

‘No one agrees except for those of us who have it’: endometriosis patients as an epistemological community

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Abstract This paper contributes to the literature on patients’ claims-making work by analysing the epistemological strategies and standards used by members of an endometriosis patient community. It draws upon focus group research with members of a support group for endometriosis sufferers, and an open-ended survey of an e-mail list for women with the disease. Lynn Hankinson Nelson’s (1993) concept of epistemological community is used to examine standards and practices for developing and evaluating knowledge used by women with endometriosis. Particular attention is paid to the use and centrality of the notion of experience within this community.

Keywords: lay knowledge, expert-lay divide, patients, endometriosis, epistemology

Introduction

Endometriosis 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. It is thought to affect up to 10 per cent of reproductive-age women (Ballweg 1995: 409). It is the third leading cause of gynaecological hospital admissions in the US, surpassing admissions for breast cancer (Candiani *et al.* 1991, Eskenazi and Warner 1997).

Although specialists have made important efforts to standardise medical protocols for endometriosis (*e.g.* American Fertility Society 1993, American Society for Reproductive Medicine 1997, Rowe 1999, Royal College of Obstetricians and Gynaecologists 2000), the disease is frequently described by both gynaecologists and patients as an enigma. While some women experience no symptoms, others suffer from severe menstrual pain, pain with sexual intercourse, chronic pain, infertility, and a range of other symptoms. There is no known cure, the cause is unclear, and the efficacy of treatment varies greatly from patient to patient.

The enigmatic nature of endometriosis causes much conflict, both within medicine and between the medical and patient communities. A particular source of physician-patient conflict concerns the relation between symptoms (patient experience) and signs (medical observations). The primary symptom is pain, intrinsically subjective and therefore elusive from a medical point of view. Because pain severity does not correlate with observable extent of disease, patient and physician accounts of endometriosis may directly contradict one another. When the lived experience of illness is contradicted by a lack of objective confirmation, others (especially physicians) may doubt the reality of the experience. This ‘epistemological purgatory’ (Barker 2002: 281) is shared by many chronic illness sufferers,

especially women with persistent pain (Grace 1995, Jackson 1992, May, Doyle and Chew-Graham 1999, Rhodes *et al.* 1999, Ware 1992, Werner and Malterud 2003).

Unsurprisingly, then, the meagre social science and nursing literature on endometriosis documents that the accounts of endometriosis patients are dismissed by their physicians, often as hysterical or hypochondriacal accounts of 'normal' menstruation (Ballweg 1997, Cox *et al.* 2003a, 2003b, Denny 2004a, 2004b, Halstead, Pepping and Dmowski 1989, Whelan 1997). This literature describes many serious problems for women with endometriosis, such as delayed diagnosis, underfunded research, widespread physician ignorance, physicians' unwillingness to share what they do know about the disease, and medical minimisation of the distress it causes; and it suggests that medical professionals do not take endometriosis seriously, probably because its sufferers are women. Certainly, medical experts' ways of representing endometriosis often undermine the credibility of patient accounts and endometriosis patients have often been represented in the medical literature as nervous, irrational women who exaggerate their symptoms (Whelan 1997, 2003).

This highly gendered 'delegitimation theme' provides an important context for this paper, helping to explain *why* there is an endometriosis patient community. But here, I wish to focus upon the actual ways in which women *confront and mitigate* delegitimation and try to escape epistemological purgatory. Thus, rather than explain *why* patients complain, which has already been done to some extent, I explore *how* they complain. I discuss the epistemological strategies of 24 women with endometriosis, mostly from Canada and the US: their representations of how they came to know about the disease, and their evaluations of their own and other community members' knowledge. The uncertainties surrounding endometriosis not only cause problems for patients; they also open up space for epistemic resistance, for the discrediting of physicians as confused, ignorant non-experts. Thus, epistemologically speaking, these women are simultaneously made vulnerable and empowered to challenge medical authority by the enigmatic nature of their disease.

Consider the illustrative case of Mercedes,¹ who suffered from chronic pain and saw several doctors in an attempt to get a diagnosis:

Nobody once mentioned the word endo[metriosis] until I asked to have a laparoscopy done – I asked. I asked for a D and C [dilatation and curettage], two years later I asked for a laparoscopy, and if they hadn't have 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. She is not alone. She is a member of an endometriosis patient community of women who interact on the Internet, in support groups, and through self-help organisations.² I argue that these women form what Lynn Hankinson Nelson (1993) calls an 'epistemological community' – a group which shares a body of knowledge and a set of standards and practices for developing and evaluating knowledge. Members of this community take great pains to become – and to present themselves as – knowledgeable about their illness. It is Mercedes' involvement in an endometriosis patient community that allows her to think of herself as an expert in her own right.

The present analysis contributes to a growing literature on the claims-making work of patient groups and their challenges to medical expertise (*e.g.* Arksey 1998, Barker 2002, 2005, Busby, Williams and Rogers 1997, Epstein 1996, Figert 1996, Kroll-Smith and Floyd 1997, Prior 2003). Examination of the endometriosis patient community clearly reflects Brown *et al.*'s (2004) notion of an 'embodied health movement': it encourages the formation

of collective identity around notions of shared experience, which it uses to critique and challenge 'bad science' while promoting the expansion of medical research and knowledge. Other authors, too, have pointed to the centrality of experience in patients' and activists' critiques of biomedical authority (e.g. Abel and Browner 1998, Pierret 2003, Williams and Popay 1994). However, the concept of experience and the uses to which it is put are rarely examined in the sociology of health. A close analysis of the *epistemological* practices and principles of these groups often takes a back seat to more explicitly political practices. The present paper does not examine patient groups' traditional 'social movement' activities that emanate from a collective identity based on shared experience. Instead, it aims to advance our understanding of how patient communities deploy the concept of experience to enhance their credibility and undermine the credibility of other claims-makers; how the concepts of experience, knowledge and science are related in patients' accounts; what patient groups *mean* by experience; and how shared interests and common themes are drawn out of individuals' experiential narratives, and used to create group solidarity.

