness and fill a vacuum created by clinicians' failure to provide a diagnosis and an effective treatment plan that addresses the patient's complaints.

In this first post we see an example of a common theme observed among the posts: how the search for medical information is used to decrease fear regarding endometriosis. This message shows a woman looking to decrease her anxiety over her upcoming laparoscopy while simultaneously adding to the medical information she has.

*I would really appreciate anyone's advice on what to expect on my diagnostic laparoscopy. I've read it depends on the person, but would love to get some feedback, from other women, who have had a lap before. ... I'm just a little nervous, I know it's a minimal surgery but ... still nervous!! Thanks.*

She appears to want to add to her fund of knowledge seeking information from others who have actually experienced the intervention. The more information she has, the less threatening the laparoscopy experience may be to her.

In the following post, the author is looking for an explanation of her symptoms.

*Hi all. ... My surgery was on Thurs. the 22<sup>nd</sup> with Dr. A. He is such a great Dr. and Man!! I have mild chronic IC, my left ovary was buried in adhesions and scar tissue and had endo on it so he removed it and the tube, my right ovary had a few small endo spots that he excised and I had a few small areas of endo removed from other places. He really did not find as much endo as I thought he would. I'm wondering if I could have been in such chronic pain from this? Could what Dr. A found cause so much pain? I know everyone is different but I'm just afraid that the pain will still be there when I'm all healed. My lower back pain was so constant and strong at times and I had such horrible bowel issues, but there was no endo found in areas you would expect to cause this kind of pain. Is it possible that my left ovary was the culprit of most of my pain? Thanks for any input. I'm optimistic yet scared at the same time, if that makes sense.*  
-J

This author is hoping that her pain was caused by what was already found by the doctor during surgery, but she is looking for medical information to back this up. She exhibits fear that the surgery she just had will not help her symptoms, as she notes the discrepancy between the limited anatomic spread of the disease and her relatively severe complaints. In other words, her disease process does not seem to validate the extent of her symptoms. Given that the doctor's findings do not seem to legitimize her suffering, she turns to the online group for possible validation.

One of the difficulties of the online support group is that the information is by definition biased, as it usually represents each individual writer's experience. Consequently, there are often omissions in the information given by the writer that would allow us to better understand her story. It is therefore difficult to know what exactly J's doctor has told her in the above post. These gaps in information may reflect the nature of an online community as by definition it is meant to be anonymous as well as a group of discontinuous posts together on a blog.

This next author is also searching for information about her symptoms. She does not indicate any interaction with a clinician regarding the symptoms. It is possible that this means that she consulted the online group first, or that she is writing the group between visits to her doctor.

*Does anyone else's day go like this?*

*I sit down, but can't sit in one position for too long. So I move from one side to the other until it's completely intolerable. It feels like a bruised tailbone but 10 times worse. So then I stand up, but after 10-20 minutes, I get my 'usual' stabbing pain in my lower right side. So I have to sit down again...and the whole process repeats itself.*

*Whenever I'm driving somewhere now, by the time I get to where I'm going, I'm usually crying from the pressure/pain in my butt!*

*Even sleeping, I have to lay on my back with my legs elevated on two pillows or on my left side. I was up until 2 am this morning just because I couldn't find a position that didn't hurt in some way.*

*This whole sitting problem is relatively new to me...any explanations?*

*Thanks, J.*

This woman is uncertain of the relation between her current symptoms and endometriosis. She is afraid that her symptoms are not all related to the disease. Because the author is asking for what is essentially a medical consultation from her sister sufferers and not from physicians, one wonders if this is a fear of the clinician response to the above symptoms. This post also shows a use of the online community as a fellowship of sufferers, as a support mechanism.

The response J. receives from N. below suggests that to help her symptoms she must use both traditional and other treatments such as yoga. This suggestion to mix different treatment modalities is quite common within the online posts.

*Hi J.,*

*This was exactly my problem for three years. I couldn't cook a dinner that took longer than 30 minutes (including clean up). I couldn't drive for more than an hour without excruciating pain that brought me to tears and made me want to run screaming from the car. I couldn't stand, sit, etc. It all hurt.*

*What I found helped: excision! Before that, soft-soled shoes (no heels), chairs/cushions that supported my legs all the way out to my knees. Sitting with proper posture (feet flat on the floor, back straight). For sleeping, you've got it: the pillows, and usually a loose fetal position. If you're a passenger in the car and you're in for a long drive, a pillow under my legs also helped. The reverberations of the car over the road always shot up my legs and aggravated me like nothing else.*

*Also try lying on the floor with your legs up a wall (your butt should be as close to the wall as you can get it). Keep your legs straight and just hang there. After awhile you might want to put your feet flat against the wall, bent at the knees, sort of like you're in a chair. That pose used to give me some relief in my lower back. Some gentle cat/cow poses will give a gentle stretch to your lower back as well.*

*My doctor put me on a low dose of Flexeril, a muscle relaxant, and it greatly helped. Certain things could still aggravate the pain, but it made life much more livable.*

*Hugs to you.*

*N.*

The author gives multiple suggestions as to how to decrease the pain and make it possible to endure the symptoms. Her suggestions are not limited to medical/surgical options, but include yoga poses, changing shoes, using specific chairs/cushions and using a pillow under the knees at night. The author implies that a multi-system approach to treating these symptoms may be more effective than employing traditional medical treatment alone. Also, this response, by showing that someone else has experienced similar symptoms, may allow for an acknowledgement that her symptoms are real and can be caused by endometriosis. Furthermore, it may provide the first patient hope that her symptoms can improve.

This next post illustrates a tension within all of the posts related to theme two: the lack of trust in the medical profession's treatment suggestions is accompanied by a simultaneous search for information from people who are not medical experts.

*Well, I'm 17 yrs old will turn 18 soon and I [have] endometriosis for about 3 years now... I have tried most birth control pills but they all [n]either made me sick or made my period even worse. I'm having surgery here in a few days but I was wondering if any one knows what other treatments are out there... Please if you know, let me know, it would be a great help, I'm tired of being sick all the time...*  
M

This writer appears to have lost any hope of getting better. She is scheduled to have surgery in a few days, yet she is still searching for other treatment options. This reflects a fear that the surgery will not work, possibly because of some doubt that her body will respond favorably. It also suggests concern about the effectiveness of the medical treatment options suggested by her clinicians. She has instead chosen to ask others within the endometriosis community for an answer. She may have given up on the medical community and hopes that effective treatment options lie within the online community.

The response to the post above takes a very traditional medical slant. The author essentially lists the medical treatment options available, as if she were writing a medical textbook.

