Staging and Profiling: The Constitution of the Endometriotic Subject in Gynecological Discourse

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INTRODUCTION

Endometriosis is defined as the presence of tissue resembling the endometrium (the lining of the uterus) *outside of* the uterus, most commonly in the pelvic cavity (CCCE, 1993:3)[1]. According to gynecologists, this tissue behaves like the endometrium, thickening during the menstrual cycle, then disintegrating during menstruation—except that, unlike the menstrual flow in the uterus, the blood and tissue cannot leave the body through the vagina. Instead, they remain within the body and form cysts and adhesions on and around the pelvic organs, such as the ovaries, fallopian tubes, peritoneum, bowel, intestines, and bladder. The most common symptom of the disease is pelvic pain (often associated with menstruation or sexual intercourse, and frequently chronic); another, much less common symptom is infertility (Barlow and Glynn, 1993:775-776; Lamb, 1987:279; Pauerstein, 1989:133-134).

In 1991, the Society of Obstetricians and Gynecologists of Canada began to plan a Canadian Consensus Conference on Endometriosis (CCCE) that would review the extant medical literature and provide "a guide for patients and physicians in the current management of this condition" (CCCE, 1993:2). A group of medical specialists, health economists, and representatives from the Endometriosis Association (a patient advocacy organization) was formed to participate in the conference. Although the CCCE's Consensus Statement begins with the claim that

"Endometriosis has never been well understood," the conference participants nevertheless were able to reach consensus on all conclusions regarding "the diagnosis, natural history, pathogenesis, relationship with infertility and pain, and medical and surgical management of the disease" (ibid). Two of the CCCE's conclusions are pertinent to this discussion: (1) the best available evidence indicates that the presence of endometriosis is not related to the age, race, social class, or personality of the patient; and (2) the standard diagnostic assessment scale for endometriosis is deeply flawed (CCCE, 1993:7)

Two gynecological codifications are criticized in these two conclusions. The first conclusion pertains to the gynecological codification of the age, race, social class, and personality of the 'typical' endometriosis patient, which I will call the 'typical patient profile.' The second conclusion pertains to the Revised American Fertility Society (R-AFS) classification for endometriosis (American Fertility Society, 1985:2), the diagnostic assessment scale referred to by the CCCE above. These two codifications, the typical patient profile and the R-AFS classification, have helped to construct and reify medical, demographic, and psychological representations of women with endometriosis. They provide particularly salient examples of the means by which professional bodies and systems of expert knowledge attempt to define subject-populations and thereby to regulate them.

Of course, subject-populations often resist such attempts at definition and regulation, and the deconstruction of the R-AFS classification and the typical patient profile undertaken by endometriosis patient groups are examples of such resistance. This will be discussed below. As well, members of professional bodies and expert systems of knowledge are not a monolithic group. As the criticisms raised by the CCCE make clear, considerable debate about the typical patient profile and the R-AFS classification exist in gynecological circles, and throughout this discussion medical criticisms of the two codifications will appear. However, the codifications are deployed in many contemporary gynecology textbooks and in many recent articles in prestigious gynecology journals. It is likely, therefore, that they continue to affect the treatment and diagnosis of women with endometriosis. Medical critics of the R-AFS classification and the typical patient profile nevertheless accept in principle the utility of classification schemes and patient profiles. Critics merely question the validity of the codifications currently in use, not their intent. Thus, I would argue that the attempt to define and regulate patient populations *per se* has gone unchallenged by gynecologists, and in that sense they *are* a monolithic group. It is this general acceptance within gynecology of the propriety of attempts to define and regulate patients in particular ways, rather than debates about whether the definitions themselves are scientifically accurate, that strikes me as curious.

The questions which I begin to address here are: How have endometriosis patients been defined through the use of the R-AFS classification and the typical patient profile? Why is it deemed necessary to define patients at all, and in these particular ways? How has the use of these two codifications affected the treatment and diagnosis of patients? How do definitions of endometriosis patients constructed via these two codifications compare with the ways in which endometriosis patients are defined within patient movements?

