

Electronic Support Groups, Patient-Consumers, and Medicalization: The Case of Contested Illness*

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This article illustrates the role electronic support groups play in consumer-driven medicalization. The analysis is based on an observational study of a year in the life of an electronic support group for sufferers of the contested illness fibromyalgia syndrome. The analysis builds on and extends scholarship concerning the growing influence of lay expertise in the context of medical uncertainty by showing how the dominant beliefs and routine practices of this electronic community simultaneously (and paradoxically) challenge the expertise of physicians and encourage the expansion of medicine's jurisdiction. Drawing on their shared embodied expertise, participants confirm the medical character of their problem and its remedy, and they empower each other to search for physicians who will recognize and treat their condition accordingly. Physician compliance is introduced as a useful concept for understanding the relationship between lay expertise, patient-consumer demand, and contemporary (and future) instances of medicalization.

The Internet is now a principal source of health and medical information. In 2002, for example, approximately 93 million American adults went online to search for information about their health (Fox and Fallows 2003; Wellman and Haythornthwaite 2002). A key component of what is now called “e-health” is electronic support groups (ESGs) for illness sufferers. Accessed as bulletin boards, newsgroups, listserves, and chat rooms, ESGs take

the form of electronic postings in which individuals—in real or delayed time—write, send, and read textual messages. There are tens of thousands of illness ESGs and many millions of participants (Eysenbach et al. 2004; Fox and Fallows 2003). In effect, nearly any sufferer of nearly any condition can type his or her affliction into a search engine and electronically connect with a group of fellow sufferers.

Even as peer-to-peer ESGs have become a ubiquitous feature of the illness experience, we know remarkably little about them. According to a study published in the *British Medical Journal*, there is a paucity of evidence regarding their therapeutic efficacy and uncertainty about how, or even if, they can be evaluated in accordance with the clinical standards of evidence-based medicine (Eysenbach et al. 2004). ESGs, after all, are social phenomena, and must be studied, at least in part, using the tools and methods of social science. What is certain is that ESGs provide laypeople with unprecedented opportunities to share information with one another and become experts in their condition (Broom 2005; Fox, Ward, and O'Rourke

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2005). As a result, the process of understanding one's embodied distress has been transformed from an essentially private affair between doctor and patient to an increasingly public accomplishment among sufferers in cyberspace.

The spectacular growth of ESGs can be seen as part of a broader contemporary cultural trend; namely, the waxing of lay expertise and the concurrent waning of deference toward expert knowledge systems (Giddens 1991). Laypeople no longer consider expertise to reside exclusively with professionals, including medical experts (Brown 1992; Brown et al. 2004; Collins and Pinch 2005; Kroll-Smith and Floyd 1997). The effects of this trend can only be described as mixed. On the one hand, the democratizing impulse represented by increased access to lay sources of health information is to be applauded; patient self-empowerment and challenges to professional hegemony are rightly seen as positive outcomes (Clarke et al. 2003; Crooks 2006; Hardey 2001; Henwood et al. 2003). The potential for lay ways of knowing to supplement medical knowledge and advance our understanding and management of human suffering is also praiseworthy (Brown 1992; Kroll-Smith and Floyd 1997; Popay and Williams 1996). On the other hand, it is possible that the increased production and exchange of lay information via ESGs and other Internet communities may contribute to "medicalization," or the processes by which an ever wider range of human experiences come to be defined, experienced, and treated as medical conditions. Whereas physicians' professional power and ambition were the principal forces driving medicalization in the twentieth century (Freidson 1972; Illich 1976), Conrad (2005) recently called on sociologists to investigate the role played by consumers, including those who form ESGs, in defining their own problems as medical and functioning as an important "engine of medicalization" in the twenty-first century.

This article takes up Conrad's charge. More specifically, the following analysis is based on an observational study of a year in the life of an ESG for sufferers of the controversial pain disorder fibromyalgia syndrome (FMS). The data for this study include all the postings to an open bulletin board given the pseudonym *Fibro Spot* from February 2004 to February 2005.¹ *Fibro Spot* is a cybercommunity with its own elaborate and distinctive cultural practices, but

this investigation expressly addresses the role that these kinds of groups and this new technology play in the process of consumer-driven medicalization.

An ESG run for and by FMS sufferers is an especially instructive case. Fibromyalgia is just one of several increasingly common illnesses characterized by disturbing symptoms for which no specific biomedical mechanism can be found (Barsky and Borus 1999; Manu 2004). As such, these syndromes are medically suspect, even while they are experientially devastating. This case study thus foregrounds a conflict between professional knowledge and lay experience, and how, in the context of such contestation, ESGs can play a crucial role in defining diffuse human suffering in medical terms and engendering patient-consumer demand for medical recognition that physicians are often reluctant to provide. The analysis, therefore, builds on and extends a body of scholarship concerning the growing influence of lay expertise in the context of medical uncertainty (Brown et al. 2000; Brown et al. 2004; Kroll-Smith and Floyd 1997; Zavestoski et al. 2004) by explicitly highlighting its propensity to promote (rather than challenge) medicalization.

BACKGROUND AND CONCEPTUAL FRAMEWORK

Contemporary Medicalization: The Role of Patient-Consumers

Despite a few isolated cases of demedicalization (e.g., masturbation, homosexuality), Western societies have become increasingly medicalized (Clarke et al. 2003; Conrad and Schneider 1992). It is widely recognized, however, that the principal forces behind medicalization in the present era differ from those that expanded medicine's jurisdiction up through the first three quarters of the twentieth century (Clarke et al. 2003; Conrad and Leiter 2004). Dramatic changes in the organization of medicine toward the end of the twentieth century, most notably the rise of corporate managed care and the corresponding decline of physicians' professional power, underlie changing patterns of medicalization. One can summarize (albeit in an overly simplified way) the standard twentieth-century story of medicalization as follows: Physicians carved out a professional niche for themselves by negating lay knowledge and practices and promoting the medical management of natural human experiences, so-

cial ills, and personal problems (Conrad and Schneider 1992; Freidson 1972; Illich 1976; Wertz and Wertz 1989). In contrast, when it comes to the forces promoting the expansion of medicine's jurisdiction in the current era, the role of physicians has declined in significance, while that of biotechnology (e.g., pharmaceuticals and genetics) and other corporate health industries (e.g., managed care), in tandem with the markets and consumers they create and serve, have increased in salience (Clarke et al. 2003; Conrad 2005; Conrad and Leiter 2004).

Although there is some disagreement about whether these "shifting engines of medicalization" (Conrad 2005) are the continuation of modernity's march toward rationalization or whether they signify a new, postmodern era of "biomedicalization," there is little disagreement that the transformation of medicine from being primarily professionally directed to being increasingly market-driven places the patient in a new role vis-à-vis medicalization (Ballard and Elston 2005; Clarke et al. 2003; Conrad 2005). Briefly stated, it is increasingly the case that patients contribute to medicalization via their consumer "desire and demand" for medical goods and services (Conrad 2005). Cosmetic surgery, adult attention deficit hyperactive disorder, Gulf War syndrome, multiple chemical sensitivity, and in vitro fertilization are just some of the instances where patients have played a crucial role in medicalizing their problems and disappointments (Conrad 2005; Conrad and Leiter 2004; Conrad and Potter 2000; Zavestoski et al. 2004). Direct-to-consumer pharmaceutical advertising specifically instructs patients to ask their doctor about particular drugs to treat many previously normal, banal, or benign "symptoms" (e.g., toenail discoloration, heartburn, diminished sexual drive in men) and to consider them as specific medical conditions or diseases (e.g., dermatophytes, acid reflux disease, erectile dysfunction) (Moynihan, Heath, and Henry 2002). The Internet can also fuel consumer demand for medical solutions to a range of human problems (Conrad 2005). When individuals search for online information to help them make sense of common symptoms, troubles, and distresses, an array of commercial and nonprofit Web sites provide them with seemingly endless detail about innumerable medical conditions, diagnoses, and treatments—many of which were previously

unknown to the individuals—to discuss with their physicians.

