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**"Well now, who's the doctor here?"
Boundary-work and Transgression in
Patient and Expert Knowledges of Endometriosis**

by

Emma Whelan, B.A. (Hons.), M.A.

A thesis submitted to
the Faculty of Graduate Studies
in partial fulfillment of
the requirements of the degree of

Doctor of Philosophy

Carleton University
Ottawa, Ontario
September 6, 2000
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and Expert Knowledge of Endometriosis**

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the degree of Doctor of Philosophy

Chair, Department of Sociology and Anthropology

Thesis Supervisor

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November 10, 2000

Abstract

This thesis is a comparative epistemology of patient and medical knowledges of endometriosis, a gynecological disease that is thought to cause chronic pain and infertility. It describes and compares the claims, claimsmaking strategies, and standards of two 'epistemological communities' (Nelson, 1993), the endometriosis patient community and the medical endometriosis community (composed primarily of gynecologists), and the relations between these two communities.

Each community has its own core claims and professed standards and strategies for knowing endometriosis. Each asserts that its knowledge is more valid than the other's, conducting 'boundary-work' (Gieryn, 1983) to establish its authority and delegitimize the claims of the other. The patient community lays claim to the realm of experience, the medical community to the realm of science. Yet, it is demonstrated that, in practice, the communities share a set of epistemic resources which they use to solve problems and assert cognitive authority. Patients draw heavily upon medical claims and notions of science to evaluate and assert claims to knowledge. Medical experts draw upon notions of clinical experience and upon the experiential accounts of patients to craft and evaluate the claims of medical science and to solve problems in clinical practice. Both draw heavily upon notions of science and experience in their claimsmaking activities, and necessarily so, because neither science nor experience alone are adequate resources for grasping the enigma that is endometriosis. The epistemic overlaps and differences between the two communities are used to good advantage by the Endometriosis Association, which attempts to enrol both patients and medical experts to establish itself as the representative of women with endometriosis and as an important player in the medical research community.

It is concluded that patient knowledges are neither dichotomous to medical knowledges, nor that patient knowledges simply mirror the claims of medical discourse. Instead, the two communities' ways of knowing are conceived as mutually constitutive--a point which troubles traditional distinctions between lay and expert knowledges.

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Introduction

The title of this thesis may seem curious. Everyone knows who the doctors are: they are experts in the *science* of medicine, distinguishable from patients, who know about the *experience* of being ill. Many comparisons of medical and patient knowledges abide by this distinction. On the one hand, they argue, we have patients' knowledge--knowledge of "illness," "experience," "the voice of the lifeworld"; on the other, we have doctors' knowledge--knowledge of "disease," "the biomedical model," "science," "the voice of medicine" (eg. Kleinman, 1988; Mishler, 1984; Tuckett et al., 1985).

The distinctions these authors draw are useful in analysing two different ideal types of information about states of ill health, and I make use of these ideal types in what follows, referring to "illness information" (experiential, contextual information) and "disease information" (scientific information). Moreover, it is probably true that, in most cases, medical professionals possess more disease information (i.e. know more about medical science), and certainly patients possess more illness information (i.e. know more about their experience and lifeworlds). These authors make the important points that patients' and medical professionals' knowledges differ in key ways and that, despite the dominance of the medical model, distinctive patient knowledges are alive and well and provide important insights. The main goal of these authors is to effect a reconciliation between two dichotomous knowledges: the subjective, contextual knowledge of experience and the objective, scientific knowledge of medicine.

My main goal in what follows is to show that medical and patient knowledges are *not*, in fact, dichotomous--and not because patient knowledge is just a derivative of medical knowledge (eg. Armstrong, 1984; Harding, 1997). Instead, I argue, the

derivation is bi-directional: patient and medical knowledges are *mutually* constitutive and defined in relation to one another. Although, in principle, doctors lay claim to the realm of science and patients to the realm of experience, in practice, the distinction does not hold. In their practical claimsmaking activities, both patients and doctors employ messy, hybrid epistemological models that draw on notions of "science" and "experience." The boundary between medicine as science and patient knowledge as experience is not a given, but a construction (Gieryn, 1983)--and a flimsy one at that, because the boundary is transgressed by patients and doctors on a routine basis.

I. Overview of the Project

The title of this thesis, "Well now, who's the doctor here?" plays upon these notions of boundary work and boundary-transgression. The question could have been asked by a doctor to assert a claim to expertise in response to an uppity patient who questions the doctor's advice--and we shall see, doctors do ask these kinds of questions of patients in their boundary-work efforts to establish their cognitive authority. But actually, the question was asked by "Mercedes," a woman with endometriosis. Endometriosis (or endo, as women with the disease often call it) is defined medically as the presence of tissue that resembles the lining of the uterus, in sites *outside* the uterus (usually in the pelvic cavity). This tissue, which forms cysts or lesions, is believed to behave as the endometrium in the uterus behaves; during a woman's period, the lesions swell and bleed, causing cramping and bloating. Because they cannot leave the body through menstruation, the clotted blood and tissue produce adhesions that may grow over time¹.

¹There is some debate in the medical literature as to whether endometrial cysts increase in size and number over time or whether the number and size of cysts remains constant. However, it is clear that, when once removed, endometrial cysts may come back. Also,

Some women experience no symptoms, while other women experience chronic pain, infertility, and a range of other symptoms.

Mercedes suffered from chronic pain, and saw several doctors in an attempt to attain a diagnosis. This is how she describes that process:

Nobody once mentioned the word endo until I asked to have a laparoscopy done--I asked. I asked for a D&C, two years later I asked for a laparoscopy, and if they hadn't of found nothing with the lap, I don't know what I would have done, then I would've been researching some more and saying "Okay, now let's do this procedure." Well now, who's the doctor here?

Mercedes is not a doctor, but she asserts that she knows more about endometriosis medicine than her doctors do, and she is not an isolated case. Mercedes is a member of the endometriosis patient community--a community of women with endometriosis who interact with one another in special patient venues: on the Internet, in support groups, and through a patient self-help organization called the Endometriosis Association (EA). The members of this community frequently challenge doctors' claims to know about endometriosis. They assert their own privileged status as knowers of endometriosis based explicitly upon their notion of shared experience, which is foundational to the solidarity of the community and to the development of its claims. It is argued that, since medical experts have not experienced endometriosis first-hand, they possess only a second-hand, inferior understanding of it.

Medical experts who treat and study endometriosis--primarily gynecologists--form another epistemological community. This community explicitly advocates a scientific biomedical model for knowing endometriosis. Members of the medical community assert that endometriosis patients' accounts of their experience are anecdotal, subjective, and

many women claim that their symptoms worsen over time.

unreliable. This is so particularly because endometriosis patients' accounts of their embodied experience, especially their pain, cannot be verified objectively by medical science and thus, it is suspected, their pain may be psychosomatic. The best way to know endometriosis, it is claimed, is through objective, scientific study--which only medical experts, with their specialized training and understanding of the pathophysiological foundations of disease, can conduct.

It is easy to see why analysts of medical and patient knowledges would think that the former represents science, "disease," the "voice of medicine," and the latter experience, "illness," the "voice of the lifeworld"; often, this is how medical experts and patients explicitly characterize their knowledge. And yet, members of the endometriosis patient community know a great deal about endometriosis science, and members of the medical endometriosis community have a great deal of experiential knowledge. Furthermore, medical experts cannot make scientific claims about endometriosis without the help of patients, and patients cannot make claims about their experience of endometriosis without the help of medical experts.

That is, patients' accounts of their experience *as* endometriosis experience are dependent upon physicians' designation and description of endometriosis as an identifiable disease entity, and upon physicians' diagnosing them with endometriosis. Much of patients' shared experience--with surgeries, drugs, clinicians--is the *result* of medical practice. Patients draw heavily upon medical knowledges to make sense of their experience, to assert the validity of their knowledge, and to contest the claims of medical experts as 'unscientific.' They rely upon the expertise of medical professionals to treat them and ameliorate their symptoms. These patients expend a great deal of time and energy to learn about endometriosis science, reading medical journals, surfing the web,

and exchanging information amongst themselves about medical tests, research on the causes of endometriosis, and the latest treatments for the disease. They often argue, as Mercedes did, that patients know more about endometriosis science than doctors do, that the claims of their clinicians are 'unscientific,' and that clinicians need to keep up to date on the latest scientific developments, as patients themselves try to do. They assert that not enough research is being done on the disease, and that much of the existing research is insufficiently scientific, 'biased' by sexism and poor methodology. While they criticize clinicians' knowledge and the available medical research, they exhibit a great respect for the principles of medical science and a strong faith in its ability to cure the disease one day.

Physicians draw heavily upon notions of clinical experience to evaluate scientific claims, to assert the validity of their knowledge, and to evaluate the validity of patients' experiential claims. Both clinical experience and medical science are invoked to construct endometriosis patients' symptoms as psychosomatic and the patients themselves as unreliable symptom-reporters. Nevertheless, clinicians have no choice but to draw heavily upon patients' experiential accounts to describe endometriosis, to treat it, and to conduct research on it--however unreliable they may consider these accounts. Each community strategically takes up and rejects the claims and epistemological standards of the other to get its own claimsmaking done and assert its privileged epistemic status, and to counter the claims of the other community and construct its members as non-knowers. Both communities draw upon notions of experience and science in their claimsmaking activities, despite the fact that they define themselves through their claims to monopolize experience or science.

Implicated in the tensions and overlaps between the medical and patient

communities is the nature of endometriosis itself. Pain is the **most common symptom** of endometriosis. There is no known cure for endometriosis and its cause is unknown. For unknown reasons, the efficacy of treatments varies a great deal from patient to patient. Consequently, endometriosis is frequently described by both medical experts and patients as an enigmatic disease. The enigmatic nature of endometriosis causes considerable conflict between the two communities, particularly regarding the relation between symptoms (patient experience) and signs (medical observations). Because the primary symptom of endometriosis is pain, an intrinsically subjective symptom and therefore elusive from a medical point of view, and because the severity of symptoms does not correlate with the observable extent of disease, patient and physician accounts of endometriosis frequently vary, even directly contradict one another.

But neither community can know about the enigma that is endometriosis except parasitically, through the knowledge of the other. The enigmatic nature of endometriosis generates conflict, but also necessitates cooperation between the communities. The primary organizer of this cooperation is the Endometriosis Association (EA). The EA is primarily a patient self-help organization, but one with many expert medical allies. Its work represents an explicit attempt to draw the interests and epistemological models of the two communities together: to act as the representative of patients, to validate their experiential knowledge, and to provide them with access to scientific knowledge; and to provide clinicians with access to patients' experiential accounts and to work collaboratively with the medical research community. The EA asserts the distinctiveness of each community's knowledge to highlight the *need* for cooperation, but it also plays upon the communities' shared appreciation for experience and science to provide a *basis* for cooperation. If the two communities were as dichotomous as the communities

themselves suggest, the EA could not do its work.

This project is a "comparative epistemology" (Fleck, 1979 {1935}:22) of the medical and patient epistemological communities and the role of the EA in mediating the relations between them. It examines each community's core claims and epistemological strategies and standards, the boundary-work in which each community engages to distinguish itself from the other, the epistemic tensions between and within the communities, the overlaps and traffic between them, and the work of the EA in attempting to direct the traffic. I advance several main arguments:

- (1) The distinction between expert and patient knowledges is not given as a result of experts' exclusive possession of scientific knowledge and patients' exclusive possession of experiential knowledge, because both the medical and patient communities draw upon science and experience in their claimsmaking about endometriosis.
- (2) Consequently, the distinction between expert and lay knowledges must be produced through boundary-work, in which each community engages to assert its status as the community that knows endometriosis best and to undermine the other community's claim to know endometriosis best.
- (3) In practice, the constructed boundary between expert/scientific and lay/experiential knowledge is transgressed routinely by both communities, because the distinctive claims of each depend upon the claims of the other.
- (4) The different knowledge resources of the communities and their shared qualities not only engender conflict, but also enable strategic, cooperative knowledge ventures between patients and doctors.

It is not that the knowledge of the two communities is identical--only patients know what it is like to have endometriosis pain, and only physicians know how to conduct

surgery, and in this sense, the distinction between illness and disease works. But, in coming to grips with the enigma of endometriosis, the knowledge of each community requires the incorporation of the other's claims and, in practice if not always in principle, the communities invoke many of the same notions about how to know endometriosis.

II. Outline of the Thesis

The first chapter delineates the theoretical framework for this project. I begin with a critique of two other popular approaches to investigating the knowledge relationships between patients and doctors: the medicalisation thesis and the Foucauldian school. I then present the central theoretical piece of the dissertation, a composite of several strands of work in science and technology studies (STS): actor-network theory and related approaches that focus on scientific practice; the literatures on boundary-work, public understanding of science, and cooperative ventures between scientists and laypeople; and Ludwik Fleck's *Genesis and Development of a Scientific Fact*, which usefully examines the relationship between lay and expert knowledges. These help us to understand the cross-fertilization between medical and lay knowledges of endometriosis.

STS frameworks, of course, tend to focus on science rather than lay knowledges, so I supplement them with some insights from feminist epistemology about the relationship among knowledge, experience, and activism and from discussions of medical representations of the body and modes of resistance to them. These form an important part of my analysis of the endometriosis patient epistemological community and its reliance on notions of experience and embodiment in its challenges to clinical practice and biomedical science.

The second chapter presents the research methodology used in this project. I

describe my methods for collecting and analyzing medical, patient, and Endometriosis Association accounts of endometriosis and the epistemologies they employ. My analysis is based upon medical literatures about endometriosis; reanalysis of transcripts from focus group research I conducted in 1994 with six members of an endometriosis patient support group; an email questionnaire conducted in January and February 2000 with members of WITSENDO, an endometriosis patient email list; and Endometriosis Association literature. I conclude the chapter with my reflections on the strengths and limitations of the study.

The third chapter describes medical claims and ways of knowing about endometriosis. It delineates the core claims and areas of contention within the gynecological community of endometriosis experts in three particular areas: classification of endometriosis and psychological and epidemiological profiles of endometriosis patients. It explicates the official scientific epistemological model deployed in medical texts about endometriosis. It examines medical constructions of women with endometriosis as unreliable claimsmakers through the classification, psychology, and epidemiology literatures--an important component of my analysis, because such constructions represent a striking case of medical boundary-work and a key source of conflict between endometriosis patients and medical experts. I conclude the chapter with a comparison of the official scientific epistemology presented in medical texts, which aims to reduce complexity and standardize knowledge, with a subtextual epistemology contained therein--one that depends upon notions of clinician experience and subjective interpretation and reintroduces complexity and variation into expert knowledge. I argue that scientism is only one component of medical ways of thinking and that this informal 'clinical experience epistemology' contradicts scientism in many ways.

Chapters 4 and 5 present my investigation of the endometriosis patient community, based upon the focus group transcripts and the WITSENDO participants' responses. The fourth chapter sets out the community's core critiques of medical experts and medical knowledge in response to medical constructions of endometriosis patients, discussed in Chapter 3. It delineates three sets of core claims made by patients about medical experts as knowers, relating to the latter's lack of knowledge, presentations of their knowledge, and willingness to exchange information with patients. It then presents six patient explanations for the shortcomings of medical experts. These explanations construct clinicians in ways that serve to dethrone their elevated social status as knowers, and employ many of the same devices that clinicians use to construct endometriosis patients. I conclude with a discussion about the ambivalent relationship of patients to medical expertise.

The fifth chapter examines the patient community's ways of knowing: what patients claim to know about endometriosis, how they claim to know, how they search for information, and how they evaluate and use information. I examine patients' estimations of the validity of various sources of information and their self-presentations as knowers. A particular focus of the chapter is an examination of the relationships among scientific knowledge, 'patient experience,' and embodied sensation in patients' presentations of themselves as knowledgeable agents in regard to endometriosis. I conclude with a discussion of the sources of resistance of which endometriosis patients make use in their epistemological struggles with medical professionals.

The sixth chapter focusses on the Endometriosis Association as a venue of the patient community and an affiliate of the medical community. I examine its attempts to draw patients and medical experts together into a network with shared goals that fosters

respect for the different kinds of knowledges that patients and experts possess. The Endometriosis Association is a self-help organization founded in 1980, with headquarters in the U.S. It now has chapters, sponsors and members in 66 countries (Endometriosis Association website, www.endometriosisassn.org/press3.htm). The EA is composed primarily of women with the disease, but also includes some clinicians, scientists, and other parties (such as family members of women with endometriosis). Most of its funding comes from the dues and donations of members and their families, but it also receives donations from medical experts and corporate sponsors (primarily pharmaceutical companies). I apply actor-network theory in an attempt to understand how the EA recruits the support of both patients and medical professionals, positions itself at the head of an expert-patient endometriosis knowledge network, and constructs itself as an authority on the disease.

I begin with an account of the formation of the EA by its founder, Mary Lou Ballweg. I then discuss the ways in which the EA presents itself as an organization interested in promoting support, education, and research; the EA's activities in each of these areas is examined in turn. The EA's support provision activities focus upon creating experiential solidarity by positing a group experience common to patients with endometriosis, and upon providing information and tacit advice about how to become a successful endometriosis patient--one that is informed and able to take a proactive role in management of the disease and interaction with medical professionals.

The EA's education activities are directed primarily to two groups: endometriosis patients and medical experts. The EA promotes patients' responsibility to know as well as their right to know. It produces a great deal of patient-oriented literature about endometriosis and attempts to position itself as the main authority on endometriosis

knowledge for patients who should know about endometriosis. The EA educates physicians through its presentations at medical conferences, distributing its literature to physicians directly, and contributing to medical texts. It attempts to recruit the support of physicians through appeals to patients' experiential narratives of endometriosis, constructions of medical expertise, scientificity, psychology, and sociopolitical arguments.

The EA's research activities involve connecting researchers to subjects and conducting its own social scientific research on women's experiences with endometriosis and, increasingly, medical research on endometriosis. The EA seeks to establish itself as an authority on endometriosis among both patients and physicians, but uses different strategies to enrol each population into its network, sometimes highlighting differences between patients and physicians, and at other times minimizing them.

The thesis concludes with a summary of the findings and arguments, an assessment of its contributions to the literature, and directions for future research.

III. Contributions of the Project

My goal here is not to assert that patient knowledges are 'better' than medical ones, or vice versa. As a feminist and a member of the endometriosis patient community myself, my allegiance to the patient community in its struggles with the medical community is strong. In this sense, I was "captured" politically (Scott, Richards & Martin, 1990) long before the research began. Yet I also appreciate the difficulties faced by medical professionals in treating and knowing about endometriosis, and recognize--as most patients do--the value of medical knowledge and practice in relieving the suffering of many endometriosis patients. My aim is to examine the conflicts and similarities between the communities, to ascertain the sources of the conflict, and to demonstrate that the

communities are not as far apart epistemologically as they so often assume. **Perhaps** this is a small step toward resolving the conflict, developing more cooperative knowledge ventures between doctors and endometriosis patients and, ultimately, increasing the satisfaction that both patients and doctors may gain from their interactions. While the cognitive authority of medicine as a science is the basis for its special status as an expert system, the scientism of medicine has been and continues to be questioned by many clinicians, and certainly by patients. The high esteem in which patients hold medical science and their efforts to familiarize themselves with its claims, and many experts' appreciations of patients' viewpoints and desire to improve patient-doctor relations (as testified by the alliances that many endometriosis experts have formed with the EA), seem to suggest that the "voice of medicine" and the "voice of the lifeworld" can be appreciated by both parties.

This is certainly not the first study to examine medical and lay knowledges. A very large, interdisciplinary literature on medical knowledge exists²; another large literature examines "folk" or lay knowledges--often described as "experience" of illness, rather than as knowledge as such (eg. Calnan, 1987; Delvecchio Good, Brodwin, Good & Kleinman, 1992; Good & Delvecchio Good, 1982; Helman, 1978; Kleinman, 1988; Popay & Williams, 1996; Radley, 1993). However, these literatures tend to focus on *either* medical or lay knowledges and, if the other is presented at all, it is not addressed in detail. Discussions of lay knowledges tend to neglect the ways in which the viewpoints of the ill may emerge through interaction in specific *patient* communities, rather than merely

²For some reviews and collections of the history, philosophy, anthropology, and sociology of medical knowledge, see Bynum & Porter, 1993, esp. Volume I; Engelhardt & Erde, 1980:371-401; Hahn & Kleinman, 1983; Lock, 1993:144-146; ten Have, Kimsma & Spicker, 1990; Wright & Treacher, 1982.

through the 'experience' of individuals or their general social and cultural context; and they tend to conflate 'experience' with knowledge, without any critical deconstruction of the ways in which the notion of experience is used by patients. Sources like Mishler (1984) and Tuckett and colleagues (1984) address interactions between medical and lay knowledges, but through the encounters of individual patients and clinicians. The development of patient knowledge as an ongoing project of *patient communities* and these communities' elaboration of 'experience' into firm knowledge claims are topics that have not been addressed in medical sociology, and which I am concerned to address here. Moreover, because medicine tends to be conceived as an overarching, internally consistent social structure in many accounts of medical and patient knowledge, the specificity of the claims and epistemological standards of particular medical specialties tends to be neglected. In focussing upon the claims and standards of a particular community of gynecological clinicians and clinician-researchers about a particular disease, I attend to the specificity of medical claimsmaking practices.

Other authors, some of whose work is reviewed in Chapter 3, have demonstrated that medical ways of knowing are characterized as much by notions of clinical experience as by notions of biomedical science. This project contributes to that literature. It also contributes to the growing literature on the elusivity of pain, the ways in which medical professionals attempt to come to grips with it, and the labelling of medically unverified pain as psychosomatic (eg. Baszanger, 1992, 1993; Delvecchio Good, Brodwin, Good, & Kleinman, 1992; Grace, 1998; May, Doyle, & Chew-Graham, 1999; Morris, 1991; Rhodes, McPhillips-Tangum, Markham & Klenk, 1999; Scarry, 1985). But it also examines the challenges that this labelling poses more generally to patients regarding their epistemic credibility, as well as the forms of patient resistance that medicine's inability to

verify pain make possible.

Theoretically, this thesis draws most heavily upon science and technology studies (STS) and contributes to that literature in several ways. It represents an addition to case studies of the tensions between official codes of practice and the actual practices of scientists and medical experts (eg. Berg, 1997; Berg & Timmermans, 2000; Jordan & Lynch, 1992). Like much of the enormous feminist literature on science (see Whelan, forthcoming for a review) and studies which combine the insights of STS and feminism (eg. Clarke, 1998; Haraway, 1997; Oudshoorn, 1994; Singleton, 1996), it demonstrates the central role of constructions of gender in medical research and clinical practice. It provides a detailed analysis of a classification system and its role in medical work and in the construction of human subjects (see also Ben-Ari, 1994; Bowker & Star, 1999; Clarke & Casper, 1996). It also contributes to the literature on boundary-work (eg. Gieryn, 1983; Kaptchuk, 1998). This literature has tended to focus on scientists' methods of dismissing competitors' knowledge, but my analysis also considers patients' boundary-work attempts to undermine the credibility of medical experts. The project represents an addition to the public understandings of science literature (eg. Wynne, 1995; Irwin & Wynne, 1996) and to the literatures on patient movements' knowledge of science and their involvement in medical research (Arksey, 1994; Epstein, 1995, 1996; von Gizycki, 1987). But unlike the latter studies, this thesis examines the work of a patient movement organization (the EA) in enrolling medical experts *and* patients, rather than taking the enrolment of patients for granted. The contradictions and problems posed by the need to enrol two populations which, in some senses, are epistemic rivals, and the ways in which the EA as an organization attempts to mediate the traffic between patient and medical communities of knowers, are described here.

Other than the EA's studies, a journal article by Ella Shohat (1992) that addresses videotaping of endometriosis surgery, and my own work (1997), there are no published social scientific analyses of endometriosis or of the interactions between medical professionals and women with endometriosis. Furthermore, to my knowledge, this is the first detailed analysis of the internal workings of any patient epistemological community, and certainly one of the first analyses of patient knowledge to deconstruct the use of the notion of "experience" in patients' claims. It is also, I believe, the first detailed, critical, comparative analysis of the epistemic tensions and overlaps between a community of medical practitioners and a community of patients, the first to examine and compare the uptake of notions of "experience" and "science" in *both* communities. I assert that the epistemic workings of each community can only be understood comparatively, in relation to the other, in agreement with Fleck's (1979 {1935}:22) notion of comparative epistemology. Medical and patient knowledges cannot be construed as dichotomous; nor can medical knowledges be construed as *determining* patients' views of illness and their bodies. Instead, I demonstrate that patient and medical knowledges are *mutually* constitutive, that claims made by patients affect medical knowledge, as well as vice versa; and that patients and doctors, as communities, develop claims and standards for knowing that are distinct from, but exist only in relation to, one another's claims and standards for knowing. I believe that this perspective presents a more nuanced picture of patient and medical knowledges and the relationships between them.

Chapter 1

Theoretical Framework

This project is a critical comparison of medical professionals' and patients' standards for knowing endometriosis. There are several available theoretical frameworks for such a project. I begin this chapter by describing two well-worn roads I decided not to take, and the reasons for my dissatisfaction with them. I then suggest an alternative approach that applies insights from three bodies of literature: first, science and technology studies, particularly the actor-network theory (ANT) approach of Bruno Latour and Michel Callon, analyses of science and its publics, and the work of Ludwik Fleck; second, debates within feminist epistemology about experience and experiential narratives; and third, discussions of the elusiveness, contested nature, and potential for resistance of material bodies.

I. Medicine and Power: Medicalisation and the Foucauldian School

A great deal of sociological literature broadly investigates questions of power and knowledge in medicine, health, and illness. Much of it takes as a theoretical framework either the medicalisation thesis or the work of Michel Foucault, or some combination thereof.

The medicalisation thesis is identified with the work of Irving Zola, Ivan Illich, Eliot Freidson, Peter Conrad, and Howard Waitzkin, among others³. It developed in the

³Eliot Freidson's work, which analyses medical knowledge via a theory of the professions, is described as somewhat distinct from the medicalisation thesis by Peter Wright (1979). However, both Uta Gerhardt (1989) and Michael Bury (1997) place him in the medicalisation thesis camp, a position which is supported by Freidson's claims that medicine constructs illness as a form of deviance, that it has acquired many of the social

early 1970s and continues to be influential. Its basic tenet is that in modern industrialized society, medical knowledge has colonised everyday life, excluding lay perspectives on health and illness and becoming a repressive instrument of social control used primarily against the poor, racial minority groups, and women. These populations are often denied care or provided with substandard care relative to other, more powerful social groups, and their bodies and health problems are more prone to be medicalised. Proponents of the medicalisation thesis advocate patient empowerment through the challenging of medical expertise and resistance to the expansion of medical authority through self-care, preventative, and alternative approaches to health care (Bury, 1997:5-6; Gerhardt, 1989:268-273; Lupton, 1997; Wright, 1979).

The approach has been very popular among feminist authors (eg. Corea, 1985; Ehrenreich & English, 1978; Greer, 1991; Lorber, 1997; Martin, 1992; Rich, 1977; Rothman, 1989; Zita, 1989). Such authors tend to make four main assumptions: (1) women are the victims of a male-dominated medicine that usurps their control over their bodies; (2) many natural bodily processes have been unnecessarily pathologized and do not actually require medical intervention; (3) women should reject pathologization of their bodies and should seek, whenever possible, to avoid unnecessary and invasive medical treatment; (4) while the female body is real, concrete, and ahistorical, representations of it are social constructions distorted by patriarchal, classist and racist assumptions; medicine has misunderstood the body, but a less distorted understanding of it is possible.

This approach has been criticized on several grounds (see Bury, 1997:5-6; Gerhardt, 1989:268-273; Lupton, 1997; Petchesky, 1987; Treichler, 1990; Wright, 1979).

control functions of religion and the law, and that its power derives from a great extent from its "monopoly of practice" (Freidson, 1988).

It unduly constructs patients as the passive victims of modern medicine, underestimating its considerable benefits and the extent to which patients desire and demand those benefits. It presents medicine as monolithic, rather than attending to the controversies within and across medical specialties and disciplines. It simplistically depicts medicine as a servant of the state, capitalism, or patriarchy. While it criticizes the social distribution of medical knowledge and care and argues that medicine is often harmful⁴, it tacitly accepts the possibility of value-free knowledge of disease and the body and usually accepts the substance of biomedical understandings of the body, health, and illness. When feminist authors reject those understandings, they often posit essentialist, naturalist, supposedly unmedicalized knowledges of the body, illness, and embodied experience that nevertheless reify existing medical categories, neglecting to acknowledge the influence of biomedicine in those 'alternative' knowledges (Harding, 1997; Oudshoorn, 1994:2-3). Finally, and importantly for this project, medicalisation theorists rarely examine or challenge the ways in which boundaries between lay and medical knowledge are drawn (Bury, 1997:5-6; Gerhardt, 1989:268-273; Lupton, 1997; Petchesky, 1987; Treichler, 1990; Wright, 1979).

Consequently the medicalisation thesis has waned in popularity, though I think we would do well to bear in mind its lessons about the unequal effects of medical knowledge on diverse social groups. As this project will make clear, medical knowledges about particular diseases and the patients who suffer from them tend to reinforce broader social conceptions about race, class, and (especially, in the case of endometriosis) gender,

⁴Wright (1979:96) notes the self-contradictory nature of the medicalisation thesis here: that medicalisation theorists are led "into a position where more treatment is demanded for the oppressed even though it is known to be inadequate or harmful." Feminist critiques of new reproductive technologies (NRTs) often exhibit this tension, arguing simultaneously that NRTs objectify and harm women, and that lesbians, single women, poor women, and women with disabilities should have greater access to them.

reifying and reconstructing classifications that have tangible effects on individuals.

With the waning of the orthodox medicalisation critique, Foucauldian approaches, which are generally assumed to be more theoretically sophisticated, have increased in popularity. This has been a recent development. Fifteen years ago, David Armstrong wrote of the "relatively minor impact that Foucault had on the field of sociology of health and illness" at the time of his death in 1984 (Armstrong, 1985:108). Twelve years later, Armstrong would state that Foucault has been "perhaps more cited over the last decade than any other theoretical source" (Armstrong, 1997:28). The editors of a recent volume on Foucault's contributions to social studies of medicine argue that "The reception of Foucault's work in the social sciences and humanities has been truly phenomenal. It is difficult to overestimate his influence over the last decade or so...The study of health and medicine is no exception and his influence is so profound here that we cannot think of a great many topics without some reliance on his work" (Bunton & Petersen, 1997:1). Indeed, investigations of knowledge of illness have become so synonymous with Foucauldianism in many people's minds that they assume any such investigation must employ a Foucauldian framework. Thus I take some pains to explain why this project does not. Moreover, a detailed discussion of my misgivings about Foucault is a useful way to introduce some of my central contentions that developed, in part, as a critical response to the Foucauldian school.

Because other volumes have demonstrated the diverse ways in which Foucault's work can be used in social studies of medicine (see eg. Armstrong, 1983; Jones & Porter, 1994; Lock & Kaufert, 1998b; Petersen & Bunton, 1997; Turner, 1987), a detailed discussion of Foucault's contributions is not presented here. Briefly, Foucault presented medicine in different ways in the course of his work (Osborne, 1994:30). His early work

depicts medicine as a field of epistemic shifts, the clinical gaze, and the constitution of the patient as object. Later, medicine is described as an agent of surveillance and normalising discourse, and then as an arena of self-care.

Various scholars have taken up each of these formulations, often in combination⁵. Thus, following Foucault, they have argued that medical discourses and practices create, rather than simply represent, describe or treat, the bodies, diseases, and patients that are the objects of medical inquiry; that consequently patients' own understandings of their bodies, and indeed their self-conceptions as patients and selves, are constituted by the clinical gaze; that medicine is an essential field in the development of "biopower," which accomplishes the surveillance and governance of populations through individual bodies, and vice versa, for example through public health programmes; and that, in taking up medical understandings, patients discipline themselves--but also constitute themselves as subjects capable of action and resistance--in part through techniques of illness prevention and self care (Armstrong, 1997; Lock & Kaufert, 1998a; Lupton, 1997:99; Waldby, 1996). In summary, Nick Fox has characterised Foucauldian work in this area as concerned with "the relationship of knowledgeability to power, the centrality of the human body in disciplines (in both senses of the term) and expertise, the construction of selfhood and subjectivity by power/knowledge and the significance of self-care within regimes of governance" (Fox, 1994:35).

Readers will recognise some continuities between these concerns and this project.

⁵See for example Geraldine Lee Traweek's study of care assistants in an old age home. She uses Foucault's notions of pastoral care, surveillance, and the clinical gaze to argue that assistants order and control residents by classifying residents into groups requiring different kinds of "emotion work," encouraging self-regulation of emotions and behaviour, and presenting surveillance and intervention strategies as in the best interests of residents (Traweek, 1996).

Like the Foucauldians, I adopt a broadly constructivist perspective. But "social constructionism has other roots and appears independently of Foucault in cognate disciplines such as in the sociology of science and in psychology" (Armstrong, 1997:21). Foucault and his followers can be described as social constructivists because they clearly privilege social relations as the source of medical knowledge. I find this no less reductive than the assumption that nature is the source of medical knowledge. I would not characterise my version as social constructivism but simply as constructivism--a distinction I will make clearer below.

There are other reasons why I do not characterise this project as a Foucauldian one. First, Foucauldians often conceive of medicine as a totalising, overdetermined system which in its effects (if not in its actions) resembles the medicalisation approach quite strikingly:

the writings of Foucault and his followers, while not necessarily using the term 'medicalisation' or adhering to the versions of power relations usually presented by proponents of the orthodox medicalisation critique, tend to present a consonant view of the world in which individuals' lives are profoundly experienced and understood through the discourses and practices of medicine and its allied professions (Lupton, 1997:94).

Second, I want to avoid the idealism inherent in many Foucauldian accounts. Bryan Turner has argued that "Foucault was not in his epistemology adopting an idealist position...On the contrary, he wanted to observe a very close relationship between power and knowledge" (Turner, 1987:11). However, it is not clear that observing a close relationship between power and knowledge precludes an idealist perspective; and in any case, I want to suggest that Foucault's investigation of the relationship between power and knowledge rests upon a notion of discourse which is profoundly idealist. Foucault attempts "to conceptualize discourse in a non-representational mode, to displace the oppositions of thought and being, word and object. Genealogy does no such thing. It

appeals to an undifferentiated body as the point of application of domination and the forms of the latter (modalities of 'the power to punish') are analysed primarily as forms of representation" (Minson, 1986:131). Jeff Minson argues that, despite Foucault's insistence on the material existence and effects of discourse, discourse is "accorded the transcendent status which is traditionally accorded to subjectivity or the objective world" (ibid:132). For example, in Foucault's account, the confessing subject "'emerge[s] only in the discourse"; but Minson observes quite correctly that the emergence of this subject also entailed specific rituals and "church furniture" (ibid:132). Similarly, in *The Birth of the Clinic* (Foucault, 1994), the *material* conditions for the emergence of the clinical gaze include practices of dissection, access to cadavers, operating theatres, and so on--not merely new ideas about the relation of disease to bodies and patients.⁶

In practice, then, 'discourse' tends to be used primarily or exclusively as a way to talk about ideas (disease concepts, beliefs about health), which seem to determine or include all else (practices, objects, human beings). When discourse includes all else, the concept loses its explanatory power⁷. Furthermore, discourse, and systems of power/knowledge that produce discourse, are conceived of as "anonymous, dependent neither on human intent nor historical context...[irreducible] to the texts of specific 'authors'...yet genealogy concerns itself principally with texts, from which we 'uncover'

⁶The notion that disease has been so radically reconceptualised is questionable as well; see the discussion on Ludwik Fleck below.

⁷Consider, for example, the following excerpt from a piece by Foucauldian Sarah Nettleton: "The terms discourse and discursive practices encompass a whole assemblage of activities, practices, events, instruments and settings. Thus a dental discourse refers to not only what is said about the mouth with teeth but also the instruments used, such as the probe and the mouth mirror, and the differential settings of dental activity such as the bathroom or the dental surgery" (Nettleton, 1994:74). If such is the case, it seems unhelpful to use the phrase "dental discourse"; one might just as well say "dentistry."

the discourse" (Fox, 1997:38). Texts have authors; analysts read them; all of these have material conditions of existence and possibility. But in Foucauldian analysis, *power* appears to be the transcendent "agent" that "can 'use' discourse" (ibid:37), and discourse becomes the touchstone of tangibility. However, in Foucault's writings, power and discourse tend to take on the roles that he denies human beings and material objects. An essentialist conception of power replaces an essentialist conception of the sovereign subject (Wickham, 1986).

Foucault, like many others (such as Thomas Kuhn, Ludwik Fleck, Bruno Latour, many feminist scholars⁸), has been concerned to establish science as an inevitably social and political, rather than potentially ideology-free, enterprise (vs., eg., Althusser, 1969 {1965}, 1970 {1965}). The Foucauldian concept of power/knowledge--with discourse as its mode of effectivity--is the linchpin of this effort, describing the mechanism by which scientific truth is specified and has political effects. But in doing so, Foucault posits another 'deeper' truth behind scientific truth--the discursive formations that his analysis 'reveals'--and, although scientific claims are relativised and the agent of knowledge is viewed as a construction of discourse, his own (authored) notion of (authorless) discourse is reified and becomes the agent in social life.

'Discourse' is an *heuristic device* used to analyse and specify the social effects of

⁸Feminist standpoint theorists have emphasized the social locatedness of all knowers and have critiqued the notion of a scientific view from nowhere (eg. Collins, 1990; Hartsock, 1983; Rose, 1983, 1994; Smith, 1987, 1992). Feminist empiricists have emphasized that scientific standards are local, communally-defined practices and therefore intrinsically social (eg. Longino, 1990; Nelson, 1990, 1993). Feminist postmodernists, drawing upon the insights of male postmodernists and poststructuralists (including Foucault) but also upon the critiques of mainstream feminist theory mounted by feminists of colour and lesbian feminists, have emphasized the social production of knowledges and knowers and posit a highly relative notion of truth (eg. Butler, 1992; Flax, 1990, 1992; Fraser and Nicholson, 1990; Hekman, 1990, 1997).

texts and the practices of speaking, reading, writing human beings, without whom texts could be neither produced nor deployed. We must be careful not to reify the device itself. While I employ the term medical discourse occasionally in what follows, I use it in a quite specific way: to designate several internally contradictory but related sets of statements by medical professionals about endometriosis and more generally-applicable, but again often contradictory, rules of making statements about it and other illnesses. I see these statements and rules as deriving from (as much as shaping) *material practices* of professional medicine and scientific claimsmaking. Such practices include visual observation, the use of specific instruments, techniques, and technologies, tactile (not simply visual) examinations of the patient, and so on. Since sets of medical statements (and in many cases rules and practices for making them) vary to an extent across medical specialities, I refer primarily to gynecological discourse. Too many different things are said in medicine for there to be "a" medical discourse; this is true to an extent of gynecological discourse, or even to gynecological discourse about endometriosis, in large part because of the different contexts and agents of practice. Other kinds of medical discourses beyond gynecology intrude into gynecological thinking about endometriosis. As we shall see, these other discourses include epidemiology, psychiatry, immunology, and toxicology.

Furthermore, I do not find it useful to conceive of bodies as *determined* by discourse, as many Foucauldians do. It has been suggested that this is their major departure from the orthodox medicalisation critique (Lupton, 1997). But Foucault's own position on the relation of the body to discourse was more ambiguous:

He obviously rejects the naturalistic view that the body has a fixed structure and fixed needs...Considering Foucault's account of what has been done to the body and how stable this formative control has been, he would also presumably reject the Sartrian existentialist extreme; if the body

were that unstable there would be no way for society to organize and control it over time. But it is harder to tell what position Foucault affirms (Dreyfus & Rabinow, 1983:111).

Not only is the stability of the fabricated body a problem; without material bodies, there could be no discourse about endometriosis. Signifiers *require* signifieds. As Chris Shilling points out, "Bodies may be surrounded by and perceived through discourses, but they are *irreducible* to discourse. The body needs to be grasped as an actual material phenomenon which is both affected by and *affects* knowledge and society" (quoted in Lupton, 1997:103; emphasis in original). Bodies, and many other referents (scallops, for instance (Callon, 1986)), are not reducible to what is said about them because ontologically they frequently contradict what is said about them. As patient accounts testify and medical experts admit, drugs and surgeries often do not eradicate patients' endometriosis symptoms, despite the fact that scientific gynecological discourse asserts that they 'should'.

David Armstrong notes in passing that the notion of a body determined (in a strong sense) discursively is problematized by the fact that Foucauldians "get ill (and sometimes die)" (Armstrong, 1985:111). So immoderate have some Foucauldians' insistence upon the discursive fabrication of the body been⁹, that one is left to conclude

⁹For example, Nettleton, in her dentistry piece, aims to "describe the discursive context in which the mouth and teeth were *invented*" (1994:74; my emphasis), as if there were no mouths and teeth, and no words for them, before dentistry arose as a profession. Also see Terry Kapsalis (1997:6): "Gynecology is not simply the study of women's bodies--gynecology *makes* female bodies. It defines and constitutes female bodies" (her emphasis). But gynecology is but one source of representations of women's bodies (there are also art, law, religion) and my research shows that gynecology does not exhaust what women think about their bodies. Despite claims that bodies and body parts are 'made' or 'invented' by medical discourses, what most Foucauldian analyses actually demonstrate is that (obviously) changing representations of the body change medical ways of acting upon and thinking about bodies, and that (more usefully) medical representations *have a strong influence upon* the ways laypeople treat and interpret their bodies (besides Kapsalis

that it is medical discourse that makes their bodies die. Medicine is in the business of curing sick bodies and preventing them from dying; if medical discourse determined bodies, they always would be cured and never would die. Chronic illness and death demonstrate the limits of medicine and its discourses, and the need for a theoretical framework that recognizes that bodies can resist their medical construction.

Although this project focusses on what is said and written about endometriosis, I insist upon the materiality underlying these processes. What doctors and patients say about endometriosis must take account of material elements and is constrained by them. The fact that we can only access entities through discourse does not reduce them ontologically to what we say about them; the fact that our looking is framed by the available discourses does not preclude our seeing things that compel us to rework our ways of thinking. Things other than discourse demand to be taken account of in the development of the endometriosis-related practices of patients and doctors.

The notion of representation is important here too: while medical discourse represents concrete bodies in particular ways, Catherine Waldby (1996:32) has argued that medical practices actually create bodies that give these representations their power. I want to extend this and argue that material practices and potentials for intervening upon bodies--surgeries or pill-taking, for instance--can force reworkings of discourses about the body. The notion that 'something is not right' with particular bodies and that it should be fixed, is not simply dependent upon vision or discursive representation, but upon the possibility of material, technological, practical intervention. Intervening in order to fix is the goal of medicine and the foundation for all its representational practices; thus material

and Nettleton, see Duden, 1991; Findlay, 1995; Harding, 1997; Laqueur, 1990). I have no quarrel whatsoever with these arguments in their less hyperbolic form.

practice must be central to any discussion of medicine. Moreover, the material practices that affect medical discourse are conducted not only by physicians. For 'the anorexic body' to be represented medically, women have to starve themselves; otherwise, there is no such thing as anorexia. Conversely, for fat to become a public health issue, people must have enough to eat. So it is not just that medical discourse changes historically and, as a result, bodily practices change; changing bodies and bodily practices force changes in medical discourses as well.

There are epistemological problems with Foucauldian perspectives too. The problems of relativism and infinite regress have been acknowledged (Armstrong, 1985:116); this is one of the consequences of the antimaterialism and discursive determinism I have described. Moreover, an interesting point is made by Ian Anderson: "The notion of the gaze...is indicative of the privilege given to visual perception by Foucault in his analysis of knowledge/power systems...However, the body is not only apprehended visually. In fact, Foucault's own preoccupation with laying bare this mode of perceiving the body actually demonstrates a blindness to other forms of perception" (Anderson, 1995:76-7). Foucault and many of his followers appear to adopt wholesale the privileging of visual sense-data in biomedical epistemology. This, however, is unsurprising, given that Foucauldian accounts almost invariably focus on the statements of *physicians*.

And this point brings me to my most serious misgivings about Foucauldian analyses: their elitism, their handling of resistance, and their neglect of patient perspectives. Medicine cannot be conceived of as a total system that contains all talk about illness and the sick body and affects all bodies in the same ways, because individual bodies--and the body politic of biopower--are sexed, classed, and raced, and disease is not

uniformly distributed among all groups in society (Anderson, 1995:68; Waldby, 1996:92)). Anderson argues that this unequal distribution demands that we attend to the *subjects* of the medical gaze, to patients.

But Foucauldian analysts tend to do this *only from the vantage point of medical professionals*. Roy Porter's general complaint that historians and historical sociologists have "implicitly endorsed the view that the history of healing is par excellence the history of doctors" (Porter, 1985:175) applies forcefully to Foucauldians¹⁰. Even critical histories of medical thought (such as those produced by Foucault and his followers) "end up, despite themselves, paying compliments to the mesmeric mystique of the medical model; like Shelley's view of Milton and the devil, the very defamations actually enhance the fascination of the villain. Radical anti-history of medicine has paradoxically only confirmed that the history of medicine is about doctors, what they know, what they do" (ibid:181). Nancy Hartsock brings a similar criticism to bear specifically on Foucault and describes the political effects of this brand of analytical elitism:

Foucault, then, despite his stated aims of producing an account of power which will enable and facilitate resistance and opposition, instead adopts the position of what he has termed official knowledge with regard to the knowledge of the dominated and reinforces relations of domination in our society by insisting that those of us who have been marginalized remain at the margins (Hartsock, 1990:169).

As a result of this assumption that all things illness-related are contained within and by medical discourse, the creative ways in which patients selectively take up, reject, or rework elements of medical discourse, and hence rework their own subjectivity, are lost. Foucault insisted that where there was power, there was resistance; but it is widely

¹⁰This fascinating piece by Porter provides real insight into the vast resources available to historians for conducting histories of lay knowledge about illness, demonstrating that the problem is not that the only available sources are 'official' accounts (as is sometimes claimed), but rather than historians have *elected* to look at only official accounts.

acknowledged that Foucault's work provides little insight into practices of resistance (Anderson, 1995; Fox, 1994; 1997; Lupton, 1997; Minson, 1986; Wickham, 1986). In Foucauldian analysis, either patients' statements, behaviour, and even their acts of resistance are assumed to reflect official medical discourses transparently, constituting them as the dupes of medical discourse (Lupton, 1997), or analysing patients' resistance is ruled out of order because analysing it would bring it back under discursive control (Fox, 1997:41).

But ignoring patients' acts of resistance is *certainly* a way to bring resistance under control and to establish the authority of medical discourse. For example, David Armstrong has argued that interest in the "patient's view" is itself an extension of the changing medical gaze, which demands of patients that they confess their views to clinicians and researchers (Armstrong, 1984). What is so astonishing about Armstrong's piece is that he relies upon the accounts of physicians (and, to a lesser extent, social scientists) *about* the patient's view and why it is important--citing not a single patient account. So "the patient's view" is once again *physicians'* views of the patient's view. And, crucially, Armstrong never considers *why* this interest in the patient's view emerged especially in the 1960s and 1970s: could it possibly have been the fact that it was in this period that psychiatric ex-patients and women's health activists demanded a change in medical approaches to patients--that is, that they resisted the extant medical discourse on history-taking? If one reads only official medical texts, of course one gets the impression that the medical texts are the source of changes in medical thought and practice.

In the vast majority of cases¹¹, patients initiate the medical encounter and hence the

¹¹Obvious exceptions are compulsory vaccination programs, state-sanctioned medical policing during epidemics, and emergency treatment of unconscious or incapacitated patients. However, these represent a minority of medical encounters in the West.

operation of the clinical gaze (Anderson, 1995). Their accounts of their symptoms, side effects, and life histories are not peripheral to, but constitute the very conditions of possibility of, medical knowledge (Anderson, 1995:77; Hunter, 1991)--and not just in clinical practice, but in research as well (Wartofsky, 1982).

Disease is an entity whose existence is confirmed through processes of social interaction. Its character emerges and is transformed. At one moment it may be an experience of red urine and symbolic danger; at another a lesion seen in the bladder by a urologist; at another a pathology specimen and residual danger. It is produced through the transformation of corporeal bodies and is constructed by the patient in pain and by the doctor who views" (Anderson, 1995:77-8).

Patients' phenomenological accounts of the experience of illness are crucial to an adequate understanding of the construction of disease in medical knowledge and popular culture and the relations between these constructions. Therefore such accounts were the focus of the research described here.

Not only do individual patients affect the development of medical knowledge. Social science researchers are beginning to demonstrate that patient movements have mounted serious challenges to established clinical practice and the foci and methods of medical researchers, to affect the very development and use of medical knowledge (Epstein, 1995, 1996; Rabeharisoa & Callon, 1998; von Gizycki, 1987). But this effectivity cannot emerge unless one attends to its possibility. Much of the resistance work performed by patients and health activists is done quietly, behind the scenes, and is unlikely to come to the attention of researchers "except when forcibly routed out and exposed by those in power" (Lock & Kaufert, 1998a:14). In this study, I demonstrate that the often quiet, behind-the-scenes work of the Endometriosis Association has made a significant impact on medical knowledge about endometriosis. Reading medical texts exclusively would not reveal this because medical journal articles reference only other

medical journal articles, not the demands and claims of patient groups. But, as we shall see, medical researchers and clinicians often must take account of these demands and claims to ensure their access to research subjects, funding and good publicity, and to maintain their legitimacy as experts--whatever the conventions of medical publishing.

The focus on official discourses misrepresents the relationships among what patients say and do, what doctors say and do, and what "official" medical discourse allows and proscribes. It leads to the erroneous assumption--implicit in much of the Foucauldian literature--that lay understandings of health and illness are *equivalent to* published medical understandings. While medicine certainly is the official source and carrier of knowledge of health and illness in Western industrialized societies, it does not exhaust all that can be said on the topic and it incorporates many insights from lay conceptions (as the work of Ludwik Fleck, discussed below, demonstrates so well).

The fact that patients do resist medical discourse is witnessed by the extensive medical literature on patient noncompliance and, even when patients do comply, we cannot assume this is because they are passive recipients of medical subjectification, rather than active seekers of relief from pain and suffering (Anderson, 1995; Lupton, 1997)¹². As I hope to show throughout this thesis, patients are quite creative in disrupting and challenging medical discourses in unpredictable, contradictory, and often very effective

¹²Lupton (1997) also observes that the notion that patients are engaging in care of the self by seeking medical advice is problematic, because the care of the self implies conscious, rational calculation; instead, she argues, patients may seek medical advice--or reject it--for unconscious or irrational reasons. My own research suggests that patients often act in desperation, on hunches or ineffable feelings about their doctors and treatments--although it is problematic to reify the distinction between emotion, intuition, and ineffability versus reason. Hunches may be the result of subconscious calculations that, when broken down, are perfectly rational. Fox (1994:33) also has difficulties with the notion of self-surveillance "which, if taken to its limits, would implicate all behaviors as self-surveillance, discourses of subjectivity, leaving little room for resistance."

ways, even as they are in some senses bound by those discourses. We will never be able to understand the limits and effectivity of medical discourses as a power/knowledge configuration unless we examine the extent to which patients actively adopt, grudgingly accept, contest and resist them (Lock & Kaufert, 1998a).

It is for these reasons that, in line with the suggestions of other authors (Lock & Kaufert, 1998a; Porter, 1985), I have elected to focus upon the reactions of some members of the endometriosis patient community to medical discourse, and upon their ways of contesting it and of constructing their own claims and themselves as knowledgeable agents. I have tried to avoid the pitfalls of "turning the idylls of the sick into one long bellyache" or of "sentimentaliz[ing] victimhood as if suffering were beautiful" (Porter, 1985:182). But my most pressing concerns are to counter these tendencies to privilege medical accounts and to assume that 'medicalisation' (either in its orthodox or Foucauldian form) is an irresistible juggernaut. Instead I have tried to represent the originality, power and intelligence of endometriosis patients' accounts of disease, knowledge, and knowers, and to document their skillful deployment of medical discourses to their own ends:

Medicalization theory harbors an...insidious assumption, the implication that the rise of medical power is in some sense ineluctable and unilinear, the ghost train speeding down the old Whiggish mainline from magic to medicine. But a people's history of health will show something much less monolithic. Here steps toward medical regulation, there the expropriation of lay healing, it is true; but it will also show that sufferers are fertile in their resources, and that feedback processes sometimes mean that medicalization boomerangs back on the faculty, as patients borrow the doctors' lines (Porter, 1985:194).

In my view, the two most useful elements of Foucault's work for this project are his keen appreciation of the influence of expert claims and claimsmaking practices in shaping (though not, I think, determining) lay subjects' self-conceptions as health-seekers

and consumers or creators of knowledge; and of the perils of assuming a 'natural' body, an essential subject of knowledge, and the 'givenness' of medical definitions of disease (though I wonder whether bodies, subjects, and disease have certain elusive *capacities* which make them both amenable and resistant to medical construction). From the orthodox medicalisation critique, I take very seriously the point that medical knowledge does not affect everyone in the same ways--that medicine *has* made victims of some types of people more than others (although often these victims are anything but passive); that it is crucial to study these inequalities in order to understand the connections between medical and more general cultural practices and knowledges; that the accounts of marginalised others have been subsumed by (though not, I think, eliminated from) the medical record; and that paying attention to these accounts can suggest ways to make medical practice less objectionable from patients' points of view. But clearly, these general principles do not a theoretical framework make; given the problems with both perspectives, an alternative framework is necessary to supply the nuts and bolts of analysis. My framework derives mainly from science and technology studies, but synthesizes it with insights from feminist epistemology and theories of medical representation and resistance to it.

II. Science and Technology Studies: ANT, PUS, and Fleck

The field of science and technology studies (STS) is growing by leaps and bounds and is wide-ranging--so wide-ranging, in fact, that it is difficult to characterise in a general way (but see Pickering, 1992 and Shapin, 1995 for two recent attempts). Here, I focus on authors and works within mainstream STS that take as one important part of their agenda the delineation of the practices by which some scientific knowledge claims become more

credible than other scientific and non-scientific knowledge claims. My account is particularly influenced by the actor-network theory (ANT) approach of Bruno Latour and Michel Callon, which is becoming quite influential in mainstream sociology. Other important authors for whom scientific practice is a crucial issue and to whose work I refer are Ian Hacking, Karin Knorr-Cetina, Andrew Pickering, Michael Lynch, Joan Fujimura, Geoff Bowker, Steve Woolgar, and Susan Leigh Star¹³. I then move on to discuss the utility for this project of some particular works within STS on boundary work, public understanding of science (PUS), and public involvement in scientific knowledge creation. I end this section with a discussion of a book by Polish microbiologist Ludwik Fleck, *Genesis and Development of a Scientific Fact*, from which I drew heavily in this analysis.

1. Studies of Scientific Practice

The STS authors I have in mind focus on scientific claimsmaking-in-process, on science as an *achievement* that develops through local, contingent, negotiated, consensus-building, collective practices. Mertonian sociology of science sought to identify the social factors that may influence, or distort, science's claims about nature, but avoided critical discussion of the methods, metaphysics, and most of the claims of science--an understandable concession, since Merton's claims for a scientific sociology required hitching the discipline's wagon to the natural sciences (Shapin, 1995). But Bruno Latour, perhaps the STS scholar who is most influential in contemporary sociology, even contests the modern notion of a nature distinct from society (Latour, 1993), undermining the very

¹³This is by no means a representative list of influential science studies scholars. See Hess (1997) for a succinct overview of the field, and the excellent edited volumes by Jasanoff, Markle, Petersen, & Pinch (1995) and Pickering (1992) for broader introductions.

disciplinary divisions that defined the Mertonian project. The result is an understanding of the natural as inextricably bound up with the social, and *vice versa*. Thus, the field of inquiry is extended, from extrascientific 'interests' and 'ideologies' that may or may not affect science, to the practices and results of science *per se*. The result is a reworking of traditional conceptualizations of power and politics:

Science is not politics. It is politics by other means. But people object that 'science does not reduce to power.' Precisely. It does not reduce to power. It offers *other means*. But it will be objected again that 'by their nature, these means cannot be foreseen.' Precisely. If they were foreseeable, they would already have been used by an opposing power. What could be better than a fresh form of power that no one knows how to use? (Latour, 1988:229; emphasis in original).

In attending to science as a form of politics, Latour's approach rejects the traditional assumption that science interacts only with nature; but he also rejects the reduction of science to a set of discursive or social practices that entirely create nature. The fact-building process is simultaneously natural, discursive, and social, because it requires the involvement and cooperation of many humans, naturally-occurring objects, instruments, and representations (Latour, 1993). The collective and eclectic nature of scientific fact-building can be discerned in three sites: the laboratory, where initial claims get constructed; the scientific community, where the claims get debated and established; and the larger community, where non-scientists (both human and non-human) must be enlisted to make the claims and to make them true.

i. The laboratory

In this literature, the laboratory is defined broadly as any locale in which the work of producing scientific knowledge claims (which may or may not become 'facts' later) is done. Three important components of laboratory practice are emphasized: materiality, inscription, and negotiation. While other social studies of science emphasize the centrality

of scientific theory in knowledge-making, materiality is the focus of studies of scientific practice; hence the shift from abstract knowledge to concrete practice (Hacking, 1983). Material constraints include the local availability of equipment and materials, the preferences of funding agencies, and the skills of available personnel (Knorr-Cetina, 1983; Latour, 1987; Latour & Woolgar, 1986). Moreover, laboratory work cannot be done without the collection of objects that Ian Hacking, in a suitably mundane way, calls "things": substances, populations, and samples that are the 'targets' of investigation, instruments that interfere with the target, detectors that measure the interference, and data generators (Hacking, 1992). The target is not simply observed; nature is chaotic and must be interfered with to produce analyzable phenomena (Hacking, 1983).

But targets, instruments, and other materials may not cooperate, despite efforts to make elements of nature as controlled as possible (Knorr-Cetina, 1983). Therefore, a conception of material, non-human agency is an important element of this literature (see, eg., Callon, 1986; Callon & Law, 1989; Latour, 1993; Pickering, 1993). In endometriosis research and clinical practice, some of the things needed to get the work done include: women's bodies, rhesus monkeys, cysts, and adhesions; laparoscopes, lasers, and drugs; measuring devices for determining the size of cysts and cameras and videoscreens which allow physicians to appropriate and record the 'vision' of the laparoscope; standardised forms for the documentation of endometriosis; computers and software for the compilation and analysis of data about endometriosis; operating theatres, anesthesia equipment, examining tables, stirrups, gowns; in short, a whole range of material artefacts and naturally-occurring entities.

Instruments and scientists in the laboratory produce reams of inscriptions, which are "not so much a method of transferring information as a material operation of creating

order...Objects appear because of the constant process of sorting" (Latour & Woolgar, 1986:245-6). The inscriptions themselves become the objects of study, replacing the original target. The profusion of inscriptions is itself a possible source of disorder, so they are combined and ordered until one inscription stands "out of and for" the masses that have been produced (Latour & Woolgar, 1986:247).

Interpreting and clarifying inscriptions so as to make them meaningful and usable is no easy task, but must be negotiated among laboratory workers. As Klaus Amann and Karin Knorr-Cetina (1990) point out, "seeing" what the data consist of is work, accomplished through talk. Researchers pore over inscriptions, interacting with one another and manipulating visual displays which help to organize the talk. Inscriptions exert a stabilizing influence in scientific discourse (Amann & Knorr-Cetina, 1990; Latour, 1986, 1987. Through various conversational devices, "evidence-fixation" is accomplished: a working conclusion upon which to proceed, rather than a definitive account of what is seen, is produced. The point is not to make the data fit a given theory, but to establish them as analyzable via reference to local interpretations, rules, and decision criteria (Amann & Knorr-Cetina, 1990). In endometriosis research and clinical practice, the meaning of visual observations of the pelvis (and of videotapes of laparoscopic surgeries) must be fixed; this requires inscription, particularly with standardized forms for the documentation of the extent of endometriosis, and (as we see in Chapter 3) fixing upon a standardized, universal system is no easy task (see also Berg, 1997; Curtis, 1998; Jordan & Lynch, 1992).

ii. *The scientific community*

Once the meaning of data has been set in the lab, they must be converted into

evidence suitable for publication if the fact is to be stabilized in the wider scientific community. The fixed-upon meaning must be made to stand out and the viability of alternate explanations of the data must be reduced (Latour, 1986). Illustrations in scientific publications help to accomplish this (Amann & Knorr-Cetina, 1990; Lynch, 1990). Textual devices, too, are used to make the journal article more persuasive. An "audio-visual display" (Latour, 1987:71) combines text and illustration, directing the reader to see the illustration in a particular way. Thus, in the presentation of new endometriosis classification systems, photographs of cysts are presented along with descriptions that direct surgeons to code the cysts they see in women's pelvises in particular ways; in Endometriosis Association literature, as in medical texts, patients are presented with diagrams of the female body with labelled parts that direct women's perceptions of their bodies in line with medical understandings of organs and tissues.

Citation makes a claim more persuasive; other texts and their authors may be recruited as allies which, in supporting the statement made by the author, raise the costs of dissension. The reader is confronted not with the isolated author of the article, but with a whole series of past authors who 'stand behind' the author's statement and whose claims must be successfully contested if the dissenter is to contest the author's claim successfully (Latour, 1986, 1987). Latour and Woolgar identify five statement types used in journal articles, which are differentiated by the extent to which they include "modalities"--statements about statements--and the types of modalities employed (they may question or enhance the facticity of the statement). Once a statement becomes an established fact or "blackbox," modalities disappear and the context of the statement's creation is erased (Latour & Woolgar, 1986). Content and context are separated. Reuniting them is a tactic for casting aspersions on the validity of the claim (Bowker, 1994; Latour, 1987; Latour &

Woolgar, 1986; Ward, 1996). In both medical and Endometriosis Association literature, citation is used to invoke the authority of the author as one who is well-versed in the arcana of endometriosis research, and thus a credible claimsmaker. In presentations of Endometriosis Association research to medical audiences and patients, patients' experiential accounts are compiled and presented in statistical form, downplaying the subjectivity of the women 'behind' the accounts and recreating their claims in a form more in line with the standards of scientific claimsmaking practice.

iii. The world 'outside' science

Once a strong network has been formed around a knowledge claim, the claim can only be contested by insiders who have the requisite material resources and allies. However, studies of scientific practice have demonstrated the great extent to which the success of scientific fact-building depends upon the manipulation of the world outside the lab and the forging of alliances with non-scientists. Science works not because it is true to the world but because the world is tinkered with to make science work. Infrastructural work--such as the development of metrological constants, the cooperation of state agencies and local residents, and the enlistment of communications media--is required to get the claim to work in the larger world (Bowker, 1994; Callon, 1986; Callon & Law, 1989; Curtis, 1998; Latour, 1987; Latour & Woolgar, 1986; Law, 1986; Star, 1991; Ward, 1996). Scientific facts must be consistently applied in order to work; they do not work in just any reality, but only in a particularly constituted one. Nevertheless, this is not a relativist position. Some scientific claims do not work, while others do work--although they cannot jump out of the network in which they exist (Latour, 1987: 195-197; Latour and Woolgar, 1986: 187-188). Not just any claim about the objects of

science will do. The only ones that will do are those that help scientists to get the objects to act in particular ways. Other claims will be undermined--that is, made untrue--by the resistance of the objects. In fact, Latour and Woolgar define reality as "that which 'resists'...that which cannot be changed at will" (1986:260, note 17).

The particularly constituted reality requires the cooperation of a great many actors besides scientists to extend scientific claims across time and space. Actor-network theorists especially extend agency to non-human "actants" (Callon 1986; Callon & Law 1989; Latour 1987; Latour and Woolgar 1986). Both humans and non-humans must be "enrolled" into the scientific network. Callon describes this process through his theory of translation (Callon, 1986; Callon & Law, 1989). Scientists define a problem, and define the actors involved so as to fit their defined problem and their proposed solution. The process is one of mutual, progressive accommodation between scientists and that which they seek to represent. The scientists must establish themselves as "obligatory passage points" through which the actors must work to solve the problem. They must keep competitors away from the actors they want to enrol. They cannot enrol all of the actors at once, so they focus on what they hope is a representative sample of the population, adjusting their projects to get the sample to cooperate with the claim they want to make. Even if they succeed in enrolling the representatives, the general population may refuse to be enrolled *en masse*. The seeds of a useful theory of power exist here: as Callon notes,

Understanding what sociologists generally call power relationships means describing the way in which actors are defined, associated and simultaneously obliged to remain faithful to their alliances...It also permits an explanation of how a few obtain the right to express and to represent the many silent actors of the social and natural worlds they have mobilized (1986: 224).

Callon notes that physical violence, seduction, transaction, and consent without discussion are possible techniques of enrolment, though ANT in general tends to emphasize scientists'

tactics of persuasion in their enrolment of allies.

If they are successful, the scientists become the general representatives of all the populations involved and can speak for and about them with authority in a "discourse of certainty." The populations have been "displaced"--moved from their original state to one more in line with the scientists' project. The end result is a "sociotechnical network" composed of links among very different and previously unconnected entities, both human and non-human (Callon, 1986; Callon and Law 1989). But scientists are not the only ones who engage in this kind of work; we shall see in Chapter 6 that the Endometriosis Association has followed a similar strategy in getting its own claims to stick, among both patients and medical professionals. It seems that the ANT theory of enrolment has wide applicability beyond the study of scientists--that, in fact, it may be extendable to many other kinds of claimsmaking.

Networks may be extended across various communities, both scientific and non-scientific, for example through the use of "standardized packages"--techniques, tools, concepts, and theories that are used in various disciplines and therefore yield commensurable projects, data, and knowledge claims (Fujimura, 1992). Both endometriosis patient and medical professional claimsmaking strategies invoke notions of experience, good science, hormones, cysts, classification, psychological dysfunction, and so on--some of which emerge out of scientific practice, others from a more general cultural stock of knowledge--and which are deployed in overlapping but somewhat distinct ways by the two communities. It is the shared quality of the standardised packages that allows for debate and cooperative claimsmaking among and between members of the endometriosis patient community and medical professionals.

Sociotechnical networks are that much stronger because of their heterogeneity; to

destroy them, many different types of actors have to be persuaded or forced to change their alliances, interests, and identities (Ward, 1996). So, non-scientist 'outsiders' are in fact integral to the process of network extension. Without their cooperation, the network will not get made in the first place and will not extend very far. The power of 'outsiders'--in this study, endometriosis patients--to resist enrolment into processes of scientific claims-making is thereby recognized.

iv. *Critiques of the ANT approach: symmetry and agnosticism*

Within mainstream STS, criticisms of the ANT approach centre around two principles made explicit by Michel Callon and supported by Latour (Callon, 1986; Callon and Latour, 1992; Latour, 1987, 1993; Latour and Woolgar, 1986): the principles of generalized symmetry and generalized agnosticism and their political implications¹⁴. Symmetry principles have been advanced in science studies for many years. Robert Merton argued that science should be studied in the same way as other cultural enterprises; later, David Bloor made the case for studying 'true' or successful scientific knowledge claims in the same ways as 'false' or unsuccessful ones--that is, one should not explain true claims via reference to 'nature' and false ones via reference to 'society' (Pels, 1996:277-278). ANT theorists extend this by arguing that non-human ('natural') and human ('social') actants should be described using the same vocabulary and explanatory principles (Callon, 1986:200)¹⁵. Drawing upon Latour's (1993) analysis of the "Modern

¹⁴See Ashmore 1996; Callon, 1986; Callon & Law, 1989; Collins, 1991; Collins, 1996; Martin, Richards, & Scott, 1991; Pels, 1996; Richards, 1996; Scott, Richards, & Martin, 1990; Singleton, 1996; and Wynne, 1996b for some discussions of the politics of STS and the principles of symmetry and agnosticism.

¹⁵Callon and Latour's principle of generalized symmetry has raised some strong ontological objections from other mainstream STS scholars (see Collins & Yearley,

Constitution", Callon and Latour argue that the natural and social sciences assign ontological statuses to humans and non-humans to create the nature/society divide. They do not deny that there are differences between humans and non-humans, but ask how these differences are defined in science (1996:356).

The principle of generalized agnosticism holds that the investigator should not take sides in the technical or social aspects of the controversy being studied because the interests and identities of the actors involved should not be fixed in advance (Callon, 1986:200; Callon and Law, 1989:77). This principle is tied to debates about the Bloorian principle of symmetry ("true" claims should be treated the same way as "false" ones) because (many argue) epistemological and political issues cannot be neatly separated. But Dick Pels (1996) argues that proponents of symmetry and agnosticism should be read not as disinterested parties, but as engaging in "knowledge-political actions," attempts to reconfigure and thereby to rule over the field (1996:280)¹⁶. Furthermore, as Vicky Singleton (1996:458) notes, the actor-network approach can be viewed as an effort to extend democracy to non-humans, and Latour's (1993:138-145) advocacy of a "Parliament of Things" is an explicitly political statement: "It is time to do for these new masses what our forebears did for humans. 'No innovation without representation' or 'no pollution without representation' could be among the *mot d'ordres*" (Latour, 1991:18). Pels points out that agnostic methodological approaches in effect make previously accepted claims seem more dubious and dismissed claims more probable, and are "often a

1992; Pickering, 1993:565-566).

¹⁶This observation bears a striking resemblance to Latour and Woolgar's (1986) argument that changing the validity criteria for scientific work in a specific field is an attempt to force others who cannot meet the criteria out of the game. The methodological principles outlined by Latour in the Appendix to *Science in Action* (1987) could be read the same way.

cool and detached way of siding with the oppressed"--a tactic which mimics the professed value-neutrality of science even as it attacks it (1996:282). But as Malcolm Ashmore (1996) points out, refusing to take sides in a scientific controversy and to treat competing claims the same way can also place STS on the 'wrong' side politically, because 'true' or successful science often is enlisted to bring to justice those who have harmed others (such as tobacco companies and other creators of health and environmental risks).

v. *Feminism and STS*

Debates about the political implications of STS and, particularly, ANT, must raise concerns for any feminist analyst seeking to use the framework. Nevertheless, there are important continuities between feminist and mainstream STS. First, both emphasize the role of social context in scientific practice (Shapin, 1995; Star, 1991; and see Whelan, forthcoming, for a more detailed treatment of the similarities and differences between feminism and mainstream STS). Part of that context is the knowledge community in which scientific practice takes place: studies of scientific practice share with many varieties of feminism, particularly the feminist empiricism of Helen Longino and Lynn Hankinson Nelson (Longino, 1990; Nelson, 1993), a view of knowledge as a communal holding rooted in local conditions and standards. This contrasts sharply with individualist accounts of knowledge, in which the knower's observations and reasoning are supposedly independent from the communities to which s/he belongs (Code, 1991:Chapter 1; Shapin, 1995).

Moreover, both feminists and science studies scholars demonstrate an interest in critically examining blackboxes, or well-established scientific facts (Star, 1991). The mainstream STS principle of generalized symmetry demands that established scientific

'truths' be analysed in the same way as claims that have been discredited. For feminists, the analysis of hegemonic 'truths' is a more pressing matter than the analysis of scientific claims that, having been discredited, are likely to have less effect on women and other marginalized groups; and the symmetry principle's effect of equalizing lay and scientific claims must be pleasing to those analysts who would champion the claimsmaking practices of laypeople. Both amount to critical analysis of taken-for-granted knowledge claims--demonstrating that the principle of generalized symmetry and its (to me) more objectionable partner, generalized agnosticism, are not necessarily prerequisite to the cracking open of blackboxes.

Furthermore, traditional epistemological approaches are challenged in both fields; both provide important critiques of positivism, empiricism, and realism. Both fields adopt a broadly constructivist position. In recent feminist work, social and discursive constructivisms have been emphasized, although material objects and elements of nature are frequently described as active parts of scientific knowledge creation (Whelan, forthcoming). In studies of scientific practice and particularly in ANT, the material takes on a more central position focussed around the notion of effectivity. Ian Hacking (1983:Chapters 1 and 16), for example, argues for a distinction between realism about entities and realism about theories. He asserts that an established entity, one which can be manipulated predictably to create other entities, is real (at least in terms of scientific practice)--"if you can spray them, then they are real" he says, in reference to electrons (1983:22)¹⁷. The STS authors upon whom I have focussed are neither simply realist,

¹⁷This argument bears some resemblance to Latour's (1987:99-100) assertion that scientists are relativists while controversy rages about an entity and realists once the controversy is settled, and that studies of scientific practice should abide by this distinction because no non-scientist has the resources to contest the reality of the entity once firmly established.

because "reality" must be worked upon in order for us to know it, nor simply relativist, because some claims really are stronger than others. Moreover, science has material, not merely discursive, effects. For Latour (1987, 1993; Latour & Woolgar, 1986), both realism and relativism are symptoms of scientific practice. Both inappropriately distinguish between natural "facts" and social factors; one denies "out-there-ness" arguing that it is merely a 'construction,' while the other takes it as given, a product of nature. For Latour, the very category of out-there-ness is a consequence of scientific practice, produced by the successful forging of connections between the natural, the social, and the discursive (Latour, 1993:25). The realist/relativist controversy is displaced; the more important question is how some claims become more credible than others.¹⁸

Thus, ANT's constructivism cannot, I think, be called *social* constructivism, because of ANT's erasure of nature/society dichotomies¹⁹. Constructivism, unlike social constructivism, is a term that accommodates nicely my argument that the diseased bodies of patients, as naturally-occurring (though socially defined) entities, are elusive and cannot be exhausted or contained by medical definitions and practices. Bodies, then, have a delimiting and constraining effect on what can be said about them. As Nick Fox has observed, "sociology has difficulty with topics which are overly 'natural'...this is because sociology as a discipline became possible through a privileging of cultural over natural

¹⁸Steven Shapin (1995:313-4) argues that Latour's (and Haraway's) attempts to develop a new vocabulary that transcends modernist dualisms (human/non-human; relativism/realism; society/nature) may be read as attempts to impose a "privileged language whose recommendation over alternatives is that it mirrors the order of existence" and thus represents a return to the quest for an Archimedean standpoint. However, it is hard to see how any attempt to produce a set of descriptive concepts could escape this criticism in the final analysis. We have seen that Foucault faces the same problem.

¹⁹Consequently, in the second edition of Latour and Woolgar's seminal STS text, *Laboratory Life*, the subtitle was changed from "The social construction of scientific facts" to "The construction of scientific facts" (Latour & Woolgar, 1986).

explanations" (1994:12). The ANT approach, I think, is one way out of this dilemma.

Despite their shared concerns, many feminists have criticized mainstream STSers for their lack of engagement with feminist work and they have insisted on the central place that gender and other systems of inequality must take in the analysis of science (for an extended discussion, see Whelan, forthcoming). Haraway (1992:332-3) suspects that this blind spot is related to mainstream STSers' attempts to avoid past approaches which assumed that science simply "reflected" social relations. But as she notes, the issue is not that science reflects social organization, but that there is traffic between the two; and she argues that the "reified technical" is just as problematic as the "transcendental social" from which mainstream STSers seek to escape. Grint and Woolgar (1995) propose that values and interests are imputed to technologies by its users or audience. Their approach is suggestive for feminism in that it suggests that women can develop readings and uses of technologies that subvert those that usually work against women. But this has its limits. As Rosalind Gill (1996:353) points out, some readings of technology are preferred and "we do not live in a semiotic democracy" where any reading is possible. Readings that hold sway tend to be those whose advocates hold particular positions and resources (Gill, 1996). The avoidance of blackboxing race and gender should not entail an inability to see the endurance of certain networks or patterns: "some networks are more stable than others" (Gill & Grint, 1995:21). A staunch refusal to consider that oppressive ideologies may be part of a network in fact amounts to assuming the oppressive ideologies are *not* part of the network or its constituent elements, a position which contradicts the ANT principle of agnosticism regarding interests and identities. Much recent feminist work on the construction of sex and gender categories neither takes the categories for granted nor ignores their effectivity (eg. Butler, 1990; 1993; Riley, 1988).

Clearly, the issue of politics is related to debates within science studies about generalized symmetry and agnosticism. Eveleen Richards points out that political agnosticism is an easier position to take when one only studies "hard" sciences, like physics, rather than "soft" sciences that have more direct effects on people's everyday lives, like medicine (Richards, 1996). The principle of political agnosticism erects a boundary between "good science studies" and "political" feminist work. When science studies scholars define feminist work as merely political, they contradict their own claims to be deconstructing the nature-society divide.

Finally, Rosalind Gill (1996) has argued that the STS rejection of foundationalist epistemology still leaves untouched the question of how to adjudicate between competing knowledge claims, a question which must be of interest to STS analysts who want to make a political intervention. Political commitments presuppose a realist understanding of the world: there is inequality, it takes such-and-such forms, etc. In his ANT-inspired analysis of AIDS activism, Epstein makes the important observation that health activist groups are committed to a realist vision of science for very good reasons:

...in the end, few activists, perhaps few people with AIDS or HIV infection, are fully sanguine about the prospect of 'living with the reality of uncertainty.' This is not surprising because activists, and people with AIDS and HIV, are confronted daily by a burning need to know whether given treatments 'work' or not, and such need does not typically take comfort in relativism. The activist critique of the randomized clinical trial unseats that methodology from the pinnacle on which it is sometimes placed, but it also assumes a greater role for such trials than [some social studies of science] analysts...would recommend (1995:425-426).

Adopting a strict realist position about science presents the moral dilemma of accepting the validity of scientific claims that, in their application, may cause suffering or oppression. On the other hand, adopting a relativist position means we are either inconsistent (our own claims about science employ a realist idiom, while we relativize science's claims), unable to

choose among competing accounts, or unable to make any firm claims.

It may be better, then, to judge each scientific knowledge claim based upon its moral, political, and material implications and its fit with epistemological standards at the local level, rather than to search for a consistent epistemo-political strategy (whether relativist or realist). Certainly, ANT does not tell us how to make political and epistemological judgments, but should be viewed rather as a precondition for making them: "In order to make a diagnosis or a decision about the absurdity, the danger, the amorality or the unrealism of an innovation, one must first describe the network" (Latour, cited in Singleton, 1996:459). Thus, it seems that ANT demands only a temporary methodological agnosticism: that we be agnostic while actually analysing the network. Once we have done so, we are free to make what judgments we see fit about the truth, politics, and ethics of science and technology. A truly politically-engaged adaptation of ANT would not shy away from making such judgments.

But even when not explicitly politically engaged, ANT can reify existing social understandings of the 'model knower'. As Susan Leigh Star (1991) has pointed out, ANT has a tendency to focus on Great Men and Scientific Victors and to gloss over or ignore the roles of support workers, those affected by science and technology, and especially those who refuse to be enrolled into the scientists' network. Not coincidentally, many of these people are female (Richards, 1996:327). Star (1991) supports Callon's (1986) notion of translation but combines it with feminist theories of marginality and split selves to develop a useful conception of resistance to practices of normalization. Thus, in emphasizing the extension of networks and the blackboxing of scientific knowledge claims, those who are not, cannot, or will not be standardized can only be defined as deviant others whose existence is trivialized and whose suffering is ignored. Networks

create not merely insiders, but also outsiders and the partially enrolled. Attendance to practices of exclusion or avoidance and their effects are integral, not peripheral, to adequate descriptions of the process of network-building (Star, 1991).

As feminist technology analyst Cynthia Cockburn has observed, in order for women's involvement in or exclusion from networks to become visible, the notion of network needs to be extended (cited in Gill & Grint, 1995:18). Adele Clarke (1998) suggests a way to do this. She views ANT as a complementary approach to her own social worlds analysis (SWA), but the latter seeks to: emphasize the mutuality of negotiations and trade-offs between scientists and the entities they seek to enrol; draw attention to those affected by, silenced, or rendered invisible by science in action; highlight differences between actors as crucial elements of the process of negotiation in scientific practice; and attend to the distribution of power and coordinating roles as an empirical topic. The literature on science and the public extends these insights in ways that are particularly useful for my analysis.

2. Science and the Public

My examination of endometriosis knowledge networks is about the relations between patients and medical experts, primarily from patients' points of view, and not the network-building activities of scientist-protagonists as in most ANT analyses. I have suggested that ANT can be used to analyse the activities of non-scientists as well as scientists. Focussing upon relations in networks necessitates attention to lay knowledge claims on their own terms; to the creation and maintenance of lay-expert boundaries; and to the possibilities for the transgression of those boundaries. For analytical help with these matters, I turn to some key STS pieces on boundary work, public understanding of

science, and cooperative work between laypersons and experts.

i. Gieryn on Boundary-Work

Thomas Gieryn's (1983) analysis of the demarcation between science and non-science has become a contemporary STS classic. Gieryn argues that demarcating the science/non-science boundary is a *practical problem* for scientists. This directs our attention away from a specification of the unique and intrinsic qualities of science that make it different from non-science, and toward an investigation of the everyday techniques by which scientists distinguish the scientific from the non-scientific. These practices, Gieryn argues, are not so different from more general social practices of legitimation and delegitimation. Science is defined primarily through contrast with other forms of knowledge, and the claims made for science vary depending on the perceived source of competition.

Gieryn provides three case studies. First, "statesman for science" John Tyndall's 19th century lectures and popular writings depicted science differently depending on whether he was contrasting it with religion or mechanics (two impediments to science's authority, government funding, and popular support). Versus religion, Tyndall emphasized science's practical utility, empirical basis, skepticism, and value-neutrality. But versus mechanics, Tyndall emphasized that science provided for causal understanding rather than 'mere' technological progress; and that science promoted "intellectual discipline" and disinterested pursuit of knowledge for its own sake, rather than for self-interest (ibid:787). Second, Gieryn describes practices of demarcation between science and pseudo-science, using arguments between anatomists and phrenologists as an example. Both appealed to principles amenable broadly to a scientific worldview, but in

opposing ways: anatomists emphasized standardized measurement, expert authority, and political disinterest; phrenologists emphasized empirical observation, skepticism and open-mindedness, and the capacity of science to adjudicate political conflicts. Third, Gieryn analyses scientists' tactics in countering proposed cuts to research funding by erecting a boundary between the context of scientific discovery and the application or consumption of scientific knowledge in order to immunize scientists "from blame for undesirable consequences of *non-scientists'* consumption of scientific knowledge" (ibid:789; emphasis in original). The report counters cuts to basic research by arguing that *applied* research has escalated the US-Soviet arms race; but also asserts that increased funding to basic research is necessary to maintain US military supremacy.

The boundary-work practiced by scientists depends on their goal: expansion (or, I would argue, maintenance) of authority is justified through contrasts that heighten their authority vis-à-vis their competitors; monopolization of a field requires defining rival authorities as pseudo-scientists, deviants, or amateurs; protection of autonomy requires displacing the blame for the consequences of science onto non-scientists (Gieryn, 1983:791-2). The first two goals apply in this project. Endometriosis experts counter one another's claims with accusations of pseudo-science, using various, sometimes competing, principles of medical science (standardized measurement versus clinical applicability in classification, for example). Clinicians dispute the claims of women with endometriosis by defining them as amateurs and by defining visual observation as a better source of knowledge than embodied experience. At other times (usually in relation to expert-competitors), they assert their clinical experience with patients as proof of the authority of their claims. Endometriosis patients and the EA engage in similar boundary-work tactics. Patients draw on their 'qualification' of subjective experience to dispute clinicians' claims;

at other times they invoke the norms of science and the authority of 'specialists' to do so. The importance of Gieryn's work is that it draws attention to the adaptability of definitions of good knowledge to desired ends and to the strategic use of contradictions in epistemological frameworks, as opposed to construing science (or, conversely, lay knowledge) as consistent and monolithic, admitting only of limited justificatory strategies.

ii. *Wynne and Public Understanding of Science (PUS)*

The field of PUS has undergone an important shift in recent years. The field initially focussed on public *mis*understanding of science and ways to remedy it (the "deficit model"). However, the influence of recent STS on some PUS practitioners has resulted in a more reflexive model which enables a critical focus on the construction of scientific knowledge claims. Thus, many PUS authors now understand publics as creatively negotiating their relationship to science in ways that reflect their existing commitments (and reveal the commitments of scientists), and that problematize scientists' interpretations of 'correct' understandings of scientific knowledge (see Irwin & Wynne, 1996; Wynne, 1993).

For some years Brian Wynne, in particular, has been concerned to point out in STS circles the importance of attending to the public's role, rather than merely the scientist's, in the development, spread, and application of scientific knowledge claims (Irwin & Wynne, 1996; Wynne, 1993; Wynne, 1995; Wynne, 1996a). Wynne has argued that ANT, and particularly Callon's (1986) discussion of enrolment and translation, contain the seeds of a more adequate understanding of the relationship between science and its publics in its

recognition of the mutuality of enrolment and the necessity of "renegotiation and restructuring of identities and interests" in network-building (Wynne, 1993:331). He argues, though, that Callon and Latour have not developed the implications of this argument. They focus on the enrolment of publics by scientists to the exclusion of the reverse; they assume that the identification of allies with the scientist is complete rather than ambivalent and provisional (recall Star's notion of partial enrolment); they describe allies' withdrawal of support as sudden 'betrayals'²⁰. Instead, Wynne suggests that we need to recognize

the importance of fundamental ambivalence and chronic instability in the identification of actors with the networks to which they have been enrolled...people are always engaged in cross-cutting networks that confer upon them different interests and identities. Each network tends discursively to reduce its actor to its own monovalent identity, but actors are usually busy trying to sustain multiple, sometimes conflicting versions, and hence ambivalence. Thus what may appear on monovalent assumptions to be a sudden total black-to-white switch of loyalties may, when the substructures of ambivalence are in focus, be seen instead as the result of relatively minor shifts of balance between what were always conflicting identities or elements of identity, as reflected in different social networks (Wynne, 1993:331-2)

Such ambivalence results in what Steven Yearley (1996:183) calls a "pragmatic epistemological flexibility," whereby non-scientists may draw upon--indeed, rely upon--scientific principles and claims at some points to make their claims, and at others disavow the worldviews or consequences of science. Science has been used to delegitimize the suffering of women with endometriosis but it has also alleviated, and (it is hoped) it eventually may cure, that suffering. So individual endometriosis patients and the EA support medical claims to authority at certain points and at others contest them, depending

²⁰Callon, at least, seems to have taken the point: in a recent publication, he and a co-author examine the central involvement of French muscular dystrophy patients in medical research on the disease and their provisional, shifting alliances with researchers (Rabeharisoa & Callon, 1998).

upon the effects of the claims on their shifting and conflicting identities and commitments. Wynne's analysis allows for a conceptualization of lay alliances with or opposition to scientists as precarious, tentative, and strategic, rather than as the result of simple credulity or mistrust.

iii. Cooperation Between Scientists and Non-Scientists

The PUS literature implies that ANT's insight that non-scientists are crucial to the building of a network needs to be fleshed out and conceived in dialectical terms: scientists, too, may be crucial in non-scientists' building of networks, depending on the "problem-situation" (Wynne, 1993) faced by the non-scientists. Analyses of cooperative ventures between scientists and laypeople further reinforce PUS analysts' contention that publics selectively take up and negotiate scientific claims. In his examination of the interactions between fishers and aquaculture scientists in oyster farming, Georges Benguigui (1987) turns Callon's (1986) analysis of scallop farming on its head. Rather than conceiving of the fishers as a component of the "social context" of scientists' work, he centres upon the *fishers'* roles as "scientific actors" that brought their own knowledge to bear in order to align scientists with their own goals and interests. Benguigui asserts that "It is impossible...to claim that the world of sciences produces knowledge (sometimes at the request of other worlds) which the external markets then consume. It would be more correct to say that the worlds inter-act [sic] and define each other, that their borders fluctuate and are more or less transparent" (1987:117-7).

Rainald von Gizycki's (1987) analysis of research on reginitis pigmentosa (a disease which causes blindness) also elucidates the role of laypeople as very active

participants in science rather than simply 'consumers.' According to von Gizycki, the German Reginitis Pigmentosa Society (DRPV)--a self-help organization similar to the Endometriosis Association in its goals and activities--played a pivotal role in the rise of the disease from relative obscurity to a central preoccupation of biomedical research in Germany: "without the development of the DRPV, neither a fundamental interest in retinal degeneration research nor any definite research objectives would have been established" (ibid:79). The DRPV secured researchers' support through the provision of research funding and, more importantly, the promise of hard to come by retinal tissue (pledged for donation by its members after their death). Von Gizycki argues that two crucial factors enabling such an organization to attain a prominent role in medical research are (1) the relative disorganization of the research field and (2) the lack of a well-established and influential professional society dedicated to the disease. If these conditions are not met, von Gizycki claims, the patient group will tend to cede responsibility for the organization and direction of research to the established professional body.

In the case of endometriosis, von Gizycki's conditions would appear to be met. Until very recently (after years of work by the EA) there was no professional society dedicated to the study of endometriosis. Certain professional societies had taken a keen interest in particular aspects of endometriosis research; in particular the American Fertility Society directed efforts to establish an endometriosis classification system, but its focus was on infertility. Research efforts were largely uncoordinated, despite the existence for some years of international endometriosis conferences. Because the primary symptom of endometriosis is pain (a little-researched topic in the field), because the professional gynecologic societies demonstrated little interest in research on cause or cure, and because

research efforts were disconnected and fragmentary, perhaps there was room in the field for the EA to establish itself as a coordinator of endometriosis research.