The first section of the paper examines the attempts of gynecologists to classify endometriosis patients into groups using the R-AFS classification. I argue that this classification groups women into 'risk populations, defining their experience, interests and concerns in ways that often conflict with patients' self-definitions and that direct medical experts to focus on particular research topics and treatment protocols. The second section focusses on the development and deployment of the typical patient profile. This profile also constructs 'risk populations' for medical surveillance. It also discredits patients' accounts of their symptoms in two ways: first, by calling into question the mental health of women with endometriosis, thus making their reports of symptoms suspect; and second, by denying that some types of women can have endometriosis, thus making it difficult for these women to obtain accurate diagnosis and therapeutic relief from their symptoms. The third section examines the ways in which patient groups are criticizing and resisting the individualizing and dividing practices reflected in the R-AFS classification and the typical patient profile, and the quite different methods they use to define endometriosis patients. The discussion is informed theoretically by the work of Bruno Latour on immutable mobiles (1986), Robert Castel on risk populations and plans of governability (1991), and Michel Foucault on techniques of individualization and resistance to them (1983). This analysis forms part of a larger examination of the efforts of endometriosis patient groups to contest gynecology's construction of the disease, its treatment, and the women who suffer from it. These efforts represent an attempt to reconfigure the boundaries between expert and lay knowledge. Such an analysis is relevant to broader sociological questions about the power/knowledge relation, the discursive constitution of subjectivity, and the role of social movements in resisting expert knowledges and individualization techniques.

STAGING:
THE R-AFS CLASSIFICATION FOR ENDOMETRIOSIS

Gynecologists have been attempting to classify endometriosis patients into "stages" of disease for over 75 years (Groff, 1989). The explicit goal has always been to predict women's chances of getting pregnant based upon the severity of their disease. None of the staging systems have met this goal very well. They have been plagued by a host of other problems as well. They often do not use standardized or translatable terminology; they use different scales of measurement; they employ inadequate sample sizes and widely variant patient populations; and they provide inadequate systems for coding different varieties and locations of endometriosis cysts and adhesions (Audebert, 1990; Buttram, 1985; Canis et al., 1993; Groff, 1989).

The failures of previous attempts at classification prompted the American Fertility Society, a professional organization of gynecologists, obstetricians, and reproductive endocrinologists, to convene a panel of endometriosis experts charged with developing a taxonomy for the Society. This was published in 1979; the version currently in use is a modification of this system and was published six years later (American Fertility Society, 1985). This "Revised American Fertility Society Classification for Endometriosis," or R-AFS classification, is the international standard for endometriosis classification because it is relatively easy to use compared to previous systems, and because it was developed by the American Fertility Society, one of the most prestigious professional associations of its kind. A standardized form was developed so that patients could be staged during diagnostic surgery. The form directs surgeons to record and rate the location and extent of endometriotic cysts and adhesions in particular sites of a woman's body using a points system, and to classify her case as one of four stages of severity (minimal, mild, moderate, or severe) based upon her total number of points (American Fertility Society, 1985; Canis et al., 1993:762). Because gynecologists believe that endometriosis on the ovaries and fallopian tubes is most likely to cause infertility, endometriosis in these areas is accorded many points in the staging system, while endometriosis on other areas is accorded few or no points (American Fertility Society, 1985).

The R-AFS classification represented "an effort to establish and document the premise that success of surgery in the infertile female was dependent on the severity of the disease" (Buttram, 1985:347). Standardizing classification of endometriosis facilitates communication between clinicians regarding treatment protocols and allows for the comparison of research into the success of various therapies in treating infertility. Because the form directs surgeons to examine the pelvis in a standardized way, and because it allows for the description of every case, it has virtually eliminated problems of incommensurability inherent in earlier classification systems. The scoring system is amenable to statistical analysis, so large numbers of commensurable cases can be manipulated by researchers interested in establishing correlations between stage of disease, treatment protocols, and subsequent fertility rates.

