"I Go On The Internet; I Always, You Know, Check To See What's New": Chronically Ill Women's Use of Online Health Information to Shape and Inform Doctor-Patient Interactions in the Space of Care Provision

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Abstract

Information about health, medications, and illness management programs is becoming increasingly available online. For women living with medically unexplained illnesses such as fibromyalgia syndrome (FMS), explorations in cyberspace and the information gathered from the Internet as a result can be used to enlighten, and sometimes misinform, them about the chronic illnesses with which they are living. In this paper, I use data generated from 55 in-depth interviews with women living with FMS in Ontario, Canada to illustrate the relational connections between cyberspace and the space of care provision. More specifically, I demonstrate the ways in which information gathered online is used to inform, and

prepare for, doctor-patient interactions in the space of care provision as a form of engaging in "patient agency." The paper provides a useful glimpse into what it is like to be a patient in the "information age." The analysis also assists in addressing the question: what is it that patients do with the health information they gather online? I conclude by revisiting how accessing health information via the Internet has implications for women's performances as patients and the (re)negotiation of traditional constructions of power in the doctor-patient relationship.

Keywords: chronic illness; fibromyalgia syndrome; cyberspace; Internet; doctor-patient interaction; space of care provision

Introduction

Fibromyalgia syndrome (FMS) is a chronic illness that primarily affects women and about which we know far too little (The Arthritis Society, 2002; Clauw and Crofford, 2003). Women's lives *with* FMS are the focus of this paper. While reported prevalence rates vary due to differences between practitioners in how (and whether) this illness is diagnosed, it is estimated that 3.4% of American women (Sinaii et al., 2002), 2.2% of the Italian population (Salaffi et al., 2005), 1.3% of people living in south-west Sweden (Lindell et al., 2000), and 3% of Canadians are living with FMS (The Arthritis Society, 2002). Such prevalence rates should be read with caution because of the uncertainties that frame FMS including its newness as a diagnostic category (Starlanyl and Copeland, 2001), the fact that some practitioners do not believe it is a real condition and will not diagnose it (Ehrlich, 2003), and reports that it is over-diagnosed (Fitzcharles and Boulos, 2003). Prevalence aside, the primary symptoms, chronic pain and fatigue (Clauw and Crofford, 2003), are devastating and can result in bodily impairments which diminish women's abilities to fully participate in society and space and to maintain valued roles, such as being a paid worker, volunteer, and/or unpaid careworker (Åsbring, 2001). The difficulty with this syndrome rests not with the fact that we do not understand the symptoms themselves. Rather, doctors and medical researchers have not yet discovered the processes giving rise to the symptoms and the cause of the syndrome. This puts fibromyalgia into a class of other medically unexplained conditions, such as gulf war syndrome, chronic fatigue immune deficiency syndrome, and restless leg syndrome. These conditions are similar not in that they share common symptoms – though some do – but in that they are all "syndromes" whereby there is no clear understanding as to what causes them or what connects the symptoms to each other or to the broader condition. The reality of conditions such as these, and others classified as syndromes (Starlanyl and Copeland, 2001; Staud and Adamec, 2002), is that there are no cures available and

their symptoms are medically unexplained. This means that the onset of such a syndrome involves living *with* it instead of being cured of it.