In a similar vein, Steven Epstein's (1995; 1996) analysis of AIDS science focusses on the roles played by activists in reconfiguring clinical research and affecting the reception and uptake of scientific claims, not just among the general public but among biomedical researchers as well. Drawing on feminist theory, social movement theory, ANT and other varieties of mainstream STS, Epstein has shown that AIDS activists have been most successful in affecting the way scientific research is done by *using strategies that scientists themselves use*. Activists learned the language and culture of science, which gained them admittance to highly prestigious institutions of biomedicine and compelled experts to engage in discussion. Epstein draws on Callon's work to show that activists established themselves as representatives of the entire HIV-positive population, thus making them obligatory passage points in scientists' attempts to recruit research participants for clinical trials and to develop research protocols with which participants (according to their spokespeople) would comply. Third, activists tied their moral and political concerns to epistemological and methodological arguments that utilized accepted notions of 'good science', in order to establish credibility and gain support from scientists and the general public. They took advantage of existing controversies among scientists about clinical trial methodologies to argue for a democratization of trial participation. Their work with the media conditioned public and expert receptions and evaluations of the claims of various scientists, changing the relative strength of expert claims within the biomedical research community. These kinds of analyses suggest concrete strategies that activists can use to affect scientific practice and the development of scientific claims. As David Hess (1997:161) points out, "If science is politics by other means, then coalition

politics can be actor-networks with other ends."

In general, the literatures on boundary-work, public understanding of science, and lay involvement in scientific research provide useful correctives to the tendency in much sociological literature to construct science as a monolithic, independent, and self-determining social structure and to construct laypeople as bystanders who either credulously 'consume' science or 'reject' it based on mistrust or superstition. Instead, alliances between scientists and the public emerge as conditional and strategic; scientific and lay knowledges emerge as relational and mutually determining.

3. **Ludwik Fleck and the Relationship between Lay and Expert Knowledge**

The work of Ludwik Fleck extends this last insight even further. While the works discussed thus far illustrate empirically the strategic alliances between laypeople and experts in the construction of knowledge claims, Fleck allows us to conceptualize more epistemologically the relationship between the claims advanced by experts and laypeople. First published in German in 1935, Fleck's *Genesis and Development of a Scientific Fact* (1979 {1935}) had little impact until quite recently. Thomas Kuhn saved the work from complete oblivion by referring to it in passing in the preface of his *The Structure of Scientific Revolutions* (Kuhn, 1970:vi-vii)²¹; but it was only after its publication in English in 1979 that the work began to have a significant impact on science studies. Some have argued (eg. Harwood, 1986) that Fleck's work is interesting mainly from a historical perspective as a relatively underdeveloped precursor to Kuhn and post-Kuhnian social studies of science. But I agree with Ilana Löwy (1988) that Fleck's work deserves

²¹See Kimsma (1990) for a comparative analysis of Kuhn's and Fleck's (and Foucault's) work.

reflection and study in its own right and that its insights are particularly germinal for investigations of medical knowledge.

i. Thought collectives and thought styles

Very basically, Fleck's argument is that knowledge and the means for evaluating and justifying it are the products not of individual minds but of social groups called thought collectives and their characteristic 'thought styles', which vary historically and cross-culturally. There exist even within one epoch and culture many thought collectives and thought styles. Some are so incommensurable as to make intercollective communication impossible; the problems and solutions that one defines will be regarded by the other as irrelevant. Thought collectives must share certain fundamental traits for real communication to be possible (Fleck, 1979 {1935}:109). The capacity for asking particular questions and recognizing particular facts emerges within collectives and their characteristic thought styles; outside those collectives and thought styles, such questions would not be asked, nor such facts recognized. When one becomes a member of a thought collective, one comes to perceive in accordance with its thought style; that focus means that other styles of perception recede and some appreciation of complexity and other points of view is lost (Fleck, 1979 {1935}; 1986 {1927}; 1986 {1935}; 1986 {1947}). "In order to see, one first has to know" (Fleck, 1986 {1947}:129). Thought collectives provide the background knowledge that directs perception.

While Fleck's position is in tune with the *relativity* of truth among various thought communities, I would argue that he is neither a relativist nor an idealist, for two reasons. First, he makes a distinction between active and passive elements of knowledge. Active associations are choices made by scientists, "usually inappropriately called 'subjective'"

components of knowledge (Fleck, 1979 {1935}:49); passive associations, usually called objective, true, or real, *derive from* active associations. An example from endometriosis science is useful here: endometriosis has been described as a maladaptation to hormonal stimulation (an active association); therefore it has been *treated* with hormones, often successfully (a passive association). While hormones often work in treating endometriosis, and therefore make the active association appear objective and true, they only come to be used through the active association.

Jonathan Harwood has charged that "active and passive are little more than a sociological reformulation of the concepts 'subjective' and objective" (1986:184). But I would argue that the novelty of this conceptualization lies in its specification of the subjectivity-objectivity *relationship* and its centrality to scientific practice. While sociologists--both relativists and realists--have tended to follow scientists and the general public in conceiving of subjectivity and objectivity as dichotomous, Fleck's position suggests that the two are mutually constitutive. Active associations delimit what can be determined objectively, providing the conditions under which 'objective' facts can be perceived; and passive associations provide empirical justification for, and may eventually become, active associations. We could say that, when passive associations do not justify active associations, the passive associations are either ignored and the thought style remains intact, or they force a reworking of active associations. Passive associations can later come to be active ones (Fleck, 1979 {1935}:95), as in Hacking's formulation whereby entities developed through scientific practice subsequently may be *used* to create theories about other entities. Fleck insists that, although facts emerge as the result of thought styles which are historically derived and constitute a kind of collective psychology, the existence of passive associations means that facts cannot be reduced to

history and psychology (ibid:83).

Second, Fleck's emphasis on experience, practice, and the interconnectedness of facts negates relativist or idealist conceptions of knowledge. Facts emerge only through "the total experience consisting of experiments, observations, skills, and transformation of concepts available within a given field" (ibid:10). The thought styles which constitute the requisite experience of researchers depend upon training and practice (ibid:98), forms of tacit, practical knowledge that entail work with materials (ibid:97). "The state of being experienced...consists in just such factors as (1) the ability to make assumptions and (2) both manual and mental practice together with a research scientist's entire experimental and nonexperimental fund of knowledge" (ibid:96). The most important capacity in research--the capacity for directed perception--emerges only through material practice, "experience" (ibid:92).

Fleck's definitions of thought style and thought collective are, as critics have pointed out (eg. Harwood, 1986; Trenn & Merton, 1979a), somewhat contradictory. A thought collective can be as broad as science in general or a particular scientific discipline, or as small as two people exchanging ideas (Fleck, 1979 {1935}:44) or even an individual who "conducts a dialogue with himself as he ponders, compares, and makes decisions" (ibid:120). Moreover, Fleck describes political parties, social classes, nations, and races as potential thought collectives (1979 {1935}:45). He defines a thought collective as "*a community of persons mutually exchanging ideas or maintaining intellectual interaction...[which] also provides the special 'carrier' for the historical development of any field of thought, as well as for the given stock of knowledge and level of culture*" that he calls "thought style" (1979 {1935}:39; emphasis in original). Elsewhere he defines thought style as "a definite constraint on thought...the entirety of preparedness or

readiness for one particular way of seeing and acting and no other" (1979 {1935}:64) and as

[the readiness for] *directed perception, with corresponding mental and objective assimilation of what has been so perceived*. It is characterized by common features in the problem of interest to a thought collective, by the judgment which the thought collective considers evident, and by the methods which it applies as a means of cognition. The thought style may also be accompanied by a technical and literary style characteristic of the given system of knowledge(1979 {1935}:99; emphasis in original).

Harwood (1986:181) has argued that "When the concept is stretched to cover so much ground, it ends up meaning little more than 'presupposition'."

However imprecise the concepts of thought styles and collectives may be, the analysis that springs from these in Fleck's work is, I think, most useful. There are three elements of that analysis that I want to highlight here: proto-ideas; esoteric and exoteric circles; and journal, vademecum, and popular science. These elements enable an expanded understanding of the connections between lay and expert knowledges; and they enable a more nuanced understanding of expert knowledges in and of themselves.

ii. *Proto-ideas*

The case study in *Genesis and Development of a Scientific Fact* is the Wassermann reaction, a blood test used to diagnose syphilis. According to Fleck, the development of this fact had strong roots in the broader culture. Wassermann and his colleague Bruck had been working on the tuberculosis bacillus, but their research had received little attention. Although tuberculosis "had done far more damage" than syphilis, it was romanticized in the popular imagination while syphilis was viewed as "the 'accursed, disgraceful disease'" (Fleck, 1979 {1935}:77). Wassermann and Bruck changed their research focus upon the encouragement of a German state official, who expressed concern

that French scientists were "far ahead in experimental biological research on syphilis" (Wassermann quoted in Fleck, 1979 {1935}:68). National rivalries and popular evaluations paved the way for a sustained research effort on syphilis as opposed to tuberculosis (Fleck, 1979 {1935}:69). Wassermann and Bruck's initial research was unpromising; they could not get the reaction to work in the majority of cases. But there existed in popular culture a conception of syphilis as a state of impure blood, and this created the conditions necessary for the positive reception and refinement of the Wassermann reaction. "Had it not been for the insistent clamor of public opinion for a blood test, the experiments of Wassermann would never have enjoyed the social response that was absolutely essential to the development of the reaction, to its 'technical perfection,' and to the gathering of collective experience" (Fleck, 1979 {1935}:77).

Fleck observes that many of the 'facts' of current scientific thought-styles have their roots in "prescientific, somewhat hazy, related proto-ideas or pre-ideas" (Fleck, 1979 {1935}:23). It is not that science picks out correct popular conceptions from incorrect ones, because proto-ideas are always so "broad and insufficiently specialized" that their truth value is indeterminable (ibid:25). Rather, the issue is whether popular ideas are useful starting points for the elaboration of more precise scientific concepts. "The value of such a pre-idea resides neither in its inner logic nor in its 'objective' content as such, but solely in the heuristic significance which it has in the natural tendency of development. And there is no doubt that a fact develops step by step from this hazy proto-idea, which is neither right nor wrong" (ibid).

Fleck provides another example of a proto-idea that has a bearing on this study: "The whole of immunology is permeated with such primitive images of war. The idea originated in the myth of disease-causing demons that attack man. Such evil spirits

became the causative agent; and the idea of ensuing conflict, culminating in victory as construed as the defeat of that 'cause' of disease, is still taught today" (Fleck, 1979 {1935}:59). Fleck describes a popular illustration of droplet infection: "One devil bacillus is very, very close to the child's mouth...The devil has been represented bodily in this illustration half symbolically and half as a matter of belief. But he also haunts the scientific speciality to its very depths, in the conceptions of immunological theory with its images of bacterial attack and defense" (ibid:117). The shift toward immunological understandings of endometriosis and the causal role of environmental toxins, not to mention medical and lay metaphors of the disease as invasive, suggest that diseases still may be conceived of as independent entities that menace the body from without²². In a focus group study conducted for the Endometriosis Association, patients drew pictures of the disease as a demon, monster, or evil man (Ballweg, 1992b); immunological research on endometriosis (fostered by the Association) can be seen as drawing upon this metaphor of disease as alien invader, as a demon which takes possession of the body when at its most vulnerable.

iii. Esoteric and exoteric circles

Not only do many scientific facts have their origins in cultural proto-ideas. Fleck argues--as ANT theorists have done--that claims become facts only through their

²²Germ theory and miasmatic theory draw upon this metaphor; only humoral theory locates disease as intrinsic to the body. The metaphor of invasion is just one of many proto-ideas used in medicine. Gynecology, for example, has used the metaphors of businesses with a chain of command, computers, machines, factories, electrical feedback, and a weeping woman to describe pregnancy, menstruation, the uterus, and the female hormonal system, and these metaphors have changed historically (see Findlay, 1993; Martin, 1992; Whelan, 1994:54-5). In Chapter 4, patients' reports of some similes used by their gynecologists are presented: the manipulation of probes during ultrasounds is like driving a stick shift; endometriosis pain for women is like the pain men experience when they are kicked in the crotch.

acceptance by non-experts. Here his discussion of esoteric and exoteric circles is important. The smaller esoteric circle is composed of "specialized" and "general" experts in a scientific thought collective; the larger exoteric circle is composed of "educated amateurs." "A contrast between *expert* and *popular* knowledge is hence the first effect of the general structure of the thought collective in science" (Fleck, 1979 {1935}:111-2). All individuals are members of multiple thought collectives, with various degrees of commitment to each depending upon whether they are members of the collective's esoteric (inner, expert) circle or its exoteric (outer, lay) circle. Individuals can be esoteric members of "a few, if any" thought collectives, but exoteric members of several collectives (ibid:105).

The exoteric circle's link to new ideas is through the esoteric circle; "most members of the thought collective are related to the works produced by the thought style...only through trusting the initiated" (ibid). But the esoteric circle depends upon the exoteric circle as well. First, experts attain and maintain their position only through the trust of the exoteric circle, and that trust can be withdrawn: "The elite panders, as it were, to public opinion and strives to preserve the confidence of the masses. This is the situation in which the thought collective of science usually finds itself today" (ibid). The legitimacy of experts depends upon their designation as such by the exoteric circle. This is perhaps particularly true of physicians, whose livelihood depends upon patients' estimations of and desire to be treated by them. Second, proto-ideas--necessary to the development of new scientific claims--derive from the exoteric circle (ibid:111-2). Third, the establishment of a scientific fact depends upon its acceptance by the exoteric circle (ibid:124). Esoteric circles deal with science in the making, in Latour's (1987) terminology, but the blackboxing of a claim requires its extension to the exoteric circle as

an integral part of the claim's network. At the exoteric level, a scientific claim "achieves a superindividual value, and becomes an axiom, a guideline for thinking" (ibid:121)--an established fact--which in turn feeds back upon the esoteric circle and constrains its thinking (ibid:112-5).

iv. *Journal Science, Vademecum Science, Popular Science*

Claims undergo a transition, then, in their passage from the esoteric to the exoteric circle. Fleck examines this in the context of four different kinds of science: journal and vademecum (or handbook) science, which constitute the knowledge of specialized and general experts respectively; textbook science, which is the pathway for initiation into the esoteric circle (not discussed here); and popular science, the knowledge of the exoteric, lay circle (ibid:112).

Journal science constitutes "the latest work" (ibid:124) which may be presented in scientific journals. It is fragmentary, provisional, and associated strongly with the author--which, in scientific thought styles, is viewed as a fault. The author erases his or her identity by using "the characteristic 'we' instead of 'I,' the specific 'plural of modesty,' which is a hidden invocation of the collective" (ibid:119) and signals that the claims are provisional (but often authorless) through such turns of phrase as "'I have *tried* to prove...,' 'it *appears* that...,' or negatively, 'It was not possible to prove that...'. Such jargon serves to shift the 'holy of holies' of science, that is, any judgment about the existence or non-existence of a phenomenon, from the individual worker to the solely authorized collective" (ibid:118; emphasis in original). Obviously Fleck's insights anticipate Latour and Woolgar's (1986) discussion of modalities and their erasure.

Vademecum science, on the other hand, is an amalgam of

alien collectives, exoteric sources, and esoteric communication of thought...[it] is the means by which exoteric knowledge, knowledge originating in other collectives, and strictly specialist knowledge are all selected, blended, adapted, and then molded into a system. Concepts originating in this manner become dominant and binding on every expert (Fleck, 1979 {1935}:123).

Vademecum science is represented in medical knowledge in the form of review articles and consensus conferences. The latter are initiatives, usually undertaken by professional societies or state agencies to bring together experts to evaluate the available evidence and produce a consensus on the 'best' current knowledge in the field based on accepted methodological principles (for an extended discussion on consensus conferences, see Thagard, 1999:Chapter 12). That is, in the process of converting journal science into vademecum science, selection is necessary. Journal science cannot be adopted entirely into vademecum science because journal science claims "often contradict each other" (Fleck, 1979 {1935}:119) while vademecum science "requires a *critical synopsis in an organized system*" (ibid:118; italics in original). Input from the exoteric circle is necessary for the incorporation of journal science into vademecum science: the Wassermann reaction passed from tentative, provisional journal science to a component of vademecum science in large part because public conceptions of syphilis and demands for a blood test made the refinement and application of the reaction a priority.

The esoteric circle, then, "resembles a column of troops on the march" with a vanguard (the inner esoteric circle, the specialist experts working on particular problems) and a main body (the broader expert community), which "always lags behind." Reports from the vanguard vary widely and change rapidly, affecting the movement of the main body, but selectively, slowly, such that the path of the main body "does not closely follow that of any one of the vanguards...The direction that the main body actually chooses from the many suggested by the vanguards is always unpredictable. Paths must first be widened

into roads, and the ground levelled, so that the terrain undergoes considerable change before it can become the garrison of the main body" (ibid:124). Journal science is changed, simplified, when it becomes vademecum science; its idiosyncracies and provisional nature are reduced. And the existing fund of vademecum science directs to a great extent the development of journal science, by providing projects, methods, background knowledge, "collective experience," and forms of perception for new knowledge, such that journal science always is forced to take account of vademecum science (ibid:111-125).

Popular science reduces complexity still further; it involves the "omission both of detail and especially of controversial opinions; this produces an artificial simplification" (ibid:112). It is in popular science that scientific claims reach the level of axioms, of definite constraints on thought. "*Certainty, simplicity, vividness* originate in popular knowledge. That is where the expert obtains his faith in this triad as the ideal of knowledge. Therein lies the general epistemological significance of popular science" (ibid:115). Here objective truths are recognized, proofs no longer needed; the journal scientists who 'missed' these truths become "the 'bad' guys" and those who caught them "the 'good' guys...This valuation subsequently reacts upon expert knowledge" (ibid:116). This account reverses the notion that science determines what is true; in Fleck's work, science is provisional for the specialists and only attains certainty when it is embraced by the populace. Furthermore, popular science is the fund from which proto-ideas are drawn.

Hilary Arksey (1994) has challenged Fleck's implication that the public always has a more remote relationship to the inner esoteric circle of medical research than the general experts (eg. general practitioners). Her study of repetitive strain injury demonstrates that "Fleck's assumption that GPs are educated and patients are not is naive...under certain

circumstances these attributes may be reversed" (ibid:462). Furthermore, Arksey criticizes--justly, I think--Fleck's assumption that the exoteric circle of laypeople acts in a rather passive way to influence medical knowledge, whereby the esoteric circle's nascent facts get confirmed "almost through force of repetition--and by repetition in more certain forms than would normally be the case within esoteric communities themselves" (ibid). She counters that laypeople's 'insider knowledge' sometimes demonstrates the potential for a much more active involvement in scientific fact development than Fleck's analysis would suggest. My analysis of the Endometriosis Association confirms Arksey's assertions.

Relatedly, Fleck's work squarely positions scientists at the centre of thought collectives; laypeople's relegation to the outer exoteric circle I think implies--incorrectly--that patients cannot be at the centre of knowledge creation and are not familiar with journal science. This study demonstrates that patients read medical journals--often, they claim, more than their doctors, who may be familiar only with vademecum science, or even may rely upon 'popular science' about endometriosis in the form of so-called 'myths' which journal science has discredited and vademecum science recognizes as dubious. Fleck's assignment of journal and vademecum science to the esoteric or expert circle and popular science to the exoteric or lay circle, then, is highly problematic. It is useful to distinguish between the various kinds of science and the varying levels of acceptance of claims in different communities, but the uptake of journal, vademecum, and popular science among experts and laypeople surely will vary considerably and is a matter for empirical investigation.

This study also demonstrates that patients (in groups and through their official representatives) develop their own claims to knowledge, drawing upon many of the same rhetorical resources as scientist-experts but also differing from them in key ways. In order

to better understand the claimsmaking strategies of patients, then, we must move beyond Fleck.

III. Feminist Epistemology: Experience and Activism

We have seen that, in Fleck's work, experience (in the form of tacit knowledge, practice and skill) is a crucial element of research work. I will develop the implications for this insight in Chapter 3, particularly in regard to the notion of clinical experience. But experience is a more explicit component of patients' claims about endometriosis. While patients' uses of experience imply a kind of tacit practical knowledge, gleaned through use of therapies and coping strategies and negotiations with (often many) doctors, the distinctive use of experience in patient accounts is its designation of knowledge gleaned from embodied sensation. For endometriosis patients, their bodies speak the truth to them (although, as we shall see in Chapter 5, that truth can be conditional upon medical confirmation).

My previous research demonstrated that women who attended an endometriosis support group considered personal experience with the disease to be an especially important *source of knowledge* about the disease. They posited, as a group, a collective experience that gave rise to a collective body of knowledge about the disease (Whelan, 1994, especially Chapter 6). Patients depend upon the notion of experience--their own and that of other patients--to evaluate medical claims and the claims of other patients. Much of the EA's work has entailed the presentation and compilation (via a huge database of self-reports from members) of the experiential narratives of women with endometriosis. 'The experience of women with endometriosis' is a key resource in the EA's claims-making

activities. It figures not merely in EA publications geared toward lay audiences, **but also** has been used as a resource in the EA's development of medical knowledge claims (for example, about links between immunological disorders and endometriosis).

This focus on experience as a form of knowledge requires critical interrogation: specifically, what do endometriosis patients *mean* by experience? What is special about experience, and how is it a form of knowledge? How does the EA sift through women's varied accounts of their experiences to derive shared interests and common themes that can be used to represent a group experience of endometriosis, and thereby to forge solidarity and commonality among women with endometriosis?

The differences between patient and medical understandings of experiential knowledge necessitate a reworking of Fleck's concepts of thought styles and thought collectives. Fleck's formulation requires that we view thought styles as composed of esoteric and exoteric circles--a useful way to understand the social relations between experts and laypersons, but not very helpful in understanding laypersons' knowledge in and of itself. Who, in the endometriosis patient community, would be members of the inner esoteric circle? All women with endometriosis? This would seem too broad a conception of an esoteric circle which, by definition, must be quite small. Patients' notions of experience do not fit neatly within any particular thought collective; they are a hybrid, seemingly, of general cultural notions about the relations between self, body, and outer world, tinged with both scientific understandings of the body and endometriosis and with feminist and women's health movement claims about rights and the body as essential source of knowledge. Furthermore, the claims developed by endometriosis patients have been advanced as direct *challenges* to the thought style and substantive claim content of medical specialists. Thus, Fleck's notions of thought collectives and thought styles, which

are quite distinct and rigid, pose problems for the conceptualization of patients' ways of thinking about endometriosis. To resolve them, I turn to feminist epistemology.

Like Fleck, some feminist epistemologists have argued that knowledge is intrinsically communal rather than individual in nature (eg. Longino, 1990; Nelson, 1990, 1993; Potter, 1993). Elizabeth Potter observes that "Alone, one person cannot make the distinction between how things are and how they seem, but two or more can make it" (1993:164). Also in line with Fleck's notion of directed perception, Potter notes that accounting for any experience involves selecting out particular aspects and dropping others from the description. These decisions about what to include and what to leave out are characteristics of what Lynn Hankinson Nelson calls "epistemological communities" (Nelson, 1990 and especially 1993). Experiential knowledge is unavoidably social, she argues, because (1) cognitive functioning--the ability to apprehend experience--is enabled by membership in a "sociolinguistic community" that possesses a language and set of concepts with which to think; (2) "public conceptual schemes" make particular experiences happen and are used to structure experience into a coherent account; (3) theories, concepts, and standards of evidence are historically and socially derived. So it is not merely that knowledge must be validated socially, but that the development of knowledge claims themselves is a social process: "communities are epistemologically prior to individuals who know" (Nelson 1993:124). The continuities with Fleck's work are clear.

In Nelson's formulation, epistemological communities share *a body of knowledge* (what I call a set of core claims) and *a set of standards and practices for developing and evaluating knowledge* (what I call an epistemological model). While I use the term epistemological communities most often in the thesis, the term knowledge communities

also is an entirely appropriate synonym. Epistemological communities have **fuzzy** boundaries, frequently overlapping such that individuals can be members of several epistemological communities at once. They are not monolithic; while communities share bodies of knowledge, standards, and categories, and all members accept some of these, they do not have to accept all of them and there may be no single belief that is shared by all members of the community. Nelson's notion of epistemological communities is therefore more flexible than Fleck's notion of thought collectives, in which strict adherence to vademecum science is required. Following Quine, Nelson makes a case for 'naturalized epistemology'--one that does not take epistemology's task to be the theoretical justification of knowledge claims, but assumes that our knowledge is justified "by its ability to make sense of and explain experience" (1993:125).

Nelson suggests that the production of claims about experience involves their narrative reconstruction "so as to make the most overall sense" (1993:126). Liz Stanley (1994) argues that individual subjects process their experiences into coherent narratives; this involves a selective highlighting of certain aspects of the experience, and particular interpretations of these aspects. Nelson's account implies that a group (for example, a social movement) must sort among various accounts of individual experience to develop an account of the 'group experience.' This too is a selective process: elements of some accounts are highlighted and other elements are dropped to provide a coherent narrative. I would argue that if the group hopes to retain all of its members, it will have to strike a compromise between the varying accounts of experience--a compromise that will avoid alienating the subjects. This is a process of negotiation among group members, each of whom must be able to 'recognize' their experiences in the group account in order to accept its ability to represent them and their experiences. If they reject the group account's ability

to represent (more or less) their particular experience, they are likely to **withdraw** from the group and seek a group that more adequately represents their understanding of their experience. The group narrative that emerges bonds members into an epistemological community that shares particular beliefs, categories, terms, and standards of evidence: a precondition, I would argue, for an endometriosis patient movement.

Social movement theory has had little to say about the role of experience in the development of collective identity and collective action. Some theorists assume experience *leads* in a fairly direct and unmediated way to engagement in social movements (Melucci, 1985:63-5). This perspective leaves untheorized the processes whereby experience is *interpreted* individually, *represented* to others, *reinterpreted* collectively by actors in a social movement, and *related* to claims about injustice and social change. Similarly, while some feminist theorists have argued that experience is the foundation of a "women's standpoint" (Smith, 1992; 1997) or a "feminist standpoint" (Hartsock, 1983), they inadequately theorize the complex mental and social processes by which subjects collectively translate *perception* into *narrative forms* that call into question the social order.

Other social movement theorists construe experience as an effect of social subjects' positioning in discursive formations (eg. Laclau & Mouffe, 1985:115). Feminist theorists such as Joan Scott (1992) have taken this position too, though they recognize the indispensability of the notion of experience to feminist discourse. It is important to recognize the role of social relations (including, but not limited to, discursive relations) in the constitution of subjectivity that positions individuals as beings who have particular types of experiences. Nevertheless, experience--particularly embodied sensation--cannot be reduced to social relations. Contrary to the one-way causal argument (discourse ->

subjectivity -> experience) employed by Laclau & Mouffe and Scott, I argue that there is a dialectical relation among these elements.

As Kathleen Canning argues, "bodily experiences shape subjectivity in important ways" (1994:386). Jane Flax argues that illness forces us to pay attention to our bodies "at times and in ways we...would not choose. Such states may at least temporarily have a high degree of independence from our interpretative activities or discursive relations" (Flax, 1993:99). Michael Bury notes that chronic illness can cause a "biographical disruption" and can force, in unforeseen ways, the renegotiation of one's identity and social roles (Bury, 1991:453). Thus, embodied experience can undermine the subject position to which discursive formations assign an individual, and in fact can force a reconfiguration of that position. Moreover, experience, when translated into experiential narrative, feeds back upon discourse and reconfigures it. Experience cannot be reduced to a mere effect of discursive formations; it is a *cause* of them as well.

One's subjectivity to a great extent is affected by one's subject-position in social formations, and experiences may accrue to one as a result of one's subject-position (Laclau and Mouffe, 1985; Scott, 1992). Women with endometriosis have certain experiences because they have been assigned--through medical diagnosis--the position 'women with endometriosis.' However, I am unwilling to go so far as to say that the symptoms women experience--chronic pelvic pain, painful periods, painful sex, painful bowel movements--are the *result* of their positioning in discursive formations. Through systems of discourse we make meaning of pain, but the sensation of pain cannot be said to be a *creation* of discourse.

However, the notion of experience itself is elusive. Researchers do not have access to women's experiences, but only to their accounts of their experiences. I cannot

present women's experiences here, but only their experiential narratives, which I see as distinct from experience as such. An experiential narrative is forged into a representation of it in formal language, a representation that may be shared with others and is hence *public* and *intersubjective*. Something is lost in the translation; narration is the paring down of an experience to make it fit into language, which cannot exhaust it.

The subject uses narration to represent itself and its engagement with the world, which results in the formation and reformation of subjectivity (Somers, 1994; Stanley, 1994). Experiential narrative is intrinsically social; it draws upon practices of meaning-making created by epistemological communities (Nelson, 1993) and upon representations of reality in the larger culture. It is thus more amenable to sociological analysis than experience, which is unavailable for analysis except through narrative. Although experiential narrative is representational, as a practice of meaning-making it may effect changes in material, practical engagement with the world (de Lauretis, 1984). Experiential narratives may feed back onto and be incorporated into other discursive forms.

Social movements work not with experience, but with experiential narratives, because only the latter are intersubjective and hence amenable to collective negotiation and deployment. A founding practice of the EA was its combination of diverse experiential narratives into accounts that attempt to represent perceived common elements of those narratives into a group experiential narrative. This process involves the dropping out of some elements of experiential narratives and the reconstitution of other elements. Group experiential narratives reconstitute the subjectivity of group members as interrelational. The group experiential narrative and interrelated subjectivity of group members constitute the group's collective identity.

This account attempts to incorporate the insight that collective action is concerned

centrally with identity politics and practices of meaning-making (Canel, 1992; Melucci, 1989). It attempts to recognize the role that discursive and, more broadly, social relations play in the construction of experiential narratives (Laclau and Mouffe, 1985; Riley, 1988; Scott, 1992). At the same time, it attempts to avoid a discursive determinist account. Subjects are conceptualized as agential and creative, as actively producing and modifying representations even as those representations and other discursive elements feed back upon their actions and consciousness. Rather than assuming that experience is reflected transparently in social movements' activities and discourses, my account outlines the ways in which negotiation of the meaning of experience happens within social groups. This approach is useful in explicating (1) the processes by which patients translate their experiences into narrative form to develop claims about endometriosis and to engage with each other, (2) the processes by which the EA forges the individual experiential narratives of its members into group experiential narratives that form the basis for collective action, and (3) the ways in which discourses about endometriosis and the experiential narratives, identities and subjectivities of endometriosis patients are configured as a result. Thus, my interest here is not in the experiences of women with endometriosis as such, but in the way that the notion of their experience is deployed by them and by the EA to contest certain expert claims but also to form alliances with each other and with medical experts.

IV. The Contested Body

Endometriosis patients and medical experts are allies in the sense that both are concerned to relieve the suffering associated with endometriosis (necessitating, in their formulations, a 'better' understanding of the disease) and, often through the Endometriosis Association, they cooperate on various knowledge creation and evaluation projects.

However, it is imperative to recognize the unequal power relations between these two communities. Patients tend to accept the epistemological foundations of scientific knowledge claims, though they posit 'experiential' knowledges as valid as well. Medical experts are more suspicious of the validity of patients' claims. The Endometriosis Association does not merely try to enrol medical experts in its network, but to alter medical claims about endometriosis and the women who suffer from it; and the endometriosis patients who participated in this study adopted a very critical approach toward the particular claims of doctors. Thus, a theory of resistance to medical representation is a necessary component of my analytic framework.

Recent feminist critiques of medical representations of the female body, usually influenced by Foucault, have advanced a radically constructivist account and asserted the impossibility of an unmedicalized female body (eg. Findlay, 1995; Harding, 1997; Kapsalis, 1997; Oudshoorn, 1994; van der Ploeg, 1995). While these critiques effectively demonstrate the wide historical variation in medical representations of the female body, radical constructivist authors often conflate material bodies and discursive representations of 'the' body, and the former are subsumed by the latter. In my discussion of Foucault, I criticized this assumption. Furthermore, women patients are assumed to accept medical representations of their bodies at face value. In many of these accounts, little if any discussion of women's efforts to contest or reconfigure medical representations of the female body is offered. Because these authors assume that the female body is always already medicalized--determined by medical discourse in a strong sense--they provide inadequate analysis of the ways in which women reconfigure and contest medical representations of the female body and of illness.

Nevertheless, it is clear that women do resist medical representations of 'the female

body', of their own specific bodies, and of illness. I posit three broad sources of resistance to medical discourses: contradictions in medical discourses; the interspaces between medical and other discourses on the body; and material female bodies themselves.

Medical discourse is a potential source of resistance because it is not monolithic or consistent. Disputes within and among medical specialties, and historical variations in medical claims, mean that a variety of medical discourses on a given bodily phenomenon is available to patients, and can be used strategically to carve out the space for redefinitions of the patient-body. Historically, women patients have engaged actively in debates between medical specialties and have helped to shape their outcome (Theriot, 1993). An adequate understanding of the knowledges of patients and the EA requires an examination of the ways in which patients make strategic use of divisions and contradictions within medicine to contribute to the making of medical claims about endometriosis; and to the ways in which medical claims about endometriosis are constructed not just by physicians, but also by women patients.

Frequently a discourse does not exhaust all that can be said on a topic within its purview; statements about that topic can be made within two or more discourses, such that discourses may be said to overlap. Within this common terrain of statement-making, different discourses can make quite different types of statements about the same topic. I call such common but contested terrains "discursive interspaces," grey areas in which two or more discourses enable divergent (even contradictory) statements about the same topic. The interspaces between medical and non-medical discourses may be useful resources in resisting medical conceptions of the female body. It is possible to play off two discourses against each other in order to undermine the claims of each to describe the reality of women's bodies in totality; elements from competing discourses can be combined to

redefine female bodies in less totalizing or oppressive ways (Lutes, 1997). **The discourses** of toxicology and environmentalism seem to have been employed in the EA's argument that environmental pollutants--a *social* problem--may cause endometriosis (Ballweg, 1995d). This contests medical explanations for the disease that centre on *individual* women's lifestyle choices, such as 'delayed' or 'deferred' childbearing (American College of Obstetricians and Gynecologists, 1983; Houston, Noller, Melton, & Selwyn, 1988) and their biological 'dysfunctions' and 'abnormalities' (Zreik & Olive, 1997).

Moreover, it becomes apparent in analysing patient accounts that they draw on a variety of discourses to represent their illness experiences and their knowledge of endometriosis: medical ones, popular psychology, and notions about rights, gender, and especially the privileged standpoint of women's experience which constitute a kind of popular feminist theory (represented strongly in EA discourse as well). And we shall see in Chapter 3 that medical experts, too, draw upon discourses other than the scientific biomedical model. The existence and subversive potentialities of such discursive interspaces, and Fleck's notion of proto-ideas, direct me to examine the extragynecological discourses upon which endometriosis patients and the EA draw to modify existing medical claims and to construct new ones about the disease. Paula Treichler's (1990) distinction between meaning and definition is also helpful here: "Unlike meanings, which are bound up in what people *think* and *have in their minds* and *intend*, definitions claim to state what *is*. A definition is a meaning that has become official and thereby appears to tell us how things are in the real world" (Treichler, 1990:123-4). This distinction cautions me to avoid focussing exclusively on official (medical) *definitions* and directs my attention to the variety of *meanings* created around endometriosis by patients as well as medical experts, and to the ways in which these definitions and meanings are negotiated by the EA.

Finally, female bodies themselves are a possible source of resistance to medical representation. The endometriosis patient and endometriosis itself so far have eluded medical attempts to represent them, seemingly for two reasons. First, there is no single clinical form of endometriosis. As Fleck (1986 {1927}) observed, while scientific knowledge aims to develop generalities about phenomena, in medicine, never does exactly the same clinical picture emerge twice. Nor is there a single 'endometriosis patient'; women with the disease have widely variant symptoms, responses to treatment, and personal characteristics. Second, medical practice, in changing the very nature of endometriosis and the endometriotic bodies it treats, can frustrate medicine's attempts to describe them (Shohat, 1992). Historically, medical representations of female bodies as unstable and unpredictable have not only authorized medical control, but have constructed those bodies as "always already exceeding the control that medicine can exercise" (Poovey, 1987:147). Physicians' concerns that women can lie about their symptoms, that their support must be enlisted in promoting particular treatment protocols, and that their bodies behave unpredictably, testify to the potentialities for the subversion of medical authority (Poovey, 1987).

Related to this elusiveness of bodies is the nature of pain and the distinction between illness and disease. Pain is the primary symptom of endometriosis. Various authors (Delvecchio Good, 1992; May, Doyle, & Chew-Graham, 1999; Morris, 1991; Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999; Scarry, 1985) have pointed to the problems that pain poses to medical professionals and patients. Pain is intrinsically subjective; there is no objective way to measure it, at least not one that consistently captures patients' experiences of it. Many authors (eg. Eisenberg, 1977; Kleinman, 1988; Robinson, 1990) have argued that there is a quintessential difference between biomedical

models of disease as measurable deviations from normal states of health, and patients' models of illness as experience. Patients may feel ill--in this case, be in pain--in the absence of any biomedical evidence to suggest they have a disease; conversely, patients may be diagnosed with a disease without feeling ill. It is not true to say that patient accounts of illness do not matter in the absence of biomedical verification of disease; these accounts are the basis for medical intervention and persistent efforts to diagnose. However, the frequent mismatch between feeling ill and being defined as having a disease points to the dangers of assuming that bodies are defined entirely by medical representations and that patients adopt wholesale medical representations of their bodies. In recounting their struggles to attain a diagnosis, endometriosis patients frequently refer to their persistent bodily feelings in spite of their epistemic invalidation through the absence of verifiable empirical evidence.

Rather than assuming that patients' (and the EA's) understanding of endometriosis is a direct and unmediated appropriation of medical representations of endometriosis, the distinction between disease and illness and the problems that pain poses to intersubjectivity alert us to the possibility that patients' understandings of endometriosis as illness may differ in important ways from medical representations of endometriosis as disease. The possibility that the understandings of laywomen may differ in important ways from those of medical experts better explains the fact of resistance to medical representations of endometriosis than the assumption that patients' understandings are a direct appropriation of medical representations²³. Unlike disease, defined as a "form of knowledge," illness as

²³Another example: Moore and Clarke (1995) demonstrate that, although feminist health activists drew upon medical representations of female genital anatomy as homologous to male anatomy, they used this homology subversively to assert an active, clitoris-based female sexuality (homologous to 'active,' penis-based male sexuality), as opposed to the passive, vaginally-based, reproduction-focussed representations of female

experience cannot be reduced to intersubjectively-available propositions; thus, "representation can never completely contain or master its subject" (Poovey, 1987:156). The very impossibility of an entirely intersubjective understanding of illness is used by endometriosis patients to assert their privileged understanding of endometriosis, one that medical experts, because of their lack of subjective experience with the disease, can never attain.

Yet, at the same time, the analytic distinction between the "illness experience" of patients and the "disease knowledge" of physicians is artificial. Patients use disease knowledge in explicating their illness experience, and physicians use patients' illness narratives to develop claims about disease. The dichotomy delineates two ideal-type ways of thinking about endometriosis, but does not translate directly into two dichotomous communities of knowers. Patients certainly privilege the "illness experience" more than physicians, and physicians privilege "disease information" more than accounts of illness experience, but both communities use both. The distinction is relative, not absolute.

V. Applying the Framework

In this section, I summarize for the reader the ways in which I apply the principal elements of my theoretical framework to the present study. I attend particularly to the relations between one of my central theoretical concepts--the epistemological community--and the social groups analysed in the chapters that follow.

sexuality found in mainstream anatomy texts. Furthermore, feminist health activists' publications used women's bodies themselves as a means of undermining medical depictions of 'the' clitoris: "the visuals and narratives...stress both the range of experiences and range of bodies women can have" (1995:280). The differences among women's bodies can be used by activists to confound totalizing descriptions of 'the female body.'

This project is framed broadly by three main theories for understanding the relations between endometriosis patients and medical experts and the mediation of the EA in those relations. The actor-networks of Michel Callon and Bruno Latour specify some of the practices whereby relations are forged, focussing on materiality, inscription, negotiation, enrolment, and translation; ANT provides the foundation for my analysis of *concrete practice* in the advancement and extension of a claim, and particularly for the work of the EA. Fleck's thought styles and thought collectives, while themselves imprecise concepts, yield the more usable notions of esoteric versus exoteric knowledges and journal, vademecum, and popular science that suggest some of the mechanisms of mutual influence between communities of patients and experts. Fleck's work provides a basic epistemological framework for the project, supplemented by Gieryn's notion of boundary-work, the PUS literature, and studies of cooperative ventures between scientists and laypeople. Together, these provide the foundation for analysing the *similarities and connections* between patients' and experts' knowledge. Lynn Hankinson Nelson's notion of epistemological communities is preferable to Fleck's concept of thought collective, because it recognizes the potential for significant, substantive differences between esoteric and exoteric groups and their ways of thinking, while retaining the potential for analyzing the similarities as well. The concept of epistemological community provides the foundation for the analysis of the *distinctiveness* of patient and medical communities.

I conceive of biomedicine--its standards and presentation methods for 'good knowledge'--as a definite scientific thought style that, because it has become so widely-accepted and possesses such social legitimacy, constrains both epistemological communities. But as we shall see, often there is substantial variance from this thought style in the actual claimsmaking practices of medical clinicians and clinician-researchers

and, especially, of endometriosis patients. I conceive of a scientific biomedical thought style as a broad, socially-accepted rubric for thinking about endometriosis, but within that thought style there exist various epistemological communities, influenced by other thought styles and proto-ideas, whose members violate the biomedical thought style repeatedly in their network-building practice. Thought style then becomes an overarching but not entirely constraining epistemic system, a set of principles for knowing; within that system exist various epistemological communities which develop their own, more specific, pragmatic standards that, on occasion, differ from the thought style and its component principles. I focus here upon two epistemological communities that make claims about endometriosis: the endometriosis patient community and the medical community²⁴.

I conceive of the members of the endometriosis patient community not as all women diagnosed with endometriosis, but as those that actively engage in venues geared specifically to endometriosis patients. Many women who have such a diagnosis do not engage in the venues of the endometriosis patient community, and not all women who participate in the community have been diagnosed officially (though they believe they have endometriosis). To be a member of the endometriosis patient epistemological community, as I define it here, means that one must participate actively in the patient community; it is through interaction with other patients that one comes to share the community's claims, epistemological standards, and claimsmaking strategies. Also, the community would attract women who *already* are disillusioned with medical care and believe that patients can learn from one another. That is, there is a dialectical relationship here: individual

²⁴Two other possible epistemological communities that take endometriosis as an object are the pharmaceutical community and the nursing community. However, I have not conducted sufficient research to determine if they constitute distinctive epistemological communities, so do not address them here.

women tentatively formulate critiques, needs and concerns; they seek out other women who share those critiques, needs, and concerns; a community develops which brings together and modifies individual women's critiques, needs, and concerns into more solid *group* critiques, needs, and concerns; and the community feeds back upon the ways members perceive and formulate their critiques, needs, and concerns in relation to the community. A woman who did not share these critiques, needs and concerns would be unlikely to seek out the community in the first place, or at least would be unlikely to feel at home enough to stay.

In this community, certain members may be considered to know more about endometriosis in *some* respects, especially the science of endometriosis or endometriosis activism. However, there is no clear hierarchy of knowers but, by and large, a virtual epistemological democracy in the sense that any woman with endometriosis can make a 'valid' claim based upon her own experience.

I posit that members of epistemological communities interact in venues, which may be distinctive to a community or which may allow interaction between members of different communities (in the second sense, my notion of venue is comparable to Clarke's (1998) notion of arena). The principal venues of the endometriosis patient community are local patient support groups, an email list called WITSEND0, and the EA and its sister organizations. The first two are distinctive to the patient community²⁵. The EA is

²⁵While there are some members of the medical community that subscribe to WITSEND0, in three years I have seen only a few posts from medical professionals; they tend to 'lurk' and do not participate actively in the WITSEND0 venue. While medical professionals occasionally made presentations at the support group from which my focus group participants were drawn, they were not considered members of the group and were not present during interaction among members. Doctors are outsiders; only women with endometriosis can be insiders in these venues. It is possible for a doctor to have endometriosis, of course; but since most members of the endometriosis medical community are gynecologists and reproductive endocrinologists, who are overwhelmingly

dominated by members of the patient community (most of the EA's members are patients), but it is a venue in which interaction between patients and medical experts occurs. In this study, I draw on the accounts of participants in each of these venues, show that these accounts are comparable, and consequently suggest that all three belong to a larger endometriosis patient epistemological community which influences accounts in all its venues. Many members of the community participate in more than one venue, which permits cross-fertilization and homogenization among the venues. Through interaction in the venues, women with endometriosis become part of an epistemological community that formulates and shares a set of core claims, epistemological standards, and strategies of claimsmaking (these are examined in Chapters 4 and 5).

The endometriosis patient community is not *just* an epistemological community--it is also a community of support and activism. But because the community shares certain standards, claimsmaking strategies, and especially core claims that are distinctive to it, it forms an epistemological community. And the support-provision and activist aspects of the community, as we shall see, are intimately connected to the epistemological aspects of the community. Support requires the construction and sharing of accounts--of knowledge claims--and the acceptance of their epistemic validity. Activism requires the creation and assertion of group claims and critiques of other groups' claims. So the endometriosis patient community is not *just* an epistemological community, but it is *always* an epistemological community. It therefore is permissible to use the terms endometriosis patient epistemological community and endometriosis patient community interchangeably.

When I refer to the ways of thinking of the members of this community, I refer to

male, this would be exceedingly rare. I know of no medical endometriosis expert who has the disease.

their epistemological model. It is the community's possession of this model and the claims that it develops through that model that make it an *epistemological* community.

It is not that the epistemological model of the endometriosis patient community is internally consistent or entirely different from other communities and epistemological models. Indeed, as I demonstrate throughout this thesis, it is very adaptable, so much so that it sometimes seems to be hardly a model at all. Patients draw on a variety of claims, standards, and claimsmaking strategies strategically to assert their status as credible claimsmakers and to discredit the credibility of others (particularly doctors). Because the epistemological model of endometriosis patients is above all a pragmatic one, it does not suppress this variety, but *encourages* it, permitting a great deal of flexibility about what can be said by patients and how they can say it, as the problem-situation demands.

But it does not permit *any* claim or epistemological standard (for example, it is emphatically not acceptable in the community to contest another patient's claim to be in pain) and only women who have, or suspect they have, endometriosis can be members of the community. The community is bounded as well as flexible, and its boundedness is what makes it a distinct community. As well, certain claims and ways of thinking are *dominant* in the community, and these lend the community its distinctive epistemological model. The dominant aspects of the endometriosis patient community, I argue, are critiques of doctors and a championing of women's experience (particularly their experience of their bodies, but also their experiences with medical treatment) as a distinctive and valid form of knowledge.

The linguistic inexhaustibility and elusivity of embodied experience resist its medical encapsulation, but patients do not seem to view these qualities as barriers to their intersubjective understanding of embodied experience. What gives resonance to

experiential narratives among patients, what makes them a foundation for a 'deeper intersubjectivity' than that which can be achieved between sufferer and non-sufferer, what makes them a basis for solidarity in the endometriosis patient community, is the fact that women with endometriosis draw on their own embodied experiences to make sense of each other's accounts. So a woman with endometriosis feels she can 'know how another feels' not merely because she has heard the other's account, but primarily because she has had comparable experiences. For example, she knows what her own pain is like and can project that to make sense of the other patient's account. The similarity is determined discursively--it depends upon being defined as a woman with endometriosis, upon others' presentation of their accounts, upon making up an account about one's own experience, and upon the assumption that one's experience is comparable to another's. But the process has a concrete referent--the patient's own body. Hence in Chapter 4, we see patients arguing that men (and women without endometriosis) cannot possibly understand what it is like to have endometriosis, no matter how many experiential accounts they may have heard, because they have not experienced it themselves. We will see a couple of patients making wisecracks about a doctor's attempt to draw a parallel between women's endometriosis pain and men being kicked in the crotch: for the patients, the two experiences simply are not comparable and the doctor is being patronizing. They believe the experiences of women with endometriosis *are* comparable, however.

The issue, as I see it, is not whether the experiences really *are* comparable at some prediscursive level (this cannot be determined, in any case, because only experiential narratives can be compared). The issue is that patients believe that the statement that "My endometriosis is bad today" has a more concrete meaning for a woman with endometriosis than it does for those who do not have endometriosis, for whom the statement is only an

abstraction. So while experience is elusive *because* it is irreducible to representation, and while experience cannot be accessed directly in this thesis, the *notion* of experience forms a crucial backdrop to women's experiential narratives and their exchanges with other patients. They struggle to put experience into words, it defies representation, but it is nevertheless a foundation for patient intersubjectivity, solidarity, and communal claims-making.

There is traffic between epistemological communities; one community often will incorporate the claims and standards of another, as Nelson points out. Women with endometriosis refer to medical knowledge, the norms of science, and the claims of medical experts all the time, but they do so to their own ends, often using the borrowed claims and standards against the medical community itself. The community permits and encourages references to medical knowledge--*as long as these references do not contradict the experiential claims of other members in the community*. The endometriosis patient community privileges certain types of explanation and certain claims, disallows some other claims, and demands that its members have the qualification of experience with endometriosis and respect that qualification in others (i.e. take others' accounts of their experience on faith). It therefore has rules and boundaries that it enforces, and a loose model for knowing about endometriosis that nevertheless proscribes and prescribes certain claims and ways of claiming. Traffic crosses borders, but the borders remain and are policed according to certain rules.

The second epistemological community I describe here is that of medical experts who treat and study endometriosis, discussed in Chapter 3²⁶. This community includes

²⁶Those who treat and/or study endometriosis may be general practitioners, reproductive endocrinologists, or gynecologists, so medical specialty is not an adequate shorthand for the community (although the latter two specialties dominate). 'The medical

both clinicians (practicing physicians) and clinician-researchers (practicing physicians who also conduct research). The acquisition of credentials--degrees, publications, licences to practice--admits one to the medical community as a proper member (although those without formal medical credentials--such as the executive of the EA--may have a close working relationship with the medical community, a kind of 'honorary member' status that nevertheless is not equivalent to full membership). These are epistemological credentials: they qualify one as a knower of the medical aspects of endometriosis, and medical practice is thought to be founded on medical knowledge which one gains through initiation into and participation in the community. Like the patient community, the medical community is not *just* an epistemological community (it is a professional one as well) but it is *always* an epistemological community because its work involves the creation and practical application of medical knowledge.

The principal venues of this community are the professional associations, such as the American Society for Reproductive Medicine (previously the American Fertility Society), the American College of Obstetricians and Gynecologists, and the Society of Obstetricians and Gynaecologists of Canada; medical conferences; and medical journals, such as *Fertility and Sterility*, *the American Journal of Obstetrics and Gynecology*, and *Journal SOGC*. The latter provide readily accessible, public records of the community's debates and central claims, and hence are the focus of my analysis here. The medical

community that treats and studies endometriosis' or 'the endometriosis medical community' are clumsy terms. I therefore refer throughout the thesis to this community simply as "the medical community." In cases where I am referring to the wider medical community--that which includes all medical specialties and interests--I make this clear when a distinction is necessary. Of course, the particular claims of each medical specialty are distinct. But in epistemological matters, there appear to be few, if any, differences between the endometriosis medical community and the wider medical community. Thus, often, no distinction is necessary in the text.

associations themselves are for medical professionals only. Members of the endometriosis patient community (usually representatives of the EA or its sister organizations) may participate in conferences or publish in medical journals, but are outsiders to the community-proper--"guest speakers," as it were, as medical professionals are to WITSENDO and local support groups.

This community possesses a formal hierarchy of knowers to a much greater extent than the endometriosis patient community. In the medical community, "endometriosis experts" are gynecologists or reproductive endocrinologists recognized within the larger medical community as specializing in treating and, especially, studying the disease scientifically. It is these experts who collectively set the standards for "good knowing about endometriosis" in a medical sense.

This community has a more strictly specified formal epistemological model than does the endometriosis patient community, whose model emerges in the process of claimsmaking rather than being set out explicitly as a model to follow. The formal epistemology of this particular medical community is equivalent to that of the wider medical community. This epistemology is scientific and objective and asserts that the best knowledge is gleaned from double-blinded, randomized, controlled clinical trials which can be replicated²⁷. It is comparable to the broader biomedical thought style. Yet, at the same time, there is a tacit, subtextual way of knowing that complements and, in many senses, contradicts the formal one: the model of clinical experience. Medical specialists in endometriosis--the esoteric circle, in Fleck's terms--not only conduct research and publish on the disease, they are also highly experienced practitioners. Their scientific

²⁷See Ted Kaptchuk (1998) for an interesting analysis of the historical rise of blinded, placebo-controlled trials in medicine and its relation to the assertion of medicine's scientificity and objectivity and to the discreditation of patient accounts.

knowledge and credentials *and* their vast clinical experience make them experts. Thus, there is flexibility in this model too: one can appeal to science or to one's clinical experience to establish one's claims as valid.

But despite the recognition of the value of clinical experience among members of this particular community and the wider medical community, it is scientific claims, not experiential ones, that are stressed in official, published representations of medical knowledge of endometriosis. It is *never* enough to have a lot of experience in treating endometriosis. A naturopath who has treated hundreds of endometriosis patients would not be considered an expert by this community; nor would a GP with similarly extensive experience. One must have the professional and scientific credentials to back up clinical experience if one is to be deemed an endometriosis expert within the medical community.

The scientism of the formal epistemological model has strategic value. Various authors have shown that the marketing of medicine as a scientific enterprise has been crucial to its social legitimation and public acceptance as a system of expertise distinct from, and preferable to, lay knowledge of health and illness--however little the introduction of scientific methods actually may have advanced medicine's therapeutic efficacy (Bynum, 1994; Gelfand, 1993:1138-1144; Hansen, 1999; Kaptchuk, 1998; Shortt, 1983; Starr, 1982). Only doctors have the training and accreditation in the science of medicine which makes them the scientists of health and illness. Because of their association with non-scientific, lay ways of knowing (and lay healing) experiential accounts may be unreliable, anecdotal. They are integral to medical knowing, as we see in Chapter 3; but they cannot distinguish it from other ways of knowing about illness. Science can. The importance of boundary-work in the assertion of expertise is clear.

This is not to say that all clinicians abide by the view that clinical experiential

knowledge must be backed up by science, or that the scientific medicine advocates always win professional debates with those who advocate different models of medicine. Battles over whether medicine should be conceived as practical art or as science have occurred historically, generally and in a variety of specialties, and occasionally the practical art side has emerged victorious (see Anderson, 1992 and Romano, 1997 for two examples).

Clinicians often prefer to rely upon their clinical experience rather than endometriosis science, because the former can be more useful in the practical treatment of patients, while endometriosis science often is not useful therapeutically. Nevertheless, in general, medicine's claim to legitimacy rests upon its status as a scientific enterprise, not as a practical art.

Thus, clinicians often find themselves contradicting the explicit model to which they, as members of the medical community, are supposed (in both senses of the term) to adhere. They are required to adhere to it publicly. Medical school requires them to learn the science of medicine, while very little instruction is provided in the experience and art of clinical practice (Comelles, 2000; Hunter, 1991; Malterud, 1995). The conventions of medical publishing require them to follow the precepts of scientific epistemology, of the biomedical thought style. To state a preference for clinical experience over medical science is a violation of the publically-professed norms of the medical community, if not to its practice (though, as Hunter (1991) argues, medical practitioners generally do not recognize the ways in which they violate scientific norms and see their clinical practice as scientifically-based). Latour (1987:4) has noted that "science is a two-faced Janus"; so is medicine. The public face of medicine (its formal epistemological model) emphasizes its scientificity, but the private face of medicine (its practical epistemology) is a mixture of the scientific and the experiential.

Thus, the formal medical epistemological model is less flexible, pragmatic, and inclusionary, and consequently less capable of adequately capturing the varying ways in which its members know in practice, than the endometriosis patient model. The formal, scientific medical epistemological model is an artificial construct, but nevertheless one that has important effects, and one that medical experts must be seen to follow. It is not equivalent to the medical community of knowers which, in its practice, employs a more flexible epistemological model that mixes experience and science together, just as the patient model does.

To summarize, the medical epistemological community has an explicit, formal, scientific model for knowing which its members often can not follow in practice because it is too restrictive. In reality, clinicians use an informal, tacit mixture of experiential and scientific knowledge and ways of knowing. Nevertheless, it is the formal model that allows members of the medical community to assert themselves publically *to be* a distinctive epistemological community that knows better than other epistemological communities (especially the patient community). The formal model lends the community its epistemological legitimacy; not following the model allows it to get its work done.

By contrast, the endometriosis epistemological community has one loose, implicit model that its members do not have to violate because it is so adaptable. Thus in the patient community, there is no divide between formal and informal models, or between formal model and practice. Indeed, the model *is* practical and informal, emerging through the practice of, in the service of, its patient-members, rather than being imposed as a definite thought constraint, as in Fleck's formulation of thought style. The patient model can incorporate experiential epistemologies and claims as well as scientific ones. Claims about endometriosis as subjective experience lend the community its claim to special

knowledge, to which others cannot lay claim; and patients do not have the scientific credentials to gain social recognition as scientific experts. Yet we shall see that patients learn a great deal about endometriosis science, and they use it to evaluate the validity of their *own* perceptions of their experiences. They do not accept science wholesale, but strategically select the scientific claims that uphold the claims they want to make and reject the others as unscientific, sexist, and so on, using critiques formulated within the community. They engage in boundary work to construct as pseudo-science the claims with which they disagree. Again, the model is flexible enough to allow this selective uptake of science. What the model does *not* allow is the use of scientific claims--or, indeed, one's own experiential claims--to deny the validity of another patient's 'experience.' A demand that its members respect the validity of the experiential claims of other patients is a fundamental feature of the endometriosis patient community.

The prestige associated with science means that, when patients make scientific claims, they have nothing to lose--they are not debasing themselves but rather enhancing their social status as claimsmakers. But the authority of medicine as a system of knowledge is based upon its claim to be scientific; experiential accounts are viewed as anecdotal and unreliable, so despite their centrality to medical knowledge, their centrality is not formally recognized (Malterud, 1995). The upshot of all of this is that the endometriosis patient community can invoke science and experience explicitly and simultaneously, using the former to uphold the latter, gaining epistemic prestige from the former and claiming special knowledgeability status from the latter; while the medical community can evoke only science explicitly if it is to preserve its distinctive social status, but implicitly must draw upon clinical experience on a routine basis.

So, in practice, the epistemological models of doctors and patients are not all that

different but, in principle, they are vastly different. And the in-principle differences affect the interactions between members of the two communities in profound ways. Members of each community appear to believe that the members of the other think about endometriosis in very different ways than they do. In a sense, they are right; clinicians cannot base their knowledge of endometriosis on their own embodied experience of endometriosis (though they can draw on their experience of pain to relate to patients), and patients cannot base their knowledge of endometriosis on their surgical observations or clinical practice (though they can read medical literature). The perception in medicine is that medical knowledge and ways of knowing are more objective and reliable than patients' knowledge and ways of knowing, which are anecdotal, subjective, and therefore unreliable. Members of the patient community counter that their embodied experience is the best foundation for 'really' knowing about endometriosis and that medical experts can gain only a second-hand knowledge of endometriosis--and not a very scientific one, at that. Both communities accept and emphasize a Great Divide between subjective experience and scientific objectivity. Yet, in practice, physicians rely upon the experiential accounts of patients and their own anecdotal, subjective knowledge to do their work, and patients use scientific knowledge on a routine basis to understand and evaluate their embodied sensations. The in-principle differences create conflict between the two communities, but often do not hold up in practice.

I conceive of the EA as a founding member of the endometriosis patient community and of its epistemological model. It demonstrates the same kind of flexible, pragmatic claimsmaking strategies as the patients who participated in this study, drawing on experience and science strategically toward the explicit goals of improving the treatment of women with endometriosis, and vociferously asserting claims developed

within the patient community. Its primary membership is in, and its fundamental solidarity is with, the patient epistemological community.

The EA's membership and executives are primarily patients who do not have medical credentials, so they cannot gain full admittance to the medical community, which is defined by professional status. However, the EA makes a concerted effort to engage with and alter the medical epistemological community, using that community's own claims, standards, and strategies to do so, as well as the claims, standards, and strategies of the endometriosis patient community. It forms strategic, intimate alliances with prominent members of the medical endometriosis community. It draws on notions of clinical experience, but appeals most of all to notions of medical science in its work with members of the medical community. It brings medical science to the patient community--constructing itself as the most reliable, "patient-friendly" source of scientific information for women with endometriosis--and patients are appreciative of this work because they, on the whole, have a healthy respect for the *potential* (if not the extant achievements) of medical science. The EA also brings patient experiential accounts to the medical community--a more challenging task because of greater disrespect for patient claims in the medical community, but not an impossible one, because many physicians increasingly are realizing that a more collegial, cooperative relationship with patients and the EA can improve doctor-patient relations and their ability to treat patients effectively.

The EA, then, has a foot in both communities; the one in the patient community is more firmly planted, but the other foot is gaining an ever-firmer grounding in the medical community. The EA attempts to draw the two communities together into *one* epistemological community that respects both medical science and patient experience as valid forms of knowledge. Its efforts to do so are analysed using the principles of actor-

network theory.

The main focus of the research described here is upon endometriosis patients' core claims, epistemological standards, and strategies for claimsmaking. Such a focus enables us to examine the public's alliances with science not as the consequence of total identification with scientific goals, but instead as precarious and strategic, in line with the observations of feminist STS and the literatures on science and the public. As we have seen, the epistemic valorization of the embodied experience of illness is central to endometriosis patients' claimsmaking strategies. It is this valorization which mainly accounts for the endometriosis patient epistemological community's variance with the biomedical thought style; it is the foundation for boundary-work and demarcation of a patient community separate from other communities. A central project of the endometriosis patient community is its production of a group experiential narrative. This narrative is deployed to mount challenges to the biomedical thought style and to assert a privileged standpoint from which endometriosis patients may speak, a reversal of the typical hierarchy of knowledge in which science and medical experts occupy the more privileged standpoint. At the same time, members of the medical community use notions of clinical experience as a foundation for their own claimsmaking and evaluations, contrary to the explicit directions of the official scientific biomedical thought style, which emphasizes reliance upon scientific research and considers knowledge based upon clinical experience to be anecdotal.

Communication between the two types of community is facilitated by standardized packages that include both experience and science as epistemic resources. The communities are therefore similar, not in the sense that biomedical scientism colonizes the minds of everyone concerned about endometriosis (as a Foucauldian approach would

suggest), but in the sense that both draw on scientific *and* experiential forms of knowledge, on proto-ideas as well as scientific ideas. I argue that focussing on the claimsmaking of laypeople, as opposed to the formal accounts of medical experts, produces a more nuanced account of knowledge about illness and the relations between experts and laypersons--one in which there is traffic between the two, mutual resistance as well as cooperation--rather than conceiving of medical experts as always-scientific knowledge makers and laypeople as the sponges which absorb the knowledge of the experts.

Sophisticated recent history from below avoids setting the underdogs apart as mere dumb animals, in Marx's classic evocation, "a sack of potatoes"; far from being passive victims ripe to be invaded and exploited, or cared for paternalistically, those below form communities engaging in complex negotiated exchanges with their betters, flexing their own muscles, much as in the Hegelian master-slave dialectic. Likewise with the sick...it is precisely the dynamic interplay between sufferers and practitioners that requires study, the tug-of-war supply and demand, patient power and doctor power. By starting with the patient we can put medical history back on its feet (Porter, 1985:185).

Likewise, I think, for medical sociology.

Chapter 2

Methodology

I begin this section with a description of the methods followed in collecting and analysing data from medical literature, patient accounts, and the Endometriosis Association. This is followed by my reflections on the research process.

I. Medical Literature

For my analysis of the medical epistemological community, I relied upon published accounts of medical claims and claimsmaking practices regarding endometriosis. Principally, this constituted research reports published in medical journals (exhibits of Fleck's journal science) and reviews of the literature, drawn from gynecology journals and books specifically about endometriosis (exhibits of Fleck's vademecum science). For the outsider, these are most accessible exhibits of the medical community's ways of knowing about endometriosis.

The medical literature on endometriosis is vast. A Medline search for medical journal articles with endometriosis as a major topic in English alone produced 3,672 abstracts, dating back to 1964. Rather than attempt the impossible--a comprehensive summary of medical knowledge about the disease--I focussed on an overview of the substantive claims and epistemological assumptions made in the medical literature on endometriosis in three particular fields: classifications for endometriosis; psychology of endometriosis; and epidemiology of endometriosis.

While I have a rudimentary knowledge of most fields of endometriosis research, I

had conducted extensive previous research in these three areas and this facilitated the analysis process. Learning about a new field of science is an extremely time consuming process. Each area of endometriosis has its own history, jargon, debates, and core texts. Because I was already broadly familiar with the classification, psychology, and epidemiology literatures on endometriosis, I was able to devote my attention to the analysis of epistemological constructions within the texts, rather than first having to learn the field in order to make sense of what I was reading. Furthermore, I was able to compile a fairly representative sample of medical publications quickly, focussing upon the journals I knew had the most material on, and were the most influential in shaping, debates in each area.

More importantly, however, my previous work suggested to me that these three fields were among the most hotly debated areas in endometriosis research, and thus were particularly apt examples of "science in the making" (Latour, 1987); that they were the fields that concentrated most on defining women with endometriosis and their credibility as claims-makers, and thus were good fields through which to examine medical epistemology; and that they (especially psychology and epidemiology) had attracted considerable attention from women with endometriosis generally and from the Endometriosis Association, which made them useful in comparing patient and medical claims.

Sources were subjected to several selection criteria in order to produce a manageable sample of literature for review. First, they had to have been published within the past 15 years in well-known American, British, or Canadian journals, or in reputable collections edited by endometriosis specialists (the vast majority of the literature cited here is American, as most of the research on endometriosis has been conducted in the U.S.).

This ensured current relevance and reputability. Second, preference was given to journal articles and book chapters that reviewed the extant literature. These reflect best the areas of current consensus and disagreement among experts. Third, particular studies that were cited frequently in the literature, and therefore deemed to have a significant impact on the field, were included. General gynecology textbooks were not analyzed in any detail and were used only as supporting material because the information in them tends to be rather dated, with little specific discussion of the areas under investigation. The resulting literature sample consisted of 37 articles, editorials, and letters to the editor in gynecology journals, and 8 chapters in edited collections on endometriosis. The sample selected reflects the controversies and core claims with the medical endometriosis community concerning classification, psychology, and epidemiology of endometriosis.

First, I determined *what* the medical researchers publishing or cited in these sources claim to know about endometriosis and women with endometriosis regarding classification, psychology, and epidemiology. I analyzed the substantive content of the medical sources in these three fields, identifying core claims and debates in each area of research. Substantive content was defined as the authors' claims to knowledge about endometriosis and women with endometriosis (their symptoms, personalities, and sociodemographic characteristics), and their summaries of medical research in the area. Given my prior knowledge of the classification, psychology, and epidemiology of endometriosis, this involved mostly rereading older sources, getting up to date on new contributions, and summarizing the claims made in each field.

The second phase of the process attempted to discover *how* medical researchers claim to know about endometriosis and women with endometriosis. I analyzed the principles set out as constitutive of 'good knowledge creation practice' and the rhetorical

devices used by authors to establish the credibility of their own claims, to evaluate the validity of competing medical claims, and to assert that particular research practices were likely to improve the making of generalizations about patients. Particular attention was paid to tacit evaluations of scientificity and objectivity. The aim of this phase was to determine the epistemological criteria by which medical researchers evaluate the validity of claims about endometriosis, and the extent to which endometriosis patients potentially could make such claims.

The analysis of medical epistemological principles was significantly more difficult than the analysis of substantive medical claims. While methodological issues were commonly discussed, explicit remarks about epistemological practice, objectivity, and scientificity were more rare. Nevertheless, attending to authors' methodological statements generated insights about the epistemological standards of the medical endometriosis community in regard to classification, psychology, and epidemiology of endometriosis, and often provided tacit evaluations of the epistemological standards of endometriosis patients. Moreover, the analysis of substantive content suggested that particular *kinds* of claims (those made by eminent experts and/or those that were generated through large studies which employed standardized scientific instruments and tests and visual evidence) were considered especially noteworthy among medical researchers. Other kinds of claims (those made by lesser specialists, general practitioners, or patients, and/or those that were generated through small studies, patient experience, clinical impressions, and anecdotal evidence) were either absent from substantive medical discussions or were (usually implicitly) disparaged through comparison with other, more "scientific" claims. Strategies of inclusion and exclusion, then, were at work in substantive discussions and these suggested which knowledge creation standards were considered

acceptable by medical researchers, even where specific methodological or epistemological critiques were not specified.

As I read each publication, I took analytic notes and copied particularly salient passages. The result was a large pile of literature summaries which then were more formally coded, using coloured highlighters and tags. The codes used were: core claims; substantive critiques and areas of contention (debates about the truth of particular medical claims); and epistemological and methodological arguments. The first two codes were further subdivided into three themes, reflecting the areas of medical study under investigation: classification, psychology, and epidemiology.

II. Patient Accounts

These were derived primarily from two sources: focus group transcripts from a related study I conducted in 1994, and an open-ended survey conducted over an endometriosis patient email list, WITSEND0. They are complemented by the EA literature, which presents the perspectives of patient-members as well as medical information about the disease. The focus group and WITSEND0 participants in this study were considered to be active members of the patient community on the basis of their participation in an endometriosis patient support group and the WITSEND0 list, respectively; many were also members of the EA. The perspectives of women with endometriosis who are not active in any of the venues of the endometriosis patient community were not members of this community, by my definition, and therefore are not included in this study.

The focus group research explored the experiences with medical treatment and physicians of six women with endometriosis who had been treated with a class of

hormonal drugs called GnRH agonists. It formed the basis of my Master's thesis (Whelan, 1994). The research was conducted at the Women's Health Clinic in Winnipeg, Manitoba; the Clinic board evaluated and approved my research proposal. Participants were recruited at two of the monthly meetings of the Clinic's Endometriosis Support Group, in January and February, 1994. After an introduction by the support group facilitator, I described the research and asked for volunteers who had used (or were using) GnRH agonists to participate in the research. Seven women volunteered, but one was unable to attend the focus group meetings.

Nine weekly meetings of approximately two hours each were conducted with the remaining six participants from March to May, 1994. The first meeting was not audiotaped to allow participants a chance to meet and discuss the plans for the research; there was a great deal of informal discussion about experiences with endometriosis and medical treatment, but this was not used in the analysis. The eight subsequent meetings in which the research-proper was conducted were audiotaped, generating approximately 450 pages of transcribed data.

The discussions were framed by a list of questions relating to these women's experiences with their doctors and the drugs, and their attempts to find information about the drugs (see Appendix 1). The first half of the interview schedule related specifically to GnRH agonists. It addressed participants' use of, reasons for using, and experiences with the drugs; their knowledge of the drugs, ways they learned about them, and evaluations of information about the drugs and of their doctors' ability and efforts to educate them about the drugs; their feelings about the role of the pharmaceutical industry in creating and disseminating knowledge of the drugs; and what they would tell other women who were considering using the drugs. The remaining half of the schedule related to participants'

general experiences with and views about endometriosis, doctors, and the doctor-patient relationship: their diagnosis, treatment, and main sources of information about the disease; evaluations of their doctors' knowledge, self-presentation as knowers, and attitudes and behaviours toward patients; self-education and the participants' role in treatment; their conception of the ideal doctor-patient relationship, and their own relationships with their doctors; and the problems with medical care faced by women with endometriosis generally.

However, the discussion was broad-ranging and I made only limited attempts to control the conversation, as it was very evident that the women in the focus group had a strong desire to use the sessions to exchange stories and information, and not merely to help me with my research. Limiting the extent to which I moderated discussion proved to be a good strategy, as many seemingly tangential issues raised by participants prompted some extremely insightful comments from other participants which were highly relevant to that study and this one. I participated actively in the discussions, offering my own opinions and knowledge about endometriosis, doctors, health care, medical research, and the pharmaceutical industry, both as a sociologist and as a woman with endometriosis. My contributions may have turned the discussion in other directions than it would have gone, had I been a less active participant

In order to assess this possibility, to generate a broader pool of participants, and to gather data focussed more specifically on the questions addressed in this study, I conducted an open-ended survey on WITSEND0, an electronic mail list for women with endometriosis. Permission from the moderator and owner of the list was obtained, and on January 25, 2000 my message was posted, inviting women with endometriosis to send me, by email, their "endo stories," with the suggestion that they use as a starting point a few

broad questions about their search for and evaluations of information about endometriosis (Appendix 2). I introduced myself to the list as a woman with endometriosis--an important point because, as I have stated, women with endometriosis often are wary of non-sufferers who 'don't understand.' I framed the research as a study of the views and struggles of women with endometriosis regarding 'information' about endometriosis, rather than using jargon like 'knowledgeability' or 'epistemology' and presenting the study as one of women's 'self-presentations as knowers.' I felt such language would be pretentious and perhaps confusing in a non-academic context, and I was concerned that it would make the women unduly self-conscious about what they said and how they said it. Obviously such jargon was unnecessary, in any case, because the participants provided the sort of information in which I was interested. Initially I received six responses, so I sent the message again two weeks later. In short order, I received an additional thirteen responses, bringing the total to nineteen.

Thirteen of the women lived in the United States; the remaining 6 lived in Australia, Canada (2 respondents), Guatemala, Italy, and England. Five limited their responses to direct answers to my questions; thirteen sent me more free-flowing narratives which included responses to most or all of my questions. The remaining participant (the Australian), who initially agreed to participate in the research, sent me a long email to explain that, upon beginning to prepare her story, she found the process too emotionally upsetting and was unable to continue. Although the email she sent me did not address my questions directly, it provided some poignant insights about the effects of this kind of research on participants and therefore is considered in the reflections section below. However, in considering trends and themes in responses, only the remaining eighteen WITSEND0 responses were used.

The personal characteristics of the participants are summarized in Appendices 3 and 4. Appendix 3 presents brief biographical introductions to each of the focus group members, based on longer versions which were approved by the participants (see Whelan, 1994:8-14). I did not specifically ask WITSENDO participants for this information; some provided it in any case, while others did not. There are two reasons why I did not ask for this information from the WITSENDO participants.

The first reason is theoretical. My focus in this research was not the experiences of individual women with endometriosis (which I tackled in my M.A. thesis), but the claims and epistemological strategies and standards of the endometriosis patient *community*. Taking seriously the claim that knowledge is intrinsically social and that it is communities, not individuals, that know means that the varying characteristics of individual participants should not be especially relevant to the core claims and epistemological standards and strategies that characterize the endometriosis patient community. Of course, a community can represent itself only through the words of its members. But despite the differences in age, nationality, occupation, education, and other characteristics identified by participants, their main claims and epistemological views are remarkably consistent because, I argue, they represent the views of a collective, rather than simply individuals. Nevertheless, certain individuals' claims arose from their distinctive experiences and characteristics (points where this is the case are made clear in the text), and therefore it may be helpful to the reader to know a little about the participants as individuals. In cases where WITSENDO participants provided this information voluntarily, *without being prompted*, I include it in Appendix 4.

This brings me to my second reason for refraining from asking participants about their personal characteristics: a methodological and ethical one. I wanted to let the

participants decide which personal information they considered relevant and appropriate to share, because I was interested in the way *they* framed their accounts. I have summarized the information they included in their accounts to me in Appendix 4, but did not probe for other information. Endometriosis is a stigmatizing disease and some women would prefer not to have their personal characteristics revealed, as this could jeopardize their anonymity. Actually, I suspect that one of the reasons the WITSENDO list is so popular is that it allows members to conceal a great deal about themselves, to avoid thoroughly 'coming out' as women with endometriosis. In short, I abide by my participants' decisions about what they felt was relevant enough to include, and what they felt comfortable sharing. Again, this approach is appropriate to my focus on the ways in which patients *construct* their knowledge and themselves as knowers, rather than on the 'whole truth' (supposedly beneath construction) of their distinctive individual experiences.

I conducted the preliminary analysis of the focus group data first, in January and early February, 2000. Transcript files were imported into Atlas TI, a qualitative data coding and analysis software program. When I conducted the original analysis in the summer of 1994, I read through all the transcripts and coded as I read. I find that when I read and code in this way, I get caught up in the stories being told, rather than the rhetorical devices and strategies used to tell the story. This leads to a focus upon the actual experiences and events being narrated, rather than an epistemological analysis of the narration, which was my goal here. In order to focus my analysis and get a fresher look at the dataset, I conducted text searches for key words relating to the group members' search for and evaluation of endometriosis-related knowledge (see Appendix 5). I then read the surrounding passages, paying attention to 'knowledge words' that mark out claims and their justification, and representations of the speaker and others (particularly other patients

and doctors) as knowledgeable agents.

Prior to coding, I had a general sense of the participants' accounts based on my initial readings of them. However, this sense was too amorphous for translation into explicit coding categories. Rather, as I conducted the focussed reading, I developed short coding phrases that seemed to me to summarize succinctly the themes raised in the passages. Each passage of text was revisited multiple times, as different key word searches pointed to the same passages of text over and over again. Codes were modified and added throughout the process to better represent and summarize the data and group similar passages of text together, and the passages were recoded accordingly. Eventually I settled upon thirteen codes, deliberately broad, catch-all categories that generated a large number of text passages and ensured that every relevant passage could be marked for more detailed analysis (see Appendix 6).

The WITSENDO responses were coded in late February 2000, in a similar fashion to the focus group coding. However, because they comprised only 50 pages in total, I did not use the search function but simply attended to the use of the key knowledge words in the text. During the WITSENDO analysis I added an additional three codes, as it had become apparent that one of my original codes, Patient Knowledge, was too broad to be useful in analysis, having been assigned to over 200 passages of text in the focus group transcripts alone. This code was subdivided into three more specific codes, Evaluation (patients' evaluations and uses of their own or other laypersons' claims), Search (patients' descriptions of their attempts to find information), and Claims (substantive assertions made by the participants). I did not recode the Patient Knowledge passages from the focus group transcripts on Atlas TI because the program is not well-suited to the task. Instead, I recoded the Patient Knowledge quotations from the focus group manually, using

the three newly-created codes.

This process bears some similarity to the constant comparative method of grounded theory (Glaser & Strauss, 1967), in that the data themselves were used to generate codes, rather than developing codes *a priori* and then applying them to the data, and the coding process was not linear but involved movement back and forth between passages and modification of codes to better reflect similarities and contrasts in themes. However, theoretical relations between codes were not established at this time, as is customary when using the grounded theory approach; instead, relations emerged in the process of writing up the analysis. Moreover, in reading for specific issues (those concerned with knowledge and presentations of self as knowledgeable), I had some preconceived notions of the kinds of things I was looking for. Although unrelated elements of women's accounts did affect my reading, these data were glossed over somewhat during analysis. Indeed, it is difficult to conceive of a dataset which could 'speak for itself' on its 'own terms' to a researcher, without any of her particular interests and foci affecting what she 'hears' from the dataset.

The reading for certain key words and concepts was based loosely upon the voice-centred relational method outlined by Mauthner and Doucet (Mauthner & Doucet, 1998). They suggest conducting multiple readings for different voices in the text: first, a reading for the plot and the analyst's response to the narrative; second, a reading for the "voice of the 'I'", or the narrator's self-presentation as agential subject; third, a reading for the narrator's construction of relationships with others, to locate the narrator in relation to her immediate social network; and fourth, a reading for the broader social/structural context within which the narration is situated.

I conducted only one formal reading for this analysis. My initial readings

(conducted in 1994 and reviewed for this research) were not conducted specifically in terms of Mauthner and Doucet's method, but in retrospect, it is evident that they focussed on plot and broader social/structural constraints, particularly those concerned with gender. The formal reading for this analysis explicitly focussed upon three elements: (1) the narrators' presentation of knowledge claims; (2) the narrators' presentations of themselves and of medical experts as knowledgeable agents (or as non-knowers); and (3) the relational aspects of the narrators' accounts, focussing in the focus group upon the interaction of the participants and, in the WITSENDO accounts, on representations of the endometriosis patient community and the narrators' relationship to it. Plot, analyst response, and social/structural constraints seep into this reading, of course, but the main focus here was on narrators' epistemological representation strategies and their relationship to and representation of the endometriosis patient community and medical community.

This process of multiple, multifaceted readings, emergent coding, and constant comparison took significantly longer than if I had merely read through and coded the transcripts once using a preset coding system. However, it allowed me to modify the codes and check my coding of data over time to increase the degree to which the codes captured the themes I was seeing and the consistency with which I applied the codes; and the focussed reading drew my attention to additional themes and rhetorical nuances that I had ignored during my first analysis of the focus group transcripts (conducted in the summer of 1994).

Because the themes identified by the codes overlapped in most passages of text, most passages were assigned to more than one code. When the coding process was completed, all marked passages and their codes were printed out and reanalysed to

identify more specific subcodes for each code category. This more specific coding was done manually in March, 2000. A simple count for passages marked with each specific subcode was performed to ensure that subthemes that seemed most salient to me actually were raised frequently by participants in the study; while this does not mean that the codes I identified adequately 'capture' the 'truth' of the data, it did demonstrate to me that I had assumed that some themes were more prominent in participants' narratives than they actually were. These themes, while interesting, were not presented in this analysis because my concern here is to delineate what I see as the 'core claims' and main arguments of the participants as members of the endometriosis patient community.

Attention was paid to overlap in the codes to identify thematic correlations in participants' narratives, and to differences between WITSENDO and focus group narratives. The latter actually were rather minimal, suggesting that the findings of this study might be generalizable to active members of the venues of the endometriosis patient communities, whether these are online communities or face-to-face support groups. Particularly representative quotations from the focus group transcripts and WITSENDO responses were marked for use in the research report. Throughout, I kept careful records of my activities and my reflections about the coding and analysis process and the data themselves, which were used later in the research report. A report of the findings was sent by email to each WITSENDO participant and to the only member of the focus group with whom I am still in contact (efforts to locate the other focus group participants were unsuccessful).

III. Endometriosis Association Literature

The EA literature occupies a middle ground between the medical literature and the endometriosis patient accounts. It presents and incorporates both the medical community's representations of its knowledge and patients' stories about their experiences with their illness and the medical world, both in patients' own words and in statistical forms. Therefore, in addition to analysing the EA literature on its own terms, I used it to check that the basic themes I ascertained in my participants' accounts were reflected more generally in the larger endometriosis community, and to supplement my understanding of central medical claims about classification, psychology, and epidemiology (the EA literature compiles, summarizes, and analyses medical research in all areas of endometriosis and highlights existing controversies in the field). My analysis also concentrated on the EA's role in promoting traffic between these two kinds of accounts. As we see in Chapter 6, the EA's work can be read as an effort to bring medical experts and patients into dialogue with one another, to document the specific claims and concerns of each (but especially of patients), and to facilitate greater cooperation between patients and experts in the development of knowledge about endometriosis.

Most of the EA literature used in this study is available only to members, the vast majority of whom are women with endometriosis. I was a member of the EA from 1992 to 1994, and from 1999 to the present. In these periods I received fifteen EA newsletters, several brochures and letters, a copy of their newsletter for teenagers with endometriosis, and a monograph of the EA-organized brainstorming sessions held at the VI World Congress on Endometriosis. In addition, I ordered from the EA its two books (published in 1987 and 1995); audiotape sets recorded at the two EA conferences (held in 1990 and 1995); three newsletter issues from 1989, 1997, and 1998 which are still available for

purchase; eleven special collections (articles on particular subjects, compiled from previous EA newsletters); and five individual articles from early newsletters (1989 and 1991) that are available for purchase separately. In 1993-94, when I was conducting my MA research, I corresponded with Mary Lou Ballweg, President and Executive Director of the EA, and Barbara Mains, the EA's Canadian Projects Director. They sent me several published and unpublished papers they authored for the EA and their letters provided me with some very helpful information about the EA and its work.

In addition to literature provided by the EA, I conducted keyword and author searches on several databases (Current Contents, Medline, and Uncover) for the Association, Ballweg, and other prominent members of the Association likely to publish journal articles; I conducted Internet searches; and I looked for contributions by the EA in medical texts on endometriosis. The latter were particularly useful in uncovering sources written by the EA and geared toward medical audiences, and thus were crucial to my analysis of the EA's efforts to recruit the support of such audiences. (The majority of literature provided to EA members is geared toward patients.)

I contacted the EA in late 1998, described my research, and invited the Association to participate. I hoped to conduct key informant interviews with Ballweg, other executives of the EA and some of the Association's medical advisors about the EA's work, its struggles to balance its work as a grassroots patient organization with its attempts to gain entry to the medical research establishment, and its medical advisors' perceptions of the EA and its effects on medical thought and practice. The initial response from the EA was enthusiastic and a copy of my research proposal was requested (which was sent to the EA in March 1999). However, the Association did not respond despite several follow-up efforts on my part. The administrators of the EA are extremely busy women and a variety

of new, time-consuming projects are underway. I suspect that these factors, rather than a discomfort or lack of willingness to cooperate with my research, account for the administrators' failure to respond²⁸. Regrettably, in order to complete the thesis in a timely fashion, I had to limit my research on the EA to an analysis of my supply of their literature--which, however, was ample and provided a great deal of information about the EA's activities.

The analysis of the literature involved a critical reading for the EA's efforts to build a network and recruit supporters among endometriosis patients and medical professionals, and the ways it attempts to reconcile the apparently different epistemological perspectives of these two communities. My analysis was framed by the EA's own tripartite description of its activities as directed toward education, support, and research, and also by my interest in the two epistemological communities of endometriosis patients and medical professionals. As a result I investigated each of the EA's three types of activities in terms of how they were used to enrol patients and/or medical professionals.

I first studied the EA's network-building efforts in regard to patients. I analyzed EA literature designed to recruit new members: the EA website; its basic yellow brochure, "What Is Endometriosis?" (Endometriosis Association, 1992 {1980}); and the package that it sends to people who express an interest in the EA, which includes a booklet describing the EA literature. I also analyzed EA literature for existing members, particularly its newsletters and its two books. The focus here was to determine how the

²⁸This impression is based upon the fact that, several months after I submitted the proposal, the EA contacted me on multiple occasions to join a small, by-invitation-only delegation of EA chapter leaders, administrators and researchers, led by Ballweg, to tour China and meet with medical professionals and endometriosis patient-activists. This would have been an excellent opportunity to observe the EA in action, so to speak, with medical experts and patients. Unfortunately, due to financial constraints, I was unable to attend.

EA represents endometriosis patients, and how it represents itself as an obligatory passage point for patients: how it constructs the problems encountered by endometriosis patients; the ways in which it suggests that joining the EA and interacting with other patients can solve those problems; the EA's construction of endometriosis patients as epistemological agents and of patients' experiential claims (drawn from letters written to the EA and its own research on patients) as bona fide knowledge; the EA's representation of medical knowledge to patients; and the ways in which the EA 'sells' itself to patients, particularly through its accounts of its research work, as a reliable and essential claims-maker. In short, I was interested in the EA's efforts to represent endometriosis patients as epistemological agents who both benefit from, and help to create, the EA's own claims about endometriosis, medical professionals, and endometriosis patients.

Second, I analyzed the EA's efforts to enrol medical professionals. My ability to do this was limited to the extent that most of the EA literature at my disposal was written for patients and thus represented *to patient-members* the EA's network-building with medical professionals. However, there were several advantages in accessing the EA's network-building accounts through this kind of literature: literature written for patients that describes the enrolment of physicians contained, I think, more frank evaluations of medical professionals' receptions of the EA as a claims-making organization and more critical evaluations of the medical research establishment than would be found in literature written for professionals. So the patient literature describes problems encountered by the EA in educating medical professionals and doing its research that likely would not appear in literature geared toward the professionals the EA is seeking to enrol.

However, I did locate several pieces written by Ballweg and others associated with the EA that were written expressly for medical professionals. Several of these were

provided by Ballweg herself. These pieces allowed me to draw some conclusions about the methods by which the EA tries to represent itself as a valid research establishment and claimsmaker to appeal to medical professionals; how the EA constructs medical professionals, endometriosis patients, and their differences and shared interests to medical audiences; and how the EA attempts to challenge and change physicians' behaviour toward patients through appeals to science, professional ethics, sociopolitical arguments, and physicians' sympathy for patients' suffering. Key to this were the ways in which the EA deploys constructions of endometriosis patients, just as constructions of medical professionals are key to the EA's enrolment of patients.

Entering the EA literature into Atlas TI was prohibited by the cost of scanning equipment and the immense time necessary to copy the literature into the computer by keyboard. Instead, relevant passages and articles were marked with colour-coded tags and highlighters to reflect four research themes: the EA as research establishment; representations of endometriosis patients and their knowledge; the EA as conduit between patients and medical professionals; and the EA as evaluator of medical claims. This facilitated data retrieval in each kind of literature (that geared toward patients and medical professionals).

VI. Reflections on the Research

The most original empirical contribution of this study was its presentation and analysis of patients' accounts about what and how they know. This component of the thesis were the most challenging and interesting methodologically and ethically because it involved the generation of new data, and it engendered the most reflection on my work as a researcher. Therefore, it is the main focus of this section. Nevertheless, some brief

comments about my analysis of the medical and EA literatures are required.

As these literatures were not original sources of data and I was not involved in their production, I cannot comment on their conditions of production. For researchers less familiar with the science of endometriosis and the work of the EA, the type of content analysis in which I engaged could pose some significant challenges. In this kind of research, it is essential to have a strong background in endometriosis science. Based upon my quite extensive knowledge of the medical literatures on the classification, psychology, and epidemiology of endometriosis, and of the EA literature (supplemented by extensive, past communications with EA executive members), I am confident that the samples I chose are quite representative of the larger literatures and of the knowledge-work of each community in the areas under investigation.

One limitation of my analysis of both the EA and the medical endometriosis community was that I relied upon analysis of the *literatures* they produced, rather than conducting original research (for example, through interviews with the EA executive and medical professionals, or observations of personal interactions within the EA or within the medical community). Such original research undoubtedly would have generated additional insights about the workings of the EA and the medical community in developing and representing knowledge and knowledgeability, insights that may have differed significantly from those provided by an analysis of the literatures. I have explained my reasons for relying upon EA literature. Financial resources and a need to limit the scope of the research did not permit travel to medical conferences or meetings of professional associations.