The R-AFS classification has been roundly criticized by many endometriosis specialists, especially regarding its ability to predict fertility outcomes (Audebert, 1990; Candiani, Vercellini and Fedele, 1990; Canis et al., 1992; Groff, 1989; Fukaya, Hoshiai and Yajima, 1993; Perper et al., 1995; Ripps and Martin, 1993). The Canadian Consensus Conference on Endometriosis refers to the R-AFS system as "the worst form of classification, except for all the others," simultaneously acknowledging its shortcomings and advocating its continued use (CCCE, 1993:7). The R-AFS classification's preferability to any other current system accounts for its continued popularity among gynecologists (CCCE, 1993:7). Although the American Fertility Society has not modified the R-AFS classification for over ten years, it has promised to do so, if and when the utility of modifications in predicting fertility outcomes has been established definitively (Buttram, 1985).

The R-AFS classification is an apt illustration of Bruno Latour's argument that modern scientific culture is concerned with "'holding the focus steady' on visualization and cognition" (1986:5). This is achieved through the production of immutable mobiles, "objects which have the properties of being *mobile* but also *immutable, presentable, readable, and combinable* with one another" (1986:7; emphasis in original)[2]. The R-AFS classification, an "immutable" because standardized and published form of inscription, allows a surgeon's view of a woman's pelvis to be converted into paper traces during surgery. These paper traces, which are mobile in a way that a surgically visualized woman's pelvis is not, can be presented to potential allies and combined with paper traces of other pelvises to support claims to knowledge about the best way to treat infertility in women with endometriosis.

Latour (1986) also points to the ways in which immutable mobiles can be used to forge alliances, to overcome dissent in the scientific community, and to incorporate previous claims to knowledge. The R-AFS classification drew on an existing professional network, mustering the support of a gynecological elite—members of the American Fertility Society—and all those who recognize the Society's expert authority. It incorporated the successes of former attempts at classification and sought to address their shortcomings, and any subsequent breakthroughs in classification undoubtedly will be incorporated into the R-AFS system. It has generated thousands of combinable surgical reports, virtually eliminating incommensurability across cases, and thus can be used to lend credibility to studies making new claims about how to best treat endometriosis-associated infertility.

The accumulation of large numbers of R-AFS stagings has been greatly assisted by the introduction of laparoscopy. This is a diagnostic and surgical technique in which a thin viewing instrument (a laparoscope) is inserted into the pelvic cavity via a small incision just below the navel. The pelvic organs can then be visualized without the necessity of large incisions (as was necessary with the older technique of laparotomy) so patients can be persuaded to undergo diagnostic surgery more easily and more often. While laparoscopy requires a general anaesthetic, the small size of incisions means that the procedure can be performed as outpatient surgery, eliminating the need for overnight hospital stays, and that recovery time is relatively short. Laparoscopic surgery has made it possible to visualize thousands of women's pelvises (often repeatedly) with minimal invasiveness relative to older surgical procedures. As the surgeon peers through the laparoscope, s/he can diagnose the condition of the pelvis and can 'stage' that condition by filling out the R-AFS classification form while the woman lies unconscious on the operating table. Then, the R-AFS form can be deposited in the case file, along with treatment plans and fertility outcomes, creating thousands of case files for the researcher, who can then correlate 'stage' of endometriosis, treatment, and fertility.