*Dear M,*

*Welcome to the group, I hope you find these ladies helpful and supportive as you continue your journey with this disease. You mention that you are having an upcoming lap, when will it be? And is this going to be your first lap?*

*Birth control pills are often assumed to be the first line of defense in controlling the symptoms and progression of the disease. The problem is that you often have to switch multiple times between different brands to find one that works right with your body chemistry. Since women with endo already have unbalanced hormonal issues, it's*

*difficult to find the right combination of hormonal strengths that will suppress the period for any length of time. For myself, I've been through most of the brands of bcps myself, and also suffered from the ongoing heavy bleeding.*

*Other bcp forms of medication including the Depo-Provera shot, the Nuva-Ring, the Orth-Evra patch (I caution using this one), the newer form of Depo-Provera (Depo-Provera SubQ10), or a Mirena IUD.*

*Once these medications are gone through, you're looking at short-term drug therapies. Danazol works similarly to Lupron by putting the body into a state of menopause while it shrinks that endo cells. It can have some pretty nasty side effects (deepened voice, change in hair growth patterns, depression, etc), but it's still not considered as severe as the Lupron side effects. It's also in pill form so that if you don't want to take it anymore, it's easier to stop taking it and wait for it to leave your body, whereas with an injection, you are stuck for however long it takes to leave your body.*

*Letrozole is an aromatase inhibitor that has been shown to actually be capable to destroying the endo cells rather than just shrinking them. The side effects are not as bad as Lupron, however long-term studies aren't available as to it's effectiveness to keep endo away for the longterm, and it shouldn't be used just a preventative treatment since it is still a chemotherapy agent.*

*Lupron, the most feared drug out there, and yet the most pushed by the doctors. Use caution, read what the women have to say, and only do this if you feel comfortable with the results that may occur.*

*There are also natural ways of symptom management. You might look at dietary options, massage therapy, acupuncture, herbs, supplements, etc. I do a combination of natural and medicinal therapies to help keep everything in check between surgeries.*

*Anyway, I hope that this shows you there are options out there.*

*Take care,  
M.*

Although it seems as if the author is well informed, she does make one major medical error in her information. Within the medical world, Danazol is considered to have worse side effects than Lupron. Danazol is often used as a second or even third line treatment compared to Lupron, which is utilized as first line after continuous birth control pills. This message is therefore representative of one of the pitfalls of non-medical professionals giving medical information. Although, the writer buttresses her opinion by

making clear that some of her knowledge comes from her own experience with the treatments, she still comes across as medically knowledgeable making her post that much more dangerous as she appears to be an expert on the treatment modalities of endometriosis.

Another pitfall of using the online support groups for medical information is the delay in accessing medical professionals as seen in the next post. It is not uncommon to see posts on the online group appearing to ask for medical information before seeing a clinician. The post below talks of new symptoms that the author has experienced throughout the weekend with significant distress.

*This weekend's pain was unlike anything I have had over the last 19 years of dealing with cysts and endo. It was a non-stop burning heat like someone was holding my ovary over a fire. Didn't matter if I was perfectly still or moving. It also felt like it was swelling up. On top of this I gained 4 pounds from Saturday morning until this morning. All I ate yesterday was some rice and tea (no appetite thanks to the pain). Any ideas, girls??? My period also affectionately called Freddie after Nightmare on Elm Street is due in a week but I have never gained this much weight and I am urinating like normal.*

*I am just fed up today. To add to all this, my car has been in and out of the shop for 4 weeks with some weird electrical problem and the stress is sure as hell not helping with the pain.*

*Thanks as always.*

*-C*

It is clear from this post that the author is concerned about her new symptoms. Yet, she does not mention any discussion of her symptoms with a medical professional. One wonders whether she has delayed seeing a clinician and is instead searching for answers from the other online group members. The danger, of course, is delay of diagnosis and treatment of another disease, or a possible endometrioma.

Other pitfalls that result from the search for medical information from online support groups can be seen through the discussions relating to Lupron, a GnRH-agonist

with a fairly large side-effect profile. One danger is the attribution of side-effects to a drug that have not been proven, as seen in the next post.

*Hi, j- -*

*So sorry to hear about your difficulties! That sounds terrible. ☹*

*Although I haven't had the weight gain symptoms, I would say that things have certainly been different for me since I took Lupron. I spent a year on the stuff back in 2001/2002 and have had residual side effects since - - especially difficult to treat, recurring yeast infections that have plagued me over and over since 2001. i had never ever had one prior to my treatment with Lupron. If I had things to do over again, i would also have avoided taking it completely!*

*I'm certainly not a medical professional, but in my mind it makes sense that something that completely shuts your system down could affect your hormonal balance. lupron affects the pituitary gland, right? I believe (and please forgive me if I'm wrong) that the pituitary kind of regulates entire endocrine system. Have you seen an endocrinologist? Hope you get things sorted out soon.*

*Take care.*

*-L.*

The author here is attributing her multiple yeast infections to Lupron. She is convinced that her new symptoms must be due to the drug, despite her own acknowledgment that she is not a medical professional. For her, given her experience, Lupron must be the culprit. Because she has decided that Lupron is the cause of her yeast infections, she states that she will never take the drug again.

The other danger shown by posts about Lupron is that the online group tends to choose one point of view on a treatment modality. Among the members of the online community, Lupron is considered a fairly negative drug with too many side effects and little effectiveness, despite the common use of Lupron within the medical community. The next message is representative of the vast majority of posts written about Lupron.

*"[S]ome people have seen an increase in growths/worsening of their condition with Lupron. And others have had lifelong side effects after stopping the drug."*

The writer views Lupron as a drug that by definition is negative. The author seems confident that Lupron can make endometriosis worse and that it has given women long-term side effects.

Within the online posts, there are few voices of opposition to this view that sees Lupron as negative. This may be due to several factors: the online groups have guidelines essentially barring negative interactions between users; the general sentiment in the groups is to be supportive; many users have had negative experiences with Lupron. Lupron shows one danger of an online community: that the majority view on an issue dwarfs any opposition. And, as the online group is meant to support its members, many may hesitate to disagree with the majority.

However, as in any controversy, there are still a few voices of opposition, as seen in the next post.