Nevertheless, focussing upon the publications of the medical community and the EA is a good way to examine the means by which their members formally represent their

knowledge and ways of knowing to both other members and the general public--the self-conscious ways in which they construct themselves as knowers and wish to be perceived by others. Even in these formal, calculated communications, both the EA and members of the medical community demonstrate illogicalities, conflicts, and diversity in their claims and ways of knowing. Reliance on the literatures, then, still allowed demonstrations of the complexities and contradictions of knowledge- and boundary-work within these two groups, and need not result in an overly simplistic, monolithic presentation.

I have explicated the processes by which I analysed these literatures, and believe that my analysis is a fair one. However, I acknowledge that my presentation is necessarily partial and selective, given the enormity of these literatures, and that my interpretation of them may be contestable. While my presentation does not exhaust all that could be said about them, I believe it does identify some of their most common and forceful themes, themes that are particularly relevant to the demarcation of 'official' expert knowledge from lay 'claims', to the contestation of that demarcation, and to the construction of the conditions and subjects of knowledgeability which are the concern of this study.

Now, to turn to the main focus of this section: my reflections upon the conditions of production and analysis of the original data developed with the focus group members and WITSEND0 participants. Before I discuss issues specific to each of these two prongs of the research, I make a few general comments that apply to both.

My concern here is not to generate generalizable data representative of all women with endometriosis. Qualitative analysis is very time-consuming and the data are difficult to manipulate into discrete categories; therefore the size of the sample must be limited. The larger the sample, the more participants' perspectives must be boiled down (usually into statistics) in order to construct, manage, and analyze the data effectively. Thus

quantitative studies generate etic data, that is, data determined by the researcher's categorizations and concepts. My aim here was to generate emic data, which gets at the perspectives of the researched.

All data gathering and analysis requires the reduction of the complexity of participants' minds and lifeworlds, and requires the researcher to interpret participants' representations. While my original analysis of the focus group data, conducted in 1994, was done in consultation with the participants, they did not participate in this analysis; nor were the WITSEND0 participants consulted during the analysis process. While my intimate knowledge of the endometriosis patient community suggests to me that my analysis of its main claims and critiques are just, I cannot be sure that the participants would agree with my analysis--especially since they, like most people, do not dissect their claims epistemologically on a routine basis and likely would view such dissection as a challenge to their status as claimsmakers--a status which is already challenged by medical experts.

Nevertheless, I do feel strongly that this qualitative study and analysis is less removed from the perspectives of the participants than would be the case if I had used, say, a questionnaire that forced participants to employ a Likert scale. My request for WITSEND0 participants' 'endo stories', my use of open-ended questions, and the free-flowing, relatively undirected conversation that occurred in the focus group all meant that, to a great extent, participants could choose what they wanted to say--though I, of course, chose which elements of what they said would be represented in this text. But providing extensive quotations from participants' accounts allows them, to some extent, to 'speak for themselves' and allows the reader to draw her own conclusions about whether or not my analysis of the presented quotations seems fair. Thus, qualitative analysis

allows for *less* flattened representations of, and more in-depth investigation into, the ways in which people make sense of their lives, although it cannot capture them entirely. This is especially true in this study, in large part because--as I have argued--much of the way women with endometriosis make sense of their lives is based on embodied sensation and cannot be transmitted through language.

My core claims in this work are that knowledge is a product of communities, not individuals; that medicine is not less 'social' than other forms of knowledge creation; and that demarcations between expert and lay knowledges are not only social creations, but weak ones given that endometriosis patients, clinicians, and medical researchers use the same resources in constructing their claims. Therefore it would be quite ridiculous of me to use the same demarcation practices here to assert that my research is scientific in the sense of unbiased, free of the 'corrupting' influences of my own assumptions about endometriosis, medicine, patients, knowledge, and the social world, or the assumptions and standards of those in my own network. In deference to disciplinary conventions, I discuss the ways in which my research does not meet the requirements of science; not because I want to argue that sociological research necessarily *should* meet these requirements, but because disciplinary conventions frame research within the discipline and therefore must be taken into account.

My research with the focus group and the WITSENDO participants is qualitative and exploratory, seeking to develop detailed analysis of the epistemological standards and self-presentation of 24 women (6 focus group members and 18 WITSENDO participants) who are active members of an endometriosis patient community. Because participants of both the focus group and the WITSENDO research were self-selected, they very well may have unusually strong opinions on the issues addressed in the research, and may not be

representative of women with endometriosis as a whole. I did not study the perspectives of women who are not active in the endometriosis patient community; because they are not active in it, they are not members of the endometriosis patient community as I describe it. It would be most interesting to compare the views of women who have endometriosis but do not engage in the patient community with active community members, to elucidate the difference that being active in the community makes to the claimsmaking practices of women with endometriosis. But the focus of this study is to compare the claims and epistemologies of the medical community and the endometriosis patient community, and in this study I present the claims of women who participate in several venues of the patient community: the WITSENDO list, the Winnipeg patient support group, and the Endometriosis Association.

The accounts of the WITSENDO and focus group participants are remarkably consistent, and in turn they are remarkably consistent with patients' accounts in the EA literature. Most of the core claims I identify in my participants' accounts (especially claims about doctors) strongly reflect the findings of studies carried out by the Endometriosis Association on several thousand women with endometriosis (Ballweg, 1998a; Lamb, 1987; Lamb, 1990) and of other studies (Halstead, Pepping, & Dmowski, 1989; Insight Canada Research, 1993). Whether this consistency is construed as evidence that the 'actual' experiences and perspectives of women with endometriosis have been well-described, or as an artefact of an emerging consensus (among researchers and patients) about 'the endometriosis patient experience', depends upon whether one is an adherent of social *science* or social *studies* of science²⁹. In any case, it seems--given the consistency of

²⁹That is to say, those who adhere to a social *science* perspective likely would take the replicated results of studies of women with endometriosis as evidence that these women's actual experiences and perspectives have been described accurately. Those who adhere

the claims made by the WITSEND0 participants and the focus group members, the accounts by patients presented in the EA literature, and the EA's own research on patients' views--that my findings may be generalizable to active members of the endometriosis patient community as a whole. This impression also is supported strongly by my own observations as a member of the endometriosis patient community: by my casual readings of EA literature, my involvement in the Winnipeg patient support group, and my reading of postings to the WITSEND0 list over the course of three years³⁰. Further research would be necessary for formal confirmation of this impression. However generalizable the findings from my sample of focus group members and WITSEND0 participants, I think that these women's accounts are exceptionally rich and interesting; that they provide some extraordinary insights about the production, justification, and evaluation of lay and expert knowledges (and of laypeople and experts as knowers); and that this makes them worthy of study.

to a social *studies* of science perspective likely would question how actuality and accuracy are defined and constructed in the studies and in social scientists' evaluations of them, and would want to examine how (and whether) a consensus about 'what women with endometriosis think' develops within the network of patients, researchers, and evaluators.

³⁰Originally, I had planned to include excerpts of posts to the WITSEND0 list in this thesis. Strictly speaking, the posts are public documents as anyone may subscribe to the list. However, the listowner claims copyright and I did not wish to contest this as she has been most helpful in the recruitment of participants from the list. Furthermore, the women on the list conceive of it as a private community of sufferers and write their messages accordingly, not as potential contributions to a research report. For these reasons, I felt ethically bound not to use these posts in the thesis, however much doing so would have expanded my pool of participants and strengthened my claims about the generalizability of my findings.

1. The Focus Group Research

There are three main issues I wish to address in this subsection: my reasons for choosing the focus group method, my unorthodox degree of involvement in the focus group discussions, and the challenges posed by the reanalysis of the dataset.

The focus group method was an excellent choice for several reasons. First, it enabled me to collect a great deal of data in a relatively short period of time. Conducting interviews with six women at once, I was able to ask a large number of questions over nine sessions in about the same time as it would take me to ask a few questions of each participant separately in one-time interviews. It also allowed me to revisit and clarify themes raised in previous meetings that seemed particularly interesting. Arranging and conducting follow-up interviews with individual participants would be very time consuming.

Second, I assumed (correctly) that the method would be more beneficial to participants than individual interviews. In fact, I underestimated the degree to which it would be beneficial to them. It allowed them to meet and share experiences, coping strategies, and frustrations. Focus groups can provide a more egalitarian and comfortable setting for participants than individual interviews because they dethrone the researcher as the director of the interview. Instead, the discussion is more free-flowing among participants, most of whom are not researchers. The researcher is outnumbered by the participants, who often share a common bond and may know each other prior to the research (Wilkinson, 1998). The women in this focus group knew each other through their involvement in the Clinic support group, although to varying degrees. Two of the participants were fast friends and their co-presence, I am sure, accounts for their immediate ease in the focus group discussions; the other members took somewhat longer

to exhibit this degree of comfort, but this did not take long with the two friends as ice-breakers. If these two friends had behaved in an exclusionary way toward "outsiders," the group atmosphere could have been quite uncomfortable for the other group members.

However, the shared experiences of the group members (all were women with endometriosis; all were members of the support group; all had used GnRH agonists; all had chronic pain)--and the fact that the group discussions were *about* those experiences--facilitated a real sense of friendship and solidarity that would be harder to achieve with a more heterogeneous group of people.

While all participants were already members of the Clinic support group, that group was quite large and did not admit of a great deal of intimate conversation among members. The focus group meetings were intimate in that there were only seven women in the room; and they were carried over nine weeks, which allowed for the sharing of much information and support between participants and the development of familiarity and a comfortable atmosphere. This focus group came to resemble the consciousness-raising groups of the second-wave women's movement, as apparently many feminist research focus groups do (Wilkinson, 1998). Every group member told me that they found the meetings validating, informative, and empowering. These benefits should make the method particularly attractive to feminist researchers and others interested in making their research relevant and empowering for participants; indeed, Sue Wilkinson makes a strong case that the focus group method meets the ethical and political aims of feminist research better than any other method (1998).

Third, the method allows for what Wilkinson (1998) calls the co-construction of meaning: the group development of perspectives about the social world. I was able to witness and participate in the emergence and refinement of group claims. This was

exciting in the original research, though not strictly necessary, since the original study was about individual women's experiences with GnRH agonists, medical professionals, and information-seeking. The data this approach generated were exceptionally valuable because the present study is concerned precisely with the ways in which women with endometriosis form and advance claims *as a community*. One focus group member raised a comment, and this generated new insights and analytic discussion among the other group members. Because of this synergism, the level of participant reflexivity, data quality, and analytical sophistication reached in focus groups can be extraordinary, strengthening the researcher's analysis and facilitating participants' involvement in that analysis (Wilkinson, 1998).

Despite these benefits, until quite recently the focus group method has been used infrequently in sociology (Morgan, 1998:39-42). The focus group method was developed by sociologist Robert Merton, who published an article about it in the mid-1940s (Merton & Kendall, 1946). However, from the 1950s through the early 1980s, it was used almost exclusively as a marketing research tool (Morgan, 1998:39).³¹ In fact, Merton developed the method as a means of evaluating audience reaction to radio programmes (Stewart & Shamdasani, 1990). As a marketing research tool, the focus group method historically has been more concerned with selling products and services than with meeting either of the primary aims of sociological research--to contribute to an understanding of social life and/or its amelioration (Chadwick, Bahr, & Albrecht, 1984:21). This partially explains its

³¹In the mid-1980s, a handful of social scientists began to publish on focus group methods (Morgan, 1998:42), and in the late 1990s, it was estimated that approximately 100 social science journal articles a year were reporting on focus group research (Morgan, 1998:42)--although of course this is still a small number compared to the number of social science publications that report on interviews or questionnaires. Several guides to focus group research written by social scientists are now available (eg. Krueger, 1994; Morgan, 1997; and the six-volume set edited by Morgan & Krueger, 1998).

traditional underutilization in sociology.

Another potential reason for the method's lack of prominence in sociology is the discipline's attempt to model itself after the natural sciences. The focus group method, like other qualitative methods but to perhaps a greater degree, does not meet the established criteria of reliability or generalizability well and troubles the notions of researcher objectivity and detachment, especially in focus groups in which the researcher is an active participant in the discussion. However, given the movement of feminism, social constructivism, discourse analysis, and poststructuralist perspectives into mainstream sociology, concerns about making one's research 'scientific' (and traditional definitions of what it means to be scientific) increasingly are being questioned (Wilkinson, 1998). Furthermore, social studies of science--the central theoretical piece of this project--has demonstrated effectively and forcefully that the demarcation between scientific and non-scientific claimsmaking practices is not so clear after all, but must be elaborated and enforced.

A more important reason for sociology's underutilization of the focus group method is a fear that participants will play 'follow-the-leader': that one particularly assertive group member may dominate the discussion and other, less assertive members may simply echo her response or remain quiet, making the apparent consensus that emerges somewhat artificial and effectively silencing certain voices. This was a concern in my focus group research, as one participant in particular clearly felt less comfortable expressing opinions that contradicted those of other group members. However, this effect can be minimized with appropriate moderation. In the focus group, I was careful to provide opportunities for everyone to speak to each topic of discussion; to intervene when a member was interrupted; to vary the order in which participants spoke, so that more

dominant members did not always speak first; and to encourage the expression of conflicting opinions, for example by pointing out the importance to the research of establishing differences among participants, expressing support and appreciation for different perspectives and experiences, and encouraging other members to do the same. Because the focus group members demonstrated such affection and concern for one another, I did not have to intervene very often.

In a rare feminist discussion of the focus group method, Sue Wilkinson (1998) asserts that a primary reason for feminist social scientists' neglect of the method has to do with common conceptions of the individual as the agent of knowledge. Feminist and non-feminist researchers often share the opinion that the presence of the researcher (let alone other participants) 'pollutes' the findings. This is an essentialist position, Wilkinson argues, because it promotes a conception of knowledge as an essence that must be 'extracted' from individuals with as little 'corruption' as possible. Against this, Wilkinson adopts a social constructivist position which conceives of knowledge as *always* constructed in and through social interaction. Because focus groups enable the elaboration of meaning in a social context, they are particularly useful for observing the *process* by which knowledge is constructed in social interaction. As such, she expresses disappointment with the tendency of focus group researchers to present their findings as excerpts from individual participants, and makes a strong case for paying attention to the interactional components of focus group discussions.

I have provided some excerpts from the focus group discussions that are indicative of the ways in which these women interacted with each other, evaluated claims, minimized conflict, and produced consensual accounts of their experiences. However, I rely most on individual participants' comments for three reasons: concision, comparability, and the

focus of the study. First, quotations from individuals provide more succinct demonstrations of the substantive trends I recognized in the discussions than do long excerpts involving several participants. Second, my research on the EA and the medical community and with individual WITSENDO participants did not permit observation of group interaction, but only of the group and individual claims advanced. To ensure methodological commensurability with these other sources, I focussed upon the communal and individual *assertions* (substantive claims and claims about knowing) made in the focus group, not the interactional processes associated with those assertions (though I discuss these to an extent). Third, and relatedly, my goal was not to examine interaction among women with endometriosis as such, but more the *results* of that interaction--the core claims, standards, and strategies for knowing which are held by members of the patient community, by virtue (I argue) of their participation in the community, and to compare these with the core claims, standards, and strategies espoused by members of the medical community, by virtue of *their* membership. It would be extremely interesting to conduct a study of the actual interactional processes of women with endometriosis, and a study comparing these and the actual interactional processes in the medical community. While these are not the focus of this necessarily limited project, they would complement it nicely and provide directions for future research.

I participated very actively in the focus group research, offering my opinions and arguments along with the other group members. According to methodological orthodoxy, such an approach should be avoided because it runs the risk of unduly influencing participants' responses. However, I would argue that this objection exaggerates the degree of awe in which research participants hold sociologists, especially sociologists who share many characteristics with the participants (in this case, I, like the participants, was a

white woman with endometriosis). Perceived common bonds go a long way toward reducing the investigator effect. Moreover, the participants in this focus group were assertive women who proved themselves both willing and able to contest my claims and interpretations and assert their own. My status as a young female student plagued by insecurities about my limited research experience (which I expressed frankly to the group) probably made me a particularly unthreatening interviewer. Had an older professor conducted the research, I suspect the participants would have been more deferential toward the researcher, but also potentially more hostile (especially if the researcher was a man since "men do not understand"), and certainly much less likely to share the intimate information and perspectives they shared with me. Moreover, I would argue that the researcher's own willingness to discuss her experiences and perspectives establishes in the group an atmosphere of openness and trust that a more reticent researcher would inhibit. Why should participants share intimate information about themselves if the researcher does not reciprocate?

Furthermore, ethically I felt obliged to participate in the discussions. As an endometriosis patient, medical sociologist, and women's health activist, I possessed information that I felt would be of use and interest to the focus group participants: information about GnRH agonists, the pharmaceutical industry's influence over medical research and the drug approval process, gynecologists in the area, and my own experiences with treatments for endometriosis. I also introduced sociological concepts and contemporary and historical research on women's health and gynecology to the group, in order to explain how I was analysing the discussion. The group members provided critical feedback that strengthened my analysis by ensuring that my misapprehensions of their perspectives were corrected and that my analysis was

relevant to the issues they faced.

These women clearly found each others' accounts of their experiences with GnRH agonists most useful (I had not used the drugs myself). However, it was evident that my contributions to the discussion were useful to participants in that they encouraged them to think more analytically and reflexively about their own experiences by placing them in a broader social context. For example, because I discussed with the participants my readings of feminist literature regarding the historical psychologization of women's reproductive health problems, several participants noted that they felt better able to resist the label of hypochondriac that their doctors were applying to them, and to think of this labelling process as a broader cultural problem that could only be solved through social action. During the focus group meetings, four of the six participants became engaged in endometriosis activism projects to educate patients and physicians, and to develop new models for endometriosis treatment that addressed women's psychological needs without dismissing their suffering as psychogenic.

Moreover, all of the women in the focus group, like many other women with endometriosis, have faced delegitimation and a lack of understanding and sympathy from physicians and laypersons who do not suffer from endometriosis, including in many cases those nearest and dearest to them. As a result, these women shared a strong sentiment that the only people who could truly understand their thoughts and feelings were other women with the disease; hence their involvement in an endometriosis support group. Being frank about my experiences and attending the larger support group meetings as a woman with endometriosis made me a member of the group, rather than an interloper who could not understand their experiences. In immersing myself in the group, I gained a richer understanding of their perspectives than would have been the case had I remained a

more disinterested observer. Over the course of several months, the focus group members became close friends, creating an atmosphere of openness and support that prompted them to share extremely personal insights and experiences. This not only generated some rare and excellent data, but made the experience more rewarding for the participants as well.

For these reasons I have no regrets about the participatory role I took in the focus group sessions though, certainly, it could be argued that my role influenced the responses. But it seems likely that the self-presentation and personal characteristics of any researcher will have a bearing on participants' statements. In this case, I would argue that my self-presentation and personal characteristics generated better data than could have been generated by a 'detached' observer and non-endometriosis patient, who simply would not be able to gain the same level of trust from these women.

The issues raised by reanalysis of the focus group data may be more problematic. Secondary analysis of qualitative research is rare but gaining credibility, as reflected by the establishment of the Qualidata archives at the Economic and Social Research Council in the UK (Heaton, 1998; Mauthner, Parry, & Backett-Milburn, 1998). Reanalysis has several benefits. Most obviously, it benefits researchers by eliminating the considerable work involved in the collection of new data, saving time and research costs (Heaton, 1998; Szabo & Strang, 1997). It also reduces the burden on participants (Heaton, 1998; Szabo & Strang, 1997). Let us not forget that it is an imposition to ask participants to take part in our research, from which they often derive few personal or tangible benefits. Women with endometriosis who are dealing with chronic pain and/or infertility, on top of family and work responsibilities, have stressful lives and often little 'well time.' If multiple analyses of one dataset can achieve comparable results to new studies, each of which demand time and energy from participants, we ought not impose on participants further.

However, several concerns about reanalysis of qualitative datasets have been raised. One concern has to do with whether or not participants consented to reanalysis of the data, and whether or not confidentiality agreements can be respected if the original researcher does not conduct the secondary analysis (Heaton, 1998; Szabo & Strang, 1997). These concerns do not pertain here because I was the original researcher and no new individuals had access to the dataset; and in the original consent agreements I made provisions for subsequent publication of the data (with the usual guarantees regarding concealment of participants' identities).

Also, it has been argued that secondary analysis of an existing dataset can entail loss of information about the context of the data's production (researcher biases, methodological protocols, and so on). Usually this concern is raised when secondary analysis is not conducted by the original researcher, so it has been argued that it is important to obtain such information from the original analyst (eg. Heaton, 1998; Szabo & Strang, 1997). However, Mauthner and colleagues (1998) question the assumption that, if the original researcher can provide the 'background information' about the study, the epistemological problems associated with the use of old datasets can be solved. They argue that this assumption derives from a "naively realist" position that treats data and background information as discrete (though related) entities, and that assumes that 'raw' data retain their meaning when separated from the context of their production. Instead, they assert, data are only meaningful within the context of their production; the data are never raw but always already formulated through the researcher's ideational framework and the interaction of researcher with participants. Thus context cannot be set aside as background information but *constitutes* the data; with this I absolutely agree. Not only is this an issue when a new researcher analyses an existing dataset, they argue, but also when

a researcher revisits her own data. In reanalysing their own datasets, Mauthner and colleagues encountered several difficulties, which I use to evaluate my own reanalysis of the focus group data.

First, Mauthner and colleagues felt they had moved on from their previous substantive, theoretical and methodological positions, such that their old dataset was less germane to their concerns than when they originally conducted the research. Certainly in my reanalysis of the focus group dataset, I felt that, to some extent, I had moved beyond the concerns and theoretical preoccupations that framed the original research. In designing the original research, my main concern was to document women's 'experiences' with medical professionals and GnRH agonists. Although I had struggled theoretically with the notion of experience for some years before I conducted the focus group research, I set those concerns aside for the focus group research because it seemed to me (and still does) that deconstructing the notion of experience is politically and ethically problematic for feminists because it can be seen to undermine the main justificatory foundation that laywomen with endometriosis possess.

I could not solve this problem, but my reading of social studies of science helped me recontextualize the problem in a new way: to examine the workings of justification strategies, rather than evaluate the truth of the claims they produce. So this work skirts around the problematic of how to justify women's claims while recognizing the theoretical limitations of the notion of experience. Instead, I explore how women themselves use combinations of 'science' and 'experience' to justify their claims, and how medical experts delegitimize them and make other claims using the same two resources. As Dick Pels (1996) has pointed out, this kind of 'symmetrical' approach has the (for me, desirable) effect of reducing the apparent differences between, and thus equalizing the relative power

of, expert and lay claims. Nevertheless, my discomfort about deconstructing women's experience remains, because I know full well that women with endometriosis may be offended by such deconstruction given their commitment to an experientially-based epistemology.

So originally, I focussed primarily on the substantive content of women's accounts, not on the way they created those accounts and used them to assert their status as knowledgeable agents. However, in the *course* of the research I became interested in precisely those questions: in exploring how, as groups, women with endometriosis make, evaluate, and justify knowledge claims, deploy the notion of experience, and so on. It was this focus group research that *generated* these interests because the focus group meetings were exemplars of this process of group knowledge construction, evaluation, and justification. So in my case, *contra* Mauthner and colleagues, there was no sharp transformation in my thinking *after* the research that made reanalysis difficult; rather, the research process itself effected the transformation as I was conducting the study. My subsequent reading and thinking changed the way I read the focus group transcripts, but I would argue this is the case to some extent whenever one analyses one's data, unless one exists in a mental vacuum throughout the data collection and analysis stages.

Second, Mauthner and colleagues felt they had experienced "a loss of privilege and closeness" from their fieldwork and the perspectives of the participants. I actually found that rereading the transcripts and listening to the tapes brought back extremely vivid memories, such that I could recall almost verbatim comments that the participants and I had made before I encountered them in the transcripts and audiotapes. The focus group research was the most powerful and memorable research experience I have had; it was my first serious engagement in feminist research and the study in which I had, by far, the

closest relationship with the participants. I am still in regular contact with one focus group member, with whom I have been reminiscing about the focus group meetings since I began the reanalysis. Maintaining this connection makes the focus group dataset perhaps a less remote experience than the original research of Mauthner and colleagues was for them. Moreover, my own status as a woman with endometriosis (a permanent identity, since endometriosis is incurable) means that I continue to be extremely interested in the disease and in other women's experiential accounts about it. It also means that their accounts continue to resonate for me, because I recognize in many of their assertions my thoughts and feelings about my own experiences. As a woman with endometriosis, I too have an experiential narrative about the disease; as a member of the endometriosis patient community, my experiential narrative is influenced by the narratives of other patients.

Nevertheless, as a secondary analyst I did have a greater critical distance than was possible when I was conducting the focus group research. At that time, I was a very active member of the endometriosis patient community, attending endometriosis support group meetings, sitting on committees and making presentations as a representative of the community, and my perspective was basically commensurate with the other members of that community. Certainly, I would not argue that my now greater detachment from the community makes me a more 'objective' analyst, but it did enable a somewhat *different* reading of the focus group dataset. My memories of the events are not identical to 'the experience itself, though they are vivid; and my current interpretation of the focus group discussions is different than it was when I first conducted the research. But I think the notion of 'the experience itself' is contestable, and the distinction between memory and experience, or between original interpretations and later ones, is not as clear as Mauthner and colleagues imply with their concerns about detachment and loss of privilege. While

one's interpretation of narratives changes over time, experiential narratives always are perspectival, not exhaustive of others' interpretations of events (nor of the possible range of interpretations that one may make of one's own experience). Therefore it is problematic to suggest that the original interpretation of participants' narratives or a given research experience is 'closer' to those narratives or that experience than a secondary analysis of them; the interpretations are simply different. All analyses are interpretive readings of other people's words, whether they are conducted the same day or years later.

Third, Mauthner and colleagues expected to find data that were missing from the datasets. "[T]he data could not supply the answers to questions that had never been raised"; and while, upon revisiting their previous research, analysts may see new themes and emphases, "these would remain as issues which had not been followed up or explored" with the original participants (1998:742). My focus group dataset was extremely well-suited to the reanalysis; indeed, my reanalysis emerged because of the observations I made during the focus group research, such that the new questions emerged directly from the old answers.

Still, during the reanalysis, I did have some new questions that could not be asked of the focus group participants, and the focus of the original research upon GnRH agonists meant that some of the participants' comments were restricted to knowledge about those drugs, rather than about endometriosis knowledge in general (the focus of the present project). As Mauthner and colleagues point out, these are real limitations. However, despite the focus on GnRH agonists, the participants often discussed in a more general way the problems they faced in developing, finding, evaluating, and using information about the disease; in approximately 16 hours of broad-ranging discussion, these issues came up very frequently. Moreover, it strikes me that whenever one analyses an interview

transcript, whether the interview was conducted yesterday or five years ago, new questions always arise because we engage with the data and think about it. This is a never-ending process, such that no matter how many follow-up interviews one conducts, each new interview generates more questions and lines of inquiry. So I think the concerns that Mauthner and colleagues raise in regard to reanalysis of old data are unavoidable conditions of research, not distinctive to reanalysis though perhaps exacerbated by it, because the longer the intervening period between research and reanalysis, the more new questions one has the opportunity to think up.

Further, while Mauthner and colleagues correctly note that data cannot "move on from or elude the conditions of their production" (ibid:742), it is precisely those conditions of production in which I am interested in this reanalysis. It is true that I was frustrated at times by the fact that in the original research, I did not ask questions that I would ask now, or asked the questions in an order or a way that I would not now. For example, the order of the questions placed the focus on GnRH agonists specifically--a decision made at the time to give the participants a chance to 'get their feet wet' with more concrete, focussed topics before the discussion ranged to more abstract issues, as well as to reflect the focus of the research, GnRH agonists. This discussion about the (as it turned out) horrendous experiences these women had with the drugs may have affected their later, more general claims about medical treatment and the doctor-patient relationship.

Yet, the current analysis is concerned in a more general way with how the focus group members, as members of the endometriosis patient community, made claims; whether our specific claims (about GnRH agonists, for instance) represented or drew upon larger 'core claims' within the endometriosis patient community; and how we justified our claims. The dataset served these purposes very well; and I am not convinced that, in these

respects, the results would have been very much different if the focus group had been talking about surgery instead of drugs, or about general issues first and more specific ones later. This is especially so since the very unstructured WITSENDO participants' statements are so comparable to the focus group members' ones; the specific statements seem to be based on more general ones that women in the community share.

Furthermore, the epistemological position I adopted during the original research was quite commensurate with that of the other focus group members (women's experience is a valid form of knowledge), and I was quite firmly entrenched in the endometriosis patient community when I conducted the research. As a result, the dataset that was produced was I think quite illustrative of the endometriosis patient community's standpoint epistemology and the broad kinds of claims it makes.

It may be impossible to answer new *substantive* questions through reanalysis (given that the claims and answers produced are constituted through the conditions of their production, by the questions asked). But I think it is possible to use secondary analysis to look at the *epistemological construction* of the substantive answers given in the original research. Epistemological construction is a condition of claimsmaking. And it is in that construction--of women making and evaluating claims about endometriosis, doctors, and their own experiences--that I am interested here. The main substantive claims I am making here are about this epistemological community, not about women's experiences as such. Rather than secondary analysis of original research, then, this analysis is perhaps better described as an analysis of the conditions of possibility of the original dataset, and of other datasets produced by women with endometriosis--a new analysis at another level, rather than a reanalysis at the same level.

Finally, Mauthner and colleagues perceived in their original datasets and analysis

positivist elements and concerns about presenting themselves as objective researchers, despite their professed concern with reflexivity. They note that even researchers committed to relativist, constructivist, or reflexivist positions may conceive of their active role in the research as "guilty secrets, and as a product of personal failure, rather than as essential parts of the research" (Ramazanoglu cited in Mauthner, Parry & Backett-Milburn, 1998:741). Certainly I share these misgivings about my early research, and about this research as well. But I think there is a danger of making our positivist leanings another guilty secret. Instead, we can understand this ambivalence not as something to be overcome, as Mauthner and colleagues suggest, but as *a condition of disciplinary knowledge production*. Sociology as a discipline is characterized by a long-standing conflict between scientific and hermeneutic traditions, and as such, it compels its practitioners to answer to both traditions in their work and to defend their preference for one or the other. While I, like Mauthner and colleagues, favour the hermeneutic tradition over the scientific one, as practitioners within the social sciences we necessarily engage with both traditions. The conditions of disciplinary production are what make knowledge creation possible; they should be conceived of not as constraints or guilty secrets, but as constitutive elements of the field of research.

2. The WITSENDO Research

While much research is being conducted over the Internet these days, Internet-specific research methodology is not yet well developed and published discussions are scarce. As a result, Internet researchers still are feeling their way with little direction. However, authors have identified several benefits to conducting research on what Kaye and Johnson (1999) call the "cyber frontier". First, there are clear benefits to the

researcher (Chen & Hinton, 1999; Coomber, 1997; Kaye & Johnson, 1999; Oppermann, 1995; Selwyn & Robson, 1998). The method reduces interviewer effect and prevents the researcher from interrupting, taking over the conversation, or unduly biasing the participant's response--all of which were concerns of mine in the focus group research. It is cost-effective and saves time. It allows access to a large pool of participants all over the world--often with one notice--without attendant travel time and costs. Purposive sampling is facilitated because particular populations (such as endometriosis patients) can be targeted directly with postings to the websites, listservs, bulletin boards, chat rooms, and newsgroups relevant to those populations. Conducting research over the Internet eliminates the need for transcription because participants type their own responses, which then can be saved in basic text, printed, and imported into word processing or data analysis software. This also increases accuracy; when interviews are audiotaped, there may be inaudible segments or the researcher may not hear accurately what the participant said. Interviews do not have to be scheduled around participants' and researchers' busy lives, and responses tend to be received very quickly. Using conventional methods, it can take a very long time to access a sufficient number of participants and complete the research.

Second, the method has tangible benefits for participants (Chen & Hinton, 1999; Coomber, 1997; Kaye & Johnson, 1999; Oppermann, 1995; Selwyn & Robson, 1998). The method is unintrusive and less intimidating for participants than traditional interviews or focus groups. Participants are not faced with a questioning researcher/stranger and, in the case of focus groups, other participants who may be strangers to them. They can respond at a time convenient for them, usually in privacy and in surroundings in which they are very comfortable (in the majority of cases, participants will be responding through

their home computer). Inequalities between researcher and participant may be levelled. Differences in race, gender, class, education levels, and age between researcher and participant are not so apparent as in face-to-face meetings. The method enables participants to determine the length and degree of detail of their response with less direction, interruption, curtailment, or (conversely) pressure to provide more information than they feel comfortable providing. Thus the method is particularly useful when interviewing shy participants (Selwyn & Robson, 1998). The method allows respondents time to formulate their responses as carefully as they wish, and to edit their responses. This is particularly advantageous in studies like this one that seek to establish how participants construct narratives to assert their status as knowers. In general, the method is extremely participant-friendly.

Nevertheless, there are significant disadvantages to conducting research over the Internet. First, although some researchers have found that electronic questionnaires tend to yield better response rates than mail-in questionnaires (see Selwyn & Robson, 1998), in many cases it is impossible to determine the response rate because one cannot tell how many potential participants have been reached (Kaye & Johnson, 1999). This was not the case with my research on the WITSENDO list; when I sent my initial call for participants, I was able to determine through a listserver command that there were 1101 subscribers to the list at the time. However, as with any email recruitment method, there is a possibility that members of the list forwarded my message to others not on the distribution list; and not all members of the list were eligible to participate because some are health professionals, partners or family members of women with endometriosis, or other interested parties. Given that only 18 women agreed to participate, my response rate obviously was extremely low. The WITSENDO listowner communicated to me that many

researchers had conducted studies over the list, and that many listmembers now were reluctant to participate because they took the time and trouble to compose their stories and never again heard from the researchers--no report on the research and no follow-up were provided. Thus, it seems that other researchers' somewhat inconsiderate approaches to this kind of research created problems for this study.

Moreover, "as electronic communication becomes more common, there will be *information overload* and research via e-mail runs the risk of becoming marginalised as a form of electronic 'junk mail'" (Selwyn & Robson, 1998: Paragraph 7; emphasis in original). It is very simple for potential participants simply to hit the delete key (Oppermann, 1995; Selwyn & Robson, 1998), especially if they (like many email users these days) are inundated with messages and, often, requests for research participants. Researchers must be careful not to exceed their welcome on the Internet by sending unsolicited (especially repeated) requests for participants to private email addresses, newsgroups, chat rooms, or listservs; this is perceived by users as spam. To avoid this problem, I obtained permission from the moderator before posting my call for participants and posted one follow-up message a week later. Additional messages to the list undoubtedly would have secured more participants, but would have risked irritating WITSEND0 listmembers (who after all do not subscribe to the list because they are interested in being research participants).

Second, the researcher is unable to confirm that participants are who they say they are with no face to face (or even telephone) contact:

The accuracy of information about age, gender, nationality, etc. can hardly be checked. Instead of relying on hard facts, the ethnographer relies on the user's trustworthiness and on her own judgement. Moreover, this uncertainty is particularly problematic in a space that has become famous for its playful possibilities. To play with one's identity, to change one's real gender for a virtual one and by doing so to becom[e] someone else,

someone whose chosen identity can be as real as the offline identity--all this is supposed to co-constitute the attraction of the internet (Wittel, 2000:Paragraph 16; see also Jones, 1994:33).

It certainly is possible that the 'women with endometriosis' that responded to my post to the WITSEND0 list were not women at all, let alone women with endometriosis. Also, it may be that participants fabricated the experiences they recounted in their responses. However, fabricating experiences can be done in in-person interviews too. Also, unless one asks for medical documentation (which implies one does not trust the participants' accounts of their diagnosis), it is impossible to ascertain that participants actually have been diagnosed with endometriosis, whether one is interviewing participants face-to-face or conducting research over the Internet. It does seem doubtful that anyone would bother to pose as a woman with endometriosis, however; and requiring medical documentation suggests that physicians should determine who can be a member of the endometriosis patient community, a suggestion I would not want to make. Some women on the WITSEND0 list (though, apparently, none of the participants in this study) have not been diagnosed with endometriosis officially, yet believe that they have the disease; by virtue of their participation on the list and their self-definition as sufferers, they are members of the endometriosis patient community. Moreover, as we shall see, endometriosis itself is contested as a disease entity within the medical community, which--if medical labelling was the required criterion--could abolish the entire 'endometriosis patient community.' Thus, self-identification as a woman with endometriosis and membership in the endometriosis patient community (through the WITSEND0 list) were the only criteria for participation in the study.

Additionally, as Robert Alun Jones points out, because the meaning of the self is unclear and negotiable in cyberspace, the Internet is a particularly interesting venue in

which to examine users' self-constructions. "[T]he more exacting our criterion of identifiability (and anonymity), the less sensitive we will be to the instability of the self in cyberspace. In sum, our ethical guidelines would destroy the phenomenon in which we have the greatest interest, and render the investigation itself trivial, if not altogether pointless" (Jones, 1994:33). Moreover, Andreas Wittel argues that distinguishing too carefully between virtual reality and 'actual' reality is not terribly helpful because it assumes the existence of an unmediated reality (Wittel, 2000: Paragraph 22). For me, what is particularly interesting in the WITSENDO responses is not *how accurately* their accounts represent 'reality' but *how* the respondents represent reality. Given the playful possibilities available to Internet users, this sort of research may be particularly useful in exploring self-constructions of the subject and its knowledge.

Third, sampling bias is a problem (Chen & Hinton, 1999; Kaye & Johnson, 1999; Oppermann, 1995; Selwyn & Robson, 1998). While purposive sampling is facilitated by Internet methods, the results of Internet research may not be representative of the wider population for two reasons. First, as with any self-selected population, those who respond to Internet studies may be those who have unusually strong opinions on the topic under investigation. Second, access to the Internet and to computers varies by region and socioeconomic status. The largest group of users is young, white, middle-class males in Western industrialized countries (although the demographics of Internet use are changing as access increases worldwide). We can safely assume that the vast majority of WITSENDO participants are women, but all of my participants live in Western countries and their race is unknown. However, it is well-known that most women who get diagnosed with endometriosis are white, middle-class, and Western (see Chapter 3); thus the demographic profiles of female Internet users and women *diagnosed with*

endometriosis (though not necessarily women who *have* endometriosis) are very similar.

Fourth, the lack of paralinguistic and non-verbal communication between researcher and participant is a considerable hindrance (Chen & Hinton, 1999; Selwyn & Robson, 1998), though of course this is a problem shared with any other research method that relies exclusively upon textual forms of communication (content analysis and questionnaires, for example). Participants' feelings about the topics being discussed are more difficult to ascertain, emphasis conveyed through intonation and facial expressions is lost, and so on. While Internet users have attempted to compensate for this problem with the use of emoticons such as :-), ;-), and >:-((signifying a smile, sarcasm or flirtation, and anger respectively), participants in this study did not use these (I suspect because they viewed their responses as more 'serious' than other emails because they were for a study). In any case using emoticons is a very crude and limited way of expressing mood and intonation. Participants in this study quite effectively used capital letters and exclamation marks to emphasize particular points and convey their frustrations with doctors. But certainly, the focus group data were much richer because in the transcripts I was able to include notes about participants' tone of voice, facial expressions, and gestures that I took during the discussions (and in some cases were noted jokingly by other participants: "Tape recorder, we're rolling our eyes!").

A related problem concerned the varying length, degree of detail, and literacy of the WITSENDO accounts. Selwyn and Robson (1998) note that accuracy is enhanced when participants type their own responses because this reduces the corruption that may result from audiorecording and transcription of oral accounts. But they also correctly point out that email communication is a hybrid of spoken and written language. As such, I find that it is frequently less readable and precise than more formal written accounts.

Many email users type quickly, with inadequate attention to sentence structure, grammar, spelling, and even the comprehensibility of their statements, writing as they would speak; but the cues provided in spoken language that allow the hearer to ascertain more fully the meaning of the account are absent. Not everyone communicates as clearly in writing (especially via email, where authors tend to be particularly sloppy) as they do in speech, and people often write *less* than they would say. Some written accounts, then, may be shorter, less detailed, and less clear than some spoken accounts. While some of the participants expressed themselves extremely well in writing and conveyed a great deal of information, other accounts were somewhat unclear, ungrammatical, stilted, or very brief. Two of the participants apologized for their writing, noting that English was not their first language.

Generally speaking, the meaning of unclear passages in some participants' responses became clearer to me in the context of their entire responses, which provided background information and insight into their ways of expressing themselves. But because this thesis provides only excerpts from the responses, I felt some minor editing (chiefly of grammar, sentence structure, and spelling) was necessary to convey the meaning of some excerpts to the reader. This was a difficult decision because it does alter the participants' voices, which I am concerned to preserve as much as possible. However, in the process of representation, researchers necessarily change participants' responses, whether by excerpting and thus taking comments out of context, or by converting the spoken word into printed text. And of course in order to represent, the researcher must interpret, which may alter the participants' intended meaning. Thus, 'faithful' representation of participants' meaning and voices is problematic for all qualitative researchers (and is subsumed entirely in quantitative research). Nevertheless, because I was present at the focus group meetings

and came to know the participants and their views very well, it was easier to provide (what seemed to me, and was confirmed by the participants' agreement of my analysis as) a more faithful representation of their assertions and perspectives than was possible with the WITSEND0 responses.

This brings us to what I view as the major limitation of the WITSEND0 research: its superficiality. The WITSEND0 participants were strangers to me, so I did not possess any background information on them that would contextualize the meaning of their responses. Their participation in the research involved sending me one email message, which allows for only limited communication of their perspectives. In their responses, most participants offered to answer any follow-up questions I might have, but due to my already enormous collection of data and limited time to complete the research, I decided that following up with participants was not possible. By contrast, I had ample opportunity in the focus group meetings, which spanned 9 weeks, to clarify, probe, and gain a real familiarity with their perspectives and experiential narratives. I still had unanswered questions, of course, but fewer of them. The focus group research provided the greatest detail, while the WITSEND0 research provided confirming evidence and elaboration of most of the themes identified in the focus group research (and while some of the focus group themes were not addressed by the WITSEND0 responses, none of them were *contradicted* by the WITSEND0 responses).

While some would argue that researcher detachment is necessary in research, I found that my detachment from the WITSEND0 participants generated much more superficial data than was the case with the focus group research. The sort of information I was interested in collecting from participants--the ways in which they construct and evaluate knowledge claims--is not the kind of information that most people readily (or at

least transparently) provide in everyday communication and is difficult to access without 'leading' questions. My involvement in the focus group research was very active, and a main reason for undertaking research with the WITSEND0 participants was to determine whether the focus group data were 'biased' by my participation in the discussions. Therefore, I wanted to avoid 'leading' questions in the WITSEND0 research.

Furthermore, I was concerned that directly asking women with endometriosis to reflect upon their own status as knowers and their ability to evaluate claims would be perceived by many (perhaps most) as a challenge to their already precarious status as knowers. As I will show in more detail below, women with endometriosis have been constructed as unreliable claimsmakers; in fact this construction is a main object of my analysis here. But the existence of this construction, and their struggles to contest it, often make women with endometriosis justifiably defensive about the claims they make and the way these should be evaluated, and suspicious of those who question the foundations of their claims. In the focus group I was able to counteract these possibilities because of my close relationship with the participants, which enabled me to demonstrate my support for their perspectives and my loyalty to the endometriosis patient community, despite the necessity of my *analytically* critical perspective as a sociologist. Yet, even in the focus group, when I pressed members to reflect upon and evaluate their claims from other, critical perspectives, some group members became a little defensive. With the WITSEND0 participants, I am certain that open questioning about their epistemological standards would be misinterpreted as personal attacks or criticisms, which not only could damage my research but, more importantly, compound the delegitimation women with endometriosis already experience. It would be very difficult to dispel this misinterpretation over email.

My concerns about potentially offending the participants, and my attempt to avoid 'leading' questions, resulted in my decision to give participants general, rather abstract guidelines, inviting them to tell me their "endo story" and providing a few optional, basic questions about their thoughts and feelings regarding their access to and quality of information about endometriosis, what sources and kinds of information they had found most useful and why, and so on. These very broad questions were so non-leading as to be rather confusing for a few participants, who mentioned that they "weren't sure if this was the sort of thing I was looking for." The WITSEND0 participants in general provided me with some insightful and interesting responses, but they did not reach the level of analysis and self-reflection that the focus group participants' accounts did. While in the focus group sessions, I could have been accused of asking 'leading' questions and conveying too much of my own perspective, these apparent faults were precisely what allowed me to develop an unusually close working relationship with participants, to determine how their perspectives differed from or reflected my initial interpretations of them, and to tease out more analytical and reflective statements from them. 'Leading' questions, then, can mean richer data and a more egalitarian researcher-participant relationship, where participants are involved actively in shaping the researcher's analysis, and meaning is created *with* participants. In the WITSEND0 research, I essentially extracted data from participants and then made meaning out of it. Given my background in feminist epistemology, the sociology of knowledge, and science studies, I have very strong misgivings about the 'objective', 'detached', 'neutral' researcher often idolized in the social and natural sciences. Taking on that role in the WITSEND0 research was at times quite uncomfortable for me. In future research, I would attempt to develop a closer, more long-term working relationship with participants.

While the ethics of Internet research have been less discussed in the available literature than issues of methodological rigour, some authors have noted that there are special ethical considerations in Internet research (Binik, Mah, & Keisler, 1999; Coomber, 1997; Jones, 1994). Primarily these have involved concerns about privacy, anonymity, and confidentiality. Regarding confidentiality, there is a remote chance that email communications may be accessed by system administrators or by determined hackers; I assumed that Internet users are aware of this, though it should have been noted explicitly in my original posting to the WITSEND0 list. Another problem is anonymity, which could not be offered to participants because their email addresses identified them. The email addresses and names of most WITSEND0 participants can be accessed by sending a simple command to the listserver (something of which participants are made aware when they subscribe), unless they send a special conceal command to the listserver to prevent them from being accessed in this way (less than 5% of the listmembers were concealed when I sent my first message to the list). Thus, most subscribers' identities as members of the endometriosis patient community are already available to the public.

However, I took all possible steps to preserve confidentiality as much as possible, within the limitations of the data collection method used. Responses from WITSEND0 participants were downloaded within two hours of being sent to the Carleton server, and stored on my computer hard drive and floppy disks, to which no one but myself has access; and participants' names and email addresses were not used in the thesis. It has been suggested that ways to avoid problems surrounding confidentiality and anonymity include providing respondents with access to anonymous remailers for email communications, or secure websites through which responses may be submitted (Binik, Mah, & Keisler, 1999; Coomber, 1997; Jones, 1994). These methods require web-

authoring expertise that I do not possess, are more time-consuming for participants, and may be daunting to participants who are relatively inexperienced Internet users or have only email access and not web access, but would be worthy of consideration in future research.

The most significant ethical issue from my perspective surrounds the effects of participation on respondents' welfare. An excerpt from an email communication from a member of the WITSEND0 list, who initially volunteered to participate in the study, illustrates the effect that recounting their experiences with endometriosis can have on some individuals:

Hi there Emma,

My emotions have run wild.

To write what you need for your research, for me, has proved to be hard. I find I can not write constructively as the pain/grief/anger and total enormity of the "cure trail" resurfaces and I find I am living the whole experience again...I feel I cannot "go back" and write about that time...I am finding it hard to focus on what is best for us now re ending the pain, let alone go back 25 years to my early teens...I can not write the many places we have looked for answers/ info etc., procedures / Drs. attitudes/ public awareness / lack of funding / IVF as I would have liked to - the pain of people's comments, family issues that befall us now due to lack of family networks/support...all get in the way...

Take care, stay well and sorry I couldn't help in your research

In subsequent email communications with this woman, she assured me that her "rollercoaster emotions...are there no matter what" and that she did not feel that attempting to participate in the research had worsened the problem. She also willingly gave me her permission to excerpt her letter in this thesis. The experience of endometriosis is painful; recounting it can be painful also.

During the extended focus group interviews, it was possible to speak privately with focus group members when the discussions seemed emotionally difficult for them.

This happened rarely; generally, the participants seemed very much to enjoy the research process because it allowed them to discuss issues of importance to them at length with other women who shared their concerns. The benefits of inter-member validation and support in the focus group setting were substantial. However, such benefits were not available to the WITSENDO participants, and I could offer only 'virtual' support by email to those whose accounts suggested that they were distressed. Although these women are members of a broader and very supportive endometriosis patient community through the WITSENDO list, it was clear from their responses that a few felt very isolated and depressed. I am most concerned that my questions might have elicited painful emotions in some participants, while I was not onsite to discuss with them the effects of the research and resources that might help them deal with any distress.

As Binik, Mah, & Keisler (1999:85) note, the risk that respondents may experience distress due to their participation is not limited to Internet research, but such research does pose some special problems. For example, they note the difficulties of monitoring participants' wellbeing and exposure to risks that may result from participating in Internet research:

In one case, researchers gave network access to poor single mothers. A boyfriend, jealous of the attention one of the participants was paying to her electronic group, beat her. The researchers did not anticipate these events and only learned of them much later, but they were able to take some helpful steps because they did follow up on the welfare of the participants (ibid).

They suggest that it is always appropriate for researchers to provide contact information for crisis counselling to participants when the study is initiated, which, in retrospect, I realize I should have provided in this research.

However, providing contact information to participants in this study is complicated by their geographic dispersion, lack of available counselling resources that are sensitive to

the issues faced by women with endometriosis (many women with the disease feel psychologists and psychiatrists dismiss their problems as hypochondriacal), and my own lack of knowledge of available resources in the many communities in which participants lived. The EA provides a 1-800 telephone crisis line but this may not be available to the three WITSENDO participants who live in Europe and Guatemala; and some endometriosis patients have told me that when they have tried to call the EA hotline, the line usually is engaged. While the WITSENDO participants have access to their online community, some of them are "lurkers" (participants who read, but do not post, messages) and may not have felt comfortable discussing their feelings about their experiences with endometriosis that the research engendered, or their concerns about the research itself, on the list--especially since most WITSENDO participants did not participate in the research and I am a member of the WITSENDO list. Thus, in this study, it was difficult to address these concerns in an effective way.

I responded to participants who demonstrated obvious distress in their responses to offer my support and ask them if there was anything I could do to help (although it seemed that their distress was the result of their actual circumstances rather than participating in the research). However, there is the possibility that others whose responses did not demonstrate obvious distress nevertheless were in need of assistance. I followed up with the WITSENDO participants in early July, inviting each of them to contact me about their perceptions of the research process, especially if they had experienced distress as a result of participating in the research, in which case I would help them try to locate counselling services. Those who responded stated that having an opportunity to tell their stories was a positive experience for them. Nevertheless, given the difficulty in providing adequate follow-up, I would take additional steps in subsequent

research of this kind, perhaps setting up an online forum which participants could elect to join so that they could communicate with each other as well as with me. The focus group research suggests that this kind of small group venue may be particularly beneficial to women with endometriosis.

Despite these ethical dilemmas, the vast majority of the WITSENDO participants thanked me for conducting the research and/or for "listening"; several stated that their reason for participating was to help other women with endometriosis. Their commitment was to contribute to research which sensitively portrays--and educates others about--the problems, struggles, and coping strategies of women with endometriosis. I hope that this research meets these criteria.

Chapter 3

The Medical Community:

Science, Clinical Experience, and Constructions of the Patient

This chapter has two aims. The first is to provide an overview and critical evaluation of the history and current state of 'official' expert knowledge about endometriosis patients, as presented in published gynecological literature. This will help to establish both the explicit epistemological standards of the gynecological research community and its judgments about endometriosis patients as potential knowers. I focus on experts' core claims--vademecum science, in Fleck's terms--and current areas of contention within the endometriosis expert community in three areas: classification, psychology, and epidemiology³². It is in these areas that gynecologists and other medical experts have made the most explicit attempts to define and describe endometriosis patients.

In order to understand the credibility struggles facing women with endometriosis, it is crucial to deconstruct medical evaluations of their credibility and of the epistemological status of the claims such women make. The development of classification systems for endometriosis and of the 'typical patient profile'--which has both psychological

³²Epidemiological studies may include any characteristic of a population that, it is believed, may correlate with the prevalence of disease in that population. Psychological characteristics of women with endometriosis therefore may be included (and occasionally are) in studies of the epidemiology of endometriosis. However, because most epidemiological studies of endometriosis are concerned with lifestyle and especially socio-demographic characteristics such as class, race, and childbearing, I differentiate between epidemiology and psychology in this chapter. The majority of studies of psychology of endometriosis seem to be conducted by gynecologists, psychologists, and specialists in psychosomatic medicine, not by epidemiologists.

and epidemiological components--will be examined as methods whereby a medical 'endometriotic subject' is formulated, the claims of this subject are called into question, and an objectivist *medical* account of endometriosis is constructed. The psychological and epidemiological constructions, in particular, have elicited strong responses from endometriosis patients and the EA because, if these constructions are taken seriously, they would militate against the epistemological credibility of women with endometriosis. The responses of endometriosis patients and the EA will be discussed in the chapters that follow.

The second aim of this chapter is to compare and contrast these official published accounts of endometriosis expert epistemology with a subtextual epistemology which, in some respects, contradicts the official version. That subtext has to do with the notion of practical clinical experience, which seems to be a crucial epistemic resource for gynecologists. We shall see in Chapter 5 that experience is a crucial epistemological resource for patients as well. However, the notion of clinical experience differs from that of patient experience in key ways; while the latter privileges embodied sensation and interpatient discussion as the foundation of experiential knowledge, the former privileges observation and technical practice. Clinical experience forms a sort of epistemological bridge between official expert knowledge and lay knowledge. It therefore may facilitate communal claimsmaking activities between experts and patients.

The distinction between these two ways of thinking--scientific and experiential--is not equivalent to the distinction between research and practice. Principles of science are invoked in clinical practice as well as in published medical research, and appeals to clinical experience appear in medical studies as well as descriptions of clinical practice. But, certainly, science has pride of place in the journals and experience is associated more

explicitly with practice.

The reason for the appearance of science *and* experience in research *and* clinical practice has to do, I suspect, with the professional activities of the authors of gynecological³³ studies of endometriosis. While only a minority of clinical gynecologists are medical researchers, virtually all gynecological researchers are practicing clinical gynecologists³⁴--and those recognised as the top clinical and surgical experts in the field tend to conduct research as well as treat patients. For these researchers, there can be no strict distinction between research and practice, not only because of their work as clinicians, but also because they are conducting applied research geared toward clinical practice. The conventions of medical research and medicine's claim to legitimacy as a system of expert knowledge require adherence to the principles of good science. However, in their work as clinicians the authors of medical studies of endometriosis accrue clinical experience and are faced with cases with which endometriosis science, at this point in time, cannot come to grips. Their research work is geared toward coming to grips with these cases as well as advancing scientific knowledge *per se*. In medical research, a distinction is made between 'basic' and 'clinical' research; the latter is the focus here (basic research tends not to be conducted by gynecologists but by microbiologists, toxicologists, and so on).

Although I did not interview practicing clinicians (save for an informal

³³I refer throughout this chapter primarily to gynecology, because virtually all endometriosis specialists are gynecologists. Reproductive endocrinology is a subspeciality of gynecology.

³⁴Epidemiologists, of course, are researchers and not clinicians; their studies are cited in this chapter. However, the majority of studies cited here are authored, or co-authored (sometimes with epidemiologists or psychologists), by practicing clinical gynecologists who also conduct research and, in many cases, teach in medical schools.

conversation with my own gynecologist), my review of gynecological research on the disease incorporates the perspectives of top practicing gynecologists because they are the authors of the studies I cite. In reviewing the research, then, it is appropriate to use the terms "gynecologist," "clinician," "researcher," and "endometriosis expert" interchangeably.

I. Defining the Endometriosis Patient and Endometriosis Science

In general, medical discourses about classification, psychology, epidemiology, and pain are organized by, and reinforce, a series of core claims and epistemological assumptions.

The first of these core claims is that disease severity is equivalent to anatomic amount of disease observable with the naked eye, or with tools that assist in the visualization of disease. Second, surgically observed severity of disease should be translated into a stage in a standardized classification system to assist in large research studies and to guide treatment. Third, endometriosis patients' self-reports of symptoms often are not supported by surgeons' visual observations and by their classification, so their self-reports may be inaccurate. Fourth, it may be that endometriosis patients who report symptoms not confirmed by actual extent of disease are suffering from psychosocial maladjustment. Fifth, in order to assess this possibility and provide adequate treatment, physicians need to know the psychosocial characteristics of endometriosis patients. Sixth, women with endometriosis--especially those with unconfirmed symptoms--may have psychosocial characteristics that make them 'abnormal' versus women without endometriosis.

The attendant epistemological assumptions are that the most reliable basis for

knowledge about the severity of disease is visual sense data; that medical taxonomical categories, at least in principle, can capture the ontological state of disease accurately; that standardizing observation mitigates the distorting effects of the subjectivity of physicians; and that patients' accounts of symptoms are of questionable validity and can be assessed by comparing them with objective signs. While the specific content of claims about classification, psychology, and epidemiology is hotly debated within the literature, the epistemological assumptions that underlie them are not. After a detailed review of the claims and areas of contention, I return to this question of epistemological assumptions below.

1. Classification

Endometriosis classification systems are used to assign women to groups representing stages of disease severity, based on the appearance and anatomic distribution of lesions and adhesions³⁵ as determined during surgical visualization³⁶. The explicitly-

³⁵Lesions, also called cysts or endometriomas, are active patches of endometriosis. Adhesions are not endometriosis as such, but are thought to be formed by the bleeding of lesions, and thus are considered indicative of old endometriosis. Both adhesions and lesions may produce pain and infertility. However, some gynecologists now argue that there is no proof of a causal connection between endometriosis and infertility, despite their co-presence in many women (*Canadian Consensus Conference on Endometriosis*, 1993).

³⁶Nowadays, endometriosis surgery usually is performed laparoscopically. The patient is given a general anaesthetic and a laparoscope, a thin tube with a light source at one end and a telescopic eyepiece at the other, is inserted through a small incision just below the patient's navel. A laser may be attached to the laparoscope and used to vaporize implants. The surgeon's view through the laparoscope may be projected onto a monitor and videotaped. Laparoscopic surgery does not require large incisions, which shortens patient recovery time, hospital stays, and operating time, reduces cost, and increases patient "compliance." Many women undergo multiple laparoscopic surgeries for endometriosis (Freidman, 1990; Roseff & Murphy, 1990; Shohat, 1992).

defined purpose of modern endometriosis classification systems is to predict women's chances of becoming pregnant after treatment, based upon the severity of their disease before treatment (Buttram, 1985; Schenken, 1998; Schenken & Guzick, 1997). Although women with endometriosis are much more likely to experience pain than infertility (Barlow & Glynn, 1993; Pauerstein, 1989), a classification system that attempts to correlate endometriosis severity and pain symptoms has not been developed.

Medical specialists have been attempting to develop a taxonomy for endometriosis since its inception as a disease category over 85 years ago (Groff, 1989). The first formal classification system was proposed in 1949 by Wicks and Larson, who lamented that without such a system, "it is left to the individual surgeon to practice what he thinks best without a road being opened to correct his decision for future reference" (quoted in Canis et al., 1993). Early attempts to develop a classification system were primarily descriptive (Schenken, 1998:269) and were modelled after cancer staging systems because the disease was thought to be invasive and progressive (Hoeger and Guzick, 1997:348). None of these early systems was widely accepted, apparently because they did not meet the two main epistemic goals of classification: standardization and prediction. Their terminology, scales of measurement, factors measured, and populations studied varied; and they were unable to correlate patients' symptoms and fertility outcomes with their classification. This lack of standardization and predictive ability made it difficult to compare data regarding the success of various therapies in treating infertility in women with various degrees of disease severity, the express purpose of later classifications (Audebert, 1990; Buttram, 1985; Canis et al., 1993; Groff, 1989).

But the definition of global standards also depends upon the standardization of material practice. Another crucial factor in the establishment and acceptance of a single

classification system was the widespread availability of new technologies which enabled more frequent surgeries, more detailed description of pelvises, and a greater demand for a standard system:

The modern era of classification of endometriosis can be dated to the 1970s when the advent of diagnostic laparoscopy, together with other technologically sophisticated diagnostic and research tools provided the means to detect and document mild degrees of endometriosis with subtle appearances and unusual locations. These advances fostered expectations for the development of more detailed and precise definitions of the disease, well-documented guidelines for treatment, and good predictive value for treatment outcome (Rock & Zoladex Endometriosis Study Group, 1995:11108-9).

i. The "Modern Era" and the R-AFS Classification

The first classification system to gain wide acceptance internationally was the Acosta scale, published in 1973. It correlated extent of disease with fertility outcomes, but it provided unclear explanations as to how to stage particular types of lesions and adhesions; demarcation between stages of severity was criticized as arbitrary; and the risk of recurrence of the disease after treatment was not addressed (Audebert, 1990; Canis et al., 1993; Groff, 1989).

The failure of the Acosta scale prompted the American Fertility Society (AFS), one of the leading gynecological associations in the world, to convene a panel of experts to develop a taxonomy, which was published in 1979 (American Fertility Society, 1979). The AFS classification was "simple, easy to use, and designed by one of the main gynaecologic societies, [so] it became almost universally accepted" (Canis et al., 1993:762). A standardized form was developed so that patients could be staged during diagnostic surgery. However, the system was not without its critics so, in 1985, it was modified and renamed the Revised American Fertility Society (R-AFS) classification

(American Fertility Society, 1985). The R-AFS form directs surgeons to record and rate the surface area and depth of lesions and the density of adhesions on the ovaries, fallopian tubes, peritoneum (lining of the pelvic cavity), and cul-de-sac in a standardized way, by inspecting the pelvis in a clockwise or counterclockwise direction to ensure thoroughness and systematicity. Due to a dearth of clear evidence regarding the effects of specific types and sites of endometriosis on infertility, points were assigned arbitrarily to lesions and adhesions on these areas (Guzick et al., 1997; Hoeger & Guzick, 1997). The resulting point total determines the stage of severity (minimal, mild, moderate, or severe) assigned to the case.

The R-AFS classification represents "an effort to establish and document the premise that success of surgery in the infertile female was dependent on the severity of disease" (Buttram, 1985:347). Because clinical experience and some research suggested that lesions and adhesions on the ovaries and tubes and in the cul-de-sac are most often associated with infertility, endometriosis in these areas was accorded the most points, while peritoneal lesions were accorded fewer points (Buttram, 1985). Endometriosis in other areas can be noted under "associated pathology" on the form, but was accorded no points and hence does not affect the stage to which a woman is assigned.

The R-AFS system possessed three advantages. First, it standardized classification. It provides a clear protocol for pelvic examination and staging, and a "common language" or shorthand for physicians to use in discussing the severity of a case (Canis et al., 1993). This, it was hoped, would facilitate comparison of data regarding the effects of various treatments and the prognoses for patients with varying degrees of disease severity (Buttram, 1985:350). Second, it was flexible enough to allow for the description of every case (Canis et al., 1993). Third, the scoring system was amenable to

statistical analysis, so large numbers of commensurable cases could be manipulated by researchers interested in establishing correlations between groups of women, stage of disease, treatment protocols, and subsequent fertility rates. The role of statistics--and epidemiology, medicine's bastion of statistics--in classification is central because these are excellent means of reducing complexity. They can reduce many complex cases into a few numbers and groupings. Indeed, Audebert argues that development of an adequate classification system depends upon "efforts and cooperation between various fields of medicine, especially epidemiology and statistics" (Audebert, 1990:135; emphasis in original).

The R-AFS classification remains the most commonly employed taxonomy in both endometriosis research and clinical practice (*Canadian Consensus Conference on Endometriosis*, 1993; Hornstein et al., 1993; Schenken, 1998). "As a matter of fact, it is so commonly used that when discussing a patient, we no longer speak about endometriosis as a whole but about minimal, mild, moderate, severe, or extensive endometriosis" (Canis et al., 1993:759) and the system "is now accepted worldwide as the endometriosis international language" (ibid:772). However, the R-AFS is widely recognized to be an inadequate classification system for many reasons, a number of which are directly related to the standardization and prediction criteria.

First, the system's predictive ability is questionable. The system does not predict infertility consistently; several studies have found no discernible difference in fertility rates among the four stages (American Society for Reproductive Medicine, 1997; Guzick et al., 1997; Schenken, 1998). Researchers have speculated that the system is based upon an inadequate current understanding of the relation of endometriosis to infertility, the causes of endometriosis, and how to treat it effectively (Fedele et al., 1990; Guzick et al., 1997).

Also, point scores neither reflect nor predict severity of pelvic pain consistently (*Canadian Consensus Conference on Endometriosis*, 1993; Fukaya, Hoshiai, & Yajima, 1993; Schenken, 1998)³⁷. As noted in a consensus report by the Canadian gynecologists' association, the R-AFS system depends upon visual assessment, which "permits an estimation of the extent of disease, but not disease activity" (*Canadian Consensus Conference on Endometriosis*, 1993:7). This report even argues that "there is an inverse correlation between endometriotic activity and classification stage" (ibid) because anatomically minimal endometriosis seems to produce more inflammatory products than anatomically extensive endometriosis. In other words, the more anatomically extensive the endometriosis, the less active and less symptom-producing it may be. Thus, the meaning of "severity" is at issue: should severity refer to anatomic extent of disease, or to symptomatology, which appears to be inversely related to anatomic extent?

Second, standardization has proved problematic. Two studies have found that reproducibility of scoring between surgeons, and even by the same surgeon, is quite low (Hornstein et al., 1993; Rock & Zoladex Endometriosis Study Group, 1995). Translation into other languages has been difficult, because the terminology used in the R-AFS classification has varying meanings in different gynecological communities (Canis et al., 1993).

In response to these and other criticisms, the American Fertility Society--renamed the American Society for Reproductive Medicine in 1995--struck a subcommittee to review the system's utility in predicting fertility outcomes (American Society for

³⁷This is understandable, given that the system was developed to predict infertility, not pain. As discussed below, efforts are currently underway to develop a system that would correlate severity with pain symptoms, though such a system does not seem to be expected in the near future.

Reproductive Medicine, 1997). The infertility committee made two main recommendations: to provide for more detailed description of lesions; and to retain the original R-AFS scoring system.

The first recommendation was to modify the R-AFS form to include space for the recording the colour of lesions, again because growing evidence suggests that the anatomic distribution and extent of disease may be less important than the biologic activity and appearance of lesions in causing infertility (American Society for Reproductive Medicine, 1997; Hoeger & Guzick, 1997). The new system asks physicians to record the percentage of total lesions described as red, white, or black (American Society for Reproductive Medicine, 1997).

Although the R-AFS scoring system has been roundly criticized as arbitrary (see Canis et al., 1993; Fedele, 1990; Groff, 1989; Guzick et al., 1997; Hoeger & Guzick, 1997), the infertility committee's second recommendation was to retain the 1985 R-AFS scoring system and cut-offs for each stage. Thus, this new focus on appearance of lesions has no impact on the stage to which a woman with endometriosis is assigned. Her point score, and therefore her stage, are still based exclusively on the anatomic distribution and extent of disease according to the 1985 R-AFS scoring system; the colour of her lesions has no bearing on that score. The infertility review committee admitted that the 1985 R-AFS system is "not a sensitive predictor of pregnancy following treatment" but warned against making "arbitrary changes" to the scoring system because insufficient data existed to support changes to the scoring system (American Society for Reproductive Medicine, 1997:816-7; see also Schenken, 1998; Schenken & Guzick, 1997). It was hoped that including descriptions of the appearance of disease on the form would facilitate future research into the relation between the appearance of disease and the anatomical extent and

location of disease, and their relation to fertility outcomes. Thus, although the R-AFS system does not work very well, the gynecological community does not have a clear sense of how to fix it; and so the basic R-AFS scoring system remains unchanged to this day (American Society for Reproductive Medicine, 1997).

As noted above, endometriosis classifications have focussed on the prediction of fertility outcomes and have not addressed pain symptoms. According to one literature review, four studies demonstrated an association between R-AFS stage and pelvic pain, but three other studies showed no association (Schenken, 1998). The *Canadian Consensus Conference on Endometriosis* report (1993:22) baldly asserts that "severity of pain does not correlate with the R-AFS stage of the disease." In the early 1980s, few authors expressed concern about the potential irrelevance of endometriosis classification systems in evaluating pelvic pain (Groff, 1989), but beginning in the late 1980s, this concern became quite widespread (Rock, 1993). A 1993 review of the literature on endometriosis and chronic pelvic pain notes that "Many investigators have...made requests for a specific scoring system" for endometriosis associated with chronic pain, due to the inability to correlate R-AFS stage with degree of pain symptoms (Ripps & Martin, 1993:713).

The reasons for this sea-change are not ascertainable from the available medical literature. We can speculate about them, however. Medical research that demonstrated the role of prostaglandins in menstrual pain--and the development of new treatments for pain--may have convinced doctors that endometriosis-associated pain was a legitimate and treatable medical problem (or perhaps a legitimate *because* treatable problem) (Mains, 1995:36). It is also likely that gynecologists were influenced in the mid to late 1980s by the women's movement and the changes it effected in popular conceptions about women.

Such changes may have made a focus on infertility to the exclusion of women's other medical concerns seem archaic to many gynecologists; witness the American Fertility Society's name-change--to the American Society for Reproductive Medicine--in 1995.

A related, and probably crucial factor, is the crisis of public confidence in medicine as an expert system. The popular news media have mounted extensive critiques of systems of expertise, most notably medicine (Rachlis & Kushner, 1989:47)³⁸ and have heralded breakthroughs in medicine that have not materialized, further undermining public trust in medicine (Todd, 1989:2). Perhaps the greatest source of growing doubts about medicine has been the critiques of activists in the AIDS, disability rights, women's health, and ex-psychiatric patients' movements. Because gynecology crosses the critical domains of health activism and feminism, gynecologists have been among the most castigated of all medical experts. 'Taking women's pain seriously' may be seen as one way to redeem the specialty and improve clinicians' relationships with their clients. Patients' complaints about the inadequacies of gynecological treatments for pain, and particularly the *documentation, organization and publication* of those complaints by the EA, surely have had some effect. The increasing inclusion of the EA in expert discussions about endometriosis, documented in Chapter 6, testifies to the impact the Association has had upon the field and suggests a growing recognition among specialists that patient organizations can be powerful allies. Cementing an alliance with the EA presumably requires some concessions among gynecologists regarding the way they think about endometriosis.

Whatever the reasons for the sea-change, the pain committee published its report in 1993. It noted the inadequacy of the R-AFS classification in relating stage to pain

³⁸For two examples of journalists' critiques of the medico-pharmaceutical complex, see Regush (1993) and Toughill (1992). Nicholas Regush was the *Montreal Gazette* reporter who broke the Meme breast implant scandal.

symptoms and included a new form to be used in the clinical documentation of pain symptoms (American Fertility Society, 1993). The form directed physicians to document the patient's descriptions of the quality of pain as either mild, discomforting, distressing, or horrible, and to indicate, on the diagram provided, the areas of pain described by the patient. Also, the physician was directed to physically examine the patient to determine "areas of tenderness found on examination"--and to differentiate these on the diagram from the areas of pain described by the patient.

The resulting description of pain symptoms does not affect R-AFS classification; the stage of disease severity to which a woman is assigned still is dependent exclusively upon her surgeon's visualization of anatomic distribution and extent of disease, not upon her pain symptoms. However, the new pain form also includes space for a surgical description of pelvic adhesions and endometriosis, and form users are encouraged to complete additional forms documenting post-treatment symptoms, examinations and surgeries at regular intervals. So, although the form it developed does not present a staging system for pain, the committee expressed a hope that the accumulation of data on patients' symptoms, physical examination, and surgical findings would eventually lead to "a classification of endometriosis and pelvic pain with statistically appropriate groupings and clinically appropriate estimates of disease stage and therapeutic response" (American Fertility Society, 1993:955)³⁹.

ii. *Analyzing Endometriosis Classification*

The R-AFS system illustrates well the characteristics of bureaucratic classification

³⁹Presumably, the committee considered it premature to offer a staging system for pain, due to criticisms that previous AFS staging systems were anecdotal and arbitrary, not based on sound research.

schemes set out by Eyal Ben-Ari in his study of classifications of child development used in Japanese day care centres (Ben-Ari, 1994). Ben-Ari notes that bureaucratic classifications are not neutral; they are practical systems, purposive and directional, embodying intentions and goals. They sanction particular definitions of reality, affecting the way their users act on reality, directing interventions along certain lines and precluding others, reducing the complexity of intervention but in the process reducing flexibility (see also Clarke & Casper, 1996; Löwy, 1993). Ben-Ari argues that the reality they define is rigid: attention is directed to some issues (eg. infertility, size of cysts) and not others (eg. pain, experience of patients). The issues focussed upon are those that are tangible and can be expressed quantitatively. Classifiers are forced to use tangible, set, quantified categories, socializing classifiers into preferred professional modes of communication and admitting of greater generalizations across cases. Intangibles are difficult to administer bureaucratically. The classifications are abstracted from ordinary speech, using specialized terminology which erects boundaries between experts and laypersons. The generalities produced are reinforced because they appear in a form authorized by experts and authorities. Because they create permanent records through writing, they are amenable to surveillance by higher-ups in the institutional or professional hierarchy, acting as a check-back on the work of the classifier. More importantly, they are key to the surveillance of the classified, allowing the systematic comparison of individuals, categorizing and schematizing lives and facilitating their organizational control. They stream individuals into predictable lines of movement through the system. They produce or reinforce narratives of normality, tending to endorse existing cultural notions about the individuals being classified (Ben-Ari, 1994).

Medical reviews of the history of classification assert that staging systems have

followed a linear, progressive path: from early, merely descriptive systems which are based on the assumption that endometriosis is a progressive, anatomically invasive disease and which were difficult to use in a standardized way; to the R-AFS, a modern, standardized system with greater predictive ability that more accurately reflects the natural history of endometriosis. However, this Whiggish version is highly debateable. The R-AFS system retains the assumption that endometriosis is a progressive, anatomically invasive disease because it stages endometriosis like cancer, assuming that 'severe endometriosis' is anatomically extensive endometriosis, rather than histologically active endometriosis. Problems with reproducibility and translation demonstrate that standardization is not so achievable after all. And, in terms of predictive utility, modern classification systems leave much to be desired. The *Canadian Consensus Conference* report's evaluation of the R-AFS classification paraphrases Winston Churchill's commentary on democracy as a form of government: "it is the worst form of classification, except for all the others" (1993:7)⁴⁰.

Experts in the field frequently describe endometriosis as an "enigmatic" disease (see eg. Audebert, 1990; Canis et al., 1993; Fedele, 1990; Groff, 1989; Guzick et al., 1997; Hoeger & Guzick, 1997). Patients' symptoms vary widely, even when the location and extent of disease is similar. The most common symptom of endometriosis is pain, an unavoidably subjective phenomenon. Medical studies routinely produce contradictory results. Some of this contradiction no doubt arises due to stringent ethical guidelines on

⁴⁰The report recommends the staging system developed by the Canadian Collaborative Group on Endometriosis, which combines the R-AFS classification with another, called the ADI classification, which provides for the recording of total area of endometriosis and its classification by lesion type (*Canadian Consensus Conference on Endometriosis*, 1993:7-8). I was unable to locate any published information regarding the extent to which this system actually is employed by Canadian gynecologists, but see the beginning of section II below.

the use of human subjects, guidelines to which other sciences are not held, and which force medical studies to employ experimental approaches and subject pools that introduce confounding variables into the research. Clinical practitioners employ highly divergent treatment protocols and their success varies, often for unfathomable reasons. There is little about the disease, its treatment, and its effects, then, that is standard and predictable. In general, endometriosis patients, physicians, and the disease itself present such a frustrating web of complexity that it is no wonder researchers persist in their efforts to construct endometriosis in a standardized, predictable way via classification. Classification represents an attempt to reduce the unavoidable complexity that is endometriosis, such that it can be acted upon (diagnosed, studied, treated) in a logical and systematic way. Indeed Alain Audebert argues that it "appears very difficult or almost impossible at this stage of our knowledge to establish a reliable classification. Nevertheless a classification is required in order to reduce the diversity of this disease" (1990:123).

The R-AFS classification reduces complexity in three areas: in medical research; in the description of endometriosis itself; and in the characterization of endometriosis patients.

a. Reducing Complexity in Research

The R-AFS classification illustrates Bruno Latour's argument that modern scientific culture is concerned with 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). 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, was translated into several languages and published as a form that can be ordered from the American Fertility Society (now the American Society for Reproductive Medicine).

However, as claims are taken up by others, they may be modified (Latour, 1986). 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. The R-AFS classification allows a surgeon's view of a woman's pelvis to be converted, via a standardized protocol, into paper traces during surgery. All surgeons are directed to examine and stage pelvises in the same way. In principle, this generates thousands of combinable surgical reports, virtually eliminating incommensurability across cases. Because staging is numerical, statistical analysis can be performed and many cases can be boiled down into a standardized form of representation. This standardization can be used to lend credibility to studies making new claims about how best to treat endometriosis-associated infertility. Surgical visualization of actual pelvises is fleeting and can only be done in a hospital, while paper traces of women's pelvises are permanent and mobile. They can be presented to potential allies and combined with comparable paper traces of other pelvises to support claims to knowledge about the best way to treat infertility in women with endometriosis.

However, in practice, immutability and commensurability are quite difficult to achieve. Other authors have demonstrated that attempts at global standardization often are thwarted by the messiness and variability of local practices geared toward specific contexts (eg. Berg, 1997; Curtis, 1998; Jordan & Lynch, 1992). Endometriosis staging is done differently by individual surgeons and in diverse local settings, such that the R-AFS

staging records used in endometriosis research may not be so commensurable after all--as the expression of concerns about the reproducibility of scoring make clear.

Increasingly, endometriosis surgeries are being videotaped, producing a record of surgical practice that is amenable to viewing and critique by other surgeons and scientists. Videotaping of laparoscopy permits a more detailed immutable mobile of an endometriosis surgery than the R-AFS form. But the detail is part of the problem. While surgeons in conversation can refer easily to a "mild case", and can even show each other completed R-AFS staging forms, having each other view videotapes is impractical. As I have attempted to show, the themes of standardization and prediction are central to classification discourse; but another central theme is simplicity (and this theme is, of course, related to standardization). While videotapes permit the transmission of a great deal of detailed information, the R-AFS classification system boils that detail down, facilitating quick discussion and reducing complexity. While videotapes are amenable to many subjective interpretations, the R-AFS system aims to provide a standardized, simple, clear "common language":

A common language is useful in both clinical practice and research. The extent of disease is essential when discussing a patient's chart. As a complete description would be too time-consuming, this should be avoided by using a word or score that summarizes the lesions...The translation from anatomical lesion to verbal description should be simple, fast, easy to use and clear, thus reducing the influence of the surgeon's interpretation on a patient score...As with any language, a dictionary is needed, with accurate and simple descriptions of the meaning of each word. This would help everyone use the words adequately (Canis et al., 1993:764-5).

Videotaping is no substitute for classification as a means of inter-physician communication. Classifying endometriosis in standardized ways allows for studies to speak to one another across divergent subject population sizes and composition and experimental protocols, toward the goal of developing predictions of treatment outcomes

by stage. A passage from a recent review of endometriosis taxonomies reiterates the need for standardized, clear, simple language and predictive ability in classification systems:

Ideally, a classification system should allow for an accurate assessment of a disease state with respect to extent, location, and perhaps nature of disease; this would allow clear communication among those who treat the disease. Moreover, an ideal classification should also be useful in the prediction of outcome based on stages of disease that should behave similarly. Additionally, classification schemes should be such that similar disease stages have similar, predictable outcomes in response to treatment (Hoeger and Guzick, 1997:347).

The reduction of subjective interpretation, difference, and unpredictability is the hallmark of the good classification because it is necessary to good research.

b. Reducing the Complexity of Endometriosis

The R-AFS classification represents an attempt to regulate and standardize endometriosis itself. Medical classifications assume "that nature can be carved at 'natural joints'", yet the joints are not always so clear and must be constructed by the classifiers (Clarke & Casper, 1996:603). The 1997 infertility review committee's modification to the R-AFS form is a case in point. The form includes space for recording the colour of lesions. This introduces a new level of subjectivity and, therefore, complexity to a system which relies on point scores based on surface area and depth of disease. Surface area and depth are amenable to scales of measurement (and indeed the R-AFS form specifies the scale to be used: centimetres). Colour is not. Even the American Fertility Society committee charged with developing a simple way to record colour uses a long list of descriptors to differentiate between lesions: "red, red-pink, flamelike, vesicular blobs, clear vesicles...opacifications, peritoneal defects, yellow-brown... black, hemosiderin deposits, blue" (American Society for Reproductive Medicine, 1997:819).

To reduce this complexity, the Society committee *groups* these descriptors. Red,

red-pink, flamelike, vesicular blobs, and clear blobs are to be classified as "red"; opacifications, peritoneal defects, and yellow-brown lesions are to be classified as "white"; black lesions, hemosiderin deposits, and blue lesions are to be classified as "black." Labelled colour photographs of various types of lesions are included on the new form to ensure that physicians categorize disease appearance in a standardized way. Thus, the recording physician is confronted with an "audio-visual display" (Latour, 1987:71) that combines text and illustration. This directs the physician to differentiate between the lesions in a particular way, to place lesions *that look quite different from each other* in the same category, and to use words to describe them that seem to contradict visual evidence (putting blue lesions in the black category, for instance, or yellow-brown ones in the white category). A potential source of variation and complexity is eliminated as the interpretive work of describing a lesion is reduced to a choice of three categories, with photographs and instructions that attempt to do the interpretation for the surgeon. Endometriosis itself is forced into simplified categories that its varying physical appearances seem to defy.

The 1997 form also reduces complexity for medical researchers because, rather than having to compare and *interpret* surgical reports that describe lesions in non-standard ways, the interpretation is already done for them in a standard language. The goal of the 1997 form is to provide as much information as possible, supplementing the information available on the 1985 forms with information about colour of lesions. But it is done in such a way as to boil that information down as much as possible, through the creation of another system of classification: one for colour.

The focus of the R-AFS classification on infertility as opposed to pain may also represent an attempt by researchers to reduce complexity. The *Canadian Consensus Conference on Endometriosis* report notes that pain "is difficult to measure, and treatment

efficacy is hard to assess...The pain associated with endometriosis has been difficult to quantify, and may be mediated by such factors as the location of the disease and depth of infiltration, as well as individual pain tolerances and cultural attitudes toward pain, menstruation, and sexuality" (1993:20). The report advocates the development of "an objective scoring system for pain and pain relief" (1993:21), but provides no indication as to how this could be accomplished, given that pain intrinsically is a subjective phenomenon. While pain and pain relief are difficult to measure, infertility and its successful treatment can be assessed more objectively; fertility presents a more concrete outcome measure for classification systems than does pain relief. Since gynecologists set outcome prediction as the goal of classification systems, and since outcomes are more difficult to measure for pain than for infertility, it is not surprising that the prediction of fertility outcomes has been the focus of classification systems.

However, gynecologists may have to rethink this strategy, given the R-AFS system's poor record of fertility prediction and a growing suspicion that, while endometriosis may often be present in infertile women, it may not actually *cause* infertility (*Canadian Consensus Conference on Endometriosis*, 1993:16-19). And of course new problems of complexity loom, given the recent efforts to develop a classification for pain with the conceptual messiness it introduces: Is pain physical, psychological, or some combination thereof? How can it be measured? How can its measurement be standardized? How does one reconcile subjective accounts of pain with objective measures of disease? While classification attempts to standardize documentation of the disease, the issues raised by the treatment of individual patients and their varying concerns and symptoms makes standardization difficult. Standardized codes must be made to work in particular clinical contexts, which often reintroduce variation and complexity. The aim

of complexity reduction in medical research is pitted against a central problem in clinical practice: the idiosyncratic nature of illness.

c. Reducing the Complexity of Patients

Perhaps the most important sense in which the R-AFS classification reduces complexity relates to patients themselves. 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 unconscious) remain. An entire "endometriosis population" can be constructed without 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.

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; a woman's pelvis is depicted as containing only a uterus, fallopian tubes, ovaries, and supporting

ligaments. Certain parts of women's reproductive anatomy are highlighted, while others recede. Endometriosis in most of these other sites has to be noted under "additional endometriosis" on the form, and cannot be factored into staging as no points are accorded to "additional endometriosis." The R-AFS classification cannot be used to establish the severity of a patient's pain; consequently, researchers would find it 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).

The R-AFS classification also attempts to reduce the complexity of women with endometriosis by constructing risk populations and plans of governability (Castel, 1991); here we see the centrality of predictability to the reduction of complexity. By correlating stage of disease with therapeutic approach and pregnancy outcome, researchers ultimately hope to use the classification to evaluate the risk of infertility for the four populations corresponding to each R-AFS stage, and to determine how best to deal with that risk. The researcher with access to large numbers of case files which include the R-AFS classification, treatment plans, and fertility outcomes of individual patients, has no need of face-to-face interactions with patients. Patients' accounts of their illness, with all the complexity and epistemic uncertainty they introduce, can be avoided. It is true that staging introduces new forms of variation among endometriosis patients by assigning them to four different categories. But while four categories of patients are more individuating than one broad category of endometriosis patients, they are very neat and tidy compared to women's experiential narratives. A woman with Stage I endometriosis may feel she has much in common with a woman with Stage IV endometriosis based upon similarities in

their experiential narratives. Staging these women differently takes the focus off these similarities and in this sense introduces divisions among classes of sufferers--and, in a sense, a hierarchy of suffering--that sufferers themselves appear to view as artificial.⁴¹ But in the process of staging, the differences among thousands of women's accounts get reduced to four categories. Quite clearly, staging reduces complexity more than it introduces individuality and variation.

Due to the lack of consensus regarding the ability of the R-AFS classification to predict the outcome of infertility treatment based upon a patient's stage, the definition of risk populations and plans of governability, or 'therapeutic management,' can be proffered only tentatively by researchers. However, this is the express purpose of the taxonomy, and the American Fertility Society has indicated that modifications to the system will continue to be made until this purpose is achieved (Buttram, 1985). Medicine is an applied science. Its classifications are not idle conceptual orderings of a chaotic world; they are meant to be put to use in treatment.

The current use of the R-AFS classification as a technique for identifying and

⁴¹My observations of the WITSENDO list suggest that some women try to use their stages to justify their claims about the severity of their suffering. Women assigned to Stage IV frequently mention their stage in their posts. It is rare for WITSENDO members to state that they have Stage I endometriosis, although medical studies often claim that the vast majority of endometriosis patients have mild or minimal disease. However, because practically everyone in the endometriosis patient and medical communities knows that R-AFS stage means very little symptomatically speaking, telling others "I am a Stage IV" does not seem to accord one a spot at the top of a 'hierarchy of suffering' within the patient community. One focus group member, Mercedes, had been classified with Stage I endometriosis, and was indignant about that because, she asserted, her pain was severe. She invoked medical claims that anatomically mild disease seems to be the most histologically active to support her assertion. Despite her R-AFS stage, other group members referred frequently to Mercedes as someone who had particularly severe problems with endometriosis because of her accounts of her symptoms, problems with doctors, and side effects from GnRH agonists. Experiential accounts seem to carry far more weight in this community than medical classifications.

dealing with risk populations, and thereby reducing the complexity of endometriosis and its sufferers, is limited because currently, diagnosis and treatment remain connected.

Women with endometriosis, at the present time, cannot be staged without visualization of their pelvises, and they are staged almost invariably by the gynecologists who subsequently treat them⁴². The continued presence of patients and their complex, varying accounts of their illness make their reduction to monolithic risk groups difficult. There currently exist no screening programmes for endometriosis or for its various stages. However, the drive to identify psychological and socio-demographic profiles of women with endometriosis can be read as the necessary preparatory work for population screening initiatives; and the development of non-surgical biochemical or genetic markers for the disease eventually may enable screening and assignment to risk populations with little reliance upon the accounts of patients. Currently, diagnostic methods are quite limited and depend to a great extent upon patient accounts of their symptoms, not least because of the clinical inapplicability of existing classification. If this changes, the patient's account may become less important as a medical resource for claimsmaking.

The R-AFS classification has assisted gynecological researchers greatly 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, until quite recently, the focus on infertility at the expense of pain was rarely questioned in these debates, and this reinforced the

⁴²Note, however, that it is quite possible to have a surgeon assign a stage to a woman's pelvis, and then to hand over responsibility for her treatment to another physician. In fact, this often happens as women with endometriosis seem to change doctors quite frequently.

assumption that infertility and not pain is the primary problem for women with endometriosis. Women's concerns about pain were diminished in importance. While patient narratives present complex individuals with particular desires, characteristics and life histories, classification reduces individuals to a stage. Groups of women are created in ways often contrary to their own accounts of their illness. The factor uniting these women is, supposedly, their desire to maintain their fertility.

The development of the American Fertility Society pain form (American Fertility Society, 1993) may eventually change this, if it results in a new classification for endometriosis pain. However, should this occur, an inevitable result is the 'flattening' of women's pain symptoms into stages that, again, suppress individuality⁴³. But the pain form is interesting for another reason: the means of knowing about pain that it proposes.