Consequently, physicians increasingly encounter concerned patients who already have information about their problems and how they might be treated. The widespread public availability of such health and medical information alters the traditional doctor-patient relationship and transforms the patient into "a reflexive consumer" who makes "active decisions concerning treatment procedures" (Fox et al. 2005:1300; see also Burrows et al. 2000; Hardey 1999; Hardey 2001; Henwood et al. 2003). More specifically, however, when the informed consumer calls for medical goods and services that fall outside established diagnostic and treatment protocols, there is a risk of medicalizing experiences that would otherwise remain outside of medicine's purview, or intensifying the extent to which already medicalized conditions fall under the medical gaze.

The informed patient-consumer is thus becoming an increasingly potent force in determining what heretofore nonmedical conditions come to be defined and treated in medical terms. What role do ESGs play in this general trend? A small number of studies conclude that the types of information and support individuals receive via ESGs represent challenges to the doctor-patient relationship by subverting the presumed flow of information from doctor to patient and privileging embodied over expert knowledge (Broom 2005; Burrows et al. 2000), but the connection between ESGs and medicalization per se has not yet been explored. As noted, ESGs operated by and for sufferers of contested illnesses, where participants typically struggle to achieve the very medical recognition that physicians often deny them, provide a particularly appropriate context for exploring this connection.

Contested Illness and Lay Expertise: Specifying the Relationship between ESGs and Medicalization

Recent decades have witnessed a sharp rise in the prevalence of illnesses characterized by a host of disturbing symptoms for which medical experts can find no explanation (Barsky and Borus 1999; Manu 2004). For example, more than ten million Americans are diagnosed with at least one medically unexplained syndrome, including fibromyalgia syndrome, chronic fatigue syndrome, irritable bowel syndrome, chronic pelvic pain, tension headache,

multiple chemical sensitivity, Gulf War syndrome, sick building syndrome, chronic Lyme disease, premenstrual dysphoria, and candidiasis sensitivity (Sadovsky 1999; Wessley 2004). These overlapping disorders are typified by numerous common and diffuse symptoms, ranging from pain and fatigue to cognitive and mood disorders. Because these syndromes are not linked to any known organic abnormality but instead are diagnosed using patients' subjective reports of symptoms, many physicians approach these diagnoses, and those so diagnosed, with considerable skepticism (Asbring and Narvanen 2003; Crofford and Clauw 2002). The fact that patients respond poorly to established treatment protocols further fuels medical suspicions (Goldenberg, Burckhardt, and Crofford 2004). In simple terms, what is at issue in the minds of many physicians is whether these syndromes are "real" (i.e., they have physical origins) or not (i.e., they are psychosomatic).

For these millions of sufferers, living with a medically unexplained syndrome means managing a constellation of chronic and often debilitating symptoms that many physicians consider to be of their own making. As such, these syndromes are important instances of the growing number of cases in which medical expertise and lay experience are profoundly incommensurate (Collins and Pinch 2005; Couch and Kroll-Smith 1997). In an effort to provide answers and solutions to their problems that are consistent with their subjective experiences, laypeople become "citizen scientists" or "patient experts" on their own behalf (Brown 1992; Collins and Pinch 2005; Kroll-Smith and Floyd 1997). This includes drawing on embodied knowledge to challenge medical expertise and producing logical accounts of their own distress (Kroll-Smith and Floyd 1997).

Given the insights of the above-cited research concerning lay expertise and medical uncertainty, it is not surprising that there has been a proliferation of ESGs run for and by sufferers of medically unexplainable syndromes. Anecdotal reports from participants suggest that ESGs provide invaluable information and social support that significantly alleviate distressing symptoms and minimize the self-discrediting impact of living with a contested illness (Barker 2005; WebMD 2005). But what interests us here is the possible relationship between ESGs and the medicalization

of common symptoms under the auspices of contested illness classifications.

For a variety of reasons, the scholarship on lay or patient expertise gives little attention to its potential link to medicalization. Medicalization is not its primary substantive concern; rather, the main focus of this literature involves how lay knowledge and expertise are used to make sense of embodied suffering when medical expert systems fail to do so (Brown and Zavestoski 2004; Brown et al. 2000; Kroll-Smith and Floyd 1997; Zavestoski et al. 2004). Medicalization is also underemphasized in this research because its empirical focus is weighted heavily toward illnesses with an environmental component, where patients often attack narrowly biomedical interpretations of their condition in an effort to politicize the environmental causes of their illness. Sufferers of contested environmental illnesses ostensibly resist medicalization (Kroll-Smith and Floyd 1997). In the case of many contested illnesses, however, sufferers are steadfastly committed to framing their problems in strictly conventional biomedical terms. Such is the case for participants at *Fibro Spot*. This study, therefore, builds on and extends our understanding of conflicts between lay and expert knowledge by demonstrating how, in some cases, these conflicts result in patient-consumer initiated medicalization claims.

The analysis that follows highlights how the dominant beliefs and routine practices of *Fibro Spot* simultaneously (and paradoxically) challenge the expertise of physicians and encourage the expansion of medicine's jurisdiction. Drawing on their shared embodied expertise, participants confirm the medical character of their problem and its remedy, and they search, as patient-consumers, for physicians who will recognize and treat their condition accordingly. *Physician compliance*—the expectation that physicians will accept patient expertise—is presented as a useful concept for understanding the link between patient expertise, patient-consumer demand, and contemporary (and future) medicalization trends. The limits of patient expertise and consumer demand are also addressed.

DATA AND METHODS

Lay-run ESGs are organically occurring social phenomena. Hence, there is much to be gained by studying them using methods that capture how they function on a day-to-day ba-

sis. This is a task for which field research is particularly well suited. In a published debate concerning the efficacy of ESGs, several leading health researchers suggest that field methods be developed for and applied to the study of these groups (Barak, Grohol, and Pector 2004; Eysenbach 2004). Field research (e.g., ethnography, participant observation, nonparticipating observation) provides a description of a natural social environment based on data that researchers collect by submerging themselves in the very setting being studied. In the case of electronic field research, that social environment is an electronic community, group, or site, such as *Fibro Spot*.

The Setting

Fibro Spot is an open bulletin board system that has been in existence for more than ten years. The Web site's staying power makes clear that it is not one of the many illness ESGs that quickly appear and then disappear into cyberspace. *Fibro Spot* is lay-created and lay-maintained, as is typical of many illness ESGs that have emerged in the last decade (Barak et al. 2004). Without question, lay ESGs are significantly more common than those created and administered by health professionals (Eysenbach et al. 2004). *Fibro Spot* does not display visitor statistics. However, a Google search provides some indication of the group's popularity relative to other fibromyalgia ESGs. *Fibro Spot*'s homepage is among the top fifty highest-ranked pages among 6,710,000 hits for "fibromyalgia" and one of the top five ESGs listed.² Although Google's ranking is not a measurement of use per se, it is strongly related to visitor traffic.³ At the very least, we can say that *Fibro Spot* is among the most electronically visible fibromyalgia ESGs. An additional justification for selecting *Fibro Spot* over other popular groups is found in the emerging ethics guidelines for conducting online research, which I address below.

Nonparticipating Observation

A crucial decision in all fieldwork is whether the researcher will participate in the social setting being studied. Because there are benefits and limitations associated with either approach, the decision to participate (and to what degree) or to be a nonparticipating observer is often determined by particular features of the field or by specific substantive concerns underlying the research (Lofland and Lofland

1995; Marshall and Rossman 1995). When it comes to studying lay-run ESGs, a strong argument can be made for nonparticipation, or what in the online world is called "lurking." The known presence of an online researcher fundamentally changes the peer-to-peer environment of an ESG (Barak et al. 2004; Eysenbach 2004). In a study of an online group for patients with heart defibrillator implants, Dickerson, Flaig, and Kennedy (2001) found that their participation in the ESG significantly altered the character of interactions in terms of both content and structure. In response, the researchers opted not to continue posting to the group but to conduct their research as nonparticipating observers. If we are interested in studying an ESG as a naturally occurring social phenomenon, the direct participation of a researcher is counterproductive. Therefore, this study uses a nonparticipating approach.