*I get what you are saying. Lupron can be bad. Lupron changed my life for the better for a long while. I took six expensive injections, and I was able to do things, I felt so much better, and I had 6 glorious months of no pain. I am seeing my surgeon in May for review, and I plan to ask to be put on it again. I realize that there are people who have had a bad reaction to it, but without it I would have been put on Danazol. I would rather not use Danazol. It isn't necessarily wise to advise others or to scare people out of using Lupron. Let people decide for themselves about it. If they try one month, possibly the[y] would know before doing it for a whole 6 months. I am really grateful for Lupron, because it set my endo in stasis and preserved my quality of life. I have had no bone loss, the hot flashes left, I did get a bit depressed, but that left too. My father takes arthritis drugs that cause stomach perforations, clots and blindness, but he risks it to preserve quality of life. I am not saying you shouldn't rant about it, but don't terrify other women into not making their own decisions. I loved it. I have had NO ill effects from it. Effexor has been a total disaster, but I don't tell others not to take it, I tell them what has happened to me. Until Tap Pharm. admits any wrongdoing, then I think the decision about Lupron should be woman's own choice, and not put the fear of God in her about using it.  
Just MHO.  
H.*

This post discusses the problem of considering a treatment as either wholly negative or entirely positive. The author suggests that it can be detrimental to the members of the online community to assume that the experiences one woman had with a drug must translate to the next woman. She proposes that all drugs have side effects and that the decision to take a medication is both personal and dependent upon whether the benefits outweigh the risks. She implies that by casting Lupron in a purely negative light, the online community has discouraged future use of Lupron by other women who could potentially be helped. The inference here is that the role of the online support group is to aid its members in decreasing the negative effects of endometriosis. She seems, therefore, to warn that casting medical information in non-neutral forms may be detrimental to finding improvement of endometriosis symptoms.

### **C. Theme Three: Endometriosis and Social Roles**

It is striking that within the online posts relating to this theme, there is very little mention of pain on its own. Rather there is discussion of pain's effect on the patients' lives. It appears that the presence of severe pain is considered to be a given. The trouble fulfilling the role of women and the loss of those dreams become the endometriosis illness narrative.

Posts included in this theme discuss the effect of the disease on the ability of its participants to fulfill their role as women effectively. The posts break down into four separate categories: 1. Professional life aspirations, 2. Ability to be a good friend, 3. Fertility and ability to act as a mother, and 4. The ability to act as a significant other/sexual partner.

## i. Professional Life Aspirations

This first post is an example of how endometriosis affects professional aspirations.

*I will be graduating from high school on May 31, 2007 at 8:30pm and while I am excited about that because high school has been challenging for me due to Endo, I am also saddened because I don't know what happens next. I have dreams and goals but I don't think I will ever be able to accomplish them due to pain and sometimes depression. All of my friends are going to college and are so excited about this upcoming August and while I can pretend all I want, the truth is that Endo bothers me day in and day out 24 hours a day, 7 days a week period or no period and all year long. I have been accepted to wonderful colleges, but may not even get the opportunity to attend and I think that is what kills me, I've worked hard for 12 years for this period in my life, now its here and my body says, 'No you can't have that, a productive life is not for you.' Sorry about the complaining but I had the dream of being an OB/GYN and gave that up when I could no longer attend school on a daily basis now it just seems as though I may never accomplish my dreams of even being a nurse. So I have a question for you ladies that have stage 4 or constant pain like myself, what do you do for a living or to support yourselves? Or do you have suggestions in case that whole college thing doesn't work? I try to be hopeful but I am also a realist and truth is it may not work for me. Regardless though, I still want to have a life and be happy but I don't have to be rich.*

...  
 Thanx for any input,  
 A.

The author here exhibits a feeling of giving up, of being defeated by endometriosis, a fear that her dreams may be out of reach. She is looking for a way to live with endometriosis while not letting the illness experience be all encompassing, leaving no other identity but that of a sick person.

The author of the next message responds to the preceding post with much empathy and kindness.

*Dear A.,  
 I've been in your shoes. Your pain comes to rule your life as you think about your future and all you see is the pain in it. Your options become limited as you fear to risk what seems like an inevitable failure. It's so easy just to say 'why bother putting myself through all that'. And who can blame us for having such a pessimistic viewpoint? They*

*don't have to live in near constant pain! High school should be filled with so many happy memories and you should be proud of your accomplishments at having made it through.*

*College is difficult and can be very stressful but there are ways to make it through. After you have registered, identify yourself to your school's disability and student wellness center. They should be able to point you into the right direction to see if there may be accommodations that can be made to help ease you through the year. The sooner you make these types of arrangements the better, as it shows that you are trying to take control over everything. It'll also make you feel as though you do have a backup plan, so you don't have to worry about what's going to happen if... Next go to your teachers, introduce yourself and explain your situation as early into the school year as you can. ...Teachers who are aware of your needs are less likely to give you a hard time[.]*

...

*Anyway, hang in there sweetie. When things look the bleakest is when often we find the answers that we've been looking for.*

*Take care and big hugs,  
M.*

This message acknowledges that the illness experience of endometriosis involves losing hope about the possibilities of the future. The author, M., has written a wonderfully empathic message explaining the feelings A. is experiencing. M. suggests that the existence of a “pessimistic viewpoint” is quite common among endometriosis patients. This acknowledgment of the fear of the future and loss of hope may allow A. to accept that these emotions are a part of the endometriosis illness experience, and therefore are normal feelings to have. But M. also offers hope and suggests that there is a road to recovery and to fulfilling useful societal roles.

## **ii. Ability to Be a Good Friend**

The following post shows not only a loss of the dream of motherhood but also illustrates how the prospect of infertility changes the interactions between the author and her friends. The author below uses the online group as a place to let out her frustrations.

[J],  
*I have been so depressed over the infertility thing for about a year now, because I know I will soon be faced with hysterectomy. I want nothing more than to have kids of my own, I am dealing with an infertility specialist who seems to know diddly squat about endo. He is doing nothing to help me get pregnant even though I have stage 4 endo, he told me to wait 6 months after I got excision surgery to see if I got pregnant naturally. He wouldn't let me explain that with stage 4 endo there are a lot of other things going on that are preventing me from getting pregnant. Meanwhile, I have friends that have like 3 kids telling me to relax about the infertility thing, and that I can always adopt, and to worry about my health first. I have gotten to the point where I am blunt about it I explain to them how pregnancy often helps endo, and that no matter whether I am trying to conceive or not, that it will keep getting worse regardless. Then I ask them to put themselves in my shoes, what if they had never had the opportunity to have their children and were faced with a limited amount of time to try before never getting that chance. How would they feel? Would they just let it go, would they not obsess endlessly about what it is causing them to not get pregnant, would they seek out any Dr. they could that might be able to help them. They would, anybody in this situation would. I just want a child. I wanted 2 but at this point I would happy with just one kid. Nobody understands the path you walk unless they have walked it themselves. And as far as my friends who rub their pregnancies in my face, I choose not to talk to them.*

The writer here vents her anger towards her friends. She describes what she believes to be her friends' inability to understand the infertility plight of endometriosis patients. This post therefore adds another element seen often within the online posts: the concept that only those with endometriosis can understand the illness experience. This feeling of us (endometriosis patients) versus them (others) is prevalent within the online community. This reflects an isolation felt by the members of the online community due to a perceived inability to communicate the illness experience to those around them in such a way that these others can legitimize the endometriosis illness experience.