The form is an interesting mix of subjectivism and objectivism. For example, on the one hand, the physician must document the patient's descriptions of the quality of pain as either mild, discomforting, distressing, or horrible--imprecise terms which undoubtedly would be used in varying ways by different patients and different doctors--and must indicate, on the diagram provided, the areas of pain described by the patient. On the other hand, the physician is directed to determine "areas of tenderness found on examination"--and to differentiate these on the diagram from the areas of pain described by the patient. Aspects of patient experiential narratives--"complaints" on the form--are pitted against

⁴³It is theoretically possible that staging could enable more effective treatment regimes which would multiply women's potential to achieve individual lifegoals (although the only lifegoal associated with the current classification is pregnancy). Classifications to date cannot advance women's individual lifegoals because they cannot be correlated reliably with symptoms or prognoses. Moreover, women with endometriosis cannot classify themselves, nor do they determine the therapeutic purpose of, or anything else about, the classification system itself. They have virtually no control over the kinds of individuality that classification permits. Should staging eventually be correlated reliably with symptoms or prognoses, women may become able to use their stages with greater effectivity.

doctors' evaluations of patient experience--"physical findings" on the form. The terms used are instructive: "complaints" suggests a much less objective evaluation of pain than "physical findings" (corresponding to the usual medical terms symptoms and signs, respectively). Furthermore, it is unlikely that patients will be filling in the "complaints" section themselves; the expression of their complaints will be left up to their doctors, which reestablishes medical authority in the documentation of symptoms. The pain form simultaneously legitimates the pain of endometriosis patients and undermines their ability to account for it.

The description to be entered by doctors under "physical findings" is comprised not merely of things like fixation of the uterus, but importantly of patient response to the doctor's touch. The documentation of that response, of course, is dependent not only upon the patient's subjective experience and expression, but upon the doctor's subjective evaluation of patient experience and expression. Therefore, "physical findings" of pain, for all its objectivist connotations, includes such clearly subjective elements as patients saying "ouch" or flinching when the doctor examines particular areas of their bodies.

It also depends, importantly, upon the doctor's *noticing* and *accepting* the ouch or the flinch as a "physical finding", that is, upon the doctor accepting the validity of the patient's communication of her experience. However, doctors do not always validate patients' expressed experience of pain. Participants in the focus group research gave the following accounts of discussions with their doctors about the location and severity of their pain:

Beth: I said "I have all this pain on my left side all the time" and she says "Oh, that's your bowel, that's your bowel." I said "It's not my bowel. It happens in the middle of the month, it happens right before my period, and it's, like, really bad." "Oh, that's your bowel..."

Bobbi: He decided he was gonna do a Pap [smear] and that was really

bad...He goes, "If there was *anything* wrong with you, you would have been on the ceiling in pain after this exam." I'm thinking, you fucking *asshole*--you didn't see the tears streaming down my face? You didn't see my jaw clenched?

These accounts call into question doctors' capacity (or perhaps their willingness) to recognize and therefore document patients' expression of pain during physical examinations.

Assuming that the physician does take notice of the patient's "ouch" and records the location of the pain correctly, the patient's pain narrative may be validated by the physician's documentation of physical findings on the pain form. But this in itself is a means of reducing complexity. Gynecologists long have been puzzling over whether endometriosis pain is the result of biological or anatomical processes, rather than psychological disturbance (see below). The new pain form apparently seeks to solve this puzzle by matching up the 'objective' physical and surgical findings of the physician with the patient's complaints. A match, presumably, means that the pain has a physical origin; no match, presumably, means that psychological variables likely are involved. The sensations of the enigmatic endometriosis patient are made more readily documentable by the pain form; thousands of patients' sensations can be cross-checked with their physicians' physical and surgical findings.

There has been a growing recognition that endometriosis pain involves more than simple anatomical distribution and extent of disease (see *Canadian Consensus Conference on Endometriosis*, 1993; Fedele et al., 1990; Schenken, 1998; Stovall, Bowser, Archer, & Guzick, 1997; Vercellini et al., 1996) and the systematic correlation of pain symptoms with surgical and physical findings could enable research that, eventually, could lead to the development of better treatment protocols for pain. But given the current status of women with endometriosis as questionable symptom-reporters, it is possible that, by

enabling the systematic comparison of patient's "complaints" with their doctors' "findings", the new pain form may further undermine women's credibility regarding their accounts of pain. By presupposing that patient complaints alone are insufficiently credible evidence upon which to base documentation of the location, intensity, and indeed the existence of pain, the AFS pain form sustains the notion that physicians are the proper arbiters of the 'truth' of pain.

It could be argued that this is nothing new, that contemporary medicine always compares patients' symptoms with clinical signs. But in most medical encounters--particularly those involving acute conditions--the question "Where does it hurt?" is answered by the patient, and the physician looks for the *reasons* why it hurts, not for confirmation that it hurts. In a discussion about chronic pelvic pain, psychiatrist Renate Rosenthal notes that acute and chronic pain are treated very differently:

Our medical system is geared toward diagnosis and treatment of acute disorders. While acutely ill, the patient's illness is not questioned. Patients who fail to improve bring about very negative reactions in their care givers. This is especially true if the exact causes for the woman's discomfort are not known and if there is reason to believe that her complaints are out of proportion to any dysfunction. As mutual frustration mounts, the patient is referred to as a 'crock,' a 'turkey,' a 'gomer,' or a woman whose complaints are purely 'supratentorial' (Rosenthal, 1993:629).

Efforts to measure and objectivize pain are applied when the pain is chronic, not when it is associated with acute conditions. Apparently clinicians feel no need to measure and objectivize acute pain because they believe it exists and has an objective basis.

So what is different about the R-AFS pain form is that it *forces a systematic contrast* between patient accounts of pain with physicians' estimations of pain, building in an assumption that these accounts can vary. And in a positivist model, when accounts vary, it means that one of the accounts is wrong. The question becomes "Does it really hurt?" and this is a question for the doctor to answer. This question becomes pertinent in

relation to endometriosis patients because, as we shall see, the question of whether they 'really' hurt or whether their pain is psychogenic is precisely what is at issue. The pain form cannot be viewed in isolation from this very strong current in medical thinking about chronic pain in general and endometriosis pain in particular.

Classification is an integral part of knowledge creation; to make broad generalizations and distinctions, obviously one must group things. However, generalizations and distinctions--especially regarding people--are not neutral or isolated phenomena. They emerge within a broader epistemological and social context which affects the development of classification systems and the uses to which they are put. I am not interested in the question of whether endometriosis patients *should* be classified (they will be classified regardless). This project is about patients and endometriosis experts as epistemic agents. Consequently, I am interested in how the actual ways patients are classified (1) posit them as unreliable claimsmakers, (2) are related to other assumptions about their unreliability, and (3) provide insights about endometriosis experts' epistemological standards. The point, then, is not that endometriosis classifications do not work therapeutically (although of course a classification system that worked therapeutically would be a wonderful development). The issue is how they work epistemologically to discredit patient accounts.

Classifications for endometriosis have focussed on infertility, not pain. Part of the reason for this, undoubtedly, is that infertility is easier to measure objectively. But it seems reasonable to argue that the assumption that the primary problem with endometriosis is that it causes infertility, not chronic pain, may be related to assumptions that fertility is a primary life goal for normal women, while pain relief is secondary in importance. And the assumption that patients' self-reports of pain need to be compared

with physicians' 'findings' suggests that the self-reports alone are an insufficient *because unreliable* basis upon which to document pain. The R-AFS classification emerged within a medical specialty that also has a strong, long-standing tradition of defining the socio-demographic and psychological characteristics of women with endometriosis, codified in a 'typical patient profile.' Classifications for endometriosis have been affected by this central component of medical thinking about endometriosis. But even more than endometriosis classification systems, the typical patient profile has contributed to the construction of a monolithic endometriotic subject and to the delegitimation of patient accounts about pain within gynecological discourse.

2. The 'Typical Patient Profile'

As we have seen Audebert argue, the science of epidemiology is crucial to the development of appropriate classifications of endometriosis patients. The typical endometriosis patient profile has two components: epidemiological and psychological. Epidemiologically, the typical endometriosis patient has been described as a white, well-educated, thin, middle-class woman in her thirties or forties who has "delayed" childbearing. Psychologically, she has been described as intelligent, perfectionistic, egocentric, career-oriented, overanxious, and, where chronic pain is present, possessed of a tendency to exaggerate pain without attempting to solve it (see American College of Obstetricians and Gynecologists, 1983; Gomibuchi et al., 1993; Kistner, 1986:398-9; Low, Edelmann, & Sutton, 1993; Treybig, 1989 for recent examples of such descriptions). The connections between classification and the psychological component of the typical patient profile are particularly strong; so far there do not seem to have been any attempts to correlate epidemiological characteristics with R-AFS stage, but the R-AFS system is

used routinely in psychological research on endometriosis patients.

Unlike the R-AFS system, 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. Nevertheless, it has been described as an identifiable entity by critics. Attempts have been made to dismantle the typical patient profile, especially by the EA and other feminist health advocates (Boston Women's Health Book Collective, 1992), epidemiologists (Eskenazi & Warner, 1997; Houston, Noller, Melton, & Selwyn, 1988), and many gynecologists (Haney, 1990; Kennedy, 1991; Pauerstein, 1989; Sangi-Haghpeykar & Poindexter, 1995). Most endometriosis researchers now seem to feel that many elements of the typical patient profile are outdated and unsupported by evidence. For example, the *Canadian Consensus Conference on Endometriosis* report (1993:70) limits its discussion of the profile to one sentence: "The largest epidemiological study of endometriosis showed no evidence that race, age, social class, or personality types were associated with endometriosis." However, despite its controversial nature, 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 & Dmowski, 1989; Whelan, 1994; and see Chapter 4 of this volume). Many of the assumptions implicit in the R-AFS classification are also integral to the typical patient profile, and the two are mutually reinforcing. I discuss, first, the psychological component of the typical patient profile and its relation to the R-AFS classification; second, I discuss the epidemiologic component of the profile, and its connection to notions about the psychological abnormality of women with endometriosis.

i. *The Endometriosis Habitus: Psychology and the Typical Patient Profile*

The identification of a bi-directional causal link between women's reproductive and mental health has a long history within medicine (Astruc, 1985 {1743}; Cayleff, 1992; Ehrenreich & English, 1978; Moscucci, 1990; Showalter, 1985; Smith-Rosenberg & Rosenberg, 1984). In contemporary gynecology, this link is still being made; endometriosis continues to be constructed as a phenomenon whose etiology is both physical and psychological. Some of the top experts in the field have supported this construction. For example, in a fascinating application of psychosomatism, Dr. Robert Kistner, one of the leading proponents of the psychological profile, 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). Kistner was a member of the committee that developed the R-AFS classification for the American Fertility Society.

Carl Pauerstein has described such claims as assertions of an "endometriosis habitus" (1989:133)--a mental and physical constitution in certain women thought to predispose them to the disease⁴⁴--which he himself rejects. Women with endometriosis, he notes, "are alleged to be slender, neat, conscientious, intelligent, goal-oriented, and

⁴⁴Habitus is a common medical term used to describe the relation between the properties of individuals and a given disease entity. Habitus is defined as "the bodily constitution or physique, particularly by reference to external appearance; sometimes it is used to indicate apparent disposition to disease..." (Walton, 1994:344). Fleck (1986 {1927}:44) invokes the term to describe a component of the "pathogenesis of a single definite case [of disease]; its disposition, diathesis, constitution or habitus, its infection, original symptom, the origin of allergy, the development of pathological symptoms etc." It is interesting that common medical usage appears to focus upon physicality, but this definition of the endometriosis habitus combines physical and personality traits; whether this is common with many diseases or only with ones considered psychosomatic is unclear. A search on Medline for habitus as a title word indicates that habitus generally appears in conjunction with body build or habits that affect it (eating behaviours, exercise).

competitive. They are said to demonstrate evidence of increased androgenic activity, such as acne, hirsutism, and slight clitoromegaly" (Pauerstein, 1989:133). Interestingly, these characteristics are tied to cultural stereotypes about gender, and the transgression of these stereotypes. Allegedly, the woman with endometriosis is masculine in physical appearance; she is unusually hairy, has acne (associated here with androgenic hormones, though it also is associated with estrogen), and has an unusually large clitoris. She has the stereotypical mind of a man as well; she is intelligent, goal-oriented, and competitive.

In edited collections reviewing various aspects of endometriosis, one rarely finds an article devoted exclusively to the psychology of endometriosis. Some gynecological review articles about pain and endometriosis (though not infertility and endometriosis) assert that psychological factors may be implicated in endometriosis-associated pain (Barlow & Glynn, 1993:782-3, 786-7; and to a much lesser extent, Ripps & Martin, 1993:710-1). However, these review pieces tend to focus more on physical causes and treatments for pain. It seems that studies evaluating the psychological status of women with endometriosis are controversial. Nevertheless, such studies are getting published: several recent articles in medical journals report on research which evaluates the "neurotic," "depressive," "aggressive," and "anxious" tendencies of women with endometriosis who have chronic pain symptoms. A detailed discussion of some of these articles demonstrates the medical 'hypochondrialization' of women with endometriosis-associated pain and the consequent delegitimation of the claims of women with endometriosis.

One study report notes in its introduction that "pelvic pain can occur in women who have no detectable peritoneal disease, which suggests a psychologic factor involved in the pelvic pain of certain women. That is, psychologic status may influence the

perception of pain" (Gomibuchi et al., 1993:723). The authors of this study measured the "aggression" (assertiveness) of 58 women with endometriosis, 51 with dysmenorrhea⁴⁵ and 7 without. Despite the small number of non-dysmenorrheic women in the sample, the authors conclude that

...women with dysmenorrhea had relatively higher scores in obstacle-dominance type of personality. This is considered the personality that simply expresses complaints without deep consideration and takes no constructive attitude to resolution of the confronted problem. Therefore it is likely that some women with dysmenorrhea may express pain *exaggeratedly* without attempting to solve it (Gomibuchi et al., 1993:724; my emphasis).

Curiously, however, the authors also assert that the women with endometriosis who did *not* report dysmenorrhea may be psychologically abnormal (have "altered personality", *ibid*) as well. They exhibited "extragression personality...in which complaints are directed toward the surrounding environment"; this they view as potential evidence that these women may unconsciously "refrain from expressing pain despite the presence of objective situations that generally evoke pain" (*ibid*). These women also exhibited an "ego-defense type of personality...that is less assertive and shows a destructive attitude in the face of problems" (*ibid*). The authors wonder

whether pain is actually absent in women who have endometriosis but do not suffer from dysmenorrhea, or alternatively, they merely do not perceive pain *despite its presence*. The results of the present study suggest that the altered personality of women without dysmenorrhea may support this last possibility (*ibid*; emphasis added).

While pain usually is the hallmark of the psychologically maladjusted woman with endometriosis, this study suggests that all women, whether or not they have pain, are maladjusted. It appears to argue that pain, rather than being an intrinsically subjective phenomenon, is an objective state which may be incorrectly perceived by patients (they

⁴⁵Dysmenorrhea is the medical term for pain during menstruation.

may exaggerate it or not feel it). This can be read in connection with the R-AFS pain form which seeks to establish the objective existence of pain compared (and therefore potentially contrasted) to patients' perceptions of it.

A second study compares the psychological profiles of women with endometriosis (n=40) and of women with pelvic pain of other origins (n=40), in an attempt to rule out the confounding effect of chronic pain itself on psychological profiles (Low, Edelmann, & Sutton, 1993). Both groups were found to have high scores for "neuroticism" and "psychiatric morbidity." Women with endometriosis were found to have slightly higher mean scores in anxiety tests for both "state" (context-dependent) anxiety and "trait" (habitual personality) anxiety than both the non-endometriosis pain group and the "normal" population. The authors conclude that their evidence "matches to some degree Kistner's description of patients with endometriosis as over anxious and perfectionists" (Low, Edelmann, & Sutton, 1993:115). Why a high anxiety score would indicate a tendency toward perfectionism is not explained. The authors dismiss alternative explanations for the high anxiety scores, such as the fact that endometriosis patients may be at greater risk of infertility, face more uncertain prognoses, and suffer from greater stigma than patients with non-endometriosis-related pain.

A third study (Waller & Shaw, 1995) investigated the psychological functioning of four groups of women: Group 1, a control group (n=38) admitted for sterilization with normal pelvises; Group 2 (n=31), with minimal or mild endometriosis (R-AFS stages I or II) who complained only of infertility and not pain; Group 3 (n=18), with minimal or mild endometriosis who complained of dysmenorrhea, dyspareunia⁴⁶, or pelvic pain; and Group 4 (n=30), women with pelvic pain symptoms and no obvious pathology at laparoscopy.

⁴⁶Dyspareunia is the medical term for pain during sexual intercourse.

Note that women at higher R-AFS stages were excluded from the study, presumably because women with advanced endometriosis are considered to have a sufficient organic basis for their pain. As would be expected, the women in both pain groups (Groups 3 and 4) reported greater problems with dyspareunia, pelvic pain and dysmenorrhea and greater scores for depression and "somatic performance complaint" (complaints about the functioning of the body) than Groups 1 and 2, who did not complain of pain. There were no differences between the four groups regarding state or trait anxiety scores and lifetime number of sexual partners. Regarding sexual satisfaction, all groups were within the "normal range" except regarding frequency of intercourse; both groups complaining of pain reported less frequent intercourse than the women in the infertility-only and control groups. Groups 3 and 4 had dyspareunia (painful intercourse) scores 3 to 4 times higher than Groups 1 and 2; yet the authors assert without explanation that "these differences [in intercourse frequency] do not seem to be accounted for by the greater dyspareunia in groups 3 and 4" (Waller and Shaw, 1995:798).

The authors are less willing to psychologize endometriosis than the authors of the two other studies discussed above; because women with endometriosis and pain had similar psychological profiles to women with undiagnosed chronic pelvic pain, the authors conclude that "It does not...appear that certain psychological features make some women more vulnerable to developing endometriosis. It is more likely that women in chronic pain have substantial distress that leads to abnormalities of psychological functioning" (Waller and Shaw, 1995:800). However, they assert that it is not clear "whether differences in psychological characteristics alter perception and reporting of pain" (ibid).

Moreover, although the authors' stated objective is to "investigate whether there are psychological differences between women with symptomatic [pain] as opposed to

asymptomatic [infertility-only] mild endometriosis" (Waller and Shaw, 1995:796), elsewhere they refer to the infertile (but pain-free) women with endometriosis as a control group (ibid:798). The description of women with endometriosis-associated infertility as "asymptomatic" (ibid:796) is also curious, especially given gynecology's focus on treating infertility rather than pain (isn't infertility a symptom?). It suggests that infertile women with endometriosis are normal/healthy while women with pain are abnormal/ill.

A fourth study compared the psychosocial and emotional state of women with unexplained pelvic pain (n=51) and women with endometriosis and pelvic pain (n=40) (Peveler, Edwards, Daddow, & Thomas, 1996). There were no significant differences between the two groups for personality characteristics or mood symptoms: approximately 35% of each group "had global severity indices indicative of probable mood disorder" (Peveler, Edwards, Daddow, & Thomas, 1996:308)⁴⁷. Forty-one percent of the unexplained pain group and 70% of the endometriosis group "reported having suffered from 'nerve trouble' at some time--this was usually described as 'stress' or feeling depressed" (ibid). (It would be difficult to imagine any human subject who had not suffered from stress or depression "at some time".) Women with endometriosis had higher mean scores for dysfunctional social adjustment than women with unexplained pelvic pain, which the authors attribute to their greater usual pain severity and greater likelihood of being infertile. In particular, women with endometriosis had higher dysfunction scores for "parenting role area"; the authors argue that, because they are from higher socioeconomic

⁴⁷The authors note that, generally, 30% of patients with physical illnesses in hospital settings "have been shown to fulfil criteria for mood disorder" (Peveler, Edwards, Daddow, & Thomas, 1996:313). Several critical interpretations are possible: (1) endometriosis is not significantly more associated with psychological problems than other physical diseases; (2) physical disease may cause mood disorder; (3) being in a hospital setting may create mood disorder. (The majority of women in the Peveler study were interviewed immediately following laparoscopy, while still in the hospital.)

groups, women with endometriosis might have children later in life, "encountering more difficulty adjusting to parenting" (1996:313). It is unclear why having children later in life might present more adjustment problems, given that young parents frequently face economic and other hardships that more established ones do not.

The authors also found that more than half of these women had received prescriptions (usually tranquilizers or anti-depressants) from their general practitioners for this "nerve trouble," and 10% of the unexplained pain group and 20% of endometriosis patients had been referred to a psychiatrist (ibid). This information reinforces the belief that women with endometriosis and unexplained pelvic pain are mentally disturbed. However, it is not in fact clear whether these prescriptions and referrals were a result of general practitioners' assumptions that women with pelvic pain and endometriosis are psychologically disturbed and hence need psychiatric treatment, or whether the women had mental health problems independent of their ascribed mental status or physical symptoms. It is clear that many physicians practicing today have been trained to consider the possibility that endometriosis, dysmenorrhea and pelvic pain are psychogenic, as a review of gynecology textbooks will attest (see, eg., Jones, Wentz, & Burnett, 1988:246-7; Kistner, 1979:633; Smith, 1993:410-11; Tindall, 1986:533).

My observations suggest that, the more recent the publication, the less likely it is to explicitly assert that pelvic pain or dysmenorrhea are psychogenic. Most of the more recent sources caution physicians against assuming that pelvic pain is psychogenic before eliminating physical causes. However, they nevertheless present psychogenesis as a viable *potential* explanation for the problem in some cases, or argue that it is a contributing (if not primary) factor in many cases (see Barlow & Glynn, 1993; Rosenthal, 1993). And it must be remembered that most established clinicians and researchers today were schooled

at a time when dysmenorrhea and pelvic pain *were* described routinely as psychogenic in medical textbooks. It is not surprising, then, that 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 or referrals to a psychiatrist, rather than treatment for the pain (Ballweg, 1992b:753; DeMarco, 1991:18; Halstead, Pepping, & Dmowski, 1989; Lauersen & de Swaan, 1988:95; Whelan, 1994:87-91).

Infertility, too, sometimes has been constructed as psychogenic in gynecological studies. A search on the Medline database (20 June 1999) revealed 23 abstracts published in gynecology journals within the last 15 years that explicitly discussed the notion that infertility may be psychogenic⁴⁸. Three abstracts did not explicitly deny or support the theory of psychogenic infertility; the remaining 20 abstracts were evenly split on the question, with 10 critiquing the theory and 10 supporting it. However, none of these abstracts--and no medical publications that I have ever come across--suggests that the infertility of women *with endometriosis* was psychogenic; generally, unexplained infertility (infertility with no observable organic basis) is constructed as psychogenic.

However, as the above analysis demonstrates, articles in gynecology journals *have* explicitly argued that the pelvic pain of women with endometriosis may be psychogenic. This suggests that, when women with endometriosis experience infertility, endometriosis is taken to be a sufficient organic cause of infertility; but when women with endometriosis experience pain, the presence of endometriosis may not be taken to be a sufficient physical cause for the pain. In the latter case, researchers address the possibility that "some women

⁴⁸Time did not permit analysis of the journal articles themselves. Had such an analysis been undertaken, more discussion of the psychogenic nature of infertility in general, and of endometriosis-associated infertility in particular, may have been evident.

are psychologically more vulnerable to developing endometriosis" (Waller and Shaw, 1995:797). The result is that, often, endometriosis is constructed as a psychogenic disease when pain is present, but *not* when infertility is present. Thus, curiously, the same disease entity--endometriosis--may be construed as a mental illness in some patients, and a physical illness in others, depending upon what symptoms patients present.

The psychologizing of endometriosis-associated pain appears to be linked to the development of classification systems for endometriosis. Gynecological researchers sometimes bend over backwards in attempts to demonstrate that the R-AFS classification system correctly predicts severity of pain, based on the assumption that women with more severe disease should have more severe pain symptoms⁴⁹. Robert Schenken, for example, reviewed 7 studies that dealt specifically with relation of pain symptoms to stage. Four of these studies demonstrated a correlation between stage and pain symptoms, while three did not. However, in his conclusion, Schenken states that "Several studies have shown that pelvic pain symptoms correlate with the stage of endometriosis" with no mention of the studies that refute this assertion (1998:274). It seems that some gynecologists fervently want to believe that their classification systems bear some relation to the severity of pain symptoms experienced by women. Only if evidence refuting such a relation is ignored and the pain of women with anatomically small amounts of endometriosis is psychologized, can this belief be maintained.

Of the four studies on psychological variables reviewed above, three made use of the R-AFS classification for endometriosis. In one, the overwhelming majority of subjects

⁴⁹Yet Fedele and colleagues found no association between pain and anatomical extent of disease as classified by R-AFS stage. They argue that "the biology and natural history of endometriosis [may] not correspond to the laparoscopic picture" and that, while small patches of active endometriosis may not impair pelvic anatomy, they may produce lots of prostaglandins, producing pain symptoms (Fedele et al., 1990:157).

in one study were classified as stage I or II of the R-AFS classification (Low, Edelmann, & Sutton, 1993). In the Waller and Shaw study (1995), only women with stages I and II were included in the study group; women with more severe disease stages were deliberately excluded. In the study by Peveler and colleagues (1996), R-AFS score did not correlate with pain symptoms; then the authors divided subjects with endometriosis into two groups, of lower and higher R-AFS scores, and women with higher R-AFS scores did report greater pain scores on one test for pain severity, but not on the other test. These authors excluded women with minimal endometriosis from part of their analysis, on the basis that "minimal endometriosis (AFS scores below 6) may not be clinically significant" (Peveler, Edwards, Daddow, & Thomas, 1996:311), despite the fact that these women, like all the other subjects in the study, reported pelvic pain lasting three months or more.

The use of the R-AFS classification in these studies, therefore, strongly suggests that, when studies of psychological factors are undertaken, women with severe anatomically-observable disease are considered to have a sufficient physiological cause for their pain, while women assigned to stages I or II of the R-AFS classification are particularly suspected of having a psychogenic basis for their pain. The R-AFS classification is apparently being used to define some patients as potentially psychologically disturbed based upon the apparent misfit between their assignment to a low R-AFS stage and the great severity of their pain symptoms.

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 medical and surgical treatment of infertility (which, at least in the endometriosis literature, is not constructed as psychogenic), while pain, which is often psychogenic, may require

counselling. The second assumption is that the anatomic amount and distribution of disease, determined via surgery and classified according to the R-AFS classification, determines symptoms. While many researchers acknowledge that the R-AFS classification predicts pain symptoms poorly and that gynecologists have had rather limited success in treating endometriosis-associated pain, it may be more comfortable for other gynecologists to dismiss as psychogenic those cases which do not support the system or gynecological claims to expertise in pain treatment. Thus, the R-AFS classification and the typical patient profile may work together to reinforce the psychologization of some women's pain symptoms when gynecologists cannot treat those symptoms effectively.

There is no clear consensus on the validity of the psychogenesis thesis in regard to endometriosis-associated pain. The findings of high rates of psychopathology in women with pelvic pain have been criticized on methodological grounds (Stout, Steege, Dodson, & Hughes, 1991), and at least two studies of the issue have argued that the psychological abnormalities found in women are more likely to be the result, rather than the cause of, pain symptoms, or even a result of the anxiety that accompanies "contact with the medical world" (Renaer et al., 1979:80; see also Waller & Shaw, 1995)⁵⁰. Most authors argue that research to date has not conclusively demonstrated the direction and causal mechanism of

⁵⁰However, in the study by Renaer and colleagues (1979:79), it is suggested that women with *undiagnosed* chronic pelvic pain may be psychologically abnormal: while subjects with pain and endometriosis and a pain-free control group were described as "very cooperative," several women with pain and no organic pathology "were not, and only 15 [out of 28] completed the [psychometric] questionnaires." The authors suggest that "It is possible that the patients who did not comply with our request had more psychological problems than those who completed the questionnaires." I would suggest that a likely alternative explanation is that women with undiagnosed pain probably are even more likely than women with endometriosis to have been told that their pain is psychogenic and therefore would be suspicious of researchers who asked them to fill out psychometric questionnaires. Paradoxically, their acts of resistance to psychologization may further psychologize them.

the relationship between psychological abnormalities and pain symptoms. However, the majority of sources reviewed for this section argue that, in at least some cases, the pain of women with diagnosed endometriosis may be psychogenic.

Most importantly, no published gynecological source examined thus far has questioned the need for studies of the relation between endometriosis, pain, and psychology. It is curious that many gynecologists--whose expertise lies in the treatment of bodies, not minds--apparently consider it important to examine the possible psychological roots of a phenomenon that they themselves define, diagnose, and treat as a physical disease. It seems contrary to their professional interests to assume that one of the largest and most financially lucrative conditions under their purview could be better treated by psychiatrists than by themselves. But as gynecologists themselves admit, their record of treating endometriosis has been anything but stellar. Perhaps their claims to expertise regarding bodily disease can be sustained only if they explain away this poor record by converting endometriosis--or at least some of its symptoms--into a mental disease beyond the purview of their expertise. Alternatively, perhaps these forays into psychology represent an attempt to broaden the purview of gynecology, to establish it as the realm of science that knows every facet of a woman: her mind, as well as her body. Historically, gynecology has never been silent about women's minds. Perhaps social scientists (eg. Gordon, 1988) need to reconsider their assumption that medicine adheres to a strict mind-body dualism in light of such holistic--and totalizing--claims-making practices within gynecology.

ii. *The Career Woman's Disease: Epidemiology and 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' childbearing (see American College of Obstetricians and Gynecologists, 1983; Chalmers, 1975:1; Goldman & Cramer, 1990; Haney, 1990; Kistner, 1986:398-9; Pauerstein, 1989; Tindall, 1986:358-9; Treybig, 1989). This 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 (see Chatman, 1976; Chatman & Ward, 1982; Goldstein, DeCholnoky, & Emans, 1980; Lamb, 1987; Lamb, 1990).

While epidemiologists generally reject the existing typical patient profile as artifactual, they are studying several other potential risk factors, such as menstrual characteristics and disorders, weight, height, hair colour, tampon use, family history, and immunological disorders (Cramer, 1987; Eskenazi & Warner, 1997; Goldman & Cramer, 1990; Haney, 1990; Houston, Noller, Melton, & Selwyn, 1988; McCann et al., 1993; Pauerstein, 1989; Vercellini et al., 1997)⁵¹. The increasing evidence that endometriosis is an inherited condition (*Canadian Consensus Conference on Endometriosis*, 1993:3) could eventually lead to the development of genetic markers. Mol and colleagues (1998) review the research on CA-125, a cancer antigen found in the blood that, to date, has been the focus of efforts to develop a biochemical marker screening test for endometriosis. The authors state that, although its general diagnostic performance thus far has been disappointing, CA-125 has already demonstrated its utility in the treatment of infertility patients with severe endometriosis. The search for another, more sensitive biochemical marker is underway (Eskenazi and Warner, 1997:254). In the meantime, epidemiological

⁵¹Strenuous exercise has been identified as having a protective effect against endometriosis; interestingly, so has heavy smoking (Eskenazi & Warner, 1997:251-2; Mangtani & Booth, 1993:86).

data about women with endometriosis are the only potential means for establishing high risk groups.

Commentaries on socio-demographic and lifestyle risk factors for endometriosis abound in the medical literature, but according to the authors of one recent review, there are few well-designed epidemiologic studies on the subject (Eskenazi & Warner, 1997). These authors reviewed studies according to whether they: (1) were cohort or case-controlled; (2) included only subjects whose endometriosis had been surgically confirmed; (3) provided clear selection criteria for controls; and (4) took into account possible confounding factors. Of almost 100 studies reviewed, only 12 met these four criteria for good study design. These and other critics have argued that the patient profile is an artifact of various medical biases and flaws in study design, but elements of the profile continue to be advanced in the gynecological literature. A consideration of medical claims about two traditional aspects of the profile--socioeconomic status and reproductivity--demonstrates this lack of consensus; but it also demonstrates the continued currency of profiling as a worthy goal. I focus here upon these two aspects because they are most related to constructions of women with endometriosis as socially and psychologically abnormal. This construction of abnormality, I argue, further reinforces the epistemological delegitimation of women with endometriosis.

Many medical texts and clinicians assert that endometriosis is less common in poor women than in middle and upper class women (Darrow et al., 1994; Pauerstein, 1989); it has been described as "a disease of the rich" (Tindall, 1986:358). The majority of epidemiological publications are quite critical of this claim but there is no general consensus. Several sources invoked this claim (Goldman & Cramer, 1990:27; Peveler, Edwards, Daddow, & Thomas, 1996:307) and other authors, though themselves critical of

it, present evidence from various studies that lend support to it (Houston, Noller, Melton, & Selwyn, 1988:793; Mangtani & Booth, 1993:85).

Certainly, however, there is consensus that women who are *diagnosed* with the disease tend to be from higher socioeconomic groups. Medical and epidemiological explanations for this are varied. It has been suggested that some studies measure socioeconomic status inappropriately, fail to control for race and age⁵², varying access to medical services, and other selection biases (Eskenazi & Warner, 1997; Houston, Noller, Melton, & Selwyn, 1988; Pauerstein, 1989; Signorello et al., 1997). Several studies have found no association between endometriosis and class (Eskenazi & Warner, 1997; Matorras et al., 1995; Vessey, Villard-Mackintosh, & Painter, 1993) or education (Darrow et al., 1994). Due to problems with those studies that show support for a SES-endometriosis link, and the existence of several large studies that show no support for this link, Mangtani and Booth probably speak for the majority of observers when they assert that "the quoted socioeconomic and ethnic differences in disease prevalence are not well founded" (1993:87).

While SES in and of itself generally is not assumed to be a risk factor for endometriosis, many authors have claimed that a related phenomenon--the greater tendency of wealthier, especially "career" women, to marry later, have fewer children, and "delay" pregnancy until a later age--may explain the correlation between endometriosis

⁵²It has often been claimed that black women are less likely to develop endometriosis, although the studies have been criticized on the grounds of flawed methodology and racist assumptions. Another aspect of the typical patient profile is age: endometriosis is thought to be more common in, and is more commonly diagnosed in, women in their thirties and forties. For discussions of race and age, See Eskenazi & Warner, 1997; Goldman & Cramer, 1990; Goldstein, DeCholnoky & Emans, 1980; Haney, 1990; Houston, Noller, Melton, & Selwyn, 1988; Mangtani & Booth, 1993; Pauerstein, 1989; Sangi-Haghpeykar & Poindexter, 1995.

and high SES (Pauerstein, 1989:130). Related to this theory is the common belief that endometriosis is thought to be connected to stress (as noted in the discussion on endometriosis and psychology). For example, according to Niels Lauersen, clinical professor of Obstetrics and Gynecology at New York Medical College, career women's stressful lives wreak havoc on their immune systems. In a book written for women with endometriosis, he argues that women working outside the home today have too many roles to balance, which leads to stress and, consequently, to endometriosis:

In these transitional times, working women are most likely to succumb to endometriosis.

How do I know this?

I'm a gynecologist, a specialist in women's health issues, a scientist who weighs the minutiae of laboratory research before making an informed decision, but I am also a pragmatist and a humanitarian. I see who suffers from what and I set about to help them in an efficient and compassionate manner. And so I notice that nearly 95% of endometriosis patients are women under extreme stress who work or have worked (Lauersen & de Swaan, 1988:7-8; emphasis in original).

By "these transitional times," Lauersen presumably is referring to recent changes in gender roles⁵³. His argument suggests that "working" women are suffering from their involvement in the work world of men, which is supposedly more stressful than the traditional (presumably work-free) world of women--a claim that stay-at-home mothers and homemakers likely would contest!⁵⁴ But critics have charged that such arguments are specious, because professional women are more likely than other women to seek medical

⁵³While Lauersen locates the problem in the social context, he does not advocate changes to that context, such as a greater sharing of work and familial responsibilities among partners of both sexes. Instructive in this regard is Waitzkin and Britt's (1989) argument that, when physicians invoke social context as a causal role in illness, they individualize it, construing illness as a problem for the individual to deal with (through therapy or tranquilizers, for example), rather than one which may be ameliorated through broader social changes.

⁵⁴On the stresses and strains faced by full-time homemakers and stay-at-home mothers, see the classic works by Freidan (1963), Luxton (1980), and Oakley (1974).

help for any health problem and probably are better able to achieve a diagnosis, due to their ability to choose their physician and the better care that wealthier, better educated private patients tend to receive (Ballweg, 1984; Breitkopf & Bakoulis, 1988:51; Kennedy, 1991).

In the contemporary medical literature, it is rare to see such bald assertions that having a career puts one at risk of developing endometriosis. Related arguments generally are more implicit and complex, requiring the assertion of two less controversial claims: first, that middle-class professional women tend to have children relatively late in life; and second, that having children late in life is a risk factor for endometriosis. The latter claim, that "family planning" causes endometriosis, was first made by J. V. Meigs in 1938; Meigs believed that years of menstrual cycles uninterrupted by pregnancy provided greater opportunity for the development of endometriosis (Houston, Noller, Melton, & Selwyn, 1988:796). This theory has some scientific support in that endometriosis often seems to atrophy during pregnancy or the use of medications that inhibit ovulation (Barbieri, 1990; Eskenazi & Warner, 1997; Goldman & Cramer, 1990; Kruitwagen, 1993)⁵⁵. Also, it is quite well-established that women with endometriosis tend to have fewer children than other women (Darrow et al., 1994; Eskenazi & Warner, 1997; Houston, Noller, Melton, & Selwyn, 1988:796; Sangi-Haghpeykar & Poindexter, 1995). Thus, the idea that low parity or nulliparity⁵⁶ may be a risk factor for endometriosis has found a receptive audience among many authors, including some who are critical of claims that race or SES may be

⁵⁵Kruitwagen (1993) goes so far as to refer to menstruation as "the pelvic aggressor"--a fascinating construction of female physiology which merits its own analysis.

⁵⁶Parity refers to the number of children born to a woman; thus, low parity refers to a lower than average number of child births, while nulliparity refers to an absence of child births.

risk factors for endometriosis (eg. Eskenazi & Warner, 1997:249; Mangtani & Booth, 1993:86; Peveler, Edwards, Daddow, & Thoomas, 1996:313; Sangi-Haghpeykar & Poindexter, 1995:986).

But while most current epidemiological reviews do not contest the existence of a link between low parity and endometriosis, they tend to look beyond the delayed pregnancy theory to explain the link. They often argue that, since endometriosis is associated with infertility, it is possible that the tendency to have few children is a *result*, rather than a cause, of endometriosis; thus, the low parity of women with endometriosis may not be "voluntary" and may not precede, but instead may result from, the development of the disease (Darrow et al., 1994; Goldman & Cramer, 1990:22; Mangtani & Booth, 1993:87; Sangi-Haghpeykar and Poindexter, 1995:990).

Darrow and colleagues (1994) conducted the first epidemiological study designed to test the hypothesis that women with endometriosis are career women who voluntarily delay childbearing. They compared 104 women with endometriosis with two control groups: 100 of their friends ("friend controls"); and 98 "medical controls", patients from a gynecology and infertility practice who did not have endometriosis (many of these women were infertile for other reasons). There were no significant differences between women with endometriosis and either control group in mean age at first pregnancy, marital history, patterns of contraceptive use, or decisions to delay pregnancy; nor were there differences in education. The authors conclude that "[o]ur results, overall, do not support simplistic assumptions that characterize endometriosis patients as career women who voluntarily delay pregnancy" (Darrow et al., 1994:506).

Although there is little evidence that endometriosis results from delayed childbearing, the phrase "delayed childbearing" is still commonly used, and rarely

deconstructed, in gynecological publications. Stephen Corson's text provides one example:

Actually, an apparent increase in endometriosis prevalence...may be a consequence of delayed child bearing in combination with methods of contraception other than those which suppress ovulation. Until very recently in human history women in the reproductive age group were either breastfeeding or pregnant, but not ovulating in either case. Women may not be bioengineered to deal with long intervals of repeated ovulation (Corson, 1992:13)

We see here a reflection of the hypothesis first advanced by Meigs in 1938; the idea still has currency. Corson notes that while this theory is "telologically [sic] attractive, little or no data are available for epidemiologic support" (ibid). But his--and many others'--invocation of the phrase "delayed childbearing" has clear implications regarding the proper reproductive behaviour of women, implications which never are criticized, even by critics of the theory of delayed childbearing. First, it implies that women should bear children early in their lives, a common assumption within medical circles⁵⁷. Second, it implies that childbearing is inevitable at some point in a woman's life. In gynecological discourse, normal women want to have children; women who voluntarily delay childbearing are psychologically abnormal; and those who don't want children at all are, apparently, too abnormal to bear mention. The focus upon *voluntarily* delaying childbearing virtually suggests that some gynecologists view endometriosis as nature's 'punishment' for deviance from the normal path of womanhood.

⁵⁷Pregnancy in women over 35 is typically characterized as high risk in the U.S. and Canada.

3. Epistemological Underpinnings: Good Science and the Containment of Subjectivity

While many physicians have challenged particular elements of the dominant classification system and the 'typical patient profile', the aims themselves are not challenged, apparently because the core claims and epistemological assumptions that underlie them are accepted by all players. The basic principle of endometriosis science seems to be that the subjectivity of patients and clinicians distorts knowledge, and must be contained. Efforts to contain the subjectivity of physicians include: the elimination of inter-physician variation in the description of endometriosis cases by providing standard classification systems and increasingly more directive staging protocols; and the enforcement of "good scientific practice" in studies on the psychology and epidemiology of endometriosis--the elimination of "myths" and personal prejudice, the validation of survey instruments, the use of large study populations and case-controlled studies, the criticism of "methodologically flawed" studies.

Containing the subjectivity of patients is particularly important because their most common symptom, pain, is intrinsically subjective, cannot be objectively measured, and often cannot be explained by traditional appeals to anatomic extent and distribution of disease. Efforts to contain the subjectivity of patients include: attempts to develop numeric scoring systems for pain that check the validity of women's "complaints" by comparing them to physicians' "findings"; psychological evaluations of patients to provide clues as to the trustworthiness of their narratives; and the development of biochemical markers and socio-demographic "risk groups" (determined scientifically) that provide a firmer basis upon which to investigate for endometriosis than the epistemologically dubious pain complaints of women. Correlating anatomic extent of disease with

symptoms, resolving discrepancies between visual data and patient narrative by employing psychological tests and statistics to make claims about patients' psychosocial dysfunction, and identifying the socio-demographic populations most prone to such dysfunction, represent attempts to objectivize, standardize, contain, and thereby control the subjective elements of disease.

The broad epistemological model advanced in many published medical sources on endometriosis accords with that set forth by Deborah Gordon in an often-cited article (Gordon, 1988). She characterizes biomedicine as based upon two basic tenets: naturalism and individualism. Naturalism is characterized by materialism: "the universe consists of discrete material essences, albeit often invisible, which are fixed and stable in their identity...Reality is directly proportional to materiality...the more physical, the more real...'Real' illness corresponds to the degree to which physical traces show up in the body" (Gordon, 1988:24). Naturalism employs a distinction between nature and human consciousness of it, between objectivity and subjectivity--in medicine specifically, between signs and symptoms, disease and illness: "Health or illness is defined more through objective data offered by the body than the experience of the patient...In medicine it is assumed that emotions can certainly cause illness, but 'psychosomatic' or 'functional' illness, not 'real' illness" (Gordon, 1988:25).

Naturalism is atomistic; parts have meaning independently of the whole. In medicine, disease has an identity separate from its host, and the body is divided into parts "approached as autonomous units" (Gordon, 1988:26). A divide between nature and culture is invoked, and adequate representation gets at nature rather than at cultural understandings of it: "Meaning is in the correspondence between representation and external reality. Disease taxonomy mirrors nature's 'real' diseases" (Gordon, 1988:27).

Cultural considerations relate exclusively to the patient's views and understandings, not to medical categories or to the diseases or biological mechanisms they represent (Gordon, 1988:28).

Naturalism is characterized by a belief in scientific progress and in nature as autonomous from time and place. Medicine is conceived of as a cumulatively progressing toward truth about disease, "primarily one truth, which is best captured in the neutral language of numbers (Gordon, 1988:29)⁵⁸. Abstractions are taken to be real entities: theorized 'causes' (disease entities) are equated with illness states, and a "hypothetical average man" used as the model to explain the cause's action on the average body (Alan Young's term, in Gordon, 1988:29). Knowers know by copying an object "as accurately as possible onto his/her mental sketchpad," but representation is not enough, as the cause of the phenomenon must be known: "Truth is behind things, not in them" (Gordon, 1988:31). Knowledge is acquired through senses, which are ahistorical and neutral. Vision is the dominant sense; it "fosters separation between subject and object", especially as compared to touch, and supports an ontology of "things-in-themselves" (Gordon, 1988:32). The agent of knowledge is the individual. Gordon argues that "This 'epistemological individual' of the empirical test of the senses contrasts with other loci of knowing--specifically in tradition or in the authority of others" (Gordon, 1988:31). Ideal knowledge is "not natural, everyday knowledge...[but] based on manipulations of both the known and the knower" (Gordon, 1988:31). The knower is manipulated in the sense that

⁵⁸Gordon argues that medicine's public has played a pivotal role in the reification of the one-truth model: "Physicians increasingly are expected to 'tell the truth' to patients about their diagnosis and prognosis, assuming that there is *a* truth to be told" (Gordon, 1988:29). However, as we shall see in the next chapter, the primary truth that endometriosis patients, who are acutely aware of the gaps and contradictions in medical knowledge, want their doctors to tell is the truth of their uncertainty.

s/he must achieve objectivity through detachment from values, bias, interest, and everyday life. The result is a distinction between knowledge and practice, manifested in the basic science and clinical years in medical education (Gordon, 1988:32)

Certainly Gordon's description applies to formal representations of what constitutes good medical knowledge--representations published in journal articles, used to evaluate the claims of studies and develop the foundational claims, goals, and protocols of endometriosis science. But there is a subtext to these articles that the attentive reader may have noticed--that of clinical experience. While this study does not investigate clinicians' views about experience directly or systematically, a good number of authors--many of them practicing physicians--have challenged the equation of the formal biomedical model with actual medical knowledge. They argue that notions of clinical judgment, practice, tacit knowledge--the fruits of clinical experience--are integral to medical knowledge and, importantly, to physicians' understanding of their own knowledge⁵⁹. These authors indicate that clinicians are not so unreflexive as Gordon's depiction of the biomedical model suggests. Rather, they argue, clinicians are keenly aware of the gaps between official biomedical epistemology and medical knowledge practice. I turn now to a consideration of these authors, and to the evidence of experiential reasoning that can be found in gynecological texts about endometriosis.

⁵⁹This is not a new argument; it was made in 1961 by Howard S. Becker and colleagues (Becker, Geer & Hughes, 1961) and Charles Hayter (1998:2) notes that, in history, "the dichotomy between the ideals of scientifically grounded medicine and actual clinical practice has long been recognized." Yet, in the sociology of medicine, medical ways of thinking still are described routinely in terms of "the biomedical model." See, for example, the recent sociology of medicine textbooks by Annandale (1998:6-7) and Nettleton (1995:3-5).

II. From Principle to Practice: Clinical Experience in Medical Accounts

For me, what really highlighted the difference between official medical discourse and clinical practice--and the inadequacies of studying only medical texts in ascertaining medical epistemologies about endometriosis--was an informal discussion with my own doctor, an established Winnipeg gynecologist and infertility specialist who treats many endometriosis patients (December 23, 1999). I asked him what he thought about the R-AFS classification and how much he relied upon it in his work with endometriosis patients. He said that he and other "experienced" surgeon-clinicians don't pay much attention to the classification because its division of stages is arbitrary and not very useful clinically. Instead, they have their own method of drawing inferences about, for example, a patient's chances of getting pregnant or getting pain relief from a particular kind of treatment. They visualize many endometriotic pelvises over the years, treat the patients, and note the outcomes of treatment for those patients. Over time, they get a "sense"--based on a great accumulation of anecdotal evidence and subjective evaluations--of how extent and site of endometriosis affect a patient's prognosis and how to treat the patient; and this sense, he feels, is a better guide than the R-AFS classification.

The process he describes is an informal one, based on a combination of personal intuition, generalizations drawn from visual evidence (but not based on any formal measure of endometrial lesions), concrete outcomes such as patient achievement of pregnancy, and patients' self-reports about how they are feeling. This kind of model stands in stark contrast to the scientific presentation of the R-AFS classification and, in its reliance on personal experience, it has much in common with patient learning and claims-making. Doctors' need to "take a look," then, may be less about establishing evidence that is objective in the usual scientific sense--the representation of external reality

in a value-free way that is not changed by the viewer--than about establishing a familiarity with the object-body. It is objective, but in the sense that it objectifies the patient--it relies on the doctor-subject's gaze of the patient-object--not in the sense that it is non-subjective. The doctor's experience and subjectivity clearly are operative here. Patients themselves claim, as we shall see, that subjective, experience-based understanding of an illness is deeper than the Other's (usually the doctor's) understanding--that no one can "really" understand endometriosis unless they have it. Doctors and patients locate "good" experiential knowledge differently, and provide different empirical foundations for that knowledge. Doctors locate it in themselves, and the foundation usually is visualization, discussion, and treatment over time of many patients. Patients locate it in themselves, and the foundation usually is the bodily sensations (especially pain) and emotions of the Self. Both are empirical, based on sensory evidence and trial and error; both are subjective, based on consciousness and perception; both are experiential. In fact, it was my gynecologist's use of the term 'experience' that most caught my attention and emphasized the inadequacies of presenting medical and patient epistemologies dichotomously, the former based on scientism, the latter on experience.

Something like the model of clinical experiential epistemology that my doctor suggested in his comments has been described by several authors, who argue that the formal epistemological model promoted in medicine does not grasp much of what clinicians actually do. The critique is summed up by Kathryn Montgomery Hunter (1991:21), who observes that

the concept of the biomedical model points to what scarcely exists in practice. Indeed it is difficult to imagine clinical medicine attempting to proceed as if it were a laboratory science, for its 'material' is not passive, nor is it made up of comprehensible or invariant objects...The idea of medicine as a science remains splendidly useful for its reification of disease and thus for the encouragement of greater precision in diagnosis and

treatment; but as an exclusive guide to the care of patients, clinicians for the most part have understood that it is more honored in the breach than in the observance. As myth, it goes on serving as an ideal of medical-scientific rigor which physicians hope to approximate but do not put into practice because of its potential harm to patients.

There are three main points to this critique, which I address in turn: (1) science is an inadequate model for clinical knowing; in practice, subjectivity and interpretivism are central to clinical knowledge creation because (2) physician experience is an integral component of clinical knowledge and (3) patients' subjective accounts of illness, though unreliable, are foundational to medical knowledge of disease. Along the way I include excerpts from gynecological texts to demonstrate how these critiques are integrated into medical understandings of endometriosis and endometriosis patients.

1. The Inadequacies of Science

Many of the authors who have made these critiques are medical experts: Kathryn Montgomery Hunter (1991) is an associate professor of medicine and bioethics at Northwestern University; Ludwik Fleck was an M.D. and microbiologist who conducted clinical tests and immunological and bacteriological research (Trenn & Merton, 1979b); Kirsti Malterud (1995) is a Norwegian family physician who teaches at the University of Bergen; H. Tristram Engelhardt, Jr. (1990) is an M.D., Professor of Medicine and Community Medicine at Baylor College of Medicine and of Philosophy at Rice University; Josep Comelles (2000) is a Spanish M.D. who now teaches in social anthropology and philosophy at the Universitat Rovira i Virgili in Tarragona, Spain; Leon Eisenberg is a professor at Harvard Medical School (Eisenberg, 1977); and Cecil Helman (1978) is a family physician in Middlesex, near London, England. That three Americans, a Norwegian, a Spaniard, and an Englishman make related arguments suggest that their

analysis may be applicable to Western biomedicine in general. The fact that they practice and teach medicine suggests that their analyses may be an important corrective to representations of medicine as a mainly scientific field of knowledge (such as that provided in Gordon, 1988).

These authors agree that the epistemological model of the natural sciences is valorized within medicine. Malterud states that

Medicine claims to be a discipline founded on scientific knowledge. Within the medical culture, knowledge is commonly interpreted as a matter that can be empirically verified by the scientific, *biomedical* model. This is considered synonymous with empirical approaches, demanding any variable be objectively observable, isolated, and controlled, as implied in the biomedical paradigm (Malterud, 1995:184; emphasis in original).

Comelles notes that "Any observer can see that modern biomedicine is not interested in knowledge of the local, political, and cultural context of disease...The model of medical practice on which biomedicine is based...is characterized by biologism, individualism, mercantilism, and pragmatic efficiency" (2000:42). Yet he notes that "the biomedical model is constantly obliged to carry out somewhat complicated negotiations with social and cultural contextual variables" that cannot be reduced to scientific fact (ibid:44); and Malterud asserts that "the traditional medical epistemology fails to represent medical knowledge adequately. The human interaction and interpretation which constitutes a considerable element of clinical practice cannot be investigated from this epistemic position" (1995:184). Hunter asserts that an "aura of scientific discovery surrounds clinical medicine"; the advances of the twentieth century have fostered a belief that clinical practice soon will become more certain and scientifically determined. Clinicians are "taught to...regard such methods as the differential diagnosis and clinical epidemiology as scientific" (1991:117). Physicians' views of their own abilities "are distorted by our narrow understanding of medicine as a realm of knowledge that is or can become as

certain as chemistry or physics" (ibid:48). They seem unaware that their method of clinical reasoning bears a greater resemblance to the interpretive human sciences than to the natural sciences of the laboratory (1991:117-8).

Fleck outlines several differences between medical and 'hard science' ways of thinking:

A scientist looks for typical, normal phenomena; while a medical man studies precisely the atypical, abnormal, morbid phenomena. And it is evident that he finds on this road a great wealth and range of individuality of these phenomena which form a great number, without distinctly delimited units, and abounding in transitional, boundary states...How does one find a law for irregular phenomena?--this is the fundamental problem in medical thinking (Fleck, 1986 {1927}:39).

Engelhardt notes another other key difference:

...all knowing is not the same. Claims made by applied and unapplied scientists differ in important ways...[in medicine] one does not simply want to know why a patient is dying, one wants to know in order to keep the patient from dying, make the dying easier, or at least accord with the wishes of the patient. Generally, one seeks power to intervene on behalf of a rich matrix of non-epistemic concerns (1990:69).

The limits of the scientific method for medicine, then, include its difficulties in dealing with the single case, with complexity and irregularity; and with its treatment of its object of study as passive material on which to be worked, without regard for the material's wellbeing.

We see in gynecological texts a recognition of these problems in debates about the applicability of scientific methods to the study of endometriosis. Certainly, many authors champion such methods:

It is without question that the advancement of conservative therapy for endometriosis-associated pain will depend on the results of well-controlled and randomized studies (Ripps & Martin, 1993:715).

...psychometric tests...have the advantage of offering standardized results to which all subjects can be compared. At the same time the results of the psychological tests are amenable to statistical procedures and can be used

to test certain hypotheses" (Renaer et al., 1979:76).

Unfortunately, many of the studies [on endometriosis]...suffer from basic design flaws, often being descriptive or anecdotal...Only recently have researchers begun to apply scientific rigor to basic and clinical investigations of endometriosis...Clinical studies, too, have become more sophisticated: the use of randomized clinical trials, meta-analysis, regression analysis, and even neural networks has threatened to thrust endometriosis from phenomenologic to evidence-based (Guarnaccia & Olive, 1997:455).

However, particularly in regard to endometriosis classification, the applicability of common scientific methodological protocols to medical research is hotly debated. In an editorial attacking the push in medical research circles for randomized clinical trials (RCTs) and statistical analysis, James Wheeler has argued that researcher bias cannot be precluded through these methods, and that RCTs cannot answer many crucial questions for medicine because of the ethical problems they raise (Wheeler, 1990a:220): sick people cannot be assigned to no-treatment control groups, for example, and human beings cannot be exposed to harmful substances or experiments.

While Wheeler certainly is not anti-scientific (he advocates validation of pain measurement scales, for example), he criticizes the use of the R-AFS classification and its reduction of endometriosis to numerical scores in a response to a critical letter about his editorial written by an endometriosis specialist. In his response, Wheeler advocates the "Verbal and graphical documentation of surgical findings, rather than reliance on unvalidated arbitrary classification scales (does anyone really think that American Fertility Society endometriosis score represents 'harder' data than pain relief using validated instruments such as the McGill Pain Questionnaire??)" and the "Inclusion of a spectrum of disease similar to what is seen clinically," rather than large pools of similar subjects who may be easier to recruit (Wheeler, 1990b:744). Despite his obviously strong understanding of statistical methods, Wheeler is harshly critical of researchers'

assumptions that "[f]ancy statistical analysis" and "unvalidated classification systems" always make for better data and more rigorous clinical studies (Wheeler, 1990a:222) and encourages researchers to consider their methodological assumptions "before blindly entering the data into a computer program" (ibid:221).

Haney notes that "Animal models of this disease have been conspicuously disappointing in their ability to provide insights into the disease process in humans" (1990:1). While Edmund Funai, an editor of *Obstetrics and Gynecology*, applauds the move to 'evidence-based' medicine that draws most heavily on RCTs rather than clinical observational studies, he notes that the latter constitute the vast majority of articles submitted to medical journals, that they "may provide useful information about the characteristics of disease," and that they "serve an important role in generating hypotheses and are often the foundation upon which future research is built" (Funai, 1997:1020). And in a piece about endometriosis classification, Terry Groff argues that "complete and accurate classifications of disease...[have] often neglected the clinical illness and its therapy" (Groff, 1989:162). Indeed, Engelhardt asserts that "Clinical classifications that are used in staging cancer are negotiated, voted on, adopted, and promulgated with the general understanding that they are *instrumental* rather than *natural* classifications. They are recognized to be artificial constructs of reality that serve the purposes of the clinician and the investigator" (1990:70, footnote 1).

But their very artificiality often makes them inapplicable to 'real-life practice,' as Groff's criticism and the complaints of other endometriosis specialists about the R-AFS classification make clear. Eisenberg could be speaking about clinicians' views of the classification when he notes that

Models are ways of constructing reality, ways of imposing meaning on the chaos of the phenomenal world...Once in place, models act to generate

their own verification by excluding phenomena outside the frame of reference the user employs. Models are indispensable but hazardous because they can be mistaken for reality itself rather than as but one way of organizing that reality (Eisenberg, 1977:18).

The critiques of the R-AFS classification similarly demonstrate that endometriosis experts are acutely aware of the complexities of endometriosis and the clinical inadequacies of simplified classification systems, however necessary they may be to research.

The accounts of Malterud and Hunter discuss the discomfort young physicians feel when the care of actual patients confronts their theoretical, scientific knowledge:

I settled as a family physician eighteen years ago.

Very soon I realized that several of the clinical problems presented by my patients were noncompatible with the 'authorized' medical knowledge...What I perceived as the essence of medicine--clinical interaction, interpretation, and judgment encountering patients as individuals--was largely missing in the textbooks...For some years, I felt awkward and incompetent, constantly reproaching myself for having forgotten or never learned the clinical facts...Experience gently taught me the art of recognizing patterns in symptom presentation, comparing these to the individual's particular needs and resources, and subsequently transferring this understanding into medical management which somehow seemed to work (Malterud, 1995:184).

Traditionally, physicians in their demeanor are anything but uncertain. They survive the appalling moment at the beginning of clinical training when they are compelled to realize that, despite their years of successful study in the basic sciences, they know almost nothing that would be of any help to a patient. Once immersed in life in the hospital, physicians take for granted the disjunction between biological science and clinical experience, between theory and practice. Overcoming it is precisely what has confirmed them as physicians (Hunter, 1991:32).

Comelles' piece is particularly interesting in this respect; much of it is based on the reports of the *pasantes*, newly-graduated Mexican doctors who were sent into the country on a one-year practicum as a programme introduced to ensure the provision of medical care in rural areas. Here is one *pasante's* take on the relation between scientific training and medical practice:

While we were at university we were immersed in an academic world and a

reality that were totally different from what we would have to face during our social service in rural areas...where the *pasantes* find themselves completely out on a limb, with no possibilities of any academic help, weighed down by a wealth of knowledge which at best could only be applied to a very limited extent and with wide margins for error. It is here, in these harsh conditions, that one becomes conscious of responsibility towards the patient (Velázquez quoted in Comelles, 2000:43).

2. Clinical Experience and its Relation to Science

This frequent inapplicability of scientific biomedicine to clinical problems requires that other ways of knowing must be brought to bear in medical practice.

While medical writings tend to emphasize scientific approaches to knowledge production, another epistemological perspective tends to be conveyed verbally, in conversations between physicians and in clinical instruction to medical students; it therefore tends to be overlooked by many social scientists:

I believe it is necessary to distinguish two levels: one which finds written expression in a codified framework based on a methodology and a theory...and another which...is never written down except casually, as a marginal note, although it is to be found in the Hippocratic texts, in medical topographies and in folk medicine. It reflects the subjectivity of the observers, their relationship with their patients, and their understandings of the cultural context, local knowledge gained as a result of long-term participation in community life (Comelles, 2000:49).

Comelles notes that the conventions of academic medical writing prohibit personal, subjective claims and rhetorical styles (see also Hunter, 1991), but the claims of subjective experience are a valuable source of information and must be passed along somehow.

"This tension is...noticeable in the few references to daily medical practice in Hippocrates' writings. He relied on oral transmission of his experience, sharing it with students at the patient's bedside, but passed on to them the account of his clinical knowledge in writing" (ibid).

But it is not only academic writing conventions that prevent the formal

documentation of experiential clinical knowledge. Fleck implies another reason why this rarely is written down: "Why even the best diagnosticians are most frequently unable to give a specific basis for their diagnosis; they only explain that the entire appearance is characteristic of such or another disease" (Fleck, 1986 {1927}:41). That is, clinicians rely upon their experiential knowledge which is tacit, gained through practice, and irreducible to intersubjectively available propositions (Dalmiya & Alcott, 1993). Vrinda Dalmiya and Linda Alcott note that practical knowledge ("knowing how") and experiential knowledge ("knowing what it is like to") emerge in the doing and cannot be codified adequately in language, unlike propositional knowledge. They use the example of knowing how to swim (practical knowledge); one can describe it in terms of propositions but learning these propositions does not mean that one has learned how to swim. The same can be said for clinical judgment, which Hunter defines as "a kind of tact that grows out of the memory of experience, both real and vicarious, a matter of sensing when to act and when to subject received knowledge to skeptical scrutiny" (1991:40). Guidelines can be taught but learning the guidelines does not mean one has good clinical judgment. Hunter illustrates this in an example from her fieldwork: "An internist, questioned by residents in attending rounds about how he knows whether to hospitalize a patient, observes, 'You get a feel sitting down and looking at them. Are they really sick? That's where clinical judgment comes in. You develop a sense--. Second-year residents develop it rapidly in the emergency department'" (quoted in Hunter, 1991:44). The internist cannot really describe how he knows; the residents will just have to learn by doing.

Observers have noted that the notion of clinical experience--whether described as clinical judgment, tacit knowledge, or the classical model of medicine--is a corrective to an overly scientific conception of medical knowledge, and in many ways contradicts that

conception. Kirsti Malterud notes that "Unofficial, implicit standards, rules, and strategies for clinical judgment exist alongside those which are official, scientific, and standardized" (1995:187). Leon Eisenberg draws explicit attention to the inconsistencies in medical epistemology:

In his actual practice, the physician employs what Polanyi and Prosch...term 'personal knowledge'; that is, he combines 'tacit' models of illness with more or less explicit models of disease. If they were to be spelt out and deliberately set side by side, these tacit and explicit concepts would display logical incompatibilities. That they are held simultaneously indicates that clinicians mediate between medical models of disease and popular models of illness just as do the patients who employ concurrently the services of herbalists, shamans, and doctors (Eisenberg, 1977:19)

Comelles makes a similar case for two contradictory but (he argues) complementary models of medical practice, the classical model which corresponds to the local practitioner, and the hospital or institutional model which promotes the strict biomedical model's scientific, formal, theory-based epistemology. The latter is the dominant one, but practice in local settings "requires an understanding of the context of the illness, the shaping of experience, of the intersubjectivity of local social life, that is *different* from the forms of practice arising out of the epistemology of the hospital model, the observation pattern of which is centered on controlling the effects of subjectivity" (Comelles, 2000:46). Consequently he qualifies Foucault's description of medical practice in *The Birth of the Clinic*: "the classical doctor practices in a different place" (ibid:45). In contrast to the formal biomedical model, which is theory-based and oriented to the scientific expert, the classical model is practice-based and oriented to the patient. And Comelles notes that most physicians are not researchers or hospital physicians, but primary health care practitioners (2000:44). This is certainly the case for gynecologists.

The classical model has a long and honourable history within medicine. Comelles cites the Hippocratic tracts: "When you go in to see the patient..., enter knowing that you

must act, since many cases do not require reflection but immediate action. So, you must use your experience to explain beforehand what is going to happen, since this puts you in a good light and is easily understood" (Hippocrates quoted in Comelles, 2000:45). Sir William Osler was another supporter of this model of medical education: "It is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself" (Osler quoted in Hunter, 1991:27). "Osler's rule declares that medical knowledge is essentially, unavoidably clinical. It is phronesis--practical and applied knowledge--and not a matter of scientific principle alone" (Hunter, *ibid*).

This is not to say that science has no role to play in clinical practice. On the contrary, Comelles observes that "Experience must be constructed not only by intuition, but by systematizing different areas of knowledge. Insofar as illness is a human and social process, the doctor must organize it around a theoretical point of reference which gives him critical distance" (2000:47). Malterud argues that the clinician must first learn the rules of science before she or he can perform as an expert (1995:188). But she quotes Wittgenstein too: "Not only rules, but also examples are needed for establishing a practice. Our rules leave loopholes open, and the practice has to speak for itself" (quoted in Malterud, 1995:192). According to Hunter, "The idiosyncracies of individual experience are to be eliminated by 'keeping up with the journals,' articles reporting clinical studies that represent large numbers of cases selected and observed so as to control the variables" (1991:45). But "These studies are in turn subjected to the test of the clinician's own experience" (*ibid*).

Particularly instructive in this regard is a series of excerpts from letters to the editor regarding a particular study by Nisolle and Donnez, two Belgian specialists (1997), and Donnez's replies to the critiques in the letters:

The assertion made by Nisolle and Donnez that the anterior colonic wall is not affected by endometriosis is incorrect; I have personally operated on 234 patients with biopsy-proved endometriosis of the rectal wall (Redwine, 1998:588).

According to our experience, endometriosis is frequently observed in the cul-de-sac...Concerning recto-vaginal adenomyosis, we should mention that in a series of 500 cases, only 3 patients required rectal resection... (Donnez, 1998a:589, response to Redwine).

One may question why only three sites have been selected that fail to mention lesions of the uterosacral ligaments, the round ligaments, and the fallopian tubes when endometriosis is indeed a peritoneal disease with overlap between the various sites. Any laparoscopist can attest to this (Rousseau, 1998:590, Canadian gynecologist and reproductive endocrinologist)

It could be that Rousseau has not had as much experience with adenomyotic nodules of the rectovaginal septum as we have had. He claimed that this pathology is rare in incidence and is asymptomatic. On the contrary, we consider that the prevalence of the adenomyotic nodule is increasing. This is probably due to environmental influence, which can be different in Canada and Western Europe. Indeed, the fact that our series, at present, represents more than 700 cases cannot only be explained by our center's high referral rate (Donnez, 1998b, response to Rousseau).

We see in these excerpts a rather competitive notion of experience, with specialists advancing numbers of patients they have treated as evidence of their greater experience with particular forms of endometriosis to refute claims made in the study, and the researcher countering those critiques with his own claims to extensive clinical experience, experience which (he argues) is greater than those of his critics. The appeals here are not to scientific principles, but to the clinical experience that differentiates experts from amateurs.

However, it is important to note that all of these clinicians are endometriosis specialists and researchers; they all have the professional and scientific credentials needed to make them endometriosis experts. I suspect that clinical experience is brought into play when official, scientific credentials cannot adjudicate between expert claimsmakers. If

Donnez was a general practitioner, it would be highly unlikely that anything he wrote would be published in this specialist journal; and all the clinical experience in the world would not provide him with a legitimate foundation for contesting the claims of Redwine and Rousseau, known specialists in the field. Credentials are prerequisites for acceptable appeals to clinical experience.

Clinical experience, then, is invoked as a means of evaluating the goodness of fit between clinical practice and scientific research results; the former are often used to discount the latter. But even in medical research itself, which usually strives to achieve the standards of the natural sciences, the role of clinical experience is clear. Consider the following excerpts from reports on endometriosis research:

Among women who complain of chronic gynecologic pain are a significant percentage in whom the complaints have no clear organic basis. The problem is well known in gynecologic practice (Renaer et al., 1979:75).

In our experience, after the surgical treatment of ovarian endometriomas, the IVF PRs [pregnancy rates] are similar in patients with severe endometriosis and tubal infertility (Canis et al., 1992:692).

...we undertook this study hoping to use information gained from previous clinical experience to design a new clinical classification that would predict the likelihood of future pregnancy, and would aid in the analysis of the results of various therapies for the disease (Palmisiano, Adamson, & Lamb, 1993:247)

Our study, like others, showed no relation between pain symptomatology and the classification score, and it is common clinical experience that a great amount of disease may be present without pain. These observations indicate that the criteria adopted in defining the rAFS classification system were somewhat arbitrary (Fedele, 1990:181)

Several authors have noted that surgical experience in diagnostic laparoscopy is essential in accurate staging of endometriosis and studies on prevalence (Candiani et al., 1991:378; Canis et al., 1993:766; Eskenazi & Warner, 1997:237; Hoeger & Guzick, 1997:351; Houston, Noller, Melton, & Selwyn, 1988:793; Pauerstein, 1989:129-30; Wardle & Hull,

1993:674). The notion of experience may refer to possession of a particular skill (such as laparoscopic skill), to the observations of the researcher in the course of the study (a rhetorical device used to present findings: "In our experience"; "a similar experience was reported by other researchers" etc.), or to background knowledge (clinical dicta or the researcher's own specific clinical experience). All are essential to the conduct of research. In fact, as Hunter argues, "In medicine, scientific experiment follows the clinical discovery of disease. Advances in clinical medicine are shaped by the need to take care of the ill...while disinterested experiments...often have little effect on practice or on the mindset of clinicians until years later" (1991:19).

The scientific method, then, is only one component of practical medical epistemology, and one that often is at the service of clinical experience. Hunter describes clinical reasoning as a hermeneutic circle: physicians take pieces of information (clinical signs, test results, and most importantly the patient's account), fit them into a probable whole (a disease entity that draws the information together), and then return to the clinical details and look for missing pieces of information to evaluate the adequacy of the whole in explaining the patient's problems. "Diagnostic tests, although they might seem to short-circuit this sort of circular, interpretive reasoning by establishing conclusive, quantitative, scientific 'facts' about the functioning of the patient's body, must themselves be chosen and interpreted. Thus, far from eliminating the diagnostic circle, the tests are readily assimilable into new interpretive loops" (Hunter, 1991:10). Thus the clinical dictum: "If a test result doesn't fit an otherwise satisfactory hypothesis, throw out the test and get a new one" (quoted in Hunter, *ibid*). Scientism, then, often is placed at the service of a more fluid, interpretive medical mode of reasoning, one in which clinical experience also plays a central role.

Hunter links the reliance on clinical experience or "judgment" versus scientific principle to the radical uncertainty of medical knowledge:

In the absence of answers that are invariably right, medical education focuses on the formation and exercise of clinical judgment. Whether viewed as an acquired skill or a personal quality--no doubt it is both--judgment is the bridge from knowledge to clinical action. The difficulty of reconciling science and praxis, knowledge and action, is illustrated by the status of the term. No one doubts that clinical judgment has a central role in medicine...a physician who is said to possess good clinical judgment has received medicine's highest tribute...Despite the cynicism with which it is occasionally regarded, particularly by the young, clinical judgment is never without honor. For everyone knows of theoretical experts who have made mistakes in applying that knowledge, and residents who are chock full of fresh new up-to-date information are well aware that they are not yet accomplished practitioners (Hunter, 1991:40).

When science is equivocal or unclear, clinical experience is particularly relied upon. As Canis and colleagues note in relation to endometriosis classification, "As our knowledge is still empirical, the conclusions of experienced and skilful surgeons such as Buttram and Kistner are obviously valuable" (Canis et al., 1993:771). The recognition of the uncertainty of medicine and the tensions between science and experience are witnessed in the following exchange in a conference discussion among endometriosis experts published in the *British Journal of Clinical Practice*:

D. R. Bromham: We must be guided by the patient's symptomatology. We must be guided by our eyes, and if we are in doubt we must decide to do one of two things: either adopt a policy of biopsying everything and letting the histopathologist tell us, or trusting our judgment and the symptomatology as discussed with the patient.

...D. K. Edmonds: I am also worried about making junior doctors more aware of the more subtle forms of endometriosis, as this may lead to more patients being labelled as having a disease or a condition that they don't actually suffer from (Cornillie et al., 1991:12-3).

Bromham's apparent discomfort with "biopsying everything and letting the histopathologist tell us" suggests another important reason for the privileging of clinical judgment or experience: the fact that most practitioners are not scientists, and an

overreliance on experimentation and lab results would mean a ceding of clinical authority to other professionals (lab technicians, research scientists). Edmonds worries about the effects of journal articles' focus upon unusual appearances of endometriosis. While journal articles, as we have seen, tend to emphasize that unusual endometriotic lesions are best identified by experienced laparoscopists, their discussion of such lesions does put pressure on young, inexperienced laparoscopists to identify such lesions, and Edmonds is concerned that this cannot be done properly without experience. So the recommendations in journal science, as Fleck has noted, are not always taken up so enthusiastically in vademecum science. The latter is best described as usual clinical practice and it relies upon experience, as well as science.

Compounding the problem of the misfit between journal and vademecum science is the fact that, with the exponential growth of published medical research in recent years, most busy practicing clinicians cannot keep up with journal science (Hunt & Newman, 1997). In such cases, years of practical experience must compensate for outdated scientific knowledge.

Endometriosis expert Dan Martin is not simply playing to the crowd when he writes, in his foreword to the Endometriosis Association's second book, that "Experience continues to be an effective teacher even for the most skilled, whether understanding and knowledge come from observing correct or incorrect diagnostic methodology, self-care, or medical treatment" (Martin, 1995:xii). The notion of experience is as foundational to practical medical models of knowledge as it is to patient ones.

3. Patient Experience and Medical Knowledge

"There exists no strict boundary between what is healthy and what is diseased, and one never finds exactly the same clinical picture again" (Fleck, 1986 {1927}:39). In this sentence, Fleck sums up what is perhaps the main reason for the disjunction between clinical practice and medicine as a science: the elusiveness and unpredictability of patients and their illnesses. These qualities necessitate that physicians constantly move back-and-forth between various elements of practical clinical experience, scientific principles, single cases in the collective and individual memories of physicians--and, importantly, their own experience of pain to understand that of patients. "Its subjective nature is such that it is only through the personal experience of pain that a doctor can have insight into the meaning of the descriptions given by patients" (J. McLeod, 1976, cited in Armstrong, 1984:742); "Although none of us can know the illness experienced by another person, we are not entirely barred from an approximate understanding. We have our own experience or the stories of our acquaintances" (Hunter, 1991:52). Fleck notes that with any medical problem, "it becomes ever and ever necessary to alter the angle of vision, and to retreat from a consistent mental attitude" (1986 {1927}:43) because no one theory of disease "will ever exhaust the entire wealth of morbid phenomena" (ibid:44).

While I argued above that endometriosis classifications and the typical patient profiles represent attempts to standardize and reduce the complexity of endometriosis, their very existence and efforts to develop them further demonstrate clinicians' and researchers' awareness of their intrinsic diversity and complexity. Were endometriosis and its sufferers easy to understand, typical patient profiles and formal classification systems would not need to exist.

It is certainly true, as Hunter (1991) points out, that physicians are aware of the

uncertainty, subjectivity and fragility of their experiential knowledge; this is reflected in their use of terms like 'clinical opinion,' 'appropriate' and 'nonappropriate' recommendations, 'belief' and 'faith' in treatment and procedures (Hunter, 1991:37). And yet, "The aim of medical discourse is always to eliminate or control the purely personal and subjective, whether its source be patient or physician, so that the physical anomalies that characterize illness can receive the attention their successful treatment requires" (ibid:52). There is a real tension in medical practice between, on the one hand, the recognition of uncertainty and subjectivity and, on the other, the need for certainty-- "especially in the face of their patients' often critical need for accuracy"(ibid:47). This is nowhere more apparent than in the clinical case presentation of medical residents, who "seek to turn an individual physician's interpretation of the patient's subjective and private experience of illness into an objective, scientific--or, from another viewpoint, a reliably intersubjective and medically recognizable--account of disease" (ibid:52).

The distinction between illness and disease is crucial here: as Eisenberg defines them, "illnesses are *experiences* of disvalued changes in states of being and in social function; diseases, in the scientific paradigm of modern medicine, are *abnormalities* in the *structure* and *function* of body organs and systems" (1977:11). The distinction recognizes an intrinsic difference between formal medical understandings of disease and its appearance in and effects on individual patients. Fleck observes that disease entities are "ideal, fictitious pictures...round which both the individual and the variable morbid phenomena are grouped, without, however, ever corresponding completely to them" (1986 {1927}:40).

In the case presentation, the resident "faces the task of translating [the patient's experience of illness], locating the malady in the medical universe and conveying its

characteristics and their meaning to others who know the medical language well but this particular patient not at all" (Hunter, 1991:52). While the style of case presentation effaces the subjectivity of the clinician, "The physician-narrator's purposeful arrangement of the events and the subjectivity of her act of narrating are taken for granted by everyone in medicine" (ibid:63). The physician's account is always derived from that of the patient; "The patient's account of illness remains the fundamental fact in clinical medicine" (ibid:14). The patient's story provides the history from which, it is said, 70-90% of diagnoses are made, so physicians are taught to record it carefully, virtually verbatim. But they are also taught to evaluate the patient as a 'historian' because her account is "Subjective, often incompletely or badly reported, sometimes unreliable or outright diversionary" and never reaches the physician as neutral facts, but as an interpretation-laden story. "That something so subjective and potentially unreliable as the patient's account of illness is so powerful can be, for the good physician, a perpetual source of uneasiness" (ibid:60).

Part of clinical judgment and experience, it seems, is the development of a capacity to gauge the reliability of the patient's narrative. In Armstrong's discussion of the rise of the patient's view in medicine, he cites two editions of a clinical teaching manual by Noble Chamberlain that address this point: "It is necessary to address the patients [sic] personality, a task which comes more easily with age" (Chamberlain, 1952, quoted in Armstrong, 1984:741); and regarding leading questions, which should generally be avoided, "the student may observe an experienced clinician will sometimes disregard this rule" (Chamberlain in ibid:742). Mary Fissell, in a piece that argues (contrary to Hunter's observations) that the patient narrative effectively disappeared from hospital medicine in the mid-18th century, cites Parisian heart specialist J. N. Corvisart: "It is thus, that too

often placed between truth and falsehood, the credulous, inexperienced, and over confident Physician, has repeatedly found himself the plaything and laughing stock of perfidious men" (quoted in Fissell, 1991:102-3).

We may view the development of the psychological component of the typical patient profile as an artefact of cumulative clinical experience with endometriosis patients, which is used to estimate the veracity of patients' accounts about pain. Cecil Helman (1988) has pointed out that such profiles exist for other diseases as well, including ulcerative colitis, hypertension, peptic ulceration, rheumatoid arthritis, asthma, Crohn's disease, and irritable bowel syndrome (and that laypeople often subscribe to psychosomatic principles). Lawrence J. Kirmayer (1988) has noted that psychosomatic medicine emerged as an attempt at holism, an antidote to biological reductionism and the failure to contend with the emotional and psychological problems of patients in medicine--in short, an attempt to recognize the complexity of the patient.

However, both Helman and Kirmayer note that these attempts to come to terms with the elusive patient end up reinforcing the very dichotomy of psyche/soma (mind/body) they seek to overcome--thereby resimplifying the patient as well as inviting pejorative estimations of patients. Recent texts on endometriosis and chronic pelvic pain also demonstrate this tension between attempted holism and the mind/body dichotomy in attempts to come to grips with the complexity of patients and their accounts of their experience:

Pain...has two components--physical and emotional--and it is necessary to treat both these components in patients with chronic pain and endometriosis. The emotional component is the method by which each individual patient copes (or alternatively does not cope) with the pain and the problems the pain creates for her; in other words it is the patient's response to the pain. Physical pain does not exist alone, there is always an emotional component, even if it is small...By the same token purely emotional pain is very rare, if it exists at all; there is always a physical

component, albeit very small...and it always requires treatment. It is invariably wrong to tell patients that their pain is emotional and not physical (Barlow & Glynn, 1993:782) [and later in the same piece] these patients can be arch-manipulators (ibid:787).

Investigation into the psychological and social factors that interact with physical factors to produce the subjective sensation of pain is needed for a variety of gynecologic disorders, including endometriosis. Patients with chronic pelvic pain frequently have abnormal psychological profiles, including a history of depression and/or dysfunctional family backgrounds. A history of sexual or physical abuse may promote the chronicity of pelvic pain. Clearly, the success or failure of treatment of endometriosis-associated pain hinges on a multidisciplinary management (Guarnaccia & Olive, 1997:458-9).

Because pain symptomatology is difficult to measure due to the reactive component influencing the patient's judgment, we used two methods to evaluate pain severity: a multidimensional score that gives more emphasis to the social impact of pain symptoms, and an analogue scale to estimate also the subjective aspect. No important difference was found using the two methods. This finding, besides offering indirect reciprocal validation of the questionnaires, is a strong evidence for the consistency of the general results of the study...[regarding dyspareunia] pain intensity was not measured because the patient's report is too influenced by her personal experience" (Fedele et al., 1990:157)

The reliance of physicians on patients' accounts of their pain is obvious: the patient experience is foundational to the treatment of pain and measurements of its success, and must be taken seriously. Yet, along with this recognition comes concern about the ability of the physician to establish the truth of the patient's experience on some other, more objective level--difficult to specify because of the intrinsic experience of pain but basic to medical notions about the body as a real, material, actionable object.

The problem of acting on patients presents other challenges to medical knowledge too. Engelhardt observes that "Since physicians must act or treat, even when knowledge is imperfect, much must be negotiated rather than discovered. Physicians and patients must agree about how to act under conditions of uncertainty" (1990:69-70). Agreeing how to act requires the development of claims about disease that are mutually acceptable

to patients and doctors--and often this requires some variance from medical judgments about proper science. Cecil Helman's (1978) study of lay models of illness in suburban England and Fleck's observations about proto-ideas (Fleck, 1979 {1935}) and their role in medical knowledge (1986 {1927}) are instructive here.

Helman argues that folk models of medicine have their own rigour and are not reducible to the biomedical model; but more crucially for this chapter, he observes that general practitioners tend to reinforce folk models in their interactions with patients because clinical encounters require negotiation between doctor and patient about what is wrong, and patients have a good deal of definitional power in these situations:

My research indicates that in Great Britain, at least, biomedicine at the general practitioner level is more flexible than had been realised; and that due to the process of 'negotiation' at the consultation the 'operational' model of the general practitioners bears a closer resemblance to the folk model, in some respects, than to the official model of biomedicine that exists in the hospitals, medical schools, and medical textbooks. Eisenberg (1977:13) has suggested that the patterning of illness is influenced by medical concepts, but the reverse also seems to be the case--particularly in general practice (Helman, 1978:112).

The folk model of fevers, colds, and chills used by their patients was reinforced in the diagnoses and treatment prescriptions of local GPs: patients were told they had a bug that was going around, and that their rash was a sign that the measles was "coming out of the system"; they were advised to drink fluids, stay in bed, keep warm, and avoid smoking. Helman demonstrates that all of these pieces of medical advice are linked to the model employed by the public. He notes that "general practice...is usually based on traditional rather than modern forms of biomedical divination--such as listening, looking, feeling, touching, smelling, and so on; and by numerous questions relating to the patient's feelings, experiences, and behaviour up to that point in time" (ibid:126). These methods are not scientific, but have more in common with the classical model of medical practice

suggested by Comelles. Helman notes that the limited time for medical consultations and the need to solve the practical problems of patients do not permit doctors to spend time disputing folk models of illness: "'My job,' as one GP put it, 'isn't to educate--it's to cure.'" (ibid:133). The effect of GPs' tacit acceptance--even promotion--of folk models of illness serves to reinforce them in the minds of the local laypeople, but importantly, it also serves to get the job of dealing with patients' complaints done in a practical and efficient way.

Fleck's argument that scientific claims often are born out of popular proto-ideas is of course relevant here. In his discussion of the specific medical way of thinking, Fleck argues that proto-ideas form a crucial part of medical practice. They may not be logical according to scientific principles, but often they allow for efficacious treatment of patients whose ailments defy the precise definitions of scientific disease entities that, Fleck argues, are idealized and fictitious anyway:

In practice one cannot do without such definitions as 'chill,' 'rheumatic' or 'neuralgic' pain, which have nothing in common to do with this bookish rheumatism or neuralgia. There exist various morbid states and syndromes of subjective symptoms that up to now have failed to find a place and are likely not to find it at any time. This divergence between theory and practice is still more evident in therapy, and even more so in attempts to explain the action of drugs, where it leads to a pseudo-logic. Not long ago the administration of camphor in the case of hemoptysis was forbidden--and a reason for it was found. Today camphor is recommended, and a 'logical' motivation has been found...It is nowhere easier to get such a pseudo-logical explanation than in medicine because the more complex the set of phenomena the easier it is to get a law verifiable for the short term, and the more difficult it is to reach an embracing idea. It is in medicine that one encounters a unique case: the worse the physician the 'more logical' his therapy (Fleck, 1986 {1927}:42).

In the early years of her medical practice, Kirsti Malterud encountered a similar problem: "I was confronted with the 'undefined' disorders--painful and vague conditions where no objective findings could be demonstrated. The obvious suffering of the patients told me that the resolution was not to deny their illness" (1995:184). What taught

Malterud how to treat these patients was not her scientific education, but her gradually acquired clinical experience, which she transferred "into medical management which somehow seemed to work" (ibid).

III. Conclusion

Clinical experience and the experience and illness models of patients are central to the practice of medicine. Efforts to make medical practice scientific continue, but are limited by the variability and unpredictability of disease and of patients, by the practical inapplicability of scientific methods and models, and by the ethical imperatives of physicians to "do no harm" and to ameliorate suffering, even under conditions of uncertainty. The roles of clinical experience in medical practice and research--as source of ideas, foundation for the adequate performance of practices integral to research, and basis for criticism of scientific claims--have been outlined. Clinicians' reliance on the experiential accounts of patients, and of lay understandings of illness, have been illustrated.

But science, too, is a crucial ingredient in medical ways of knowing about endometriosis. Scientific rhetoric and methods have had some unpalatable effects for endometriosis patients: they have been used to undermine patients' claims about their experience of pain and to construct them as psychologically disturbed and therefore unreliable, for example. However, it is important to note that physicians' clinical experience also has been integral to these developments: both the epidemiological and psychological components of the typical patient profile emerged from clinicians' observations of endometriosis patients, and endometriosis classification systems' focus on infertility and scoring of lesions emerged out of surgical observations of the pelvic

condition of infertile women.

My purpose here is not to champion science or clinical experience; both clearly are essential to medical practice. Neither is innocent in the development of medical claims that have delegitimated the claims of women with endometriosis, but they have also counteracted each other's deleterious effects on the study and treatment of patients. Clinical experience with endometriosis patients and careful attention to their accounts of their illness have been used to challenge scientific claims about endometriosis classification, psychology, and epidemiological profiles. Similarly, scientific research has undermined the claims of clinical experience that, for example, only white career women and psychological misfits get endometriosis.

Rather, my purpose here is to demonstrate that medical understandings of endometriosis are not exclusively scientific, and patient accounts are not exclusively experiential and subjective. In fact, medical understandings bear some striking resemblances to patient understandings. Both draw upon popular conceptions of illness, psychology, science, and experience. They draw upon them using different rhetorical styles, often making different claims and embodying differing goals, such that Kathryn Montgomery Hunter has argued

...the medical narrative is all but unrecognizable as a version of the patient's story--and all but useless as an explanation of the patient's experience. A silent tug-of-war over the possession of the story of illness is frequently at the heart of the tension between doctors and patients, for that tension is in part a struggle over who is to be its author and in what language, a struggle for the interpretation of life (and death) events (Hunter, 1991:13).

However, a recognition of the similarities between medical and patient epistemologies enables us to understand why boundary work between lay and expert knowledges is so self-consciously performed. In order to stake out their respective claims to be privileged knowers, patients and experts must differentiate their knowledges from each other's: the

former mainly lay claim to the realm of experience, the latter mainly to the realm of science.

But the two kinds of knowledge are not so distinct as the mutual boundary work of patients and doctors suggests--both draw not only upon the other's realm but also upon the actual accounts of the other. Recognizing this produces a more nuanced analysis of both medical and patient knowledges, one that is more attentive to the complex epistemological shifting and creativity that members of both of these communities exhibit in their struggles to come to grips with illness and disease.

Perhaps most importantly, a recognition of the shared epistemological strategies and knowledge sources of patients and doctors provides a foundation for arguing that mutual appreciation of each other's claims to knowledge, greater communication, more cooperative knowledge ventures, and more productive dialogues across these communities are possible. This is a much more optimistic perspective than those presented by the medicalisation theorists and Foucauldians discussed in Chapter 1. In these perspectives, respectively, patients are either faced with the untenable choice of being victimized by biomedicine or rejecting a system of knowledge that can benefit them; or they are trapped within a monolithic medical discourse that colonizes their minds and even their modes of resistance, determining all that can be thought and said about their illness. Instead, I argue, this distinction between powerful medical expertise and powerless patient-bodies is untenable, because patient and medical ways of thinking are mutually constitutive: doctors are forced to come to terms with patients' bodies and narratives, just as patients must wrestle with the claims of medical professionals. Patients emerge not as passive victims or epistemic sponges but as active contributors to and--with their recalcitrant bodies--challengers of medical knowledge. The relation described is one of mutual

accommodation and influence as well as conflict, and defies any easy distinction between scientific expertise and experiential knowledge because both patients and doctors make use of these two resources. Distinctions between patients as representatives of illness and the "voice of the lifeworld" and medical professionals as representatives of disease and the "voice of medicine" (Kleinman, 1988; Mishler, 1984) are not so clear after all. At least epistemologically, patients and doctors need not be viewed as the "adversaries" that some authors have made them out to be (eg. Todd, 1989).