Even though there may be a sound substantive reason for conducting a nonparticipating observational study, there are empirical consequences associated with doing so. Insofar as they capture all the public activities of a group, downloaded electronic communications can be thought of as nearly perfect field notes (Stone 1995). Keeping a record of observations is not dependent on the discretions, proclivities, or skills of the researcher. There is effectively a full textual record of what takes place in the public arena of *Fibro Spot*.⁴ Nevertheless, under the conditions of nonparticipation, the researcher is unable to follow up on the implied meaning of an author's posting or its implications for readers. This can be particularly problematic when postings are haphazardly and hastily written, as can be the case with computer-mediated communications (Mann and Stewart 2003). Likewise, a nonparticipating researcher cannot ask questions about the nature or significance of private e-mail communications between group members, despite the importance these exchanges may have to online communities. Even as there are widely recognized benefits of unobtrusive measures of social life (Lofland and Lofland 1995), including online social life (Dickerson et al. 2001), simply downloading electronic communications yields data that are stripped of important context. Based as it is on nonparticipating observation, the analysis presented in this article necessarily underappreciates various nuances in the daily life of *Fibro Spot*.

Not interacting with online research subjects also raises a set of ethical concerns. *Fibro Spot* was selected for a number of reasons that exemplify a position in an ongoing debate concerning what obligations researchers have to protect the privacy of ESG participants, given the public nature of the Internet. Using several criteria outlined by Eysenbach and Till (2001), we can say that *Fibro Spot* is significantly more public than private. First, the group is an open bulletin board, which means that it does not require users to register or subscribe. When an ESG requires registration, the group is less public. Second, *Fibro Spot* is a large group. With well over 200 participants, individuals are less likely to think their postings are intimate than would individuals in a group with only a handful of participants. The group also archives its exchanges on its home page. By providing a full electronic history of its postings, *Fibro Spot* intentionally increases its public visibility beyond its current and active participants. Finally, there is nothing posted on *Fibro Spot's* Web page outlining "netiquette" restrictions concerning who is free to use the materials, who owns or has copyright to the posted materials, and the like. In contrast, *WebMD*, the largest e-health site, operates ESGs that contain the postings of thousands of individuals, but, legally, *WebMD* claims ownership over all the material that appears on their Web site. In sum, the explicit public character of *Fibro Spot* justifies using the group's interactions without their consent (Hewson et al. 2003).

Regardless of how public an ESG is, Eysenbach and Till (2001) maintain that researchers should never lurk and should always seek the informed consent of participants. Unfortunately, this position effectively precludes the study of natural social group dynamics on the Internet. Not only does the known presence of a researcher in a cybercommunity alter routine patterns of interaction, but it would never be possible to gain the consent of all members in a group, especially given the intermittent and infrequent participation patterns of many users. Ultimately, insisting on informed consent in all cases is no less simplistic than its counterpart—namely, that all Internet activity is public and, therefore, ethical guidelines need never be established. It is possible to evaluate where a group falls along a public-private continuum and make nuanced decisions, both about the appropriateness of

lurking in specific online contexts and about when informed consent is and is not necessary.

Data and Coding

There are interesting questions about what downloaded electronic communications represent. In what ways are computer-mediated communications similar to or dissimilar from other types of qualitative data, and how does one go about analyzing them? Electronic support groups exist as texts. Accordingly, electronic field research must rely on textual, discourse, or content analysis (Denzin 1999). Electronic postings, however, are not simply texts. They are also social interactions (Hine 2000; Mann and Stewart 2003). Most postings at *Fibro Spot* are seeking a response or providing one to other participants. A nonobtrusive research method was used in this study precisely to capture the natural interactive character of daily life at *Fibro Spot*. Accordingly, the postings are analyzed in terms of thematic content and in terms of interactive threads that tie individual postings to one another.

All postings to *Fibro Spot* from February 2004 to February 2005 were downloaded and analyzed using NVivo, a computer-assisted qualitative data analysis software program. Two approaches were employed in coding thematic content. First, codes were created for preidentified conceptual concerns, including illness reification, embodied versus professional expertise, and consumer demand for medicalization (Barker 2005; Broom 2005; Clarke et al. 2003; Conrad 2005). I identified postings or sections of postings that addressed the essence of these pre-established codes by closely reading through the entire year of online exchanges. In this process, relevant and pronounced patterns emerged from the data beyond those captured in the pre-established codes. Accordingly, additional codes were created to represent these emerging themes and applied in subsequent readings of the data. For example, the limitations of patient expertise and physician compliance were identified through this strategy. This latter technique more closely approximates an interpretive (Waitzkin, Britt, and Williams 1994) or grounded theoretical approach (Charmaz 2006).

In addition to coding for substantive or thematic content, postings were identified as belonging to particular social threads. A social thread refers to all postings that connect to a

particular sequence of social interaction among participants (Denzin 1998). The postings cited in this paper are examples of social threads. The overwhelming majority (more than 90 percent) of messages at *Fibro Spot* are part of at least one social thread; many postings are part of multiple social threads.⁵

Participation at Fibro Spot

Between February 2004 and February 2005 there were 249 participants in *Fibro Spot*. Fibromyalgia is highly feminized—approximately 90 percent of those who meet the diagnostic criteria are women (Hawley and Wolfe 2000)—and the participants at *Fibro Spot* reflect this fact. Roughly 92 percent of participants ($n = 227$) identify themselves as women. Fourteen men participated: Eight were diagnosed with FMS, two were husbands of fibromyalgia sufferers, and four were “third parties” (e.g., individuals posting advertisements for fibromyalgia products or treatments). The gender of eight participants could not be determined either by username or posting content.

Collectively, the 249 participants contributed a total of 1,814 postings. The frequency with which these individuals contributed postings varied considerably (see Table 1). One hundred thirteen individuals (45.4 percent) posted only one entry during the entire year; 56 individuals (22.5 percent) posted two or three entries. As measured by actively posting, the overwhelming majority of participants (nearly 70 percent) quickly dropped in and then out of *Fibro Spot*. In contrast, there were some individuals who contributed postings with more regularity, including some who were highly active participants. For example, 16 percent of individuals posted between 4 and 10 entries, slightly more than 8 percent posted between 11 and 20 entries, and slightly less than 8 percent posted more than 20 entries during the course of the year. Only three individuals posted at

least one entry a month; the most active participant contributed a total of 145 postings. As seen in Table 1, 19 individuals contributed 1,012 of the postings during the year observed, more than 50 percent of all postings. Finally, it is important to acknowledge that, in all likelihood, the most frequent participants of *Fibro Spot* are lurkers—that is, individuals who never post a single message but who read the postings of others. In a study that monitored an ESG for smoking cessation, lurkers constituted 95 percent of those who logged onto the group’s site (Schneider, Walter, and O’Donnell 1990); other researchers suggest that for every active newsgroup participant there are 20 lurkers (Smith 1999). Even though we can only speak in general terms in the absence of data, it is safe to assume that lurkers are common and frequent visitors at *Fibro Spot*.

FINDINGS

According to Conrad (2005), medicalization happens when some problem gets defined in medical terms, “usually as an illness or disorder, or using a medical intervention to treat it” (p. 3). Electronic support groups provide individuals—active participants and lurkers alike—with the opportunity to come together to make sense of their suffering. By writing and reading about their distress, ESG participants collectively define the nature of their problem and the possible means of its solution. As the following representative exchanges demonstrate, participants at *Fibro Spot* come together to define their shared suffering and its remedy mainly in ways that encourage medicalization.