### **iii. Fertility and Ability to Act as a Mother**

The next post shows the common struggle with the possibility of infertility within the endometriosis community. The author below is struggling with the possibility of not

having her own children. Her hopes of having children may not come to fruition. She is forced to endure physical pain in order to keep alive the hope of becoming a mother. The author here does use humor while at the same time saying several times that “ENDO SUX,” implying that she is quite angry because she has this chronic illness.

*I totally agree with D. – endo sux! I have had endometriomas removed/ovaries resected at all of my 3 surgeries. I can feel the cysts beginning to grow a few days after my period ends, then during ovulation I'm doubled over. I am not ready to give up my ovaries yet, still trying to preserve my youth ☺ I don't have any children yet and just can't give up the idea yet that maybe, just MAYBE, I still have the option to have my own. Thankfully, I don't have the problem of my cysts rupturing. UGH, it sounds terrible! I am glad you were able to find some relief. There's no better way to say it... ENDO SUX*

The next post echoes the common dilemma within the endometriosis community seen in the last two posts: whether, due to deteriorating disease, to have a hysterectomy and thereby choose not to have children.

*I am having excision surgery and possible hysterectomy in August. This will be my 3<sup>rd</sup> endo surgery this year. The pain is horrible and constant and my pain clinic doc said there just isn't any long-term solution for someone my young age with chronic pain. He said sure the narcotics work but long term it's not a good idea. I am afraid to have hyst due to wanting children but I can't be on disability forever and not work or have friends or even not be able to walk many days a month. IS not having kids worth it? Will the excision alone be enough? So far no laser treatments have worked.*

This message, in discussing a hysterectomy, reflects how the endometriosis illness experience may affect all parts of the author's life. She is weighing the possibility of never having her own children versus living with her life as it is now, without a job and on disability and without a social life. As in the two previous posts, her posts reflects the need to choose between the different roles of women in society in the face of deteriorating disease, the need to choose between dreams. She, however, does not exhibit

as much blatant anger. Instead, she seems to be looking for a solution. She is looking for a change, the implication being that she believes the status quo to be unacceptable.

#### **iv. Ability to Act as a Significant Other/Sexual Partner.**

The next message turns us to another common subject within the online posts: the effect of dyspareunia on sexual relationships. The author exhibits a strong concern about the effect her last stint in the Emergency Room has had on her husband's sexual interest in her. She believes that her husband is worried about hurting her as he did the last time they were intimate. While being understanding of this sentiment, she is frustrated that the illness has influenced her sexual life to this extent. Her sexual life has not lived up to the idea she had of a newly wed.

*It also stinks that I am a newlywed and my husband will not even think of touching me – last time we were intimate I ended up in the emergency room....so I understand his reluctance but WOW that was like 3 weeks ago!*

*So thank you for letting me vent my frustrations – lame in comparison to most of you.*

*So stay strong I will be thinking of all of you and share your pain and frustrations. Please let researchers find a cure for us!*

The poem below gives a global overview of the endometriosis illness experience.

*One day while depressed, I wrote this, and thought this may help you some... there IS a future for us endo sisters!*

*'It's All in Your Head'  
All the tears I cried because of you  
Every day I could not work  
Each precious child you stole from me  
And they say "It's all in your head"*

*It's all in my head?*

*The heart-wrenching fall of more tears?  
 The soul-sobering, "Sorry, I can't, too sick"?  
 The days off work, the nights in pain?  
 "It's all in your head" we are told*

*And all of my sisters  
 "It's all in your head"  
 Repeated doctor after doctor  
 "It's all in your head"*

*And the number grows  
 Day by day, minute by minute  
 We dread our next saying those words  
 When we break and believe  
 We want nothing more  
 Than an out, than an end*

*But I, I am lucky  
 I have a ring of friends  
 A ray of light, a circle of hope  
 And one by one  
 'It's all in your head'  
 Is no more*

This poem touches on infertility, the inability to work, the difficulty being social with friends, and the physical pain. Furthermore, the author adds to the illness experience the idea that she feels she is always fighting to make her illness experience legitimate especially to clinicians. The poem also shows much sadness and loss associated with endometriosis. She talks of wanting a way out of the illness experience, out of the sadness, the hopelessness. As she ends her poem with "a ring of friend ... a circle of hope," she seems to imply that the way out of the despair is hope that she receives from her friends. For her, having her friends believe her illness experience allows her to rekindle her dreams. This is one of very few posts that show hope, reinforcing the idea that hopelessness is an important aspect of the endometriosis illness experience. Additionally, the illness experience that the author above describes is one

that affects all facets of her life and her dreams; all the potential roles she as woman can play: mother, co-worker, friend and patient.

Clinicians should take note of the need to teach patients that hopelessness and fear are a normal part of the endometriosis illness experience. Furthermore, given the results above, physicians should approach endometriosis as an illness that permeates all aspects of their patients' lives.

#### **D. Theme Four: Seeking Communication**

This theme reflects a discussion within the group members of how best to convey the endometriosis illness experience to those not personally afflicted with the disease, while attempting to justify the point of view of the patient herself. These online posts help teach how to explain illness to others outside the online community, and they represent a reaction to assaults against the community itself and its goal of seeking acceptance of the endometriosis illness experience.

The posts are generally divided into four separate categories: 1. Interaction with children, 2. Interaction with friends, 3. Interaction with significant other/sexual partner and 4. Interaction with clinicians/medical personnel. This last category is the most common of the four within this theme. There seems to be a consensus that responsibility for the misrepresentation and misunderstanding of the endometriosis illness experience starts with clinicians. While the patients write about their interactions with the four classes of individuals noted above, it is striking that they say little about coworkers and work supervisors. This may relate to the findings of Gilmour et al. (29) regarding the

perceived need to maintain privacy around endometriosis in the work setting due to the personal nature of a reproductive disease such as endometriosis.

## **i. Interaction with Children**

The following message is a suggestion on how to explain the endometriosis illness experience to children of endometriosis patients.