This creates the possibility of defining risk populations and plans of governability (Castel, 1991). By correlating R-AFS stage of disease with therapeutic approach and fertility outcome, researchers can evaluate the 'risk' of infertility for the four populations corresponding to each R-AFS stage, and how best to 'treat' that risk. Whether or not a woman has experienced problems with infertility, her doctor may prescribe hormonal therapies or perform surgery to 'protect' her fertility, all based upon the 'risk' of infertility suggested by her R-AFS staging. Furthermore, non-surgical markers that would determine the severity and activity of endometriosis, for example through a blood test, are currently being investigated (Audebert, 1990). Such markers may eventually enable wholesale screening for various degrees of endometriosis, assignment to risk populations, and treatment—all without actually establishing the infertility of the women being screened. Thus, the standardization of endometriosis classification opens up a whole realm of technological possibilities and techniques of governance.

The widespread use of the R-AFS classification allows for discussion of endometriosis among researchers and clinicians without direct reference to the women who suffer from it. The women who have been classified are absent from such discussion; only the paper traces of their surgical evaluation (performed while they were under general anaesthetic) remain. Thus, the concerns of individual patients can be more easily ignored. Needs and desires of an entire 'endometriosis population' can be constructed without any input from patients. In Latour's (1986) terms, patients are made "flat," easily understandable, the complexity of their lives reduced to a stage. Women can be grouped in ways that defy the diversity of their life circumstances, concerns (medical or otherwise), and desires. Again, this grouping, this development of 'risk populations' lends itself to plans of governability that may run entirely contrary to the wishes of individual endometriosis patients.

Witness the prioritizing of concerns about infertility in the R-AFS classification: the express purpose of classification is to improve the treatment of endometriosis-associated infertility. The stage of 'severity' is determined by anatomical distribution and extent of endometriotic cysts and adhesions, and is unrelated to the patient's degree of pain or other symptoms. The diagrams of staging examples provided by the American Fertility Society (1985) as an accompaniment to the standard classification form mainly depict endometriosis on the ovaries and fallopian tubes, where it is supposed to affect infertility. Other sites at which endometriosis may be more likely to cause pain than infertility are not depicted in the diagrams or on the R-AFS classification form. Certain parts of women's reproductive anatomy are highlighted, worthy of notice, while others fade into obscurity. Endometriosis in most of these other sites would have to be noted under "additional endometriosis" on the form, and would not be factored into staging as no points are accorded to "additional endometriosis." Thus, the R-AFS classification cannot be used to establish the severity of a patient's pain; consequently, researchers would find it exceedingly difficult to use it to develop new treatments for pain. The R-AFS classification holds the focus steady on infertility, and pain recedes. This is despite the fact that pain is the most common symptom of endometriosis, with infertility a distant runner-up (Barlow and Glynn, 1993:775-776; Lamb, 1987:279; Pauerstein, 1989:133-134). And of course, in the emphasis on infertility, we get a clear indication of gynecology's construction of the proper desires of women: having babies, not living without pain.

To sum up: the R-AFS classification has greatly assisted gynecological researchers in making claims to knowledge about the relation between endometriosis, infertility, and treatment, and in getting those claims to stick. Whether or not those claims are 'true' and whether or not the R-AFS stage accurately predicts a woman's chances of getting pregnant are matters of debate in gynecology. However, the focus on infertility at the expense of pain is rarely questioned in these debates, and this reinforces the assumption that infertility and not pain is the primary problem for women with endometriosis. 'Risk populations' are defined, treatment plans and research geared toward those populations. Pain becomes a matter for private discussion in the doctor's office and for an experimental, individualized approach to treatment; infertility becomes a matter for 'hard' scientific investigation and research on new treatment protocols. The R-AFS classification is both a symptom and a cause of this focus. The concerns of many women about pain diminish in importance. Artificial groups of, in other ways, vastly different women are created (the one factor uniting these women is, supposedly, their desire to maintain their fertility above all else). Women are reduced to a stage, their individual characteristics and life histories obscured. Their records are combined with other women's records and previously-accepted claims about endometriosis to reinforce researchers' new claims about treatment protocols, which focus on infertility in accordance with the gynecological definition of women's desires. The R-AFS classification works in conjunction with the typical patient profile to psychologize and delegitimize pain and to identify fertility as the proper concern of women and their gynecologists.