But it is not merely social scientists who argue that doctors and patients are adversaries; endometriosis patients, at least those who participated in this research, make the same argument. They assert that patients and doctors possess distinctly different kinds of knowledge, that patients' knowledge often is 'better' than doctors', and that many doctors are unreliable claimsmakers--making the same kinds of assertions about doctors that doctors make about them with the aid of classification and the typical patient profile. They therefore pose a direct challenge to medical constructions of endometriosis patients and in turn challenge the credibility of doctors. The symmetry does not end there. We have seen in this chapter that the thinking of medical experts exhibits a tension between scientism and experiential knowledge. The same is true of patient accounts. I turn now to an examination of these accounts, describing in the next chapter the claims that some women with endometriosis make about doctors and medical knowledge, and in the one after that, the ways in which they assert their own credibility as claimsmakers.

Chapter 4

The Patient Epistemological Community I:

Patient Accounts of Doctors' Knowledge

We saw in the last chapter that clinicians and clinician-researchers depend upon patient accounts to do their work, yet have misgivings about the reliability of endometriosis patients as claimsmakers. In this chapter, it is demonstrated that, despite patients' reliance on clinicians and medical research for relief of their symptoms and information about endometriosis, they harbour similar doubts about the credibility of the claims made by clinicians and researchers.

We also saw in the last chapter that there is a tension between two models of medical knowing--science and clinical experience--although the official epistemological model of medicine is scientistic. Patients' accounts also do not recognize these two models explicitly, privileging the official model: they tend to depict medical ways of knowing in relation to medical science, not clinical experience. Either medical knowledge is scientistic and therefore oppresses endometriosis patients by objectifying them and denying their subjective experience; or medical knowledge (especially the knowledge of particular clinicians) is not scientific enough because it is biased or based on myths that 'good' science would discredit. Clinicians' experiential ways of knowing are discussed rarely in participants' accounts, and when they are, they tend to be disparaged as biases or refusals to consider alternative claims. Yet, as will be discussed more fully in the next chapter, patients rely on their *own* experience, as well as medical science, to make claims and establish themselves as knowers.

We shall see throughout this chapter and the next that, like the medical experts described in the last chapter, endometriosis patients selectively take up and reject 'science' and 'experience' in their descriptions of doctors' knowledge (or lack of it) and of themselves as knowers. Patients' ways of thinking about endometriosis are practical and contextual. Attending to particular problem-situations means that patients must adopt a pragmatic approach to epistemology, drawing on different resources at different times to reject or assert different kinds of claims, to position themselves as credible agents of knowledge and their doctors as pseudo-experts, and to get the kind of medical care they want.

But unlike the medical community, in which an explicit, restrictive epistemological model is set out and therefore often must be contradicted in pragmatic problem-solving, the patient community does not have an explicit, restrictive epistemological model. Patients' epistemological model is bounded, emphasizing some claims and ways of knowing over others and restricting membership in the community to those with particular credentials of knowledgeability. But the model is looser, more flexible, allowing for greater adaptation to particular contexts of knowing and asserting knowledge than is the formal medical model. As a result, patients do not *have* to contradict it. So there is not the same distinction between principle and practice in patients' knowledge as there is in the knowledge of medical experts; patients are not required to choose between principle and practice, because their principles for knowing are so flexible and implicit.

The result of this flexibility is that the patient model is internally contradictory but--and as a result--it works well for them. It allows them to make a wide variety of claims and appeal explicitly to different foundations for knowing: to science and experience, to anecdote and published study, to the stories of other women and of doctors as well as

one's own stories of one's experiences. Within the patient community, all of these are considered to be valid bases for making knowledge claims, although the ultimate arbiter of truth is one's own experience. But, as we shall see, one can evaluate critically one's own experience, using other sources of knowledge (other women's experiences, medical tests, research on the disease). The key, though, is that only the *self* can conduct a critique of its experience; other patients are not permitted to critique a patient's experiential narrative. This constitutes a strong form of epistemological etiquette and an area of claimsmaking immunity for women within the community.

This chapter discusses *what* research participants claim to know about medical professionals and their treatment of endometriosis patients, intended to parallel the focus in the previous chapter on medical claims about patients. Two kinds of core claims are addressed here: participants' observations about doctors' knowledge, attitudes and behaviour, and participants' explanations for the problems they identify. My presentation of these observations and explanations is accompanied by excerpts from the focus group discussions and WITSEND0 responses⁶⁰ that illustrate my assertions--my own attempt to provide a rationale for my core claims. These participants' comments say a great deal about doctor-patient relations and medical knowledge surrounding endometriosis. They also provide the groundwork for an elucidation of the workings of the endometriosis

⁶⁰The use of italics in excerpts represents participants' emphasis, not mine. Ellipsis marks indicate my deletions of parts of focus group discussions or WITSEND0 responses. Minor spelling, grammar, and punctuation corrections have been made to some excerpts from WITSEND0 responses to improve clarity. Focus group members chose their own pseudonyms, a practice which made for some rather unorthodox choices, but also much hilarity and a more comfortable atmosphere. To differentiate WITSEND0 participants from each other and from focus group members, I assigned them alphanumeric codes based on the order in which I received their responses. For example, excerpts from the first WITSEND0 participant's response are labelled W1.

patient epistemological community, of *how* the members of this community claim to know--a task that will be taken up more seriously in the next chapter.

In this chapter, I rely more heavily upon focus group discussion than on WITSENDO participants' responses. There are three reasons for this. First, the focus group research yielded a much greater amount of material. Second, the focus group discussions reached a deeper level of analysis regarding medical knowledge than did the WITSENDO responses, due both to the greater extent of focus group discussion and my probing questions. Due to time constraints and the constraints of gathering data by email, I was unable to ask WITSENDO respondents follow-up questions that undoubtedly would have elicited more self-reflection and analysis from the participants. Third, emphasis reflects the different foci of the two studies. The focus group participants were asked mainly about their experiences with clinicians, whereas the WITSENDO participants were asked mostly about their search for, and evaluations of, information about endometriosis. I therefore draw more heavily on the WITSENDO participants' responses in the next chapter. Nevertheless, all of the main observations made by the focus group participants found support in the WITSENDO responses, though some of the explanations they provided for these observations were not raised by WITSENDO participants.

It is important to note that my delineation of participants' claims here is somewhat artificial. In their accounts, as in ordinary speech, participants did not address each observational and explanatory claim discretely in turn; they presented them in various permutations and combinations, often making many claims within one short passage. Close attention was paid to common co-occurrences of particular claims in order to elucidate the correlations participants were making among the issues they identified. However, my attempt to present a coherent summation of their claims inevitably resulted

in some loss of complexity, both of the claims themselves and of the relationships between them.

I. Contextualizing the Critiques

On average, focus group members had consulted 7 doctors before they found one with whom they were satisfied. Most WITSENDO participants did not provide comparable data, but mentioned consulting several, and in some cases many, doctors regarding their symptoms and treatments. Most participants also noted that they had difficulty achieving a diagnosis; in the majority of cases, diagnosis was not achieved for many years. In addition, all of the women who participated in this study are part of larger patient venues, from which they have heard of many women's profoundly negative experiences with doctors. Therefore, participants' positive evaluations of doctors are outweighed by more negative evaluations. On the whole, the participants in this study painted a bleak picture of doctors' treatment of women with endometriosis. Accordingly, the central observations and explanations that emerged most often took the form of criticism of doctors, rather than praise.

Patients use the term "doctor" to denote both general practitioners (GPs) and specialists (gynecologists and reproductive endocrinologists), and often in their comments they do not distinguish between GPs and specialists. There seem to be two reasons for this. First, these patients do not subscribe wholeheartedly to official medical distinctions between specialists and generalists because they feel that many "so-called" specialists actually know little or no more about endometriosis than GPs. Even some doctors recognized in the medical community as top endometriosis experts were considered uneducated or unskilled by the participants who had consulted them. The meaning of

expertise is at issue here. While an expert often is conceived as one who possesses formal credentials and is recognized as an expert by a community of other experts, many of the participants in this study imply that, to be an expert on endometriosis, one must be (1) thoroughly familiar with endometriosis research and (2) effective in therapeutic intervention, that is, good at fixing patients' problems with endometriosis. As we saw in Chapter 3, therapeutic efficacy is difficult to achieve in regard to endometriosis: it is an enigmatic disease and notoriously difficult to treat. More importantly, therapeutic efficacy ultimately is determined by how the patient feels. In this definition of an expert, then, *patients* become the arbiter of who is and who is not a 'true' expert.

A second reason that participants often use the generic term doctors is that these patients seem to feel that all doctors, whether specialists or generalists, are trained within the same overarching medical model that tends to produce similar attitudes and behaviours in virtually all physicians (with the rare, and highly valued, exceptions of doctors who are particularly sensitive, well-educated, and 'patient-friendly'). In other words, all doctors go to medical school and are subject to similar kinds of professional socialization. Individual clinicians often were depicted as personifying a larger medical model or medical establishment that oppresses women with endometriosis. As a result, participants often did not distinguish between the beliefs and practices of a 'medical establishment' or 'medical model' writ large, and the beliefs and practices of individual clinicians. Yet, at other times, participants did make this distinction: for example, they would appeal to accepted 'best practices' in gynecology to criticize their clinicians' lack of knowledge. Again, we see the flexibility of their model.

Patients can compare and contrast clinicians' knowledge with that of the 'medical establishment', using the corpus of medical research both as a source of critique of clinical

practice and as an explanation for the inadequacies of clinical practice, *because* most research is oriented to clinical practice. Medical research serves both to undermine the practice of certain clinicians in some respects and to support it in others, and patients can use this to their advantage as the occasion demands. Individual clinicians can be compared and contrasted; medical studies can be compared and contrasted; so, too, medical research can be compared and contrasted with clinical practice. Patients are able to adapt their critiques of individual clinicians and their relation to the medical establishment by playing on the contradictions and complexities presented by medicine as a matrix of individuals and of structure, of science and of experience, of source of relief and of oppression.

These shifting strategies demonstrate an awareness among endometriosis patients of the tensions in the corpus of medical thinking and practice about endometriosis-- tensions among competing claims in the medical research, among the beliefs and practices of different clinicians, and between medical research and clinical practice. These tensions are exploited by patients to call into question the elevated epistemic status of individual clinicians, particular medical claims, and the entire medical system of expertise, and thereby to elevate patients' claims and patients' status as claimsmakers in comparison. Gieryn (1983) has shown that the *adaptability* of strategies and definitions of good knowledge and good knowers are essential to boundary-work in science. Experts adapt their strategies and definitions to discredit competing claims and to construct competitors as pseudo-experts; so do patients, and in their adaptations, they are able to construct accredited medical experts as pseudo-experts who "don't really know what they're talking about."

Despite the many critiques levelled against clinicians and the medical establishment

in general, it is important to point out that many participants had found medical practitioners with whom they were satisfied, in the main. Some spoke of their clinicians in glowing terms:

Bobbi: [of a GP] It was good because she was honest...and *she listened* to what I had to say...she expressed her concern and was open...all the cards on the table--she said "If anything happens, if you don't feel good, you call me." And it was just wonderful, and I felt better. I was scared shitless but she was honest and abrupt and said "I don't know this much" and we researched it together.

Mercedes: [of her new gynecologist] He is wonderful. He's just super...I was just screaming, I was so excited. He's sending me for a whole bunch of tests. He's good, he's good...And he's the first doctor I went to and I didn't have to take my clothes off.

W7: [of her current nurse practitioner] I feel she is very informed and open to alternatives. She is willing to consider options and keeps an open mind about them. She knows that this will not go away and is very understanding when I am having a particularly bad time with it.

These comments reflect not only the qualities that women with endometriosis value in a doctor, but also the problems they encountered with other doctors. These reviews are so enthusiastic because the participants have had profoundly negative experiences with other doctors. Beth contrasts the "ideal" doctor-patient relationship with her perception of the reality of doctor-patient relations, in a statement that nicely encapsulates many endometriosis patients' main observations about the medical profession and their explanations for what they observe:

Beth: The ideal doctor-patient relationship would be a doctor who you can communicate with, who will accept whatever you say as fact, instead of you're some neurotic woman that, "well, get used to your periods 'cause that's life," uh, somebody who has an open mind, somebody who listens to you, and somebody who takes you seriously, instead of making you go to see them so they can get rich and rich and rich and you're only sicker and sicker and sicker and nothing ever happens.

II. Patients' Core Observations about Doctors

I identified three kinds of core observations about doctors and medical knowledge in participants' accounts. First, I discuss their core criticisms about current *levels* of medical research and clinical knowledge. Second, their core criticisms about clinicians' *presentations* of their level of knowledge to patients are discussed. Third, criticisms about clinician-patient information *exchanges* are discussed.

I. **Levels of Medical Knowledge**

The most common claim here, made by virtually every participant, is that doctors do not know much about endometriosis. There are two facets to this claim. First, it is asserted that little is known about the disease from a biomedical standpoint, and that not enough medical research is being done. Most WITSENDO participants made this assertion when asked about their impressions of medical knowledge and research:

W13: It definitely needs to be improved...I think that there needs to be more awareness campaigns to the doctors. And publicly so that more research money is dedicated to endometriosis which is more common than Parkinson's or Alzheimer's, but more funding is directed to those two causes...They need to do research on what causes endometriosis, in order to find better ways to diagnose it, and cure it if possible.

W10: It is a disease with no cure, no well-understood basis...and very little research dollars spent!

W1: I find the knowledge lacking but hopefully...more research, which doesn't appear to be [occurring] that much, will finally give us the answers we are searching for.

W3: My impression of the medical community is that they have no clue how to handle it. This disease is so out of control and so hard to recognize without surgery, they have tried to sweep it under the carpet for many years.

W17: It's frustrating that the more informed I become, the more I realize how little the medical community knows about the condition...I feel the medical community (for the most part) just considers this to be about

menstrual cramps, so they don't take the condition seriously. After all, cramps and periods aren't talked about much. I believe this also hinders research in the field. The whole situation leaves me feeling angry and powerless. A lot of the time, I just try not to think about it.

The women in the focus group also asserted that there was a general lack of biomedical knowledge about endometriosis, but due to the focus of that study, talked more specifically about the lack of available information on GnRH agonists:

Mercedes: It states in all those [medical] journals, there are no studies done [on long-term side effects] after six months. There were none ever done.

Celeste: Yeah, so I don't know! Do you go back to the drug company?

Mercedes: No, they don't have them either, I phoned there. I phoned three separate times and asked them and they said there were no studies done after six months.

Bobbi: There isn't enough information about these drugs *period*... *Access* to info is a problem because there is little info.

So, medical research is crucial and more is needed. This claim demonstrates these patients' strong respect for medical expertise in the abstract, in its capacity to alleviate their suffering, even as they recognize that this potential is not being fulfilled currently. The promise of the science is asserted, even as the medical scientific community itself is lambasted for not fulfilling its promise, for 'wasting itself,' as it were.

The second facet of the claim that medical knowledge about endometriosis is insufficient is that many doctors--especially general practitioners but also many gynecologists--are not familiar with the existing medical knowledge about the disease. All of the focus group participants and 15 of the 19 WITSEND0 participants made this claim (the remaining four did not comment on clinicians' knowledge levels in general):

Beth: My GP, I don't think he knows anyways. He thinks [endo] is a nasal polyp or something [all burst out laughing]...

Mercedes: But then a lot of gynecologists don't know, 'cause my GP sent me to a gyne with the same symptoms, I told him the same symptoms for five years! He didn't know what it was.

W2: I think that only a few doctors are really knowledgeable about endometriosis. Family practitioners are really not prepared to answer to the needs of a woman with endometriosis. Most gynecologists know about this disease but they are far from being experts in it.

W13: I went to some doctors that told me endometriosis was curable, didn't even know what endo was, or I just simply knew more than they did. I think that there needs to be more awareness campaigns to the doctors.

Related to this criticism of doctors' knowledge levels is the claim that doctors often give patients inappropriate advice. Participants identified two senses in which doctors' advice was inappropriate.

First, they asserted that such information often was factually inaccurate: doctors perpetuate "myths" about endometriosis, many of which are related to the typical patient profile discussed in the last chapter:

Beth: I said "I think I have endo." And he said that only people in their-- about thirty to thirty-five get endo. Somebody my age [early 20s] wouldn't have endo.

W14: The information provided by my first gyn was, in retrospect, quite hilarious: "we find this prevalent in white women with A-type personalities who are stressed by demands of career and family."

Acika was told by one gynecologist that her symptoms were due to her age, "that when you get older you have problems!" She was 36 at the time. A GP told her that her pain symptoms were "emotional." In fact, seven WITSENDO participants and all of the focus group members stated that doctors had either overtly suggested or implied that endometriosis symptoms were psychosomatic (a theme that will be discussed in more detail below). Doctors' claims that pregnancy or hysterectomy would cure the disease were particularly likely to draw criticism.

W12: The problem is that there are too many doctors with no knowledge of endo and [they] are performing hysterectomies right and left. They are so uneducated that they think hysterectomy is the answer...What many of them do not know is that it still comes back after a hysterectomy....Another thing about uneducated doctors is that they think having a baby will cure

endo. False. It will put you in remission for 9 months but after you have that baby it comes right back.

W9: Pregnancy, despite what many doctors say, is *not* a cure. Any woman can have endometriosis regardless of age or race. Hysterectomy is not a cure...My general impression from what I've seen on WITSENDO is that most doctors are unwilling to learn about endometriosis, and continue to perpetuate myths, such as 'just get pregnant,' or 'you're too young to have endo' to women. On WITSENDO, I see lots of women who are told that their pain is caused by emotional stress and that they should seek counselling...I've had many doctors tell me that pregnancy would cure my endometriosis.

Second, participants asserted that doctors' advice sometimes was contextually inappropriate: it was unreasonable or ill-suited to the specific circumstances of patients. Again, the pregnancy prescription was invoked by both categories of participants, as an example of contextually inappropriate advice. As one WITSENDO participant put it, "It will go away, go and get pregnant.' I was a 20 year old single woman when I was told this" (W8). Another noted that "many women still get advised to start a family when even intercourse causes excruciating pain" (W2). Beth noted that her gynecologist was "concerned with the fertility issue and believes if I want children, I must do it now. I can see her point but she doesn't see mine--that I'm not ready at 25 for kids."

In focus group accounts, discussions of contextual impropriety and factual inaccuracy often were combined. Two examples illustrate this. First, Zoë related that, after revealing to her doctor that she and her husband had just separated, he continued to advise her to get pregnant to treat the disease:

Mercedes: What a thing to suggest to people that are single, to get pregnant!...I mean, that's terrible.

Emma: They should just never suggest it, period.

Mercedes: Well, it doesn't cure it!

Emma: They should never suggest it anyway.

Mercedes: I know.

Zoë: I mean, getting pregnant to have a child is one thing, but getting pregnant to get rid of a disease? I mean, it doesn't make sense!

Here, the "pregnancy prescription" is considered both contextually inappropriate because it often does not take individual women's particular circumstances and cultural understandings of parenthood into account, and factually inaccurate because it doesn't treat the disease effectively, as many doctors claim.

In the second example, Beth related that, after she had been using GnRH agonists for a month and a half, her doctor told her "to eat three cans of sardines a day" to increase her calcium intake and thereby counteract the bone density loss that is associated with GnRH agonists. This elicited shocked and derisive responses from other group members, for two reasons. First, most had been told by their doctors that calcium could not be absorbed when one was on the drug, so they deemed Beth's doctor to be committing a factual error. Second, they deemed it unreasonable to expect anyone to eat three cans of sardines a day, a contextually inappropriate piece of advice.

2. Doctors' Presentations of Their Knowledge

One of the qualities the participants most prized in a doctor is honesty: honesty about prognoses, about treatments and their side effects, and most of all honesty about what they do and do not know. Participants were enthusiastic about doctors who would admit their uncertainty, and highly critical of those who would not. This theme was particularly common in the focus group discussions:

Acika: The GP and the gyno I have now are both willing to share what they know, but they also are both quick to say what they don't know.

Celeste: I have asked him different questions and he has said "We don't know because we don't have enough information." So he has been honest in that way.

W12: If I had one phrase that I wish about 90% of gynecologists would say it would be "Yes, I am uneducated about endometriosis but I am proud to admit to you, my patients, that I do not know what is wrong with you."

Strongly connected to this theme was a frustration with the conflicting stories that many women got from different doctors and medical publications. WITSEND0 participants commented on this problem:

W5: No one really knows why we get it or how to get rid of it. Many experts disagree as to what are useful treatments...some doctors still feel that a hysterectomy is the cure as well as getting pregnant. Some also feel that surgery and Lupron are the cure-all. Basically no one agrees except for those of us that have it.

W11: Endo is agonizing and extremely frustrating. The studies say one thing and then a different study says something opposite.

Focus group members echoed this frustration. They cited the conflicting information as evidence that there was no definitive medical word on the subject and the doctors were feigning a certainty they could not possess, given the current state of medical knowledge:

Emma: So is it that you can't get the information? Because in some of these cases they don't really know, right? I mean, the jury's still out?

Mercedes: But then they should *say*, they should be honest and say they don't know. Maybe that's why I've gone to four doctors and am on my fifth doctor, 'cause none of those doctors have given me the same answer twice. So you tend to wonder, who's telling the truth? Who knows for sure? If they were just honest and said "Mercedes, I don't know; I'll be honest with you, I don't know." Then I'm satisfied! But don't beat around the bush and give me some bullshit thing and then I'm on to someone else, I mean, that's stupid.

Bobbi: ...All the doctors I had seen vehemently had their own opinion-- "*This* is what I believe, a hysterectomy cures it." And the other one says "*No*, a pregnancy cures it. And there was no "well, maybe" and so everywhere I went it was a different opinion and nobody was willing to say "well, I could be wrong." They were all *right* according to themselves.

There seems to be a contradiction, however: although many of these women wanted their doctors to admit their uncertainty, some expressed dissatisfaction when such uncertainty was admitted:

Beth: You know, it's like specifically, what are the long-term side effects [of GnRH agonists] and they go "We don't know!" That's not very satisfying.

Bobbi: Maybe I want more answers that aren't there.

However, the contradiction resolves itself because, while women want doctors to admit their uncertainty, they also feel that many doctors have not worked very hard to familiarize themselves with the information that *is* available on endometriosis. Their criticism, then, is that doctors arrogantly *pretend* to know, but do not even try to find out about endometriosis.

W15: I suppose that my biggest frustration is that there is such a wealth of information now, and yet out of the 30 or so doctors I have seen in the past 2 years only 3 of them knew anything about endo.

Mercedes: You know what, if they're told that this drug will treat this disorder, disease, whatever, then they should have more information. I mean, they just prescribe these drugs. They've been told by a drug company "Well, we use it to treat endo." They should know more about it or they shouldn't be prescribing it.

3. Doctor-Patient Information Exchanges

Information exchanges between doctor and patient, and doctors' and patients' reactions to those exchanges, were remarked upon again and again by both focus group members and WITSENDO participants. This topic generated some of the most vitriolic comments about doctors, but also some of the most positive ones. It seems that willingness to teach patients, to take seriously or "listen" to patients' statements, and to share information respectfully, are the qualities that the participants prize most in their doctors. The participants repeatedly described a good doctor-patient relationship as an informational partnership:

Acika: I always say someone that will work *with* me.

Emma: As opposed to?

Acika: Telling me what to do.

Emma: So what do you mean by working with you?

Acika: Um, basically what the others have said--someone who will listen to me, share their thoughts on the issue, and come to a joint decision on

what action to take.

Mercedes: The ideal doctor-patient relationship is when the doctor listens to you and asks questions and then in turn you listen to him and ask questions. It should almost be like a marriage in a way, that you are both interested in the same thing. When your paths start going separate ways then it is time to move on and find someone that is after the same thing that you are.

W9: If you see a doctor who is intelligent and open to learning new things, even from his or her patients, then he or she will know a lot about endometriosis.

Doctors that took the time to do research and explain endometriosis, treatments, and related information to patients clearly and in detail, and that were receptive to patients' accounts of what they had learned, received rave reviews. Acika's collaborative relationship with her doctors was the envy of the focus group. She described that relationship in the following terms:

Acika: My feelings are always respected. My thoughts, although I feel they're respected, the doctors [GP and gynecologist] would challenge them...If I make a statement, "Why do you think that? Where are you getting your information, and then reaching that conclusion? Well, what about this aspect? Have you looked into that?" If I say yes, and I say but when I found it, I disregarded it for whatever reason, "Oh, fine, as long as you're seeing the whole picture."

Emma: Okay. So they're sort of checking that your information is as complete as they'd like it to be.

Acika: Yeah.

Emma: How does that make you feel?

Acika: Good!

Emma: You don't mind them doing that.

Acika: No, I don't, because they are also open to me doing the same for them.

She went on to say that, when her gynecologist couldn't answer one of her questions, he would say "If you find the answer first, let me know, and if I find out what's going on, I'll call you." She regularly brought him the results of her research, and he responded positively. He set aside plenty of time for appointments so that they could discuss all of her questions and findings. He arranged for tests she wanted that other doctors had

refused to arrange, and asked pharmacists and other gynecologists about treatments that would work with her disability (she has cerebral palsy and some medications make her spasms worse). The only problem: this doctor was so busy that her appointments had to be scheduled weeks in advance and were often postponed--not a surprising problem, given the excellent care he provided to his patients. At the end of the focus group meetings, Acika was beginning a search for a new gynecologist.

Celeste, too, spoke very highly of her gynecologist. He provided her with pamphlets about endometriosis and treatments, encouraged her to ask questions, answered her questions as fully as he could, and was frank about the state of medical knowledge and the lack of available answers to some of her questions. "[H]e's blunt, he tells me where things are at...I'd rather have that than some doctor keep covering things up for six months when he could've told me right off the bat." However, this doctor became ill and had to leave his practice; during the focus group sessions, Celeste repeatedly expressed her fears about the looming search for a new gynecologist.

At the other end of the spectrum was Bobbi, who had consulted fifteen to twenty gynecologists; she could not be more specific as she had lost count. On one occasion, she heard one gynecologist discussing her case with an intern as she sat in the examining room. He told the intern he was going to recommend Danazol, an androgenic hormonal treatment:

I heard him say "Yeah, and some women can get deepening of the voice and facial hair growth"...I couldn't hear the rest, and then I heard him say "But they're rare, so we don't need to tell her about that." So *then*, I was on guard, and I didn't--I just knew I couldn't trust him. And so he came in and gave me these little, "Okay, Danazol, you know, you might gain a little weight, GnRH, yeah, you might gain some weight, have some hot flashes. So that's about it." And that's all he said. So I said "I'm gonna investigate these" and he was *really, really angry* that I was gonna--that I wasn't gonna decide then.

During another consultation, the same doctor asked her why she wasn't on the pill; she replied that she and her partner were not having sex because it was too painful for her, and when they did in the past, they always used condoms and spermicidal foam. He replied that if she wasn't on the pill, she must be trying to get pregnant. After he left the examining room, a nurse came in and gave Bobbi a prescription for the pill--which her doctor had not told her he was planning to prescribe. "Without even explaining to me why, [he] just sort of gave this prescription to the nurse to give to me."

Bobbi's experiences with doctors were not uniformly negative; recall her enthusiastic description of her doctor above. This doctor was a general practitioner at a women's health clinic who admitted she knew little about GnRH agonists. She brought the *Compendium of Pharmaceuticals and Specialties* (the standard drug reference manual for Canadian doctors) into the examining room; she and Bobbi read through the information together. She encouraged Bobbi to call her if she had any problems or questions she could help her answer. Unfortunately, this doctor moved to another city. When Bobbi saw another general practitioner at the same clinic,

She went and got the same book, and was hiding off in another little room, you know, researching what she was gonna dictate to me, like that's how I perceived it. So then I went and I walked in and asked her what she was doing, and I said "You know, Dr. [name] used to look through the book with me. Why don't you bring it into the room?"

Comparing the clinic doctors with the others she has seen, Bobbi said

They were all horrible....what I found here [at the clinic] was a willingness to say "We don't know, we're not sure," whereas before it was like, "Well, it must be this" and "You don't know anything," you know, "why are you even bothering researching, you can't comprehend this." And there was no sharing of information...it had to be kept medical knowledge.

There are two facets to Bobbi's claim that are reflected more generally in participants' accounts. First, participants assert that many doctors demonstrate little

readiness to provide them with information. Second, participants assert that doctors often demonstrate an unwillingness to take patients' knowledge claims and searches for information seriously.

i. Doctors provide little information

Participants identified three topics about which doctors gave them insufficient information, or none at all: the disease of endometriosis itself; endometriosis symptoms and how to deal with them; and treatments for endometriosis.

First, several felt they were not given adequate explanations, or any explanation at all, about the disease of endometriosis.

W17: He gave me the medical explanation of endo being uterine tissue that's migrated and is growing elsewhere in the body, but not much else. Mostly he explained what he would recommend as far as fertility.

Mercedes [explaining why obtaining the label of endometriosis wasn't a relief to her, as it was for other group members]: 'Cause I guess I'd never heard of it, he didn't really explain to me what it was, he just said "You have endo" and left the room--and left me there to cry for 10 minutes. And it was my husband who told me what it was. And uh, then when he [the doctor] came back, of course I wasn't listening, 'cause I--I guess I was in shock. I didn't think there was any--I mean, I thought I was gonna die, 'cause he didn't even say what it was.

Second, participants wanted, but rarely received, information about endometriosis symptoms and how to deal with them and their effects on their lives.

Zoë: But I've found that when they've said "Okay, yeah, that's a symptom of endo," nothing more was said about it.

Celeste, Beth, Mercedes: Yeah / that's right.

Zoë: And then there's the other end where they're asking you how your sex life is and how intercourse feels. That's what I was asked. "Yes, this is part of your endo," no solution or nothing else discussed about it, and then every visit was "So how is your sex life?"

W9: No doctor has ever told me how to affect my symptoms with diet, or even that diet has any influence. This was simple enough to do and the results have been truly amazing.

W18: I have had no formal discussions about the fact that I am living with a chronic disease that has and will continue to disrupt my life. "Just go on the pill, want me to send you to a surgeon? We got it all." Oh, and let us not forget "Maybe you should consider another line of work."

Third, especially in the focus group discussions, participants complained that their doctors were not forthcoming about the range of available treatments, the way that particular treatments work, and their potential side effects:

Mercedes: Like, I was not told about a GnRH drug [upon diagnosis]. It was Danazol or hysterectomy, and to me hysterectomy was pretty drastic.

Emma: Okay, what about conservative surgery?

Mercedes: That wasn't suggested to me until I'd been on Lupron for three months, and that was then by another doctor...

Emma: So, is it fair to say that you kind of--every time you exhaust one option, they present you with a new one?

Mercedes: Mm-hmm, and it changes all the time.

Emma: But they've never presented you with all of them all at once?

Bobbi: Bingo!

Mercedes: Bingo is right!

Beth: They don't explain technically. It's kind of like, "Eat this apple and you'll be okay." I think when it's your body and it's your hormones and it's your fertility and it's your sex life, I think you should get a bit more of an explanation.

Celeste: Maybe I should have asked him more questions, I don't know, but he didn't seem too concerned about the side effects [of GnRH agonists]?...my concern was the long-term and he didn't really give me a complete answer of what I wanted?...and he never mentioned anything about a bone density [test], I'd never heard of it until now when I came here.

W14: Time and time again I've tried to be tough and courageous enough to question doctors, demand detailed information about surgeries and treatment, only to be shut down by abrupt answers to my questions or a "don't worry about it" attitude.

A related theme raised in the focus group was that doctors sometimes explicitly refuse to send women for tests that would provide them with the information they wanted. Before Acika found her current gynecologist, "I had trouble getting an ultrasound; that's all I wanted was an ultrasound. It took me eighteen months and five gynecologists."

Before her diagnosis, in an effort to determine what was causing her symptoms, Mercedes asked for an AIDS test and was refused "because [it] was wasting, I don't know, medical money." Five of the six focus group members asked their gynecologists about bone density tests, because taking GnRH agonists is known to decrease bone density, a risk factor for osteoporosis. Only Acika's gynecologist did not raise objections to her request; in fact, she had three such tests done. Zoë's gynecologist dismissed the test as unnecessary and she did not investigate further. Bobbi, Beth, and Mercedes requested the test from their gynecologists, none of whom would refer them because they said the test was unnecessary and expensive; eventually they persuaded their GPs to send them for the tests. All three discovered they had significant bone density loss. Zoë, a nurse, investigated and learned that a bone density scan cost only \$75.25; the group members were furious.

b. Doctors are dismissive toward patients who make claims or seek information

Focus group members' accounts of doctors' refusal to send them for tests speaks not only to doctors' unwillingness to provide information to patients, but also to their dismissal of patients' knowledge claims and attempts to find information. A kind of epistemological discreditation was described: participants felt that many doctors dismiss knowledge claims made by patients and do not believe that patients have the ability to understand medical information about endometriosis. Acika, Beth, Bobbi and Mercedes all noted that physicians responded with hostility or disparaging remarks to their claims about endometriosis and their efforts to learn more about the disease.

Acika: My doctor, at the beginning, told me that reading could be dangerous for you [group members laugh]. I told him that stupidity could be more dangerous, therefore he should take a lesson from me [more laughter]. That's the last time he ever made a negative comment on

information I brought him.

Mercedes provides two examples. First, she asked a hospital to recommend a fertility specialist and an endometriosis specialist. They gave her the names of two doctors, both of whom worked at the same gynecology practice. The fertility specialist became very angry with her when he learned she had consulted several other gynecologists, including the endometriosis specialist in his practice. So shaken was Mercedes by this experience that, when she was referred to a third gynecologist in the practice because of suspected cervical cancer, she was afraid to make an appointment.

Mercedes: I'm just sick and tired of going back and these doctors regularly jumping down my throat and saying "What the hell are you seeing me for? You've seen four doctors in the past two months."

Zoë: Well, you say "That's my right."

Mercedes: And I said "Because if two of you had given me the same answer," I said "then I wouldn't be doctor-searching."...I said "But none of you are giving me"--I told them that though! You know what they do? They turn off their little tape recorder and they walk out. They don't like anybody that gives them action.

Zoë: Right. / Beth: No.

Mercedes: That's what Dr. [name] did! Oh, but--

Zoë: But you gotta stand your ground! I mean you gotta [say], "This is my right!"

Mercedes: Oh, but then they walk away! And then I sit there and think--

Zoë: My right is for a second opinion. It's your body.

Emma: Or a third, or a fourth, or a fifth, or however many I want.

Zoë: Exactly. / Celeste: Yeah, exactly.

Emma: And if you don't like it then, you know, stop being a doctor.

Mercedes: But I guess I'm so easily intimidated once I'm in that chair?

Zoë: This is why these fucking doctors--they think they're God, for God's sakes. I mean, it's just disgusting!

Mercedes: Yeah.

Zoë: And they're getting upset *basically* because you've gone to see somebody else.

Mercedes: Yeah.

Zoë: That's the *only* reason. They don't even think of why.

Beth: It's their egos.

Zoë: It's their egos, exactly.

Given her considerable difficulties with gynecologists, Mercedes turned to her general practitioner for help.

Mercedes: My GP said he'd work with me: "Yes, I'll get you all the copies of the O.R. reports, I'll get you your file from your gynecologist for the last eight years, all your Pap test results." ...The minute he got all that stuff for me, and I said to him "Okay, now I want copies of it," he said "Why? Are you a doctor?" Right away he turned on me. I said "Look, you said you'd work with me," and I had a tape recorder. I was taping *him* this time! [Beth laughs] I put the shoe on the other foot. And I said "You said you'd work with me," and I said "and now you're turning your back on me." And he turned around, and he was pissed off and he left, and when he put my file down on the nurses' station, I stole my file.

Zoë: It's your *right* to look at your file!

Mercedes: So then he charged me [a fee], 'cause he knew I took it...I took my O.R. reports, my D&C reports, all my stuff, and he went and saw another patient and his nurse came and said "Are you waiting for me or the doctor or what?" I said "Yeah, you're supposed to Xerox this stuff for me." She said "Oh, okay." She went and Xeroxed it for me. I mean, I lied to her.

These two excerpts raise many central issues. Patients' conceptions of their right to access medical knowledge--whether by 'stealing' copies of their files or by 'doctor-searching'--and their attempts to resist experts' control over that knowledge will be addressed in the next chapter. But here we also see several of the participants' main claims about doctors: that doctors believe patients cannot understand medical knowledge; that doctors believe patients are not well-informed about medical matters; that doctors attempt to control the dispensation of medical knowledge; and that doctors become angry when patients attempt to wrest that control from them. These themes were raised again and again by the focus group participants.

Beth had read that there were two approaches to conservative surgery for endometriosis: cauterization, an older technique, and laser surgery, a newer and, some experts claim, better technique. Beth wanted to discuss their relative benefits with her gynecologist:

Beth: And then I said to her all this stuff about this laser business, and I was all in a panic, and we got into a big fight, and she called me a layperson [group members gasp; Bobbi yells "What?!"]. I got mad at her.
Mercedes: A who?

Beth: She said, "You laypeople don't understand." [group members gasp, sigh, and snort]. And I said "Wait just a minute--"

Mercedes: What's a layperson, sorry.

Zoë: A person with no medical knowledge.

Emma: A non-expert.

Bobbi: Inferior?

Beth: Yep. So that's when I said "Wait a minute, I've put up with enough." I said "I'm *not* a layperson, this is *my* body, and I've just about had it with you doctors. You don't explain nothing." And I said "You're not touching me until you explain it." [group members ask for the name of the doctor; Beth provides it]. She *is* good, it's just we had a rough start because [pause]--I think she's okay in what she does, but personality clash.

Bobbi: No, she's not. If she has an attitude like that? To even slip up, saying a layperson, you know, the attitude's there.

Zoë had the opposite problem: because she is a nurse, her doctor assumed she was aware of existing medical knowledge about endometriosis and could do her own research in the medical library, that he didn't need to explain it to her. However, because Zoë worked mainly as a cosmetic and general surgery nurse, she felt she knew little about endometriosis. When she did extensive reading in the medical library and brought what she had read to her gynecologist, her presentations were dismissed as irrelevant. Her doctor told her that treatment approaches discussed in American publications she read were not available in Canada, and that the monitoring protocols they recommended for patients taking GnRH agonists were unnecessary. "And at that point I was so confused as to what I did read, what we do here, what we're allowed to do here and what we're not allowed to do, I had nothing to fall back on to go back at him, so [pause] I just kinda said [laughs] 'Okay.'" In a later focus group meeting, Zoë reflected on the incident: "You know, 'you're *totally* misinformed' almost, instead of like, looking at what kind of information you *did* get from that, and then let's kind of incorporate that into the Canadian model? And what you can have here?"

WITSEND0 participants did not discuss their doctors' reactions to their reading of medical texts. However, one of them, and several of the focus group participants,

remarked upon doctors' perceptions of patient-based knowledges, particularly support groups and the WITSEND0 list:

W7: I have told some doctors about the [WITSEND0] listserv and the fact that many women on it have had a hyst[erectomy] and are still having problems. The doctors ignore that (except the current one).

Bobbi: Well, whenever I had anything to say--and it was usually things that I felt aggressive or assertive about because I had the information, particularly from the support group--and both times I used that, it got knocked...there were two particular cases. One was with uh [names gynecologist], we were talking, I questioned him about bone density tests, 'cause he was putting me on Lupron for nine months. And um, immediately he just said "Oh, you've been talking to the women in the support group, haven't you?" And uh, insinuating that they were a bunch of hysterical, neurotic women, you know, "*Oh! We need this test*" and you know, freaking out about that, and freaking out about this. And then, another doctor told me that my only options were hysterectomy and pregnancy, and uh, I said "Well, pregnancy doesn't always cure it, and neither does a hysterectomy." And he goes "*Yes, they do. I've seen dozens of women with endometriosis and uh*" and I said "Well, the women in the support group--" and he just goes [in a loud, aggressive voice] "*Well, those women in that support group over there, they know nothing.*" So I found my thoughts were dismissed, yeah.

Emma: What about your feelings, or did you discuss those with your doctor?

Bobbi: No. Um-mm. They only things um--you know, I could almost predict those would be disregarded. I would only talk about things that I kind of had proof: "*Well, I know a woman who's had a hysterectomy*" and that would still get thrown down, you know, invalidated.

Bobbi's account raises a related issue: doctors' delegitimation of patient claims drawn from personal experience. All six of the focus group participants and 10 of the 18 WITSEND0 participants asserted that some doctors had dismissed their expressed symptoms, ideas, and/or concerns as unimportant or irrelevant. Doctors' delegitimation practices took several forms. In the pre-diagnosis stage, most participants were told repeatedly by general practitioners that their severe cramps with each period were merely the result of normal menstruation, something they had eaten, or gas. Pain during sex resulted from "not being relaxed enough." Most participants were advised to accept

pelvic pain as a normal part of womanhood and/or were prescribed pain medication without further investigation.

The participants expressed frustration with the 'run-around' they got from doctors, especially general practitioners, in the pre-diagnosis stage:

Zoë: There's a real reluctance to act on it, I find. I mean, it was two years before I saw the gynecologist. It was, "Yeah, probably [endo] is what you have, but let's do this and this and this"...until I'm like crawling on my knees, can't move, you know, then [the GP said] "We'll send you to a gynecologist."

Celeste: From in my early 20s, I would say, I went to [the GP] telling her that I was having pain and all this kind of stuff, and basically she didn't believe me, and she said "Well, you're supposed to have this pain because it's a woman's thing," blah blah blah, et cetera.

Beth: [The GP] did nothing. And then I came back three months later and I said, "OK, that's it. Everything out. I'll sign whatever papers you want, I'll sign 'em in blood, I want everything out." *Then* he referred me.

W17: I was in high school typing class, with cramps, when I got really hot and excused myself to go to the restroom--where I fainted twice! My mother was a teacher there, and immediately took me to the doctor. All he did was give me a prescription for Motrin, didn't suggest an possible causes, and didn't even do a pelvic exam.

Other women discussed the delegitimation they dealt with *after* diagnosis. In most cases, achieving a diagnostic label legitimates the patients' complaints, converting subjective illness state into objective disease entity. However, a diagnosis of endometriosis does not always have such an effect; rather, after diagnosis, the focus of delegitimation may shift from the symptoms to the disease itself.

Acika: My GP, when I was diagnosed, *he* had the pathology report, the report from my surgery, um, he had that report that said I had endo, to what degree, etc. His comment was, "Oh, I see there's nothing wrong with you."

W16: After the surgery they told me that I had a lot of adhesions inside (they cut them) and that [there was] no problem..."only cystic endometriosis."

Physicians' strategies for discrediting patients' claims to illness are adaptable; before diagnosis, doctors can argue the symptoms are imaginary; after diagnosis, they can argue the disease is a non-problem. As we saw Gieryn (1983) suggest in Chapter 1, adaptability in definitions of good knowledge is the hallmark of successful strategies to establish boundaries between experts and non-experts. As we see in Chapters 5 and 6, the research participants and the EA demonstrate similar adaptive capacities.

Some focus group participants even noted that their accounts of their sex lives and menstrual periods were invalidated by doctors; recall Bobbi's doctor's prescription of the birth control pill despite her statement that she was not sexually active, and when she was, she used alternative forms of contraception. Both she and Celeste recounted their doctors' reactions to their accounts of their menstrual periods:

Celeste: The only thing that bothered *me* was because I had still gotten a period when I was *on* the drug [GnRH agonist] and he said "Oh no, that's not a period." And so I went in for this test just to see where my estrogen level was...he said "It's fine, it's at 25"--or whatever it's supposed to be--"so the drug is working." But for him to say "Oh no, that wasn't a period"--well, what was it then, that I had for five days in a row? To me it was just like a period I've had before except I didn't have the pain...He seemed to think he knew what he was saying and yet I knew he wasn't telling me my experience.

Bobbi: I had missed a period...I'd gotten rushed into [hospital, because of pelvic pain]...I mention that because I had bled after the exam at the [hospital] and uh, for about [pauses] 20 minutes, it was really painful...so anyway, we [she and her regular gynecologist] got into an argument about whether or not that was my period. So "You didn't miss a period, you had a period." And I said "Well, I *bled* because they tried to do a *Pap* and it was *painful*." And he said no, no, no, it was a period...

Mercedes: We should all have 20 minute periods! [all laugh]

Bobbi summarizes: "I didn't know if I was having a period, I didn't know if I was sexually active...I didn't know anything. Anything."

More generally, the resounding impression I got from reading the focus group and WITSEND0 accounts was that the vast majority of the participants feel that most doctors

are indifferent to their suffering and have little interest in learning more about endometriosis in order to better treat it:

Mercedes: I don't think they take endo seriously enough. The whole medical profession should be sat down and taught that endo is a serious enough disease and should not be written off or taken with a grain of salt. We are in pain and have been complaining about the pain for a very long time.

W8: I get so frustrated by the lack of understanding from doctors and people I have come across in the medical field. It's like nobody can be bothered, "It's not life threatening so why bother us with it? It will go away, go and get pregnant." No, you're right, it's not life threatening, you can't die from it, but believe me sometimes you wish you could because you just can't see an end to this constant unbelievable pain that you experience day in and day out.

III. Patients' Explanations of Doctors' Behaviour

To summarize the core observations discussed above: the majority of participants assert that most medical professionals know little about the disease; that most doctors are unwilling to admit that they know little and pretend to know more than they do; that most doctors are unwilling to teach patients what they do know; and that most doctors exhibit dismissive attitudes toward patients' claims and attempts to seek out medical knowledge. No participant contradicted any of these claims. In participants' accounts, these four tendencies are clearly connected. Participants provided several interrelated explanatory arguments that depict doctors' ignorance, pretensions to knowledge, reluctance to teach, and epistemological delegitimation of patients as points in a kind of vicious circle. In many of the excerpts from focus group transcripts and WITSENDO responses quoted above, participants' explanations for doctors' knowledge levels, attitudes and behaviour are suggested. In this section, I discuss the explanatory factors they present in more detail. There are six basic, interconnected explanatory factors that I want to address here:

insecurity; bias; chronicity; objectivism; the doctor-patient gap; and medical expectations of patient passivity.

1. Insecurity and Expert Status

Participants argued that doctors' lack of knowledge and insecurity about that lack of knowledge have several effects. They lead to a high level of defensiveness regarding their expert status, and a reluctance to self-educate, teach and learn from patients, and admit to patients what they do not know.

Beth: I think maybe--nobody knows very much about this disease, they don't really have a cure for it like they do for a lot of other diseases--that they're very insecure about it? And because of that, they act totally aggressive to hide their insecurity.

Bobbi: The doctors don't know the answers, but want to uphold their pedestal position and bluff it.

Acika: I get the same thing with my C[erebral] P[alsy]. Anytime I go, any problem I see the doctor about, the first response is "What do you expect? You have CP."

Emma: So they sort of blame all your other health problems on your CP?

Acika: Yeah.

Emma: Why do you think they do that?

Acika: 'Cause they don't know anything about CP, and they're very nervous about looking.

W15: Now if you and I can get on the net and learn as much as we have, why can't the doctors do it? Maybe their precious egos are just too fragile.

The suggestion seems to be that, in order to commit time and energy to self-education, and to be open to learning about the disease from patients, doctors first must be willing to admit to themselves and to their patients that they do not know enough about endometriosis, or that their patients may know more about endometriosis than they do. But to do so constitutes a threat to their professional egos and their status as experts--something physicians seek to avoid at all costs. Here we see endometriosis patients using

psychologization tactics to discredit physicians as claimsmakers, just as medical authors discredit endometriosis patients as claimsmakers.

2. **Doctors' Biases toward Endometriosis Patients**

Participants identified two main senses in which doctors and medical researchers are biased toward endometriosis patients: they are sexist⁶¹, and they believe that women with endometriosis are psychologically disturbed. These biases lead to the epistemological discreditation of endometriosis patients, and the delegitimation or minimization of their symptoms and hence of the disease itself. These, in turn, lead to a lack of research, and to clinicians' disinterest in learning more about endometriosis and in exchanging information with patients.

The first component of this argument is that the medical establishment is sexist. Sexism was raised as an explanatory factor for many unsatisfactory aspects of doctors' behaviour. For example, focus group members and especially WITSENDO respondents argued that the effects of medical sexism included a paucity of research on endometriosis and doctors who are poorly educated and unconcerned about the disease.

Beth: I have a comment to make, the thing with Lupron? They went and made it for prostate cancer first?...I just think that shows how sexist the research is...They always do things for men first, and then "Oh yeah, let's give this to the endo victims, let them have a whirl at it."

⁶¹While one participant (Beth) preferred female gynecologists because she felt they had a better understanding of 'female problems' than male ones, most participants felt there were no substantial differences between male and female gynecologists in their attitudes toward female patients. Clinicians are sexist, according to the focus group participants, because gynecology as a whole is sexist and all gynecologists (male or female) are subject to the same kind of professional socialization within a sexist discipline: clinicians' attitudes and behaviour reflect the more generally sexist medical establishment. None of the WITSENDO participants explicitly discussed the differences between male and female doctors.

Zoë: I think...a lot of them generally think women blow things out of proportion.

Acika: Um-hmm.

Zoë: So your call, which maybe, you know, you've suffered with this for a few days, which I think most of us do instead of calling right away, it's taken the other way, that really it's not that bad.

W3: If this was a man's problem, there would be more research.

W6: ...most of our treatments are either ineffective, harmful, or hand-me-downs from the men's conditions they were developed for. I really do believe that this disease would be cured, or at *least* taken seriously, if it affected men. Women's lives, ambitions, energy, capacity for sexual enjoyment, etc., are disposable; if this disease takes it away from them, they're just supposed to live with it.

Second, all focus group participants and 7 WITSENDO participants argued that many clinicians think that endometriosis is "all in our heads." Here we see the effects of the typical patient profile in clinical action:

Acika: [Before diagnosis] I went to a new GP who wasn't much better, told me I'd be fine. It was emotional [all laugh]...The GP I had when I was first diagnosed refused to um [pause] acknowledge endo as a disease. It was a psychological condition.

Celeste: When we had to do that call-down to these women about the [clinic] support group last week, some of them I happened to--we just started talking. And all of them that I talked to for more than two minutes, they all said that their doctors had said that they were crazy, that it was in their mind that they had endo. Now are all doctors like that in Winnipeg, are they all thinking that you're crazy?

W6: I saw a number of doctors over the years who told me that my symptoms were insignificant, psychosomatic, or even non-existent.

These two explanatory concepts--psychologization and sexism--were explicitly and causally connected in focus group participants' accounts, and in one WITSENDO account: that is, doctors think women with endo are crazy in large part *because* they are women. All doctors have been trained within a medical model with a history of sexist conceptions about women and psychosomatism; male doctors can't understand or relate to the experiences of women with endometriosis. Participants explicitly connected the sexism-

psychologization issue to the epistemological discreditation of women with endometriosis, to the belief that endometriosis is not a real disease, to lack of research on the disease, to conflicting approaches to treatment, and to a general lack of medical education about endometriosis:

Beth: I've never had a dentist say to me [in an indignant voice] "Well! Why did you leave this dentist" or... "Well! You've *seen* so many dentists!"...

Zoë: ...I just saw the dentist last week...when I walk in and I'm sitting in the chair, he says "Do you have any problems? Are any of your teeth bothering you?"...

Beth: And you're not going keep going to him and saying "This tooth hurts" and he'll look at it and say "Oh, yeah."

Zoë: Well no!...And I said to him, "Well, how long ago was it when you fixed [a particular tooth]?" 'Cause I wanted that information. And he looked at the chart and gladly gave it to me.

Beth: And you know why? Because men have teeth and men have toothaches so they are real. That is why. That is why toothaches are fixed.

Emma: But why do you think that's the case [that women's diseases are underresearched]?

Mercedes: Because we're whiners.

Zoë: The long history of it all, you know? That our uterus is connected to our brain.

Mercedes: It's the same reason that a woman going through menopause-- and I mean, they tell you you're crazy, and "Oh, it's PMS again" and stuff...But I mean it's the same thing, a woman in menopause. Nobody understands it.

Zoë: Especially men.

Beth: Probably 99.9% of us with endo never get diagnosed with endo for years. When we do get diagnosed, we all get conflicting stories of treatment, which of course they can say 'cause we're all *unusual* cases and we're all different, but you would think [laughs] there'd be some sort of similarities there. Whereas probably 90% of people with strepthroat will get antibiotics if they go to the right hospital on the right night. So [pause] I think it's 'cause it's a female thing...It's in our heads.

Zoë: Yeah. I think that's the bottom line.

Celeste: We can't handle pain.

Beth: Yeah, we can carry on the species but we can't handle pain at all. That's why men give birth.

Zoë: And I think there's the expectation of women to say "Look, put up or shut up," too. 'Cause we've done that for a long time...

Celeste: But if it was a *man* that had endo--

Zoë: Oh! Exactly.

W4: Bottom line, research is not occurring, teaching about endo is not occurring, if you are a male you don't empathize with the pain a woman is feeling, therefore it is all in our heads.

3. **Chronicity and Complexity**

The third argument is that doctors' lack of self-education, unwillingness to admit uncertainty, and dismissive behaviour toward endometriosis patients' questions and self-education attempts arise from a medical model that focusses on acute conditions that respond to treatment in a predictable way. Such a model cannot adequately deal with chronic illness. This makes the medical model--and hence the doctors trained within it--ill-suited to the task of treating and understanding endometriosis. Doctors become frustrated because their trusted model doesn't work for endometriosis. Rather than reject the model, in which they have a great personal and professional investment, they reject endometriosis as a insignificant disease unworthy of serious study, and reject its sufferers as whining, belligerent hypochondriacs.

This way, doctors' self-concept as experts remains intact, because the problem lies not in their training and knowledge, but in the patient; and biases about endometriosis patients and women more generally reinforce the comforting notion that the source of doctors' inability to treat endometriosis effectively lies not in the medical model, but in the characteristics of women with endometriosis. Here we see the connection to arguments 1 and 2.

Chronic illness by definition cannot be cured, and cure--or at least relief of suffering--is the goal of the medical model and of clinical practice. Understandably, inability to cure or relieve symptoms is a source of frustration for doctors. According to participants, it is sometimes handled by dismissing chronic illness or symptoms, or

constructing them as psychosomatic. This is especially the case with chronic pain.

However, participants argue, women with endometriosis vary greatly in their symptoms and treatment needs, and approaches to treatment must be very individualized. Often, symptom management is participants' primary goal, because they know there is no cure. These points tended to come up in the focus group discussions when I asked participants to compare and contrast the treatment of endometriosis with that of other medical conditions, but they were also raised by WITSENDO participants.

W9: And I do think it's important to have a doctor that I can see regularly who understand[s] the chronic nature of the disease. One issue that is ongoing for me and others with endometriosis in the US is the undertreatment of pain...Most doctors don't seem to know much about treating chronic incurable illness. Even my nurse practitioner, who knows very well that there is no cure, gets frustrated that there is nothing she can do to make my pain go away permanently. Pain treatment is often used as a last resort, when it really ought to be a treatment option if other options are unacceptable.

W12: It's not like a broken leg where they can just cast it up and send you home and you are healed. You may cast 25 legs that year, but it was basically the same procedure. Women with endo are all different and each woman has a special case.

Emma: Well, what about things for like, okay, strep throat or pneumonia or the 'flu or whatever. Like how is that different?

Zoë: I think it's different because there's concrete reasons for it. They can take chest X-rays and there's, you know, number one to five that you treat pneumonia with and [pause] that's it.

Beth: Because, you know, strep throat, they give you penicillin, see ya, you're out of here, whatever. You come to them with this, and they're very defensive, 'cause they don't wanna look like they don't know.

Bobbi: ...when my appendix ruptured, it was, you know, I grit my teeth and tried to bear it out and I almost *died!*...and everybody...would always remark "Wow! You have an unbelievable pain tolerance!" And I almost [pause] I almost prided myself on it, you know? [group members murmur agreement]...And then I remember when I was going in for my lap[aroscopy], uh [pause] the doctor said something along the lines of "Well, I don't know if we'll find anything, because I think you have a pretty low pain threshold"...it just pissed me off and I was *so mad*...Like, this doctor who I'd only been seeing for a month of my life. Just because it's period pain and not appendix pain, it's invalid?

We see suggestions here of the connections between criticisms of the medical model's approach to chronic illness and another of the participants' critiques of the medical model: its objectivist orientation. A WITSENDO participant and a focus group participant make the connection between chronicity and objectivism more explicitly:

W7: My impression of the medical community is that they do not know how to treat endo and are not interested in finding out how to treat it. It seems like, if it doesn't fit into a neat little category that magically goes away when you have surgery or take a pill, they don't want to deal with it. One doctor told me repeatedly that I 'should' feel better after he did surgery and acting like I was wrong because I didn't feel better. When I told him that, if anything, I felt worse, he became clearly angry with me. After that, he suggested I should see someone else.

Zoë: [responding to my argument that much 'objective' medical information often is subjective information, such as reports of symptoms, extracted from patients and then objectified] But doctors never put any value toward anything subjective. There's a problem.

Emma: No, but [medical information] *is* subjective. That's what's so funny.

Zoë: But they--their automatic thought is "no, it's not." You know, I'm going through the same experience with my hand [which she injured during a fall, causing chronic pain and a lack of function]. My hand--the doctor did surgery, thought it would work, it's *not* working, I'm telling him subjectively it's not working and he keeps telling me "Well, I *did* what I was supposed to do, so *of course* it's gonna *work*." Totally disregarding the function of my hand, which is kind of objective but it's being told by me, so.

Procedures that should work, based on medical understanding of the object of the patient-body, do not work because, especially in the treatment of chronic illness, there is no such thing as *the* patient-body. Rather, there are complex and varied subjects whose bodies respond in highly variable ways to treatment. As a chronic disease, then, endometriosis poses a serious challenge to biomedical science's notions of objective knowledge. Symptoms often cannot be measured or monitored objectively, and may vary greatly from individual to individual; treatments relieve symptoms in some patients and not in others; even the empirically-verifiable extent of cysts and adhesions often has little relation to

symptoms. The scientific biomedical model of acute illnesses with empirically-verifiable symptoms that respond predictably to treatment, of cause and effect, cannot lay hold of endometriosis and other chronic conditions.

Here, the patients' critique seems to support the clinical practice model of medicine, in which each case is different and must be treated accordingly, versus the scientific model. However, in many clinical cases, neither the scientific model nor the experience drawn from clinical practice can lay hold of endometriosis. Whether doctors rely upon medical research or past clinical experience to treat endometriosis, in a great number of cases, patients report that they continue to suffer from debilitating symptoms. If clinicians found that, by rejecting medical science and relying on their clinical experience (or vice versa), they could treat endometriosis successfully, they would undoubtedly do so. But endometriosis continues to be described as an enigmatic disease that is notoriously difficult to treat. Thus, it is not that one or the other model of medical thinking works better in treating endometriosis; often, neither one works. The *fact* that neither one works in many cases means that the knowledge of physicians--whether scientific or clinical-experiential knowledge--is amenable to critique by patients.

4. Objectivism, Objectification, and the Rejection of Subjectivity

We have already seen that, according to participants, chronicity's status as medical enigma is due to the objectivism of the medical model, which is ill-suited to the treatment of chronic illness. Medical objectivism was also connected in participants' accounts to the psychologization of endometriosis: illness which cannot be established as objectively present may be construed as psychogenic.

Beth: I have a question: How come if you have an ear problem, you can phone your ear, nose and throat doctor and get in to see him without your

GP? How come if you have an acne problem, you can phone a dermatologist and get in to see him without your GP? Now, if you have reproductive problems that are unreal, you've gotta pussy-foot around with your GP forever?

Emma: That's a very good question. Why do you think that you have to go through your GP for this and not for other things? You got any ideas?

Bobbi: Because our word isn't good enough, essentially. The GPs validate it.

Zoë: Because we're all these neurotic hypochondriacs and the GP's there to screen it.

Bobbi: If you've got an earache, that's real and it doesn't need to be validated.

The medical hierarchy, then, is organized such that general practitioners weed out potentially psychosomatic problems and provide validation of those "objective" cases deemed fit to be referred to specialists. However, this hierarchy only applies for conditions like endometriosis, where the possibility of psychogenesis is thought to exist.

Participants' critiques of medical objectivism were complex and took several forms. Mercedes in particular made some interesting critical comments about medical objectivism, and I use these to introduce the themes raised by the participants. First, in response to Zoë's account of her doctor's recommendation that she should get pregnant when he knew she was just separating from her husband, Mercedes said "I swear to God they don't have brains! They don't think before they speak, honest to God. You're just a number, like cattle filing through." Here we see the notion that doctors do not take patients' individual concerns and needs into account, raised above in relation to participants' critiques of the contextually inappropriate advice that doctors often provide. The implicit criticism here is not only that medicine is based upon a misguided notion of "the" body, rather than one of multiple bodies that respond to diseases and treatment in different ways. It is also that patients are more than their bodies; they are subjects and, as such, demand personalized care regimens that take their lifeworlds into account.

A second theme related to patient subjectivity and medical objectivity is the notion

that doctors mistrust patients' accounts when they contradict accepted medical wisdom regarding endometriosis, symptoms, treatments, and side effects. When Mercedes told her doctor about some health problems she was experiencing while using Lupron, and asserted that these were due to the drug, he told her that was impossible:

Mercedes: They sort of have a list on what to go by, what symptoms are for what? And if you tell them anything different, well, that's not true, right? 'Cause it's not on their list?...

Zoë: But that information's very subjective. I think that's part of the reason too.

While most doctors appeared to use "objective" information to dismiss patients' subjective accounts, Acika suggested that objectified medical information need not be used in this way. She noted that her gynecologist relied upon it to better understand her experiential narratives, not to question their validity:

Acika: He's relating it more to my experience and uh, he actually comes out with "Wow! I didn't realize that this problem went to such degrees." So it's a positive thing...It's like, when I share something with him, this is my experience, he accepts that as reality and tries to work with me to whatever, deal with it, you know. But then bringing in the information that broadens his understanding, he realizes that it was more extensive than he understood at the beginning?

Emma: But, okay. So why doesn't he realize that it's extensive based on your subjective experience?

Acika: 'Cause he doesn't understand the mechanics of it? And then he reads it. Like, I'll give you an example. I may go to him and say "I get severe back pains, and they only last six hours." Then he accepts that, he won't say "It's all up here" [points to her head]. But then he reads the literature that explains that when the endo is...expanding, growing, that it may touch a nerve until it expands past that nerve, so that's why the pain is six hours or whatever. So that gives him the understanding of *why* it's happening?...He knows it's [the pain] hard on me, but when he realizes what's wrong, it's like "Wow! It must be even more than what I'm getting from what she's saying."

This suggests that the use to which medical professionals put objectivism is discretionary, not intrinsic to objectivism itself. Objectivism, then, can be used to validate patients' accounts and to give clinicians a fuller appreciation of the "endometriotic experience."

The notion that patient accounts are subjective and therefore suspect when they contradict medical knowledge was connected in a later focus group discussion to the notion that doctors rely heavily on visual evidence to evaluate the validity of patients' verbal accounts. Mercedes told us that one of her gynecologists "just wants to do surgery--I mean they all wanna look! What is so [laughs]--I mean, they all just wanna look, they don't care about what you say, just 'Here, take your clothes off.'" This comment initiated one of the many discussions about Pap smears throughout the focus group meetings. Group members complained that Pap smears are unnecessary because they are not a helpful diagnostic tool for endometriosis: doctors may want to look, but what they see cannot really tell them anything. As we shall see in the next chapter, for the endometriosis patient community, feeling, not seeing, is believing.

The standard medical practice is to conduct a Pap smear once a year to test for cervical cancer. Focus group participants--and I suspect many women with endometriosis--were subjected to Pap smears much more frequently. The process is often extremely painful for women with endometriosis. The fact that doctors do Pap smears so frequently, and often are not very gentle when they do them, demonstrating little sensitivity to the pain they cause the patient, was cited as evidence that doctors have little sympathy for, and are unable to "read," patients' embodied sensations:

Bobbi: ...it was hard because I was having a hard time leaving the house [because of pain], let alone having to get a Pap done every time I went out. Like, I was having a weekly Pap or something, and it was just [pause] you know, I hadn't been able to wear tampons for about six *months* and they wanna do *Paps*?...[Her gynecologist] decided that he was gonna do a Pap and that was really bad...He said that my cervix was fine, so I said "Well, the other doctors have found a problem with the cervix" and he said "No, your cervix is fine!" He goes "If there was *anything* wrong with you, you would have been on the ceiling in pain after this exam." I'm thinking, you fucking *asshole*--excuse my language--you didn't see the tears streaming down my face? You didn't see my jaw clenched? Like I might not *scream*, I might not tell you "Oh, *ouch, ouch*" but I might, you know,

clench my teeth and cry, and you're telling me that it wasn't *painful* and that there's nothing *wrong*?

Participants argued that objectivism leads to insensitivity, dehumanization, and the objectification of patients. They claimed that doctors treat patients as objects to be acted upon, rather than subjects to be actively engaged in medical treatment and treated with respect. In one conversation, four focus group members discussed their experiences as patients in teaching hospitals:

Beth: I didn't realize I was going to be a *teaching patient*!...that experience was very [pause] hard, and humiliating 'cause there were, like, five people in there at the same time and they were all looking and I never thought I'd ever go back to a doctor.

Mercedes: They did that to me, in a hospital for a D&C. Put the little boots on, lace 'em up to your knees, strap you into the stirrups and you're like this and they're sitting all there lookin' at ya, like here, have a look, eh? [group members groan]...It's like, put that needle into me and put me out. I was so embarrassed...

Beth: I don't mind if they put you out and then have a look, or if they put a think in your arm, okay, fine, but I don't think we need everyone looking, everyone poking.

Mercedes: I didn't have a blanket on me at all, 'cause one's working on the legs trying to strap me into these stirrups and someone else is attaching the leads, you know, to you, and the other one's trying to put the intravenous in and put you out...It was just the most humiliating experience...

Celeste: That's like them ding-dongs, when I was in hospital having surgery last year, I had them come in.

Bobbi: I remember when I was getting my ultrasound...all the doctors around...And so he's trying to aim the ultrasound thing [a probe inserted into the vagina]. And so all the students have to take turns holding it to get it positioned right [group groans; someone says "oh, please"]... meanwhile this is before diagnosis. I'm still, you know, in a *lot* of pain, not using tampons. So I'm crying while this whole thing's going on, and they're going "Oh, just another minute"...and this one student couldn't get it, and he [the instructing doctor] said to her, "Oh, it's just like driving a stick shift; once you get the handle of it you can do it no problem." And I just looked at him, and I said "*Bad* analogy," and he goes "Oh yeah, I guess you're right."

5. Experience and the Doctor-Patient Gap

The participants' critique of medical objectivism and objectification is also connected to their assertion of an unbridgeable doctor-patient gap: that, because doctors do not have endometriosis, they cannot understand what it is like to have the disease. We have seen suggestions of this theme throughout this chapter. As a result of this doctor-patient gap, participants asserted, doctors are disinterested in the disease and make little effort to understand the 'endometriosis experience':

Bobbi: ...[M]ost of them didn't try at all to understand the impact of it on my life and I would say "Look, I'm trying to complete my B.A. here"--this is when I was really bad, and I'd been essentially off my feet for about three months, and it was dictating my life, and it just seemed so inconsequential to them. "Oh, so you spend another month in bed." You know, of course it has no impact on their life, but for me I just wanted to get my life back on gear so I could, you know, not lose my job, get going again with school so I would graduate that year, and they didn't--it didn't matter, it was um [pause] you know, okay!

Some participants note with approval doctors' attempts to understand the endometriosis experience. However, they seem to be asserting two preconditions for such attempts: doctors must acknowledge their inability to understand fully, and they must rely on patients' experiential accounts--taken at face value rather than interpreted in the doctors' own terms--before they can gain what little understanding of endometriosis they can. Otherwise, patients cannot accept their sympathy as genuine, rather than paternalistic:

W8: I have a pain and emotion book which I write in frequently and I showed it to my consultant the other week and he has now asked me to type it up and send him a copy so he can publish some of it in the British Medical Journal to show the "real side" to endo and not just the medical side. This is so doctors can see a real account of someone's stress and pain caused by this illness and to show "it's not all in our heads" and that we are not putting it on. He also wants to show it to junior doctors so they can get another perspective into endo rather than just learning from a textbook.

Contrast this with Celeste's account of her doctor's efforts to bridge the experience gap,

and the other focus group members' responses:

Celeste: ...even though it's a man, and he said "Yes, endo can give you a lot of pain" and he gave me an illustration of, um, hitting a man's penis or something, I don't even remember [group members snigger], excruciating pain that they have, that would be something like what endo is to a woman. [Noting other participants' cynical expressions] Well, he's a man and he will never know, but anyways I guess he was just trying to relate it to me as to what kind of a pain it would be for a man.

Zoë: What, were you supposed to go home and try it, or?

Celeste: I guess so, I don't know [Zoë and Bobbi snigger].

Emma: Well, maybe he was just trying to be--sort of an empathy thing, like from *his* perspective what it would be like.

Celeste: Yeah! This is what it would be like. This is what he thinks, thought.

Zoë: [doubtfully] Okaaaay.

Emma: Well, it's probably his attempt to make a connection with the patient, to bridge the gender difference.

Celeste: Yeah. I think that's all it was.

Zoë: Hmm!

Bobbi: Well, he could say that--it could've been worse! [laughs] Like pulling a chest hair out! He could've belittled it more...

Celeste: But I think he--he tried to understand to the extent that he could. I mean no one can ever understand it unless you're going through it yourself.

The sarcasm evinced in other group members' responses suggests that they view Celeste's doctor's attempt to relate women's endometriosis pain to a male experience as a paternalistic minimization of the disease. Celeste's comment that "no one can ever understand it unless you're going through it yourself" suggests that she--at least in response to the other group members' responses--has her own doubts about the possibility of a male doctor and a female endometriosis patient bridging the experiential gap.

Other group members explicitly asserted that male doctors' professed understanding were disingenuous:

Mercedes: They can't even imagine what it feels like.

Zoë: No!

Mercedes: They can't! They can only pretend.

Beth: [speaking of her female gynecologist] When she talked about menopause and that, I don't get angry, whereas when I have a male--I don't

know, I just don't think it's right that men go on and on about hot flashes [a symptom of GnRH agonists] when they'll never know what they're like...I don't know, like to me, I find it insulting. Like, at least she's probably either in it or gonna be in it soon, so she can kind of relate in some way?

Recall also one WITSENDO participant's claim that "if you are a male you don't empathize with the pain a woman is feeling." Many endometriosis patients have felt very invalidated by doctors in the past and search actively for doctors who are sympathetic and understanding. On the other hand, members of the endometriosis patient culture fervently believe, because their experiential accounts have been discounted so often, that doctors and others (especially men) cannot relate to their experiences and view their attempts to do so as patronizing. There is a clear assumption here that the patient-doctor gap is unbridgeable in principle as well as in practice; only experience yields true understanding. This is a strong epistemological statement that will be addressed in more detail in the next chapter.

6. Expertise and Patient Passivity

Participants' notions about the relative power of patients and doctors, and the nature and culture of expertise, are central to their observations and explanations of doctors' attitudes and behaviour. They argue that doctors' ignorance and disinterest in endometriosis, and their reluctance to exchange information with patients, stem from their social status as experts and their expectation that patients should be passive recipients of care, rather than active participants. There are several subthemes here.

First, focus group members stated repeatedly that most doctors do not like to spend much time with patients. They prefer patients who ask few questions and leave the office quickly so the next patient can be seen. While Acika, Celeste, Zoë, and Mercedes felt that their current doctors spent ample time with them during appointments,

demonstrating a clear willingness to answer questions, the consensus was that such doctors are the exception rather than the rule. Group members and a WITSENDO participant cited the profit motive, sexism, lack of compassion, the fee-for-service system, insufficient use of other health care workers in teaching patients, chronicity, and the model of the passive patient as implicated in these problems:

Bobbi: [When asked if she trusts her doctor]: No, because he doesn't tell me everything. He won't answer questions, and won't take the time to explain things...New doctors [should get] personality training, sexist awareness, more time for patients--eliminate fee for service.

Zoë: I think--well, there has to be um [pauses] more using nurse practitioners and that kind of thing, where you're having more preventative medicine and more information given than you do in the system now. Because, like I think Beth said, you're basically shuffled in and shuffled out and you've, you know, still got questions and half the time they're not wanting to be answered.

Beth: Yeah, that's a good idea.

Mercedes: ...they don't allow you enough time to sit and have these questions answered...I get very intimidated when I go into a doctor's office because they have always made me feel that I don't know anything about my body and that is why they are in the doctor's position and you are in the patient position. We are to be seen and not heard, and only seen for a brief moment...I honestly think they go to medical school just so they can pick and choose their working hours and have more free time to spend on the golf courses or the ski slopes. A golf game gets more time and compassion.

W9: Clearly doctors who choose to remain ignorant about endometriosis, despite the vast availability of information about the disease in current medical journals, are doctors who wish to have easy patients who will have babies or routine Pap smears. Doctors make a lot more money delivering babies than they do treating endometriosis patients, and it's typically easier and less frustrating.

Second, focus group members noted that doctors like patients who 'know their place'--as suggested by Mercedes' comment, "We are to be seen and not heard." As discussed above, many participants noted that doctors disparaged patients' information searches and their ability to understand medical information. Doctors are the experts;

patients should listen and follow advice.

Mercedes: I think when I walk into the doctor's office and tell them my feelings or thoughts they sit there and wonder why I am coming to see them if I am so knowledgeable...It is my understanding that the medical doctors do not think that we are intelligent enough to understand information because, after all, they spent many years of schooling that made them into some kind of Gods, and only they are intelligent and we just listen. That is why it takes so long to be diagnosed with endo or any other disease, female.

Beth: A lot of the doctors just want you to listen to them and get out of their offices...[it's] like a parent-kid relationship and they kinda expect us to do what they say.

Not only doctors have this expectation; according to the participants, many patients do as well:

Zoë: 'Cause the old--not so much our generation, but people...who've never been in the health care system, other than perhaps for a medical exam every five years, for example, if that--they have no idea. And they still have that old idea of what doctors are supposed to be, and you don't question what they say, and you don't contribute anything to the conversation. Whatever they say goes.

Bobbi: ...we've talked about [names doctor] before, right, in a negative light? And I know one woman who *adores* [same doctor], she just thinks he's the *best doctor* in the world and it depends on what she was looking for, you know? She wants a doctor that she can just go in and this doctor will say "Here, this is what we're gonna do now." This is a doctor that, you know, the traditional [pause].

Zoë: Yep. And she would take a passive role.

Bobbi: Yeah, and that's what she wants, and she's happy.

Doctors sometimes attempt to discourage patients from taking a more active role, questioning medical claims, or asking pointed questions, by using jargon and other practices that the participants deemed intimidating, seemingly in an effort to silence challengers to their expert authority. Focus group participants were highly critical of doctors' use of jargon and other intimidation tactics, and of the role that professional socialization plays in encouraging clinicians' use of 'medicalese':

Zoë: I think it all stems to going back to the way that they're taught, the

medical students are taught, because they're taught these--their books they use have all the old--they're not even taught the equivalent [layperson] name. When I went to nursing school we were taught both, and you better memorize them and learn them. But they're not in medical school.

Emma: So they see the thing and they don't know what it is in layperson language? [laughs]

Zoë: Well, they can't think that way, a lot of them, 'cause they're so wrapped up in this medical terminology stuff. It's like a different world.

Mercedes: I've always said right from day one, any time I get a test done, [the doctor says] "this is wrong" or whatever, and I say "Now tell it to me in English." And I've always said that. I mean why do they feel they have to? Why do they feel they have to talk to us in these big horking words?

Bobbi: ...if I challenged any of their advice, that became really problematic. They *didn't like* me challenging what they were telling me to do? Either questioning it or outright refusing. So it's been--the doctors have been really non-interactive, I guess, opposite I guess of what you've [Acika] had. And I've doctor-hunted, so...[of one doctor] If he feels his authority challenged, he almost *retaliates* in standing up taller and using bigger words, and we saw that when he was at one of our support group meetings. Um [pause] if somebody asked a question that was slightly challenging or didn't have a clearcut answer, rather than answering the question, he would go off on a different tangent, and I remember he got talking about um [pause] a woman was asking about hysterectomies--I'm going off on a tangent here--and rather than saying it really completely, he just sort of charged *down* her, saying "Well, do you know anything about hysterectomies? What *kind* of hysterectomy do you mean? Do you mean the blah-blah-blah-blah, or the double oophorectomy?" And he just used these *huge* terms and she was like [gasps] I don't know! And you know, he just belittles any challenger to his authority.

Endometriosis patients, as a community, use more accessible, shorthand terms for long and difficult to pronounce medical terms, such as lap for laparoscopy and hyst for hysterectomy. The most striking example, though, is the use of the term "endo" for endometriosis: a term that is distinctive to the patient community. I see the use of such special terms as an attempt to undermine the boundary that medical experts have erected around their knowledge through their use of jargon, and to establish a boundary of a different kind: a boundary around the patient community. Using the term endo signals that one is a member of the patient community, privy to that community's own specialized

jargon.

IV. Conclusion: Expertise and Ambivalence

Virtually every participant in this study harshly criticized many doctors' apparent lack of knowledge about endometriosis, pretensions to knowledge, reluctance to share information with patients, and reluctance to take seriously the claims of endometriosis patients. Their explanations for these perceived inadequacies included doctors' professional insecurity about their lack of knowledge; their sexism; their tendency to psychologize and dismiss chronic conditions they cannot cure; their objectivism and objectification of patients; their lack of subjective, experiential understanding of endometriosis; the culture of expertise; and the enforced passivity that the medical model assigns to patients.

Yet, despite these critiques and insights about the problems with the medical model, all the participants demonstrated a great respect for medical science and expertise in the abstract, even if they were critical of existing levels of medical research and clinical expertise. They used medical information to evaluate their own embodied experiences and the claims of other patients, a point that will be discussed in more detail in the next chapter. They mentioned "specialists," "educated" doctors, and "endo experts" who "really know what they're doing"--that is, who know the science and are effective at treating endometriosis--although they sometimes noted that access to these busy specialists was a problem (almost all are located in major cities). They asserted that clinicians need to take endometriosis seriously, educate themselves, and listen to patients; and that more money needs to be devoted to medical research on endometriosis. If these changes were accomplished, medical science could find the cause of endometriosis, which

would lead to a cure; and clinical prowess could help to alleviate their problems. Overall, participants demonstrate a strong faith in the scientific method and in the expert system of medicine.

Beth: They are given information, they are given data, whatever, histories. They are supposed to solve it; they're investigators...If they can't solve the problem, they shouldn't be in that field. And if they can't make the effort to solve that problem, then I think they're probably at the very bottom, they're the straggler, they didn't care, they didn't *bother* to study to figure things out so [pause] you know? Like, it seems like somebody who's nutty enough to study to get straight As in med school is probably nutty enough to listen to you and maybe piece it together? 'Cause I'd imagine med school would be hard.

Zoë: I think what we're saying too is that we want a specialized clinic, specifically for this [endo], where there's specific doctors that only do this kind of surgery.

Bobbi: And the numbers say it's needed.

Zoë: Yeah. And so you can come to this clinic and feel at ease, that is, they're educated and they're knowledgeable and [pauses].

Bobbi: Exactly.

Mercedes: One field.

Zoë: Yeah...I think that the more they specialize, the more expert they'll get at these types of issues. Don't tell me that you're obstetrician has been on call all weekend delivering all these babies and he's read his medical journal.

W10: I am a scientist myself and appreciate seeing the sources cited [in a book on endo for laywomen], since they are from peer-reviewed journals...I know of very few current clinical trials (one at NIH only, and that one is based on essentially two papers on raloxifene's effects on rats and the results on number of offspring etc. are not that impressive...). We need more research into the mechanisms of the disease process.

W18: There are still too many theories on the cause [of endometriosis], or is it the effect of something else that we do not recognize yet? I believe that soon after there is concrete evidence of why this is happening, we can work on fixing it.

The legitimacy of medicine as a system of expertise was founded upon public acceptance of the notion that medicine does not simply *treat illness*, as lay healers also do, but that medicine, because it understands the *cause* of illness through the application of science, it can *cure* or *prevent* illness. Thus Bert Hansen (1999:629) writes that, in the late

nineteenth century, the popular imagination came to support "two intertwined notions: 'medicine is scientific' and 'medicine makes progress.'" If the participants in this study and the claims of the EA (see Chapter 6) are any indication, it seems that the endometriosis patient community subscribes to the notion that medical science leads to therapeutic progress.

However, further discussions about the nature of expertise in the focus group revealed that this trust in scientific medicine is undermined by a feeling of powerless dependence:

Zoë: You feel...you've got to put up with anything and everything just to get an answer!

Beth: I guess I put myself in a position where I had to trust her 'cause she did my surgery, but it wasn't so much a trust, it's more like [sighs] well, I woulda done anything. So it was more like desperation than trust really [pause]. I woulda let them cut off my leg if it would've helped.

Their perspective on medicine might better be described in Giddensian terms as "pragmatic acceptance," a making-do or "pragmatic participation which maintains a focus on day-to-day problems and tasks" (Giddens, 1990:135). Focus group members and WITSENDO participants might express this as "the system of gynecology is woefully inadequate, but we have no choice but to use it and sometimes it can be useful, so we'll get what we can out of it." For example, both focus group and WITSENDO participants discussed their 'doctor-hunting' and means to persuade doctors to provide the treatments and diagnostic procedures they desired. They also noted that, while treatments often had unwanted side effects or did not completely eradicate pain, they did provide some relief, and that excellent doctors do exist, if one has the tenacity to search for them.

At the same time their perspectives are tinged with "radical engagement," active efforts to subvert elements of the expert system of medicine and to make changes to that

system (Giddens, 1990:137). Both WITSENDO participants and focus group members noted that they had directly challenged or refused to comply with their doctors' advice, and speculated on the best ways to raise public awareness and increase research funding for the disease. The focus group participants became noticeably more radically engaged as the group meetings wore on. Several became involved in activist work; one conducted research for the Clinic on homeopathic treatments for endometriosis. The group members discussed strategies for developing a "blacklist" of doctors for women with endometriosis.

More generally, there was a noticeable change in the confidence, attitudes, and critical analytical abilities of some participants as the group discussions wore on. In the early focus group meetings, Mercedes stated several times that she was "stupid when it comes to anything medical" and that, as her doctor had predicted, she did not understand the medical journals she read (although her accounts of treatments and tests suggested otherwise). In the final focus group meeting, she revised her account: "...when I said I was gonna go and research in the journal, he said 'You're just gonna get frustrated 'cause you won't understand it anyway.' Well, I surprised myself. I understood a lot of it...I can use a dictionary." Celeste had not conducted as much research as the other group participants when she began the focus group, and her accounts suggested she had been the least assertive with her doctors. During the fifth focus group meeting, she made the following comment:

Celeste: And the thing is now, even with having our little meetings here-- I'd done some, a little bit of research on my own before, just getting a couple of books through here [the Women's Health Clinic], and just some other information. But now I'm ready to go find out *more* stuff, go get some more books if I have to, just [pauses] get more knowledge, because I mean I've certainly got a lot here, a lot of stuff that I didn't know before. But it's now--my interest is I wanna keep going on this, I need to know more on what there is on this, where can I find out more about it.

Emma: Oh, that's great.

Zoë: And I think, you know, I feel more empowered too.

Celeste: Yeah!

Zoë: You know, to relate to the medical system and with the doctors.

Celeste: Because before I was so--even though a couple of times I went to the support group here, I was still sort of on my own.

Acika: Um-hmm!

Celeste: I mean, you talk to a few people, "Okay, yes, I've got endo, what are you doing about it" blah blah blah, "who's your doctor?" But now with just having this group here, you can vent your feelings more and stuff, and it's just--it's different.

Zoë: The understanding's there.

Celeste: Yes, the understanding. Yeah.

It appears not only that women with endometriosis develop their critiques of medical expertise in groups, but that they also develop their own claims to knowledge through engagement with other women with endometriosis. Key to this development are notions of experience, self-education, and interpatient empathy. In the next chapter, I address the self-presentation of women with endometriosis as knowers and the epistemological strategies they use to evaluate their own and doctors' claims to knowledge.

Chapter 5

The Patient Epistemological Community II:

Patients' Accounts of Their Own Knowledge

For a variety of reasons, endometriosis patients take great pains to become--and to present themselves as--knowledgeable and rational agents. In this chapter I address the substantive claims that patients make about endometriosis, their representations of how they came to know about endometriosis, and their evaluations of their own knowledge and that of other women with endometriosis. I conclude with an analysis of the endometriosis patient epistemological community: the kinds of claims patients make, the strategies they use to create and justify those claims, and their standards for valid knowledge. Again, I do not include in this definition all women who have been diagnosed with endometriosis, just those who are members of endometriosis patient venues (the Endometriosis Association, support groups, and/or online groups such as WITSENDO).

Many participants in this research were participants in more than one of these venues, such that claims patients make and claimsmaking strategies they use in one group tend to appear also in other groups, creating an endometriosis patient community comprised of different intersecting arenas. Such patients tend to be very active information-seekers and claims-makers. Members of the patient community seek and participate in information-sharing and support provision (epistemological validation as well as emotional support). They explicitly locate themselves as members of a *community of sufferers* who share common experiences and perspectives, despite differences among sufferers. The women on the WITSENDO list often refer to each other as "endo sisters";

participants in this study use 'we' unselfconsciously to refer to endometriosis patients-in-general who 'feel the same way,' 'have the same experiences,' and are differentiated from 'them', the medical community. "Basically no one agrees except those of us who have [endometriosis]" (W5); "They have to start listening to what we have to say" (Mercedes). The participants themselves conceive of endometriosis patients as a community that knows and thinks in particular ways.

However, the epistemological standards of the endometriosis patient community are not laid out as explicitly as those of the medical research community. Because the medical research community is founded upon the goal of creating knowledge, it must be explicit about how it should go about creating knowledge. The endometriosis patient community did not emerge primarily as an epistemological community; its founding purpose was the exchange of support among patients. Increasingly, being supportive of each other meant providing each other with information and helping each other evaluate information and develop new claims about endometriosis, treatment, and doctors. With this emergent focus on information provision developed standards and judgments about what is and is not good knowledge, and how to go about acquiring and developing it. But these were not developed self-consciously. Epistemological standards, in the main, are tacit in the endometriosis patient community. Members of the community draw upon the explicit epistemological standards of science in some cases, but reject them in others. This is not troublesome for endometriosis patients; their goal is not philosophical consistency but good decision-making about medical treatment and other illness-related issues (what drugs to use, how to get doctors to believe what one is saying, etc.).

The epistemic standards of the endometriosis patient community are, above all, pragmatic and contextual; formal, binding agreements about what standards to use and

how to use them would limit the community members' ability to adapt their thinking to the problem-situations at hand. Patients' epistemological standards, however contradictory, work: they enable them to make decisions about what to do and who to believe, and to assert that they know what they are talking about. These strategically shifting standards are discernible from the claims they make about how they know and what constitutes good or useful information. We saw in Chapter 3 that formal standards and definitions of good knowledge are no guarantee of epistemic consistency: despite the rigour with which the standards of good science are debated and asserted within the medical literature on endometriosis, clinical experience (a subtextual, informal epistemology) sneaks in and disrupts the neat characterizations of how an endometriosis specialist can and should know. In actual practice, both medical and patient epistemologies are inconsistent *because* they are pragmatic.

I. What Patients Claim to Know

I asked the focus group members what they knew about GnRH agonists; and I asked the WITSENDO list members what they had learned about endometriosis. I deliberately used the rather vague terms "knew" and "learned" rather than "heard," "read," or "experienced," in order to determine whether women spoke of their knowledge as derived from personal experience, medical sources, or both. In general, participants incorporated both experiential knowledge and medical knowledge into their accounts, but to differing degrees. I focus here on participants' explicit responses to the question of what they know. When asked what they know, participants often regurgitated *medical* claims about endometriosis as disease. However, in their accounts more generally, most of their claims present their more *experiential* understanding of endometriosis as illness.

This suggests that some patients know that, in the wider social world, their experiential accounts do not have the same authority as medical accounts and do not get to count as 'real' knowledge. Thus, when someone asks them what they 'know', they assume this means "What do you know about the official medical body of knowledge about endometriosis?" To present one's self as knowledgeable, one has to invoke medicine, the socially-approved expert system for knowing about endometriosis. Yet, the participants themselves understand endometriosis primarily through their experience--however little the rest of the world may value experiential accounts as a valid source of knowledge about endometriosis.

Six WITSENDO responses to the question were framed mainly in terms of medical research and knowledge of the disease, although they also provided editorial remarks about the inadequacies of medical research and clinicians' knowledge. Here is one example:

W9: Endometriosis is a chronic, incurable disease. The characteristic lesions of endometriosis behave like endometrial tissue implanted in areas of the body other than the endometrium, such as the pelvic lining. It is most commonly found in the cul-de-sac. It is frequently misdiagnosed and goes undiagnosed in women because doctors don't know much about it. The average delay in diagnosis for a woman my age (35) is 9 years, and that is how long it took for me to be diagnosed. It can only be diagnosed through laparoscopic surgery...Endo is known to recur after treatment. It is not known whether endometriosis is progressive. In some women it is more aggressive than in others. Endometriosis can be found anywhere in the body, including the eye and the lung. The cause is unknown although researchers still hold to Sampson's Theory of Retrograde Menstruation from the 20s--that menstrual blood flows up into the fallopian tubes and into the pelvic cavity and endometrial implants are formed. Other research shows that while all women have retrograde menstruation, not all women have endometrial implants. Symptoms of endometriosis include pain during menstruation, pain with sex, pelvic pain (all the time or intermittently), diarrhea, painful bowel movements, pain with urination. About 30-40% of women with endometriosis experience infertility. Some women have no symptoms. The severity of lesions found is not correlated to the amount of pain. A woman with mild endometriosis can have severe pain, and a woman with severe endometriosis may present with no

symptoms. Women with endometriosis often have allergies and other autoimmune diseases such as Hashimoto's disease, fibromyalgia, interstitial cystitis, Crohn's. It really isn't clear what percentage of the population has endometriosis, as it seems that statistics on this vary widely depending on the source. Even at a conservative estimate of 15%, it is a fairly common disease.