An important element of negotiating life with a chronic illness, for many, is seeking out information which can be used to come to a greater understanding of one's changed/changing body and possible treatment options. The increasing amount of health information available online (Campbell, 2004; Dickerson, 2006; Parr, 2002) is leading many to investigate cyberspace as a place in which such information can be accessed easily using search tools. As Radin (2006) suggests, patients' easy access to health information on the Internet is shifting the nature of communication in doctor-patient interactions and in the landscape of the health care system in general in that it is a social institution which is premised on a certain type of information or communication flow (namely that from doctor to patient). Furthermore, as doctor-patient relationships have shifted over time, from once being more paternalistic to now being more adult-adult, there are increasingly more expectations of patients (Goodyear-Smith and Buetow, 2001), including involvement in decision-making (Warner and Procaccino, 2004). One such expectation could then be that *both* parties come to the interaction as prepared as possible. Engaging in activities outside the space of care provision, such as turning to the Internet to supplement information shared in the doctor's office, is one way that the power afforded to the "adult patient" in this relationship can be established or maintained. Thus, engaging in such activities can also be done as a result of (mutual) expectations and not solely out of the patient's desire to increase her control over the interaction. Radin (2006, 593) makes a similar suggestion when she states that "this change [in communication style] rewards people who seek information, while it may place at a disadvantage those who continue to rely wholly on their doctor's concern." Furthermore, Dickerson and Brennan (2002) suggest that the Internet and health information available online are redistributing access to power in the doctor-patient relationship. This is not, however, to suggest that all doctor-patient relationships have shifted to the adult-adult style model, that paternalistic attitudes toward patients no longer exist, or that becoming an informed or information-rich patient by exploring the Internet will always lead to increased control or power. For example, some doctors continue to discipline patients who pursue non-Western treatments against their advice (see Crooks and Chouinard, 2006, for an example), others dismiss (Henwood et al., 2003) or are sceptical (Dickerson and Brennan, 2002) of "lay information," while others look down upon shared decision-making in general (Holmes-Rover, 2005).

Women are more willing and likely than men to use the Internet to find health information that will assist in shaping how one understands and/or manages a chronic illness (Campbell, 2004; Pandey et al., 2003). They are also more frequent users of health services, are more likely to be the primary health-related decision-maker within their family units (Nicholson et al., 2005), and are more likely to be active participants in the doctor-patient relationship than are men

(Campbell, 2004). Dickerson (2006) suggests that women most frequently search for information about diagnoses, prescriptions, medical procedures, and treatments when traveling through cyberspace. And Pandey et al. (2003) have identified three different motivations for women accessing health information online; they are: (1) to pursue good health; (2) to research an existing or newly developed health condition; and (3) to circumvent seeing a doctor. However, recent studies have shown that there are significant differences in how and whether women access information online. Wyatt et al. (2005) contend that having a computer at home does not necessarily mean that a woman will search out health information. Their work has shown that some women prefer not to access the Internet at all despite having access to a computer, or to search for health information on a computer outside the homespace where there is less likelihood that another family member will know what types of information they are accessing. Henwood et al. (2003) point out that not all patients want to take more responsibility for their health and as a result some women are not interested in augmenting the information they receive from the doctor. Also, the digital divide (the divide between the "haves" and "have nots" with regard to Internet access and computer knowledge) informs who has access to such information (Dickerson and Brennan, 2002; Dickerson, 2006; Wyatt et al., 2005). There are also differences in the contents of websites and the perceived or actual quality of information shared online. We know, for example, that women are more likely to trust information posted on sites that do not seek financial gain and that end in .edu or .org domain names (as opposed to .com) (Dickerson, 2006). Dickerson (2006) also suggests that women prefer to use health websites that facilitate interpersonal communication and networking such as those that have associated online support groups or feature message boards. This small, but growing, body of literature serves to remind us that there is a gendered nature to women's access to and use of health information found on the Internet.

In this paper, I investigate chronically ill women's use of the Internet as a place in which to access health information. More specifically, I use the experiential evidence shared by 55 women living with FMS in in-depth interviews to illustrate relational connections between cyberspace and the space of care provision. The space of care provision is the place in which the doctor-patient interaction occurs; it is shaped by larger forces, such as the organization of the health care system and the social construction of lay and professional knowledge, and by micro forces, such as one's intersectional performance as a chronically ill patient and woman. These data stem from a larger project which investigated chronically ill women's negotiations of health care services and doctor-patient interactions. During these interviews I did not directly ask about the women's Internet use. Rather, the data shared here emerged from the women sharing experiences of preparing for appointments with their doctors. With this in mind, it is important to consider this paper a starting point. What I mean by this is that the issues put forth here were not probed in the interviews but, instead, came out of the findings and so it is impossible to assess how common the experiences shared by

each of the women were both in relation to the other interviewees and also other women living with chronic illnesses. Nonetheless, the paper provides a useful and critical glimpse into what it is like to be a patient in the "information age." The data presented here also assist in addressing the question: what is it that patients do with the health information they gather online? Finally, it also extends our understanding of how and why chronically ill women use the Internet from beyond simply considering the types of health information available (Parr, 2002), or the ways in which such women immerse themselves in virtual communities (Gold, 2004; Barker, 2005), to examining what it is that they do with such knowledge and how it can inform particular acts of agency and even (re)negotiations of power hierarchies.