PROFILING: THE TYPICAL PATIENT PROFILE

Unlike the R-AFS classification, the typical patient profile has not been codified into a formal document. It exists instead in fragments, statements made in clinical practice and medical literature[3]. Attempts have been made to dismantle the typical patient profile, especially by feminist health advocates (eg. Ballweg, 1984; Boston Women's Health Book Collective, 1992), epidemiologists (eg. Houston et al., 1988; Pauerstein, 1989), and some gynecologists (eg. CCCE, 1993:7; Kennedy, 1991). Yet, elements of the profile continue to appear in contemporary gynecology textbooks and recent articles in prestigious gynecology journals, and continue to be presented by doctors in their conversations with patients (Boston Women's Health Book Collective, 1992:587; Halstead, Pepping, and Dmowski, 1989; Whelan, 1994). The typical patient profile has two components: demographic and psychological. I will discuss the latter component first.

I. Psychological components of the typical patient profile

The identification of a bi-directional causal link between women's reproductive and psychological health has a long history within medicine (see Astruc, 1985 [1743]; Cayleff, 1992; Ehrenreich and English, 1978; Moscucci, 1990; Showalter, 1985; Smith-Rosenberg and Rosenberg, 1984). In contemporary gynecology, this link is still being made; women with endometrial cysts and adhesions continue to be represented as psychologically disturbed. The typical endometriosis patient has been described as intelligent, perfectionistic, egocentric, career-oriented, over-anxious, and having a tendency to exaggerate pain without attempting to reduce or eliminate it (Gomibuchi et al., 1993:724; Kistner, 1968:329; Treybig, 1989:10). Some of the gynecologists who support the profile are considered top experts in the field, such as Dr. Robert Kistner, one of its leading proponents and a member of the committee that developed the R-AFS classification for the American Fertility Society. In a fascinating application of psychosomatism, he has characterized the typical endometriosis patient as "the *mesomorph eccentric*...it's that type of individual who simply has to clean out the ashtrays all the time" (cited in Older, 1984:135; my emphasis).

Several recent articles in reputable medical journals report on research which evaluates the "neurotic," "depressive," "aggressive," and "anxious" tendencies of women with endometriosis—or at least those who have chronic pain symptoms (Gomibuchi et al., 1993; Low, Edelmann and Sutton, 1993; Waller and Shaw, 1995; see also Renaer et al., 1979). An evaluation of this research suggests three conclusions about the current thinking of gynecologists regarding pelvic pain in women with endometriosis.

First, if a woman is diagnosed with endometriosis, her pain is more likely to be considered organic than the pain of a woman who has not been diagnosed with endometriosis. An undiagnosed woman's pain is more likely to be considered psychogenic. Thus, if physicians cannot diagnose the cause of pain, they may be more likely to attribute it to psychological dysfunction on the part of the patient than to their own inadequacies as diagnosticians.

Second, the pain of women with minimal or mild endometriosis (Stages I and II of the R-AFS classification) is more likely to be considered psychogenic than the pain of women with moderate or severe endometriosis (Stages III or IV). Thus, the R-AFS classification can have important ramifications for patients: if they have severe pain and are classified as having minimal endometriosis, their pain may be less likely to be treated seriously by their physicians. In fact, many women with endometriosis who complain of pelvic pain have been told by their doctors that they were neurotic, overreacting to pain, or uncomfortable with their femininity or sexuality, and they have often received prescriptions for tranquilizers rather than treatment for the pain (Ballweg, 1992:753; DeMarco, 1991:18; Halstead, Pepping and Dmowski, 1989; Lauersen and deSwaan, 1988:95). Thus, the R-AFS classification can be used to define some patients as psychologically disturbed based upon the extent of their endometriosis and the severity of their pain symptoms; in this case, the R-AFS classification and the typical patient profile work together to reinforce existing assumptions about the root causes of women's pain symptoms.