Illness Reification

The core symptoms of fibromyalgia (pain, fatigue, headaches, sleep and bowel irregularities, cognitive and mood disorders) are regrettably common in the general (healthy) public

TABLE 1. Number of Postings (NOP) to *Fibro Spot*

NOP by Individual	Number of People with This NOP	% of People with This NOP	Cumulative % of People with This NOP	Total NOP	% of Total Postings
1	113	45.4	45.4	113	6.2
2	40	16.1	61.5	80	4.4
3	16	6.4	67.9	48	2.6
4–10	40	16.1	84.0	242	13.3
11–20	21	8.4	92.4	319	17.6
21+	19	7.6	100.0	1,012	56.0
Total	249	100.0	100.0	1,814	100.0

Note: Mean = 7.28; median = 2; mode = 1; maximum = 145.

and are especially widespread among women (Barsky and Borus 1999; Verbrugge 1990; Waldron 1995). Moreover, the list of additional symptoms said to be associated with fibromyalgia is extensive; one popular self-help book, for instance, proposes nearly 100 common “symptoms” (Starlanyl and Copeland 1996). To say that fibromyalgia symptoms are common and diffuse, however, is not to suggest they are imaginary or inconsequential. There are many within the population who experience such symptoms as both real and troubling, and, when they come together at *Fibro Spot*, they readily forge an alliance. The following exchange is exemplary in this regard:⁶

Kelly: Hi, all. I'm new here so be gentle with me. I am a 56 year old grandmother of 3, newly diagnosed. I have been suffering for years, but so many different things, all over the place, that it took a while for my doctor to realize what was happening. I'll give you the short list; sleeplessness, allergies (food, medications, and pets), joint pain, arthritic symptoms, sinus infections, I think that's enough. I was afraid that everyone was starting to see me as a hypochondriac! [...] I have been through all the blood tests and x-rays, which of course showed nothing wrong. I hope I hear from others out there. This is good therapy, just putting all this crap in print.

Ruby: Kelly, Hello, Welcome to the group. I am fairly new, and am still amazed to have found that others have the same symptoms. It is such a relief to know that I am not alone. I too suffer from chronic sinus infections, joint pain, sleep troubles, restless legs, and the list goes on. [...] I hope this helps you a bit—you aren't alone.

This characteristic exchange both presupposes and corroborates the existence of a *shared* condition, despite the lack of evidence of such a condition in the barrage of medical tests to which most participants, like Kelly, have been subjected. By writing and reading postings at *Fibro Spot*, participants transform a collection of symptoms into a unified entity. At the same time, having described a wide range of possible symptoms, it becomes easy to recognize the overlaps between their own symptoms and those of fellow participants. In this way, routine exchanges at *Fibro Spot* both define what fibromyalgia is and authenticate its existence. From the point of view of participants, shared symptoms, rather than objective medical evidence, substantiate fibromyalgia as

an organic disease. This social process is called illness reification.

Reification, or the process by which socially constructed abstractions come to be regarded as actual material things, plays a crucial role in consumer-driven medicalization. Specifically, it is a core feature of lay expertise upon which subsequent consumer demand is based. From the standpoint of clinicians, fibromyalgia is “simply a label” (Goldenberg 1999) or a “construct” (Bennett 1999). However, it can hardly be experienced as anything less than concrete by *Fibro Spot* participants who come together and endow it with “disease” status. Collective affirmation of the objective, thing-like status of FMS is an essential step in consumer-driven medicalization. In its absence, the certainty that underlies lay expertise and compels consumers to seek medical recognition and treatment would be lacking.

Skeptical Dependency on Medical Expertise

Many physicians will not diagnose patients with fibromyalgia or treat patients who have been so diagnosed (Asbring and Narvanen 2003; Crofford and Clauw 2002). Consequently, like shared symptoms, the shared experience of medical disparagement strengthens participants' sense of illness solidarity. The following exchange reveals this social dynamic:

Sarah: Hello Family! [...] my new doctor appointment was today. Was not good!! First of all she is 4 months out of medical school. She looked over my chart and immediately wanted to change all medications that I am taking. . . . I said no, the ones I am taking now are just fine. She wasn't pleased about that. “Now about your fibromyalgia, I will not prescribe pain killers for fibro.” I sat there with my mouth open. She went on to tell me the fresh out of med school approach to fibro is exercise, diet. I said what about the pain. She preceeded to tell me the pain was “ALL IN MY HEAD, THERE IS NO PAIN, YOU JUST IMAGINE THERE IS.” My first thought was jump up out of this chair and slap the B—!! Instead I said you are an idiot!! Then I walked out. . . . She is a doctor at a large clinic in [city where she lives]. So I called their patient advocacy phone line to report the way I was treated. So if anyone knows a doctor in my town please, please, please e-mail me. I cannot even count the number of doctors I have been to, to just get diagnosed.

Gini: Good Evening FM'ily- Sarah- I am so

sorry that you were treated that way. It's scary that some doctor's have so much ego and ignorance about this disease. I hope you have luck finding a new doctor.

Vivian: Sarah—I'm sorry you had to go through that ordeal with your new doctor who truly is ignorant on the subject of fibromyalgia. I hope you find a new one soon who is knowledgeable about fibro instead. I went through the same thing with 2 of my doctors telling me that most doctors did not believe fibromyalgia exists. . . . I really didn't have time to waste with this kind of nonsense. I told one of the docs that he didn't have a clue.

Marilyn: Oh, Sarah, I'm so sorry about your appointment. That has to be one of the worst nightmares of Fibro. It's like having a car that won't start, and standing in front of a mechanic who says, "There's nothing wrong with it." You CAN'T fix it yourself, and now you have to find someone else. [. . .] I think your doc has not seen enough pain in school to be compassionate and willing to deal with pain. You can't truly learn about dis-ease in a book or a school. You should have kicked her in the shins and asked if it felt like it was in her head!

This typical exchange at *Fibro Spot* depicts a number of key dynamics that promote consumer-driven medicalization. For example, the exchange powerfully illustrates participants' insolence when physicians refuse to recognize and treat their suffering as a "real" disease. Vivian recounts telling one doctor that he didn't have a clue, whereas Sarah describes confronting and reporting her doctor before beginning the difficult search for a more knowledgeable replacement. In her retelling of this medical encounter, Sarah reports challenging her doctor's refusal to prescribe pain medications—a perennial complaint of women patients in general and fibromyalgia sufferers in particular (Barker 2005; Calderone 1990). Sarah also rejects her doctor's advice to self-treat fibromyalgia with diet and exercise, and is incensed by the interpretation that her pain is a psychosomatic symptom over which she has control. In other words, Sarah is dismissive of any advice from her doctor that frames her illness as anything other than an organic entity, fully worthy of orthodox medical intervention.

As the exchange unfolds we see participants supporting one another—as "FM'ily"—in the face of medical doubt and derision. Gini, Vivian, and Marilyn appear to be more than ca-

sually familiar with "ignorant," "egotistical," and "clueless" doctors. Nearly all fibromyalgia sufferers endure invalidating and discrediting experiences like that described by Sarah (Asbring and Narvanen 2001; Barker 2005; Crooks 2006). The dilemma is straightforward: Patients are certain of their illness but physicians can find nothing wrong. Because medicine doubts the existence of symptoms that cannot be seen or measured, patients' apparent good health is, in Marilyn's words, "one of the worst nightmares of fibromyalgia." Although fibromyalgia eludes medicine's gaze, the experience of fibromyalgia symptoms leaves no room for doubt, a point Marilyn sarcastically drives home by suggesting a kick in the shins for the skeptical doctor. Likewise, Sarah's dismissal of her doctor's "fresh out of medical school" approach, and Marilyn's claim that it isn't possible to learn about "dis-ease" from a book or a school, further accentuate the discrepancy between the foundational basis of lay/experiential and professional/expert knowledge (Brown 1992; Kroll-Smith and Floyd 1997).

Despite participants' criticism of doctors' professional ignorance, this exchange also speaks to their nagging dependency on professionals. After all, they are unable to "fix themselves." Participants' paradoxical stance toward experts—characterized by a combination of distrust and reliance—is identified as a distinguishing feature of the contemporary era (Giddens 1991). Laypeople no longer unquestioningly accept the opinions of experts, yet they face complex problems they are unable to solve on their own. What is insufficiently appreciated, but is exemplified at *Fibro Spot*, is that skeptical dependency can fuel consumer demand for medical solutions to a broad range of individual and social problems. When laypeople seek medical remedies for their hardships, they may be undeterred by medical experts who question the suitability of such a course of action.