In the section that follows, I frame the analysis in a conceptual discussion of the doctor-patient interaction or relationship and the dynamic roles of both power and agency within it. Situated in feminist materialist theory, I argue that the health care system is a social institution in which relationships informed by patriarchal, hierarchical, and gendered traditions and stereotypes are played out in the space of care provision. Following this is a brief overview of the larger study and participant profile. The analyses are presented in the two sections that follow. First, an overview of the women's use of the Internet and explorations of cyberspace is provided. Second, I discuss how some of the women literally brought this cyber-information into the space of care with them as a way to negotiate the doctor-patient interaction, enact agency in decision-making, and even gain a source of power in the larger doctor-patient relationship.

Power Enacted in Place: Conceptualizing the Doctor-Patient Interaction

I posit that the health care system is a social institution that informs the enactment of both power and agency within the space of care provision. According to Sebrant (1999), male values and characteristics are considered normative within this system, which reinforces the patriarchal nature of this hierarchal institution. Furthermore, despite the fact that most of health services employees are female, those in the highest ranking and most senior positions – those who hold the most power and control over decision-making – continue to be men (Sebrant, 1999; DiCowden, 2003). I contend that it is realities such as these that have traditionally set the tone for the treatment of chronically ill female patients as being "in need" of help and guidance, if not even of having decisions made for, instead of with, them.

Interactions between doctor and patient provide a lens through which the control of, use of, and access to power can be examined from a feminist materialist theoretical perspective. In such a case, power is a social structure that informs institutional systems, such as that of the delivery of health services, and the agents of such systems, in this case doctors. Further, as Gesler (1999, 18) reminds us,

"power is…manifested locally in medical situations; it is felt in situated activities, in concrete medical settings." Within Western medical practice, patients are often treated as "child-like" unless they can demonstrate to doctors that they have equally valid, yet often different, sources of power, such as money (Goodyear-Smith and Buetow, 2001). According to Goodyear-Smith and Buetow (2001), doctors hold the balance of power regardless of the specific type of doctor-patient relationship (e.g. doctor as sole decision-maker, doctor as shared decision-maker) due to their access to material resources and knowledge. However, because of advances in technology, patients increasingly have access to more technical and detailed information regarding health and wellbeing and doctors no longer have a monopoly over this type of knowledge. Through his study of men living with prostate cancer, for example, Broom (2005) argues that the Internet is now a space of empowerment and control for patients looking for health information; yet, this new found information is sometimes constructed as a challenge to a doctor's authority. Dickerson and Brennan (2002), for example, contend that some doctors are sceptical about the quality of information available online, while others perceive that patients who use the Internet to access health information are more likely to question their advice or pursue untested/unscientific treatments. Other doctors may not be willing to discuss cyber-information at all and can feel particularly challenged when patients bring it into the space of care provision (Schwartz et al., 2006). Regardless of outcomes, the Internet and female patients' access to health information online are challenging, disrupting, and in some instances even reshaping the traditional power hierarchies found in health care practice.

In addition to being hierarchical, power in the doctor-patient relationship is also gendered. This reality is due in part to the male monopoly over social and political power, which is reflected in both the organization and delivery of health services where, at least traditionally, male doctors of high social standing have made decisions *for* female patients in particular (Goodyear-Smith and Buetow, 2001). Further, there are gendered (mis)conceptions about what falls into the "medical realm." For example, natural processes undertaken by women's bodies, including menstruation and menopause, have been medicalized as a result of such gendered practice. Gannon (1998) suggests that women's socio-economic positions may be determinants of their health statuses. Cahill (2001) argues that female patients' social positions assist in shaping their experiences of health care, such that a woman's access to material resources can result in her being constructed as having a valid source of power by a medical professional. Cahill (2001), like Gannon (1998), also argues that women's natural bodily practices are medicalized and that this is rooted in a patriarchal health care system that constructs women as being abnormal and also as being victims of their reproductive systems in particular.