Third, women with pelvic pain are more likely to be considered psychologically dysfunctional than women who complain of infertility. One study used infertile women as a control group in their psychological evaluation of women with minimal and mild endometriosis (Waller and Shaw, 1995). That is, infertile women were assumed to be psychologically normal; the study population was women with pelvic pain. The researchers assumed that pelvic pain is related to psychological dysfunction, and that infertility is a legitimate organic problem requiring gynecological treatment. Of course, the R-AFS classification's emphasis on the problem of infertility to the exclusion of pain suggests this as well. Again, the R-AFS classification and the typical patient profile work in tandem, in this case to reinforce gynecological assumptions about the proper concerns of women and the veracity of their claims about their bodily experiences.

Thus, the psychological component of the profile reflects two underlying assumptions in the R-AFS classification. The first assumption is that gynecology should focus on the treatment of infertility, while pain should be left to psychologists. As one research team put it, "patients with chronic pain...can be arch-manipulators" and psychologists are better trained to deal with such personalities (Barlow and Glynn, 1993:787). The second assumption is that the anatomic amount and distribution of disease, determined via surgery, determines symptoms. This is a claim which some gynecologists dispute, given the wide range of symptomatology in women with similar anatomical amounts and distributions of endometriosis. These critics argue that histological analysis (microscopic analysis of the activity of endometriosis tissue, such as its production of pain-producing substances) tells us more about women's symptoms than anatomic distribution and amount of disease (Groff, 1989). In fact, women with anatomically minimal endometriosis often have more pain than women with anatomically severe endometriosis (CCCE, 1993:7). However, gynecologists generally are more skilled at surgery than histological analysis, and treating infertility is more lucrative than treating pain; hence, the focus on surgery and infertility is hardly surprising. Professional interests should not be discounted.

II. Demographic components of the typical patient profile

The typical endometriosis patient has been described as a white, well-educated, middle-class 'career woman' in her thirties or forties who has 'delayed'[4] childbearing (American College of Obstetricians and Gynecologists, 1983; Chalmers, 1975:1; Goldman and Cramer, 1990:17-18; Haney, 1990:10; Kistner, 1968:329; 1986:398-399; Tindall, 1986:358-359; Treybig, 1989:10). This demographic profile is still frequently referred to by clinicians, the media, and gynecology texts, although research has demonstrated that women of all ages, races, and socioeconomic statuses, with and without children, have endometriosis (Chatman, 1976; Chatman and Ward, 1982; Goldstein, De Cholnoky and Emans, 1980; Lamb, 1987, 1990). Critics have argued that the patient profile is an artifact of, for example, the substandard medical treatment received by poor and young women and by women of colour, who may never get properly diagnosed (Chatman, 1976:987; Ballweg, 1988; Breitkopf and Bakoulis, 1988:51; Houston et al., 1988:788; Kennedy, 1991:9).

The demographic component of the profile is related to the notion of risk populations which can be diagnosed and treated according to their group characteristics (Castel, 1991). While epidemiologists generally reject the existing typical patient profile as artifactual, they are studying several other 'potential risk factors,' such as menstrual disorders, tampon use, smoking, family history, and immunological disorders (Cramer, 1987; Goldman and Cramer, 1990; Haney, 1990; Houston et al., 1988; Pauerstein, 1989). Many of these factors would be amenable to screening and prevention programmes if their causal effect was definitively established (Cramer, 1987)[5]. Wholesale screening for endometriosis is not currently cost-effective or desirable because the disease can only be diagnosed surgically, but if efforts to develop a non-invasive test for the disease are successful, it may become feasible (Houston et al., 1988:798). If these 'risk factors' are validated by these screening procedures, one's lifestyle choices (smoking, choosing tampons over sanitary napkins) could become, theoretically at least, the target of medico-moral governance projects.