Lay/Embodied Versus Professional/Medical Expertise

As foreshadowed in the exchange above, another persistent theme found in the postings at *Fibro Spot* is the inherent validity bestowed on embodied expertise. The postings from *Fibro Spot* participants convey, in no uncertain terms, a belief that their shared embodied experience trumps the presumed "expert" knowledge of

doctors. The following exchange exemplifies this sentiment:

Angela: One of my doctors warned me about places like this [online groups], telling me I would read what others wrote and then have the same symptoms myself. I can't believe that this is true but while I read some of the old posts, I remember saying to myself, "I have that, or yes that is what I feel."

Yolanda: Don't let doctors treat you like some type of idiot. That's how they deal with not dealing with FMS. It's too big of a pain for some of them to acknowledge they don't know enough about it and can't fix it. What I find in reading others' symptoms, etc. is that i'm not nuts, and this really is happening to me. Find a different doctor.

Susie: Angela, Don't let your doctor tell you that you will "feel" what you read. You will finally find out what you feel is real!! They don't usually like that because then you come back to them saying "HEY! This is wrong and I want us to work on it!" Hang in there dear one. Find a new doctor.

Yolanda and Susie encourage Angela to disregard her doctor's comments about the contaminating influences of ESGs. They explain how, despite expert opinion to the contrary, fibromyalgia is "real" (i.e., not psychosomatic) and reading the posts of others only confirms this reality. If doctors fail to acknowledge this fact, participants are encouraged to find a new doctor. This exchange, therefore, demonstrates the social process of illness reification at work, but it also draws our attention to another paradox: Participants at *Fibro Spot* challenge medical expertise in an effort to have physicians recognize their shared suffering in strictly orthodox medical terms. When Angela raises the possibility that at least some of her fibromyalgia symptoms have a complicated psychosocial origin, the suggestion is quickly and ardently banished by other members of *Fibro Spot*. In effect, the dominant discourse at *Fibro Spot* reproduces the very mind-body dualism through which medicine negates the "reality" of participants' suffering. Rather than critiquing scientific medicine's core assumptions (i.e., "real" illnesses are demarcated by observable pathophysiology), participants simply challenge the competence of particular doctors. In other words, even if physicians have lost a good deal of their cultural omnipotence (McKinlay and Marceau 2002), the strong desire to frame one's suffering within scientific medicine's

core assumptions demonstrates that medical discourse still garners significant cultural authority.

There are some important parallels here to the work of Kroll-Smith and Floyd (1997), who explain how persons with multiple chemical sensitivity criticize the medical profession but draw on the "rational, Enlightenment language of biomedicine" (p. 34) in an effort to create a logical account of their somatic suffering. However, unlike those with multiple chemical sensitivity or other contested environmental illnesses, participants at *Fibro Spot* do not resist the depoliticizing and individualizing features of medicalization by drawing attention to the influence of external factors on their well-being (Brown 1992; Brown et al. 2004; Kroll-Smith and Floyd 1997). As seen at *Fibro Spot*, when laypeople "unhinge" (Kroll-Smith and Floyd 1997) or "re-appropriate" (Giddens 1991) expertise from professional experts, they can also do so in ways that embrace the biological reductionism of medicine and promote rather than deflect medicalization. Fox et al. (2005) came to a similar conclusion in their study of an online support group for individuals taking a weight-loss drug; even though participants were empowered to become expert patients, they paradoxically accepted and perpetrated "a conservative and constraining biomedical perspective" (p. 1305).

Empowerment without Power

The next exchange further underscores how participants at *Fibro Spot* endorse medicalization by challenging physicians who discredit their embodied experience. At the same time, however, it also demonstrates the limitations on patient empowerment, participants' awareness of those limitations, and the combination of resolve and resignation with which they struggle to make their voices heard.

Becky: I know that several of you have had problems with doctors. I wanted to share my recent experience with a new primary care doctor. . . . She had told me that I could control the pain with my head. She had said to me, "The pain is not killing you. You are not dying from it." She also told me to get a job and that she didn't like couch potatoes. Anyways, I decided to go back to her one last time, but this time was going to be different. This time I was in charge. . . . I explained all about my new diagnosis and my difficulty in showering, dressing, lifting a glass of water, and walking. I explained my

pain to her in detail. After all was said and done she said, "I don't believe you are disabled." I replied, "Then this conversation is over"!!! My reason for sharing is that we can not let doctors intim[id]ate us anymore. . . . From now on I will not let this happen. If when I get a new primary he or she isn't listening or treats me in a way that I don't want to be treated then I will tell him or her and I will find a new doctor. I feel that this is important. Instead of letting doctors get us down let us take control of the situation. Afterall, we choose them and pay them not the other way around. They are not God and we are not at their mercy.

Gretchen: Thanks Becky for your inspirational words. The hard thing about being sick is that you don't feel good. When you don't feel good it is harder to fight for what you need. It's kind of ironic. The ones that need the most help have the softest voices. God willing, I am going to do something to get FM on the national map. . . . People in chronic pain need chronic pain medicine. . . . Just give us what we need and we'll go away. That is what I would like to say to someone. I don't know who yet. I'll figure it out.

Becky's posting chronicles a single patient's tenacity. She tells the skeptical physician the diagnosis for her condition and her corresponding physical limitations. Becky then encourages others at *Fibro Spot* to follow her lead: Patients must confront doctors who discount their illness. They need to find doctors who are willing to listen to them, believe in what they say, and treat them the way they want to be treated. After all, patients pay doctors; and, as the saying goes, "The customer is always right." At the same time, Becky's frustration and the predicament in which she finds herself illustrate the barriers patients face in the medical marketplace. Patients must negotiate with physicians for access to medical resources, a dependency made all the more palpable in Gretchen's plea for pain medication: "Just give us what we need and we'll go away."

Again the paradoxical nature of *Fibro Spot's* message is revealed. Participants encourage one another to recognize that they are not at the mercy of doctors, and yet, as their comments plainly reveal, they both recognize and bemoan the power that doctors have over them. *Fibro Spot* participants empower one another to persevere in the face of disparagement, but the only real power they have is the consumer power to search for a less reproachful provider. Even

this type of agency can be appreciably restricted by managed care organizations. In sum, participants contribute to the medicalization of their own suffering, but not under conditions of their own choosing.

DISCUSSION

One is necessarily limited to citing only a few examples when presenting qualitative data of this nature. Thus, the above exchanges represent only a very small fraction of postings to *Fibro Spot* during the course of the year. Although these few exchanges by no means reflect the full breadth of topics and themes discussed by this community, neither is their ethos contradicted elsewhere in the group's routine interactions. These exchanges are highly typical of postings to *Fibro Spot*, even if they are not exhaustive.

These emblematic exchanges reveal mechanisms through which the social life of *Fibro Spot* engenders medicalization. The collective life of *Fibro Spot* contributes to medicalization, not because the symptoms described as fibromyalgia are not real or all in the heads of sufferers. Rather, through routine social interaction on the basis of very real (and yet very common) symptoms, the notion of a disease entity becomes reified, even in the absence of orthodox biomedical evidence. From the perspective of participants, fibromyalgia must be real; otherwise, why would they all experience such similar symptoms? In the process of sharing details about their experiences with common forms of embodied suffering, they define and affirm the existence of fibromyalgia as a medical entity. Stories of medical disparagement, narrated by participant after participant, further solidify a sense of illness camaraderie: Participants become "FM'ily." A host of knowledge claims concerning fibromyalgia circulate and come to be reinforced through routine interactions. For example, participants vigorously defend the physical origins of fibromyalgia and reject contradictory claims. Participants dismiss doctors who claim that fibromyalgia is primarily a mental illness (or even an illness that stands at the mind-body crossroads) or a condition that they can effectively treat themselves through diet, exercise, or other lifestyle changes. Grounding their claims in their shared embodied expertise, participants challenge the expertise of individual physicians, but they do so in an effort to gain what is frequently denied them: the recognition

and treatment of their suffering by members of the medical profession.

These exchanges, therefore, reveal patient-consumers' quest for what I shall call *physician compliance*. Physicians and health researchers have long been interested in improving patient compliance (Gold and McClung 2006). Accordingly, they study ways to increase the likelihood that patients will accept medical expertise and follow doctors' orders. Medical sociologists have criticized much of this research on grounds that it conceptualizes the ideal patient as an "obedient and unquestioning recipient of medical instructions" and attributes noncompliance to patients' lack of knowledge (Stimson 1974:97). In effect, the sociological critique of this research is that the very notion of patient compliance represents a form of social control premised on the unquestioning acceptance of medical authority (Zola 1972).