These accounts pick up on various medical rhetorical devices. First, they tend to use the passive voice ("It isn't clear," "research has shown," "more research is needed," "endo has been linked to"). Second, participants used particular medical phrases ("may present with no symptoms," "characteristic lesions," "once cycling is resumed"). The use of the passive voice and medical phrases help to construct endometriosis as objective medical entity in 'the' body rather than as patient experience--as disease rather than illness--and constructs participants' claims as reflective of scientific fact rather than perception or opinion. Hints of endometriosis from the 'patient's perspective' appear in the passages above too: "even when you have a hysterectomy it is not a sure thing you will be cured," "that is how long it took for me to be diagnosed," "women don't get the care they need." This is what makes them distinct from scientific medical accounts, in which endometriosis often appears as free-floating entity that affects "the" reproductive organs, but not persons, and in which the context of diagnosis and treatment is erased.

Two WITSENDO participants combined in roughly equal measure medical concerns about the disease and more patient-centred interpretations. These accounts, while invoking medical knowledge as in the first category, tend to emphasize the active voice. As a result, the focus is more upon uncertainty and subjectivity (on claims-makers and knowledge seekers), rather than on endometriosis as known object. They evoke *process* in a struggling *knowledge community* rather than static, independently-existing facts. These responses, then, draw upon medical claims but reconfigure them as situated knowledges: claims that are made by agents who are members of epistemological

communities. Here is an example.

W5: I have learned that the disease is "mystical." No one really knows why we get it or how to get rid of it. Many experts disagree as to what are useful treatments. Some doctors still feel that a hysterectomy is the cure as well as getting pregnant. Some also feel that surgery and Lupron are the cure-all. Basically no one agrees except for those of us who have it. We all agree that it's a terrible disease to fight. Studies suggest that different herbal treatments as well as dietary changes can help (I've found this to be somewhat helpful too, but no cure-all). I've read different opinions about how the disease can be different "types"--clear to white, red, and the dark purple. Usually the clear to white seems to cause more pain and it is also harder to find in a lap. The red and purple types seem to cause more fertility problems though. Our own hormones (i.e. estrogen) seem to feed the disease as well as possible chemicals from the environment (i.e. dioxins and other hormonally active agents). I also know that not enough research has been done to determine causes, cures or better treatments.

Further along the continuum, four WITSENDO participants answered the question by invoking the endometriosis patient experience. Here are two examples:

W12: I have learned that endo is like a demon that never leaves you alone until it has taken over your career, family, social life, mental stability, pain tolerance, and your entire life! It forces you to live by its rules. It is something that I have learned that you have to accept and make your life work or else it will control you and your relationships with people around you. I have also learned that bowel and bladder problems stem from endometriosis. I have also learned that there are so many women affected by this awful disease. It is also very hereditary. I also learned that you need to find a specialist in endometriosis that is well-educated and listens to you as a person, not just as another patient.

W4: I have learned why I had needle searing pain during my periods while I was younger. I must educate myself because the gyns and GPs of our current medical establishment have no pride in achieving excellence.

These responses present a conception of knowledge that is quite distinct from that presented in the responses cited above. These participants primarily present experiential narratives that posit a uniquely patient-centred knowledge. Endometriosis is depicted more as illness than as disease; the lifeworld context of the experience of endometriosis and medical treatment is emphasized. Three of these four respondents were highly critical of clinicians' knowledge and this, I think, affects these women's knowledge presentation

strategies. That is, in *comparison* to medical knowledge of endometriosis, which is considered unreliable, the experience of endometriosis emerges as a relatively more reliable form of knowledge for these women. Hence, the question "what have you learned?" cannot be answered by invoking medical knowledge--medical knowledge is unreliable--but only by what these women 'know for certain': their own experience and the 'general experience' of the patient community.

This leaves six WITSENDO participants. They did not explicitly answer the question "what have you learned?" but provided accounts of their personal experience with the disease. It is not clear whether they chose not to answer the question, or thought that their experiential account *showed* what they had learned about the disease--based upon their experience. If the latter is the case, this would mean that 10 of the 19 WITSENDO participants thought that what they had learned was gained primarily through experience, rather than investigation of medical claims.

At the focus group meeting in which the question "what do you know about GnRH agonists?" was raised, only four group members were present; two of them (Beth and Zoë) responded, and the other two simply stated that they knew basically the same things. The remaining two participants who were not in attendance answered the question at another time (Acika during a telephone interview, Bobbi in a written response). Acika's, Zoë's, and Beth's responses to the question combine medical claims (how the drugs act on "the" body) with experiential elements (how they affect patients):

Acika: I know that the drug affects whatever it is in the brain that sends the signal for ovulation to the ovaries and that causes a pseudomenopausal state, and that the normal effects of menopause will occur.

Emma: Okay. Anything else that you know, just off the top of your head, about side effects, symptoms, how it affects other parts of your body, that sort of thing?

Acika: Yeah, I read about a lot of the side effects and watched for them. And I heard different women speaking at the [Clinic support] group. I

didn't realize that some of the effects I had would be associated with the drug.

Emma: Yeah. Okay.

Acika: When I heard the other women talk about it, then I realized it was a side effect.

Emma: Okay. Um [pause] so is that about it? [pause] What side effects did you read about, or what side effects did you know about I guess is a better question.

Acika: Nausea, appetite change, weight change, sleeping patterns, hot flashes.

Zoë: GnRH analogs prohibit the release of estrogen, and puts you in a menopausal state, and along with that you get all the changes that go along with menopause.

Beth: I read that they uh go to your pituitary gland and they bind to sites where the normal--what is it--gonadotropin hormone is [laughs nervously], and that when you start taking them [pause] when you start taking them, your symptoms get worse? 'Cause your body knows something's up, and it seems to produce, like, too much estrogen at first? And then it's like a feedback loop or something like this, and then the brain kinda shuts off, like once they're all attached, somehow? [laughs].

Emma: Okay/ Zoë: Mm-hmm.

Beth: And then the estrogen goes down, and something about the FSH [follicle stimulating hormone] goes up and the LH [luteinizing hormone] doesn't go up and then the LH goes up and stuff like that that nobody cares about and uh [pause; clears throat] the liver stuff is in one of the CPS articles on one of them, that it'll elevate your cholesterol and that? And uh [pause] I read about leucopenia? Decreased white blood cells? So you're more prone to infections? Which is also true with Danazol. And some people, if you're--actually they should have taken blood tests on us because some people, their white counts go down so low that they are very low and you can get infections easily and [seeing surprise on Zoë's face] they never did that on you either.

Zoë: No. That's the first I've heard of that.

Beth: I think it's in the CPS.

Mercedes: Yeah, it is.

Beth: And then I read a little bit about the bone density. It said like [pause] they did studies and, six months, and these people lost 18% but then after a year they were back to only like a 6% loss.

A degree of uncertainty about medical information is demonstrated in both Acika's account ("...whatever it is in the brain that...") and in Beth's account. In this regard, Beth's account is particularly interesting: normally confident and matter-of-fact in her delivery, Beth became much more tentative when discussing medical information. At the end of

many of her statements her voice grew higher in pitch, as if she was asking a question, and she laughed nervously, which prompted me and Zoë to reassure her and encourage her to continue with our "Okay" and "Mm-hmm." When she presented a claim (regarding leucopenia) that Zoë had not heard before, Beth invoked the CPS (*Compendium of Pharmaceuticals and Specialties*), which is the standard drug reference manual for Canadian physicians. Whether this was an attempt to provide Zoë with a source should she wish to find out more, or an attempt to establish the validity of her claim by reference to a recognized medical authority, is unclear.

What is clear in all of these accounts is an attempt to relate medical information (gleaned from sources external to the self, especially through reading) to patients' embodied experience of the drugs (gleaned both from reading, from other women's accounts, and from bodily sensations and the self's interpretation of them): Zoë's "you get all the changes that go along with menopause"; Beth's "your symptoms get worse," "your brain knows something's up"; and Acika's discussion of the side effects other women discussed, and how she was able, from that information, to explain her own embodied experience.

Bobbi's response to the question "What do you know about GnRH agonists?" was brief: "A lot! Almost everything I could get my paws on. I could recite it in my sleep." The emphasis here--as in a minority of the WITSEND0 accounts above--is on Bobbi as epistemological subject, her search for information and her assimilation of that information, rather than its content. This brings us to the next issue: women's accounts of their search for information.

II. How Patients Search for Information

The effect of Bobbi's statement is to establish her as a valid knower--a strategic move for her because, as we saw in the last chapter, she reported many encounters with doctors in which her assertions had been invalidated. In general, the participants in this study seemed concerned to establish that they had "done their homework"⁶²--that is, that they had done a great deal of information-gathering about endometriosis and were therefore knowledgeable and credible claims-makers. I asked focus group and WITSENDO participants about the sources of their information in an effort to understand the process by which these women came to consider themselves as knowers, and the extent to which they drew upon the knowledge of medical researchers, clinicians, the Endometriosis Association, and other women with endometriosis in formulating their own claims. All the participants in this study consulted more than one kind of source.

All of the WITSENDO participants are, of course, members of the WITSENDO list; thirteen of them specifically mentioned WITSENDO (and often other similar Internet-based, patient-centred resources such as bulletin boards and newsgroups) as a primary source of information. The Internet generally (with the WITSENDO list as one component thereof) was cited as a source by 14 of the 18 participants; five of these specifically mentioned medical sites such as medical literature databases (Medline, for example) or doctors' websites. Twelve participants cited the Endometriosis Association as a primary source, with eight specifically mentioning *The Endometriosis Sourcebook* (Ballweg & the Endometriosis Association, 1995). Twelve participants cited books generally as a primary source; when described, these books were most often geared

⁶²This phrase is used by the Endometriosis Association (1999:65); see next chapter for a discussion.

toward a lay audience of women with endometriosis. However, six participants did cite medical publications (books and/or journal articles) as important sources. Six also mentioned doctors as sources of information, usually with the qualification that most of the doctors they consulted had provided no, little, or only basic information. Surprisingly, only three participants mentioned support groups as primary sources of information. However, all of these women are members of WITSENDO, and the list serves as a virtual support group, perhaps adequately filling the needs that other women satisfy by attending face-to-face support groups. Moreover, face-to-face support groups are not available in all communities. Other sources mentioned by one or two participants were relatives, "other women with endometriosis" generally, pamphlets obtained from doctors, and formal education (one participant attended nursing school and "touched on" endometriosis during her education).

None of the focus group members consulted Internet sources (the meetings were conducted in 1994 before most people could obtain Internet access). However, three of them conducted research on GnRH agonists at the University of Manitoba medical library. All six read books about endometriosis, most commonly books written for a lay audience; four of the six also read the sections on GnRH agonists in the *Compendium of Pharmaceuticals and Specialties*. All six read the package insert pamphlet that came with the drug; most also got pamphlets and/or videotapes from their doctors before they decided to try GnRH agonists. Two called the manufacturers in an effort to learn more about Lupron; another called a prescription drug information hotline at the main teaching hospital in Winnipeg; several consulted pharmacists. Some focus group members were also members of the Endometriosis Association and read its newsletters and first book, *Overcoming Endometriosis* (1987). All, of course, were members of the Women's Health

Clinic support group and exchanged information verbally, and often in the form of articles, books, and videotapes, with each other and with other support group participants.

The factors that led these women to search for information on the disease varied. For some women, their search was precipitated by a particular medical event such as diagnosis, the initiation of a new treatment, or impending surgery:

W16: I went again to the surgeon and he told me that it was endometriosis and that I had to have 6 shots of Enantone⁶³ and 2 months after I would have another ultrasonography to see the dimension of the mass [cyst]. At this point I had my first shot and started to "surf" the Internet to see if I was able to find something about endometriosis. I found a lot of sites and I joined the WITSEND0 list...I read all the e-mails of the WITSEND0 women, a lot of articles, and "pieces" of medical books about endometriosis. I created several "dossiers" on it and I learnt a lot of things.

W17: When I was in my 20s, my stepsister...had numerous surgeries for endo before eventually having a hysterectomy. But I still didn't look into it until the doctor told me last summer that there was a good chance that I had it...Before the surgery, I bought a couple of books (including the [Endometriosis Association's] *Endometriosis Sourcebook*) and looked up info on several medical web sites.

The focus group members, too, tended to conduct research in response to diagnosis, to facilitate treatment choice, and to prepare themselves for particular treatments (GnRH agonists primarily)

Other women began actively to search for information when they became disillusioned with the medical treatment they were receiving. Recall that Bobbi's decision to investigate Danazol was the result of hearing her doctor tell an intern that he didn't need to tell her about rare side effects. One WITSEND0 participant was diagnosed with endometriosis during surgery for an unrelated problem at a military hospital. Because her surgeon did not tell her anything about the disease,

⁶³Enantone is the Italian trade name for leuprolide acetate, the monthly injectable GnRH agonist which is known by the trade name Lupron in North America.

W4: ...I didn't think it was anything important. About one month later on a business trip, I told a business associate about the surgery and the endo and he became furious [that she had been given no information about the disease]. His reaction and my ignorance sent me to the book store where, by the grace of God, I literally found the *Endo Sourcebook* and bought the only copy. I began to read and boy, did I get angry. The first thing I did is went and obtained a copy of the surgery report from the archive room. The military hospital had not placed a copy in my medical records. This is unacceptable, but you can bet there is a copy in there now. I have a copy with me whenever I move as well, I treat it like a passport.

In this passage we see that the central criticisms of doctors presented in the last chapter are integral to understanding many participants' self-education processes. The criticisms reflect a common disillusionment with medical expertise that these women describe as *causal* to their perception that self-education was necessary to finding good health care or, in cases of more extreme disillusionment, managing their own care. In accordance with cultural expectations of doctors, most of these women initially expected the clinicians to explain endometriosis to them, be knowledgeable about the disease, take it seriously, and solve their problems. These hopes were disappointed. Along with this disillusionment came a realization that becoming a more active health care consumer was necessary, and self-education was viewed as an integral part of that:

W12: At this point it was constant [pain], 24 hours a day seven days a week. My doctor would not listen to me, even after going to the emergency room and calling his office everyday. All they would do is keep prescribing me more pain killers. I was on Codeine for 2 months, Naproxen after that⁶⁴, continuous 4-8 [pills] every day. I finally figured out that this doctor had no clue and [I needed] to find a specialist. That is when I started to do my research.

W2: The most useful thing I have learned is that women are alone in the fight of this disease since most doctors are not informed enough. The reason why this has helped is because it forced me to learn about

⁶⁴Naproxen is a painkiller that works by inhibiting the production of prostaglandins, substances believed to cause pain. Naproxen and Ponstan, a similar medication, are frequently prescribed to women with primary dysmenorrhea and dysmenorrhea secondary to endometriosis.

endometriosis.

For these women, there is a contrast between widely-held cultural expectations of doctors--that they should be well-informed and make serious attempts to solve health problems--and their actual encounters with clinicians who often demonstrate an inability to cure or even alleviate their problems and often exhibit a striking disinterest in their suffering. In a sense, these women took on the culturally prescribed role of physician that their physicians appeared to reject. Since the physicians would not take endometriosis seriously and knew little about the disease, these women compensated by attempting to become experts themselves on the disease and taking the disease more seriously than they did before. In the accounts, the relationship between learning and taking seriously is reciprocal: learning more about the disease led them to take it more seriously (as in the case of the woman who began reading about the disease and became angry that her doctor had treated it so lightly); and taking the disease more seriously (for example, because of worsening symptoms and consequently greater impact on their lives) led them to investigate the disease more thoroughly.

At the same time, the participants discussed the barriers they faced in becoming endometriosis 'experts' and the strategies they used to overcome these barriers, especially in the years before the Internet when lay access to information was more limited. Two barriers mentioned were their lack of familiarity with medical language and the difficulties of accessing medical information. Strategies used to overcome these barriers included using a medical dictionary; consulting acquaintances with medical training, including doctors; and compiling snippets of information from diverse sources.

Mercedes: I went to the medical library...Journals, lots of books and stuff and took a whole bunch of journals out and didn't understand them anyway...So I would read up on stuff and then I would phone my brother in [city] who's in the medical profession--not gynecology, he's in cancer

research, but he still understands medical terms, so we would have lengthy conversations on what does this mean, and what does this mean. I'll never forget the day I asked him what libido was! [group members laugh] I mean you're just reading so much, eh, and just loss of libido and he says "Mercedes, you can't be serious!" "Yeah, what does it mean?" Yoy! Since then I've bought myself a medical dictionary.

W14: I would scan every book store's shelves for anything I could lay my hands on. Most books regarding women's health included little if any information on endo so for many years I pieced together the bits of information I could find...

W15: I was told the only sure cure was a partial hyst⁶⁵ (at age 26 and no children). Tried to do research, but there was very little info in public libraries and had to go to the medical library (no Internet at that time)...

The phrase "had to go to the medical library" suggests a certain reluctance. It is clear from WITSENDO participants' responses that more of them investigate medical information about endometriosis through the Internet (for example, doctors' websites and medical journal article databases) than by actually going to a medical library. WITSENDO participants explained this preference in terms of ease of access, but there may be another factor at work here: the medical library may be perceived as a professional sanctum which is intimidating for laypersons, especially those not accustomed to conducting library research. It is less intimidating to download information anonymously from a medical website than to enter a space generally reserved for professionals and professionals-in-training and either wade around in a sea of books and journals hoping to come across relevant information, or demonstrate one's ignorance by asking for help. Certainly, the focus group participants--none of whom were Internet users in 1994, when the research was conducted--implied that research in the medical library was unpleasant and discomfiting. Three of them did use the University of

⁶⁵This participant is referring to a hysterectomy in which the uterus is removed but one or both of the ovaries and fallopian tubes is retained.

Manitoba medical library. As a nurse, Zoë was quite comfortable doing so; Bobbi and Mercedes had never before entered a medical library and went together. First they had to find out where the library was. They recounted that they were seized with giggling fits during their time in the library, and that they had difficulty understanding what they were reading. Not surprisingly, Bobbi portrays the experience as a chore:

Bobbi: ...we sort of gave each other the nudges...we'd go and we'd do our research...And uh, *force* ourselves to go down to the medical library.

Barriers to access, such as the use of jargon in medical texts and their housing in inaccessible, pseudo-private spaces reserved for medical professionals, exacerbate the onerous nature of learning a broad field of arcane knowledge. With the realization that self-education was necessary came a certain level of resentment, again tied to cultural expectations about experts and social divisions of labour: knowing about disease is the job of physicians, not patients. In response to focus group members' assertions that clinicians needed to become more expert in the area of endometriosis, I suggested that society's dependence on experts and the professional monopolization of knowledge was responsible in large measure for the powerlessness of patients. When I suggested that laypeople would be well-advised to rely less on experts and educate themselves instead, some focus group participants became indignant:

Celeste: I expect him to give me some information. That's what I'm going to him for. He might not have all the answers, but he should certainly have some...

Beth: I agree with Celeste. They're the doctors, they should give us information. We've got our own jobs to do.

When I questioned Beth about this statement more closely, however, it turned out that she was not advocating a strict division of labour between doctor and patient. Rather, she was advocating shared responsibility and cooperation in information-gathering between doctor and patient--the informational partnership model discussed in the last chapter:

Emma: But some people say, "Well, no wonder patients are powerless; they don't take responsibility for learning themselves." And I know you guys have, but you've *had* to. Would it be that way if your doctor had given you all the information? Or would you be content to just sort of have the doctor spoon-feed you? And I'm not trying to be insulting here, but I guess what I want to find out is, how far are we willing to go to take control of our own health care and how much do we want the doctor to do?

Beth: Well, I think that probably even if we had all gotten the information, we still would've looked for more.

Emma: Yeah?

Celeste: I would.

Zoë: Yeah.

Mercedes: Yeah.

Beth: We had to do everything, but at least if they would've met us halfway.

Acika also emphasized that the information that doctors provided was insufficient and that more independent self-education efforts were necessary to supplement doctors' basic educating practices.

Acika: The doctors who say they've had the most recent medical research or whatever--when my doctor presents something like that to me, I say, "Great, where can I read about it?"

Emma: So it sounds like you're saying you think it's really important that you do the reading yourself, rather than just having them tell you something.

Acika: Right.

Emma: Okay. Why do you think that's so important?

Acika: Um, because if he tells me about it, it will give me an overview, and if it's something that's important, I want to know the whole thing.

In general, the importance of self-education and interpatient education was strongly emphasized by focus group and WITSENDO participants alike, not merely as a supplement to doctors' expert knowledge, but often as a *replacement* for experts. This is deemed a crucial step in taking control of one's health care, a priority which arises in large part because of these women's critical evaluations of clinicians' knowledge.

W14: New information on diet and endo has resulted in uncovering many links to my pain and other symptoms. I can now give a detailed explanation of candidia, the effects of evening primrose oil and flax seed oil, the importance of a grocery list of vitamins, supplements, and organic

food. Years ago I was washing painkillers down with coffee.

W4: I must educate myself because the gyns and GPs of our current medical establishment have no pride in achieving excellence. I will help all who are suffering because we will both learn more.

W5: I have learned a wealth of information from the Endo Association and their books and newsletters. I occasionally hop on the net to see if there is any new info I can find. I have read about 7 different books cover to cover multiple times to make sure I didn't miss something the first time. I learned some but very little from my doctors...It seems to be a "self-educate" disease.

Celeste: I would tell them [other women with endo] to read as much information as they can on the drug, whether it's through your doctor giving you a pamphlet, or getting some books--something. Find out for yourself because if you don't, your doctor isn't gonna give you that much help, I don't think.

Given the prevalence of support groups, self-help books, patient organizations, and Internet websites, mailing lists, and bulletin boards devoted to chronic health problems, it is clear that the demand for patient-oriented information about chronic illnesses is high. While many women with endometriosis are deeply dissatisfied with their doctors, their need for information cannot be reduced simply to clinicians' inadequacies as teachers and communicators. Some WITSENDO and focus group members were being treated by doctors who provided them with a good deal of information, yet they still subscribed to the WITSENDO list, attended support group meetings, and/or read EA literature. While one of their motives for doing so is related to their need for support and empathy, they cited these venues as crucial sources of information as well.

Self-education fills informational gaps left by doctors and enables patients to challenge their doctors' claims with their own socially-legitimated knowledge; many members of the endometriosis patient community can describe the findings of medical studies in detail and provide citations for their claims. However, and just as importantly, self-education also engenders in them a sense of empowerment and control over

endometriosis itself. In the next section I discuss in more detail the ways in which women with endometriosis evaluate claims and claims-makers, including themselves.

III. How Patients Evaluate and Use Knowledge

In this section, I address in turn the participants' evaluation of the utility of various knowledge sources, their accounts of how they put those sources to use, and their strategies for evaluating the information gleaned from such sources and for presenting themselves as credible claimsmakers. Framing this discussion is a conceptualization of sources as conveying *kinds* of information that fall along a continuum, from pure 'disease information' to pure 'illness information.'

We have seen that several analysts have distinguished between disease, which refers to biomedical definitions of measurable deviations from normal states of health, and illness, which refers to patients' experience of bad health (eg. Eisenberg, 1977; Kleinman, 1988; Robinson, 1990). Following this, I conceptualize disease information as medico-scientific information about endometriosis and treatment, such as anatomy, pharmacology, or physiology, that discusses endometriosis in purely objective terms without reference to patient experience. Illness information is conceptualized as patients' descriptions and evaluations of their subjective experience of endometriosis, focussing on physical sensation, psychological and emotional implications, and social context, and not explicitly related to medical understandings of endometriosis as disease.

In actuality, sources of information about endometriosis are devoid of such purity; they convey some combination of these two ideal types of information, because lay conceptions of illness and scientific conceptions of disease are implicated in one another. There is no medical understanding of disease without the experiential narratives of persons

who are ill, such that disease information appropriates and reworks illness information; and persons who are ill construct their illness narratives to a great extent via reference to medico-scientific understandings of disease. The disease/illness distinction, then, is a useful heuristic device that, because it simplifies the relations between patients' experiential narratives and medical claims about disease, allows us to dissect those relations. Below, I discuss in detail the interconnectedness of disease information and illness information in patient accounts.

1. What sources are most helpful, and why?

Fourteen of the 18 WITSENDO respondents directly answered the question about their most helpful sources, and most answered it by listing more than one source of information. Fewer discussed their reasons for listing these sources. The most commonly cited sources were the WITSENDO list and other Internet-based patient groups, the Internet in general, books on endometriosis (particularly *The Endometriosis Sourcebook* by the Endometriosis Association), and the Endometriosis Association in general. All of the focus group participants answered the question, and they too relied on similar kinds of sources (except for the Internet, which was not widely available in 1994). Discussion here is divided into three categories of sources: medical sources; lay-oriented publications; and patient groups.

i. Medical Sources

Recall from the last chapter that participants were deeply critical of clinicians' level of knowledge about endometriosis, their willingness to convey what they did know to participants, and the perceived insufficiency of endometriosis research. It is not surprising,

then, that not one of these women cited clinicians as her overall most helpful source of information. However, several women did cite them as useful sources, especially in their initial stages of learning about the disease, or in particular areas of knowledge:

W1: When I was finally diagnosed, after a lap to rule out ovarian cancer, my gyn was pretty informative, but with only the basics.

Beth: Surgery, I'd have to say my main source would be my doctor. I read a lot of books and I heard from a lot of people, and I heard all the wrong things. So I got the truth from my doctor.

Thus, physicians often provide basic initial information, which the participants then use as a way into their knowledge search. Once they have a rudimentary understanding of the disease, how it is thought to work on the body, and the names of drugs and surgeries available to them, they are in a position to pursue more detailed information. One cannot conduct a search on the Internet for information about specific kinds of treatments for endometriosis, for example, without knowing what key words to use. Clinicians often provide those key words. However, understanding what those words mean must often be gained through independent research, and for this participants tended to turn elsewhere.

Medical sources more generally, such as medical journals and doctors' websites, were cited as important sources by a number of participants. This was particularly true of four participants with scientific or health profession credentials, and their accounts emphasized these credentials:

W1: I am a scientist myself and appreciate seeing the sources cited, since they are from peer-reviewed journals.

W2: I am not a doctor, but have a degree in Biology so I tried to understand this disease from a medical point of view too...Much invaluable knowledge came from lectures by Dr. Dubin in Santa Monica, CA, who is dedicated to helping women learning about this disease.

It is likely that these women's professional socialization and training facilitate their

understanding of and search for technical medical information, and affect their evaluation that professionally-oriented sources of information are important to consult (*vis-à-vis* patients with no medical or scientific background). W16, for example, included a prefatory note in her account of her information search: "I stop for a moment to tell you that I am a biomechanic engineer...[and] Project Manager of 14 grant-funded research projects. This is to make you understand that it is 'natural' for me to do research about something."

It struck me that this information might have been presented not simply for background purposes (most other participants did not discuss the nature of their jobs, presumably because they didn't see such information as relevant to endometriosis or their efforts to understand it). Presenting professional credentials could well be a strategic move toward epistemological credibility. That is, these participants seemed to assert their scientific credentials in such a way as to demonstrate the goodness of fit between their worldview and that of medical science, implying that they understood medicine well and that their subsequent presentations of it therefore could be trusted.

For example, in the focus group discussions, Zoë (a nurse) frequently intervened to clear up other members' uncertainty about medical information, to provide "inside information" about particular physicians and the health care system, and to make assessments about knowledge politics among patients and health professionals. When Mercedes recounted that her doctor had cautioned her that she would not understand medical journals, Zoë responded "And I totally agree with that, for the layperson." She confirmed medical information presented by other participants, and in general her statements often were treated with more deference than those of other group members. In fact, I asked Zoë to make inquiries about medical information on behalf of myself and the

focus group members. She was the only focus group member to volunteer to accompany me to the medical library to conduct research and analyze medical presentations of endometriosis and GnRH agonists. Although others echoed her concerns, she was the most insistent on the need to develop standardized treatment protocols and on clinicians' responsibility to keep abreast of the latest scientific research on endometriosis. Although Zoë was a cosmetic surgery nurse and had little training in gynecology, on occasion she presented herself (and was accepted by others) more as nurse than patient. She used the passive voice, technical terms, and medical abbreviations and spoke in the abstract about the health care system and medical expertise more than other participants. Of all the group members, Zoë's rhetorical style and substantive foci most closely resembled those of clinicians and medical researchers⁶⁶. The group members' (including my own) deference to Zoë regarding medical matters indicates that, to a degree, we too accepted the "cognitive authority" (Addelson, 1983; Wendell, 1996) of medicine, despite our acute awareness of its limitations.

⁶⁶It is interesting, too, for me to note the extent to which Zoë's rhetorical style resembled my own, for example in its more theoretically abstract analysis of the politics and structure of health care. This is due, I am sure, both to her nurse's perspective on the health care system and her reading and training in social science during her nursing education. Another group member, Bobbi, was an Honours sociology student and also was more comfortable discussing broader social and political influences on health care. When group members discussed the politics of gender in medical knowledge, I often used the passive voice and presented myself as an authority on such matters. As a result, I considered it necessary to conduct additional research to evaluate whether or not my remarks were solely responsible for the strongly feminist analyses made in the focus group discussions. In the WITSENDO accounts, the same kinds of analyses emerged despite the listmembers' lack of awareness that I am a feminist scholar. In fact, the endometriosis patient community as a whole has quite a strong feminist orientation. I suspect that there is a dialectical relationship here: that this community's orientation is both result and cause of the individual political commitments of its members, since it is likely that women's groups attract women who already hold to feminist principles, and that individuals who seek out such groups for other reasons may become feminists by osmosis.

At the same time, however, the cognitive authority of medicine was questioned routinely by participants. While participants sometimes explicitly criticized doctors for perpetuating "myths" or providing contextually inappropriate advice, criticisms were more often implied. Focus group members signalled that they thought their doctor's actions or remarks were inappropriate by supplementing their accounts with sneers, snickering, snorts, and sarcastic tones of voice. Quite consistently, other members responded by rolling their eyes, shaking their heads, laughing, groaning, sighing, snorting derisively, or making sarcastic exclamations such as "What?!" or "Oh *please!*" Only very occasionally was a group member's suggestion of her doctor's impropriety questioned by another member. Generally, group members communicated to each other their support for each other's critiques and their mutual perceptions of the impropriety of doctors' advice, producing a tacit communal evaluation which did not require overt statement or justification.

Some WITSEDO participants made their critiques more explicit, perhaps because they had no assurances that I shared their perspective about the doctors' actions or statements that they were criticizing. However, most of them assumed that I did, and signalled their disapproval of doctors' claims in more subtle ways. For example, they ended accounts of doctors' advice with exclamation marks or supplemented their account with information that contradicted the doctors' advice, or with sarcastic asides (which, as we have seen in many of the quotations presented thus far, are exceedingly common in endometriosis patients' talk about doctors).

W9: I've had many doctors tell me that pregnancy would cure my endometriosis (I am now a mother of a 3 year old, and I still have chronic pain that resumed shortly after birth even though I breast fed my daughter). Another doctor recently told me that I couldn't have endometriosis still because I was able to conceive. The same doctor told me that I had an attitude problem when I refused to go on the pill. I explained that I had

tried the pill (in various brands) for 15 years for pain and it has never worked. Needless to say I never went back to his office!

W15: ...the local ob/gyn (or quack, as I call him in my kinder moments) went in, spread the endo around, and refuses to let any other doctor correct his mistake.

Often, the claims of medical professionals were called into question by invoking other, non-professional sources of information judged to be highly credible by participants. In other words, for the vast majority of participants, the cognitive authority of medicine was not enough--the authority of experience was crucial to understanding and presenting claims about endometriosis as both illness and disease.

ii. *Lay-oriented Publications*

In this category I include books and Internet sources geared toward endometriosis sufferers and resources (books, newsletters, and conference audiotapes) published by the Endometriosis Association. Of the 18 WITSEDO respondents who described their most useful information sources, seven listed one or more of these sources as among their most useful, and one focus group member (Bobbi) noted that Endometriosis Association newsletters were her main source of information on both GnRH agonists and endometriosis. She did not directly explain why. However, her reasoning can be inferred from her responses to my questions about the availability of information about GnRH agonists and the role of the drug companies in producing and distributing that information (Bobbi was not at the meeting where these questions were discussed, so she provided the following written comments):

There isn't enough information about these drugs *period*...Access to info is a problem because there is little info. What little there is, the drug companies don't release it, especially not to the consumers. Yes, I have tried to get more. However, when I called the drug company, they said they didn't have any other info besides the one six-month study (which I

feel is *bullshit*)...They have a vested interest in marketing the drug, making it appear innocuous, and concealing the 'negatives' or delegitimizing the 'uncomfortable' side effects. The Lupron pamphlet says it all. They play/lie with the numbers. They word it in more positive ways, and I believe the numbers *are* outright *lies*...The doctors don't know the answer, but want to uphold their 'pedestal position' and bluff it.

Recall too from the last chapter Bobbi's descriptions of clinicians' refusal to share information with her. This, combined with her assertions that there was not enough medical research being done on either endometriosis or GnRH agonists, and that the medical knowledge that did exist was misleading, suspect, or even fabricated, demonstrates that Bobbi clearly did not feel that clinicians or medical publications could provide her with a sufficient understanding of endometriosis or GnRH agonists.

Yet, at the same time, Bobbi was someone who considered it crucial to acquire medical information about the drugs, as witnessed by her trips to the medical library and her attempts to get information from the manufacturers of Lupron. She describes an incident when she was away from Winnipeg and needed someone to give her her monthly Lupron shot, so she went to the local hospital:

Bobbi: I had to fight to get my Lupron shot because it was a very dangerous drug, and blah blah blah blah, even though I had a note that I'd got to get an injection. They were very frantic about Lupron there, they didn't wanna give it, and uh warned me about how danger--dangerous it is, and I'm going, like, "no shit!"

Emma: Well, how did that make you feel though? Did it scare you more, or [pause].

Bobbi: It scared me, and yet it also [pause] it made me mad 'cause I thought [pause] *No kidding!* Like, like, I *knew* about this, do you think I'd be [pause] um [pause] I-I don't know, I was angry that um [pause] I thought [pause] I'm *not that careless about my body* to jump into something with my eyes closed.

Bobbi's equation of not researching the drug with being careless about one's body gets at a crucial element of modern Western conceptions of the self and medicine: that self-determination comes through knowledge and that the self is the steward of the body.

The combination of these two principles means that patients must educate themselves about their bodies--generally through biomedicine, the expert system in Western culture that provides knowledge about the body--and use that information to care for the body. Deborah Gordon (1988:41) argues that the naturalist, individualist epistemology of medicine is intimately connected to the modern self, a self which is "independent of society and culture, owner of his or her own symptoms, increasingly able now to detach self from body to observe, cultivate, and even contractually join the physician in rationally treating his or her own case." Such a self is "no longer a victim, but in the omnipotent driver's seat" in relation to disease. Biomedicine, then, becomes an important venue for the assertion of one's autonomy (ibid).

But in order to assert that autonomy, one must first engage with biomedical knowledge--the basis for responsible stewardship of the body. Bobbi did this by reading Endometriosis Association literature about endometriosis and the drugs used to treat it, and also by 'reading up' on the drugs in the medical library. Because of her distrust of the expert system of medicine and the pharmaceutical industry's pivotal role in that system, and her strong feminist and patient advocacy principles, she found the Endometriosis Association literature more trustworthy regarding medical matters than medical literature itself. Bobbi's perspective, then, is somewhat conflicted: on the one hand, she accepts the principle that medical science is capable of providing trustworthy information about drugs, but has a strong sense of the 'corrupting' effects of power and therefore distrusts the stewards of that knowledge (clinicians and researchers) because of their biases and their close association with drug companies.

In other words, Bobbi's views about medical science are similar to the Mertonian and medicalisation perspectives (not surprising, given that she is a sociology student).

Corporate, patriarchal, and professional interests are at play in the development of scientific information about endometriosis. Medical science *can* approximate the truth, but only when it is free of the corrupting influences of power. When I suggested that expertise, specialization, and the privatization of medical knowledge were responsible for many endometriosis patients' difficulties with clinicians, she responded "I don't think the problem is that they're specialized, which is what you're saying, but just that what we're saying isn't validated." Her advocacy of a large database of information about the drugs, provided by women who have experience with the drug and not funded by the pharmaceutical industry, suggests her faith in scientific representations in the abstract and her belief that they can accurately reflect the experience of patients. So for Bobbi, there is no inevitable contradiction between experience and medical knowledge; the contradiction arises because of 'polluting interests' and 'biases' (sexism, the profit motive, inequalities between patients and doctors) that corrupt medical knowledge.

The implications of all of this are that Bobbi believes the Endometriosis Association literature is the most credible source about GnRH agonists for several reasons. First, unlike the drug companies, the EA has no axe to grind (it seeks only to provide 'the truth about GnRH agonists' to endometriosis patients). Second, Bobbi seems to feel that, unlike clinicians, the EA is respectful of and seeks to represent accurately female patients' experiential narratives, incorporating them into its accounts. Third, and importantly, the EA combines patient experiential narratives with *good science*, presenting and evaluating medical research in detail according to widely-accepted scientific ideals (disinterest, balance, freedom from social and political corruption). Hearing about other women's experiences is of crucial importance to Bobbi, but science is a necessary supplement to that kind of knowledge, and she accesses it mainly through Endometriosis

Association literature.

These themes are echoed to an extent in the WITSENDO responses. The reasons WITSENDO participants viewed such sources as useful were that they provided detailed, accessible, technical information about endometriosis. Accessible here should be read two ways: easy to understand and easy to find. Lay-oriented books and websites about endometriosis tend to provide quite detailed overviews of medical research and thinking about the disease, with citations that provide the sources of information; and through the Internet, the most recent developments in endometriosis science are readily available. However, this information tends to be presented in a way that laypeople can understand easily. While medical literature provides similar kinds of substantive information, as we have seen, it presents significant barriers to non-experts. Most participants therefore seem to prefer sources geared specifically to them.

W13: Books and the Internet. Books because they have in depth information about the disease and my health concerns, the Internet because I have been able to find support and recent knowledge about endometriosis.

W14: [describing the Endometriosis Sourcebook] It provides a great breadth of information on causes and treatments that are scientific enough to arm one with the right information.

W5: The Endo Sourcebook from the Endo Association has been my most helpful source. The audiotapes from previous conferences acquired from the Endo Association have really helped too. The newsletter can become a little technical, but helpful at times...books and websites because they are authoritative--I need information to *prove* documented facts of the disease to doctors, insurance companies and my employer as often as I need the info for myself.

I find the last two responses particularly interesting: that published sources "arm" one because they are "authoritative" and therefore particularly useful in negotiating with doctors, insurance companies, and employers. Here we see the practical limits of subjectivism and the idealization of situated knowledges. Patients not only need to make

sense of endometriosis to themselves and among each other--areas in which standpoint epistemologies and experiential, subjective accounts are likely to be quite useful. They also must present claims to those who are less likely to view them as credible claimsmakers. Experiential accounts from an epistemologically discredited person--one with a disease that often is labelled psychosomatic--are unlikely to hold much water with medical experts, employers, and insurance agencies (a special consideration in the US, as health care benefits may be cut off if the patient cannot demonstrate the medical validity of their suffering).

For example, the statement "It feels like someone's sticking a knife in my abdomen" may capture well the embodied sensations of many women with endometriosis, and is likely to elicit a chorus of "Me toos" from women with endometriosis. They can compare their own embodied sensations with descriptions presented by the speaker and, if they are comparable, judge the speaker to be credible because she is capturing the reality of the endometriosis experience: she "knows what it's like."⁶⁷ But from the point of view of most social actors, for whom medicine is *the* culturally-validated epistemic framework for talking about illness, a patient's account of how she feels is not in itself proof of disability or disease; the documentation of clinicians is required.

Relatedly, of course, medical experts and insurance companies do not recognize the validity of women's standpoints, but tend to subscribe to scientific realism and objectivism: either one has a disease that can be apprehended somehow and objectively documented by expert-others, or one does not. If one does not, for the purposes of doctors and insurance companies (and often employers, friends, partners, and family

⁶⁷Yet, even when a patient's account of how she feels is not reflected in other patients' bodily sensations, these others are unlikely to discount the patient's account. I explain the reasons for this below.

members as well), one has no right to attention, treatment, and social benefits. Thus, patients need "authoritative" knowledge--that is, claims for which sources that carry some epistemological authority can be cited--not only to satisfy their own culturally-inbred assumption that medical science has something of value to say about disease (and is therefore crucial to the stewardship of the body). They also need it to convince others that their suffering is real and that therefore their assumption of the sick role--with all the rights and benefits that entails--is permissible. This is not merely necessary to one's self-conception as a rational being, as one whom others believe. It is a practical strategy for maintaining material well-being--the ability to keep one's job, to get coverage for medical bills, to get surgeries and prescriptions to alleviate pain and infertility.

Zoë's account of her hand injury in the last chapter--which, according to her surgeon "must be fixed" although her ability to use her hand remained severely limited--is illustrative of this issue. Her concern was that the absence of medical validation of her suffering would lead to her being denied further disability benefits. A surgical nurse is unemployable unless she has full use of her hands, and Zoë worried that she would be unable to find a job in another field. A WITSENDO participant, who has had a hysterectomy but still suffers from intense chronic pain, wrote in a heart-wrenching way about the effects of endometriosis on her life and the problems she faces as a result:

W15: I am very ill at this time, cannot even work at my own business (which I built and made a success of, starting from nothing). No longer have any insurance and no money and don't know what to do...If they [doctors] don't understand endo, they seem to think it's in your head or some non-diagnosis like IBS [irritable bowel syndrome]⁶⁸, or they will go in

⁶⁸Irritable bowel syndrome too has been described as a psychosomatic disease. It is interesting that this woman--whose own suffering has been delegitimated--applies the term "non-diagnosis" to IBS. Whether she is arguing that IBS is not a real disease, or that the diagnosis itself does not lead to effective medical intervention because of its *construction* as psychosomatic, is unclear.

and make a bigger mess than you started with and then deny everything. This disease has just about completely destroyed my life, my business/career is gone, my marriage is shaky, I'll never have children and I have no social life of course. If you have any ideas of someone, somewhere who might help please email me...

Because she has had a hysterectomy, considered by the vast majority of doctors to be the definitive treatment for endometriosis (she 'can't' have endometriosis anymore), this woman has been unable to convince doctors, insurance companies, and perhaps even her husband that her suffering is legitimate. Unable to enrol clinician allies and sources that are sufficiently authoritative to establish that her bodily sensations have an organic basis, she is in quite desperate straits. Such an extreme case demonstrates what can happen to women with endometriosis who cannot present the kind of socially-legitimated knowledge that affirms and provides a rational explanation for their bodily sensations, and that they seek from published works on endometriosis.

Aside from their medical information content, publications geared toward endometriosis sufferers often include the personal stories of women with the disease. This is particularly true of the Endometriosis Association literature, as we shall see in the next chapter. For now, suffice it to say that I suspect one of the reasons that the participants found lay-oriented books (especially those written by the Endometriosis Association) so helpful is that they *combine* technical medical information (in simple language) and experiential information--the narratives of other women with endometriosis. The latter is of inestimable importance to the participants. I turn now to the sources that are most explicitly concerned with the 'endometriosis experience': patient groups.

iii. Patient Groups

In this category I include the WITSEND0 list, other Internet-based resources where women with endometriosis are the primary participants (such as bulletin boards and chat rooms), and support groups (mainly the Women's Health Clinic group in Winnipeg from which focus group members were recruited). These kinds of sources were most often cited as helpful in participants' responses. Seven of the 14 WITSEND0 participants who addressed the most helpful source question listed the list or "other women with endometriosis" as their most helpful source. Six others emphasized how important their membership in a support group, online chat group, or WITSEND0 list had been to them, although they did not explicitly describe these as their most important source. The focus group members' responses were surprising: all five focus group members present at the meeting where I asked the question listed the group itself as a main source of information.

Zoë: I'd say now as an ongoing thing, [my main source] would be mostly [pauses] this group.

Emma: Like, this research group?

Zoë: Yeah, just sharing information.

Emma: Wow. That's about everything, like, not just the GnRH but everything?

Zoë: Everything.

Gratifying as it was for me to hear that the focus group meetings were so useful to the participants (an unanticipated consequence that highly recommends the focus group method for this kind of research), it is also startling to realize that the participants got more information from approximately eighteen hours of focus group discussion than from many years of clinical encounters with physicians.

What is it about 'hearing from other women' that is so valuable? WITSEND0 and focus group participants provide several answers: reduced feelings of isolation or abnormality; provision of information about medical matters in greater depth and detail

than that provided by other sources; honest information about treatments and prognoses; help with doctor-hunting; sharing of coping strategies; support, understanding, camaraderie, and the opportunity to "vent."

W2: Even if it may sound weird, I found that endo sufferers are amazingly helpful to learn about this disease. I have learned about symptoms, surgery failures, helpful hints on how to deal with the pain, and incredible support.

W14: ..I've relied on newsgroups with fellow sufferers to share the latest info on treatments, coping strategies and experiences with healthcare professionals. Through other sufferers I've uncovered doctors who specialize in endo, detailed studies on treatments, information on drug treatments and natural therapies.

W6: The best information has been info from other patients--they suffer symptoms that are *not* documented endo symptoms but that I have, which makes me feel less abnormal, they spend more time sharing information than any doctor has spent on it, they tell me things the doctors don't (like that Lupron might not help, a lap might not help, too many laps can be worse than endo itself, etc.). I guess the *kinds* of information are 1) big picture--all the risks/benefits/possibilities rather than just best-case-scenario as doctors generally provide, 2) personal experiences and 3) coping strategies (like how to dress for a lap, how to get through bowel prep, how to plan ahead for the sudden menopause of Lupron, like dressing in layers for hot flashes)...women with endo...know things the books never mention, like undocumented side effects.

W8: [discussing the WITSENDO list] ...these are people who suffer the same so can give better advice than any doctor could.

Zoë: I think that a lot of the information we need is just choices and what people have tried. You know, you've tried Lupron, I've tried Synarel, well let's, you know. And then you have the power to go to your doctor and say "Lookit, I'd like to maybe look at Synarel as opposed to the Lupron," or whatever...

Mercedes: [objecting to the fact that doctors don't refer women to the Clinic endometriosis support group] But you know what, if it's giving you some relief or peace of mind or something, they send people to support groups for everything else...it doesn't cost you anything to come here and, you know, listen.

Zoë: And I think there should be a directory, you know, like the Colostomy Association, before patients are gone from the hospital they are given the name or they are visited by somebody personally--

Mercedes: Yeah, exactly!

Zoë: --before they even leave the hospital, and that person follows up with them. Now, you can get as involved with them as you want, but this is a

person who has gone through what you've gone through and it is so helpful.

Note the centrality of the notion of experience in these accounts. For the participants, hearing from others means hearing about others' experiences. Other patients' experiential narratives were judged by the majority of participants in this study to be their single most important source of information about the disease.

2. How are these sources put to use?

We have already seen some ways in which women use the sources just described. They use technical information gleaned from books, the Internet, and Endometriosis Association literature to negotiate with their doctors, employers, and insurance companies. They use 'experiential' information provided by other sufferers in many ways. These include helping them find a good doctor; finding ways to cope with symptoms, side effects, and other problems associated with having endometriosis; finding explanations for unexplained health problems (which, for example, may be related to endometriosis); reducing their sense of isolation and abnormality (there are others who are going through 'the same thing'); getting information about surgeries, treatments, and endometriosis in more detail than other sources; and getting honest information about drugs and surgeries. Venues like WITSENDO also fulfil other needs not strictly informational but related to 'knowing about' or understanding what it is like to be a woman with endometriosis: support, empathy, and uncensored opportunities to express negative emotions (like anger and hopelessness) that may meet with negative reactions from others in the woman's life who do not have a chronic illness. There are other uses to which women with endometriosis put these sources, however, ones that I find particularly interesting.

First, women use medical information to evaluate the validity of statements made

by clinicians. Their basis for disputing medical claims is often other medical claims, which they access through reading, obtaining medical tests, or asking other women about the results of their tests or conversations with their doctors⁶⁹. Participants confirmed or denied their own doctors' claims by adopting medical frameworks and by seeking out the perspectives of other medical experts. Contradictions among medical claims, among clinicians, and between research and clinical practice, provide a space for comparison and critique. Two excerpts from the focus group discussions illustrate this:

Mercedes: He phoned after the results [of the blood density test] came back and said to me..."your spine has a high risk for fracture"...All these doctors said "Lupron will not do that to you...there's no reason why you would have bone density loss." I said "Well, I smoke, I drink coffee, I don't exercise, I don't drink milk, I never did, I'm on that drug that causes bone density loss. Don't you think I'm at a high risk, or could be at a high risk for osteoporosis?" "No"...I phoned TAP Pharmaceuticals to tell--to ask them? 'Cause from what I understand, if you have bone density loss it's minimal, and it comes back...if you've only been on the drug for six months. That's what they told me, that's what I understand. So why is my spine at high risk, not low risk, or medium risk, it's at high risk...But what defines a high risk for osteoporosis? You know, like [pause] I mean, I didn't drink milk as a kid, but I'm adopted so I have no medical background whatsoever, but I know that smoking--if you smoke and if you drink coffee, and I mean that's all I *do*!...

Zoë: ...And the part with all that too, with the reading I did, was you know, yes, you should be estrogen-replaced to a point to combat the bone density loss, but they're still in study form with that, so in one sense they're saying "Yes, in six months it is reversible" but yet then you're getting other information saying that "No, without estrogen replacement it's *not* reversible."

Beth: Every lap should be videotaped and kept on file in one designated area, so if one doctor's done a lap and missed it, it can be seen by a whole bunch--like, they should have a panel that looks through every lap...I read in a book that there's other people that have it but they just miss it...

Bobbi: I'm not too sure they're educated. Like, I know my doctor was one of the dinosaurs. You know, he thought pregnancy would cure it, and the endo cells he found were all classic brown, and so I'm wondering how much he missed because, guaranteed, that's all he was looking for.

⁶⁹So, other women with endometriosis often became 'surrogate knowers' that fill in for the absent medical researcher or clinician from whom they heard the claim.

Beth: Yeah, yeah, that's it, a lot of them only look for black or brown spots and they miss the other ones.

Women who could not find other medical information to help them evaluate their doctors' claims or challenge them in an authoritative way tended to go along with their doctors' claims, but with some reluctance:

W17: My doctor recommended six months of Lupron after my laser surgery, saying that he's seen this help with fertility treatments. However, none of the resources I could find cited studies that said it would help...I decided to try it because of the doctor's recommendations.

It seemed that the participants in this study often considered *published* medical information to be more reliable than that presented by their clinicians. This is in accordance with biomedicine's own explicit epistemological hierarchy, where scientific knowledge derived from the laboratory has greater authority than clinical experience. H. Tristram Engelhardt Jr. notes that this has ramifications for patients with diseases (like endometriosis) for which a clear relation between symptoms and objective indicators of disease often cannot be established:

Absent a lesion or a physiological disturbance to account readily for the complaint, the complaint was likely to be regarded as *male fide*. This requirement was credible because the laboratory sciences had become the basic medical sciences in an important ontological sense. They were seen as disclosing the reality underlying clinical findings. On the other hand, clinical observations...now became secondary (quoted in Wendell, 1996:123).

Women's use of information gleaned from medical *research* to evaluate clinical opinion follows biomedicine's emphasis on scientism and objectivity. Clinical opinion, as we have seen, often may be based on a clinician's 'experience,' is defined as 'anecdotal,' does not meet the criteria of good science, and therefore, within the official biomedical epistemological hierarchy, is considered less valid than the results of randomized, controlled clinical trials (the closest equivalent to laboratory findings in most applied

medical research). Yet, in practice, clinicians themselves often rely more heavily upon their clinical experience than upon the claims of medical science to which, as members of the expert system of medicine, clinicians are supposed to adhere.

The research participants, then, often seem to evaluate experientially-derived knowledge differently, depending on the identity of the person claiming the experience. While *patient* experience was much valued by participants--they often used it to discredit the claims of both researchers and clinicians--they nevertheless value medical research as more reliable than the experientially-derived claims of their physicians. This raises an obvious contradiction: women with endometriosis expect clinicians to take their experiential claims seriously, yet often they do not take seriously the experiential claims of clinicians. Focus group participants also asserted that they wanted their doctors to act as a resource to help them evaluate what they read (for example, Mercedes stated that doctors should be able to "confirm what you've learned"). However, it seems that both focus group and WITSENDO participants felt that doctors can only perform this role when they become "educated"--by reading their medical journals and 'listening' to women with endometriosis--and, as we saw in the last chapter, they asserted that most doctors were not educated. The clinical experience of their doctors, then, is an insufficient basis for doctors to teach patients or help them evaluate what they read. While the official epistemological hierarchy of biomedicine ranks scientific research as the best form of knowledge, clinical experience as the next best, and patient experience as the worst because the most removed from scientific research, patients place their own experience at the top of the hierarchy, followed by scientific research and then clinical experience. Using the standards of the medical establishment against the members of that establishment is a clever strategic move. But the irony is obvious: endometriosis patients'

experiential accounts have been judged invalid because they are not scientific, but patients themselves deem clinicians' experiential accounts invalid because they are unscientific.

Second, women with endometriosis often use the claims of medical science to evaluate each other's assertions, which again demonstrates the extent to which they take on medical epistemological standards. I have observed this occurring many times on the WITSENDO list. Because the WITSENDO participants in this study responded only to my questions and not to one another's responses, their accounts provide no examples of this phenomenon. However, in the focus group discussions, there were several examples; here is one:

Beth: I'd already been on it [Synarel] for a month and a half, and then she [her gynecologist] told me, "You'd better start eating all this cal[cium]"-- she told me to eat three cans of sardines a day [group members gasp], and she told me to exercise...which was really weird because when I was here last time, uh, your doctor [to Mercedes] and Bobbi's doctor told you not to even bother with the calcium 'cause you don't absorb it [while on the drug].

Zoë: Mine said that too.

Mercedes: They said you can drink two litres of milk every sitting while you eat and your body won't absorb it.

Zoë: Yep...

Beth: But don't you think--like, they say at night is worst, where your osteoplasts from your bone break down your bone to get calcium in your blood stream for your body to use, your heart to use, everything to use--if you kept a lot of calcium in your blood stream, don't you think it would prevent them from breaking the bone down?

Emma: There's only certain types of calcium as well that your body will absorb.

Mercedes: Yeah.

Zoë: Because if you take a supplement, like a pill, by the time it gets to the bone there's, like, maybe a little pin drop.

Beth: What if you take TUMS?

Zoë: No.

Beth: Well, that's what I'm trying, I'm taking TUMS.

Zoë: Well, I mean I guess it can't hurt, but [pauses].

Note Zoë's concession that "I guess it can't hurt," which disputes Beth's scientific claim about calcium and its absorption, but in a gentle way that makes some concessions to Beth's point of view. Generally, while focus group participants sometimes did contest the

claims made by other group members, they were careful not to discredit the other's status as a rational being. It seems that, even when members of the endometriosis patient community believe that another sufferer's claims are patently false, the community's norms of support and respectful interaction take priority. In no case in the focus group research (nor in 3 years as a member of the WITSEND0 list) did I observe a single case in which one patient questioned the validity of *another patient's account of her experience*. Other kinds of patients' assertions (especially about medical science) were questioned at times (and are questioned frequently on the WITSEND0 list)--but always very carefully and respectfully, so as not to contribute to the delegitimation that so many endometriosis patients already have experienced in interactions with their doctors.

Things are quite different in the medical community. It does seem to be quite uncommon for one physician to tell a patient outright that another physician is wrong and, as Mercedes' account in the last chapter illustrated, physicians tend to discourage patients from seeing more than one doctor simultaneously. However, as Chapter 3 demonstrated, conflicts about the validity of scientific and clinical-experiential claims rage openly within the medical community--often quite vociferously--and are published for all to see.

Third--and we have seen this already in excerpts from the focus group discussions--one's own experience and one's interactions with other women with endometriosis are used to evaluate medical claims (made by both researchers and clinicians). When a patient hears an account from another patient that contradicts what a clinician or study claims, this often causes the patient to call into question the veracity of the claim. The degree to which the patient questions the claim seems to be related to the perceived degree of separation between the contradictory claimsmaker and the original source of the contradictory claim. The source of the claim must be evaluated in order to gauge its

credibility. This is related to endometriosis patients' valorization of personal experience. The most believable claim is that which comes from one's own embodied sensations; accounts of bodily experience by others with whom one interacts and whom one trusts come next; and what others may have read or heard is still less trustworthy. So, when their own 'experience' or the experiential account of someone they know directly contradicts what a clinician or study claims, women with endometriosis often take this as proof positive that the claim is false. When other women report what they have 'heard,' this may be cause for doubting the clinician's claims, but follow-up is often deemed necessary. Compare these excerpts from the focus group meetings:

Celeste: I had still gotten a period when I was *on* the drug and he said "Oh no, it's not a period"...well, what was it then that I had five days in a row? To me it was just like a period I've had before except I didn't have the pain...He seemed to think he knew what he was saying and yet I knew he wasn't telling me my experience.

Bobbi: ...another doctor told me that my only options were hysterectomy or pregnancy, and uh, I said "well, pregnancy doesn't always cure it, and neither does a hysterectomy." And he goes "*Yes, they do. I've seen dozens of women with endometriosis*"...I would only talk about things that I kind of had proof--"*Well, I know a woman who's had a hysterectomy*"--and that would still get thrown down, you know, invalidated.

Mercedes: He wants to cut some sort of nerves on either side of my uterus, and--

Celeste: Yeah, that's what I had done.

Mercedes: Yeah, but I've heard a whole bunch of horror stories about having those nerves cut and I'm not too keen on it.

Celeste: Like what?

Emma: Problems with carrying a child to term, I've heard that.

Zoë: Mm-hmm.

Celeste: Really?

Beth: Really!

Mercedes: Yeah, loss of bladder control [pause].

Emma: Again though, Celeste, it's all, you know--

Mercedes: Could be all hearsay.

Emma: --it's some people, not other people? You know, so don't--

Celeste: Well no, this is good to know because I'm seeing him in May because I'm getting another lap done in June, and so this is good because I wanna ask him these questions, and he'll answer them.

Mercedes: Well, what did you have cut? Maybe I'm giving you the wrong information.

Celeste: Well [sighs] by the uterus, those three nerve things, whatever you wanna call them, I don't remember the name of them. He shortened them.

Emma and Zoë: He shortened them?

Mercedes: Oh, okay, shortened is different from just disconnecting them, so to speak.

Celeste: Oh no, he didn't disconnect them, no, he just shortened them...

Beth: It wasn't ligaments at all, was it?

Mercedes: Uterosacral ligaments?

Celeste: I don't know. He was talking about nerve endings, he said there was the three nerve endings, I understand that they are attached somewhere, and he said "I shortened them" he said "because that should help you so the pain isn't going to be as bad."

Zoë: How do you shorten a nerve ending?

Emma: Yeah.

Beth: No, I know, I don't understand that.

Mercedes: I don't understand that either.

Celeste: Well then I don't know, but then I'm sure as heck going to ask him!

In the first excerpt, Celeste questions the truth of her doctor's claim because she "knows" her embodied experience and the doctor's claim contradicts it. In the second excerpt, Bobbi "knows" that hysterectomy doesn't cure endometriosis because of her personal knowledge of other women who told her they had hysterectomies and still have the symptoms of endometriosis. Other patients' narratives of their experience override the doctor's claim. In the third excerpt, Celeste is uncertain about her doctor's knowledge because she hears from other group members that the surgery he performed on her may cause incontinence and miscarriage. However, the other group members--in an attempt to calm her fears--point out that the claim may not be true, and rather than rejecting her doctor's claim, she decides to seek further explanation from him to clear up the ambiguity. In this last case, what women she knows have 'heard' is not sufficient reason to reject her doctor's knowledge, although it is sufficient reason to ask him for clarification.

Fourth, some women in this study use both medical information and the experiential accounts of other women to interpret their own experience, especially their

state of mind and physical sensations.

Bobbi: 'Cause I was anxious and depressed and confused and I couldn't remember things [while she was taking Lupron] and you know I--um [to Mercedes] remember when we found [in the medical library] how it affected your short-term memory and the cognitive things, and things like that, and it was true.

W11: I have found things like WITSENDO to be the most informational, because other people often recognize symptoms or causes I would never have attributed to endo but, when thinking about them, they are true for me too.

Acika: I would recommend that women keep records of both before the drug, during and after, and that they talk to other women, that when you hear other women experience what you are, you realize that what you're experiencing is part of side effects, etc.

Mercedes: I had quite a few of the side effects [of Lupron] but then some of the side effects that I had weren't listed on there. That's when you think "Am I going crazy? Is this just me?" You know. Like what [pause].

Emma: So the list [of Lupron's side effects] acted as sort of confirmation that what you were going through was legitimate?

Mercedes: Right! I never read the list for three months, like, I didn't even know.

The fact that these women draw on medical knowledge and the experiential accounts of other sufferers to explain their experiences suggests that, in fact, their understanding of their personal experience is not an unassailable foundation from which to advance knowledge claims--that their experiences must be *interpreted* through the application of other forms of knowledge. Interestingly, this is particularly so when the experiences in question have to do with thoughts and emotions. However, the legitimacy of these women's physical sensations--pain was the one they talked about most--were rarely questioned by participants. In fact, their bodies were viewed almost as sources of knowledge that 'spoke' to participants, telling them 'something was wrong' (although the knowledge of expert others was required to define what that something was). Thus, just as experience often needs to be confirmed by others to be constituted as knowledge,

experience (particularly bodily sensations) may disavow the knowledge advanced by others. Even when women's symptoms were brushed off as meaningless by physicians, their bodies 'told' them otherwise--a phenomenon which is captured well by Laurence J. Kirmayer's (1992) phrase "the body's insistence on meaning."

Bobbi: It'd been about six or seven weeks since my last injection, so by the time I had it, I was three weeks late...so a while later, I ended up getting a period and I had looked at my records [of her symptoms]...and it was exactly like the period that I got when I first began it [Lupron]. So I figured *aha!* My body had just gotten to a point that it almost thought that things were back to normal, or to a point, that when I had the next shot it was reacting in the same way as when I had the first shot.

W16: I had the third shot of Enantone and a week later my face and neck became red and I had an itch everywhere in my body. My body had enough of the shots!

Mercedes: I just said "I want one [a lap] because there's *something* wrong with me and you don't seem to be finding it out! Like, I'm sorry! I mean, there's something wrong here...When I was 36, I asked for a lap to be done. I knew that this pain was not normal...

Recall too, from the last chapter, Zoë's account of her supposedly fixed hand injury, whose "symptoms are saying that no, they're not [fixed]." As Kirmayer (1992) notes, bodily sensation is understood and explained through language, but it exceeds the grasp of language. In their contradiction of the rationalism and objectivism of medicine ("you 'should' feel better"), bodily sensations presented a different order of knowledge to many of the participants in this study, an order of knowledge that is tacit and extraverbal, but nevertheless undeniable. As Beth pointed out to me, this is reflected in the fact that participants continued to search for answers to their symptoms despite being told repeatedly that there was no 'truth' to what they were feeling.

Beth [referring to the fact that Bobbi saw 15 gynecologists in search of treatment for her symptoms]: But would you take your car to 15 mechanics and they still can't figure out what it was--wouldn't you think there's a problem there?

Emma: Yeah, of course. But if the doctor tells you there's nothing wrong

with you, it makes you wonder, doesn't it? Where if a mechanic says there's nothing wrong with your car and it's making weird noises, you think "Yes, there is!" But when a doctor says there's nothing wrong with you when you feel sick, you might feel "there's nothing wrong with me!" Beth: But she [Bobbi] kept going.

The reason that Bobbi kept going to doctors was not just because she believed in the capacity of biomedical knowledge to provide an objective explanation for (and hopefully change) her bodily experience, but also because she *believed* what her body was 'telling' her, even in the absence of medical verification.

3. Self, Body, and Mind

The way that women with endometriosis conceptualize their bodies is complex, however. While sometimes the body is equivalent to the self (as in the statement, "I'm sick"), at other times the ill body is depicted as alien from--and a burden to--the self: "Someday hopefully I will like my body again and there will be a cure" (W8). At still other times, the disease of endometriosis is the alien, and the body is burdened with it. I asked focus group members about the way they think of their bodies:

Acika: I talk to my body.

Emma: But you know, in the process of talking to it, you're seeing it as something other than yourself. Aren't you?

Acika: Um [pause] no.

Emma: You don't think?

Zoë: No, it's just an extension of what's going on up here [points to head].

Acika: Yeah. I say, you know, "What's wrong?" and "What should we be doing?"

Emma: Um-hmm. So you sort of fragment yourself into the speaker and the--

Acika: Yeah! Yeah.

Emma: But you don't see it as something separate.

Acika: No.

Emma: It's just a bifurcation you use to--

Acika: Yeah.

Zoë: I do the same thing.

This conceptualization is more complex than the strict mind-body dualism posited in most

accounts of medical knowledge (eg. Gordon, 1988). Such accounts tend to be based on *medical* models of the body, and seem to assume that patients adopt such models wholesale by objectifying their bodies and experiencing them as alien to their selves. Acika's account suggests that this assumption is simplistic, and that fragmenting one's self into mind and body is rather a self-talk device to *enhance* a holistic conception of one's self as both mind *and* body. People with chronic illnesses and disabilities often speak of this as "listening" to their bodies. The mind-body dualism of scientific medicine, on the other hand, treats the body as passive text which must be read, but does not speak. The more informal epistemology of clinical practice requires that the patient act as a kind of sign language interpreter, who understands what the body is saying even though the doctor cannot hear it, and who translates the body's speech into a language the doctor can understand. In this sense, clinical practice epistemology is more commensurate with patients' conceptions of a speaking body than scientific biomedical epistemology. But in neither case does the body speak directly to the doctor as it does to the patient.

So integral is one's body to one's self that it is presented in some participants' accounts as the basis for patient rights. For example, several focus group members suggested that patients have a right to access medical information, obtain second opinions, and make treatment decisions on this basis:

Beth: I think when it's your body and it's your hormones and it's your fertility and it's your sex life, I think you should get a bit more of an explanation.

Zoë: But you gotta stand your ground! I mean you gotta [say] "This is my right!...My right is for a second opinion!" It's your body.

Mercedes: After all, it is your body and you should have the last say what you want done to it.

It is difficult to find a word that encapsulates the focus group members' conceptualizations

of their bodies without reifying mind-body dualism; to say the self is the steward or owner of the body, or has a relationship to it, does not capture the degree to which their bodies are inextricable from their self-concepts. On the other hand, there is enough of a self-body distinction that one cannot say the self is *identical* to the body. Clearly, for many of these women, their bodies are a fundamental source of self, understanding, critique, puzzlement, and misery all at once.

Further complicating the mind-body-self triad is the relationship of mind to self. This too is complex for many women with endometriosis. A major consequence of the medical construction of endometriosis as psychosomatic is that women with endometriosis often begin to doubt their own mental abilities (and therefore their conceptualization of themselves *as* selves, since a self is a being that is conscious and able to reason), and to worry about others' evaluations of their mental health. Both complicate their ability to posit themselves as knowers. On one occasion, Bobbi even became concerned that I might think she was a hypochondriac because she asserted that she suffered from so many side effects while taking Lupron:

Bobbi: I wanna say that they weren't hypochondriacal, like I wasn't um looking at the list [of side effects]. I made sure that the way I did it [recorded her side effects] was at night I'd say "Gee, did I feel okay today?" and then I'd write *that* down, and *then*--it was more time consuming--but *then* I would take the list, and then go by the chart. That way I wouldn't see all the possibilities, you know what I mean? I would just go by that day. [pause] Rather than "Oh, maybe I *did* have a headache", I was just going by what was strongest in my mind.

Most often, these women staunchly defend their mental health, and in some cases they dealt with medical psychologization by arguing that it was the *doctors* who were irrational or psychologically disturbed, not them. For example, when Acika related the problems she was having with her first general practitioner, she prefaced her account by stating "Then my GP went weird on me; I think he was into the booze or something."

Group members referred to doctors (individually and collectively) as "idiots" on several occasions. However, many admitted to questioning their own mental health as a result of doctor's delegitimation of their suffering, especially in the pre-diagnosis stage when no objective answer could be found to explain it. And here we see the sense in which bodily sensation--often presented by women with endometriosis as undeniable truth--becomes suspect. Achieving diagnosis tended to allay these concerns about their mental health because--in their own minds, if not in their doctors'--they had an objective label for their suffering that was recognized as legitimate by medical science.

However, especially for the focus group members, mental health sometimes did become a serious concern after diagnosis. We have already seen this in excerpts regarding the effects of GnRH agonists on their moods and cognitive abilities. The causal model proffered by focus group participants is, however, vastly different from that advanced in the medical typical patient profile. The latter argues that psychological or social dysfunction are the *cause* of or a predisposing factor in endometriosis; one young medical student I spoke to several years ago told me "There's a certain subset of the population that has endometriosis--headcases." The focus group participants, and a couple of WITSENDO participants, reversed this: psychological and social dysfunction are *results* of endometriosis. Specifically, the burden of living with chronic pain may cause serious psychological and emotional problems:

W5: Too many people (general public and doctors) feel this disease is just in our heads or that we can't handle the pain effectively. Granted, sometimes we cannot deal with it well because of the length of time fighting it and we sometimes lose hope, but it is a very real disease with very real pain.

W8: My life is totally different now, I'm not as carefree as I used to be I JUST WANT IT TO STOP, I CAN'T TAKE IT ANYMORE, I WANT MY LIFE BACK I WANT TO BE A NORMAL WOMAN AGAIN.

Furthermore, focus group participants argued that certain drugs used to treat endometriosis--specifically GnRH agonists--may cause depression, irritability, confusion, anxiety, and memory loss. This hampered their ability to learn about the drugs and endometriosis; it engendered concerns about impression management and self-control; and it alienated them from themselves:

Mercedes: [explaining her reasoning for taking Lupron] It was a big enough shock finding out I had endo, I didn't know what it was. Now give me a break from the pain and let me think. That was hard because I got memory loss on the drug. It was terrible, just awful.

Bobbi: ...I'd feel numb and I'd start shaking and I thought I was just gonna blow up or something, and um [pause] then I'd start crying, and like I was a *wreck* and um *no* timing and I'd be sitting there and then all of a sudden it happened. It happened in a professor's office who now, I think--I'm worried about him thinking I'm a basket case or something...I had no control, I was scared to talk to anybody 'cause I didn't know if something would start--if I'd be talking to them and the next thing you know I'd be crying, and you know? It--it was really [pause] driving me nuts.

Beth: There's a lot of side effects that I'm experiencing, I'm not gonna tell her [the gynecologist].

Emma: You're not gonna tell her.

Beth: [snorts] Are you kidding?

Emma: 'Cause you don't trust her?

Beth: Well! I mean mental problems? Like, you think [pause] she's--she's--she's a good doctor but I mean, you know, she's gonna think I'm a nut.

Bobbi: The thing though--like you [to Emma] were saying what it's like for you, like when you're in pain. See, you know that, and um you're comfortable with yourself? But when you're on the drug, it's like you don't *know* yourself anymore. And you're *not* comfortable with yourself; you have lost some control over your actions and your moods and your thought patterns. Whereas prior to that, if you're in pain or whatever, you're still you. You know?

Zoë: And you retreat or whatever you need to do, but--

Bobbi: Yeah. You still feel like you're in control.

When the focus group members conducted research on GnRH agonists, one of their most important (and most reassuring) findings was that the *Compendium of Pharmaceuticals and Specialties* listed mood and memory disorders among the reported

side effects of the drugs. This reassured them that their problems were drug-related.

Beth--the only group member still taking the drug during the focus group discussions--was particularly interested in hearing about other group members' psychological and emotional side effects:

Beth: Do you guys feel that you're mentally the same as you used to be before you went on it?

Bobbi: No.

Beth: Are you serious? You mean you stay this way?

Bobbi: [laughs] It gets better. It gets better.

Beth: It does?

Mercedes: It gets better, but I find I still have anxiety...

Emma: [to Beth] Why, are you having a lot of those problems?

Beth: [sighs] Yeah.

Mercedes: And you think you're going crazy.

Beth: Yeah, I was thinking I should phone and find a psychiatrist today.

Mercedes: No, it's all normal.

Bobbi: Yeah.

Beth: But everybody acted weird, I mean, different? You did?

Bobbi: Absolutely.

Here we see in action the role that patients' experiential accounts play in legitimating the claims and experiences of other patients. Beth is 'normal,' not 'weird,' as those who had not taken the drug might assume.

The focus group members seemed to work with a distinction between externally-inflicted mental disorders and 'internal' mental disorders. The latter were not dissociable from the self and therefore were a challenge to the integrity of the self. Being able to attribute their mental disorders to the drugs was experienced as a relief by focus group members, because the rational 'core self' remained intact beneath the effects of the drug, even though the disorders--and their profound effects on these women's lives--remained.⁷⁰

⁷⁰Five of the six women had partners while taking the drugs. Three of them experienced break-ups--largely, they claim, as a result of their erratic behaviour while taking the drugs. One of these had to seek treatment for depression, which she asserts was drug-related.

However, as the above excerpts make clear, these women were clearly concerned that their status as credible claimsmakers was undermined by the drug. Beth worried that her doctor would think she was "a nut," which would affect her ability to negotiate successfully with her doctor and form the kind of informational partnership she was trying to build with her; Bobbi, who was planning an academic career, worried that her professor would think she was "a basket case." The epistemological discreditation of doctors, combined with the mental and emotional ramifications of chronic pain and drug treatments, are serious barriers to the self-presentation of women with endometriosis as credible claimsmakers.

IV. Knowledge, Resistance, and the Endometriosis Patient Community

It seems evident that women's self-education efforts and their strategies for claimsmaking and evaluation of others' claims are central to their capacity for resisting epistemological discreditation and the passive role assigned to patients in the traditional medical model. I therefore end this chapter with a discussion of the means by which women with endometriosis attempt to disrupt a socially-legitimated epistemological hierarchy in which laypersons are positioned beneath experts, and offer my own interpretation of the contradictory rules and standards of the endometriosis patient epistemological community.

In general, the importance of self-education and interpatient education was strongly emphasized by focus group and WITSENDO participants alike--not merely as a supplement to doctors' expert knowledge, but also as a crucial step in taking control of one's health care. Here we see again the centrality of participants' critiques of medical knowledge and clinicians discussed in the last chapter. *Without coming to the conclusion*

that doctors know little about endometriosis and are unwilling to teach patients what they do know, these participants undoubtedly would not have been so motivated to educate themselves about the disease, and educating themselves permits a reevaluation of themselves as knowledgeable agents active in their self-care, rather than passive patients. Thus, their critiques of medicine are the first steps that lead these women to resist medical authority, undertake extensive self-education, take charge of their illness, and assert their own status as epistemological agents.

As the actions of the participants in this study make clear, resistance to medical authority can take many forms. Mercedes brought her own tape recorder into medical consultations--reversing the usual practice whereby clinicians are the sole recorders of consultations. She also 'stole' her medical file. When Acika's doctor warned her that reading could be dangerous, she responded that "stupidity could be more dangerous." She also brought a long list of questions to each clinical consultation "and the doctor knows I ain't leaving that room until they're answered...If I'm not satisfied [with the quality of his answers], I argue." Participants contested their clinicians' claims by bringing in medical research, Endometriosis Association literature, and reports from other sufferers and other doctors, and by insisting on the validity of their accounts of their bodies against their clinicians' accounts.

There are other, more passive forms of resistance. Many participants in this study "doctor-hunted," the results of which are resistance toward individual clinicians' monopolies over individual bodies, rejection of clinicians they consider inadequate, and disruption of the guild-like nature of the medical profession by pitting doctor against doctor in a competition over clinical expertise and the respect they demonstrate toward patients. Many participants also did not comply with the advice of their clinicians, for

example by refusing recommended drug treatments and surgeries and by cutting short courses of drugs against the wishes of their doctors.

Participants tended not to dispute the category of expertise. They simply took issue with the attribution of expertise. The fact that most of the participants named other sufferers and endometriosis patient groups as their most useful source of information suggests that most think patients are 'the real experts.' Three participants explicitly argued that they themselves are more deserving of the label expert than most clinicians:

Mercedes: Nobody once mentioned the word endo until I asked to have a laparoscopy done; I asked. I asked for a D&C, two years later I asked for a laparoscopy, and if they hadn't of found nothing with the lap, I don't know what I would have done--then I would've been researching some more and saying, "Okay, now let's do this procedure." Well now, who's the doctor here? They have to be able to listen to us, I don't know [pause]. They're not gonna get knowledge reading their journals or going to their meetings...Look at how many years we've been listening to what they have to say. They should start listening to what we have to say.

W14: At times I feel like an expert and I am convinced I have a solid understanding of endo--certainly more than the many doctors I've encountered.

W8: I found doctors to be useless when it came to diagnosing my illness. In the end I was having to tell them the best time to do the laps and what the best course of treatment would be for me.

In order to justify the argument that patients are often the 'real' medical experts, they must first establish that clinicians lack an adequate scientific knowledge of endometriosis, that the scientific foundation for the cognitive authority of doctors is in many cases illusory, and hence that the authority of these clinicians cannot be sustained. We saw how they go about this in the last chapter. Foundational to their deconstruction of clinical expertise is their own self-education. In order to make the case that most clinicians do not have an adequate scientific understanding of endometriosis, they employ what they have learned about endometriosis science to point to areas where their clinicians

are misinformed, and to educate other women in the community. However, as Beth says, patients "have our own jobs to do" and cannot devote themselves entirely to understanding endometriosis or to teaching other sufferers, and there are structural limits to the extent to which patients can appropriate medical expertise. They cannot, for example, write prescriptions for themselves or conduct surgery on one another. Because they do not have the requisite credentials, they cannot become socially-recognized medical experts on endometriosis, however much knowledge they may possess. They partially compensate for the exclusionary practices of expert systems by asserting their own special expertise: the expertise of illness experience, which experts cannot possess.

I have emphasized the importance of the notion of shared experience already, but it bears repeating here because, in the participants' accounts, shared "experience" is the foundation of the patient community. It plays several roles. First, and most obviously, it provides a basis for solidarity; in talking about how their experiences are similar, women with endometriosis make a community of sufferers. Talking about experience still requires abstraction, because experience must be translated into language in order to be shared. However, the assumption in the community is that this translation is fairly direct. Articulations of experience get their power among endometriosis patients *because they have their own experiences to draw upon* in interpreting another woman's experiential narrative, which is assumed to represent her actual experience directly and faithfully. Women with endometriosis do not need to have had all the same experiences; what is essential is that an experiential affinity is recognized. The patient community plays a central role because it works to document a matrix of experiences common, in a general way, to women with endometriosis: experiences with doctors, with symptoms, with medical treatments. One simply has to have had some of these experiences to be able to

recognize one's self in the total matrix of endometriosis patients' collective experience⁷¹.

Of course, it is absolutely crucial that all of these characteristic 'endometriosis experiences' are linked to categorization: to being diagnosed with endometriosis, and to the assertion of similarities between these experiences and contrasts with the experiences of those without endometriosis. This has to be done discursively. Without the label of endometriosis, there is no endometriosis patient community. We can see that the categorization of women with endometriosis as such is foundational to their sense of community. But for these women, community stems from their belief that they actually have had similar experiences that are comparable *ontologically*, not merely discursively. This comparability exists, they believe, at a level deeper than language, although it must be expressed in language and in formats developed by the patient community (see Chapter 6 and Robinson, 1990 for more on this point). Following the implicit formats for describing one's experiences allows others to recognize it as similar to their own experiences; but again, the similarity has a tangible referent--their own experience--which is what makes the similarity so powerful.

Moreover, the community defines a matrix of experiences that people without endometriosis *do not have*. These others exist in varying distances from the community of endometriosis patients; other chronic pain patients, for example, may be seen as a related community with which endometriosis patients share some experiences. A woman with endometriosis who says the disease causes her no problems is, first of all, unlikely to participate in the endometriosis patient community and, second, is unlikely to feel or

⁷¹But still, it seems that the greatest solidarity is felt among women whose descriptions of their experiences are extremely similar; one reason Bobbi and Mercedes felt so close to one another was that they reported having very similar, extensive side effects. In a sense, then, there seem to be subcommunities within the larger community--a point that suggests an avenue for further research.

engender the same sense of solidarity with other endometriosis patients. Reporting and sharing problems and experiences is an act of community creation. The key to solidarity and empathy is the mutuality of experience.

Second, and relatedly, the notion of experience allows women with endometriosis to draw a boundary around their community (insiders who have the requisite experience and outsiders who "can never understand"). None of the participants really explained *why* personal experience was valuable or why it gave women with endometriosis special insight into the disease. But I think a crucial element is that the notion of experience forges a link between being and knowing, enabling patients to posit themselves as knowledgeable and as active subjects at the same time--indeed as knowledgeable *because* they are active, experiencing subjects. Most of them cannot deploy credentials because they are laypersons, but citing experience gives them a special epistemological status, something that those without the disease (including doctors, their primary competitors for credibility and those most likely to discredit them epistemologically) cannot do.

Whatever experience *is*, deploying the notion of experience is clearly a key rhetorical strategy of women with endometriosis. This brings us to the third role of the notion of "experience": it is drawn on as a substantive resource in claimsmaking, a resource that has content as a book does. Thus, we "learn from" experience and in turn can use that knowledge to teach others--even that we have a *moral responsibility* to use our experience to teach others.

Bobbi: These are my records [flips through pages of notes about her side effects while taking Lupron]--like I figure they're gonna have to be of use, right, and I figured--like at the time, I thought there were less women on it than [there were] at the time. Now I know, oh, there's *more* of us, but at the time I was terrified and I thought it was real experimental and I was going to keep these records and *women were gonna know and if nothing*

else they would know these are some of the side effects, you know, that instead of this list [from the manufacturers] of hot flashes, they'd know more, right?

As we have seen, however, there is no unassailable foundation for knowledge in the endometriosis patient community. One's own interpretations of embodied sensations, one's mental abilities, the accounts of other sufferers, and medical information from all sources are open to critical evaluation. The one limit is that one patient's *experiential* account cannot be criticized by another patient, although patients may conduct critical evaluations of their *own* experiences. Otherwise, the model for knowing in the endometriosis patient community is fraught with tensions and contradictions. Medical expertise is highly valued, but the experts are often misinformed or uninformed and can never really understand. Subjective experience is foundational to understanding, but often must be confirmed by others (intersubjectivity as objectivity) or by 'objective' evidence such as test results or surgical diagnosis. Other endometriosis sufferers understand each other's experiences, but they are "all different"; at the same time, standardized treatment protocols are required.

Because their epistemology is pragmatic, geared to particular problem-situations, the way these women think is a mixture of standpoint theory, medical objectivism, realism, and relativism--whatever works in the context. Contrary to understandings of discursive formations that set rules about what can and cannot be said which agents then follow (eg. Laclau & Mouffe, 1985), endometriosis patients often break the rules, tying together claims about disease and illness in roughly equal measure and using each to critique the other, and develop new rules as a result. The flexibility of their model results in tensions and contradictions, but also reflects the tensions and contradictions in the problems faced by endometriosis patients: their need both to engage with medicine and to criticize it, both

to assert the validity of their experience in the face of medical denials, and to evaluate critically what their experience means. An entirely consistent epistemological model would not allow them to adapt in the same way. They have to draw on various resources to resolve the puzzles they face on a day-to-day basis: how to make sense of pain that persists despite medical treatment that 'should' fix it; how to evaluate their mental health in the face of medical psychologization; how to resolve their dependence on and hope in medicine and their awareness of its inefficacy.

Yet at the same time, there are identifiable themes in the model endometriosis patients use to make sense of endometriosis--however contradictory--that I have tried to lay out here. The participants described and evaluated the foundations of medical and patient/experiential knowledge about endometriosis. They considered the deeper meaning of medical expertise, tensions between objectivity and subjectivity, and the philosophical foundations of medical and patient knowledge. They asserted the special value of patients' experiential knowledge, attempting to explain how they know what they claim to know. Their basic, unstated premise is that knowing about endometriosis as both scientific disease *and* illness experience is crucial to managing it.

It seems likely that the self-education drive among chronically ill people is related to a perceived need not only to improve symptoms or negotiate with doctors, but also to *grasp or master* the problem. These terms capture not only the sense of understanding, but also of seizure and control, to which understanding is related. Through understanding, the disease is objectified; it can thereby be contained and acted upon:

We objectify our situation to the extent that we can overcome a sense of it as what determines for us our paradigm purposes and ends, and can come to see it and function in it as a neutral environment, within which we can effect the purposes which we determine out of ourselves (Charles Taylor cited in Gordon, 1988:21).

Objectifying disease as an entity that affects, but is essentially separate from, one's self allows patients to maintain a sense of control, autonomy and freedom--notions which, as Deborah Gordon argues (1988) are intrinsic to modern conceptions of the self: "...the disengagement that naturalism prescribes is important not only as a means to an end--a means to freedom through control and knowledge--but also as an end in itself. To be disengaged means to be free to be one's own unique author" (Gordon, 1988:40).

While Gordon is speaking mainly about medical experts' thinking here, the statement applies even more profoundly to patients. In thinking of the self as distinct from the disease, patients carve out spaces that cannot be touched by the limitations and torments of illness--spaces for enjoying life and embodiment and for carrying out valued activities. So on "good days" (ones where the pain is less), the disease can be compartmentalized, even temporarily forgotten, if it is seen as separate from (or as only one component of) the self. Other, more enjoyable aspects of the self can be experienced at those times.

While disease is a distinct entity, illness is a state of being and as such, intrinsic to the self. Thinking of one's self as an "ill person" is an identity and thereby more limiting than thinking of one's self as a "person who has a disease."⁷² Illness resists compartmentalization and objectification; disease encourages it. So, in many circumstances, the notion of the mind's transcendence over the body, the fragmentation of the self, and the objectification of the body may be experienced as emancipatory for people

⁷²Similarly, in previous focus group and interview research with women with disabilities, they emphasized their preference for the term "person with a disability" rather than "disabled person" because they asserted that they were "people first." They did not want to be thought of (or think of themselves) primarily in terms of their lack of ability; they "have abilities too."

with chronic illnesses and disabilities, for whom embodiment can be so problematic (Wendell, 1996, especially Chapter 7). Indeed, Charis Cussins (1998) argues that infertility patients actively participate in their own objectification as a means to the end of having a child, an end which they value highly and perceive as a means of self-actualization. In contrast to many feminist critiques of the objectifying effects of infertility treatment on women, Cussins argues that objectification may enable agency. Similarly, although women with endometriosis criticize the medical objectification of patients (Mercedes: "you're just a number"), they also ask for, and participate willingly in, technological practices that objectify them and their bodies. They request ultrasounds and bone density X-rays and ask to view videotapes of their laparoscopic surgeries. They do this as a means to the end of obtaining the treatment they need to attain good health and to "get their lives back"--to go to work, have pain-free sex, get pregnant, carry out family responsibilities, have a healthy old age free of osteoporosis. To attain these ends, they feel, they need the information that sometimes only medical objectification can provide.

The participants spoke of knowledge as power: of becoming "armed" with knowledge to "battle" the disease and "go back at" their doctors. A chronically ill person who understands her disease from a medical as well as an embodied, experiential perspective may be better able to evaluate and, if necessary, contest her doctors' claims and have those evaluations and contestations validated, because she can present herself as a knowledgeable and rational agent, rather than a hysterical hypochondriac. She may also learn how better to control symptoms and side effects (for example, through medical treatments or changes in her diet). Finally, she may aim to predict the future and thereby prepare for it:

Mercedes: I wanted to find the information because [pause] um [pause]
'cause I wasn't having the pain, I knew that I was gonna take it [Lupron]

for six months, that was giving me time to decide do I still want to get pregnant, do I want to have a hysterectomy, what do I want to do? I decided I still wanted to give it one last shot at getting pregnant, now I wanna research anything done on this drug as far as getting pregnant.

This sense of control may be illusory. Mercedes took Lupron not only to relieve pain and enable her to "think about what to do next" without the stupefying effect of constant pain. She also took it in the hope that it would shrink the endometriosis enough that she could become pregnant. Months after her final injection, she still had not become pregnant and her pain was back to its previous level. However, finding out about GnRH agonists and their effects on endometriosis enabled her to mediate, at least temporarily, the hopelessness and helplessness that chronic pain, infertility, and epistemological discreditation by clinicians had engendered in her.

The participants in this study had a fractured relationship with endometriosis: one with the medical disease of endometriosis, knowledge of which was derived from medical understandings, and one with the subjective illness of endometriosis, knowledge of which was derived from "experience" and experience-talk with other women. The apparent contradictions in the standards for evidence and rules of engagement within the endometriosis patient community reflect not only the artificiality of metaphysical dichotomies--knowing versus being, subjectivity versus objectivity, absolute truth versus relativity, theory versus practice, science versus experience. I think they also reflect the contradictions of living with a chronic illness, which confound the distinction between ontology and epistemology. Chronic illness is something that is often experienced as an object which is alien to one's self, but at the same time it is always with one, an integral part of the self.