STRATEGIES OF RESISTANCE: ENDOMETRIOSIS PATIENT GROUPS

Bruno Latour has argued that

> A man whose eye dominates records through which some sort of connections are established with millions of others may be said to *dominate*. This domination, however, is not a given but a slow construction and it can be corroded, interrupted or destroyed if the records, files and figures are immobilized, made mutable, less readable, less combinable or unclear when displayed (1986:29; emphasis in original).

The ongoing efforts to improve the R-AFS classification and to replace the typical patient profile with a more satisfactory set of risk factors for endometriosis have corroded the dominant codifications and will undoubtedly lead to their modification or replacement. These efforts represent attempts at inclusion: the inclusion of cases of endometriosis in women that do not fit the typical patient profile; the inclusion of new findings about the staging of endometriosis and its correlation with infertility. We see this strategy of inclusion at work in the critiques of researchers and their attempts to develop 'better' sets of risk factors and 'better' systems of classification.

Also, patients have contributed to the critiques of the R-AFS classification and the typical patient profile, but their critiques do not represent a move toward a more inclusive and totalizing gynecological knowledge. Rather, they represent a strategy of resistance to forms of medical individualization.

Preliminary analysis of endometriosis patient groups suggests some impressions about how this strategy works, drawing upon some principles outlined by Michel Foucault (1983) for analyzing resistance to techniques of individualization.

Foucault argues that many recent social movements are "struggles which question the status of the individual...they assert the right to be different...On the other hand, they attack everything which separates the individual, breaks his links with others...and ties him to his own identity in a constraining way" (1983:212). Patient groups, such as the U.S.-Canada Endometriosis Association, local support groups, and the WITSENDO list server on the Internet, emphasize the simultaneous variety and community of experience among women with endometriosis. Women retain their personal identities and provide their own accounts of their experiences, which are not flattened to make them more combinable (Latour, 1986), as with the R-AFS classification. Patient groups construct a web of accounts that cross over at many points but retain their own trajectories. As Foucault argues, these groups

> are not exactly for or against the "individual," but rather they are struggles against the "government of individualization"...[they] revolve around the question: Who are we? They are a refusal of these abstractions...which ignore who we are individually, and a refusal of a scientific or administrative inquisition which determines who one is (1983:212).

Foucault describes several "modes of objectification that transform human beings into subjects;" one of these is "dividing practices" which divide people into groups. The typical patient profile divides women into groups: women who are at risk for endometriosis and women who are not. The R-AFS classification divides women with endometriosis into four stage classifications. Patient groups have challenged the typical patient profile by pointing to research that women of all ages, races, and classes, with and without children, have endometriosis. They have defied the R-AFS classification by emphasizing the importance of chronic pain as well as infertility, by legitimating women's claims that they experience severe pain despite minimal endometriosis, and by arguing that histological analysis may tell us more about a woman's experience of pain than anatomical analysis via surgery. Patient groups include women who have the symptoms of endometriosis but have never been diagnosed, and many discussions among patients challenge the ability of the R-AFS classification to explain symptoms or therapeutic outcomes. The dividing practices of gynecology are challenged in the process.

Foucault also emphasizes the ways in which many new social movements oppose "secrecy, deformation, and mystifying representations imposed on people" (1983:212). By providing simple explanations of the R-AFS classification system, patient groups translate inaccessible medical jargon into everyday language. By emphasizing the significance of pain symptoms as well as or even more than infertility, patient groups encourage women with endometriosis to contest pejorative representations of their psychological health based upon their symptoms. By publicizing and conducting research which demonstrates that all sorts of women have endometriosis, patient groups encourage women to demand definitive diagnosis, even when their demographics do not fit the typical patient profile.