In the case of fibromyalgia, the tables are turned. *Fibro Spot* participants define the ideal doctor as one who unquestioningly acknowledges patient expertise, and they attribute noncompliance to doctors' lack of knowledge. There is an expectation that doctors will concur with patients' (i.e., consumers') definition of the situation (i.e., they have a discrete physical illness) and the definition of the solution (i.e., they need a fibromyalgia diagnosis and access to the host of medical treatments recommended by fellow sufferers). Discrepancies between their embodied expertise and medical expertise concerning the existence or character of fibromyalgia are swiftly and consistently dismissed.

Of course, it is important not to overstate the power patients have in the context of the health care system or within the doctor-patient relationship. Consumer demand for medical solutions does not go unfettered (Conrad and Leiter 2004); it can be stymied by corporate or public insurance and managed care organizations, as well as by providers within those organizations. As seen in the exchanges at *Fibro Spot*, physicians remain powerful gatekeepers to many medical and social resources upon which patients are dependent. It is precisely this dependency that fuels the existence of groups like *Fibro Spot* and motivates patients in their quest for medical affirmation and treatment. Nevertheless, as seen in these typical exchanges, the search for physician compliance, premised on an unquestioning acceptance of patients' embodied knowledge, represents a

significant challenge to the traditional doctor-patient relationship and the epistemological assumptions upon which medical knowledge and practice are based. However circumscribed, patient-consumers seek physician compliance. When such compliance is not forthcoming, many continue to shop for what they really want.

Unfortunately, what they really want offers very little remedy. Even as fibromyalgia sufferers routinely comment on the profound significance of having a name for what is wrong with them (Barker 2005), there is scant evidence that being diagnosed with and treated for fibromyalgia translates into any long-term improvement in health status (Goldenberg et al. 2004; Wolfe et al. 1997). Indeed, many clinicians would argue that the medical diagnosis and treatment of fibromyalgia has little promise of reducing the suffering it represents because fibromyalgia is not, in essence, a discrete medical problem (Bohr 1995; Hadler 1997).

The failure of medical therapeutics to meaningfully lessen the suffering that characterizes fibromyalgia thus points to a well-recognized drawback of medicalization: It can obscure the broader social forces that diminish our health and well-being (Zola 1972). Consistent with this view, I argue elsewhere (Barker 2005) that the fibromyalgia diagnosis medicalizes a vast constellation of common complaints that are associated with social, economic, and personal hardships that characterize the lives of many women. Because *Fibro Spot* participants vigorously defend the conceptualization of fibromyalgia as an organic illness, with origins located in their individual bodies, they effectively preclude any discussion of the social circumstances in which their symptoms emerge. Their strategy makes sense, given that they are commonly disparaged as the likely culprits of their own predicament. Their strategy is even more understandable given the gender-charged character of the interpretation that their symptoms are "hysterical" or psychosomatic. All the same, by focusing intently on gaining medical legitimization, *Fibro Spot* participants remain largely silent on the social circumstances in which suffering is grounded and experienced.

Although there is something vaguely political about *Fibro Spot* (i.e., sufferers come together, articulate their collective grievances, and actively seek restitution), it is nevertheless

intrinsically depoliticizing in that participants help one another define their collective predicament as located within their individual bodies and encourage one another to seek individual restitution in the form of medical recognition and treatment. *Fibro Spot* participants draw on their embodied expertise to challenge medical expertise, but not in an effort to politicize the causes of their illness or make collective demands, as is the case of sufferers of contested environmental illnesses (Brown et al. 2004; Kroll-Smith and Floyd 1997). Similarly, an enormous gulf separates *Fibro Spot* from the grievances and demands of the women's health movement of the 1970s that explicitly drew attention to the negative impacts of patriarchal society on women's health and called for the demedicalization of women's routine health care (Morgen 2002; Ruzek 1978). In addition to highlighting the dramatic differences between our current neoliberal political climate and the radicalism of the early 1970s, the dissimilarity between the agenda of *Fibro Spot* and the women's health movement brings into focus a central theme of this paper: the increasing role that patient-consumers have come to play in defining their own problems as medical problems in an era characterized by a waning of medical experts' cultural authority.

CONCLUSION

Successful cases of medicalization in the twentieth century required that physicians dismantle lay practices and knowledge in their efforts to promote the medical management of human problems. In contrast, lay practices and knowledge are increasingly crucial factors in advancing consumer demand for the medical management of human problems in the twenty-first century. This article investigated an electronic support group for fibromyalgia sufferers as illustrative of this trend. Several processes have been identified whereby fibromyalgia sufferers utilize ESGs to contribute to the medicalization of their own experiences. These processes include illness reification, patients' skeptical dependency on physicians, and the cultural authority conferred on embodied knowledge. The limitations of patients' empowerment have also been noted. Whether these same processes are also typical of other illness ESGs is a matter for further research.

At a minimum, there are reasons to expect that processes of this sort are also commonplace within ESGs that are managed by and for

the sufferers of other medically unexplainable syndromes. I hypothesize that many new ESGs for sufferers of yet-to-crystallize syndromes will appear in the future, and here, too, we can expect to see similar mechanisms at work. Grounding their claims in embodied expertise, such online communities will demand that new functional somatic syndromes and other contested illness classifications be created and recognized. To give one example, online support groups are now mounting demands for the medical acceptance of Morgellons, a condition that most physicians consider to be delusional. Patients, however, maintain that they suffer from an organic condition characterized by itchy fibers under the skin that often appear blue or red in color but that "fluoresce when viewed under ultraviolet light" (Morgellons Research Foundation 2006). But there will also be less fantastical examples, given our cultural impatience and intolerance for even low-grade pain and suffering, coupled with our strong desire to have these discomforts medically classified and treated (Barsky and Borus 1995; Kleinman 1986). The potential magnitude of this trend is significant. After all, from one-third to half of the physical complaints seen in outpatient clinics are simply medically unexplainable (Kroenke and Rosmalen 2006). As individual sufferers of more and more symptoms (ranging from the mundane to the bizarre) interact with one another in cyberspace, we can anticipate many similar instances of consumer demand for new and controversial medical classifications to capture human suffering.

Some of the social processes by which participants at *Fibro Spot* contribute to medicalization may also be at play in the case of ESGs for accepted illnesses. Consider, for example, ESGs for sufferers of accepted chronic illnesses that lack established and effective treatment protocols. Participants within these ESGs also commiserate, collaborate, and support one another. They share details and information about their symptoms, treatment options, and medical encounters. In the process, they generate and disseminate lay knowledge about the character of their disease and its proper treatment. Because lay knowledge relies on different rules of evidence than does medical and scientific knowledge (Brown 1992; Brown et al. 2004; Kroll-Smith and Floyd 1997; Popay and Williams 1996), ESG participants can easily come to different conclusions about their situ-

ation than do their physicians. Because there is no overarching authority to resolve these disputes (Collins and Pinch 2005; Giddens 1991), patient demand for medical goods and services they learn about online but that are not deemed necessary by physicians can broaden and intensify the medical management of already medicalized conditions. Insofar as patients recognize their potential conflict of interest with economizing health care providers and organizations, the managed care environment will increase the likelihood that patient-consumers will persist in realizing their demands; that is, they will seek physician compliance (Barsky and Borus 1995).

The limitations of this study point to a number of important areas for future research. For example, interviewing participants in tandem with observing their online behavior would add depth to our understanding of the influence these groups have on processes of medicalization. What do participants report learning via participation, and how does that knowledge shape their subsequent medical care demands? We also need studies that assess the impacts of ESGs and ESG participation from the point of view of physicians and other health care providers. Are felt pressures for physician compliance experienced as a contributing factor in expanding the jurisdiction of medicine? Finally, studies that directly observe how patient-provider interactions are influenced by ESG participation are needed. To what extent do ESG participants actually challenge their individual doctors by referencing the knowledge claims of their illness communities, and to what effect?