Epistemological communities and the experiential credential

In this era of rapid growth in self-help and mutual aid, facilitated especially by the Internet, it has become customary to describe patients' interaction with one another as *community*, regardless of whether the interaction happens face to face or online. Researchers argue that such interaction amounts to community because it offers emotional, social, informational, and practical support. These forms of support help to (re)form patients' identities and worldviews in line with the group, as well as cope with biographical disruption and problems with healthcare providers (Allsop, Jones and Baggott 2004, Barker 2002, 2005, Broom 2005, Landzelius 2006, Pleace *et al.* 2000, Radin 2006). I want to extend this a little further and suggest that we might think about how these interactions constitute *epistemological communities* as well as social, informational, or political ones. They not only share knowledge, but collaboratively formulate and defend an understanding of what *counts* as 'good knowledge' in order to challenge medical authority and develop patient-centred knowledge claims. Feminist epistemologists provide some resources for this. Elizabeth Potter (1993: 164) argues that all knowledge claims are communitarian in nature. She also notes that accounting for any experience involves emphasising some aspects and dropping others (1993: 166). And according to Lynn Hankinson Nelson, these decisions about what to include and what to leave out depend upon our membership in 'epistemological communities' (Nelson 1993). Like all knowledge, experiential knowledge is unavoidably social, for three reasons: (1) the apprehension of 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' help to make particular experiences happen and to structure experience into a coherent account; (3) theories, concepts, and standards of evidence are socially derived. So it is not merely that knowledge must be *validated* socially, but that the *development* of knowledge claims is a social process: 'communities are epistemologically prior to individuals who know' (Nelson 1993: 124). For Nelson, epistemological communities share a body of knowledge and a set of standards and practices for evaluating and creating knowledge. Their boundaries frequently overlap, so individuals can be members of several 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.

Groups that use 'experience' as an epistemological foundation must sort among individuals' experiential narratives to develop an account of experiences-in-common that define the group. Elements of some accounts must be highlighted and other elements and accounts dropped or subsumed to make a coherent narrative, a practice Rafalovich (cited in Barker 2002: 283) refers to as 'levelling'. But if the group hopes to retain all its members, it will have to strike a compromise between varying accounts that will avoid alienating the subjects. This involves drawing comparisons between members' experiences that speak to/include aspects of their accounts that they deem most central to their individual experience. In other words, individual group members must be able to 'recognise' their experiential narratives in the group account in order to accept its representativeness. If they reject the group account's ability to represent them, they would likely withdraw from the group. The group narrative that emerges bonds members into an epistemological community that shares particular beliefs, categories, terms, and standards of evidence.

Such is the case in the endometriosis patient community I describe here. Members represent their experiences as paradigmatic. They draw upon the experiential accounts of others to make sense of their own experiences, to reinforce their claims, and to evaluate and challenge medical claims. The result is a collective experiential narrative that generates a sense of commonality and belonging, one taken to form the basis of the patient 'community'. Experience, conceived as a social form of knowledge defined, validated, and deployed by a collective, becomes a kind of epistemological qualification – an *experiential credential*. For groups whose epistemology is experience-based, this form of knowledge becomes the basis for challenging medical experts: without the requisite experience, doctors lack the appropriate epistemological credentials. I aim to show why and how experience becomes crucial to patient community members in asserting their own knowledgeable ability and critically evaluating medical claims.

Methodology

As with many chronic illnesses (Barker 2005, Charmaz 2000, Garro 1994, Grace 1995, May, Doyle and Chew-Graham 1999, Rhodes McPhillips-Tangum, Markham and Klenk 1999, Ware 1992, Werner and Malterud 2003), the suffering caused by endometriosis is invisible and subject to social discreditation. Moreover, the disease affects intimate aspects of female embodiment: menstruation, sexuality, fertility. Members of the community often assert that only those with endometriosis can truly understand it, and tend to be somewhat guarded toward 'outsiders,' making research on the community from outside quite difficult. My status as a woman with endometriosis enabled me to conduct extensive qualitative research within the community over 10 years, from 1993 to 2002, using a variety of research methods and sources of data.

This paper focuses upon two phases of research. First, in 1994, I conducted 20 hours of focus group meetings with six women recruited from an endometriosis support group in Winnipeg, Canada. The focus of the sessions was GnRH agonists,³ the group of drugs now considered the treatment of choice for endometriosis, as I hoped to understand how women gathered, evaluated, and used information about a specific element of the endometriosis experience, a medical treatment. The discussion, however, revealed that these women had developed quite sophisticated epistemological strategies that they applied to many issues beyond GnRH agonists. The resulting data provide a wealth of information about how these women thought about information, and themselves and their fellows as knowledgeable subjects. My interest in women with endometriosis *as* an epistemological community developed

out of these discussions. Thus, the transcripts were reanalysed later for their insights into women's strategies and views about knowledge surrounding endometriosis.