CONCLUSION

The R-AFS classification and the typical patient profile constitute the 'endometriosis population' as primarily and properly concerned with fertility maintenance, rather than pain relief. Pejorative psychological identities are assigned to women with endometriosis, especially those who suffer from chronic pain. A demographic profile of endometriosis patients is constructed, making it difficult for certain categories of women to attain accurate diagnosis and appropriate treatment. The self-professed desires and concerns of individual women are obscured and a one-dimensional, unilateral gynecological description is substituted. Women are grouped into 'risk populations' requiring therapeutic governance, expanding indications for medical intervention from treatment to prevention. The variety of the circumstances and symptoms of women with endometriosis recedes from focus and the 'endometriotic subject' rises to the fore.

The preceding analysis has attempted to demonstrate that the R-AFS classification and the typical patient profile are alive and well within gynecological discourse, not to deny that the codifications have been criticized both within and without the profession of gynecology; clearly, these codifications are controversial. The content of many of the patient and expert criticisms of the typical patient profile are strikingly similar, and both patients and experts have questioned the arbitrary staging and the prognostic utility of the R-AFS classification. In the final analysis, however, experts and patient groups are pursuing contradictory goals. While experts are attempting to forge ever more 'accurate,' totalizing descriptions of the endometriotic subject, endometriosis patient groups emphasize both the similarity and variety of experience and life circumstances among women with the disease. Their accounts of the disease retain patient authorship and are not 'flattened' to make them more combinable; they also challenge the legitimacy of dividing practices within gynecological discourse, demystify medical jargon, and present conflicting medical accounts about what women with endometriosis are 'really' like. Thus, informed patient critique becomes possible and is openly encouraged. Rather than forging constraining identities and risk populations, the goal for endometriosis patient groups seems to be, as Foucault (1983:216) puts it, "not to discover what we are, but to refuse what we are."

NOTES

1. Adapted from a paper presented at the Graduate Student Work-In-Progress Seminar, Department of Sociology and Anthropology, Carleton

University, February 7, 1997. Thanks to Bruce Curtis, the Work-in-Progress Seminar participants, and the Alternate Routes editorial collective for their helpful comments; and also to Annette Burfoot, Roberta Hamilton, David Lyon, Christine Overall, Barbara Mains, Mary Lou Ballweg, and participants in earlier focus group research for helping me think through the politics of endometriosis knowledge.

2. The notion of immutable mobiles is a core component of Latour's (1986; 1987) actor-network theory, which aims to identify the local, contingent, consensus-building activities engaged in by scientists to obtain credibility for their claims. Scientists accomplish this by recruiting supporters in scientific and extrascientific communities, often by 'piggybacking' their new claim onto established ones. This makes it difficult to dispute the new claim because to do so would be to take issue with an accepted stock of knowledge and all of its adherents. In order to attain widespread acceptance, a claim must be *mobile*; that is, it must be able to move freely between different contexts and localities. The R-AFS classification, for example, has been translated into several languages and has been published as a form that can be ordered from the American Fertility Society. However, as claims are taken up by others, they may be modified. In order to maintain the recognizability of their claims across different contexts and in the hands of different users, scientists attempt to make their claims *immutable*. The presentation of the R-AFS classification in the shape of a published form resists its substantive modification. See Callon, 1986, Callon and Law, 1989, and Ward,1996 for applications and further development of actor-network analysis.

3. For some recent medical discussions of the typical patient profile, see American College of Obstetricians and Gynecologists (1983), Barlow and Glynn (1993:787), Chalmers (1975:1), Goldman and Cramer (1990:17-18), Gomibuchi et al. (1993:724), Haney (1990:10), Kistner (1986:398-399), Pauerstein (1989:130-133), Tindall (1986:358-359), and Treybig (1989:10).

4. The term 'delayed' implies that childbearing is *desirable* at a young age (often explicitly stated by gynecologists), but a moral or instinctual *imperative* at some point in a woman's life (a more implicitly held assumption).

5. At least one of these factors (smoking) is already a focus of projects that target individuals for moral reform, although these projects so far have not added endometriosis to the long list of ills and abuses inflicted on the population by tobacco users.

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