Until there is more systematic research of the sort described above, many of the conclusions of this study concerning the current and future role of ESGs in consumer-driven medicalization remain tentative. What is certain is that lay ESGs and other Internet communities will dramatically shape the illness experience and the practice of medicine in the future. Electronic support groups have the potential both to impact the physician-patient relationship and to advance trends toward medicalization. Sociologists must pay attention to these crucial trends as a matter of future research.

NOTES

1. *Fibro Spot* and the names of participants used in this paper are pseudonyms. Nevertheless, one can never guarantee the

anonymity of research subjects when doing research using public electronic documents, given that online search engines make it possible to trace electronic postings (Walstrom 2004).

2. Specific rankings are not reported to preserve anonymity. This search was conducted in early 2007.
3. Google's listing order is based on a measure of interconnectedness (i.e., how frequently a particular site is linked to other sites, and how well linked those sites are to others). Regarding the relationship between ranking and utilization, the earlier a site appears in a list, the more likely an individual will visit the site. More importantly, the more "in-links" a site has, the more opportunities an individual has to link to that site while visiting other sites to which it is linked.
4. *Fibro Spot* does have a moderator who, according to the group's Web page, can delete messages that violate stated "netiquette." Many posts that clearly violated the group's netiquette standards, however, were not removed. For example, there are several postings that promote commercial products, as well as several exchanges that capture nasty personal fights. It is impossible to know how many posting violations were removed; clearly, many were not.
5. Less than 10 percent of the postings are not a part of a social thread. These are messages to which no one responded. There are no obvious patterns to these "ignored" messages. Their content ranges from the trivial (e.g., comments about agreeable weather) to the profound (e.g., suicide threats). Likewise, the authors of these ignored messages include regulars as well as first-time posters.
6. The chains of postings presented in this article are not necessarily as they appear on *Fibro Spot*. For example, in some cases there are messages that fall between the postings as presented, but any omitted postings were not a part of that particular social thread. The content of individual postings, however, is presented verbatim. Because *Fibro Spot* participants frequently use ellipses in their postings, I use [...] to denote places where I have omitted a section of text from the original posting. Ellipses not in brackets appeared as such in the original posting.

REFERENCES

- Asbring, Pia and Anna-Liisa Narvanen. 2001. "Chronic Illness—A Disruption in Life: Identity-Transformation among Women with Chronic Fatigue Syndrome and Fibromyalgia." *Journal of Advanced Nursing* 34:312–19.
- . 2003. "Ideal versus Reality: Physicians' Perspectives on Patients with Chronic Fatigue Syndrome (CFS) and Fibromyalgia." *Social Science & Medicine* 57:711–20.
- Ballard, Karen and Mary Ann Elston. 2005. "Medicalisation: A Multi-dimensional Concept." *Social Theory and Health* 3:228–41.
- Barak, Azy, John M. Grohol, and Elizabeth Pector. 2004. "Methodology, Validity, and Applicability: A Critique on Eysenbach et al." *British Medical Journal*. Retrieved May 17, 2005 (<http://bmjournals.com/cgi/eletters/328/7749/1166>).
- Barker, Kristin. 2005. *The Fibromyalgia Story: Medical Authority and Women's Worlds of Pain*. Philadelphia, PA: Temple University Press.
- Barsky, Arthur and Jonathan Borus. 1995. "Somatization and Medicalization in the Era of Managed Care." *Journal of the American Medical Association* 274:1931–34.
- . 1999. "Functional Somatic Syndromes." *Annals of Internal Medicine* 130:910–21.
- Bennett, Robert. 1999. "A Contemporary Overview of Fibromyalgia." *National Fibromyalgia Research Foundation*. Retrieved May 1, 2001 (<http://www.myalgia.com/NFRA999a.htm>).
- Bohr, T. 1995. "Fibromyalgia Syndrome and Myofascial Pain Syndrome. Do They Exist?" *Neurologic Clinics* 13:365–84.
- Broom, Alex. 2005. "Virtually He@lthy: The Impact of Internet Use on Disease Experience and the Doctor-Patient Relationship." *Qualitative Health Research* 15:325–45.
- Brown, Phil. 1992. "Popular Epidemiology and Toxic Waste Contamination: Lay and Professional Ways of Knowing." *Journal of Health and Social Behavior* 33:267–81.
- Brown, Phil and Stephen Zavestoski. 2004. "Social Movements in Health: An Introduction." *Sociology of Health and Illness* 26:679–94.
- Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Meadow Linder, Joshua Mandelbaum, and Theo Luebke. 2000. "A Gulf of Difference: Disputes over Gulf War-Related Illnesses." *Journal of Health and Social Behavior* 42:235–57.
- Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gesior Altman. 2004. "Embodied Health Movements: New Approaches to Social Movements in Health." *Sociology of Health and Illness* 26:50–80.
- Burrows, Roger, Sarah Nettleton, Nicholas Pleace, Brian Loader, and Steven Muncer. 2000. "Virtual Community Care? Social Policy and the Emergence of Computer Mediated Social Support." *Information, Communication and Society* 3:95–121.
- Calderone, Karen. 1990. "The Influence of Gender on the Frequency of Pain and Sedative Medication Administered to Postoperative Patients." *Sex Roles* 23:713–25.
- Charmaz, Kathy. 2006. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Thousand Oaks, CA: Sage.
- Clarke, Adele, Laura Mamo, Jennifer R. Fishman, Janet K. Shim, and Jennifer Ruth Fosket. 2003. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." *American Sociological Review* 68:161–94.
- Collins, Harry and Trevor Pinch. 2005. *Dr. Golem: How to Think about Medicine*. Chicago, IL: University of Chicago Press.
- Conrad, Peter. 2005. "The Shifting Engines of Medicalization." *Journal of Health and Social Behavior* 46:3–14.
- Conrad, Peter and Valerie Leiter. 2004. "Medicalization, Markets, and Consumers." *Journal of Health and Social Behavior* 45(extra issue):158–76.
- Conrad, Peter and Deborah Potter. 2000. "From Hyperactive Children to ADHD Adults: Observations on the Expansion of Medical Categories." *Social Problems* 47:559–82.
- Conrad, Peter and Joseph W. Schneider. 1992. *Deviance and Medicalization: From Badness to Sickness*. Philadelphia, PA: Temple University Press.
- Couch, Stephen R. and Steve Kroll-Smith. 1997. "Environmental Movements and Expert Knowledge: Evidence for a New Populism." *International Journal of Contemporary Sociology* 34:185–210.
- Crofford, Leslie and Daniel Clauw. 2002. "Fibromyalgia: Where Are We a Decade after the American College of Rheumatology Classification Criteria Were Developed?" *Arthritis and Rheumatism* 46:1136–38.
- Crooks, Valorie A. 2006. "'I Go on the Internet; I Always, You Know, Check to See What's New.'" *ACME: An Internet E-Journal for Critical Geographies* 5:50–69.
- Denzin, Norman. 1998. "In Search of the Inner Child: Co-Dependency and Gender in a Cyberspace Community." Pp. 97–119 in *Emotions in Social Life*, edited by G. Bendelow and S. Williams. London: Routledge.
- . 1999. "Cybertalk and the Method of Instances." Pp. 107–25 in *Doing Internet Research: Critical Issues and Methods for Examining the Net*, edited by S. Jones. London: Sage.
- Dickerson, S. S., D. M. Flaig, and M. C. Kennedy. 2001. "Therapeutic Connection: Help Seeking on the Internet for Persons with Implantable Cardioverter Defibrillators." *Heart Lung* 55:205–17.