In the context of chronic illness, it has traditionally been the case that women's experiences of pain have been more likely than men's to be classified as

psychosomatic or even hysteric in nature and thereby be ignored or treated by mental health practitioners. Werner et al. (2004) suggest that FMS has been placed into a category of "new psychiatric disorders" or "modern hysteria" by some, particularly medical professionals. Throughout the practice of modern Western medicine, women have routinely had to fight in order to have their bodily experiences recognized as being physical symptoms and not psychoses while, more recently, simultaneously working to have their natural bodily experiences be de-medicalized (DiCowden, 2003). Chronically ill women seeking treatment from health service practitioners such as GPs (general practitioner/family doctor) and specialists must therefore negotiate the patriarchal nature of the power that has traditionally shaped relationships between doctors and patients. Such patients can also exercise agency through actions such as accessing information from the Internet (Broom, 2005), engaging in decision-making such as changing doctors, or even by choosing to look less healthy or more like an ill person within spaces of care provision (Werner and Maltrud, 2003).

Participant Overview and Research Methods

The research reported on here was conducted for my doctoral dissertation. I developed an interest in exploring FMS and women's lives *with* it after conducting research for my Master's degree with women who were experiencing different types of musculoskeletal diseases. It was during that project that I was first introduced to FMS and its contested nature. Women who had developed FMS and were living in one of three Ontario communities – namely Hamilton, North Bay, and Sudbury – were sought out in the present study. The purpose of the study was to document and explain the life-changing, and also simultaneous, processes of negotiating a changed and changing socio-spatial life after developing a chronic illness and of becoming a chronically ill patient and negotiating the health care system. More specifically, I examined the ways in which women's bodily experiences, roles and routines of everyday life, relationships with others, and negotiations of social institutions were affected by, and sometimes changed as a result of, their lives with FMS. A snowball sampling strategy was used to identify participants and the data were collected between August 2003 and January 2004 after first receiving approval from McMaster University's Research Ethics Board. In-depth interviews were conducted with a total of 55 women, all of whom lived in Ontario, Canada. Their ages ranged from 35 to 88 with the average being 58 years. On average, they had lived with the symptoms of FMS for 14 years, with the shortest period being less than a year and the longest being 54 years. The average length of time since diagnosis was just under nine years (ranging from less than a year to 23 years). Further, the women lived with an average of 1.3 chronic illnesses in addition to FMS, which ranged from a minimum of no other conditions to a maximum of five others.

The questions asked of participants during the interviews were structured using a guide organized under six subheadings: (1) background information; (2) experiences within spaces of health care; (3) experiences outside spaces of health care; (4) everyday life; (5) identity; and (6) demographics. References to cyberspace and information gathered from the Internet most frequently came up when the women talked about how they prepared for appointments with their doctors, how they characterized their relationships with their doctors, and the types of information they expected to obtain while in the space of care provision. The interview data were transcribed verbatim after all interviews had been completed. These transcripts were then entered into NVivo, which is a qualitative data management program. A coding scheme consisting of ten free and 152 tree nodes (organized by 12 parent categories) provided a means by which to organize the data. The constant comparative technique was employed in data analysis. The primary form of comparison was at the "between nodes" level, particularly between conceptual and experiential nodes. For example, in this study overlaps were continually found between codes such as "agency," "appointment preparation," and "information," leading one to ask: what is the role that agency plays in the women's preparation for appointments with practitioners with regard to information-seeking behaviours? In order to maintain anonymity, pseudonyms chosen by the participants are referred to in the analytic discussion that follows.