*I just thought others might be able to use these suggestions if they're fighting surgery.*

*I printed a picture of me with both of the kids, and hand wrote a poem on there. I'm giving them to my MIL [mother in law] who's taking care of the kids, to say the Endo Angels delivered them overnight.*

*This is us together  
 Before mommy got so sick  
 That I'll be better quick  
 I had Endo Angels  
 Surrounding me with love  
 They're going to help us all  
 Sent from God above  
 The doctor took out the [yucky]  
 That was making me hurt so bad  
 Just watch, soon I'll be me!  
 And we can all be glad  
 I love you!  
 And, for my [hubby] to give the kids, I printed up the endo angels picture and this poem:*

*Mommy's Endo Angels  
 I know you two are scared  
 Because I cannot play  
 So I sent you my angels  
 To watch you day by day  
 You'll watch me get stronger  
 And know I am going to be ok.  
 Soon, I'll be back on my feet  
 A little more each and every day  
 And, after a while longer  
 I will be ready to PLAY!  
 I love you!*

*These are meant for my 5 and 7 year olds... Maybe you can re-write in your own instances...*

*Just thought might be able to help those with surgery in near future*

This poem gives a glimpse into how endometriosis has changed the interaction between the author and her children. The referral to her children as “Endo Angels” shows how all-encompassing endometriosis is in her life. Even her children have been affected by the illness experience. She talks of being unable to play with them as she used to. But the poem tries to reframe the prospect of surgery in a positive light. She states that she will be healthier after the surgery than she was before. It is this positive view or the decision to reflect this that may allow her children to have faith that everything will be all right and to see their experience with their sick mother in a more benign context. This post also shows a woman trying to bring her family into the endometriosis illness experience and attempting to communicate with her children about an important dimension of her life.

## **ii. Interaction with Friends**

The next author attempts to learn how best to communicate the endometriosis illness experience to her friend who she believes is no longer able to support her effectively.

*Hi, Ladies!*

*I haven't been part of this group for long, but your posts and your words are so encouraging. I struggle like you all with this disease daily. It wipes me out and causes crazy pain. Anyway, I am struggling with a friend who is VERY close to me. I am a teacher and work with her daily. She came to my house last night and basically told me that I didn't have cancer, so I should be thankful. I should also basically get over it. I was shocked. I don't think I whine too much. There are days that I struggle to get out of*

*bed and go to work. She really hurt me. I don't know how to handle it. She asks me everyday how I am and I want to tell [her] why do you care? I feel like she doesn't want me to talk about it and I should be okay and normal. She was a very strong good support to me during surgery and a few weeks after, so she is the LAST person I thought would tell me to basically get over it. I can't help the pain. I can only control it. I just don't know how to handle her. I am so tired from this disease anyway. She just made it a lot worse. Do you ladies have any suggestions?*

*Thanks so much!  
[B]*

The author feels that her friend is suggesting that endometriosis is not a severe illness and that because she is not dying she should not complain. She thinks that her friend is trivializing her illness experience by wanting her to pretend to be healthy. This experience of having trouble interacting with and explaining the illness experience to those outside the fold (i.e. non-endometriosis survivors) is not uncommon and ironically part of the very experience she is looking to communicate to her friend.

The following post, a response to the previous message, is an example of the coaching that takes place within the online posts. Here the author, S., is training B., to interact more effectively with her friend.

*I think a great many times that cancer has such 'good' PR (like all the breast cancer awareness) that anything else gets thrown to a 'back burner'.*

*Your friend should know that similar to cancer, endo IS something that grows inside your body in a foreign place.*

*Possibly, she was just trying a different [tack] to get you to feel better, but she should realize that for you, it's not the best approach. It could be interpreted as being dismissive to how frustrated you feel. I would let her know, if she is your best friend, that you don't understand her remarks, and would like her to further explain them. There are a great many things I am thankful that I DO not have, but I am NOT thankful to HAVE this problem, and dealing with this problem, and the ignorance people also HAVE about this problem make it all the more frustrating.*

*I used to feel kind of shy saying things to people who were my friends in fear of 'losing' them. I've since realized from therapy and experience, that if you CAN'T say those kinds of things to your friends, they really aren't your friends to begin with.*

*-S.*

S. suggests that the original writer, B., not give up on her friend just yet. S. tells her to try and continue the discussion, by explaining that she, B., did not understand the original remarks of her friend. S. also suggests that B. tell her friend that it is possible to be both thankful for not having a cancer and to be extremely upset that she has endometriosis. Furthermore, she both acknowledges and legitimizes the first author's feelings of being dismissed by her friend, showing that this experience is not an isolated one.

### **iii. Interaction with Significant Other/Sexual Partner**

This next message is an example of the many posts that illustrate the struggle to communicate with a significant other regarding sexual relations. The author of the post below has difficulty communicating with her fiancé about dyspareunia and the effects it has on their relationship. She feels guilty about not being able to be sexual as often as she would like. Furthermore, she is upset that her fiancé feels responsible for her extreme physical pain after intercourse. She wants to convince him that the dyspareunia is not his fault and to improve their interactions.

*I feel completely lost - - I am trying to be open about everything with my fiance[e], but it's all so new and hard for ME to understand, let alone try explain it all to a male. (No offense to men, at all... Women just understand all this a little better...) After intercourse I have to sit in a hot shower/bath and just cry it hurts so terribly. He feels terrible for "hurting me" although I try to explain it has nothing to do with him - - it's not his fault), I feel bad for not being sexual enough... Just looking for support... Thanks for your time!*

#### **iv. Interaction with Clinicians/Medical Personnel**

The next few messages display an anger about clinician attitudes towards pain. In contrast to the posts above, there is little discussion of how to better communication between doctors and patients. Instead, the suggested solution is simply to switch clinicians with no attempt to fix the problem.

This next post discusses a visit with a physician who left the patient feeling alone and believing that she was making up the illness.

*Hello, I haven't written in a while, I just wanted to share what happened today because I'm at a loss. Some of my doctors are blaming my pain on psychological issues and it is just plain wrong.*

*I've got a handful of doctors I see on a regular basis. I just got back from an appointment with one of these doctors, whom I had always trusted and believe to be an excellent Dr. We were discussing my Endo... (and you should know for the story that I was the victim of a violent rape about 6 years prior). Can you see where this is heading? My doctor told me that my pain is caused by, NOT by the Endometriosis, but is a somatic response from the trauma! A psychological problem! And this is not the only time I have been told this. I'm so upset. I have to say that I know the pain is not a 'psychological issue[.]' After the rape I was in therapy for quite a while, and I did seek proper help. I believed that I have dealt with the ordeal the best I can. And although traumatized, I moved on with my life, went back to work and even went to graduate school. Besides, I had this pain before the rape! Why am I hearing that my Endo, which has been photographed with a camera, biopsied, and tested, is being called a head case? I'm insulted, hurt and speechless. How does one contend with the so called 'medically educated –all knowing – scientific – definitiveness' of a doctor who makes a comment such as this, puts it in my medical record, and uses it to make decisions about my care. No wonder I'm still ill! I also know the best thing to do would be to switch doctors, but I'm tired of moving from doctor to doctor. I need some continuity in care, and besides I'm actually running out of doctors to switch to! (unless I pay out of pocket for a doctor that insurance won't cover)*

*I desperately need to have my Endo removed and some of the doctors I have seen understand this, only they are at a loss for advice on how to help. I've been living with this nightmare for 15 years. I've seen more doctors than I should have to. I've had 2 surgeries in the past year, and my Endometriosis is still alive and well. Neither doctor removed the Endometriosis (pointless surgeries!?! I think so.) How do I get proper*

*treatment? I[t] seems that all these barriers, myths, and improper diagnosing are factors weighing heavily on Endo patients['] ability to get proper care. This is not fair! Can anyone share any of their own opinions/stories[?] I feel I'm reaching the end of my rope. I just don't know what to do.*

*-Thanks. [N]*

There are anger, frustration and sadness in this post. She believes that the doctor essentially told her “It’s all in your head.” His lack of belief in her symptoms may have added to the already difficult situation of getting treatment for the endometriosis. But, even if the physician is in fact correct in his interpretation that the trauma of the rape has contributed to her physical symptoms, her negative reaction is very significant. This shows the potential to isolate a patient further who clearly needs help. The perception of the delegitimization of endometriosis by clinicians may in itself create a barrier to correct medical care, further delaying both diagnosis and treatment of endometriosis.