In order to expand upon this research and broaden my enquiry to a different patient venue, I conducted an open-ended survey on an electronic mailing list for women with endometriosis, WITSENDO, in 2000. List members were asked to e-mail me their 'endo stories'. While a few broad questions about their views on endometriosis information were included, I encouraged participants to frame their narratives as they saw fit, as their means of representing their knowledgeability were the central focus of the study. Eighteen women responded, 14 from the United States and the remaining four from Canada, Guatemala, Italy, and the UK. Thus the research conducted reflects primarily North Americans' perspectives, which may or may not be generalisable to other areas of the world. However, the two participants from Europe and the one participant from Central America did strongly echo the themes presented by the other participants.

These two projects represent a small sample of 24 women, but the investigation of complex epistemological practices does not lend itself to large datasets. The current study makes no claims to represent the views of all women with endometriosis. The women who participated in this research were all members of endometriosis patient venues, often driven to them after highly negative experiences with medical treatment. It is probable that women who do not participate in these venues have different attitudes toward information-seeking, medical treatment, and experiences with endometriosis. But by definition, women who do not participate in such venues are not members of an endometriosis patient *community*, at least not in the same sense. The research is exploratory, the findings suggestive. The analysis seeks to build theory and identify future avenues for research on this and other patient communities.

Both focus group transcripts and the electronic responses of survey participants were coded using Atlas TI™ (Muhr 1997). The data were searched for knowledge-related keywords, and coded to reflect key themes. Codes were modified throughout according to the inductive, constant comparative method of grounded theory (Glaser and Strauss 1967). The practice of reading for 'knowledge' concepts was developed out of the voice-centred relational method outlined by Mauthner and Doucet (1998), who suggest conducting multiple readings for different voices in the text. The formal readings for this analysis focused on three elements: (1) the narrators' presentation of knowledge claims; (2) the narrators' presentations of themselves and physicians as knowledgeable agents (or not); and (3) the relational aspects of the narrators' accounts, focusing on the focus group interaction and the WITSENDO participants' representations of the endometriosis patient community.

There are significant differences between the two phases of research. In the focus group research, participants presented their accounts of endometriosis within a face-to-face group conversation. Focus groups provide a fairly egalitarian setting for participants; because they outnumber the researcher, they often share a common bond, and they may know each other prior to the research (Wilkinson 1998). Such was the case here as these women were all members of the same support group. This situation naturally lends itself to what Wilkinson (1998) calls the co-construction of meaning: the group development of perspectives about the social world. In the WITSENDO research, my communication with participants was exclusively electronic and their accounts were written in isolation from one another. The only audience was me, a researcher and stranger who had never before participated on WITSENDO – although my self-identification as a woman with endometriosis mediated this somewhat by making me a member of the community. There was also a six-year lapse between the two projects. Yet, despite careful attention to differences between WITSENDO and focus group narratives, these were actually very minimal, suggesting that conclusions may be generalisable beyond this study. Further research on this front is warranted.

Women who participate in WITSEND0 develop their 'endo stories' over time through their interaction within a *community*, not as isolated individuals (see also Barker 2005, Robinson 1990). Thus, the WITSEND0 accounts are also exhibits of the co-construction of meaning, albeit in a less obvious sense than the focus group accounts.

What do patients claim to know?

In general, participants incorporated both experiential and medical knowledge into their accounts, but to differing degrees. When explicitly asked what they knew, some participants regurgitated *medical* claims about endometriosis. They drew upon medical rhetorical devices, such as the passive voice, medical terminology, and statistics. These help to present participants' claims as scientific fact, not personal opinion. But hints of endometriosis from the patient perspective, from a community of sufferers who share experiences, appear too: 'The average delay in diagnosis for a woman my age (35) is nine years, that is how long it took for me to be diagnosed' (W9). This makes them distinct from medical accounts, reminding us of the personal and social context of the disease – a disease which happens to a *community* of women.

This lifeworld context becomes even more apparent in accounts that presented a uniquely patient-centred knowledge:

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.

The critique of clinicians' knowledge is crucial. It is in *comparison* to medical knowledge that the experience of endometriosis is presented as a (more) reliable form of knowledge. Hence, the question 'what have you learned?' is best answered by what these women feel they 'know for sure': their own experience and the 'collective experience' of the community.

Between these two extremes lie responses which combine and relate medical and patient-centred perspectives. Medical knowledge may be invoked, but generally in the active voice. The focus is more on uncertainty and subjectivity than on endometriosis as known object. Such accounts evoke *process* in a struggling knowledge community rather than static, independent facts. These responses, then, reconfigure medical accounts as 'situated knowledges' – partial, invested, community-based – rather than disinterested and transcendent 'views from nowhere' (Haraway 1991):

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.

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 . . . 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 realise that some of the effects I had would be associated with the drug. When I heard the other women talk about it, then I realised it was a side effect.

A degree of uncertainty about medical information is demonstrated in all these accounts. These women attempt to resolve this uncertainty by relating medical information to patients' experience of the drugs (gleaned both from other women's accounts, and from interpretations of embodied sensations). 'Experience', then, becomes the arbiter of medical truth.

How do community members acquire knowledge?