Negotiations within Cyberspace: Searching out Information about FMS

As noted above, health information is available in abundance online. For example, a Google search of the term "fibromyalgia" conducted in early April, 2006, resulted in a total of 11,700,000 hits. Here I consider the women's use of the Internet both directly through their own searches for information, and indirectly through having cyber-information given to them while attending support group meetings (in that support groups are a channel for the dissemination of health information accessed online). Support groups (Page and Wessley, 2003) and cyberspace (Parr, 2002; Gold, 2003) are places that people living with chronic conditions are increasingly visiting in order to access health and medical information and make contact with others experiencing similar symptoms. A total of 40 of the women had attended a support group meeting at some point after developing FMS, and 20 talked about having gone online to access information about FMS. Information gathered from these and other sources was not only used to inform women about FMS, it was also used to assist some of them in negotiating the "patient" role. For example, researching FMS on their own assisted the women in determining when appointments were needed and also in identifying the most important topics and treatments to be discussed. This information can also inform chronically ill women, including those living with contested illnesses, as to how best to perform their roles as patients. The *fmnetnews.com* (Fibromyalgia Network,

2006) website, for example, states that information found there will help in "teaching patients how to help their doctors take better care of them." And on the website *Fibromyalgia-Symptoms.org* (Fibromyalgia Symptoms, 2006), patients are given the following advice about working "with" doctors:

> …It may also be helpful for you to keep a file folder or binder with any information you have collected regarding fibromyalgia syndrome. This will enable you to access information quickly and easily, and use it to your best advantage. If your health care provider does not specialize in treating fibromyalgia disorder, it might be a good idea to ask him [sic] to become familiarized with this information. Sharing an interest in the background of fibromyalgia will help to cement a great doctor-patient relationship.

This example illustrates how patients are encouraged not only to gather and keep information but also to share it with their doctors by bringing a folder or binder into the space of care provision, a practice which is discussed in greater detail in the next section.

Cyberspace was a place in which the women's medically contested bodies became literally invisible while they searched for information to assist with legitimating and/or treating and managing their biophysical symptoms. Thus, their searches for health information were connected to their lived bodies while conducted in the inbetweeness of cyberspace, or what Madge and O'Connor (2005) have argued is a liminal space. The women did not need to be concerned with others' readings of their physical presences or of how to engage in embodied performances of the ill female self or patient while online. It was a place where information could be sought out which could potentially lead to gaining knowledge that could assist them in better managing their lives with FMS and possibly even gaining a source of power in negotiating the doctor-patient relationship as vis-à-vis being in a better position to engage in informed decision-making. Tracey B., for example, desired a greater role in decision-making in treatment options. She believed that information accessed via the Internet afforded her the knowledge to do so:

> I wish they'd [doctors] be more open about it. Open about suggestions, because our education now for our day and age comes off the Internet. And what I do is research … I ask around. And then I go to the Internet and I plug in my stuff and find out what it could be.

Thumper, on the other hand, used information gained online to develop a greater understanding of FMS and of what she was told while in the space of care provision:

> My daughter had looked on the Internet …. See, as soon as I got all this information and you hear from other people you start going: oh okay, now I'm understanding all this stuff. See, it all starts to make sense when you have the information in front of you …. Well, when you go to the doctor with this [FMS], they don't know. They can't tell you. So I think they should research it. And research – you have to!

Her concern was less with engaging in shared decision-making and more with being able to augment the limited information shared by her doctor. In this instance we can also see how her daughter had become an actor in her health knowledge network through having access to the Internet.

Two women talked openly in the interviews about how they thought that not having access to the Internet was a disadvantage to developing a greater understanding of FMS. Frances explained that she irregularly participated in a support group as a way of gaining access to information due specifically to the fact that she did not have access to the Internet where she would be able to get up-to-date information about FMS. As she said: "You know, I want to be updated on anything … [but] I don't have Internet." Margaret A. linked her lack of knowledge about FMS post-diagnosis to not having Internet access:

> When I got the diagnosis nobody knew what that [FMS] was. Nobody had even heard of it that I knew. So, and it took me a lot of time to find out other people that had it, or, you know, find…because I didn't have the Internet at that time. And it took me a long time to find out what it was.