The following post was written during another similar discussion of the failure of doctors to legitimize the suffering experience caused by endometriosis.

*Can I also add, it just doesn't seem wise to have a doctor 'treat' you when he or she won't listen to you... I was thinking about this before – with all other doctors, it seems that they treat me to the limits of their knowledge, education or experience, regardless of my problems or concerns. With the excision experts, it seems our concern guides them. With regular docs, I might as well have been talking to a brick wall. Most think I don't know what I'm talking about, because they don't have the time or inclination to realize that they don't know it all. If their mind can't comprehend it, then it just can't be 'real.' [i]t can't be 'legitimate.' You have pain? Well just take this antidepressant, this Pill, this or this or that. Just shut up!*

The author believes that most doctors have not truly listened to her and that they put no credence in the idea that medically she understands the illness that she is suffering from. Furthermore, she seems very insistent that in not finding a way to treat the true cause of the illness and simply treating the symptoms, the clinicians are in fact ignoring

her. If the symptoms cannot be medically proven as real, should the patients who suffer from those same symptoms then not be legitimized as sick? What causes doctors to doubt the sickness of their patients? This topic may be an important area of future research. But Delea suggests that doctors may tend to doubt the sickness of their patients when their biomedical framework does not help them make sense of their patients' complaints (34).

The author of the next post discusses the meaning of the specific phrase commonly found within posts regarding clinicians: "It's all in your head."

*The phrase, "It's All in Your Head" has two meanings: 1. that our brain is getting messages from our nerves and then telling us that we hurt (this is the correct definition of the phrase that applies to chronic pain patients, and 2. We (the dr that is saying this) don't believe that the physical problem could cause this much pain so we are very frustrated and don't know what else to do to help you because we have tried everything we can to help you.*

...

*Hang in there hun and know that we are here for you hun. It's just very frustrating when we have to run in to drs who just don't know what to do with a complicated case.*

*((Hugs))*,

*[K]*

This is an example of the difficulty and mistrust that exist in the interaction between patient and clinician. The experience of feeling dismissed by a clinician as somehow making up the physical pain of endometriosis seems quite common according to many of the online posts. The author above is suggesting that the frustration felt by the clinicians due to the difficulty of treating endometriosis translates into the delegitimization of the physical pain of endometriosis. Furthermore, she also shows a glimpse of the frustration the patients feel with the doctors' reaction to a difficult disease. Ironically, it is the frustration from both the clinicians and the patients over the

difficulties associated with endometriosis that ultimately fuels the mistrust that exists between both sides.

As suggested by this next post, when patients believe that clinicians are refusing to legitimize endometriosis the patients may become alienated. The author in the following message, as a protective measure against the pain of the experience, keeps certain medical information to herself. Although she seems to argue in favor of keeping information from doctors, as she is not a trained medical professional, this omission of information could result in delayed diagnosis and treatment or even misdiagnosis.

*I understand that you feel hurt, I would feel the same way too. I don't understand why there are so many rotten doctors out there who would dare to question whether a woman with endo is or is not in pain. It's the main symptom!!! That's why the majority of us went after a diagnosis/treatment – because of pain!!*

*This is why sometimes I feel it's best not to tell doctors what they don't need to know.*  
-[M]

The final statement above raises an important issue: that clinicians and patients are disagreeing on what information is important with regards to endometriosis. This theme as a whole reflects the struggle to improve communication between the members of the online communities and those not personally afflicted with the disease, especially clinicians. The posts within this theme reflect a need for the medical community to acknowledge the importance of the illness experience, something the members of the online communities seem to believe has been generally lacking within their interactions with their clinicians.

## V. DISCUSSION

This study examines illness narratives of women with endometriosis who employ online support groups. The work was focused on two Computer Mediated Social Support groups. The study found that the matters women with endometriosis deem most important focused on four major themes within the online posts reviewed: 1. Legitimizing the Disease and Seeking Support, 2. Search for Medical Information, 3. Endometriosis and Social Roles, and 4. Reaching Outside the Endometriosis Community.

As previously stated, studies of endometriosis online support groups have been limited (23-25). These reports differ from the present study in that their data were obtained from directed questions or interviews. The present report is unique in that I posed no questions to the online participants. The posts therefore remain a reflection of what the patients themselves chose to address.

Although my status as a woman with endometriosis may have resulted in some bias with regards to the interpretation and choice of the online posts, this status also gave me access to the online support groups as well as considerable insight into the endometriosis illness experience. In addition, the subjects of the study are a self-selected population of patients who have joined the online support group. In general, there are three groups of patients online: 1. patients with an established diagnosis of endometriosis, 2. patients who feel that they may have endometriosis; i.e. with chronic pelvic pain or severe pain with their menstruation, 3. patients who have been recently diagnosed with endometriosis and are looking for information. In general, the posts suggest a general user population suffering from severe endometriosis.

Messages in theme one show the use of the online support groups to affirm and legitimize the illness experience of its members as well as to seek support. The online posts indicate a need to legitimize endometriosis despite an official diagnosis from clinicians. This implies that even though a diagnosis may legitimize the disease, it does not legitimize the illness experience. It is the shared experience, it seems, that allows for a legitimization of the illness experience through the online support group. Furthermore, members often considered the collective online support group as a pseudo-family, which is strong testimony to the group's impact as a support mechanism for its members.

To my knowledge, none of the previous qualitative studies done on endometriosis discusses the use of online support groups to achieve a legitimization of the illness experience. However, the use of online support groups for guidance and as a method of social support has been shown by Loader with regards to diabetes (36).

With respect to theme two, the individuals seeking medical information are not medical professionals. They are lay people searching for information that may be used to dilute their fear of endometriosis. Their postings reflect a distrust of information given to the members of the online community by their clinicians. At times, it even seems as if the medical information given by the medical community must be supported online, implying that the lay endometriosis patient may be considered more knowledgeable about endometriosis than the medical professional. The search for medical information may also contribute to social legitimization of the illness. Furthermore, it may fill the vacuum created by clinicians' failure to provide a diagnosis and an effective treatment plan that addresses the patient's complaints.