The response of Bobbi, a focus group member, 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 is on Bobbi as epistemological subject, her acquisition of information, rather than its content. The intent of Bobbi's statement is to establish her as a valid knower – a strategic move because she reported many invalidating encounters with doctors. In general, participants seemed concerned to establish that they had 'done their homework' and were therefore knowledgeable and credible. Examining their sources of information helps us to understand the process by which these women came to consider themselves as knowers, and the extent to which they drew upon medical knowledge and the patient community's knowledge. All the participants consulted more than one kind of source. The overarching theme was the preference for lay sources and their own community's epistemic perspective over the medical perspective.

The Internet was cited as an important source of information by 14 WITSENDO participants; but while only five mentioned medical Internet sites, 13 named lay sources like the WITSENDO list. Twelve cited the Endometriosis Association, and 12 cited books, usually ones for a lay audience; only six cited medical publications. Six also mentioned doctors as sources, with the proviso that most of the doctors consulted had provided no or little information.

None of the focus group members consulted Internet sources (at the time, access was limited). However, three conducted research at the local medical library. All six read books, usually ones written for a lay audience. Most also read sections of the *Compendium of Pharmaceuticals and Specialities (CPS)*, the standard drug reference manual for Canadian physicians, and got pamphlets or videotapes from their doctors. Several were members of the Endometriosis Association and read its newsletters and first book, *Overcoming Endometriosis* (1987). All were members of a local support group in which much information was exchanged.

The factors that led women to search for information on the disease varied. For some, their search was precipitated by a medical event such as diagnosis, a new treatment, or impending surgery. Others began to search for information when they became disillusioned with their treatment. Bobbi's decision to investigate Danazol was the result of hearing her doctor tell an intern that he didn't need to tell Bobbi about rare side effects. One WITSENDO 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,

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* [the Endometriosis Association's second book] 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.

Becoming disillusioned with doctors seems to be the standard first step for these women in deciding to become more active healthcare consumers. Self-education was viewed as an integral part of that:

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 endometriosis.

Since physicians would not take endometriosis seriously and knew little about the disease, this provided an epistemological opportunity: these women compensated by 'becoming experts' themselves and taking the disease *more* seriously than they did before.

At the same time, the participants discussed the barriers they faced in becoming endometriosis 'experts' – such as a lack of familiarity with medical jargon and difficulties in access to information – especially in the years before the Internet when lay access to information was more limited (*c.f.* Hardey 1999). Strategies used to overcome these barriers included using a medical dictionary; consulting acquaintances with medical training; 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 [names city] who's in the medical profession – not gynaecology, 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.

W15: I was told the only sure cure was a partial hyst⁴ (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 reluctance. Looking for medical information on the Internet is more convenient; but also, the medical library may be perceived as a professional sanctum which is intimidating to laypeople, especially those unaccustomed to research. Bobbi and Mercedes had never before entered a medical library and decided to go together for moral support. They were seized with nervous giggling fits, and had difficulty understanding what they were reading. Bobbi portrays the experience as a chore: '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'. The fact that they went together is a testament to the importance of patient community in crossing the expert-lay divide.

Barriers to access exacerbate the difficulties of learning a field of arcane knowledge. With the realisation that self-education was necessary came a level of resentment, tied to cultural expectations about experts and social divisions of labour: knowing about disease is the job of physicians, not patients.

- 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.

However, Beth was not advocating a strict division of labour, but rather, shared responsibility and co-operation in information-gathering:

- Beth: Well, I think that probably even if we had all gotten the information, we still would've looked for more.
- Author: Yeah?
- Celeste: I would.
- Zoë and Mercedes: Yeah.
- Beth: We had to do everything, but at least if they would've met us halfway.

Acika also emphasised that the information that doctors provided was sketchy, and that independent self-education was a necessary supplement. The importance of self-education and mutual aid was strongly emphasised by focus group and WITSENDO participants alike, not merely as a supplement to doctors' expert knowledge, but often as a *replacement*:

- 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 seven 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.

But while many women with endometriosis are deeply dissatisfied with their doctors, their need for information cannot be reduced simply to clinicians' inadequacies as teachers. Some had doctors who provided them with a good deal of information, yet they still subscribed to the WITSENDO list, attended support group meetings, or read EA literature. Self-education, facilitated by the patient community, enables patients to challenge their doctors' claims with their own communally-legitimated knowledge. Just as importantly, it engenders a sense of empowerment and control over endometriosis itself.

What sources are most helpful, and why?

In general, participants were deeply critical of clinicians' knowledge about endometriosis and their willingness to share what they knew. Thus, while medical sources were often *consulted*, no one cited clinicians as her most helpful source. Several, however, considered doctors useful starting places or authorities on particular subjects:

- 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.

Physicians often provide basic initial information, which the participants used as a way into their knowledge search. A discussion with a clinician may provide the key words that allow one to conduct an Internet search. For an understanding of what the words *mean*, however, participants tended to turn elsewhere.

Other medical sources, such as journals and doctors' websites, were cited as helpful by some – particularly participants with scientific or health professional credentials, which their accounts emphasise. W16, for example, included a prefatory note in her account: '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 is likely that these women's training facilitated their research and affected their high esteem for 'expert' sources of information. But also, presenting professional credentials is a strategic move toward epistemological credibility. In the focus group discussions, Zoë (a nurse) tended to speak most authoritatively on medical matters. Having worked primarily in cosmetic surgery, Zoë's knowledge of gynaecology was limited. However, the group's deference to Zoë indicates that, to a degree, we too accepted the 'cognitive authority' (Addelson 1983, Wendell 1996) of medical professionals.