Margaret viewed having access to cyberspace as being essential to her ability to understand advances in FMS treatments and to connect with non-local others who shared her experience. Ann had a very unique experience when undergoing a medical test. She recounted it in the interview:

> Now, I've had to resource and research my illness myself. And, when I had this problem with my MRI and when he said to me "Well, you know, don't you know from the Internet?" And, I'm like "No." I didn't have a computer at that point.

In this instance it was expected that she would have read up on this test online prior to the appointment. What these women's comments reflect is the reality that, in the information age, having access to health information at one's fingertips is being constructed as an essential part of patient-hood by some.

Several participants were quick to point out that the information available online may not always be accurate. Arlene said: "You have to do your own

research. And there's lots of bad stuff on the Internet. Like, there's lots of bad information ….." Sheila's comment was similar: "… any information or problems that I have with the fibro, I … go on the Internet, which is so full of nonsense [laughter]." Darlene too was sceptical about the reliability of cyber-information:

> I can look up [on the Internet] every once in a while, you know, when I get the urge to see if there's anything new out there. But, basically, I would rely more on my family physician because you have to be so careful about what you see on the Internet.

Their comments are not unfounded. Several studies have documented inaccurate and sometimes harmful information being posted online and the negative consequences of such misinformation (for example, Crocco et al., 2002; Matthews et al., 2003; Benotsch et al., 2004). Despite this, at least 20 of the 55 participants actively traveled through cyberspace looking for all types of information related to FMS.

Negotiations within Cyberspace: Going Online to Gather Information to Prepare for Doctor-Patient Interactions

The doctor-patient interaction is a critical point for the exchange of information (Thorne et al., 2004). As such, it is not surprising to learn that many of the women engaged actively in preparing for appointments with doctors. They did things such as practice the conversation, anticipate answers to doctors' questions, make an agenda, prepare notes, and compile information gathered from sources such the Internet as preparatory activities. The women undertook such activities for a variety of reasons and not solely as a way to exert more control during the interaction or gain power in the larger doctor-patient relationship. For example, some women reported having limited amounts of time to spend with their doctors. As a result, they spent time preparing for appointments in advance in order to maximize the face-to-face time they did have. Others were concerned about wasting doctors' time and put effort into researching issues in advance to ensure that booking an appointment was warranted. At the same time, many of the women experienced challenging and sometimes disabling interactions and relationships with doctors and sought information from the Internet and elsewhere to inform their decision-making. Three women spoke openly about the gender stereotyping they had to overcome (e.g. continually having symptoms misread as being menopause) in order to ultimately be diagnosed with FMS. Seventeen others reported leaving a GP's practice in order to find a doctor who would recognize the diagnosis or who, at the very least, was willing to assist them in managing the symptoms of FMS. The women often sought out doctors who were younger or female as they were *perceived* to be more supportive of treating patients living with FMS. This was a dangerous practice though because most cities and towns in the

province of Ontario are underserviced and there is no guarantee that one will be taken into a new family practice after choosing to leave another. In the discussion that follows, I consider specifically the women's experiences of bringing cyber-information with them into the space of care provision as a way to shape and inform the doctor-patient interaction.