Chapter 6

Drawing the Communities Together:

The Endometriosis Association

The Endometriosis Association is a self-help organization founded in 1980 by Mary Lou Ballweg and Carolyn Keith, with headquarters in Milwaukee, Wisconsin. In twenty years it has progressed from a local support group, to a U.S.-Canada organization, to an international "network of chapters, groups, sponsors, and women with endometriosis in 66 countries throughout the world" (Endometriosis Association website, www.endometriosisassn.org/press3.htm). The Association's membership is composed primarily of women with the disease, but also includes some clinicians and clinician-researchers (principally gynecologists), scientists, and other parties (such as family members of women with endometriosis). Its current 36 medical advisors include many of the top gynecologists and reproductive endocrinologists in endometriosis research and clinical practice, from the U.S., Canada, South Africa, Italy, Norway, England, Russia, Taiwan, Belgium, and France (Endometriosis Association website, www.endometriosisassn.org/advisors.htm).

Its activities and philosophy are summarized in the two mottos that appear in the Association's logo: "Education • Support • Research" and "Together We Make A Difference." The EA educates patients, physicians, and the general public about endometriosis, provides support to women with the disease, and conducts and lobbies for research on the disease. Its philosophy is that bringing women with endometriosis into contact with one another and with others interested in endometriosis, such as clinicians

and researchers, facilitates successful coping with the disease and, it is hoped, will lead to a cure one day. To these ends, the EA attempts to enrol patients and their families, physicians and researchers into a network of endometriosis knowledge and practice, the hub of which is the Association.

As we have seen in the three previous chapters, medical literature constructs endometriosis patients as unreliable claimsmakers through the deployment of rhetorical strategies that appeal to science and clinical experience; endometriosis patients respond by deploying similar strategies to problematize clinicians' claims to knowledge about endometriosis and to assert their own status as knowers. This chapter examines how the EA deals with these tensions and overlaps between and among lay and expert views about endometriosis and the ability to know it. The EA is primarily an organization of patients: it was founded to provide services to patients, it is run primarily by patients, and the vast majority of its members (and financial supporters) are patients. The EA's strongest alliances, consequently, are with endometriosis patients. Throughout this chapter, we see that many of the EA's principal claims echo the core claims of patients discussed in the last chapter: many doctors know little about the disease; many patients have been treated terribly by doctors; self-education is absolutely essential if patients are to get the kind of care they want; talking with other women about the disease is enormously helpful and informative; patient experience is a valid source of knowledge.

Yet, the EA as an organization is concerned to enrol the support of medical experts--mainly gynecologist clinician-researchers--who can lend their weight to the claims of the EA and help it to conduct research and to educate patients and other doctors about the disease. The primary reason for the EA's interest in enrolling medical experts is that (it hopes) this will benefit patients: better treatments can be developed, perhaps a cure

found; uninformed, insensitive doctors can be reeducated to provide better care for patients; patients can become 'armed' with information about the disease that can help them make decisions about treatment and get the kind of care they want. The EA recognizes that, in order to meet these objectives, the support of eminent clinician-researchers is essential. The patients who participated in this study were not aiming to enrol doctors through their participation; and most patient venues (including the WITSENDO list) are geared exclusively toward patients. While most of the EA's literature is geared toward patients, much of it, it is hoped, will be read by medical professionals too. So some of the EA's literature courts medical professionals, presenting somewhat less harsh versions of the patient community's critiques than the participants in this study presented. Nevertheless, the essential critiques are extremely similar. The EA is perhaps the strongest force in the endometriosis patient community, a founding venue of that community. The EA reflects the community's main claims and critiques, and has played a central role in developing those claims and critiques. It is even likely that many of the claims and critiques of endometriosis patients originated with the EA (though this cannot be demonstrated, because before the EA existed, most patients did not have a venue in which to make their claims heard).

My main purpose in this chapter is to show that the EA's success as an organization depends upon its ability to enrol *both* patients and medical professionals into a network of allies. I attempt to show that this enrolment depends upon the EA's strategic ability both to minimize tensions and to make productive use of tensions and overlaps between patient and medical perspectives. The EA makes productive use of the tensions and overlaps in the sense that it uses the perspectives and arguments of each side--medical and lay--to establish itself as the route through which both patients and doctors can (and

should) develop a fuller knowledge of endometriosis. The EA minimizes these tensions in that it facilitates cooperation between patients and doctors, and it argues that they share a common bond in their commitment to conquering an enemy-other: endometriosis. In its network-building activities, the EA represents endometriosis as both disease (objective medical entity) and illness (subjective patient experience). The EA attempts to establish itself as 'not just another support group,' but as an obligatory passage point for both laypeople and experts seeking to lay hold of endometriosis.

Below, I review literature published by the EA, drawing upon its books, pamphlets, newsletters, website, and publications in the medical literature. I begin with an "official" account of the formation of the EA and an analysis of the ways it combines scientific, political, and experiential rhetorical strategies to justify the EA's existence and activities and to create a network of allies. Second, I describe some of the EA's support-provision, educational, and research activities, providing examples of their network-building strategies along the way. I conclude with a summary and analysis of these strategies and the challenges posed in building such a network, drawing upon the actor-network approach described by Bruno Latour and Michel Callon (Callon, 1986; Callon & Law, 1989; Latour, 1987; Latour & Woolgar, 1986).

I. Representing the Formation of the EA

Mary Lou Ballweg, the co-founder of the EA and its President and Executive Director since its inception in 1980, recounts the formation of the Association in "Why the Endometriosis Association Was Started," her introduction to the EA's first book, *Overcoming Endometriosis* (Ballweg & The Endometriosis Association, 1987:1-10). While of course the EA is comprised of a large number of women with endometriosis,

office staff, and advisors (including many medical experts), Ballweg plays a highly visible and directorial role. Her introduction is interesting not merely for the information it provides about the EA's formation, but for its *representation* of that formation, which itself reveals a great deal about the philosophy of Ballweg and her organization.

1. Ballweg's account

Ballweg begins with a description of her fulfilling career before endometriosis ("In 1978, I was flying high" (Ballweg, 1987:1)) and pinpoints the event--a flea infestation of her Milwaukee apartment and its repeated fumigation in the autumn of 1978--which Ballweg associates with her sudden and persistent exhaustion. "Somehow, it seemed, something related to the fleas, the insecticides, and the exhaustion had upset the balance in my body. (And my cat's, too, for in a few months he died of feline leukemia)" (Ballweg & The Endometriosis Association, 1987:2). She describes the subsequent deterioration in her health, including the return of dysmenorrhea from which she had suffered as a teenager, and her search for "medical answers" (ibid). She recounts that she was tested for a variety of diseases, and that when all the tests came back negative, her internist suggested that she needed a vacation. We can recognize in her response many of the themes raised in the participant narratives in the last two chapters:

If he and the other doctors I saw were at a loss to explain my illness, why not just say so instead of making me, already fearful and vulnerable, feel worse with the sly blaming and impugning of character? Couldn't they just say they didn't know? Why wasn't there a profession called "medical detective" who'd help me track down the problem? (ibid)

Ballweg states that she began to suspect the problem was related to her earlier dysmenorrhea "[b]ecause the swelling in my lymph glands in most parts of my body had begun to subside but not in my groin" (ibid). She therefore "started reading up on

women's health problems. Fortunately, I had good general resources because of my involvement some years earlier in helping to start a women's reproductive health clinic" (ibid). She then "pushed for a laparoscopy" because she "couldn't go on without an explanation" (ibid). With dwindling finances and family and friends increasingly withdrawing--"To see such an active, alive, happy person suddenly become bedridden was too much for some of those around me"--Ballweg "promised myself that when I was well again I'd do something" to combat the isolation, confusion, and medical indifference faced by women with endometriosis (ibid:3).

When laparoscopy confirmed that Ballweg had endometriosis, she searched for more information and realized there was little available. "In fact, there was almost nothing to read about it except in gynecological textbooks and a smattering of small research studies, many so skimpy and conducted with so few research subjects that they wouldn't stand up to research standards in other fields (nor in endo now, only seven years later)" (ibid:3-4). In her reading, Ballweg encountered the typical patient profile. Her response to it is worth quoting at length to show how she deploys personal experience, sociopolitical critique, and the norms of science to deconstruct the profile:

It seemed, according to the text, that the disease afflicted white, well-educated, perfectionistic, thin "career women." My years of work on black/Hispanic issues and in the women's movement and my own experience in trying to obtain a diagnosis made me instantly doubt this. *White* women? Well, had they looked for it in black women and other women of color? A review of research materials available showed they had not. (A 1982 study by Drs. Donald Chatman and Anne Ward disproved this stereotype with its findings of endometriosis in black teenagers.)

"Well educated"? I doubted it--if a woman like me, who perhaps fit the stereotype, had had to push for a diagnosis of this disease, how was it going to get diagnosed in women who didn't fit the stereotype?

"Perfectionistic"? Had they done psychological testing on these women? And even if they had, if only certain women were being diagnosed, how were they controlling for this diagnostic bias? I could find no studies--the "psychological" profile of women with endometriosis was unsubstantiated speculation by a few doctors. Their speculations were

picked up as "truth" by media, and myth had begun.

"Thin"? Had any studies been done? After all, it's pretty easy to weigh people, and medical charts contain weight--a retrospective study could easily document the weights versus heights of women diagnosed as having endometriosis. Curiously, even such a simple thing had not been studied. Yet the statements were made as if this had been studied and documented. (In fact, the first study tracking height/weight in women with endo was not published until 1986, and no difference in weight was found between women with endo and those without it.)

"Career women"? It seemed this idea came out of the observation that endometriosis symptoms abated during pregnancy. (Of course--no periods!) From that observation to a belief that pregnancy would *prevent* it was a leap of faith. The belief that a state of pregnancy alleviated the disease was the reason doctors put women with endometriosis on the birth control pill--to induce a state of pseudopregnancy. But I had been on the pill for a total of nearly 5 years since the age of 19--the equivalent of 6.6 pregnancies.

And what about all those [dysmenorrhea] symptoms from the age of 15-16? Was I a "career woman" at 16? And what if I *had* tried to get pregnant at 20? All the textbooks were clear on the fact that infertility was frequent in endometriosis. How did the doctors who started this "career woman" idea know whether there weren't lots of women out there with the disease who had greatly wanted children and hadn't been able to get pregnant? And who knew whether there weren't thousands of homemakers hiding out at home, so to speak, with symptoms, who had been treated as I had--like a hypochondriac (Ballweg, 1987:4-5).

A course of birth control pills alleviated symptoms, but had to be discontinued due to a near-stroke. Ballweg relates that at this point she "started searching for other women with endometriosis. I felt sure that some of them must have figured this out, could give me guidance, tell me the truth about pregnancy, the hormones used for the disease, and other aspects of it" (ibid:5). She was unable to find other women with the disease, and found that most people had never heard of it. Ballweg's friend (and later partner) who was trained in group facilitation began a self-help health support group to help her. In that group, she learned "the self-help health philosophy of Dr. Ric Biek" but was frustrated by the other group members' lack of understanding of her ill health:

I was the only one in the group who had a serious health problem...
Healthy people, who probably took their health for granted just as I had before I was sick, seemed to regard their health as a matter of personal

accomplishment. While this belief was comforting for *them*, it created more pain for those unfortunate enough, like me, not to be healthy.

I decided only a group of other women who'd "been there" was likely to understand and provide the emotional support I needed to come to terms with this baffling experience of endometriosis (ibid:5-6).

Carolyn Keith, health education coordinator at the Bread and Roses Women's Health Center in Milwaukee, whom Ballweg knew through the Feminist Writers Guild, invited her to help train the clinic staff on endometriosis. "At the end of my talk, I said what I had really needed in my bout with endometriosis earlier in the year was a support group of women with endometriosis. Carolyn and Fran Kaplan, founder and director of Bread and Roses, said they'd help me start one" (ibid:6). Ballweg then goes on to describe the "instant success" of the support group:

Within the first six months, word-of-mouth was spreading the news that there was a group of women with endometriosis in Milwaukee. Mail started coming in from all over the U.S. (and then from Canada and later other countries as well). The women poured out their hearts and souls in the letters and confirmed how devastating and misunderstood the disease had been for them, too. To keep up with the volume of mail, we started publishing pamphlets and articles that answered the most commonly asked questions, at least where there was any kind of "answer."

To find answers for the unanswerable questions (of which there were and still are dozens!), the group decided to push for research, even if we had to do it ourselves (ibid).

With headquarters in Ballweg's home, the group produced and distributed a pamphlet on endometriosis and a questionnaire which, by October 1980, had been completed by more than 300 women; this "represented more data than had ever been gathered on women with endometriosis!...Armed with solid information on the disease, we began to work to educate ourselves, other women with the disease, the public, and the medical community" (ibid).

Ballweg mentions alliances with several health professionals as key to the Association's early development. These include Dr. Karen Lamb, a registered nurse and

assistant professor of preventive medicine, who helped develop the data registry and served as its director for several years; and Dr. Richard Mattingly,

who at first told me on the phone, when he heard of the group, "Aren't you women making a mountain out of a molehill?" He said pretty soon there would be a support group for people with fallen arches! However, when we invited him to come to speak to the group (he was, after all, author of one of the gynecological textbooks in widespread use and internationally known as a professor of gynecology) and he saw and heard the women and their husbands, he began to reassess the impact of endometriosis on people's lives. Eventually he became very supportive and helpful (ibid:7)

As the Association grew, support groups and chapters were started in cities throughout the U.S. and Canada. "Gradually, a network of members of the Association grew so that today women diagnosed with endometriosis need never feel all alone with the disease, as I did in 1979" (ibid).

Ballweg then finishes her own endometriosis story, recounting problems with insurance programmes, searches for "good specialists", worsening symptoms, a surgery, pregnancy, and finally a hysterectomy. Ballweg relates the experiences of other women in the patient community to her own experiences and to her work as an activist:

Obviously, if my experiences had not also been that of thousands and thousands of other women, I wouldn't be writing this introduction to this book today. Even today, as hundreds of letters come to the Association every week, I still find it hard to believe that all this need, frustration, and pain was and is occurring and is so routinely ignored. I still find it hard to understand and believe that an estimated 70 percent of the women who come to us have been told at one time or another, in one form or another, that their symptoms are in their heads: "psychosomatic," "hypochondriac," "frigid," "You're just the nervous type," and so on and on.

The letters and accounts of experiences with endometriosis keep me motivated. And, if that wasn't enough, the fear that my daughter, who's had severe candidiasis⁷³ problems since before the age of two, might

⁷³Candidiasis is the medical term for an excess of *candida albicans*--a yeast--in the body. Apart from chronic yeast infections, candidiasis is associated with a range of other physical and mental symptoms. The Endometriosis Association has argued that there is a connection between candidiasis and endometriosis in that both seem to be related to dysfunctions of the autoimmune system (Ballweg & The Endometriosis Association,

develop endometriosis later is compelling motivation indeed! (ibid:9)

Ballweg ends her account with a rousing call for collective action:

Alone, we are powerless against this disease and the "rock of ages" of taboo about women's bodies. We are but one drop of water. But *together* we're the river that can carve out the Grand Canyon, cutting through the walls of prejudice and taboo and ignorance. *Together* we can overcome endometriosis! (ibid:10; emphasis in original).

2. Analysis of Ballweg's story

Ballweg's account is a highly personal one, weaving together narratives of the effect of endometriosis on her wellbeing, career, and social relationships into what Ian Robinson (1990) calls a "progressive narrative"--a positive reconstruction of events in line with the narrator's personal goals where the narrator features as hero, and which may take the form of detective story. Ballweg's dramatic account certainly takes this form as she recounts the way she put 'clues' (from her body and readings) together to solve the mystery of endometriosis. Her story follows a standard model: protagonist suddenly faced with tragedy but, after struggle, emerges victorious. Robinson notes that progressive narratives provide "a sense of transcendence over, and in the end a sense of group, as well as personal control of the biomedical trajectory of the disease" (ibid:1179).

We can see that Ballweg's opinions and her account of her experience with endometriosis and medical professionals strongly resemble the patient accounts presented in the last two chapters. Robinson draws on N.K. Denzin's notion of the "universal singular" to argue that illness narratives create a solidarity among patients: "Every life story is unique, yet representative of every other life story" (ibid:1177). The distinction between self and reference group, between "I" and "we", becomes blurred. As we saw in

the last two chapters, women frequently used the first person plural, assuming that all women with endometriosis share their experiences and concerns. While accounts like Ballweg's are

in part addressed to the self and constitute a representation of the individual self, together they also constitute an accumulated and collective experience. To the extent that these 'self-stories' are socially visible in oral accounts, or available in written or circulated form, they form a body of images moulded by previous narratives, and conditioning future ones (Robinson, 1990:1177).

Ballweg explicitly draws parallels between her story and the stories of other women with endometriosis that are sent to the EA. In doing so she contributes to the creation of a format or model for the stories of other women with endometriosis and, crucially for the EA, establishes a foundation for experiential solidarity which serves to establish herself and her organization as an effective representative of all women with endometriosis. Such an account is an especially effective way to recruit and establish one's self as the representative of people who feel isolated and delegitimated, as women with endometriosis so often do.

Ballweg's account squarely positions her as author by discussing her personal struggles with endometriosis and her struggles to build the Association, to convince doctors to take the Association seriously, and to come to terms with medical accounts of endometriosis and the lack of available information and support for patients. Her account is not linear, but flips back and forth between various time periods, explaining what she was thinking "at the time" and what she knows now. In fact, she does not always distinguish carefully between these. As a result, the history she provides of her initial evaluations of, for example, medical claims seems somewhat revisionist and presentist. This is because, in illness narratives, "a sense of congruence may need to be developed--and a coherent story created--with plausible accounts for any disjunctions between [self-

]perceived illness, others['] designation of sickness and medical perceptions of disease" (Robinson, 1990:1174). The need for congruence fights with the need to document confusion in Ballweg's account; for the purposes of enrolment, she must provide a coherent narrative that establishes her as both rational and astute evaluator of knowledge claims *and* once-confused and -isolated patient who needed the kind of information, guidance and support that the EA now provides. Her narrative has to document confusion and mastery in carefully balanced proportions.

Simultaneously attending to these contradictory narrative requirements establishes Ballweg as the perfect representative for women with endometriosis: as knowledgeable enough to evaluate medical claims critically on patients' behalf and to spearhead scientifically-sound research projects (key to enrolling medical professionals as well as patients), yet as someone who understands *through personal experience* the isolation and confusion women with endometriosis feel.

As we have seen, experience-sharing is a strong solidarity-building tool among women with endometriosis; really it is a *requirement* for entry into the endometriosis patient community. Had Ballweg presented herself in her account as someone who just knew the science but did not have endometriosis, or who had no symptoms and was diagnosed quickly and easily by uniformly supportive and respectful medical professionals, or who had endometriosis but did not reveal her personal story, her account of the EA's formation would not have the same network-building power. Instead, in documenting her struggles, she emerges as an endometriotic everywoman with whom most endometriosis patients can identify strongly, and who herself understands the endometriosis experience in such a way as to represent it reliably to non-sufferers. And of course Ballweg's claim that, through her involvement in the EA, she is no longer confused

and isolated communicates that women who join the EA will eradicate their confusion and isolation too. So the apparently contradictory elements in her narrative actually serve some important network-building functions.

In Ballweg's account, disjunctions between illness (her 'experience'), sickness (others' perceptions of her as a sick person), and disease (medical evaluations of her as a diseased body) are dealt with by appeals to, variously, proper scientific protocols for medical research, her embodied experience, and sociopolitical judgments. So, to counteract early medical tests that delegitimated her claim to illness, she invokes the notion of professional egos (doctors won't admit it when they can't figure something out). To justify a possible connection between her symptoms and endometriosis--a connection that no doctor had made, which is not surprising because many of her symptoms are not usually associated with endometriosis--she invoked her observations of her body (eg. swelling in her groin).

Importantly, endometriosis was verified by diagnostic laparoscopy, which recasts her initial hunch--that she had endometriosis--in a favourable light. Had it not been verified eventually, her initial hunch likely would have cemented her assigned identity as a hypochondriac (and she would not have ended up heading an Endometriosis Association). Instead, she emerges as astute detective because medical science proved her hunch right. Appeals to embodied knowledge eventually must be verified, even in Ballweg's account.

To counteract other medical claims, she invokes sociopolitical analyses gleaned from her work as a feminist and health activist, her embodied experience, and her understanding of good science. We see this in her discussion of the typical patient profile. So, she knew from her pre-endometriosis days as an activist that racism is at work in medical diagnosis and research; she deduced that this is the reason why only Caucasian

women are thought to develop endometriosis. She had taken birth control pills for years and still experienced symptoms, and she knew taking birth control pills for years is like being pregnant; so she deduced that the claim that pregnancy cures the disease must be false. (Here we see a combination of embodied-experiential and medical claims.) The claims of the typical patient profile were based on few studies and studies that did not control for confounding variables.

So, Ballweg switches between scientific, sociopolitical, and embodied perspectives to delegitimize challenges to her claims and to establish herself as a credible claimsmaker and critic to a variety of audiences, appealing to the values and perspectives of social activists, patients, and medical experts simultaneously. Ballweg is a talented network-builder.

Also important in Ballweg's account are the suggestions it makes about the *kind* of network that must be built and the mundane resources, such as money, space, affiliations with other activists, computers, and volunteer labour, that are necessary to create an organization like the EA. Because in the early days the Association lacked funds, Ballweg describes her and her partner's purchase of a large house as key to the Association's growth because it provided the necessarily rent-free space for meetings and offices (Ballweg, 1987:7). In this account, Ballweg does not explain exactly how "word-of-mouth was spreading the news that there was a group of women with endometriosis in Milwaukee", but the mechanisms by which the word was spread clearly are key to the development of the EA beyond the local support group level (and to the formation of the support group itself, given Ballweg's initial difficulties in finding other women with endometriosis). It seems clear that Ballweg's connections to the women's movement and especially to the women's health centre in Milwaukee were important in this regard.

Ballweg enrolled Carolyn Keith and Fran Kaplan from the centre to help in the creation of the support group; presumably, initial support group members were recruited with their help. In the final chapter in *Overcoming Endometriosis*, Ballweg recounts that the group initially met "at Milwaukee's Bread and Roses Women's Health Center and in our homes" (Ballweg & The Endometriosis Association, 1987:301). As the group grew, a letter to the editor (presumably written by Ballweg) was published in *Ms.* magazine and 700 other women with endometriosis sent letters to the Association; to cope with the large number of inquiries, the Association began developing pamphlets and fact sheets (ibid:303).

The Association's establishment as a research organization depended on their recruitment of medical allies and volunteers and access to computers. The large number of filled-out questionnaires could not be managed manually, so

through some of our medical advisors, we went to the Medical College of Wisconsin to see if we could get some advice and use their computer. There we found a fairy godmother--Dr. Karen Lamb, a professor and researcher in the Department of Preventive Medicine. She has worked with us ever since. Combining the resources of the college and the volunteer power of our members (just to code the first 365 questionnaires took over 900 hours of volunteer time!), we were able to start our data registry, the only data bank of information on endometriosis in the world (ibid:304).

Dr. Karen Lamb's professional position and credentials lent credibility to the Association's research efforts. However, it is important to note here the central role of EA member-volunteers in the research work, and the fact that it was women with endometriosis who approached the university and spearheaded the endeavour. This demonstrates the inadequacy of the scientist as protagonist approach of actor-network theory that Susan Leigh Star (1991) has criticized on the basis that it focusses little attention upon the crucial roles of support workers and non-scientists in the creation of scientific knowledge. There are undoubtedly many such cases where laypeople are key to research endeavours

(especially in medicine, where at the very least human subjects must be enrolled), and in every large research project, support workers play a crucial role.

The enrolment of physicians--such as Dr. Richard Mattingly--required that they be persuaded that endometriosis was a serious problem for women (and, interestingly, for their husbands). Mattingly's support, it seems, was not secured by Ballweg's critique of medical claims, but by women's despairing accounts of endometriosis as illness experience. In the early days of the Association, physicians may have been unlikely to take seriously the EA's criticisms of endometriosis science, as the EA had not yet established itself as an authority on medical knowledge of endometriosis. That authority would come later and, as we shall see, it came largely *as a result of* the EA's alliances with medical professionals, who would lend their expert weight to the EA's claims. But to make this happen, medical professionals first had to be enrolled. Based upon Ballweg's account, the EA seems to have appealed first to the illness experience and the sympathy of physicians. Perhaps this was deemed a safer tactic with which to secure the initial support of medical professionals than a critical deconstruction of medical claims.

Ballweg's account of her early enrolment activities draws upon a variety of rather contradictory elements. These include a professed commitment to expertise, the scientific method, and value-neutrality in research; a critique of many expert claims not merely on the basis that such claims were "really" unscientific, but also using the sociopolitical critiques of feminism, anti-racism, and the women's health movement; emotional appeals to help the "victims" of endometriosis, based on anecdotal experiential narratives that revealed the suffering of endometriosis patients; and appeals to the benefits of solidarity and empowerment that derive from collective action by laypeople. This is a pragmatic blend of appeals to experience, radical politics, and scientific authority that has served the

EA well, however internally contradictory it may be. It allows the EA to enrol quite a variety of allies, a prerequisite in establishing a strong network (Ward, 1996).

The importance of these early enrolment efforts becomes more obvious when we examine the later activities of the Association. As Ballweg's account of the early days of the EA makes clear, the Association's plans were significantly more ambitious than those of the average local support group: "the group determined to push for research, even if we had to do it ourselves" (Ballweg, 1987:6). We turn now to an account of the EA's activities to explore how these ambitious plans were realized.

II. "Education • Support • Research": The Activities of the EA

The EA's support activities are geared toward patients. Educational efforts are directed toward both patients and medical professionals. In analysing the EA's research activities, it quickly became apparent to me that, while these activities required the cooperation of patients as research participants and funders, the EA's accounts of its research primarily seem to be meant to increase its credibility among medical professionals (primarily those active in the medical research community) and to 'educate' physicians about correct and incorrect ways to conceptualize endometriosis and the women who suffer from it.

I begin this section with a discussion of the EA's work as a support organization for women with endometriosis, much of which, I argue, also can be read as patient education work. I then discuss other methods by which the EA educates patients and medical professionals⁷⁴. I conclude this section with a discussion of the Association's

⁷⁴The EA also directs its educational efforts toward the general public, but due to space constraints and the nature of this project, I focus here on its work with medical professionals and patients.

work in promoting, administering, and conducting research on endometriosis and its sufferers. It should be noted that these three kinds of activities--support provision, education, and research--are interconnected in the EA's philosophy. Part of providing support to women means conducting research toward prevention and cure. Other research represents women's experiences with endometriosis in order to educate others about the concerns and needs of women with the disease, so that these women can access the support and understanding they need. Part of educating women and doctors requires conducting research to provide a foundation for educational practices and to make a persuasive case for changes in medical professionals' behaviour. And support for patients often means providing them with usable medical or coping information, or research to show them that others share their perspectives and experiences.

1. Support for Patients

As we have seen, the EA began as a support group. According to the Association's signature yellow brochure, its local chapters continue this function, holding meetings "to allow informal information-sharing about endometriosis and support and help with problems arising from it" (Endometriosis Association, 1992 {1980}). The EA also provides a toll-free crisis call hotline staffed by "members who are willing to listen and offer suggestions and help during times of pain, difficult decisions, or other crises due to endometriosis" (ibid).

It is clear from these statements that the Association conceives support services as strongly connected to information provision. Indeed, the mutual support that women with endometriosis provide one another--either through the Association, on WITSENDO, or in the Winnipeg clinic support group--very often takes the form of information exchanges.

"Non-informational" support takes the form of commiseration, listening, and encouragement not to "give up"; I often observed the operation of these kinds of mutual aid on the WITSENDO list and in the focus group discussions. My analysis of the EA is based upon their publications, which obviously do not exhibit this sort of interaction between women with endometriosis. However, the EA provides for a kind of virtual support between writer and reader by publishing letters from endometriosis patients in its literature for women with endometriosis. The publication of such letters serves two main functions for patients: it creates experiential solidarity and thereby reduces individualization and isolation; and it provides information and advice for patients. I discuss these in turn.

i. Creating Solidarity and Deindividualizing the Endometriosis Experience

Publishing women's letters conveys to endometriosis patient readers that there are others with similar experiences and similar understandings of those experiences. This can combat feelings of isolation and validate the patient's perceptions about their experiences. For example, recall one WITSENDO participant's evaluation of *The Endometriosis Sourcebook*: "I found the letters from fellow sufferers to be a tremendous help. At last I was not alone" (W14). Note the use of "fellow" here; this is another illustration of Robinson's (1990) argument that the sharing of illness narratives helps to create solidarity among patients. Virtually every chapter of the *Endometriosis Sourcebook* begins with a series of excerpts from patients' letters to the Association that relate to the chapter topic. Treatments, pain, infertility, doctor-patient relationships, sexuality, coping strategies--all are introduced with a selection of experiential accounts from women with endometriosis.

The similarities among these accounts is striking, and they establish experiential

themes that are subsequently addressed in the main text of the EA literature. Establishing experiential themes establishes that issues presumably faced by the reader are widespread. The biomedical, social, and political circumstances that create these experiential themes often are addressed in the letters and in the text that follows. This in turn reduces for the reader the likelihood that her perceptions and experiences are abnormal or "in her head," externalizing the problem and mitigating the reader's responsibility for the problem. If other women have faced the same problems, the cause of the problem must be the disease itself or societal reactions to the endometriosis sufferer--not the sufferer's own thinking or actions.

This is particularly important as self-doubt and self-blame, and others' doubt and blame of the self, are common experiences for women with endometriosis. Ballweg's own account of the early meetings of the group illustrates these themes well:

Each [woman in the original support group] thought she was partly at fault for her problems: if only she'd been more assertive with the doctors; if only she hadn't ignored the symptoms for so long; if only she hadn't been too embarrassed to tell someone when she was a teen and the disease was setting in; if only she'd stood up to her husband when sex hurt too much; if only she'd tried a few more doctors; if only, if only, if only...

But in hearing each other's stories, we realized we'd all had similar problems and perhaps weren't individually at fault (Ballweg & The Endometriosis Association, 1987:302-3).

So ultimately the kind of support that hearing or reading other individuals' accounts provides is derived from a deindividualization process that counteracts the individualization of health problems so endemic to modern Western culture.

Individualization makes people responsible for their own health (recall Ballweg's comment that well people often "regard their health as a matter of personal accomplishment"), and hence blameable for their own illness. In providing patients with access to the accounts of others with the same illness, organizations like the EA and local support groups

deindividualize health problems and thereby counteract self-blame.

This illustrates some of the limits of Foucauldian approaches which assume that self-help and health education inevitably contribute to individualization and the care of the self in ways that ultimately bolster bio-politics, the governance of populations through expert knowledges (eg. Gastaldo, 1997). While certainly the EA promotes self-care, which seemingly is analyzable in terms of Foucauldian notions of self-discipline, its self-care model and its deindividualization efforts in certain senses confound biopolitical governance techniques and critically situate these techniques in an explicitly social and political context. Hence, the EA implies that women with endometriosis are being 'forced' into self-blame by cultural and biomedical conceptions of individual responsibility for health and illness.

In presenting its self-care advice, the Association is cautious, emphasizing that self-care techniques may not work for everyone and that women should not consider themselves as failures or assume they are not trying hard enough if the techniques do not work. This itself is a form of individualization and subjectification, obviously, but not one that transparently reflects biomedical governance techniques. In fact, increasingly, the EA is constructing endometriosis as a *social* problem--one caused by dioxins generated by industrialization. Rather than effect an individualization of the problem, then, the EA is concerned to deindividualize and socialize endometriosis, such that the responsibility for the disease lies not with individual patients but with society as a whole. And of course, this makes everyone in society a potential ally of the EA.

ii. *Providing Information and Tacit Advice*

The second function played by published letters is informational. Establishing experiential themes and their biomedical, social and political causes is itself a kind of information, such that reading the letters of others not only provides emotional support, but also information about general patterns in the endometriotic experience that the reader can use to evaluate the meaning of her experiences and place them in a broader social context. On a more practical level, such letters often provide hints as to how better to negotiate the difficulties associated with having endometriosis. For example, excerpts of letters in the *Sourcebook* document specific problems encountered by patients. As two examples of the hundreds in the book illustrate, these letter excerpts describe strategies used by patients to deal with these problems or, at the very least, suggest what not to do:

I consented to a hysterectomy...I felt very disappointed that I had undergone major surgery in the hopes that it would cure the disease. I must encourage those who have been diagnosed with endo to seek expert medical advice...Hysterectomy is definitely not a cure. I strongly recommend those with endometriosis educate themselves about the disease, explore and evaluate all possible treatments available (quoted in Ballweg & The Endometriosis Association, 1995:101).

I feel it is very important to write about my experience with Lupron Depot. I would like anyone considering the drug to realize that once you have that monthly injection, if your body does not tolerate it, you're still stuck with it in your body for 31 days or more.

I developed an allergic reaction, which erupted as hives and welt patches covering me from head to toe. I went to my physician and later to the emergency room, but their usual treatments were to no avail...because of the staying power of the drug, there was little that could be done...After one week of watching this drug travel through my body, intense itching, pain, and swelling so bad that I spent two days with my hands in ice packs, I am just starting to get some relief.

I would like to urge any woman considering the drug maybe to try the daily dose first, to be sure her body can tolerate it. I would hate for anyone else to have to live through the nightmare I have (Ballweg & The Endometriosis Association, 1995:163-4)

The information provided in these letter excerpts is a form of patient education

because it teaches patients how to make better decisions, how to take control of their medical care, and which options to explore. Again, though, by publishing several letters which demonstrate a range of experience and varying degrees of "success" achieved with different approaches, the EA does not present a rigid disciplinary model of correct behaviour for endometriosis patients. Rather, an empirical approach of trial and error is advocated: this may work for you; if not, try this or that. The emphasis is on individual negotiation of ways and means, but in a way that simultaneously reminds women that others have been through the negotiations. By printing multiple letters for each category of experience (organized by cause of experience, eg. infertility, hysterectomy, specific drugs, alternative therapies), the EA literature practically ensures that any woman reading the letters will find one that resonates somehow with her own perceptions of her experience, thereby mitigating the individualizing ramifications of self-care advocacy.

2. Educating Patients

Besides educating patients by publishing the letters of women with endometriosis, the EA publishes a great deal of other patient education literature, including overviews and evaluations of medical knowledge and patient-centred knowledge (coping strategies, lifestyle issues, ways to negotiate the doctor-patient relationship, and so on). The EA's two books (Ballweg & The Endometriosis Association, 1987, 1995), its newsletters (published 4 to 6 times annually), special collections of past newsletter articles on particular topics, and audiotapes of the EA's two conferences (in 1990 and 1995) provide extensive discussions of surgical techniques and hormonal therapies, reports on medical conferences, and reviews of scientific research in particular fields (such as endometriosis and the urinary tract, genetic and familial aspects of endometriosis, and possible links

between endometriosis and cancer).

The EA's publications provide references to medical publications and are written in accessible language. Medical terms are defined, scientific research methods and statistical measures explained and, often, editorial notes included to provide background information or critical commentary. A glossary of medical terms is included in each of the books and in some newsletters where a great deal of technical information is provided. Reviews of medical research in EA literature are comparative, discussing contradictions and uncertainties in the medical literature.

For example, an article on the urinary tract in the EA newsletter reports that "the exact number of women with endo who have urinary tract difficulties is unknown," discusses contradictory research findings on this question, and wonders "if the incidence of urinary involvement with endometriosis is higher" than most studies suggest (Yap, 1992:1). Here, as is often the case in EA literature, it is suggested that these uncertainties may be resolved, and the advanced hypothesis proven, by EA data and member narratives: "In the Association Data Research Registry, 24.9 percent of the 3,020 registry participants reported that their doctors had told them endometrial implants were located on the bladder" (ibid:1-2). While clearly, the medical literature is a crucial resource for the EA in its patient education efforts, its internal contradictions and deficits tend to be acknowledged, and solutions to these tentatively suggested, based on the EA's own data (constructed as scientific by frequent references to the large sample) and on members' narratives. Thus, as in the patient accounts in the last two chapters, ultimately patient experience is deployed as an arbiter of the truth of medical claims. Science is evaluated through the prism of patient experience.

EA literature compiles reviews of medical literature, patient letters and patient-

centred data generated by the Association to educate patients, and it often provides cartoons, jokes and tips about how to negotiate the disease, medical care, and related issues (presented as "coping strategies" in the two books). These elements appear alongside one another or are intermingled.

So, for example, in the urinary tract article cited above, reports on medical research include data the EA has compiled from members; this occupies the top half of several newsletter pages, while patient letters relating to the issue are printed on the bottom half of the pages. A simple hand-drawn diagram of the urinary tract and pelvic organs occupies a corner of one page; on another page is a cartoon of a woman dragging her bladder behind her on a rope around her neck, with the caption "I went to my urologist three different times with my bladder." The last section of the article discusses "Practical Applications," which begins

Now, how do you assimilate the information about urinary tract endo into something you can practically apply to your life? Sometimes a lot of information can make you feel overwhelmed and confused. In the long run, however, taking time to sift through information should help you learn more about your body and how to improve your health. It is our responsibility to educate ourselves, because many of us have discovered we can't expect health practitioners to do the job (ibid:7).

The author then provides a series of tips: how to get effective treatment given HMO and personal financial constraints; how to educate doctors about endometriosis; how to find practitioners of a new specialty called urogynecology; strategies to reduce bladder pain and keep an empty bladder; how to maintain general good health; how to keep a sense of humour and "be creative" by keeping puzzles or reading material in the bathroom and decorating it; how to reconceptualize the doctor-patient relationship ("try thinking of your doctor as a partner, not a superior...YOU are the only one who really knows how your body feels" (ibid:8; emphasis in original)); how to "help your doctor" by

keeping track of amount and type of drinks, and frequency and amount of urination ("You can buy a device that fits in your toilet to measure your urine in cc's and ounces" (ibid) with a description of what the device looks like, where the reader may have seen it before, where you can buy it, and how much it costs); and how to "achieve balance" between accepting limitations and not being "passive and giv[ing] up trying to improve my health" (ibid:8). The result of this kind of article is a holistic pedagogy that includes medical information, practical suggestions to achieve better health and health care, and experiential narratives.

Interestingly, there seems to be an increasing focus on medical information in the EA literature, along with (seemingly paradoxically) a somewhat decreasing reliance on medical authors. Just over one third of the EA's first book (1987) discusses specific medical treatments and reviews medical research; the remainder is devoted to social science research, coping strategies, and information about the EA. In the second book (1995), articles on medical treatments and scientific research (including research administered and funded by the EA) comprises over half of the book. The change is particularly apparent when the surgery sections of each book are considered. The first book is 306 pages long (not including the foreword, appendix, glossary, and index); the second book (same items excluded) is 439 pages long. In the first book the surgery section is only 18 pages long and 10 of those are written by gynecologists (consultants to the EA). In the second book, the surgery section is 91 pages long and EA members themselves (usually Ballweg) wrote or co-wrote all but two articles in the surgery section of the second book⁷⁵.

⁷⁵The two exceptions are an article on ethical surgical practice guidelines by gynecologist Veasy C. Buttram, Jr. and an EA-funded study by Karen Lamb and two other MDs on whether hysterectomy cures endometriosis. These articles combined equal

i. *Authority and Access: How the EA Promotes and Sells its Literature*

The increase in technical information and the decrease in professional authorship seem to reflect a growing emphasis on the EA itself as expert authority, rather than as gateway to professional advice. The Association presents itself (justly) as the most complete and authoritative source of lay information about the disease. The EA's two books are available through bookstores and a diagnostic kit⁷⁶ can be ordered by non-members through the Association. All other EA materials--the newsletters, conference audiotapes, videotapes, contact lists (members in the area who have volunteered to provide information and support to other members), and the physician registry (a list of physicians who are members of the Association, available by state of residence) are available only to members of the EA (Endometriosis Association, n.d.). The EA also points out that the medical information on endometriosis is now so extensive that it is impossible for individual patients to keep abreast of it all, and the EA therefore provides a crucial service in summarizing and evaluating the available research. Thus, any woman who wants to learn about endometriosis must--should and has to--become a member:

Members tell us that the [Association's] newsletters provide the hope and help they need--and the best information anywhere on how to cope with endometriosis...Our material has been highly praised for the succinct, factual, and direct way it answers questions most of us have in the course of coping with endometriosis. You can't find better lay materials on endometriosis anywhere (Endometriosis Association website, "Benefits of Membership," www.endometriosisassn.org/Benefits.htm).

Sorting through the research studies is a critical part of "thoughtful dissection"...Because we act as a clearinghouse and can pool the

16 pages of the 91 page total.

⁷⁶This includes an information sheet, "How Can I Tell If I Have Endometriosis?" with a symptoms chart, information on symptom development and patterns, tips on diagnosis...[and] an illustrated booklet describing the procedure [presumably laparoscopy]" (Endometriosis Association, n.d.:8).

experiences of hundreds and sometimes thousands of women and because we can represent women, not a product or a service or a practice, we are not completely dependent on the willingness of physicians, researchers, and drug companies to study well and share completely this kind of information. (Not to mention that a clearinghouse is needed because, with so much new information coming forth, no one person could possibly keep up with the whole field.) With 15 years of background and growing sophistication we are indeed able to struggle through that process... Struggling through the type of process I've just described is not something newcomers or the typical girl or woman with endometriosis could possibly do. As Dr. Olive wrote in his textbook on endo, "Local and national associations serve a critical purpose as educators in the community. Newly diagnosed women, as well as those merely suspected of having the disease, are bombarded with an array of often conflicting information. Consumer organizations can provide an unbiased source of information and guidance for these women. Educating the patient population is guaranteed to provide the greatest impact in promoting quality care for those suffering from endometriosis" (Ballweg, 1995b).

We are pleased and proud to offer members the best literature on endometriosis in the world. Nowhere else can you find the accurate, highly-informative literature, based on the experiences of women with the disease and our research, that is available from the Association...our book, **OVERCOMING ENDOMETRIOSIS**, [is] sometimes referred to as "the Bible" for women with endometriosis...Want to keep up on the latest developments in research and treatment of endometriosis? There's only one way--become a member and stay a member. The newsletter and meetings will help you be sure you don't miss important developments that might make a big difference for you (Endometriosis Association, n.d.:inside front cover).

However, the EA is mindful of the fact that some women who would benefit from membership cannot afford the dues, especially given that some women with endometriosis are financially in dire straits because they cannot work due to disabling symptoms and/or have enormous medical bills to pay. It therefore has a gift membership programme whereby other members are encouraged to pay for a gift membership for a woman in need, who is asked to pay the money back when she is able so that another can benefit from the programme (Grotberg, 1999). Moreover, annual dues are relatively inexpensive (\$31 Canadian for "members"--women with endometriosis--and \$37 for "associates"--those who have not had endometriosis, such as physicians) (Endometriosis Association, n.d.).

ii. *The Responsibility to Know: Configuring the Patient as EA Member*

Like the patient letters, descriptions and evaluations of medical knowledge and coping advice teach the reader what to do and what not to do--that is, how to be a more successful woman with endometriosis. In doing so, of course, they help to define what it means to be a successful woman with endometriosis. Successful here does not necessarily mean cured or pain- or symptom-free, but in control and knowledgeable--in control *because* knowledgeable. With its focus on self-education and self-care, the EA's tacit definition of a successful endometriosis patient is one who, first and foremost, takes 'responsibility' for her disease. And this happens only through a thorough knowledge of her disease and ways to treat and cope with it, as in the urinary tract article, which claims "taking time to sift through information should help you learn more about your body and how to improve your health. It is our responsibility to educate ourselves" (Yap, 1992:7).

This definition of the successful patient is developed throughout the EA literature, as suggested in a section of the last chapter of *Overcoming Endometriosis*, "Our Self-Help Philosophy":

The basic philosophy of the Endometriosis Association is one of self-help, that is, those with the disease helping themselves and others with the disease. This philosophy embodies in it the concepts of self-responsibility (to inform yourself and take action in order to make the best decisions for yourself) and the right to be treated with dignity, to be informed, to choose and make decisions yourself regarding your health, body, and spirit. We believe that--because of the extremely personal nature of this disease with its serious effects on health, sexuality, fertility, and self-image--no one (medical professionals, Association individuals, or anyone else) should make the important life decisions that often face a woman with endometriosis except for the woman herself (ibid:305).

Note that this philosophy does not discuss the right or responsibility to give or receive emotional support, as it very well could have. But commiseration is not the main goal of the EA. Rather, not only the right to information, but the *responsibility* to know

are stressed. While I have argued that the presentation of patient letters and the tone of EA literature generally is one that mitigates individual responsibility for *ill health*, the Association tacitly places responsibility for being *ill-informed* on individual patients--or at least upon those who know about the EA but still choose to remain ignorant. While Ballweg's account of the days before the EA was formed makes it clear that she could find hardly any information on endometriosis, at least she tried. Now, the implication is that there is no excuse for the ignorant patient *because the EA exists*.

This nicely sets up the EA as obligatory passage point for successful (i.e. assertive, well-informed) endometriosis patients. "Obligatory passage point" here reflects not just the actor-network theory sense of necessary ally or conduit between parties, but obligatory in the sense of a duty. Becoming a member of the EA (or at least reading its literature, most of which is available only to members) becomes something of a moral obligation for patients. The implication--although the EA would never put it this way--is that, unless they take the necessary steps to educate themselves (through the EA especially), patients have only themselves to blame if they do not secure good treatment. This provides further support for my claim that, according to the endometriosis patient community, the self is the steward of the body. Responsible stewardship requires an informed self (cf. Foucault, 1988) and joining the EA is the way to become an informed self. While the informed self cannot be blamed if the body does not cooperate and treatments do not work, this blame is only mitigated if the self is informed.

Certainly self-education is presented more as a strong recommendation than as a moral imperative in most of the literature geared toward patients. But the notion that patients have a responsibility to know becomes more explicit in the Association's contribution to a publication geared toward Canadian gynecologists. This publication is

the report of the 1999 *Canadian Consensus Conference on Endometriosis* (Rowe, 1999) which was organized by the Society of Obstetricians and Gynecologists of Canada to bring medical specialists together to review new medical research on the disease and to update the clinical practice recommendations made in the 1993 *Consensus Conference* report. A Canadian EA representative participated in the consensus conference and the EA contributed a chapter on The Patient Perspective. In that chapter, the EA asserts that some patients

...wish to deny, despite the extent of their symptoms, that the disease is going to be difficult to manage or that it may seriously affect their lives...Because of the social milieu surrounding endometriosis, the denial detour along the road to acceptance tends to be very prolonged. We see it frequently in women who fail to take steps to learn about the disease, or to find a specialist, or to prepare for a variety of eventualities. Instead, they simply stick their heads in the sand, ostrich-like. Then they come to the Association in crisis, often having made poor decisions in the interim (Endometriosis Association, 1999f:64).

This likely is meant to soften the blow when gynecologists read the EA's claim, further along in the article, that gynecologists also often engage in denial about their inability to cure or treat endometriosis effectively. Criticizing patients as well as doctors makes one appear more balanced, less 'biased', not a 'doctor-basher'⁷⁷. However, only particular endometriosis patients are being criticized in this passage: ones that do not take the necessary steps to educate themselves about the disease and ones that come to the EA 'too late.' A later passage in the same piece reinforces patients' responsibility to learn:

As difficult as it may be for the patient and physician, a thoughtful sharing

⁷⁷The EA seeks to enrol doctors to get its aims met. This dissertation does not. Given the often horrific accounts of experiences with doctors that I have heard from personal acquaintances who have endometriosis, and from many of the women who participated in this research, my concern is to document those accounts, and to show how 'doctor-bashing' helps patients to delegitimize medical professionals' claims to know vis-à-vis their own claims to know. Moreover, 'doctor-bashing'--used very strategically--is in many cases a crucial technique for the EA in enrolling both patients and 'good' doctors.

of information about the difficulties of the disease will actually be more helpful in the long run than the ups and downs of unwarranted hope for a complete cure. That kind of up-and-down cycle also tends to keep the patient from doing the things that would most help her find certain equilibrium and cope with the disease for the long run. That is, "doing her homework"--a phrase in frequent use at the Association--and building her support network, particularly with other women with endometriosis. This entails listening to their stories, mapping out scenarios for different eventualities, and so on (Endometriosis Association, 1999f:65).

The phrase "doing homework" has moral overtones. The student who does not do her homework is not only likely to fail, but it also shirking her responsibilities as a student.

While these passages are rather critical of some patients' sick role behaviour, they also advance many of the main claims of the endometriosis patient community presented in the last two chapters. They assert that doctors should exchange information with patients, and should be honest about treatments and the uncertainty of prognoses. They advocate both the importance of patients conducting research to learn about endometriosis, and the importance of exchanging information with other women, thus asserting the validity and importance of the endometriosis patient community itself. However, they differ from the patient narratives presented in the last chapter in that, again, the Endometriosis Association is presented as the *obligatory* passage point for patients wishing to join the endometriosis patient community and educate themselves about endometriosis, rather than as just one (though an important) possible venue.

iii. Beating Out the Competition

There are other informational venues for endometriosis patients, of course, such as the WITSEND0 list, other Internet resources, and local support groups which are not administered by the EA. The EA's *Consensus Conference* piece notes the existence of the WITSEND0 list and other Internet resources, provides the EA's own website address,

and acknowledges that the Internet can be an important source of information and support "for women in areas outside of Association groups and chapters, who need to connect from home because of pain/disability/family issues, hectic schedules or who need support in the middle of the night or at other times when group or group members are not available [sic]" (ibid:66)⁷⁸.

However, the piece also cautions that

as a spate of articles has recently described, much of the information on the Internet can be inaccurate or confusing...no clear standards have yet evolved to separate editorial content from advertising, or to identify clearly the sources of information and the personal or organizational biases of those sources. The Association has received numerous complaints from its members about inaccurate or sales-oriented information, and worse, on the Internet. Despite such problems, the Association decided it had to be on the Internet to help meet our mission to provide support and accurate information. We see our website and other online services as extensions of our many ongoing programmes. The Association has also appointed members to monitor the Internet so that we can be a continuing presence on the mailing lists. The roles of these representatives will be to answer questions that arise related to the Association, alert users to needs that arise on the Internet, inform participants of resources and serve as our official representatives to these groups (ibid:66).

In casting aspersions on widely accessible, alternative sources of patient information such as websites (they may be biased, inaccurate, "and worse"), this account seeks to establish the EA as the most reliable source of information for patients, such that it is qualified to judge other sources and act as consumer watchdog on behalf of doctors and endometriosis patients.

Warnings about non-EA sources of information appear in literature geared toward endometriosis patients as well. In *TeenSource*, the EA's newsletter for teenaged members,

⁷⁸Note that the implication here is that all endometriosis support groups are administered by the EA, which does not seem to be the case; the Winnipeg Clinic support group has only a loose affiliation with the Association. Again though, the construction is that the only way to access services is through the EA.

the following advice from a teen with endometriosis is presented: "Research and learn about the disease. Knowledge is important, but always be careful. Don't believe everything you read. Fact check information with reputable sources like the EA...Remember, the two books written by Mary Lou Ballweg and the EA are excellent sources of information" (Rice, 1998:3). The aim of these warnings is to encourage patients to go to the EA first, and to encourage doctors to point patients to the EA first.

There is indeed a lot of information of dubious quality on the Internet. However, my own observations of the WITSEND0 list, the Winnipeg Clinic support group, and the focus group meetings, as well as the accounts of the participants in this study, suggest that claims rarely are met with unquestioning acceptance by women with endometriosis.

The EA's concern about some women being led astray may be valid--especially for women who, unlike those I have observed and interviewed, have not been members of the endometriosis patient community for some time, or are not well-educated on the state of the art of endometriosis treatment. However, the EA's criticisms and surveillance of other educational venues also help to build their network. The strategy seems to be to bring all resources for women with endometriosis under the control of the Association, or at least to discredit those that threaten its status as the main source of information for patients or that deviate from the EA's view of appropriate information for patients.⁷⁹

⁷⁹For example, a member of the Women's Health Clinic staff in Winnipeg told me that, when the Clinic developed its own brochure about endometriosis (Women's Health Clinic, n.d.), it was contacted by the Endometriosis Association (with which it has a loose association, though the Clinic support group by no means can be considered an EA chapter) and apparently rebuked for developing the brochure because the EA felt it undermined the Association's "What Is Endometriosis?" brochure (personal communication, 1994). This despite the fact that the Clinic brochure provides contact information for the EA (among other resources, such as the WITSEND0 list and books written for patients) and its substantive contents certainly are in line with the philosophy of the EA regarding treatments, causes, symptoms, diagnosis, and self-help.

Furthermore, by appointing members to monitor and participate in other venues, the EA uses these other venues (such as the WITSEND0 list) as recruitment sites and sources of free publicity. This effectively enrolls these venues and their participants into the EA network. This, of course, further reinforces the notion of one endometriosis patient community.

The EA, then, seeks to establish itself among health professionals and patients as *the* information source for patients. In effect, the *Consensus Conference* piece enjoins doctors to encourage their patients to join the Association, suggesting that doing so will result in a patient who understands better, therefore copes better, and therefore feels better (and, presumably, is therefore less troublesome). It attempts to enlist the help of doctors in enforcing patients' responsibility to know as well as their right to know, and attempts to establish the EA as the most reliable agency through which these rights and responsibilities can be met.

3. Educating Doctors

The *Consensus Conference* piece does not seek merely to persuade physicians to direct their patients to the EA; it also attempts to reeducate physicians and to change their behaviour in ways favoured by endometriosis patients. Other efforts toward these ends include attending and presenting at medical conferences, mailing literature to physicians, and encouraging patient-members to promote the EA to physicians. I discuss each of these in turn, returning to a consideration of literature that the EA writes for medical audiences at the end of this section.

i. *The EA at Medical Conferences*

Ballweg presents "Joe with Endo"--a series of cartoons depicting a man dealing with the common problems related to endometriosis and medical treatment, designed to bring into more vivid relief the gendered aspects of endometriosis--in her speeches to medical and patient audiences, often enlisting doctors to take the part of Joe (Ballweg, 1995f). The EA has attended and staged exhibits at many medical conferences, including the meetings of the Society of Obstetricians and Gynecologists of Canada (SOGC), the European Society for Human Reproduction and Embryology, the American Fertility Society, the American Association of Gynecologic Laparoscopists, the American Academy of Environmental Medicine, and the International Federation of Gynecologists and Obstetricians (FIGO) (Endometriosis Association, 1993a; 1994a; 1994b; 1997; 1999b; 2000c).

At the 1997 FIGO conference in Denmark, the EA distributed almost 1,200 clinical textbooks to participants and recruited new physician-members from several countries (Hummelshoj, 1997). At the Sixth World Congress on Endometriosis in Québec in 1998, members of the EA participated on panels, attended dinners with clinicians and scientists, and organized brainstorming sessions with experts on various topics. It also coordinated a symposium at which Ballweg presented the EA's survey of 4,000 members to conference participants and at which leaders from the EA and its sister organizations internationally spoke about the problems of women with endometriosis to an audience of clinicians and researchers (Ballweg, 1998b; Endometriosis Association, 1999d; Henderson, Wood, Hummelshoj, & Kregsman, 1998; Hummelshoj, 1998). EA participants at that conference wrote enthusiastically about the EA's reception there: "For the first time at the World Congresses, the EA was recognized, officially, as an authority

in itself" (Henderson, Wood, Hummelshoj, & Kregsman, 1998).

Over the past few years, it appears that the EA's involvement in and education efforts at medical conferences have intensified, often at the invitation and with the support of eminent experts and with the financial backing of pharmaceutical companies and professional societies. At the 1994 International Federation of Gynecologists & Obstetricians (FIGO) in Montreal, the EA's booth was funded by a grant from the SOGC (Endometriosis Association, 1994b). The EA's involvement in the 1998 World Congress was largely due "to the leadership of Conference organizers, Rodolphe Mahieux, M.D. and André Lemay, M.D., Ph.D. (an Advisor to the Association), and the interest and support of the international headquarters of Zeneca Pharmaceuticals"; Searle Pharmaceuticals supported the brainstorming sessions organized by the EA and funded the mailing of the EA's summary of the sessions to everyone who attended the World Congress (Ballweg, 1998b:1).

ii. Distributing EA Literature

In addition to its efforts at medical conferences, the EA uses direct-mailing to get its literature to physicians. For example, in 1985, the first direct-mail project to all American gynecologists was conducted; in 1989, the same was done for Canadian gynecologists (Endometriosis Association, 1989). In 1992, a brochure was developed and mailed to ob/gyn residents in North America (Endometriosis Association, 1992c). For the first Endometriosis Awareness Week (officially recognized in the U.S. and Canada after hard lobbying from the EA), the EA mailed free press kits containing "readymade artwork...case histories of five women with endo, fact sheets and other helpful information" to "nearly a thousand U.S. health and medical editors" for their use in

publications (Endometriosis Association, 1993b:16).

The EA also recruits its patient members to provide literature to their doctors. Over the years, the EA has provided other literature to patients for distribution to physicians, often with associated "perks" for members. For example, one of the Association's advisors and a leading American endometriosis surgeon, Dr. Dan Martin, prepared a colour atlas for physicians documenting the various appearances of the disease. Members were asked to mail in a coupon with their doctor's name and address so that the atlas could be sent to them, free of charge; in return, the EA would send these members "a beautiful 57-page booklet on new surgical techniques, laser results, and pain charts" (Endometriosis Association, 1992a:15). When I rejoined the Association in 1998, members were able to order two copies of a small clinical textbook about endometriosis published for medical audiences (Corson, 1992), on condition that they provide the name and address of the clinician to whom they would provide the second copy. According to its newsletter, the EA distributed 20,000 copies of this textbook to clinicians (Endometriosis Association, 1999a).

The EA recently developed a brochure for gynecologists on endometriosis and dioxins (Endometriosis Association, 1998b). In its newsletter heralding the brochure's development, the EA asserts that "The area of toxicology is not one that most gyny have studied. Yet, endo is increasingly being linked to dioxin and related chemicals. Therefore we believed it important to begin to alert gyny to the relationship between endo and dioxins" (Endometriosis Association, 1999b:13). In February 1999, a copy of the brochure was mailed to all EA members. In an enclosed letter, members were enjoined to "Please give the blue brochure to your gynecologist" (personal communication, Endometriosis Association, February 9, 1999). The brochure cites 31 sources, only two

of which were authored by the EA; the remainder are medical journal articles, medical conference papers, and a few reports from the EPA (Environmental Protection Agency) and the CDC (Centers for Disease Control). As we shall see, the EA has been at the forefront of promoting research on the links between endometriosis and dioxins. This mailout is a direct attempt to educate physicians, through their patients, about the EA's claims--but it demonstrates that these claims have the backing of credentialled experts. In the final section of the brochure, "What you can do," there is one suggestion: "Join the Endometriosis Association."

Physicians also are used to get the EA message out to other patients (potentially new members of the EA). Members frequently are asked in the newsletter to provide copies of the EA's signature yellow brochure (Endometriosis Association, 1992 {1980}) to physicians and other health care professionals, so that they in turn can distribute them to other patients. Handouts for patients were included with articles geared toward physicians in *Ob/Gyn Management* and *Patient Care* (Endometriosis Association, 1999a). The result is a patient-member/physician/patient-non-member network of information-sharing, with the EA at the centre coordinating the activities.

iii. The EA in Medical Publications

In addition to conferences, mailings, and the use of members as literature distributors, the EA educates physicians through its contributions to medical publications. Researchers affiliated with the EA have published the results of EA-funded and -directed research in medical journals (eg. Dmowski et al., 1997; Rier, Martin, Bowman, & Becker, 1995) (see the Research section below). The EA itself contributes articles about the "patient perspective" to medical journals and books. Here I review three of these articles,

which provide some particularly useful exemplifications of the devices used by the EA to educate physicians.

One is the 1999 *Consensus Conference* piece (Endometriosis Association, 1999). The second is an article by Martha Whitney (a social worker whose correspondence address is listed as the EA office in Milwaukee) about a study of the value of interpatient networking conducted through the WITSENDO list and published in *The Journal of Reproductive Medicine* (Whitney, 1998)⁸⁰. The third is an article by Ballweg, critiquing the psychiatric diagnosis of somatization disorder⁸¹ and its relation to endometriosis in a special issue of *Obstetrics and Gynecology Clinics of North America* on endometriosis (Ballweg, 1997). These three pieces combine five kinds of knowledge claims--patients' experiential narratives, definitions of expertise, and claims about scientificity, psychology, and sociopolitical 'biases'--in their attempts to change physicians' behaviour by changing their minds.

a. Experiential narratives

All three pieces use excerpts from patient letters to the EA to educate physicians about the 'endometriosis experience,' because "women with endometriosis...tell the story best in their own words" (Endometriosis Association, 1999:62). Excerpts are used to document women's negative and positive evaluations of physicians, providing directions to physicians about appropriate and inappropriate behaviour (note the strong resemblance of

⁸⁰This piece has little to say about medical matters and doctor-patient relations, focussing instead upon interpatient communication; as a result, it is referred to less than the other two pieces.

⁸¹Somatization disorder is the official DSM classification for physical symptoms in the absence of physical disease, where psychological factors are considered responsible for the symptoms (Ballweg, 1997:443).

these quotations to the claims of other endometriosis patients in Chapters 4 and 5):

I think many health care professionals feel that the patient does not have the necessary background to understand all the issues and err on the part of not giving the patient credit for understanding and having input into decisions made which directly (and intimately) concern her health (quoted in Whitney, 1998:334).

My GYN has been very sympathetic and has never questioned whether my pain really exists or not. He has given me articles from med. journals and has answered all my questions. He has treated me like an intelligent person and has told me what he can do, and what he CAN'T do. Being kept informed about my condition has given me a feeling of some control over this problem (quoted in Whitney, 1998:334; emphasis in original).

...between the ages of 13 and 17, the doctors decided I had a mental problem and conduct disorder. The doctors said I was using this pain as a way to get attention. They told me this was all in my head even after several laparoscopies that showed I had the disease...When I was 17, I was referred (again) to another doctor. This doctor did a laparotomy that lasted 3 hours. He said I had the worst case of endometriosis he had ever seen...He told me my pain was real and not in my head (quoted in Ballweg, 1997:441-2).

One physician told me that in his 20 years of clinical practice he had found that 90% of his patients' menstrual complaints were due to psychological problems. He informed me that if I got married and had a child, my symptoms would go away...Finally, I found a female internist/endocrinologist specializing in infertility who listened carefully to my history (a first) (quoted in Ballweg, 1997:442).

At the time of diagnosis I was told that my illness might be consequence of a therapeutic abortion...I can't tell you the grief this statement caused me, which is only now lifting as I learn that there is no science, absolutely no science whatsoever, behind the assertion. Isn't it time for our medical professionals to admit that sometimes they do not know the reason for things happening? (quoted in Endometriosis Association, 1999:63).

Reproducing these letters in publications geared to medical audiences fulfils several goals:

it educates physicians about the ways in which endometriosis and its treatment are experienced by patients; it evokes sympathy for women with endometriosis from physicians; it provides experiential "evidence" for the EA's claims about some physicians' inappropriate behaviour; and it enjoins physicians to change their behaviour.

There are other roles for patient accounts in these pieces, however. Such accounts demonstrate that physicians and patients share certain interests and experiences and can help each other to a fuller understanding of endometriosis, and establish the EA as the representative of patients with endometriosis. For example, the *Consensus Conference* piece notes that physicians and patients alike experience endometriosis as "baffling" (Endometriosis Association, 1999f:62), creating a foundation for patient-physician solidarity; and it states that the letters excerpted were "selected from among the hundreds of thousands of letters" the Association has received from Canadian women since its inception (ibid:62), positioning the EA as an authority on the patient experience of endometriosis. Likewise, the Ballweg piece refers to the "thousands of stories of medical dismissal" that patients have communicated to the EA (1998:444). The networking piece states that "Physicians are in a good position to help these women connect to a vast network of information and support, such as what the Endometriosis Association offers" (Whitney, 1998:334).

After documenting the harms that come to women when physicians inappropriately refer them to psychiatrists and they are diagnosed with somatization disorder, Ballweg's piece on the disorder makes the following statements in a section entitled "Reclaim Your Patients, Be Our Partners":

Gynecologists must stop the psychologizing of endometriosis. Gynecologists must not allow mental health practitioners to claim this disease as theirs...Endometriosis patients represent a sizable component of most gynecologic practices, and because the disease is so often a chronic condition, the need for ongoing medical care is great. Women with endometriosis deserve the support of gynecologists and organized gynecology to ensure that it is science, not conjectural bias and untested myths, that holds sway in the field (Ballweg, 1998:450).

Here, Ballweg cleverly combines a suggestion that mental health professionals are usurping patients and hence service fees from gynecologists by psychologizing

endometriosis (designed to appeal to gynecologists' mercenary side and their sense of disciplinary boundaries), with an appeal to science and sympathy for patients.

Gynecologists can agree with Ballweg on ethical and scientific grounds: somatization disorder is a scientifically questionable diagnosis; these letters show how terribly women with endometriosis suffer when they are incorrectly diagnosed. Or they can agree with Ballweg because they recognize the professional and financial benefits that would accrue to them if they 'reclaimed' endometriosis from psychiatric professionals.

Regardless, Ballweg shows, gynecologists and patients both have a vested interest in depsychologizing endometriosis and should join together to accomplish this goal; and the way to do this is through the Endometriosis Association. Patients win because their suffering is no longer dismissed as psychological by their gynecologists; doctors win, for the reasons Ballweg outlines; and the EA wins, because the disease of endometriosis is legitimated, the organization is legitimated along with it, and more experts are recruited to the cause, further establishing the EA as a health organization with epistemological muscle.

b. Definitions of expertise

Second, the EA appeals to definitions of expertise to educate physicians in these pieces. The patient letter excerpts cited above reiterate many of the core claims made about doctors that were documented in Chapter 4. But these EA publications geared toward doctors place much greater stress on women's experiences with "good physicians" than my participants did. It is important, when seeking to enrol physician support for the EA and patients and to change physicians' behaviour, that positive examples and role models be provided; as the saying goes, you catch more flies with honey than with

vinegar. Thus the following patient testimonial appears in the *Consensus*

Conference piece:

I must say I could never have gone through this without the support of my gynecologist. He gave me endless encouragement beyond the call of duty, and to this day I consider him a very valuable friend. I hope for the sake of Manitoba that this man continues to practise here, because a lot of people have already benefitted from his compassion (quoted in Endometriosis Association, 1999:63-4).

A uniformly negative portrayal of physicians would be more likely to alienate physicians and make them defensive than to secure their support. Instead, the EA appeals to definitions of *expertise* and clinical experience to reeducate physicians and effect changes in their behaviour that, it argues, would benefit patients.⁸² For example, Ballweg's piece presents the symptoms listed in the DSM as indicative of somatization disorder, arguing that "Gynecologists experienced with endometriosis would easily make the diagnosis of probable endometriosis based on this list" (1998:443). Later, she notes that women diagnosed with endometriosis may get diagnosed with somatization disorder if their symptoms "are judged 'in excess of what would be expected from the history, physical examination, or laboratory findings.' Most clinicians are aware of the well-documented lack of a relationship between the amount of misplaced endometrial tissue and the symptoms of endometriosis" (ibid:444).

By asserting that no *real* expert would mistake endometriosis for somatization disorder, Ballweg places the onus on physicians to prove their expertise by *not* making somatization disorder diagnoses in women with endometriosis--which of course brings these physicians in line with patients' and the EA's goal to eliminate the psychologizing of endometriosis. Similarly, the *Consensus Conference* piece, in documenting the problems

⁸²Recall too that many participants in this study appealed to definitions of expertise or lack thereof to explain good and bad behaviour in physicians.

women encounter with physicians, emphasizes that these problems tend to occur with "non-specialists." It also notes that testimonials from patients "indicate that particularly knowledgeable and skilled physicians are also seen as heroes" (ibid:63). A tacit definition of expert is presented, with particular associated codes of conduct. This not only enjoins physicians not to treat women in the inappropriate ways specified, and encourages other types of behaviour (promising the reward of being viewed as a hero), but it also allows individual physician-readers (most of whom will be gynecologists with an interest in endometriosis) to differentiate themselves from non-specialists--so long as they follow the rules for appropriate expert conduct set out by the EA.

c. Scientificity

The EA's publications for medical audiences deploy medical tenets and notions of scientificity to educate physicians. We have seen references to scientific evidence already. Ballweg's (1998) piece on somatization disorder is replete with such references. For instance, she argues that

Many of the studies [on somatization disorder and chronic pelvic pain] are poorly performed with small numbers and lump all types of pelvic pain together as if it were one entity. Sweeping generalizations are pulled from small amounts of hard data. An appalling lack of knowledge of endometriosis is displayed (when the investigators even bother to break out the numbers of women with endometriosis in their samples).

Moreover, the study designs and tools used are often unscientific; scales often have not been validated" (Ballweg, 1998:448).

There are other examples of the use of medical tenets and scientific principles in the *Consensus Conference* piece's critiques of medical claims about pain and hysterectomy. It argues that women's pain is frequently minimized and undertreated because some physicians assume that their symptoms are the result of "normal" period pain. Appeals to medical notions about pain, pathology, naturalness and normality are

used to counter this assumption: "We need all physicians to help teach that nature does not create an ongoing, monthly bodily function to be inherently painful--pain is a warning sign" (ibid:63). Certainly the idea that pain is a sign of pathology is a basic medical tenet. The contradictory medical tenet--that pain is not always a warning sign of pathology, but can be psychosomatic--is dispensed with via accusations of 'victim-blaming' (a sociopolitical critique) and appeals to scientific theories that endometrial implants may not be the cause of the pain:

One article, emanating from a specialist's hospital, even suggests that women "develop a new, pain-free point of view." The article presumes that women with endometriosis who have had surgery performed by the specialist could not possibly still have endometriosis; this at a time when we really do not know what endometriosis is, or if the endometrial implants [removed during surgery] are responsible for the pain. This is simply a more sophisticated version of blaming the victim, implying that she is so used to pain that she continues to feel it despite the removal of the disease, or that she imagines or manufactures it (ibid:65).

Hysterectomy as a cure is dispensed with via appeals to the EA's own research, couched in scientific terms through the use of statistics:

Hysterectomy and the removal of the ovaries have been widely proclaimed as the cure, without any follow-up studies. Recently, the Association conducted one; unfortunately, for about one-third of the patients, hysterectomy and the removal of ovaries did not offer a cure or even a relief of symptoms. In that survey, forty-four percent of those receiving estrogen replacement therapy experienced a return of symptoms (ibid:64).

This passage even implies that the EA is *more* scientific than many medical professionals, because it uses empirical research to evaluate the accuracy of medical assumptions. So if physicians wish to be regarded as scientific, they are disallowed from making assumptions or perpetuating "myths" (eg. hysterectomy cures endometriosis) without good scientific evidence. Conversely, properly scientific doctors are critical of the sorts of claims that the EA and endometriosis patients also oppose--another similarity that can be used to create solidarity.

d. Psychology

Certainly, the EA *never* makes the argument that women's physical symptoms are psychologically-based and in fact, as we have seen, vigorously opposes this argument. But we already have seen that the *Consensus Conference* piece psychologizes endometriosis patients in one respect: because the truth about endometriosis is so upsetting, they are "in denial" and this explains their lack of knowledge and poor treatment choices. The *Consensus Conference* piece also asserts that some *physicians* are "in denial"--about the "basic fact" that the disease cannot be cured (another appeal to scientific facticity). The piece suggests that professional egotism is the reason for this denial: "No one, including the physician, should expect to cure an incurable disease. Too many practitioners, rather than face that basic fact about endometriosis, choose instead to make the patient feel badly about herself, or doubt herself. This is putting ego needs ahead of the welfare of the patient" (ibid:65). Similarly, in Ballweg's somatization disorder article, she argues that "Perhaps the physician who wishes to avoid being blamed for not recognizing symptoms or keeping up with medical advances is choosing to exonerate himself or herself by labelling the patient with a psychiatric diagnosis" (1998:446)--a kind of displacement diagnosis.

By using the same tactics of psychologization that physicians often use to discredit patients' claims, the EA argues that the medical claims to which it objects are the result of psychological dysfunction *in doctors* (egotism, denial, transference, although rarely official psychological diagnostic categories). (And recall from Chapter 4 that participants also used this strategy to discredit physicians). The physician proves his or her mental health to the EA by not making these objectionable claims.

e. Sociopolitical arguments in EA medical publications

Finally, these EA contributions to medical publications contain arguments about physicians' sociopolitical biases--especially biases toward women. For instance, Ballweg asserts that the definition of somatization as an exaggeration or misinterpretation of "normal bodily sensations...bolsters the myth that women are not accurate reporters of their own symptoms and are more likely to suffer from psychogenic disorders"(1998:445). To back up her argument, she cites scientific studies of physicians' variable behaviour toward women and men presenting the same complaints, for which women are more often prescribed psychotropic medications or counselling than are men . Elsewhere, Ballweg wonders "How is it possible that simple logic does not suggest that if a psychiatric diagnosis supposedly affects primarily women there may well be some real discrimination occurring?" (1998:446) and asserts that "In all the decades since Freud, women have been told their symptoms are in their heads. For the majority of the millions of women with endometriosis, the kind of thinking behind somatization disorder is simply a new twist on that old bias about women" (451-2). On this account, a physician who suggests that many women with endometriosis suffer from somatization disorder is hidebound and sexist. Enlightened physicians would not advance such a claim.

Sociopolitical arguments are less explicit in the *Canadian Consensus Conference* piece, but are implied. For example, the *Consensus Conference* piece suggests that it is politically incorrect for physicians to tell women to have babies in order to cure endometriosis:

Among the all too common themes is the "have a baby" answer to endometriosis, regardless of a woman's desire to have a baby or her own and her partner's needs. This presentation of a life choice (and the decision to reproduce is perhaps the most profound choice of all in life) as a medical prescription infuriates and insults patients. In addition, as a

treatment, it is scientifically unsound (ibid:64).⁸³

Toward the end of the article, the experiences of endometriosis patients are summed up and linked to social inequalities between (female) patients and (usually male) doctors:

From the patient's perspective, endometriosis is almost indescribable. It is taboo, it is embarrassing, it is frightening, it is sneaky, and it is sadistic. It, and the treatment the sufferer receives from others because of it, can lead to a deep feeling of having been betrayed by one's own body. "It"--this disease--has the power to destroy your dreams, your dreams of a loving relationship with your husband or partner, your dreams of having children, your work goals, your dreams of a healthy body, and your plans for building a financially secure and happy life. It can strip you to your barest vulnerabilities. It may hurl you into a world where your vulnerability and powerlessness are emphasized. You are a young woman, perhaps only a teenager, yet you must find a way to navigate the power relationship of patient-and-doctor (often made worse by our society's male/female power imbalances) at a time when you are confused and frightened (ibid:65-6).

Note that in many of the EA's assertions described here, different *kinds* of arguments are made simultaneously, effectively bolstering one another. While in the patient-oriented literature, sociopolitical or psychological critiques of physician behaviour are often presented in isolation, in these pieces for gynecologists such critiques tend to be "backed up" by appeals to scientific authority, expertise, and professionalism, or by emotional appeals to physicians' sympathy for suffering patients. Scientificity, professionalism, and sympathy are basic principles of contemporary medicine, and appeal to physicians in both of their roles--as experts and as caregivers. It is likely that sociopolitical judgments alone would be less effective in educating physicians and securing physicians' cooperation with the rules of appropriate physician conduct than their combination with tenets basic to the medical profession. By combining the principles of

⁸³Here once again science is invoked by the EA to counter a common medical claim, and once again we see the parallels between the EA's critiques and those of the WITSENDO and focus group participants.

the medical community (sympathy, professionalism, scientificity) with components that emerge from other fields (psychology, sociology, feminism), are more foreign, and pose more of a challenge to medical thought and practice, the EA's physician education efforts probably are more successful than if they presented psychological, sociological, or feminist arguments alone.

These combinations attempt to reeducate physicians by bringing their way of thinking more in line with the EA's hybridization of psychology, sociology, feminism, experience, and science--a hybridization which, as we saw in Chapters 4 and 5, seems to characterize the ways in which members of the focus group and the WITSEND0 list think about endometriosis too. The symmetry between my participants' claims and those of the EA is clear. This, I argue, is the case because all of these claims are framed by a broader patient community that develops core claims and standards and strategies for knowing; the EA is one venue in this community.

But it is also important to reiterate a point I made in Chapter 1: the dialectical interplay of individual patients' accounts and the community's claims. The EA, as a venue of the community, takes the patients' accounts and ascertains what is common about them to develop an account of the Endometriotic Everywoman's Experience through which, in turn, individual women with endometriosis come to interpret their own experiences. But the Everywoman account, while it supercedes individual accounts and feeds back upon them, is *derived from* individual accounts. Thus individual women's experiential narratives affect the claims of the community just as the claims of the community affect the women's experiential narratives. The "universal singular" (Denzin in Robinson, 1990:1177) of illness narratives means both that individual narratives can be used to forge a group narrative, and that the group narrative affects the ways the individual narratives are told.

4. Research

The EA's activities in research are extensive and varied. They include connecting medical researchers with endometriosis patients that may be willing to participate in clinical studies; conducting original research on the experiences of endometriosis patients; and conducting scientific medical studies on the disease. I discuss each of these in turn, focussing particularly on the ways in which patients and medical experts are recruited to participate in these activities, and concluding with a discussion of the reception of the EA's research among medical professionals and patients.

i. Linking Up Researchers and Subjects

In its newsletters, the EA occasionally publishes calls for research subjects for new studies, usually ones on treatments for endometriosis. Members are provided with a short description of the study, potential benefits to them, and information about how to contact the researchers. The benefits to members are free treatment and monitoring, usually from top endometriosis specialists. Given the high costs of specialist treatment in the US, participating in these studies may be of real benefit to some EA members. While medical studies of treatments frequently provide only a placebo to the control group, in all the studies advertising for subjects I have seen in EA newsletters, some active treatment for subjects is provided. For example, in a study comparing Synarel and Lupron, each participant would receive an active form of one of the drugs (Endometriosis Association, 1992d); and in a National Institutes of Health study, each participant would receive raloxifene (a selective estrogen receptor modulator) and surgical excision of endometriosis, or placebo and surgical excision (Endometriosis Association, 1999e).

More recently, the EA has stepped up its recruitment efforts in response to reports

from researchers

that they were experiencing difficulties in patient recruitment for their research studies despite ads in newspapers and on the internet. Because we know members appreciate knowing about new studies, and in some cases, wish to participate (all treatments, office visits, and surgeries are free in such studies), we have mailed materials about these studies to those in geographic areas across North America where studies are occurring (Endometriosis Association, 1999e:8).

In 1999, the Association carried out direct mailings to women with endometriosis to help researchers locate subjects for a study comparing Abarelix-Depot (a GnRH antagonist) and Lupron, for one investigating the effects of various dosages of Synarel, and for the NIH raloxifene study (Endometriosis Association, 1999b, 1999e, 2000c).

The EA also helps recruit participants for basic science and symptomatology research on endometriosis, such as a Canadian study investigating the effects of pregnancy and lactation on endometriosis symptoms (Endometriosis Association, 1999g). Perhaps the researcher who has benefitted the most from the EA's assistance with subject recruitment is Stephen Kennedy, a researcher studying the familial and genetic components of endometriosis. Given its interest in the basic causal mechanisms of endometriosis, the EA is strongly supportive of Kennedy's work. On several occasions over the past decade, the EA has issued calls for participants in Kennedy's studies, which began in 1993⁸⁴ (see, eg., Dearborn & Association staff, 1994; Endometriosis Association, 1993d, 2000b). Based in Oxford with 56 collaborating centres internationally, the OXOGENE study (as it is called) has recruited over 1,250 families thus far, and more families are being sought (Endometriosis Association, 2000b). It appears that the EA's assistance has been key to the success of the OXOGENE project: "Dr. Kennedy has said

⁸⁴When I first contacted the Association for help with my research in 1993, I mentioned that members of my family also had endometriosis. Mary Lou Ballweg encouraged me to participate in Kennedy's studies.

he would never have gotten his study underway if it had not been for the support of the Association, which has helped recruit families since the project's inception" (ibid:2).

There are often conditions attached to the EA's agreement to assist in the recruitment of subjects. In March 1993, the report on a survey of Canadian women with endometriosis, commissioned by Syntex, the manufacturers of Synarel, was published (Insight Canada Research, 1993). Subjects were recruited through the EA. According to Barbara Mains, previously the EA's Canadian Projects Director, the study was conducted to test Syntex's hypothesis that physicians were not telling patients about Synarel, a self-administered nasal spray, preferring the injectable form of GnRH agonist "because it gives them control over compliance. The fact that the monthly injection brings the patient into the doctor's office, and the doctor gets paid for administering the injection, was felt to be a contributing motive" (Mains, personal communication, 20 January 1994). The EA agreed to participate

...on the condition that we participated in the design of the questionnaire. We wanted data on the experiences of Canadian women: the pathway to diagnosis, the number of physicians consulted, the number of treatments, the success of treatment. Syntex wanted to find out what women were being told by their doctors (specifically, what they were being told about the nasal spray), where women got their information, and how they rated their doctors as information providers.

We described the purpose of the survey in our newsletter, which included a business reply coupon. Canadian members who were willing to be interviewed returned the coupon to Insight Canada [the research company that conducted the survey] (Mains, personal communication, 20 January 1994).

The EA is not usually given to helping drug companies market their product; though it often receives funding from the manufacturers of drugs used to treat endometriosis, these tend to be unrestricted grants (meaning recipients can use them as they see fit) and tend to be directed toward general education and research projects, rather than distributing information specifically related to the drugs. In this case, clearly, the EA was able to gain

information that would be useful to the Association, and to help test Syntex's hypothesis that physicians are not presenting a full range of treatment options to patients--which, if true, would be of great concern to the EA. The EA's cooperation with pharmaceutical companies is selective and strategic.

ii. *Experiential Research*⁸⁵

As we have seen, the EA began its own research efforts by documenting women's experiences with endometriosis and setting up a data registry to draw together those experiences. From the 300 completed questionnaires which the newly-established EA took to the Medical College of Wisconsin in the autumn of 1980, the registry grew to 3,020 cases according to a report published in 1995 (Ballweg & The Endometriosis Association, 1995:372).

The registry includes information about the personal and demographic characteristics of women with endometriosis (age, marital status, education, family income, hair colour⁸⁶); symptomatology; age of onset of symptoms; age at diagnosis; medical therapies attempted and their outcomes; severity of effect of symptoms on patients' lives; other medical conditions such as allergies; number of doctors seen; whether

⁸⁵In addition to the EA's own social scientific research on women with endometriosis, it also assists social scientists and students who are conducting similar research. For example, during my Master's thesis research, the EA provided me with literature, pointed me toward useful sources, and connected me with another student who had conducted research on counselling approaches for women with endometriosis. The EA also has helped some social scientists to recruit research participants. However, because the focus of this work is the epistemological relations between medical professionals, patients, and the EA, I do not discuss the EA's collaborations with social scientists here.

⁸⁶It has been suggested that women with red hair are more susceptible to developing endometriosis, and this has found some support in the results of the EA's surveys (Ballweg, 1998a:8).

or not physicians or family members ever told respondents that there was "nothing wrong"; and feelings about the services and care they received for endometriosis (Ballweg, 1995g, 1998a; Lamb, 1987, 1990). The EA has presented data from this registry at many medical conferences and much of the literature published by the EA and by the registry's director Karen Lamb is based upon these data. As the following excerpt from Ballweg's address to a scientific meeting on the environment and women's health shows, the data registry is foundational to the EA's representation of women with endometriosis and its challenge to the typical patient profile:

Women with the disease have been much maligned--supposedly they were white, stressed-out, perfectionistic, upper-socioeconomic-level women who brought the disease on themselves by postponing childbearing. Only when the Endometriosis Association began in 1980 and systematically gathered data were we able to disprove all these myths. With the largest Research Registry on endometriosis in the world (established with our leading medical advisors and housed at the Medical College of Wisconsin), the association has categorically disproved these myths. Endometriosis is, in fact, an equal-opportunity disease affecting all races, personalities, and socioeconomic groups, as well as all ages of females from as young as 10 or 11 to as old as women in their 60s and 70s...Rather than blame women, as some in the medical establishment have done without any scientific proof, the Endometriosis Association has been systematically studying all aspects of the health and experience of women with endometriosis, listening to the stories of hundreds of thousands of women with the disease, and publishing reports based on our studies in medical journals (Ballweg, 1995e:371).

Note in this passage the references to "scientific proof" and "systematic" data-gathering. The EA's presentation of this research tends to be in the form of statistics and tables, lending a scientific authority to data provided by patients with no clinician verification. When completing the surveys, women answer questions related to the severity of their pain (mild, moderate, or severe), symptoms associated with endometriosis (including some that are not described much in the medical literature, such as low-grade fever, low resistance to infection, dizziness, headaches, and fatigue), and other medical

conditions (which may or may not have been diagnosed officially by a medical professional). While letters from individual women describing these problems are easier to dismiss as the rumblings of hypochondriacs, presenting the same information as "data" in the form of statistics compiled from three thousand subjects lends a scientific validity to the information that (for many scientists) it would not otherwise have. The data registry makes women's experiences appear more objective although, as Karen Lamb pointed out in her address to the Endometriosis Association's tenth anniversary conference in 1990, the subjectivity of patients lies beneath: "Medical care statistics are simply people with the tears wiped off" (Lamb, 1990).

This objectification of patient experience--supplemented by more obviously subjective accounts in the form of patient letter excerpts--seems to have gained the EA access to many medical venues through which to dispel "myths" about endometriosis, argue for changes to medical care on patients' behalf, and establish itself as an authoritative representative of women with the disease. In most of the EA's contributions to medical publications (as in the three pieces described in the Educating Doctors section above), the focus is on presenting the experiences of endometriosis patients and analysing the social, economic, and psychological problems and biases faced by women with endometriosis. In these contributions, quantitative data from the registry are supplemented with qualitative data, usually letter excerpts from endometriosis patients, and the two kinds of data are used in mutually reinforcing ways.

Ballweg and most of the Association executive do not have medical degrees, which are essential if one wishes to author scientific papers about the medical aspects of endometriosis. Consequently, medical research administered and/or funded by the EA tends not to be authored by Ballweg and other non-scientist EA members, but by their

medical associates or directors of research, all of whom have scientific credentials. It is unclear from the Association's literature whether professional social scientists are involved in the design, coding, and analysis of experiential data about women with endometriosis (though Lamb is a registered nurse and, in nursing, a great deal of social science research on health matters is conducted). However, apparently medical publications are more willing to authorize Ballweg and other non-scientists in the EA to speak about social scientific research despite their apparent lack of formal credentials as social scientists. Presumably this authorization is granted on the basis of the EA's *experience* in working with women with endometriosis on social and psychological issues, and perhaps also on the basis of Ballweg's experience as herself a woman with endometriosis.

Thus, it seems that medical experts share with my research participants and with the EA certain assumptions about who can know what about endometriosis: medical experts may know best about endometriosis as disease, but patients and their representatives know best about endometriosis as illness experience. When the EA discusses medical matters, it refers to its medical advisors and cites medical publications; when patients discuss medical matters, they refer to their physicians or to EA literature which is based upon medical advice and literature. When the EA and patients discuss experiential matters, they refer to themselves, fellow endometriosis patients, and EA literature. There is a tacit division of labour that all parties seemed to accept--at least until recently.

But now, the EA is challenging this division of labour in two ways. First, it uses the experiential data from the research registry to advance *medical* claims about the disease. In various medical journals, Lamb has used data from the research registry to argue against the claim that tampon use is a contributing factor in endometriosis; to

demonstrate an increased risk of endometriosis among women who have relatives with the disease, especially on the mother's side; and to argue that allergies tend to be common in the families of women with endometriosis (Ballweg & The Endometriosis Association, 1995:372-3). These findings direct medical researchers' attention to the potentially genetic and autoimmune bases of endometriosis. At a conference on women's health and the environment, Ballweg explained how collection of data for the registry led to the EA's forays into research on the role of dioxins and autoimmune disorders in endometriosis:

Because of our attention to the whole woman and our long-standing research program, we at the Endometriosis Association have recently been able to make possible a major breakthrough linking endometriosis to environmental toxins--especially dioxins... Breakthroughs in women's health are possible if one *listens* to women with the health problems being studied. Because we've been listening to *all* the health problems of women with endometriosis for so many years, because we had documented that immune dysregulation clearly was part of the endometriosis picture, because we have always had a research program, and because we had the funds available to support a colony of research monkeys at least briefly, we were able to realize the significance of endometriosis being the cause of death in the dioxin-exposed colony...If we had not had that background, the colony would have been dispersed completely, and the valuable information they held would have remained unknown. I shudder to think how many more decades it would have been before we discovered the link to organochlorine toxins (Ballweg, 1995e:373-4).

So, by this account, new directions for medical research emerge through serious attention to, and compilation of, lay accounts about health and illness. This presents a very different picture of scientific work than that of the scientist-genius who, seemingly through divine inspiration, 'has an idea' independently. As Fleck argues, scientific ideas often have their genesis in lay 'proto-ideas'; and the ideas of laypeople similarly depend upon the circulation of scientific ideas beyond esoteric circles (for the EA to find out that many women with endometriosis suffer from allergies, patients must have a conception of allergies). This circulation of ideas between laypeople and experts is, as Fleck points out, endemic to all forms of scientific knowledge. But while medical literature obscures the

productivity of that circulation, the EA's account makes it explicit. My analysis also shows that the EA facilitates and mediates the circulation by telling patients about medical claims, telling doctors about patients' claims, and drawing the two populations together to work on claims as a collective.