At the same time, that authority was questioned routinely. Focus group members signalled their disapproval of physicians' advice with sneers, snickering, and sarcasm. Quite consistently, other members responded by rolling their eyes, shaking their heads, laughing, groaning, sighing, or exclaiming 'What?!' Only very occasionally was a group member's disapproval of a physician questioned. Generally, group members communicated support for each other's critiques, producing a tacit communal evaluation of physicians which did not seem to require overt statement.

Often, physicians' claims were questioned by invoking non-medical sources of information judged to be highly credible. These included books and Internet sources geared toward endometriosis sufferers, and resources published by the Endometriosis Association. Seven WITSENDO members listed one or more of these sources as among their most useful. One focus group member (Bobbi) noted that Endometriosis Association newsletters were her main source of information on both GnRH agonists and endometriosis, because of her mistrust of medicine and the pharmaceutical industry:

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 . . . They have a vested interest in marketing the drug, making it appear innocuous, and concealing the 'negatives' or delegitimising 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.

Bobbi's perspective is conflicted: she accepts the principle that medical science is capable of providing trustworthy information about drugs, but she has a strong sense of the 'corrupting' effects of the interests of the stewards of that knowledge (clinicians and researchers). So for Bobbi, there is no inevitable contradiction between experience and medical knowledge; but the contradiction arises because of 'polluting interests' and 'biases' (the profit motive, inequalities between patients and doctors) that corrupt medical knowledge. Bobbi sees the Endometriosis Association literature as the most credible source about GnRH agonists because it is produced by an endometriosis patient organisation, and she believes its goal is only to provide the truth to patients.

These themes are echoed in the WITSENDO responses, which represented patient organisation sources as useful because they provided detailed, accessible, technical information about endometriosis. Accessible here means both easy to understand and easy to find. Such sources provide quite detailed overviews of medical information about endometriosis with citations, but in a way that laypeople can understand:

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.

Published sources produced by endometriosis patient organisations like the EA are said to ‘arm’ one because they are ‘authoritative’ and therefore useful in negotiating with doctors, insurance companies, and employers. Here we see the practical limits of situated knowledges. Patients need to make sense of endometriosis not only to themselves and other patients (whose experiences are likely to be similar), but to non-patient others. Experiential accounts from a person with a disease that has often been portrayed as psychogenic (Ballweg 1997) are unlikely to hold much water with medical experts, employers, and insurance agencies. For these audiences, science is more persuasive: either one has a disease documented by experts, or one does not. Thus, patients need authoritative knowledge, from sources that carry epistemological weight, to convince others that their suffering is real and their assumption of the sick role is valid. Organisations like the EA produce such sources for community members’ use in these negotiations, without erecting barriers to understanding, as expert sources can do.

Aside from medical content, books by patient organisations usually include sufferers’ stories. One of the reasons that such books are helpful is that they *combine* medical information in simple language with the narratives of other women with endometriosis, relating the two kinds of information that are necessary to community members in negotiating the disease. Seven WITSENDO participants explicitly described the list or ‘other women with endometriosis’ as their most helpful source; six more emphasised the importance of support groups or the WITSENDO list. And, surprisingly, five focus group members described the focus group itself as their main source of information. The majority in both the focus group and the WITSENDO sample found the patient community to be their most important source of information about the disease.

What is it about ‘hearing from other women’ that is so valuable? Participants provide several answers: reduced feelings of isolation and abnormality; information about medical matters in greater depth and detail than other sources provide; *honest* information about treatments and prognoses; help with doctor-hunting; sharing of coping strategies; support, understanding, camaraderie, and the opportunity to ‘vent’.

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.

- Zoë: I think that a lot of the information we need is just choices and what [medical treatments] 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 'Look, I'd like to maybe look at Synarel as opposed to the Lupron', or whatever . . . 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.

The sharing and comparison of patient accounts is particularly generative for an epistemological community because it combines epistemic and informational support with emotional and social support. This powerful combination engenders a sense of belonging and knowledgeability all at once – indeed, of belonging *through* shared tacit knowledge ('knowing what it is like to'), transformed into propositional form.

How are these sources put to use?

Women use medical information to negotiate with their doctors, employers, and insurance companies. They use 'experiential' information to cope with symptoms and side effects; to find explanations for unexplained health problems which may be related to endometriosis or its treatment; and to reduce feelings of isolation and abnormality (others are going through 'the same thing'). Community venues like WITSENDO also fulfil needs not strictly informational, but related to knowing *what it is like* to be a woman with endometriosis: support, empathy, and uncensored opportunities to express anger or hopelessness, which may elicit negative reactions from others. There are three other uses to which women with endometriosis put these sources that are particularly interesting.

First, women *use medical sources to evaluate the validity of clinicians' statements*. Their basis for disputing medical claims is often other medical claims, which they access through reading, through their or other women's test results, or through other women's accounts of conversations with doctors. Participants confirmed or denied their own doctors' claims by seeking the perspectives of other medical experts, often 'second-hand' through other patients. Community members, in consultation with one another, identify contradictions among medical claims, among clinicians, and between research and clinical practice. This provides opportunities for comparison and critique:

- Mercedes: [I tried] to get a bone density done and they wouldn't do it. And [the doctor] said that Lupron wouldn't cause bone density damage enough to be noticeable, and if it did, like if it caused any, it would be reversible.
- Zoe: And then, but you couldn't find any information to back that up.
- Mercedes: No, 'cause I talked to the TAP Pharmaceuticals and I told them that I had this bone density done and she right away said to me 'That had nothing to do with the drug'. So I mean, I don't know, maybe it didn't, like I don't know.
- Beth: Oh, YEAH! (sarcastically)
- Mercedes: . . . And then I get the doctor who says, 'well, you're off the drug now'. Meanwhile he was the one that said 'You won't have bone density loss from the drug, and if you do it's gonna be so small that it's not gonna show up anyways and it's gonna be reversible'. Well I don't call high risk small!
- Zoe: 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', like it's all this confusing garbage that's going on.