Whelan found similar results in her study noting that the illness experience is considered to be a type of knowledge that only the members can know, making all outsiders, including the medical community, at best “pseudo-experts” on endometriosis to the members of the group (24). She believes this search for medical information to be a response to the clinician’s “unwillingness to share information with patients.” She does not, however, link the search for medical information to the search for social legitimization of endometriosis (24).

Loader also does not connect the search for medical information and social legitimization (36). In his study on the use of the online support group within a diabetes population, he maintains that the experience of fellow members in the online community is considered comparable to medical opinions obtained from clinicians. This differs from both my findings and Whelan’s findings (24) derived from the endometriosis population in online support groups who seem to put their own knowledge above that of the medical community. Loader, however, adds that the increasing dissatisfaction among patients with medical knowledge pushes the members of the online communities to both elevate the relative level of their own ‘medical’ knowledge through the support group itself, while promoting the illness experience as a significant genre of medical expertise (36). Applied to the endometriosis community, the gaps in the medical establishment’s knowledge of endometriosis in terms of both etiology and effective treatment push the online patient population to increase their own knowledge of endometriosis both in terms of medical information and as an illness experience, with the hope that this will improve their quality of life. “With online CMSS, the advice provided through face-to-face medical consultation can be checked, verified and discussed within a virtual forum” (36).

This mistrust of medical information from the medical establishment may be somewhat dangerous, as the resulting posts searching for medical information may lead to changes in medication and medical decisions made as a result of information ultimately provided by non-medical personnel.

Posts included under the theme Endometriosis and Social Roles, theme three, discuss the effect of endometriosis on the ability of its patients to fulfill effectively their roles as women. The posts are generally divided into four separate categories: 1. Professional life aspirations, 2. Fertility and ability to act as a mother, 3. Ability to be a good friend, and 4. The ability to act as a significant other/sexual partner. These findings show the endometriosis illness experience to be characterized by a change in the role the patient can play as a woman. Furthermore, the posts here generally show both loss of dreams and of hope.

The results here parallel other previous studies that have found social relationships, the future and the interruption of their lives by endometriosis as key concerns of patients with endometriosis (23, 29). However, the previous studies cited above do not look at these concerns in an integrated fashion. They therefore do not discuss the impact of endometriosis on the ability of women to play the social roles expected of them. This finding, however, has been alluded to in a previous study by Harris et al on chronic pain (37). This paper states that in general, chronic pain is known to “interrupt behaviour, interfere with functioning, and ... affect a person’s identity: their sense of who they are and what they might become” (37). Furthermore, it has been shown that patients with chronic pain discuss the “loss of inter-personal contacts and the

impact of this on the patient's construal of [her] self," paralleling the results of this study (37).

The loss of hope and dreams found in theme three has also been discussed by Weinstein (38). She states that endometriosis may cause a multitude of "life disruptions and even insurmountable losses." These losses may be related to career goals, parenthood, independence, social roles, and notions of femininity among others. Weinstein goes on to make a parallel between grieving a functional loss as in endometriosis and the process of grieving related to death. For her, part of the endometriosis illness experience is going through the four elements of grief: "denial, isolation, anger, guilt and depression" (38). This concept of grief is one to be studied in more detail in the future.

The final group of posts, theme four, searches to convey the endometriosis illness experience to those not personally afflicted with the disease while justifying the point of view of the patient herself. These posts help teach how to explain illness to others outside the online community and therefore legitimize the illness experience.

The importance placed on having their illness experience understood by the non-endometriosis community is paralleled in Whitney's paper (25). She found that the participants were seeking validation of their experiences with the disease and wished to be believed by those hearing their reports. They wished their support system to be knowledgeable about the disease as well as understand the symptoms of endometriosis. Finally, the participants wanted those in their support network to share their knowledge of endometriosis.

The anger and mistrust of clinicians shown within theme four has been previously noted by Cox et al. (27). With regards to the relationship between physician and patient,

Cox et al. found that lack of knowledge and negative attitudes of general practitioners and non-specialist gynecologists, resulted in both trauma and depression experienced by the women (27). This finding suggests a need by physicians to change their approach to patients with endometriosis. This mistrust may be, in large part, due to the struggle that members of the online community have in persuading the medical community to legitimize endometriosis.

In general, all four themes show a clear use of the online websites to legitimize both the illness experience of its members and the disease process itself. The illness narrative that the members tell is one that affects all facets of their lives: professional and personal as the disease can cause both infertility and dyspareunia. It is this illness experience that the members of these online support groups are searching to have accepted by those not within the group.

One reason for the strong need to legitimize endometriosis may be due to the type of illness narrative the members of the online groups are telling. The majority of the population seems to be what Frank has termed the “deeply ill” (39). “Illness is ‘deep’ when perceived [by the patient herself] as lasting, as affecting virtually all life choices, and as altering identity” (39). For Frank, the deeply ill tell three general illness narratives at different times within the illness timeline. The first, the restitution story is defined by a narrative of “getting sick, suffering, being treated, and through treatment being restored to health” (39). The second type of illness narrative, the chaos story, is one in which “disability can only increase, pain will never remit, physicians are unable to understand what is wrong or unable to treat it successfully” (39). The third narrative type is called the quest story. Here, “illness is lived as a quest: as a condition from which something

can be learned (though not in a didactic sense), and this learning can be passed on to others. Quest stories are being told when the teller claims new qualities of self and believes illness has been responsible for these changes” (39).

It is the chaos story that is most predominant within the posts reviewed in this study. Frank warns that ignoring the chaos narrative threatens to alienate further an already marginalized population, the deeply ill, as it represents how bad illness can get. The chaos narrative makes us, as a Western society, uncomfortable (39). By definition, it puts us on edge. “If our culture loves the restitution narrative that any illness can be cured, it fears the chaos narrative that, with illness, troubles multiply. [...] The chaos narrative – with its vision of how awful life can get—threatens deep health” (39).

The online support groups may therefore serve as a supportive, non-threatening environment in which the members are able to tell their chaos narratives. The members of the online groups are both telling and listening to the chaos narrative, allowing them to create some distance from the story they are living. It is with this distance that the storyteller may start to see the possibility for moving forward. The recounting of this illness narrative allows the members of the online community to “render meaningful the changed circumstances and experience of their situations” (40). Perhaps, the support group ultimately allows the members to tolerate their own state of chaos, even though they may not be ready to relate a quest narrative.

The quest story, on the other hand, does not show up much within the posts. However, there is some sign that the members of the online community are moving from the chaos story to the quest story. The simple telling of the chaos story allows for the change of the narrative to something closer to the quest story.