We turn now to a discussion of the second way in which the EA is challenging the division of labour in regard to knowledge creation about endometriosis: its recent work as a medical research establishment.

iii. Conducting Medical Research

The EA originated as, and to a great extent remains, a patient-centred organization. It began as a source and champion of endometriosis patient perspectives, not as a member of the medical endometriosis research establishment. Its interest in medical knowledge began, as most patients' interest does, in a desire to acquire information whose application could alter the subjective experience of endometriosis. But since 1992, the EA's interest has changed and it has become more directly involved in the creation of medical knowledge about endometriosis.

Mary Lou Ballweg recounts that, at a workshop on the pathophysiology of endometriosis in Washington in September 1991, researchers from the U.S. Air Force and NASA reported on findings of endometriosis in rhesus monkeys that had been exposed to radiation. The authors concluded that "Endometriosis in our monkey colony was conclusively linked to whole-body-penetrating energies of ionizing radiation" and concluded that women exposed to "penetrating doses of protons or x-rays should possibly be considered to be at higher risk of developing endometriosis than unexposed women" (Fantom & Golden quoted in Ballweg, 1995d:377).

Hearing about this study reminded Ballweg of another, mentioned to her earlier by endometriosis researcher and EA advisor Dr. Paul Dmowski, in which rhesus monkeys exposed to PCBs had developed endometriosis. "I began a fascinating detective effort to track down information about those monkeys once and for all" (ibid). She linked the study to James Campbell, an Ottawa physician who had reported the study's findings to the Ontario Association of Pathologists in October 1985; at the time the study generated little interest. "The study was conducted by the Canadian federal government to determine the effects of PCBs in food. The endometriosis finding was a surprise to the researchers" (ibid:378). Ballweg reported in the EA newsletter that the findings of the study were never published and the PCB-exposed colony was euthanized "in part due to concern that demand for further study would entail significant costs--as if a society with untold numbers of women with endometriosis and other health problems doesn't entail significant costs!" (Ballweg, 1992a:3).

Ballweg contacted Campbell and learned from him that another study evaluating the long-term effects of TCDD (dioxin) on rhesus monkeys had been done, and two of the animals had died of endometriosis⁸⁷. The research team had since disbanded, but one member of the team, Dr. Bob Bowman, had continued to study the behavioural effects of dioxin on the monkeys' offspring.

And EPA [Environmental Protection Agency] funding for the colony had run out. Our efforts to secure further funding failed. The university where the monkeys are housed began selling them but had not yet shipped them. I called an emergency board meeting of the Endometriosis Association, and

⁸⁷Dioxin and PCBs are organochlorines, toxic chemical compounds that result from the combination of chlorine and organic substances, usually because of industrial processes such as waste incineration. They do not break down in the body but are stored in fatty tissues and build up over time. They have the ability to disrupt the endocrine and immune systems, though how they do this and their specific effects on human health are not entirely known (Ballweg, 1992a; Lebel, 1998).

we decided to fund the colony for two months and carry out laparoscopies on the entire colony to determine if endometriosis was present in those still alive (Ballweg, 1995d:379).

Association advisor and prominent endometriosis surgeon Dr. Dan Martin conducted laparoscopies on the monkeys with the assistance of Dr. Paul Dmowski and the EA's vice president of research, immunologist Sherry Rier. They found a perfect dose-dependent relationship between dioxin exposure and endometriosis: a control group of monkeys that had not been exposed to dioxin had no or minimal endometriosis, monkeys that had moderate exposure tended to have moderate endometriosis, and those that had severe exposure to dioxin had severe endometriosis, based on the R-AFS classification (Ballweg, 1995d:379).

The EA began to raise money to support the colony for at least three years, after which the monkeys were expected to be in menopause. Members of the EA were asked to contribute (Ballweg, 1995d:379). In the first three weeks, members contributed over \$40,000 (Endometriosis Association, 1992b). The EA also encouraged its members to ask their doctors to contribute to the research fund (ibid). Dan Martin, the physician who conducted the laparoscopies on the monkeys, contributed "nearly \$9,000 through his nonprofit organization, the Fertility Institute of the Mid-South" (ibid:1).

The EA also conducted immunological research on the monkey colony to test the hypothesis that endometriosis is associated with immune dysfunction. Sherry Rier describes the research in an Endometriosis Association newsletter (Rier, 1992). Monkeys with endometriosis and controls were compared as to the ability of immune cells in the blood to produce substances called cytokines; either too much of these substances or too little can produce disease. Monkeys with endometriosis were found to differ from controls in this respect.

The findings of the studies on the monkey colony have been published in medical journals (Coe et al., 1998; Rier et al., 1993a, 1993b; Rier, Martin, Bowman, & Becker, 1995) and presented at gynecological, immunological, and environmental science conferences (Ballweg, 1995d:379). The EA feels that the findings in rhesus monkeys may extend to humans. Ballweg asks:

Is it possible, based on the PCB study, to speculate that the disease of endometriosis might have been a mild, mostly tolerable disease in the past (except presumably for a few unlucky souls) that has become severe and distinctly intolerable with the additional effects of pollutants in our bodies? Perhaps these studies will help explain why there seems to be an epidemic of endometriosis worldwide in this century (Ballweg, 1995d:378).

This research has led the EA to advise its members about how to minimize exposure to dioxin (Ballweg, 1995a; Ballweg, 1995c; Ballweg & Gould, 1995). It has also led the EA to lobby for, and encourage its members to lobby for, environmental legislation--for example, to prevent the chlorine bleaching of tampons, a byproduct of which is dioxin (Endometriosis Association, 1998a). The EA was a founding member of a coalition of over 200 organizations in 9 countries, called Health Care Without Harm, that is dedicated to eradicating hospital waste disposal practices that are harmful to the environment and educates the public about the health effects of dioxin and other endocrine-disrupting chemicals (Endometriosis Association website, www.endometriosisassn.org/news.htm).

Ballweg acknowledges that "All this information on environmental pollutants and their health consequences can certainly feel overwhelming" but argues that "information is the first step toward taking action. And action is what's needed, both individually and socially...And remember, *together* we can make a difference. If indeed toxic pollutants are a part of the endometriosis story, *only* working together will make it possible for us to overcome this nightmare" (Ballweg, 1995c:392). Not only does the EA's research on

dioxin provide it with an entry into the medical research community and a basis for educating individual women and doctors, it also provides a basis and direction for social action.

In the past few years, the EA has repeated its appeal for research funding in most of its newsletters. It has received enormous donations from private individuals. EA board member Tracy H. Dickinson's donations over 14 years funded an eponymous Research Chair at Dartmouth Medical School, currently held by Sherry Rier. In 1999, the Quadrucci family (whose daughter has endometriosis) made a \$1 million donation to the EA's Millenium Campaign for the Cure, an attempt to raise \$2.6 million. Seventy-seven percent of these funds will be used to fund medical research (the remainder will be devoted to education and support work). Some of the money will go to research at Dartmouth Medical School and to fund independent research projects overseen by the EA's international scientific advisory board. The remainder will help to fund an Endometriosis Association research facility at Vanderbilt University's School of Medicine. Vanderbilt approached the EA and offered them the facility, laboratory space, institutional support, and a \$2 million start-up grant, if the EA could raise \$1 million (the Quadrucci donation covered that) and provide ongoing funding to help staff the facility. The EA also will help to determine the direction of the research undertaken (Endometriosis Association website, www.endometriosissn.org/news.htm and www.endometriosissn.org/millenium.htm; Endometriosis Association, 1999i).

The EA website sets out the reasons why Vanderbilt approached the Association and provides a good overview of some of the research-related accomplishments of the EA which I have not had space to discuss here:

- Our research registry on endometriosis was the first--and largest--in the world. Our second data registry is now being established.

- Studies pointing the way to important immunological understanding of the disease.
- Major breakthrough research showing that dioxin and other toxic chemicals can cause the development of endometriosis, and possibly cancer and other health problems to which those with endometriosis are susceptible.
- Our successful effort to convince Congress to allocate \$5 million to endometriosis research in 1990-91
- Our funding of a number of investigators and research sites
- The establishment of the Tracy H. Dickinson Research Chair of the Endometriosis Association at Dartmouth Medical School, which has further expanded our noted work on dioxin and immune aspects of endometriosis.
- The NIH [National Institutes of Health] Endometriosis 2000 Conference in 1995, bringing endocrinologists and toxicologists together to better understand the new dioxin findings. This conference was initiated in response to the Association's testimony about our dioxin research at a Senate hearing.
- The proven commitment of our members and donors to research (EA website, www.endometriosisassn.org/news/htm)

The EA's own literature presents a truly extraordinary series of accomplishments in medical research, lobbying and fundraising. These accomplishments can be traced to two essential factors.

The first was the EA's original research on the experiences and health of women with the disease. This research alerted the Association to the possibility that endometriosis may be part of a broader immune dysfunction syndrome. More generally, the research on endometriosis patients' experiences allowed the EA to gain entry as participant in, rather than observer of, the medical research community; this research allowed it to make distinctive, patient-centred contributions to medical knowledge about endometriosis.

The second factor was Ballweg's connections to members of the endometriosis research community (Dmowski, Martin, Rier), who alerted her to the existence of the dioxin-exposed monkey colony and the apparent association between organochlorides and endometriosis, and who lent the necessary scientific credibility to the EA's initial research

efforts. That is, the EA's research activities are contingent upon its connections to both knowledge communities: the experiential knowledge community of patients and the scientific knowledge community of medical researchers. The EA has become such a successful organization because it has linked both of these communities into one network of knowledge and research practice.

A final, important point: it is very fortunate that the EA has been instrumental in linking endometriosis to broader issues of environmental pollution and immune dysfunction. Increasingly, medical researchers are arguing that endometriosis, at least defined as the presence of endometrial tissue outside the uterus, is not a disease. The reason for this is that endometrial implants outside the uterus have been found in many asymptomatic women undergoing laparoscopy for non-endometriosis-related reasons. Moreover, research by Thomas D'Hooghe and colleagues showed that minimal or mild endometrial implants came and went in baboons upon whom laparoscopy was repeatedly performed. Thus, it may be that endometrial implants outside the uterus may be normal, occurring in all women from time to time, and may not cause symptoms. The question then becomes, are the symptoms of women "with endometriosis" due to endometriosis or some other factor? (see, e.g., Koninckx, 1995; Koninckx, Oosterlynck, D'Hooghe, & Meuleman, 1994; Wardle & Hull, 1993).

Now obviously, if endometriosis is not a disease, the very existence of an Endometriosis Association is called into question. The experiential similarities among women with endometriosis are framed by the fact that they are all women *with endometriosis*. The disease is what makes these women a disease constituency⁸⁸. Otherwise, they become a more diffuse network of women--some of whom are infertile,

⁸⁸The term is Steven Epstein's (1995).

some of whom have painful periods, some of whom have pain during intercourse, and so on. There will be overlap between these specific groups (some will be infertile *and* have painful periods, for example), but it is having *endometriosis* that unites these women and that backgrounds the differences between them (socioeconomic, racial, ethnic, et cetera). Having endometriosis constitutes their shared experience *as* the shared experience of endometriosis, organizing their experiences into a coherent, explainable whole (we have these experiences because we are women with endometriosis). Disease constituencies cannot exist without a disease.

The EA's work on organochlorides, endocrine disruption, and immune dysfunction, however, provides an alternate and potentially very broad foundation for its existence. The EA literature demonstrates a keen awareness of this:

If one looks closely at the most confusing health problems of modern women--breast and ovarian cancer, osteoporosis, the autoimmune diseases that afflict primarily women, endometriosis and its related diseases--one finds a rather constant theme of hormonal/immunological dysregulation. Why are women in modern society plagued by these diseases? There isn't going to be enough money to fund all of the research needs of women, or of men for that matter, if we continue to look at our health needs in a piecemeal fashion, disease by disease. And the specter of women's health groups fighting each other for a piece of the limited funding pie is too gruesome to fathom...Instead, let's work smarter . . . [Ballweg's ellipsis] let's look for the synergy, the ways that smart research might pay off in many ways for many women. Basic research that addresses the hormonal and immunological differences in women compared to men could go a long way to helping provide desperately needed answers for all of these problems (Ballweg, 1995e:374).

In this passage, Ballweg positions the EA's work on hormonal and immunological dysfunction as central to the concerns of other disease constituencies and to the women's health movement generally, and as basic research that must be done if "all of these problems" are to be solved. If endometriosis ceases to exist as a disease entity, the Association perhaps has assured itself a future role as advocate, initiator, funder, and

authority in this essential field of research--a role that may enable it, with a strategic name change, to become a key node in a new and broader network of researchers and patients. And paradoxically, it is its original commitment to understanding the disease entity of endometriosis and to representing the endometriosis patient constituency that may enable it eventually to overcome the destruction of that disease entity and constituency.

iv. *Medical Perceptions of the EA as a Research Establishment*

It is difficult to ascertain precisely how the EA's work is regarded within the medical research community, given that I did not interview medical experts and little has been published in the medical literature about the EA itself. However, some inferences can be drawn.

We have already seen that EA members appear to be very supportive of the EA's research activities, given their generosity in providing research funds to the EA and their apparent willingness to participate in the EA's research by responding to surveys. Similarly, many key medical experts have been very supportive of the EA's work. The EA's frequent presence at important medical conferences attests to this, as does the Society of Obstetricians of Gynaecologists of Canada's inclusion of EA representatives in both of its Consensus Conferences on endometriosis, and of EA-authored chapters in the conferences' reports (*Canadian Consensus Conference on Endometriosis*, 1993; Rowe, 1999). The EA's list of medical advisors and expert speakers at the EA's two conferences reads like a Who's Who of endometriosis experts⁸⁹. The EA has many supporters among

⁸⁹They include David Adamson, Michel Canis, Donald Chatman, Paul Dmowski, Jacques Donnez, Stephen Kennedy, Philippe Koninckz, Arnold Kresch, André Lemay, Dan Martin, Camran Nezhat, David Olive, Mark Perloe, David Redwine, Paolo Vercellini, Bob Franklin, and Robert Schenken. The reader may recognize many of these names from the citations in Chapter 3.

the medical endometriosis community.

Much of the EA's legitimacy among medical experts appears to derive from its research efforts, as suggested by these comments from EA representatives at the sixth World Congress on Endometriosis:

When I presented our Association's research showing an average delay in diagnosis of six years at the Brussels [World] Congress [on endometriosis] it was received with skepticism by many. Yet, six years later they were all talking about long diagnosis delays as though the phenomenon had been known since time began. For me it showed how important it is for groups like ours to do research into the topics that we know about, because we have expert knowledge and insights that need to be communicated and shared with health professionals (Ros Wood in Henderson, Wood, Hummelshoj, & Kregsman, 1998:5)

With the largest research data registry in the world on endo, we can provide information and valuable data, and with almost 19 years experience, we can help, guide, and advise physicians and women in countries where previously there has been little focus on the disease. For the first time at the World Congresses, the EA was recognized, officially, as an authority in itself (Lone Hummelshoj in Henderson, Wood, Hummelshoj, & Kregsman, 1998:5)

The EA's studies on dioxin and endometriosis have prompted a significant amount of new research and speculation on the relation between toxicants and reproductive health (eg. Koninckx, Braet, Kennedy, & Barlow, 1994; Lebel et al., 1998; Mayani, Barel, Soback, & Almagor, 1997; Shahara, Seifer, & Flaws, 1998; Zeyneloglu, Arici, & Olive, 1997), a relation that appears to have generated little interest before. Medical authors are substantially more cautious in their evaluation of the meaning of the results than the EA itself, pointing out that the effects of dioxin on animals may not extend to humans, and that the effects of the compound seems to vary across species (studies have also been conducted on rats and mice) (Shahara, Seifer, & Flaws, 1998; Zeyneloglu, Arici, & Olive,

1997)⁹⁰. Still, every source on the topic I consulted referred to the articles of Rier and colleagues, so the EA's research appears to have had a significant impact.

In general, evaluations of the research have been positive: "Rier et al. may have provided the strongest evidence linking endometriosis to organochlorine exposure" (Lebel et al., 1998). The role of the EA in the research was not mentioned in the medical literature I consulted on the topic; instead, only Rier and her scientist co-authors are named. This suggests the limits of the scientific authority accorded to the EA itself; rather, its credentialed researchers act as the representatives of the EA's research efforts to the medical research community.

When the EA itself authors contributions to medical publications, its contributions tend to be about patients' experiences or critiques of medical research, rather than presentations of the dioxin research. In fact, in the 1999 *Consensus Conference* document, the EA's contribution was relegated to an appendix (in the 1993 report, it was in the main body of the report). The conference chairman explains the reasoning behind this:

Initially, there was some debate as to whether the consensus document should include a chapter on the patient's perspective on endometriosis, as this consensus document and the consensus statements are based on quantitative research. The patient perspective section relates many anecdotal examples spanning several decades of women's experiences with their disease and with their treating physicians. It is obvious that for some women their management has been perceived as suboptimal. Thus, to the reader, many of the statements may paint a totally negative picture of the women who suffer from endometriosis. We must realize that many women are relieved of their symptoms or infertility with the use of current

⁹⁰Strangely, no author I consulted raised concerns about the small sample size of the EA's monkey colony. There were only 17 monkeys in the colony when the EA gained access to it, and fewer than two thirds of these were exposed to dioxin (the rest were assigned to a control group by the original investigators) (Zeyneloglu, Arici & Olive, 1997:318). I could find no reference in the EA literature to this fact. Perhaps such small sample sizes are usual in research of this kind.

therapies. As physicians providing care for these women, we must be constantly aware of the need for a sympathetic and supportive approach, an issue which is vital from the consumer's perspective. The committee eventually decided to include this section, because it does bring to light the emotional and physical upheavals that are often associated with endometriosis. It has become very clear to us that good qualitative research in this area would be of great value. We have, therefore, included the Patient's Perspective section as an appendix to this document (Yuzpe, 1999:2).

Note chairman Yuzpe's interpretation of women's criticisms of the mistreatment they have received from physicians: their criticisms, he states, may be seen to reflect badly on *patients*, not physicians. It is not clear whether Yuzpe himself misread the obvious point of the EA's article, or suspects that physicians reading the piece will make it. In any case, it provides support for the claims of the participants in this study that physicians refuse to accept responsibility for their inadequacies, and deflect it by placing it upon patients. Again, we see the adaptability of boundary-workers in interpreting claims to assert their status as experts and to delegitimize challengers to their authority.

Apparently there are limits to the EA's in-group status in the medical research establishment. Its frequent relegation to providing the "patient perspective" may seem to undermine its authority as a source of knowledge. However, the reverse also can be said: that it is the EA's representation of the "patient perspective"--and the EA's invariably is the perspective sought when "the patient perspective" is wanted--that gains it access to medical venues and, as we have seen, provides the foundation for its medical research as well.

Interestingly, the prominent role of the EA--and its sister endometriosis patient organizations in the U.K. and Australia--in lobbying for research and popularizing medical knowledge has led at least one research team to complain of the potentially deleterious effects on medical research:

During the past two decades interest in endometriosis has mushroomed, and the mass of data produced in innumerable studies has become difficult to control...interest in this disease is not confined to the scientific press but also weekly 'news magazines' have included articles on it. However, according to Olive and Haney, too much has been published with few facts. Endometriosis associations for patients and doctors have been formed in the U.S., Australia, and Great Britain. Endometriosis could even become 'big business' based on a multitude of highly motivated women (Candiani et al., 1991:380).

The passage makes some interesting suggestions: that knowledge of endometriosis should remain in the hands of the scientific community, at least until the facts are certain; that popular explications of the disease are unreliable (note the scare quotes around 'news magazines'); and that the work of 'highly motivated women'--a phrase reminiscent of the typical patient profile description of endometriosis patients as aggressive--may commercialize endometriosis science (that a great deal of endometriosis science is funded by pharmaceutical companies indicates that endometriosis is already 'big business'). This passage acts to erect a boundary between disinterested, not-for-profit, cautious scientists and the scientific press, on the one hand, and an alliance of aggressive endometriosis patients, populist news magazines that print dubious information, and commercial interests, on the other.

However, this passage was published almost ten years ago and seems to be an isolated case. Given the EA's frequent inclusion in medical conferences and publications, its close working relationship with eminent experts, and the fact that the Association was approached by Vanderbilt to establish the research institute, it seems clear that the EA's involvement in important endometriosis research now is well-known and respected. It is unlikely that a traditional support group would have been approached by Vanderbilt University to establish a research centre.

Other disease constituencies have achieved great influence over scientific research;

AIDS activists generally are considered most notable and remarkable in this regard.

Obviously AIDS activists have raised great sums of money for medical research. Steven Epstein has shown that they also have "challenged the formal procedures by which clinical drug trials are designed, conducted, and interpreted; confronted the vested interests of the pharmaceutical companies and the research establishment; demanded rapid access to scientific data; insisted on their right to assign priorities in AIDS research; and even organized research on their own, with the cooperation of allied medical professionals" (Epstein, 1996:32). However, he also shows that their involvement in basic research on the disease was confined to trying to work with researchers to "sketch out...the most fruitful avenues of inquiry" and "evaluate the broad strokes of the studies that come out" (Epstein, 1996:321).

The degree of the EA's involvement in basic research on endometriosis--finding the monkey colony, raising funds from patients to support it, initiating a new line of research, hiring researchers to do it, reporting on the research at medical conferences, partnering with universities to create research institutes, and so on--seems to be quite unusual (see von Gizycki, 1987 and Rabeharisoa and Callon, 1998 for accounts of two patient organizations whose integral involvement in medical research is similar to that of the EA). It is these activities that appear to have established the EA as more than just a consumer watchdog or lobby group within the medical community, but as a source of new medical knowledge as well.

However, these activities ultimately hinged on the EA's ability to enrol not merely medical experts, but also endometriosis patients. Their experiential accounts formed the basis for the EA's data registry, which first gained EA representatives entry to medical conferences as speakers rather than audience members; they formed the basis of EA-

authored literature for medical professionals, gaining them access to medical publications; data provided by patients first led the EA to the suspicion that endometriosis was associated with a broader immune system problem and to the decision to track down and study the monkey colony; and the EA's membership has provided the funding necessary to conduct studies and attract still more funding for its research. And the EA is well aware of the centrality of its membership's support to all its endeavours, as demonstrated by Ballweg's conclusion to her report on the dioxin research in *The Endometriosis Sourcebook*: "Association members can be proud of these accomplishments--they would not have happened without us" (Ballweg, 1995d:381).

III. Building the EA Network

The EA has been extraordinarily successful in obtaining the support of patients, clinicians, and researchers. I end this chapter by highlighting some of the EA's activities that it uses as network-building strategies to enrol each of these three populations. As Michel Callon argues (1986), the would-be network builder has to define a problem that constructs the identities and interests of those it seeks to enrol, and to establish itself as the obligatory passage point through which these parties must work if the problem is to be solved. The EA is faced with the task of enrolling a variety of allies with somewhat different interests and identities and somewhat distinctive claims and ways of knowing. As I have suggested above, the EA's success depends upon its ability to negotiate these differences in such a way as to satisfy the epistemological standards and interests of patients, clinicians, and researchers.

1. Enrolling Patients

The endometriosis patient community can be characterized as one in which personal experience is valorized, medical practitioners in general are criticized, and science in the abstract is respected. The EA draws upon all of these seemingly contradictory components in its attempts to enrol patients.

First, in order for the EA to enrol patients, it has to take the notion of personal experience seriously and demonstrate that it accepts the validity of women's experiential accounts. The EA demonstrates this in many ways. The EA presents patient letters in its writings as *evidence* to be accepted at face value, and it bases many of its claims directly on women's experiential accounts. Its research registry is based upon women's own reports of their cases and their experiences with the disease and medical treatment, and the majority of the EA's literature is based upon this registry (Ballweg & The Endometriosis Association, 1995:372). In all its publications, the EA demonstrates its respect for the stories women with endometriosis tell about their experiences.

Patients argue that only other women with endometriosis understand their experiences. The EA's leaders discuss their own experiences with endometriosis in their writings. Ballweg's story of the creation of the EA deploys her experience as an endometriosis patient: the intense and chronic pain; others' (especially doctors') delegitimation and construction of her suffering as psychological; her difficulties in obtaining a diagnosis; the lack of availability of clear and consistent information about endometriosis; her struggles to find ways to relieve her symptoms. This establishes Ballweg as someone who shares many of the experiences and perspectives of other women with endometriosis, suggesting both that she understands those women and that she can act as an effective spokesperson for them.

Patients want access to other women's experiential accounts, both to diminish their feelings of isolation and to acquire 'first-hand' information from other women who have had to negotiate the same problems they face. The EA provides patients with direct access to other women with endometriosis through its local support groups, crisis call volunteers, and hotline. It provides access to other women's accounts through the publication of women's letters and research registry data. Furthermore, as part of the celebrations to mark its twentieth anniversary, the EA plans to expand its role in this area by publishing a new book:

Send us your endo story, poem, or art depicting an endo-related theme, because another special part of our year-long celebration is in the planning. In response to requests from many members, we're going to do a book of women's endo stories. It will be a very real and human way to illustrate the devastation endo can bring and the unsinkable spirit of strong sisters (Endometriosis Association, 2000a:1).

The fact that this book was requested by the membership demonstrates how important the EA's experience-sharing function is in the eyes of women with endometriosis.

Second, endometriosis patients in general have quite negative views about the majority of medical practitioners although, usually after much searching, many women have found physicians they like. The EA represents these views in its publications, documenting the struggles that women face and the shortcomings of their clinicians in literature written both for the membership and for physicians. In addition, the EA attempts to change physician behaviour deemed problematic by patients by pointing out, in literature geared toward physicians, the effects of this behaviour on medical care and patients' opinions of clinicians. It also provides information to patients about how to find a good physician, for example by distributing a list of physicians who are members of the EA (and therefore, presumably, sympathetic to patients and to the aims of the EA). In the past, the EA asked members to nominate physicians for the "best doc" competition; names

of these doctors and testimonials from patients were published in EA newsletters (see eg. Endometriosis Association, 1990; Endometriosis Association, 1993c). (In more recent years, this competition seems to have been discontinued.)

Third, although endometriosis patients tend to be critical of actual practitioners, they exhibit a clear respect for the tenets of science and its potential to alleviate their suffering and find a cure for the disease. The EA demonstrates that it shares this perspective by appealing to the principles of good science in its criticisms and descriptions of research. Good science should be unbiased and good studies should control for confounding variables and use a large sample size to demonstrate representativity, for example; bad science contains "myths" about which "no studies have been done." The EA uses scientific rhetorical devices in its presentation of its own claims, presenting statistically the "data" gleaned from its "surveys" of patient experience.

If my research is any indication, the EA echoes strongly the concerns, perspectives, and experiential narratives of women with endometriosis, and in this sense it emerges as a good representative. But the EA does not just represent patients as they exist in nature, so to speak; it also attempts to configure them in ways that strengthen the EA.

First, endometriosis patients are constructed as needing information in order to make the best treatment decisions and to relieve their suffering; in fact, women are represented as having a *responsibility* to seek information about the disease. The EA presents itself as the best source of patient information about the disease. However, to gain access to most of the EA's information about endometriosis, patients must become members. Thus, the EA constructs itself as an obligatory passage point for women with the disease, attempting to strengthen its network by enrolling more allies and securing more membership dues.

Second, patients are constructed as wanting, more than anything else, a cure for endometriosis, and the EA uses this construction to justify its involvement in medical research and to lobby for donations from its membership:

As one board member from some years back said, **'if your daughter has endometriosis, what do you want to give her--a support group or a cure?'** Not that she meant to belittle the tremendous importance of support groups or good information or better treatments for those of us who already have the disease. Through the Association, we've been able to work together to provide those for ourselves and will continue to do so. But ultimately we all want a cure. Only research provides that hope...**Please give generously and ask your family to contribute...** (Endometriosis Association, 1994c:1; emphasis in original).

We have seen that the EA derives a great deal of its funding for research, as well as education and support, from its patient-members. Without this support, the EA could not have conducted the research on dioxins that gained it a foothold in the medical research arena. The EA encourages its membership to donate by appealing to their desire for a cure that, it argues, its research into the toxicologic and immunologic aspects of endometriosis makes possible. The EA appears to have been quite successful in this regard; at last available report, \$1.5 million had been raised for its Millenium Campaign for the Cure (Endometriosis Association, 1999c).

Third, the EA constructs endometriosis patients as needing and desiring to become an international community, and uses this construction to extend its network throughout the world. In a recent newsletter, the EA present seventeen reasons why the EA should be international (Endometriosis Association, 1999h:5), appealing to women's sense of experiential solidarity, community, and mutual aid and their desire for a cure and better treatment from physicians:

Research progresses faster when we coordinate as a global unit...we will be less dependent on physicians and scientists sharing (or not sharing) new developments with us...Patients' perspectives in all countries are essential to keeping research on track, to help make the disease real to researchers,

to help keep researchers focused and motivated...Active, organized patient groups have visibility and status that allow them opportunities to dispel existing and potential myths throughout the world...The elimination of harmful environmental toxins linked to endo is only possible on a global level...New groups can launch and gain credibility faster by utilizing our literature, support services, partnerships, and 19 years of experience, allowing women to get the help they need sooner...Treatment can improve for all women and girls through our ability to internationally distribute up-to-date materials for physicians and scientists and to share treatment experiences (Endometriosis Association, 1999h:5).

This passage uses arguments emanating from the patient community (physicians do not share information; insufficient research on endometriosis is being conducted; myths about women with endometriosis hamper their care; women with endometriosis need to share information and support one another) to support arguments that promote the goals and claims of the EA (environmental toxins cause endometriosis; women with endometriosis--through the EA--should participate in medical research directly; the EA should be an international organization). The EA has translated its "What Is Endometriosis?" pamphlet into 20 languages and 5 more translations are underway (Endometriosis Association website, www.endometriosisassn.org/brochures.htm). It now has members, chapters and affiliate organizations in 66 countries (ibid, www.endometriosisassn.org/press3.htm). First, the EA linked women with endometriosis in Milwaukee, and gained some limited attention; second, it linked support groups and chapters throughout the U.S. and Canada, establishing itself as a powerful lobby group in North America. By linking individual endometriosis patients throughout the world, the EA has become an extraordinarily strong lobby group for women with endometriosis, and consequently is a far more powerful force for change in endometriosis research and treatment.

2. Enrolling Clinicians and Researchers

Most of the EA's enrolment activities have been directed toward specialists and not general practitioners. I suspect there are several reasons for this. First, the EA can establish itself as a recognized authority on endometriosis only through the support of already-recognized authorities on endometriosis, and these are specialists, not general practitioners; entry to the endometriosis research establishment is gained only through their support. The EA faces obligatory passage points as well. Second, specialists are more likely to be interested in endometriosis-specific information and patient organizations than general practitioners, and hence are more agreeable to the EA's advances. Third, specialists are likely to derive more tangible benefits from an association with the EA than are general practitioners.

The EA in a sense bypasses general practitioners and undistinguished gynecologists, focussing its enrolment efforts on those expert clinicians and researchers who can lend it the authority it needs to affect general practitioners and undistinguished gynecologists. Therefore, throughout this section, I refer primarily to the EA's efforts to enrol gynecologists and reproductive endocrinologists, especially those that are active researchers.

The EA uses several methods to enrol physicians into its network. Most obviously, the EA offers tangible benefits to endometriosis specialists and researchers. It provides them with access to research subjects by promoting studies to its membership in its newsletters and, often, contacting them directly to encourage them to participate. Currently the EA is recruiting basic and clinical researchers to take up fellowships at the new endometriosis research centre at Vanderbilt (Endometriosis Association website, www.endometriosisassn.org/news.htm), and has awarded some research grants to

independent researchers. Physicians who become associate members of the EA are named in the Physician Registry to which EA members have access; several of the WITSENDO participants in this study found their doctors through the EA. Members similarly have access to the EA's list of medical advisors, whose work with the Association casts them in a favourable light to the EA's membership. Finally, physicians who are nominated by EA members in the "best doc" competition receive very positive free publicity. So the EA acts as a subject recruitment agency, funder, and even employer of endometriosis researchers and as a publicist of sorts for physicians in search of clients. It may be unlikely that the EA could break an endometriosis specialist's career, but it certainly could help to make it.

The EA gets its literature into the hands of clinicians through direct-mailings and its membership. Texts provided to physicians by these methods may be authored by medical experts (such as Dr. Dan Martin's atlas of laparoscopic appearances of endometriosis, and Dr. Stephen Corson's clinical text on endometriosis (Corson, 1992)) or by the EA itself, but in the latter case (such as in the EA-authored dioxin pamphlet), the EA's claims often are backed up by references to published medical studies. Packaging its claims in these ways ensures that EA's literature for the medical community will carry some weight because they meet at least two of its requirements for valid claims: that they be authored by credentialled experts and that they be backed up by science.

As we saw in Chapter 3, the "official" epistemological model of endometriosis specialists (that presented in medical journals) is scientistic: it draws upon the broader thought-style of biomedical science. It valorizes claims derived from vision, 'good science' practice (eg. randomized controlled clinical trials), professionally-trained experts, and objective observation (objective both in the sense of value-free and unbiased and concerning objects external to the self). Claims that emerge from physical sensation (eg.

the experience of pain), subjective observation or experience (value-laden and/or internal to the self), laypersons, and non-scientific methods explicitly are considered anecdotal or unreliable in the formal epistemological model.

Yet the official scientism of journal science is counteracted by other, more humanistic tendencies in medicine. Clinicians must not only treat disease, but also illness--the patient's experience of the disease, that is, her symptoms. This is especially the case with chronic diseases, of which only the symptoms can be treated to make the patient more comfortable. Moreover, patient satisfaction and the legitimation of medical expertise have become more pressing concerns for experts as a result of an escalation in rates of chronic illness that medicine cannot treat effectively, increased patient non-compliance with medical advice, greater patient access to medical information, and an increased tendency for unsatisfied patients to 'doctor-shop.' In addition, there has been a general decline in the social status accorded to expertise in general and to physicians in particular, occasioned to a significant degree by powerful health activist movements such as the women's health, AIDS, and disability rights movements, heralded breakthroughs that have not materialized, and a greater awareness of the medical mistakes (Mizrahi, 1986; Todd, 1989).

It therefore has become increasingly difficult for physicians to adopt a "doctor knows best" position in relation to patients. Contemporary physicians must walk a fine line between maintaining the scientific epistemology upon which their esoteric status was founded and still depends, and improving relations with their patients. We see this tension between humanism and scientism in excerpts from medical journals in Chapter 3, and in the SOGC *Consensus Conference* committee's deliberations about whether or not to include the EA's patient perspective chapter (based on "anecdotal" evidence, i.e. patient

letters). It is important to note that, despite the quantitative, scientific emphasis of that committee's report, the committee did decide to include the EA piece.

Because of the somewhat contradictory elements of scientism and humanism in medicine, enrolling specialists poses some challenges to the EA. It must negotiate tensions between its insistence on the validity of patients' experiential knowledge even in the face of science, necessary to enrol patients, and its desire to enrol clinicians, and especially clinician-researchers, for whom *patients'* experiential knowledge is considered dubious (though we have seen that clinicians often valorize their own *clinical* experiential knowledge).

Moreover, the EA seeks to change physician behaviour by appealing to their desire as caregivers to relieve women's suffering, and that suffering is communicated best in women's experiential narratives. As Karen Lamb reminds us, statistics are people with the tears wiped away. But the tears must be seen for sympathy to take effect. And clearly, the EA's own deeply-held conviction that women's experiential accounts are a form of knowledge that needs to be "heard" by doctors if patient care is to be improved places a moral imperative upon them to present women's subjective accounts.

So, the EA combines scientific and experiential presentation modes to satisfy the objectivist, scientific orientations of physicians as scientists and to appeal to the sympathetic, humanist elements of physicians as caregivers. The EA presents women's experiential accounts in the aggregate form of percentages via reference to its data registry, emphasizing that it is the largest in the world and providing evidence of large sample sizes. But it also presents excerpts from patient letters, using these to establish more specific qualitative themes in patients' experience and to make a moral and emotional case for specific changes in physician behaviour. Subjective, experiential accounts are

'disguised' as statistics to satisfy the requirements of objectivism and scientism, but those same accounts also are presented at face value. The two presentation styles work to reinforce each other, effectively overcoming the contradictions between subjectivism and objectivism.

EA literature directed to physicians employs other elements of existing medical thought-styles as well. It makes use of definitions of expertise and professionalism with which physicians are familiar and to which they have some sort of professional commitment. The novel element that it introduces is sociopolitical analysis, but claims made through this kind of analysis are bolstered by kinds of claims that are more palatable to physicians (appeals to good science, professionalism, sympathy for the suffering patient). And critiques of physician behaviour are tempered with praise for professional, well-educated (that is, aware of scientific advances), and sympathetic physicians to provide positive, encouraging role models. To undermine what it calls "myths" about women with endometriosis--to dispute common medical claims about the psychology and epidemiology of endometriosis patients--the EA appeals to science, professionalism, compassion and expertise. That is, the EA makes strategic use of the contradictions between professions about the medical thought-styles (scientific, value-free, compassionate toward patients) and actual medical claims (unproven, damaging "myths" about women with endometriosis), forcing physicians to repudiate those claims so that they can maintain the consistency and legitimacy of their thought-style.

IV. Conclusion

I have tried to demonstrate in the chapters thus far that medical ways of thinking about endometriosis are not completely distinct from patient ways of thinking. However, both patients and medical professionals demonstrate a *belief* that their ways of thinking are vastly different, and their substantive claims are often directly contradictory. For example, endometriosis patients say patient experiential knowledge is the best knowledge of all; medical experts say patient experiential accounts are inherently suspect. What I find so fascinating about the work of the EA is the way it successfully navigates these seemingly contradictory elements of patient and medical models, claims, and interests so as to draw these two communities together and to highlight the similarities between them.

The EA's work accomplishes four central goals. First, it remains true to the convictions and goals of patients by asserting the validity of patient experience, by counteracting pejorative medical constructions of endometriosis patients, by lobbying for changes in physician behaviour, and by pushing for new research approaches to find definitive treatments for endometriosis. Second, its work as a research establishment, its scientific rhetoric, its affiliations with leading experts and professional groups, and its solid support from patients make the Association a force to contend with in the medical community. Third, the EA has established itself as the only valid source for accurate, 'scientific' representations of endometriosis patients' characteristics which clinicians and researchers feel they need to manage such patients effectively. But it does so in a way that does not offend endometriosis patients because it actually *has the patients represent themselves*. Fourth, the EA provides advice to patients about how to find a suitable doctor and how to negotiate the doctor-patient relationship, points out to doctors what they are doing wrong, and enjoins them to change their behaviour in ways specified by

endometriosis patients--that is, it *helps patients to manage doctors effectively*. That the EA manages to do all of these things simultaneously, apparently without alienating either the patient or the medical community, is quite extraordinary.

Conclusions

The EA's success is a testament to several central arguments that I advance in this thesis. First, patient communities are capable not only of resisting, but of changing medical thought and practice by framing experiential accounts and scientificity in ways that establish them as experts and call into question the expertise of medical professionals. Second, to accomplish these changes, patients require the cooperation of medical experts, but there are ways to obtain this cooperation because medical experts need patients' cooperation too. Third--and this is the key epistemological point--cooperation and alliances are possible because medical and patient knowledges and ways of thinking are not as different as physicians and patients appear to believe, and as the illness/disease dichotomy suggests. The distinctions between illness and disease and between exoteric and esoteric circles are useful for describing, respectively, different ways of thinking about health problems and different social communities, characterized by differing allegiances, professed epistemological beliefs, and social status. Certainly, medical experts talk more about endometriosis as disease and patients talk more about endometriosis as illness.

But these distinctions do not define two *dichotomous* epistemological groups. The patient and medical communities both deploy objectivist/scientistic elements ("disease" information) *and* subjectivist/experiential elements ("illness" information). Therefore each community's ways of thinking are internally contradictory, and there is much traffic between the two communities. This traffic and these contradictions and commonalities provide the basis for the building of a hybrid thought-community--the EA--one that has proven itself capable of enrolling both doctors and patients into an endometriosis network.

I. Summary of the Thesis

In this section I review the major empirical findings of the study and the arguments that I advance. I address each of my three prongs of the study in turn: first, the medical endometriosis community; second, the patient community; and finally, the EA.

1. The Medical Endometriosis Community

My analysis of this community in Chapter 3 highlighted two epistemological models: the official, formal model for knowing about endometriosis and the tacit one that seems to characterize clinical practice.

The official model for knowing endometriosis as presented in the classification, psychology, and epidemiology of endometriosis literatures emphasizes several core claims and epistemological assumptions. The core claims are: (1) the severity of endometriosis is equivalent to its observable anatomic extent; (2) observable severity should be translated into stages via a standardized classification system to enable research and guide treatment; (3) patients' "complaints" of their symptoms often are not confirmed by clinicians' observed "physical findings," so the former may be inaccurate; (4) patients whose symptom reports vary from clinical findings may be psychosocially maladjusted; (5) doctors need to know about the psychosocial characteristics of endometriosis patients in order to assess the validity of their complaints; and (6) patients may be psychosocially abnormal compared to women without endometriosis. The epistemological assumptions that underlie these core claims are: (1) visual data is the most reliable form of data; (2) medical taxonomies can capture the ontological status of disease accurately; (3) standardizing observation mitigates the corrupting effects of clinician subjectivity; and (4) patients' accounts are of questionable validity and must be cross-checked against objective

signs. These assumptions mirror those of the more general biomedical model outlined by Gordon (1988) in their emphasis on the distorting effects of subjectivity, reality as materiality, the patient account as subjective and the clinical account as objective, vision as the dominant sense, and the distinction between objective knowledge and subjective clinical practice.

The core claims and epistemological assumptions were examined via an analysis of literature in three fields of medical research on endometriosis: classification, psychology, and epidemiology.

Endometriosis classifications are purposive and directional, enforcing particular *definitions* of reality and attempting to preclude more fluid *meanings* (Ben-Ari, 1994; Treichler, 1990). They focus on quantifiable, objectifiable characteristics, such as fertility and measurable extent of disease, to the exclusion of intangible, subjective aspects, such as pain. The goals of classification are standardization and prediction, and classification systems for endometriosis represent efforts to reduce complexity in three senses. First, the production of the R-AFS classification as an "immutable mobile" (Latour, 1986) aims to standardize researchers, surgeons, and staging protocols to prevent variation and the distorting effects of subjectivity. But standardization is difficult to enforce, given the lack of reproducibility of scoring and many physicians' insistence that the R-AFS classification is inapplicable to clinical practice. Second, the classification attempts to reduce the complexity of endometriosis itself, assuming that the disease may be separated into distinct stages, and focussing on infertility as a more tangible outcome measure than pain. However, stages must be defined and have been criticized as arbitrary and, increasingly, clinicians are calling for a classification system that accounts for the most complex symptom of all and therefore the one that most needs to be classified: pain. Yet, means

for capturing pain taxonomically and objectively remain elusive. Attempts to capture the truth of pain rely upon the subjectivity of patients and of physicians in reading patients' subjective accounts. The complexity of patients remains problematic because, despite attempts to 'flatten' patient accounts into a stage and to objectivize patients' accounts of symptoms, the objective validity of these accounts remains intrinsically uncertain and unverifiable.

Medical experts have attempted to determine the validity of patient accounts by developing a typical patient profile that describes the women most likely to develop endometriosis. It has two main components: psychological and epidemiological. The psychological component is connected in research practice to the R-AFS classification, which is used to establish 'objective' disease severity in order to evaluate whether patients' pain severity is psychosomatic. Studies of patients' psychological characteristics are depicted as scientific through the use of 'validated' psychological scales, scientific rhetoric, and statistics. Although the findings of studies which report that endometriosis patients are psychologically abnormal are controversial, the goal of establishing the psychological makeup of women with endometriosis is not questioned.

The epidemiological component of the profile has asserted that 'career' women are most likely to develop endometriosis, principally because they 'delay' childbearing. Endometriosis is constructed tacitly as nature's punishment for deviance from the proper path of womanhood. Such accounts have been criticized as unscientific on methodological grounds but, again, the importance of such studies is not questioned. The construction of endometriosis patients as psychologically and socially abnormal contributes to their discreditation as reliable claimsmakers and enhances the relative credibility of medical claimsmakers.

Despite the dominance of the formal, scientific epistemological model of medical knowledge of endometriosis, another informal, subtextual model is often applied in clinical practice: the model of clinical experience. Clinicians who champion the clinical experiential model of knowing make three charges.

First, science is an inadequate model for clinical knowledge; in practice, subjectivity and interpretation are fundamental components of medical work. The scientific model cannot deal adequately with the complexity and irregularity of the clinical case, because it posits diseases as ideal-types, from which actual cases frequently vary. Nor can the scientific model deal with the 'material' of medicine--patients, whose welfare must be protected in research, who can refuse to consent, and whose active input is an essential component of clinical research and practice. In the endometriosis literature, medical experts have argued that established scientific research protocols often are inappropriate in clinical studies, and that existing classifications for endometriosis are inapplicable to clinical practice.

Second, there is a fundamental gap between scientific medical knowledge and clinical practice, and clinical experience fills that gap. While rarely formally documented, clinical experience is an essential attribute of the good physician, and can be acquired only through practice. Science is useful in systematizing clinical experience, and scientific credentials are prerequisite to making of valid experiential claims. However, scientific claims themselves are subjected to experiential evaluation--especially in cases where science is equivocal. Endometriosis experts have deployed the notion of clinical experience in a variety of ways: as the possession of practical skill; as a foundation for observation in research; as a means of adjudicating between the competing claims of clinicians and researchers with comparable credentials; and as background knowledge,

without which neither clinical treatment nor research can be conducted.

Third, patients' experiential accounts are foundational to medical research and practice, however unreliable they may be deemed by clinicians and researchers. Clinical experience is thought to assist clinicians in evaluating the validity of patients' accounts. Furthermore, clinicians draw upon popular proto-ideas and folk models of illness to effect patient compliance and get the work of diagnosis and treatment done, tacitly acknowledging the necessity of cooperation between clinicians and patients in definitions of health and illness.

Several conclusions are drawn. First, notions of both science and clinical experience are crucial to the conduct of clinical practice and medical research. Second, neither 'science' nor 'clinical experience' is innocent in the epistemological discreditation of endometriosis patients; both notions have been used to these ends. However, they also serve to undermine each other in this regard. For example, science has been invoked to criticize the typical patient profile, and clinical experience has been invoked to undermine the R-AFS classification. Third, the contradictions between and among scientific and clinical experiential claims may be used to undermine medical delegitimation of patients' epistemic credibility, and to undermine the epistemic credibility of medicine itself. Fourth, boundary-work must be performed to stake out claims to credibility and special expertise, and both science and clinical experience are used in medical experts' boundary-work. Medicine's credibility has rested upon its claim to the science of disease, which differentiates it from lay knowledge; but in practice, endometriosis experts use notions of clinical experience to undermine each other's claims and to assert their privileged status as knowers. Finally, it is concluded that notions of clinical experience are as central to medical ways of knowing as are notions of scientificity. This troubles the boundary

between medicine as scientific system of expertise and lay knowledge as experientially-based, and provides a foundation for my argument that lay and expert knowledges of endometriosis are not dichotomous.

2. The Endometriosis Patient Community

Unlike the medical community, the patient community does not have an explicit, formal epistemological model; the community was not founded as one dedicated to developing and applying knowledge, as is the case with the medical community, but instead as a venue for mutual support. However, as mutual support entailed the sharing of information, the community has come to develop and advance many claims about endometriosis and medical and patient knowledges of it. A flexible, pragmatically-oriented model for knowing, geared toward the solution of concrete problems faced by endometriosis patients, has evolved, and it is discernable through an examination of patients' claims about the medical profession and their self-presentations as knowers. Membership in the community is restricted to sufferers of endometriosis, who interact through several community venues. Members of the community have a strong in-group perspective, referring to the collective "we" of endometriosis patients, and also a strong sense of the out-group--medical experts.

In Chapter 4, I described several forms of critique that 24 members of the patient community make about doctors and their knowledge. First, they assert that insufficient medical research has been conducted; that most clinicians possess little knowledge about endometriosis; and that this is evident from the factually inaccurate and contextually inappropriate advice they advance to patients. Second, they assert that doctors present themselves as authorities on the disease, feigning a certainty they cannot possess given the

conflicting nature of many medical claims about endometriosis. Third, they assert that doctors provide little information to patients, and are dismissive toward patients' claims and self-education attempts. They describe the boundary-work in which their clinicians engage: delegitimation tactics, attempts to restrict patients' access to medical knowledge, and constructions of the patient community as an unreliable source of knowledge.

Patients advanced several explanations for these shortcomings of clinicians. First, they asserted that doctors' social status as experts makes them defensive and reluctant to admit their ignorance. Second, they asserted that the sexist nature of the medical profession, combined with the psychologization of women with endometriosis, contribute to the epistemic discreditation of endometriosis patients and to the minimization of endometriosis and its symptoms, such that knowing about endometriosis and taking patients' claims seriously are not priorities for clinicians. Third, patients argued that the chronicity and complexity of endometriosis call into question the validity of the biomedical model, which is better suited to the treatment of acute illness; physicians therefore transfer their frustration about their inability to treat the disease appropriately to patients. Fourth, and relatedly, patients assert that the objectivism of the medical model contributes to the dismissal of patients' symptoms, which cannot be verified visually, as psychosomatic. Fifth, patients asserted, doctors cannot understand endometriosis because they have not experienced it. Sixth, patients charge that models of medical care assume patient passivity and ignorance, such that doctors are paternalistic, incensed by assertive patients, and prone to using intimidation tactics to enforce patient passivity.

Overall, patients were highly critical of most clinicians and the extant medical research, but demonstrated a profound respect for medical expertise and science in the abstract. Nevertheless, their trust in the expert system of medicine was undermined by

their sense of powerlessness and dependence. They exhibited a mixture of pragmatic acceptance and radical engagement in their reactions to medical expertise, emphasizing the need for self-education, engagement in the patient community, and overt and covert forms of resistance to clinicians. Members of the patient community make strategic use of contradictions within the medical literature and between the medical literature and the claims of individual clinicians to assert that medical professionals do not know endometriosis. Their critiques of clinicians should be read as attempts to disrupt the boundary between lay and expert knowledge; to counter medical constructions of endometriosis patients as unreliable claimsmakers with symmetrical claims about medical experts; and to erect new boundaries between patients who know and medical professionals who do not.

In Chapter 5, I examined patients' presentations of their own knowledge. Patients incorporated medical and experiential claims into their accounts of what they know about endometriosis, relating 'disease' information about the science of endometriosis (which they seem to recognize as the information that bears cognitive authority culturally) to 'illness' information about their and other patients' experiences of endometriosis. Their accounts present the social processes of learning about endometriosis, and depict knowledge about endometriosis as communally, rather than individually, derived.

Participants described their search for information about endometriosis, presenting themselves as diligent information seekers. All consulted several sources, including books written for lay audiences, medical publications, support groups, the Endometriosis Association, and the Internet, particularly patient lists such as WITSENDO. They described barriers to accessing information, such as medical jargon and inaccessibility (especially in the days before the Internet).

Patients' evaluations of the information they obtained expressed a great need for medical information, as well as information from other patients about their experiences. Some patients presented credentials to establish themselves as capable of understanding medical information; others asserted that they knew much more about the disease than their doctors, despite their evident lack of scientific credentials. No participant cited clinicians as their most helpful source of information about endometriosis; clinicians seem rather to provide very basic information which the participants then use to conduct their own research. Lay publications, especially those published by the EA, were valued highly because they were perceived to be unbiased sources of medical knowledge and because they included other women's experiential accounts. Patient groups were deemed the most helpful source of information by the largest number of participants because they reduced feelings of isolation and abnormality; provided the most detailed, honest information about medical treatments, doctors, and coping strategies; and created venues for mutual support, empathy, 'venting' of negative emotions, and camaraderie.

The uses to which participants put these sources of information reveal the contradictions in their model of knowledge. The most explicit principles advanced in the community are (1) that patients form a community of sufferers who share common perspectives and experiences; (2) that these communal perspectives and experiences are valid forms of knowledge; and (3) that the only people who truly know endometriosis in an intimate way are those who suffer from the disease. But while patients valorize their individual and collective experiences as a foundation for knowing endometriosis, they tend not to recognize clinical experience as a valid form of knowledge. Instead, they subscribe to the official epistemic hierarchy of medicine, in which published, scientific claims are more reliable than those derived from clinical experience. This strategically turns the

standards of the medical community against the credibility of its individual members. A tacit hierarchy of claims is presented by patients, with one's own experience as the most reliable form of knowledge, followed by the experiences of other patients, the claims of medical science and, last of all, the claims of individual clinicians. Nevertheless, in practice, medical science clearly is a crucial resource in evaluating patients' own experiences; patients used the claims of individual clinicians to evaluate those of other clinicians, medical science, other patients, and their own experiential claims; the experiential accounts of others were used to evaluate the validity of the claims of medical science and individual clinicians. The only non-negotiable claims appear to be those presented by other patients about their experiences, which must be accepted as valid as a condition of membership in the community.

In general, there was a clear contradiction in patients' accounts between the assertion that embodied experience is a solid foundation for knowing, and the need to interpret it through medical claims and the experiential accounts of other patients. This suggests that, while personal experience is valorized in the community, in practice it is not always a rock-solid foundation for knowing. This contradiction seems to result from the relationships posited between self, body, and mind by these patients as a result of living with chronic illness and medical psychologization. The body is sometimes depicted as the self, and at other times one component of the self, or even alien to, the self; it may speak to the self in clear, direct ways, or be incomprehensible; it may be a burden to the self, or the basis for patient rights. Patients suggested a similarly fractured relationship between self and mind. The labelling of endometriosis as psychosomatic, and the effects of drugs on their mental processes, caused some participants to doubt their reason. They dealt with this through reversals of the typical medical arguments: symptoms or side effects are not a

result of the mental instability of endometriosis patients, but *cause* instability; and it is not patients that are mentally disturbed, but doctors. Patients used medical information and the accounts of other patients to confirm that their symptoms and side effects were not psychosomatic, but 'real' or 'normal.' The core, reasoning self remains intact in such understandings, enabling patients to resist the psychologizing practices of doctors.

The patients' accounts made some direct linkages between knowledge and resistance. Their self-education and strategies for making and evaluating claims were key to their resistance to medical constructions of endometriosis patients as unreliable claimsmakers. Self-education was viewed as essential to controlling the disease and one's medical treatment. It was conducted largely in response to doctors' lack of willingness to share their knowledge with patients. Some patients expressed resentment at having to take on a self-educating role, pointing out that it is the job of physicians to provide patients with information. But it was also evident that, once patients began to educate themselves, they learned of the inadequacies in medical knowledge, which reduced the cognitive authority of their clinicians in their minds. They consequently became better able to challenge the claims of their clinicians, and more confident in their status as epistemic agents. While these participants did not question the notion of expertise as such, they did take issue with the attribution of expertise: some asserted they were more knowledgeable than their clinicians. This assertion would be impossible to sustain without the self-education about medical knowledge in which these women engage.

There are, of course, limits to the notion of patients as experts. Patients do not have socially-recognized credentials in medicine and most cannot devote themselves to the full-time study of endometriosis. However, they compensate for these inadequacies by asserting their own special area of expertise: that of illness experience. The notion of

illness experience plays several roles in the patient community. It provides a basis for solidarity among patients because the illness experience is constructed as *shared* by the members of the patient community. It defines a boundary around the community based upon knowing through being, and defines outsiders (including medical professionals) as pseudo-experts. Finally, experience is conceived as a form of knowledge that has content, which patients have a responsibility to share with one another.

It is argued that the contradictions and tensions in the patient epistemological model reflect the need to adapt it to varying problem-situations; but also that they reflect the contradictions of living with a chronic illness. Patients seem to consider both medical information and experiential knowledge to be crucial to managing a chronic illness. Medicine cannot cure the disease. Experiential information provides coping strategies and epistemic validation, but the cognitive authority of the experience of patients--especially those with an illness that is suspected to be psychosomatic--is not recognized socially. Patients need medical information to effect some relief, if not a cure, and to convince others that their suffering is legitimate. Furthermore, while the experiential model of endometriosis as illness identifies illness with the self, the medical model of disease as objective entity allows dissociation of the self from the torments of endometriosis. Endometriosis, as a chronic illness, is perceived by patients variously through medical knowledge as an objective disease, and through experiential knowledge as subjective illness. Both kinds of knowledge are crucial to managing a disease that is an ever-present burden.

3. The Endometriosis Association

This thesis demonstrates that medical and patient communities share many epistemic resources and that their claims--indeed, their very existence--are based upon mutual dependence. However, we also have seen that there are many serious conflicts between these two communities. The Endometriosis Association attempts to draw the patient and medical communities together, highlighting shared goals and the contributions each community can make to the other's knowledge, to establish itself as the obligatory passage point through which each community must work to engage with the other. The success of the Endometriosis Association as the centre of an endometriosis knowledge network depends upon the resolution of certain central tensions between patients and medical experts. The EA manages this by appealing strategically to the epistemological standards and core claims of each community.

The EA, as a founding venue of the endometriosis patient community, reflects many of that community's core claims and epistemological principles. It posits a collective experience of endometriosis patients, and attempts to establish itself as a representative of this collective experience by drawing attention to the representativeness of its organizers' own experiences with endometriosis. It insists upon the validity of patients' experience as a foundation for knowing endometriosis. At the same time, it caters to patients' strong desire to familiarize themselves with medical knowledge, by compiling, summarizing, and evaluating medical claims to assist patients in their decision-making and negotiations with medical experts. It attempts to establish itself as the most reliable, complete source of medical information for patients, posits that individual patients cannot 'take on' the entire corpus of medical knowledge unaided, requires that patients join the Association to access the bulk of this information, and emphasizes patients' responsibility to know about the

disease--through the EA. The Association constructs other potential sources of patient information as unreliable or confusing, and has representatives engage in non-EA patient venues to monitor them and enrol them into the EA network. As a result of these strategic activities, the EA has become the most widely-recognized representative of and information source for endometriosis patients.

The EA also has been very successful in forming alliances with many eminent medical experts on endometriosis. It attends medical conferences, enlists its patient-members to spread the EA's word to their doctors and, by virtue of its status as patient representative, has been invited to contribute to medical publications. In those publications, the EA attempts to construct doctors and enjoin them to change their behaviour in ways commensurable with endometriosis patients' constructions of the ideal doctor and with the goals of the EA. To do so, it introduces elements of critique that emerge within the patient community and are relatively foreign to the medical community. But these are balanced and bolstered by positive evaluations of doctors and appeals to doctors' sympathy for patients, their professional interests, their notions of expertise, and medical valorizations of science--components that are widely accepted within the medical community.

The EA's research activities demonstrate a similar strategic approach to enrolling both patients and doctors simultaneously. It connects medical researchers and patients, gaining the researchers access to subjects and the subjects free treatment--impressing upon both communities the advantages of collaboration. It has conducted research on the experiences of endometriosis patients, presenting them in a scientific form conducive to the formal epistemological model of the medical community. Patients' experiential accounts get represented and validated; medical professionals get information about the

social and psychological characteristics of their patients.

While, until recently, the EA's role in the medical community was primarily that of 'illness experience spokesperson,' increasingly it has become involved in medical research itself. Again, this represents a drawing together of the patient and medical communities because patient narratives provided the foundation for new lines of medical research and raised the funds to support it, while the medical researcher allies of the EA conduct and design the research, obtain publication credits from it, receive research funding, and gain good publicity among a large population of patients.

The success of the EA in enrolling the support of both patients and medical experts demonstrates the promising foundations for cooperation that exist between these two communities. The EA exploits and defines these foundations, but does not create them single-handedly. Overlaps between patient and expert knowledges already exist, because both appeal to notions of science and experience and each community must rely upon the claims of the other to make its own 'distinctive' claims. Patients only become endometriosis patients through medical definitions of disease and diagnosis; thus they can only have 'experience with endometriosis' by virtue of the claims of the medical profession. The medical profession can only define endometriosis as a disease and diagnose it through the experiential accounts of patients. Patients evaluate their experiences through the prism of medical knowledge, and medical claims depend upon patients' accounts and bodies as clinical and research subjects. Neither community can exist as an epistemological community independently. The mutual dependence, different explicit epistemological principles, and varying interests of the two communities cause conflict between them, but without cooperation, neither community could make its claims.

II. Contributions to the Literature

Aside from the work of the EA, endometriosis has been addressed in the published social scientific literature only by one researcher (Shohat, 1992) besides myself. Yet it is one of the most common and medically challenging gynecological diseases, affecting millions of women worldwide. This study provides important insights into the knowledge politics surrounding the disease, and the struggles of both patients and medical professionals to come to grips with it. Moreover, to my knowledge it is the first study to compare systematically the epistemological models and practices of a specialized medical community and a community of patients; the first to examine the contradictions and uses of notions of experience in *both* medical and patient communities; the first to posit the notion of a distinctive epistemological community of patients, rather than simply to examine patient knowledges as individual or as derivations of general social beliefs about illness; and the first actor-network analysis of a patient organization that focusses on its enrolment of *patients* as well as scientists.

The study contributes to existing social scientific literatures on pain and its medical construction as psychosomatic (Baszanger, 1992, 1993; Delvecchio Good, Brodwin, Good & Kleinman, 1992; May, Doyle & Chew-Graham, 1999; Morris, 1991; Rhodes, McPhillips-Tangum, Markham & Klenk, 1999; Scarry, 1985) and, surprisingly, it is one of only a handful of studies to attend seriously to the central role of gender in this construction (see also Grace, 1998). It contributes to the extensive literature on the role of constructions of women in medical, especially gynecological, thought and practice (eg. Moscucci, 1990; Showalter, 1985; Ehrenreich & English, 1978; Smith-Rosenberg & Rosenberg, 1984; Todd, 1989).

Its contributions to the STS literature are several. First, it demonstrates the

fruitfulness of an actor-network approach in analysing the claimsmaking and network-building activities of laypeople, as well as scientists (see also Epstein, 1995, 1996; Rabeharisoa & Callon, 1998) and, seemingly, is the first study to extend Gieryn's (1983) classic conception of boundary-work systematically to an analysis of patients' efforts to define their knowledge as a more valid form of expertise than that of medical experts. It provides further evidence to support contentions that actual scientific and typological practices frequently are underdetermined by official codes of practice (eg. Berg, 1997; Berg & Timmermans, 2000; Curtis, 1998; Jordan & Lynch, 1992). Relatedly, it provides empirical support for the notion that clinical experience is a key resource in medical accounts, and that official models of scientific epistemology often are contradicted in medical practice (eg. Comelles, 2000; Engelhardt, 1990; Fleck, 1979 {1935}, 1986 {1935}; Hunter, 1991).

This thesis demonstrates the utility of Nelson's (1993) conception of epistemological communities through an empirical application which more specifically elucidates the overlaps and tensions between two communities of knowers. Rather than construing different communities of knowers either as entirely distinct thought-styles or as esoteric and exoteric circles which adhere to the same claims and epistemic principles, as Fleck does, this study demonstrates the accuracy of Nelson's suggestion that two communities can make quite distinct claims and employ apparently distinctive epistemological models while still sharing common epistemic resources and adhering to some of the same claims. The endometriosis patient community and the medical expert community share many notions about endometriosis as a disease, deploy notions of good science and experiential knowledge, and draw on the claims of each other in developing their own knowledges; but they present very different estimations of their relative statuses

as knowledge communities and weigh patients' experiential accounts, scientific accounts, and clinical experiential accounts quite differently. Supplementing Nelson's notion of epistemological communities with Gieryn's conception of boundary-work allows us to examine how boundaries between communities get established, how one community constructs its rival as a community of pseudo-experts--in short, how epistemological contests between communities work.

In view of Nelson's insights about the overlaps between communities, the thesis attempts to rework Fleck's notion of esoteric and exoteric circles and the relations between them, arguing, as Arksey (1994) does, that patients cannot be relegated to the exoteric circle because they often possess more esoteric knowledge than supposed experts. Despite Fleck's concern to establish the relationships between esoteric and exoteric knowledges, he took the viewpoint of medical experts for granted in assuming that laypersons act only passively to influence the development and validation of medical knowledges. My analysis attends to practices of resistance by patients vis-à-vis medical expertise, and demonstrates that, through the EA and with the cooperation of medical allies, their experiential accounts have provided the explicit foundations for new lines of medical research--not vague proto-ideas, but actual claims that environmental toxins cause endometriosis and that endometriosis is related to immunological disorders. This mirrors the recent findings of Rabeharisoa and Callon (1998) in relation to muscular dystrophy. The involvement of patients in medical research is becoming much more direct and active, and this thesis provides a contribution to the sociological analysis of this trend.

Finally, this thesis demonstrates the inadequacies of two common conceptualizations within the sociology of medicine, health and illness of the relations between medical and patient knowledge. It demonstrates that medical knowledge and

patient knowledge are not equivalent, the result of medical discourse's total colonization of lay understandings of health and illness, as some Foucauldian analysts imply (eg. Armstrong, 1984; Foucault, 1994; Harding, 1997). Instead, patients frequently resist medical discourse, developing their own claims to knowledge that undermine the very foundations of medicine as the socially-sanctioned system of expertise about health and illness (see also Lock & Kaufert, 1998b). Nor are medical and patient knowledges dichotomous, the one concerned with science, disease, and "the voice of medicine" and the other with experience, illness, and "the voice of the lifeworld" (eg. Kleinman, 1988; Mishler, 1984; Tuckett et al., 1985). The issue is not how to effect a reconciliation between two dichotomous knowledges, but to examine the ways in which the *rapprochement* is being realized already in practice--however little medical experts and patients may realize it.

Indeed, I argue that the conflicts between the communities--as well as the foundations for their cooperation--result from the fact that they deploy each other's knowledges to make their own, in ways which the other community often finds objectionable. It seems that, if endometriosis patients stuck to experience and did not challenge the claims of medical science, they would have little difficulty with their clinicians; and that, if medical experts adhered strictly to the scientific model--of which patients approve--and did not challenge patients' experiential claims, they would have little difficulty with patients. It is because each intrudes upon the other's turf--challenges the boundaries of the other's realm of knowledge--that the conflicts occur. But I have tried to show that this transgression of boundaries is necessary, that it enables the cooperative ventures between patients and medical experts that we see in the work of the EA and its medical allies, that enables them to speak across the boundaries to one another. As Fleck

pointed out 65 years ago, two truly distinct thought-styles cannot communicate with one another (Fleck, 1979 {1935}:109).

III. Directions for Future Research

The thesis demonstrates that knowledge claims and practices surrounding endometriosis are rich sites for analysis. Further research is required to determine whether the conclusions drawn from my necessarily limited analysis of the endometriosis patient and medical communities are generalizable although, based upon my involvement in the patient community over several years and my readings of the medical literature on endometriosis, it seems likely that they are. The thesis raises several issues that warrant further analysis.

First, there is the obvious question as to whether endometriosis patients that are not active members of the patient community--that are not members of the EA and do not participate in support groups and email lists like WITSENDO--share the views of active members of the patient community. Nelson's and Fleck's contentions that knowledge is communal, the striking similarity among patient community members' accounts, and my argument that the claims of these community members to a great extent *derive from* their participation in the community, suggest that patients who are not active participants may think quite differently about themselves and medical experts as knowers. However, this is an empirical question that awaits further study. My concern here was to document and compare two explicitly-defined and bounded communities of knowers, not to ascertain the views of all women with endometriosis or of medical professionals who are not endometriosis experts.

Second, the conflicts and relations between the 'two epistemologies' of medicine--

scientism and clinical art/skill/experience--warrants further investigation. Interviews with medical experts, in endometriosis and other fields of medical knowledge, would prove instructive in this regard. Few such studies have been conducted. While Helman's (1978) study of family practitioners and Hunter's (1991) more anecdotal account provide some evidence for contemporary physicians' views on science versus clinical experience, much of the literature has been primarily theoretical or historical (eg. Comelles, 2000; Engelhardt, 1990; Fleck, 1986 {1935}; Romano, 1997). More studies that closely investigate the practical epistemological methods of contemporary physicians are needed to elucidate the relationship between science and clinical experience in clinical reasoning.

Third, my research indicates that members of the patient community demonstrate extraordinary solidarity and a strong adherence to a form of epistemic etiquette in avoiding inter-patient conflict and in refraining from questioning other patients' accounts of their experiences. In only a handful of instances have I witnessed an actual argument between members of the community. It would be interesting to examine further how conflict is avoided and diversity is managed within the community and whether, when questioned in detail and in private about their perceptions of others' experiential accounts, members of this community continue to adhere to the 'united front' they presented in this study. Relatedly, there may be sub-communities within this larger one, based on affinities among group members whose experiences and personal characteristics are particularly similar. For example, the focus group research suggested that women who have taken GnRH agonists may feel a particularly strong form of solidarity with one another, and a weaker (but still significant) one with other endometriosis patients.

More generally, the notion of patient epistemological communities appears to be a useful theoretical device and may warrant application in other studies on patient practices

of resistance to medical knowledge. While such studies (eg. those presented in Lock and Kaufert, 1998b) demonstrate that patients do resist medical knowledge in a wide variety of ways, the role of epistemological models developed within patient groups and the modes of resistance and boundary-work they encourage remains relatively unexplored. Indeed, the notion of boundary-work has been little applied to analyses of laypersons in general, implying that only scientists engage in boundary-work to assert cognitive authority and dismiss competitors as pseudo-experts. This study demonstrates that patients engage in boundary-work and epistemological modelling too, and examinations of this work in other lay communities would provide further insight into the politics of knowledge and lay practices of resistance to systems of expertise.

Another issue raised by this study is the relation between medical constructions of chronic pain as a psychosomatic phenomenon, and that these constructions are related to gender--specifically, to cultural constructions of women. Further investigation is required to determine whether the construction of women's chronic pain is routinely described as psychosomatic, or whether this is particular to chronic pelvic pain; whether the chronic pain of men is constructed as psychosomatic; the special challenges that chronic pain, reported most commonly by women (National Advisory Council on Aging, 1997) and often constructed as a 'women's issue,' poses to men; and the differences between medical treatment of male and female chronic pain. The author plans such an investigation in the near future.

Finally, Ludwik Fleck's call for a new approach to epistemological investigations appears appropriate:

I do not agree with the view that the sole or even most important task of epistemology consists in this kind of examination of the consistency of concepts and their interconnections within a system.

Whatever is known has always seemed systematic, proven,

applicable, and evident to the knower. Every alien system of knowledge has likewise seemed contradictory, unproven, inapplicable, fanciful, or mystical. May not the time have come to assume a less egocentric, more general point of view and to speak of a comparative epistemology? (Fleck, 1979 {1935}:22).

Most explicitly epistemological investigations in social and philosophical studies of medicine focus exclusively on medical professionals. My focus on patient epistemology was an effort to remedy that. I found a comparative approach extremely instructive because it highlighted not only the differences between patient and medical ways of knowing--which had already been observed by many scientists--but also the crossovers and foundations for cooperative claimsmaking ventures. Focussing empirically on either patient or medical ways of thinking tends to invite a glossing-over of the one not under direct investigation, an oversimplification that serves as an artificial basis for stark contrast and, in turn, invites an oversimplification of the epistemology being studied. Empirical investigation of both simultaneously draws attention to the complexities of knowing in any community, because in reading supposedly dichotomous epistemologies side by side, one is struck by how artificial the dichotomies actually are.

Appendix 1: Focus Group Discussion Questions

1. Which GnRH analogs have you taken? (Synarel, Lupron, Zoladex?). Why did you take this particular drug and not one of the other GnRH analogs?
2. Are you still using GnRH analogs?
3. Why did you decide to take GnRH drugs as opposed to another treatment or surgery? What factors influenced your decision?
4. How did your doctor respond when you decided to use GnRH analogs?
5. What side effects, if any, did you experience while taking GnRH drugs? How did they affect your life?
6. Are you still using GnRH analogs?
7. For how many months will you take this drug altogether? (or, if you're now off the drug, for how many months did you take it?)
8. Which other treatments have you tried for endo? (include pain killers, alternative treatments, medicines, surgeries etc.) How do GnRH drugs compare to other treatments you've tried?
9. How did your doctor monitor you when you were on the GnRH analog? For example, did s/he perform blood and bone density tests, ask how you were tolerating the drug, what side effects you were experiencing, etc.?
10. If you have finished the drug, did you complete your doctor's recommended length of prescription, or did you stop taking them early? If you stopped taking them early, what factors influenced your decision to stop?
11. Off the top of your head, what do you know about GnRH analogs?
12. What did you know when you first decided to take them?
13. What have you learned since?
14. Where did you get your initial information? What was the source of that information? Later on, after you started taking the drug, what additional information did you get? What was the source of that information?
15. Do you feel satisfied with the amount of information you currently have about GnRH drugs? If yes, why? If no, why not? What kind of information would you like? How could you go about getting it? Have you ever tried to get certain information about the drugs and been unable to do so? If so, why?

16. How would you feel if your doctor told you nothing or little about the drug but gave you a list of medical sources to consult? Would you consult the sources? Why or why not? Are there other types of sources (aside from medical) that you'd want to consult?
17. How do you feel about the fact that the makers of GnRH drugs have funded much of the medical research and conferences about endo and GnRH drugs in particular? Do you see this as a problem? If yes, why, and how could the problem be overcome? If no, why isn't this a problem?
18. Based on your experience, what would you add, if anything, to the information you received before starting on GnRH drugs, for other women considering using them?
19. How old were you when you first experienced the symptoms of endo? When did you first visit a doctor about them? When were you diagnosed?
20. How many doctors have you seen related to your endo? How did they differ, if at all, and why? Why did you see more than one doctor?
21. What factors led to your diagnosis?
22. Has your doctor ever suggested that pregnancy would cause a cure or regression of your endo?
23. In general, how would you characterize the treatment you have received for endometriosis from doctors?
24. Giving specific examples if possible, how would you describe
 - a) your doctor's (doctors'):
 - understanding of the extent to which endo affects your life?
 - degree of supportiveness for what you're going through?
 - degree of time commitment to you during visits, phone calls, etc.?
 - degree of willingness and ability to share information about endo and treatments with you, and to answer all your questions?
 - respect for your feelings and thoughts?
 - respect for your experiences with symptoms and treatments?
 - respect for your intelligence/capacity to understand information?
 - ability to admit his/her own ignorance or uncertainty about endometriosis, symptoms, treatments, surgery, etc.?
 - perspective about the role patients should take in their treatment? (Specifically, his thoughts about how active patients should be in their own health care, and how much information they should want, according to your impressions of your doctor?
 - b) your own:
 - ability to ask all questions that concern you?
 - role in your treatment?
 - willingness and ability to educate yourself about the disease, treatments, surgery etc. independent of your doctor?
 - feelings and thoughts during visits with your doctor?

- willingness/ability to contradict your doctor or to refuse treatments or procedures you oppose or are worried about when your doctor suggests them?

25. What, to you, is the ideal doctor-patient relationship? How does the ideal differ from what you have experienced?

26. How does the treatment you've received from your doctor for endo compare to the treatment you received from other doctors and/or for other health problems, if they differ at all? If they differ, why do you think this is the case?

27. Do you trust your doctor? If yes, why? If no, why not?

28. Which personal characteristics do you think have affected your relationship with your doctor, in what ways, in a positive or negative way, and why? (For example, your class, race, sex, ability, age, marital status, education, personality, etc.)

29. How has your relationship with your doctor affected your treatment experiences with GnRH analogs?

30. If there are any aspects of your relationship with your doctor(s) that you are unsatisfied with, describe them. How could these problems be resolved?

31. What specific issues did you want information about, and did your doctor give it to you to your satisfaction?

32. How would you rate your doctor's explanations about (a) endo, (b) treatments, (c) side effects and how to manage them, (d) surgery? (Excellent; good; fair; or poor?)

33. What or who is your main source of information about endo? About treatments? About surgery?

34. The following table represents a survey done by the Endometriosis Association that deals with some doctor-patient issues. Which of the suggestions in the table apply to your feelings about your own doctor(s)? Which do you disagree with?

How would you suggest that medical professionals improve their ways of relating to and treating patients with endometriosis?

Improve attitudes toward patient	27.5%
Improve communication skills	24.9%
Provide patients with educational materials	17.6%
Increase professional education	17.3%
Give patients choices and treatment alternatives	9.9%
Make referrals to individual/group with same problem	2.8%

Appendix 2: Participant Recruitment Message to WITSENDO

Dear listmembers,

I'm a Ph.D. student in sociology at Carleton University in Ottawa, Canada. I'm also a woman with endometriosis (diagnosed 9 years ago, but doing well now on continuous BCPs). My mother and my paternal aunt also had/have endo (both had hysterectomies in their 30s but continue to have health problems that they suspect are due to endo). So I've had a personal interest in endo for many years, and since 1992 I've been doing research on women's experiences with endo.

My current doctoral thesis research is on medical and patient knowledge of endometriosis. Of course there is a lot of published *medical* information on endometriosis, but not very much that's available regarding women's thoughts and feelings about endo and medical approaches to endo. My research aims to help change this. I've done focus group research with women with endo, but I'd like to broaden my perspective by getting input from other women with endo. So I'm writing to ask for volunteers to participate in my research.

I'm interested in receiving women's "endo stories," with a particular focus on women's thoughts and feelings about information regarding endometriosis. Some questions that interested participants could consider are:

- what have you learned about endometriosis?
- how did you learn about it?
- what KINDS of information have you found most helpful, and why?
- what SOURCES of information have you found most helpful, and why?
- what are your impressions of medical knowledge and research on endometriosis?

Women who are interested in participating can send their responses to me at ewhelan@chat.carleton.ca. Responses will be kept strictly confidential. Names and identifying characteristics will not be used in the thesis nor in any publications that are based on this research. Within a couple of months, I'll write up a summary of the results and email them to the women who participated (and to this list, if people are interested).

Thank you very much in advance for your help with my research, and good health to you all.

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Appendix 3: The Focus Group Participants

The following information was true in 1994, when the focus group meetings were held. It is a shorter version of the participant-approved accounts provided in my M.A. thesis (Whelan, 1994).

Acika, age 41, was diagnosed with endometriosis at age 38, 22 years after her first visit to a gynecologist regarding symptoms. A former resource teacher, she was forced to discontinue her work due to endometriosis symptoms. At the time of the research, she was living on social assistance, but worked as an artist in her home. Acika also has cerebral palsy, which limits her choice of treatments for endometriosis. The first GnRH agonist she tried gave her severe side effects; she tried another with greater success. Her inability to find any information about women with disabilities who have endometriosis was a primary motivation for participating in the research. After a period of "doctor-hunting," she had found a GP and a gynecologist with whom she had excellent relationships characterized by mutual information sharing.

Beth, a 24 year old laboratory technologist who juggled two jobs, reported that she had severe pain symptoms since menarche. At age 18 she consulted her GP who, she said, "kept giving me the run-around." After she insisted that she wanted a hysterectomy, he sent her to a gynecologist. She was diagnosed shortly thereafter, five years after her first report of symptoms. Beth was the only focus group member still using a GnRH agonist at the time of the research. She was experiencing many physical and severe emotional side effects. She was not searching for a new gynecologist, but felt her gynecologist was disinterested in her emotional and psychological wellbeing, did not have enough time for her, and did not always explain medical information thoroughly.

Bobbi, a 22 year old university student, was diagnosed with endometriosis in 1993, seven years after her first visit to a doctor about her symptoms at age 14. Her endometriosis hampered her ability to do her schoolwork; at one point, she reported, she was bedridden for four months because of severe pain. Her severe physical and emotional side effects while taking GnRH agonists contributed to the dissolution of her common-law relationship. After consulting 15 to 20 gynecologists (she had lost count) and being dissatisfied with all of them, she had given up the search for a good gynecologist and was overseeing the management of her disease herself, with help from general practitioners at the Women's Health Clinic. In 1994, she was considering a hysterectomy.

Celeste, a 34 year old woman, worked full-time at a local charitable agency. She had painful periods since menarche. When in her early twenties, she began to complain about her symptoms to her GP, but said her doctor did not believe her. In 1992, when the pain became excruciating, she got a referral to a gynecologist and was diagnosed that same year, about ten years after her first medical consultation regarding symptoms. She had undergone conservative surgery along with a course of GnRH agonists, which caused her few side effects. At the time of the research, she had been attempting to get pregnant without success for about a year. She was very satisfied with her former gynecologist, but he closed his practice due to his own health problems, so she had begun to see another. She worried that, like other women with endometriosis that she knew, she would have to

embark on a demoralizing search for a good gynecologist.

Mercedes, a 37 year old homemaker, was diagnosed with endometriosis in 1993, 25 years after her first visit to a GP about her symptoms. She wanted to get a full-time job but felt unable to commit to one because of her frequent, severe pain attacks. She also was trying to get pregnant, but was having difficulty conceiving despite the use of fertility drugs that, she felt, exacerbated her endometriosis symptoms. While using GnRH agonists, she experienced severe emotional and physical side effects. Mercedes had seen five gynecologists in the six months preceding the focus group meetings and had been dissatisfied with them all. During the meetings, she found one who, she felt, took her problems seriously and treated her with respect.

Zoë, age 31, first sought treatment for severe menstrual pain at age 17. She was diagnosed twelve years later at age 29. She had been working full-time as a nurse but, at the time of the study, was unemployed and living on a disability pension due to a hand injury that made it impossible to do her job. She also experienced significant side effects while using a GnRH agonist. Her problems with the drug and endometriosis contributed to her separation from her husband and a severe depression for which she had to seek medical treatment. Only one gynecologist had treated her for endometriosis, and she was generally satisfied with him. However, she felt that was insensitive regarding her personal life and, because she was a nurse, he often provided little information, assuming she would find it on her own.

Appendix 4: The WITSEND0 Participants

W1 is an American woman who has attended nursing school. She credits the WITSEND0 list with helping her find a good specialist, who performed a hysterectomy 3 years ago. She reports that she has not "had any of that godawful pain, since my surgery."

W2, also American, stated that she had a degree in biology. She was diagnosed in 1996 after a severe pain attack. That gynecologist provided little information so she sought a second opinion and received some pamphlets about endometriosis.

W3, also American, is 39 years old and has two children. She was diagnosed at age 37 but reports having problems with her immune system, heavy, painful periods, and severe gas and constipation for years. She consulted many doctors before diagnosis. Her current doctor "seems unconvinced this should even be a problem for me."

W4 is 44 and was diagnosed in 1996 during surgery for an unrelated health problem. She works for the U.S. Military and reports considerable difficulties in achieving information or appropriate care, including referrals to gynecologists, from the military medical personnel. She asserts that this is a common problem for women in the military.

W5, also American, reports having seen three gynecologists about her symptoms. The first told her it was due to gas; the second scheduled a laparoscopy and was the most helpful; the third, considered a top endometriosis specialist, told her that if she got pregnant, the endometriosis would go away.

W6, also American, is very happy with her current doctor, an endometriosis specialist who provides her with a good deal of information. However, she has consulted about 20 other doctors since developing symptoms, and these other doctors provided her with little information.

W7, also American, describes "15 years of fighting" with endometriosis and doctors. She consulted several doctors about her symptoms and was misdiagnosed several times before she was diagnosed with endometriosis in 1986. Since then, she has consulted five gynecologists and reproductive endocrinologists and has only been satisfied with her current one, whom she has been seeing for several years.

W8 is an 28 year old Englishwoman who has suffered from endometriosis symptoms for eight years. She has had eight surgeries for endometriosis, has severe pain, and is infertile due to endometriosis and polycystic ovarian cyst syndrome. She recently began *in vitro* fertilization treatment. She "found doctors to be useless when it came to diagnosing my illness."

W9 is a 35 year old American woman who experienced a nine year delay between reporting her symptoms and achieving a diagnosis, though her response indicates that she has experienced pain for at least fifteen years. She is currently seeing a nurse practitioner with whom she is very satisfied, but before that, she consulted a series of gynecologists whom she feels knew little about the disease but pretended otherwise. She was told that

pregnancy would cure her endometriosis. She now has a 3 year old child and continues to suffer from chronic pain.

W10 is an American scientist with a doctoral degree. She did not discuss her personal experiences with the disease, but raised concerns about the lack of medical research on the disease and the inadequacies of the existing research.

W11 is a 21 year old American university student. She experienced severe pain since menarche at age 14, and was diagnosed at 17 when her pain got so bad that she was unable to walk. She found her first gynecologist condescending and believes his surgical skill was dubious. After switching to a second gynecologist, a second surgery revealed that her endometriosis was extensive. Two years later, her symptoms worsened. Last year she had a third laparoscopy with a third gynecologist; this reduced her symptoms somewhat, but she still suffers from a great deal of pain.

W12 is a 23 year old American woman who was diagnosed two years ago. She believes she has had the disease since menarche, as she always has suffered from heavy, painful periods that required several days in bed. The first doctor she consulted, at age 20, mentioned endometriosis to her. She consulted a second doctor who "said I had nothing wrong with me." She found a new doctor who conducted a laparoscopy and diagnosed her. Several surgeries and courses of medication later, she was in constant pain and decided her doctor "didn't have a clue." She found a specialist with the help of the Endometriosis Association, is very satisfied with her, and has "never felt better."

W13 is a 30 year old Guatemalan woman who began having severe pain symptoms with menarche at age 13. In 1984, she consulted a gynecologist who prescribed birth control pills. She was diagnosed in 1993 during a visit to the U.S. She has consulted three gynecologists and reproductive endocrinologists and has had five laparoscopies. For many years she has suffered from severe pain; in recent years, she learned that she is infertile and has polycystic ovarian syndrome as well. She has been receiving infertility treatment since June, 1999 but so far has not become pregnant.

W14 is a 33 year old Canadian woman who was diagnosed at age 28, after complaining to doctors about her pain and other symptoms for eight years. She has had three surgeries for endometriosis and expects to undergo a fourth soon. Her experiences with the two gynecologists she has consulted have been primarily negative; they provide little information and become defensive when questioned. She currently is searching for a new gynecologist.

W15 is a 38 year old American woman who has had very painful periods since menarche at age 11. At age 22, symptoms exacerbated and she began searching for a doctor who could diagnose her. Four years later, she was diagnosed by a doctor who told her that a partial hysterectomy (where one ovary is retained) would cure her. She had the operation. Seven years later, her symptoms returned and her remaining ovary was removed. Four years after that, her symptoms returned. She had another surgery with a gynecologist who, she feels, made the endometriosis worse. She has consulted "30 or so" doctors in the past two years, has been unable to find help and reports that she is very ill, has lost her business and health insurance, and cannot pay for further medical treatment.

W16 is a 39 year old Italian biomechanic engineer. She has had severe pain and vomiting with her period since menarche in 1972. She did not seek treatment because she thought her symptoms were the effects of normal menstruation. In 1995, her pain became considerably worse and she had a laparoscopy with a surgeon who, she feels, was not very skilled. He diagnosed endometriosis but described it as a minor problem and provided no information about the disease. She has had five surgeries and two courses of a GnRH agonist, and has been treated by five doctors. Currently, she is in moderate pain every day and is looking for a new specialist.

W17 is a 33 year old American writer and journalist. She was diagnosed in 1999, although she feels she has had endometriosis for 18 years. At age 15, she consulted a general practitioner who gave her a painkiller prescription. She concluded that she just had bad cramps and did not seek medical treatment again. She began taking birth control pills in her early twenties, and they eased her symptoms. After she discontinued them, her severe pain returned and she consulted a reproductive endocrinologist, who diagnosed her but provided little information. Currently she is being treated with a GnRH agonist and has had good results, but is concerned about the future.

W18 is a Canadian woman who was diagnosed in 1997, "after ten years of torture and testing." She reports that, before her laparoscopic diagnosis, she thought she was going to die because her symptoms were so severe. She is frustrated that the doctors she has consulted do not recognize the extent to which her chronic symptoms affect her life and do not recognize the inadequacies of currently available treatments.

Appendix 5: List of Keyword Searches Conducted in Atlas TI

A snowballing procedure was used, such that new keywords for searching were added to the list as previous keyword searches revealed their use in focus group discussion. Asterisks indicate "wildcard" searches that accomodate different word endings.

- know, didn't know, don't know, knew, known, knows, knowledge
- find, found
- inform
- experience
- research
- underst* (includes understood, understand, understanding)
- librar* (includes library, libraries)
- book
- journal
- article
- read
- ask
- think, thought
- belie* (includes believe, believed, belief, beliefs)
- feel
- expla* (includes explain, explains, explained, explanation)
- learn
- true, truth
- false
- right
- wrong
- lay
- listen
- question
- answer

Appendix 6: Basic Codes List

Docs: Delegitimation - instances where patients felt their concerns, thoughts, ideas, sensations, feelings etc. were being delegitimated/not taken seriously by doctors

Docs: Eval Patient Knwlg - patients' impressions about what their doctors thought about patients' capacity to understand information or their credibility as claims-makers

Docs: Paternalism - instances where patients felt they were being talked down to

Docs: Uncertainty - patients' comments re. doctors' ignorance or willingness to admit their lack of knowledge or uncertainty to patients

Docs: Willingness to teach - doctors' openness to patients' suggestions or ideas, willingness to share information, or to teach patients about endometriosis

EA - comments about the Endometriosis Association and its activities

Exp as Knwlg - comments about the value of their own experiential knowledge, or things learned through the experiential accounts of others

Med Research - comments about medical research and knowledge about the disease

Patient-Doctor Gap - comments about the differences in the perspectives of patients and doctors, and attempts to overcome them, or similarities between the perspectives which undermine the gap

Patients' Eval of Doc Knwlg - patients' comments about doctors' claims and levels of knowledge, inappropriateness or appropriateness of information provided to patients, and truth value of doctors' claims

Patient Knwlg - comments concerning what patients know and how they know it (sources and kinds of information) and evaluations of that knowledge

Patient Uncertainty - comments concerning patients' confusion, uncertainty, or ignorance

Psychology - comments about the psychologization of women with endometriosis, their own evaluations of their mental state, doctors' evaluations of their mental state, and their evaluations of doctors' mental states

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