Fourteen of the women spoke of actively taking information sought outside of sites of health care into the space of care provision, most often for the purpose of sharing such findings with their practitioner. This was most frequently done in order to share ideas about treatments for FMS such as medications and non-Western approaches that had not been explicitly brought forth by their doctors. The reasons why women chose to do this were not discussed in the interviews but were likely informed by multiple sources, including websites. For example, at the bottom of a printed article entitled "Chronic Pain Sufferers Suffer in Silence" (Gardner, 2004) from *MedicineNet.com*, a large box appears which reads: "Review This With Your Doctor – Reliable, Relevant, & Produced by Doctors." It can be understood that this site is advocating for patients to discuss information found online with their doctors – information which is made available in a printer-friendly version where people are told to do exactly this. *Fibrotalk.info* (Fibrotalk, 2005) provides a "pain diary" sheet and suggests that people print off multiple copies, place them in a binder, fill them out on a daily basis, and then take them along to appointments with doctors as a way to supplement or inform the conversation. *Fibromyalgiasymptoms.org* (Fibromyalgia Symptoms, 2006) also recommends that people take hard copies of doctors' records away with them when leaving the space of care provision in addition to bringing information with them to the appointment as a way of being an active patient. Another way that patients can exert agency, take some decision-making control, and possibly secure power in the doctor-patient relationship, then, is by bringing information into the space of care provision instead of simply taking it away with them, whether in the form of knowledge or hard copies of records, such as print-offs from the Internet.

Support groups were a site of information dissemination. Information shared during meetings often came in the form of stories from other members and from print-offs of information gathered online. Thus, in some instances support groups were another type of space relationally connected to cyberspace through the flow of cyber-information, just as the space of care provision was. Sheila attended a FMS support group in Hamilton regularly and talked about how she informed her practitioner about other treatments based on what other group participants shared. As she said:

> With being in a support group, you know, different people take different things …. Now, when I went last month one woman told me about this particular drug, so I asked the doctor about it, so she put me on it. Like, she's good that way. I mean, since she really

doesn't know either [about the pharmaceutical]. She said "I don't know why anybody would take that but let's try it" and it's worth a try and if it works, great, and if it doesn't, fine. So she's good that way.

In this particular instance, Sheila had used information shared at the support group to put forth a "case" to her doctor as to why she should be prescribed a certain pharmaceutical. For Doreen, being the educational coordinator of her local support group meant that she had access to a great deal of resources, including folders of information printed from the Internet, archived newsletters, and self-help books. She also routinely updated the files using information accessed both in-print and online from sources she deemed to be trustworthy. She distributed handouts to the other members and prepared information packages for local doctors. The information she gathered from the Internet, books, and newsletters that she circulated during meetings was used by many group participants to inform their doctors about FMS. However, Freda had not had positive experiences of taking print information distributed at her local support group, including items gathered from the Internet, into the space of care provision. She had asked her former GP to review the information and place it in his patient library only to learn that he did not have one. Her current GP said "I must've been off on maternity leave" when Freda asked if she had received the package of information she dropped off for her. Her comments suggest that this type of strategy is successful only if both the doctor and the patient are receptive to reviewing packages and making them available to others.

Doctors' responses to the health information women accessed online were varied. When Tracey B. was searching for a diagnosis of her physical and mental symptoms she went online to search for information that might assist in understanding her changing body. Upon finding information about FMS on the Internet, she printed off copies of websites and took them with her to the pain specialist she was seeing at the time. Her experience of doing so was as follows:

> I did ask the pain specialist [about FMS]. I said I was talking to some friends about this fibro thing. So I went on the Internet, got some information off it. And [at] my last visit with the pain clinic doctor I said "What do you think of this?" and handed him the form – the stuff that I printed off. And he just kind of balked at it like "No such thing, it's a cop out, just a cover up."

After being unsatisfied with this specialist's attitude about the legitimacy of FMS as a diagnosis and also his treatment recommendations, she then pursued diagnosis elsewhere after learning more about FMS online. She was certain of the fact that it was the correct diagnosis despite her inability to convince the pain specialist of this on her own or with the information she had collected using the Internet. Tracey B. continued to search online for information about FMS regularly and printed

information for her GP in preparation for appointments. Tammy, Ann, Marilyn, and Tracey A. had all found their GPs to be receptive to receiving and reviewing information they had located online about FMS. Tracey A. said that she had "helped some of the doctors along the way to find out more about it [FMS]" as a result of searching for information in cyberspace. She found that being her own advocate and preparing for doctor-patient interactions by seeking out new information was the best strategy for negotiating appointments and that doing so allowed her to accomplish a greater sense of working in partnership with doctors. Marilyn and Ann shared a similar experience. Ann stated that: "Now I provide information for him [the doctor] – fibromyalgia-related information. Because I'm reading all the time and trying to, you know, figure out what I can do for myself." And Marilyn commented that:

> He [GP] has gotten a lot of my research, actually…. So I thought, okay, if he wants to read it, research it [FMS] with me – which he does – then that way he can help me better understand it because he's the doctor. He knows more about all this stuff. Then he can help me understand it, which is good.