The participants in this study often presented *published medical research* as more reliable than their clinicians' accounts. This mirrors biomedicine's formal epistemological hierarchy, in which experience is 'anecdotal' and less valid than randomised, controlled clinical research – even if in practice, clinicians themselves often rely more heavily upon their clinical experience (Hunter 1991, Malterud 1995). But members of this patient community seem to evaluate experiential knowledge differently depending on the identity of the person claiming the experience. Participants valued *patient* experience highly and used it to discredit both researchers' and clinicians' claims, but they consistently considered medical research more reliable than their physicians' experiential claims. Using the standards of the medical establishment against the members of that establishment may be a clever strategic move, but the irony is obvious: endometriosis patients' experiential accounts have been judged invalid in biomedicine because they are not scientific, but these patients deem clinicians' experiential accounts invalid because they are not scientific. Clinical experience is unscientific whereas research is (ideally, at least) scientific; the latter trumps the former. Patient experience, however, trumps both. Thus, this is a principled hierarchy, but one which tends to be about seeking confirmatory evidence for the 'best' evidence-embodied experience.

Secondly, 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. Here is an illustration from the focus group discussions:

- 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?
- 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].

Zoë's 'I guess it can't hurt' disputed Beth's claim about calcium in a gentle way that made some concessions to Beth's point of view. Even when members of the community believed that another sufferer's claims are patently false, the community's norm of supporting members' status as rational beings took priority. Patients' assertions about medical science were questioned at times, but never in a way that contributed to the delegitimation that many of these women experienced in interactions with doctors. Never in my studies of this community have I observed a patient questioning the validity of another patient's account of her experience.

Thirdly, *one's own experience and the experience of other women with endometriosis are used to evaluate medical claims*. When a patient hears an account from another patient that contradicts what a clinician or study claims, this often causes the patient to question the medical claim. But the source must be evaluated to gauge its credibility. The most believable claim comes from one's own embodied sensations; accounts of bodily experience from others one knows come next; and what others may have read or heard is less trustworthy. So, when their own or an acquaintance's 'experience' directly contradicts what a clinician or study claims, these women often take this as proof positive that the claim is false. What other women have 'heard' may be cause for doubting the clinician's claims, but follow-up is 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?

- Author: 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].
- Author: Again though, Celeste, it's all, you know . . .
- Mercedes: Could be all hearsay.
- 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: . . . 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?
- Author: 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 other women's experiential accounts. In the third excerpt, what women Celeste knows have 'heard' is not sufficient reason to reject her doctor's claim, only to ask him for clarification.

Fourthly, some women 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 recognise 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 realise that what you're experiencing is part of side effects, etc.

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 claims. Instead, their experiences must be *interpreted* through other kinds of knowledge. This is particularly so when the experiences in question have to do with thoughts and emotions. However, the legitimacy of physical sensations 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 experts were required to define what that something was. So, 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 by physicians as meaningless, their bodies ‘told’ them otherwise – what Laurence Kirmayer (1992) calls ‘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 laparoscopy] 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 . . .

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 to many of the participants an order of knowledge that is tacit and extraverbal, but undeniable. As Beth pointed out, this is reflected in the fact that participants continued to search for answers despite being told repeatedly that there was no ‘truth’ to what they were feeling.

Beth [reacting to the fact that Bobbi had seen 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?

Author: Yeah, of course. But if the doctor tells you there’s nothing wrong with you, it makes you wonder, doesn’t it? . . . 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.

Bobbi kept going to doctors not just because she believed in the capacity of biomedical knowledge to provide an explanation, but also because she believed what her body was ‘telling’ her – even in the absence of medical verification.

Self, body, and mind

The way that women in the endometriosis patient community conceptualise their bodies is complex, however. Sometimes, the body is equivalent to the self (‘I’m sick’). At other

times, the ill body is depicted as alien to – and a burden to – the self: ‘Some day hopefully I will like my body again and there will be a cure’ (W8). At still others, the disease of endometriosis is the alien, and the body is burdened with it. For 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 symptoms as psychosomatic is that women with endometriosis often begin to doubt their own mental ability, and to worry about others’ evaluations of their mental health. Both complicate their ability to posit themselves as knowers and to rely on their experience as a valid form of knowledge. 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 challenges 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 with: ‘Then my GP went weird on me; I think he was into the booze or something’. Participants sometimes referred to doctors (individually and collectively) as ‘idiots’. However, many admitted to questioning their own mental health when doctors delegitimated their suffering, especially before diagnosis when there was no explanation for it. At such times, embodied experience – often presented as undeniable truth – becomes suspect.

While the participants denied that the symptoms of endometriosis were *caused by* psychological dysfunction, they did point to several ways in which psychological dysfunction may *result from* endometriosis. First, 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 ANY MORE, I WANT MY LIFE BACK I WANT TO BE A NORMAL WOMAN AGAIN.