It is ironic that it is the telling of the chaos narrative that very often isolates the teller even more. There is no doubt that the culturally negative associations with the chaos narrative contribute to the need to legitimize the chaos narrative itself.

The second reason for the need to legitimize the endometriosis illness experience stems from a general misunderstanding of endometriosis itself. In Western culture, validation of an individual's symptoms, the disease, comes about by physician establishment of a diagnosis (34). This then facilitates the legitimization of the illness experience, the psychosocial impact of the disease, by friends and family (35). When the doctor does not fulfill his role of legitimizing the disease, as in the case where he provides no diagnosis or where he finds it difficult to link symptoms to a disease process, then it is difficult for the patient to find legitimization of the illness experience (34). The many gaps in our knowledge of the endometriosis disease process itself leads, therefore, to a mistrust of the illness narrative told by endometriosis patients. If clinicians are unclear as to what actually causes the pain symptoms of endometriosis, this doubt about the disease in general may translate as a doubt of the patient herself.

The results show a clear and important problem within the medical system. Having a chronic illness with its major symptom being chronic pain, the sufferers of endometriosis are left with a lack of trust and a lack of understanding of their physician counterparts; the clinicians reciprocally lack trust of these same patients. As Kleinman puts it:

*If there is a single experience shared by virtually all chronic pain patients it is that at some point those around them—chiefly practitioners, but also at times family members—come to question the authenticity of the patient's experience of pain. This response contributes powerfully to patients' dissatisfaction with the professional treatment system and to their search for alternatives. Chronic pain discloses that the training and methods of health professionals appear to prevent*

*them from effectively caring for the chronically ill. Reciprocally, chronic pain patients are the bête noire of many health professionals, who come to find them excessively demanding, hostile and undermining of care. A duet of escalating antagonism ensues, much to the detriment of the protagonists (35).*

The antagonism that Kleinman refers to results in a difficult relationship. The patients begin to find any way to not see the doctor, often delaying treatment for fear of being treated in a negative way, be it as a drug seeker or with the statement of “It’s all in your head.” This results, as we have seen, in the online posts that ask for medical advice from non-medical professionals. This can clearly be a dangerous practice as patients then begin to change medication dosing or to add supplements that with their medications may have serious side effects. Or, the patients may simply wait to see their doctors until their condition is very severe and therefore harder to fix.

This phenomenon creates a circular pattern in which the physician is annoyed by the patient due to the disease itself, its chronicity and its difficult treatment course. Furthermore, the physician has undoubtedly experienced malingering or drug-seeking behavior in a certain subset patients. Unfortunately, the behavior of a few reflects poorly on the collective, adding to physician doubt of patients with endometriosis. Additionally, physicians may have trouble believing in a patient’s pain when there is no tangible proof of its existence. Pain is one of the few things in medicine where physicians must intrinsically trust the patient to be honest in a system where clinicians have been taught to always double-check that the patient is telling the truth.

As Kleinman says: “For chronic pain syndromes are almost by definition conditions in which the degree of pathology does not seem to explain the severity of perceived pain or the limitations in bodily functioning the pain produces” (35). It is this

inability of physicians to both correlate the level of pain with the number of endometriotic implants and corroborate chronic pain that leaves the endometriosis community frustrated and angry, feeling as if the medical community consistently doubts the existence of endometriosis as a true disease.

*In this setting the pain patient feels pressure to convince self and others that the pain is real—hence the unwillingness of many pain patients to accept psychosocial explanations that appear to deny that their pain is founded in a ‘real’ bodily experience deserving of somatic remedies and a legitimate medical sick role (35).*

So what is the solution to the lack of communication and trust between physician and patient? According to Kleinman,

*One of the core tasks in the effective clinical care of the chronically ill—one whose value is all too easy to underrate—is to affirm the patient’s experience of illness as constituted by lay explanatory models and to negotiate, using the specific terms of those models, an acceptable therapeutic approach. Another core clinical task is the empathetic interpretation of a life story that makes over the illness into the subject matter of a biography. Here the clinician listens to the sick individual’s personal myth, a story that gives shape to an illness so as to distance an otherwise fearsome reality. The clinician attends to the patient’s and family’s summation of life trials. Their narrative highlights core life themes—for example injustice, courage, personal victory against the odds—for whose prosecution the details of illness supply evidence (35).*

Given these considerations, treatment of endometriosis should be given through a multi-practitioner group of reproductive-endocrinologists, a psychiatrist, a pain specialist and a nurse whose job is to explain not just the physical ramifications of endometriosis but the illness experience itself. Along with the physical symptoms, the patients should be warned that endometriosis will potentially affect the relationships they have with co-workers, significant others, friends, and family. Infertility should be discussed not only in medical terms but also it should be made clear that it may be difficult to deal with the possible failures involved with trying to get pregnant. In warning the patient of the

potential psycho-social issues related to endometriosis, it will be easier then to pull in the necessary supports for that aspect of the illness. The responsibility of addressing the psycho-social issues of endometriosis should be shared by all the clinicians seen by the patient.

There are several small changes that both general obstetricians/gynecologists and reproductive endocrinologists can implement in their practices. As Weinstein suggests, physicians can provide handouts of frequently asked questions regarding endometriosis (38). These handouts should include diagnosis, treatment modalities including pain medications, infertility workup, and the psycho-social impact of endometriosis. Other suggestions include referrals to support groups both online and person-to-person, and to hold meetings once a month to answer any questions patients and their family members have (38).

It is necessary to train clinicians in the management of patients with endometriosis to emphasize treatment of both the disease and its psychosocial impact on the patients. This training should begin in the second year of medical school with a workshop or program that would include a patient with endometriosis discussing her illness experience. In addition, the training of physicians on issues relating to chronic illness in general must be increased. I suggest that this be done in the fourth year of medical school with a required program in which patients discuss their illness experience and students are taught about the difference between disease and illness as well as the importance of the illness narrative. This course must focus on training the medical world to accept all types of illness narratives including the Chaos and Quest narratives, without judging those patients, as this attitude only succeeds in further isolating a population

already marginalized. This same course should be continued in medical internship years and obstetric/gynecology residency.

Overall, the study indicates that the patients were often dissatisfied with the treatment they had received from medical professionals who generally focused on the physical manifestations of the disease. On the other hand, the group's communications reflected a broader understanding of the illness experience that was frequently ignored by the medical profession. These results lead to the notion, deserving of further study, that the endometriosis peer groups may be an important adjunctive measure in the armamentarium of endometriosis treatment. In addition, the findings suggest that the training of physicians in the management of patients with endometriosis needs to be re-conceptualized to emphasize treatment of both the disease and its psychosocial impact on the patients.

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