- Eysenbach, Gunther. 2004. "Response to Barak." *British Medical Journal*. Retrieved May 18, 2005 (<http://bmjournals.com/cgi/eletters/328/7449/1166>).
- Eysenbach, Gunther, John Powell, Marina Englesakis, Carlos Rizo, and Anita Stern. 2004. "Health Related Communities and Electronic Support Groups." *British Medical Journal* 328:1166–70.
- Eysenbach, Gunther and J. E. Till. 2001. "Ethical Issues in Qualitative Research on Internet Communities." *British Medical Journal (Clinical Research Edition)* 323:1103–1105.
- Fox, N. J., K. J. Ward, and A. J. O'Rourke. 2005. "The 'Expert Patient': Empowerment or Medical Dominance? The Case of Weight Loss, Pharmaceutical Drugs and the Internet." *Social Science & Medicine* 60:1299–1309.
- Fox, Susannah and Deborah Fallows. 2003. "Internet Health Resources." *Pew Internet and American Life Project*. Retrieved November 26, 2005 (www.pewinternet.org).
- Freidson, Eliot. 1972. *Professional Dominance*. Chicago, IL: Aldine.
- Giddens, Anthony. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford, CA: Stanford University Press.
- Gold, D. T. and B. McClung. 2006. "Approaches to Patient Education: Emphasizing the Long-Term Value of Compliance and Persistence." *American Journal of Medicine* 119:32–37.
- Goldenberg, Don. 1999. "Fibromyalgia Syndrome a Decade Later: What Have We Learned?" *Archives of Internal Medicine* 159:777–85.
- Goldenberg, Don, Carole Burckhardt, and Leslie Crofford. 2004. "Management of Fibromyalgia Syndrome." *Journal of the American Medical Association* 292:2388–95.
- Hadler, N. M. 1997. "La Maladie est Morte, Vive le Malade (The Disease is Dead, Long Live the Disease)." *Journal of Rheumatology* 24:1250–51.
- Hardey, Michael. 1999. "Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise." *Sociology of Health and Illness* 21:820–35.
- . 2001. "'E-health': The Internet and the Transformation of Patients into Consumers and Producers of Health Knowledge." *Information, Communication and Society* 4:388–405.
- Hawley, Donna and Frederick Wolfe. 2000. "Fibromyalgia." Pp. 1068–83 in *Women and Health*, edited by M. B. Goldman and M. C. Hatch. New York: Academic Press.
- Henwood, Flis, Sally Wyatt, Angie Hart, and Julie Smith. 2003. "'Ignorance is Bliss Sometimes': Constraints on the Emergence of the 'Informed Patient' in the Changing Landscapes of Health Information." *Sociology of Health and Illness* 25:589–607.
- Hewson, Claire, Peter Yule, Dianna Laurent, and Carl Vogel. 2003. *Internet Research Methods*. Thousand Oaks, CA: Sage.
- Hine, Christine. 2000. *Virtual Ethnography*. Thousand Oaks, CA: Sage.
- Illich, Ivan. 1976. *Medical Nemesis: The Expropriation of Health*. New York: Pantheon.
- Kleinman, Arthur. 1986. *Social Origins of Distress and Disease: Neurasthenia, Depression, and Pain in Modern China*. New Haven, CT: Yale University Press.
- Kroenke, K. and J. G. Rosmalen. 2006. "Symptoms, Syndromes, and the Value of Psychiatric Diagnostics in Patients Who Have Functional Somatic Disorders." *Medical Clinics of North America* 90:603–26.
- Kroll-Smith, Steve and Huge H. Floyd. 1997. *Bodies in Protest: Environmental Illness and the Struggle over Medical Knowledge*. New York: New York University Press.
- Lofland, John and Lyn Lofland. 1995. *Analyzing Social Settings*. Belmont, CA: Wadsworth.
- Mann, Chris and Fiona Stewart. 2003. *Internet Communication and Qualitative Research: A Handbook for Researching Online*. Thousand Oaks, CA: Sage.
- Manu, Peter. 2004. *The Psychopathology of Functional Somatic Syndromes*. New York: Haworth Medical Press.
- Marshall, Catherine and Gretchen B. Rossman. 1995. *Qualitative Research Design*. Thousand Oaks, CA: Sage.
- McKinlay, John B. and L. D. Marceau. 2002. "The End of the Golden Age of Doctoring." *International Journal of Health Services* 32:379–416.
- Morgellons Research Foundation. 2006. *Researching an Emerging Infectious Disease*. Retrieved September 15, 2006 (<http://www.morgellons.org>).
- Morgen, Sandra. 2002. *Into Our Own Hands: The Women's Health Movement in the United States, 1969–1990*. New Brunswick, NJ: Rutgers University Press.
- Moynihan, Ray, Iona Heath, and David Henry. 2002. "'Selling Sickness': The Pharmaceutical Industry and Disease Mongering." *British Medical Journal* 324:886–91.
- Popay, Jennie and Gareth Williams. 1996. "Public Health Research and Lay Knowledge." *Social Science & Medicine* 42:759–68.
- Ruzek, Sheryl Burt. 1978. *The Women's Health Movement: Feminist Alternatives to Medical Control*. New York: Praeger.
- Sadovsky, Richard. 1999. "An Overall Review of Functional Somatic Syndromes." *American Family Physician* 60:1551.
- Schneider, S. J., R. Walter, and R. O'Donnell. 1990. "Computerized Communications as a Medium for Behavioral Smoking Cessation Treatment: Controlled Evaluation." *Computers in Human Behavior* 6:141–51.
- Smith, Mark A. 1999. "Invisible Crowds in Cyber-

- space: Mapping the Social Structure of the Usenet." Pp. 195–219 in *Communities in Cyberspace*, edited by M. A. Smith and P. Kollock. New York: Routledge.
- Starlanyl, Devin J. and Mary Ellen Copeland. 1996. *Fibromyalgia and Chronic Myofascial Pain Syndrome: A Survival Manual*. Oakland, CA: New Harbinger.
- Stimson, Gerry V. 1974. "Obeying Doctor's Orders: A View from the Other Side." *Social Science & Medicine* 8:97–104.
- Stone, A. R. 1995. "Sex and Death among the Disembodied." Pp. 243–255 in *The Cultures of Computing*, edited by S. L. Star. Oxford, England: Blackwell.
- Verbrugge, Lois. 1990. "Pathways of Health and Death." Pp. 41–79 in *Women, Health, and Medicine in America: A Historical Handbook*, edited by R. D. Apple. New York: Garland.
- Waitzkin, Howard, Theron Britt, and Constance Williams. 1994. "Narratives of Aging and Social Problems in Medical Encounters with Older Persons." *Journal of Health and Social Behavior* 35:322–48.
- Waldron, Ingrid. 1995. "Gender and Health-Related Behavior." Pp. 193–208 in *Health Behavior: Emerging Research Perspectives*, edited by D. S. Gochman. New York: Plenum.
- Walstrom, Mary K. 2004. "Ethics and Engagement in Communication Scholarship." Pp. 174–202 in *Readings in Virtual Research Ethics: Issues and Controversies*, edited by E. A. Buchanan. Hershey, PA: Information Science Publishing.
- WebMD. 2005. "Fibromyalgia Support Group." *WebMD*. Retrieved July 1, 2005 (http://boards.webmd.com/topic.asp?topic_id=13).
- Wellman, Barry and Caroline Haythornthwaite. eds. 2002. *The Internet in Everyday Life*. Malden, MA: Blackwell.
- Wertz, Richard and Dorothy Wertz. 1989. *Lying In: A History of Childbirth in America*. New Haven, CT: Yale University Press.
- Wessley, Simon. 2004. "There is Only One Functional Somatic Syndrome: For." *British Journal of Psychiatry* 185:95–96.
- Wolfe, Frederick, J. Anderson, Daniel Harkness, Robert Bennett, Xavier Caro, Don Goldenberg, I. Jon Russell, and Muhammad Yunus. 1997. "Health Status and Disease Severity in Fibromyalgia: Results of a Six-Center Longitudinal Study." *Arthritis and Rheumatism* 40: 1571–79.
- Zavestoski, Stephen, Phil Brown, Sabrina McCormick, Brian Mayer, Maryhelen D'Ottavi, and Jamie C. Lucove. 2004. "Patient Activism and the Struggle for Diagnosis: Gulf War Illnesses and Other Medically Unexplained Physical Symptoms in the US." *Social Science & Medicine* 58:161–75.
- Zola, Irving Kenneth. 1972. "Medicine as an Institution of Social Control." *Sociological Review* 20:487–504.

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