Secondly, focus group participants argued that endometriosis *treatments* – specifically GnRH agonists – may cause depression, irritability, confusion, anxiety, and memory loss.

This hampered their ability to think; it made impression management and self-control difficult; and it alienated them from themselves:

- Mercedes: [explaining why she chose to try 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.
- Beth: There's a lot of side effects that I'm experiencing, I'm not gonna tell her [the gynecologist].
- Author: You're not going to tell her?
- Beth: [snorts] Are you kidding? 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: When you're on the drug, it's like you don't *know* yourself any more. 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? . . . You still feel like you're in control.

When the focus group members conducted research on GnRH agonists, one of their most important findings was that the *CPS* 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 discussions, was particularly interested in others' 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 . . .
- Author: [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.

This illustrates the role that the community plays in legitimating patients' claims and experiences, and indeed their status as rational beings. Beth is 'normal' – not 'weird,' as those who had not taken the drug might assume. A tentative experiential *claim* by Beth – that the drug is making her 'act weird' – becomes a form of *group experiential knowledge* when confirmed by other participants. 'Alone, one person cannot make the distinction between how things are and how they seem, but two or more can make it' (Potter 1993: 164).

Knowledge, resistance, and the endometriosis patient community

These women's resistance to the expert-lay divide and medicine's assignment of passive roles to patients depends upon their self-education efforts. These efforts, in turn, are enabled by the participants' critiques of medical knowledge and clinicians. *Without coming to the conclusion that doctors know little about endometriosis and are unwilling to teach patients what they do know*, these participants 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. Thus, their critiques of medicine are the first steps for these women in asserting their own status as epistemological agents.

Participants tended not to dispute the category of expertise. They simply took issue with its attribution. The fact that most participants named other sufferers and patient groups as their most useful source of information suggests that most think patients are 'the real experts.' Some women explicitly argued this:

Mercedes: 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.

In order to make the case that most clinicians do not have 'a solid understanding', women with endometriosis use what they have learned about endometriosis science to point out where their clinicians are misinformed, and to educate other women. However, as Beth points out, patients have their 'own jobs to do' and cannot devote their entire lives to learning and teaching about endometriosis. Also, there are structural limits to patients' appropriation of medical expertise; they cannot write prescriptions or conduct surgery. Without the requisite credentials, they are not socially recognised medical experts on endometriosis, however much they may know. They partially compensate for the exclusionary nature of expert systems by asserting a monopoly over their own special expertise, the experiential credential.

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 are meaningful to endometriosis patients *because they have their own experiences to draw upon* in interpreting another woman's experiential narratives. Women with endometriosis do not need to have had all the same experiences; what is essential is that an experiential affinity is recognised. 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. One simply has to have had some of these experiences to be able to recognise one's self in the matrix of endometriosis patients' collective experience.

Of course, all of these characteristic endometriosis experiences are linked to categorisation. Without the medical elaboration of an entity called endometriosis, there can be no

endometriosis patient community; and the labelling of women *as* endometriosis patients is a discursive act performed by physicians. Paradoxically, while personal experience is the foundation of this community, personal experience alone does not gain one entry to it; for, although women can have embodied experiences that ‘seem like endometriosis’ whether or not they have been diagnosed, they are not *endometriosis experiences* until women are diagnosed with endometriosis by a physician. Endometriosis is a medical category, not a ‘natural’ one. Women may suspect they have endometriosis, but until they receive medical confirmation via laparoscopy, they may have ‘something else’. There are several conditions whose symptoms can be very similar to endometriosis (e.g. pelvic inflammatory disease, irritable bowel syndrome, polycystic ovarian syndrome). As with many chronic illnesses associated with epistemic discreditation (e.g. Barker 2005), the key turning point in the typical endometriosis story is the diagnosis, which women usually describe as a validation of their embodied experience and credibility, and a boost to their self-esteem and sense of control. Ultimately, *entry* to this patient-experience-centric community is policed by the discursive act of medical labelling.

That said, medical labelling is a necessary but nevertheless insufficient source of community; a feeling of belonging to/with one another stems from these women’s belief that they have had similar experiences *ontologically*. This comparability exists, they believe, at a level deeper than language; but it must be expressed in language and in formats developed by the patient community to enhance its recognisability from patient to patient (see Robinson 1990).

The second use of the notion of experience is that it allows women with endometriosis to draw a boundary around their community; insiders have the requisite experience and outsiders can never understand. 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 that those without the disease (including doctors, their primary competitors for credibility and those most likely to discredit them) do not have.

Thirdly, whatever experience *is*, it is drawn on as a substantive resource in claims-making, a resource that has content as a book does. Women in the community suggest that we can *learn* from experience and use that knowledge to teach others – even that we have a *moral responsibility* as community members 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?

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 perspective may be better able to evaluate her doctors’ claims, to contest them if necessary, and to have those evaluations and contestations validated, because she can present herself as a knowledgeable agent, rather than a hysterical hypochondriac. She may also learn how better to control symptoms and side effects. 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 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 caused.