Marilyn's comment clearly illustrates how bringing information into the space of care provision can be an element of a partnership-style doctor-patient relationship.

Concluding Discussion

The women's experiential evidence reveals one way in which the doctor-patient interaction can extend beyond the site of health care. Here we have seen how information gathered in cyberspace via the Internet can be used by chronically ill women to inform their negotiation of the larger doctor-patient relationship. In essence, relational connections are drawn between these disparate spaces, which are linked by the information carried between one and another. Informing oneself about FMS, developing shared decision-making, and engaging in two-way information transfer were all positive outcomes of accessing health information online but were shared only by a limited number of participants. Engaging in such an activity also demonstrates that women allocated time, effort, and energy to preparing for doctor-patient interactions. These were events that needed to be planned for and were not to happen without such preparation. The contested nature of FMS makes this particularly important given that there is no single course of treatment and that different practitioners and reliable sources of health information, whether in-print or online, recommend different treatments. A desire to appear as credible patients, to be more "in control" of doctor-patient interactions and develop partnership or adult-adult style relationships with practitioners, and, in some cases, to resist gendered stereotyping of their symptoms also explained the development of this strategy. Information seeking was done out of a desire to become more

informed about FMS and possible treatments for it and led to the women becoming more knowledgeable patients. Ultimately, the acquisition of such knowledge can potentially lead to the creation of another source of power in the doctor-patient relationship and possibly to the development of partnership-style working relationships with practitioners as demonstrated most clearly by Ann and Marilyn's experiences.

Though not discussed throughout the paper, the participants' experiences underscore the importance of having access to material resources for chronically ill women's abilities to "take charge" of the illness experience. More specifically, having access to the Internet in order to search for information about FMS, and to income with which to purchase self-help books, internet access, a computer, and treatments not covered by medicare can mediate the ways in which the health care system and doctor-patient relationships shape such patients' actions and interactions both within and outside the space of care provision. Ann spoke openly of this during the interview: "Well, there's another really expensive thing. You can't do all that research on your own and find out the connections if you don't have access to all this modern technology." The women's comments reveal that having access to the Internet and seeking health information in cyberspace is a necessary component of negotiating patient-hood in the information age. However, prohibitive costs or even a remote geographic location can prevent some women both from performing this duty and from connecting with similar others in a safe virtual space. Some of the women also expressed concern over the accuracy of this information. While informed decision-making, whether shared with a doctor or made on one's own, can potentially lead to positive outcomes, if the information is not sound then the outcomes are unclear. Despite some of the women's positive discussions of using the Internet to access information about FMS and the bringing of such information into the space of care provision, we can also understand that there are still challenges to engaging in this particular practice including whether or not doctors will even be receptive to engaging in shared-decision making or to reviewing cyber-information with patients. Such a practice, though, is only one of the ways in which health information accessed online can be used. Along the same line, learning how to (re)shape or even simply negotiate the doctor-patient relationship is only one of the many potential outcomes of chronically ill women's travels through cyberspace. Meeting similar others and becoming part of a virtual community (Gold, 2003), learning about the course of one's illness (Parr, 2002) in a way that can assist in planning for the future, or gaining the confidence to ask questions and feeling empowered to make decisions (Dickerson, 2006) are a few others.

Finally, Gesler (1999, 22) contends that "medical knowledge and language are sources of power and are used in medical situations to control others. However, power relationships can be contested and difference can be made into a positive force for better health." What this paper has shown is that, for this group of

chronically ill women, one way to contest the traditional imbalance of power between doctor and patient was to become informed about FMS through gaining access to information online and sometimes even through the practice of bringing such information into the space of care provision.

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