Conclusion

Traditionally, the literature on patient communities has elucidated the common embodied experiences, reactions against medical mismanagement, and struggles to obtain help and information experienced by patients. The argument of this paper is that such responses, reactions and struggles may *emerge from and, in turn, help to constitute* specific views about what actually counts as knowledge and how to adjudicate competing claims. In the case of the endometriosis patient community examined here, these are explicitly epistemological views which are shared and consensual, and which seem to emerge from participation in patient community venues. Patient communities are not merely about griping, mutual support, political resistance, or sharing experiences, then. They are increasingly about claim formulation, defence, resistance, and adjudication, and the formulation of principles to guide such activities. As patients increasingly gain access to and exchange medical information, particularly via the Internet, the line between political resistance and epistemological action blurs. Since, in contemporary society, 'power resides in the codes that order the circulation of information', new social movements focus upon mounting 'symbolic challenges to the dominant codes' (Melucci 1989: 47). Patient movements may be read in precisely this way.

But while the importance of symbolic challenges and the central role of experience in patient movements have been recognised (Abel and Browner 1998, Brown *et al.* 2004, Pierret 2003, Williams and Popay 1994), the epistemic processes and rules by which patients mount these challenges using experience have not been sufficiently examined. This paper begins to fill that void through a case study of an endometriosis patient community as an epistemological community.

The endometriosis patient community examined here does not have an explicit epistemological model based upon formalised principles. It is formally dedicated to mutual support, not to the development of knowledge like the medical expert community. However, as mutual support entails the sharing of information, the community has developed and advanced many claims about endometriosis and medical and patient knowledges of it. A somewhat flexible, pragmatic model for knowing, geared toward the solution of concrete problems faced by endometriosis patients, has evolved, and it is discernable in patients' claims about the medical profession and in their self-presentations as knowers. Their accounts present the social processes of learning about endometriosis, and depict knowledge

as communally, rather than individually, derived. Participants presented themselves as active knowledge seekers, but described barriers to accessing information and contradictions in existing knowledge of endometriosis. 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 valorise their individual and collective experiences as a foundation for knowing endometriosis, they tend not to recognise clinical experience as a valid form of knowledge. Instead, they reinforce the official epistemic hierarchy of medicine that places scientific claims above 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. 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. While personal experience is valorised in epistemic *principle* in the community, in epistemic *practice* it is not always a rock-solid foundation for knowing because of the assaults of pain, drugs, and doubting physicians on the rational self. Like other forms of knowledge, 'experience' can be contested by others and must be validated by others. Medical information and the accounts of other patients were used to confirm that experiences were 'real' or 'normal'. The core, reasoning self thus remains intact, enabling patients to resist epistemic discreditation.

The patients' accounts made some direct linkages between community, knowledge and resistance. Self-education was conducted largely *in response to* doctors' unwillingness to share information with patients, and largely *through* the resources of the patient community. Once patients educated themselves and each other, they learned of the inadequacies in medical knowledge, which reduced the cognitive authority of their clinicians. 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. They compensated for their lack of expert credentials by asserting their own special area of expertise: the experiential credential. The validation of illness experience as a form of knowledge is done by the community, not by isolated individuals. 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. Further research is necessary to determine whether the kinds of epistemic strategies and rules used by members of this patient community are used in other patient communities as well.

Patient epistemological strategies and their challenges to biomedical authority are particularly interesting in the current climate. Through the championing and standardisation of 'best practices,' the rise of evidence-based medicine has functioned to bolster arguments for professional autonomy and medical authority in the face of increasing challenges. Conversely, the emergence in the same period of the competing discourse of

'patient-centredness' has often been read as a capitulation to patient and consumer demands. Yet, it can also be used by individual clinicians to champion clinical experience (with patients) and justify clinicians' refusal to be standardised and regulated (Armstrong 2002). In addition, the clinical interest in patient experience can be read as a form of surveillance that extends medicine into more and more areas of personal life (Armstrong 1984). The current conflict between evidence-based and patient-centred medicine demonstrates the conflicting tendencies within medicine – the chinks in biomedicine's epistemological armour. Endometriosis patients exploit such cracks, challenging both the expert-dictated standardisation of evidence-based medicine through their appeals to embodied patient experience, and the individuation of the patient-centred model through their thoroughly communitarian brand of experiential narrative. In distinguishing their community from others who can never know, women with endometriosis help to erect the boundary between experience and science, between the voice of the lifeworld and the voice of medicine (Mishler 1984). This may represent a form of resistance to the incursion of medicine into the lifeworlds of people with chronic illness, one which keeps patient experience for patients alone.

It seems clear that we cannot understand conflicts between physicians and patients and the challenge to biomedical authority in the present day simply as the result of patient demands for *more* or *better* medical information *from physicians*. What *counts* as good health information, and *whose* information is best, are at issue. The challenge of embodied health movements is not merely political; it needs to be addressed at the much deeper level of epistemological strategy and principle.

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Notes

- 1 'Mercedes', like the names of all research participants quoted in this paper, is a pseudonym. Focus group members chose their own pseudonyms; WITSENDO participants were assigned codenames from W1 to W18.
- 2 According to the Endometriosis.org website (2005), at least 24 countries now have national self-help organisations for women with endometriosis. These organisations have become significant players in medical research, clinical, and political communities, particularly in North America, the UK and Australia. To my knowledge, only North American groups have been analysed in the published social science literature (Capek 2000, Whitney 1998).
- 3 GnRH agonists at the time of the research included four brand name drugs: Lupron (leuprolide acetate), Suprefact (nafarelin acetate), Synarel (buserelin acetate), and Zoladex (goserelin acetate).
- 4 This participant is referring to a hysterectomy in which the uterus is removed but one or both of the ovaries and fallopian tubes is retained.

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