

# Patient Power and Control: A Study of Women With Uncertain Illness Trajectories

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*The authors interviewed 12 women diagnosed with chronic fatigue syndrome and 13 with fibromyalgia with the aim of determining the strategies they perceive themselves as using to gain control over their situation during the health care process. The results highlight various strategies that the women report applying to find a way of managing the illness and to influence caregivers. They describe, for example, how they try to gain control over their situation by acquiring knowledge about the illness. The women also describe various power strategies they use in their interaction with the caregivers to take command of their situation, namely exiting, noncompliance, confrontation, persuasion/insistence, making demands, and demonstrative distancing.*

**Keywords:** *chronic fatigue syndrome; fibromyalgia; knowledge; patient power; control; uncertainty*

**O**ur aim in this article is to discuss how women with chronic fatigue syndrome (CFS) or fibromyalgia (FM) define their potential for gaining control over their situation during the health care process and of influencing the latter in their encounters with health care providers. In this article, we highlight issues of perceptions of patient power and informal strategies that patients report employing when interacting with health care providers. The focus is therefore on the women's accounts of encounters with health care providers, and their definition of these situations, not on their actual behavior.

The article is based on an interview study involving 25 women with CFS or fibromyalgia. CFS and fibromyalgia are two chronic illnesses with partly overlapping symptomology. Like many chronic illnesses, they are distinguished by uncertainty regarding diagnostics, the prognosis, and the appearance of symptoms. Both illnesses are characterized by criteria diagnoses (Fukuda et al., 1994; Wolfe et al., 1990) and affect women to a higher degree than men. It is important to eliminate other explanations of the symptoms before establishing a diagnosis. A consequence

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**AUTHORS' NOTE:** Financial support for this research has been provided by the Swedish Foundation for Health Care Sciences and Allergy Research, the Swedish Rheumatism Association, and a grant from the Public Health committee, Stockholm County Council. This support is gratefully acknowledged. Thanks also to Madeleine Jeanneau, Ph.D., for comments on an earlier version of the article.

QUALITATIVE HEALTH RESEARCH, Vol. 14 No. 2, February 2004 226-240

DOI: 10.1177/1049732303260682

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of this is that these patients often undergo many examinations and investigations (Bombardier & Buchwald, 1996).

CFS and fibromyalgia are characterized by uncertain illness trajectories (cf. Corbin & Strauss, 1988). A number of earlier studies have shown that the acquisition of knowledge is important for patients who have uncertain illness trajectories to create an understanding of the illness, to reduce anxiety, and to gain control over the situation and its consequences (Jerret & Costello, 1996; Pinder, 1990). Knowledge also provides the necessary conditions for making informed choices (Giddens, 1991; Pierce, 1996) that patients as well as health care providers make use of in their interaction. The acquisition of knowledge about the illness, treatments, and so forth emerges in the present study as a significant strategy for gaining control and influence in the interaction with the health care providers. Knowledge is thus regarded as a fundamental power resource, and the women, according to the interviews, create several strategies for using knowledge to affect the health care process in accord with what they have defined as desirable or essential. Although medical knowledge is primarily a power resource for the doctor, the patients describe how they use this same knowledge against their doctors. However, the main focus of this article is not the notion of knowledge as a fundamental power resource but how the patients describe and define their possibilities in terms of the strategies in which the power is used. Earlier research has not thoroughly addressed patients' perceptions of such strategies.

### **POWER AND CONTROL IN THE PATIENT-HEALTH CARE PROVIDER INTERACTION**

Our results highlight patients' perceptions of power strategies and also call attention to an interactionist-influenced perspective on power and control, according to which power is regarded as relative. Wentworth (1980) discussed the issue from this perspective, defining power as "a relative, potentially shifting control of resources which could affect the outcome of relations when non-routine situations generate a choice point where action can be constructed" (p. 114). Wentworth's definition of power is of interest, as it incorporates an action-oriented element, namely that power is exercised through action when a situation involving choice arises and connects power to interaction in nonroutine problem situations. For example, it is possible that doctors meeting patients with difficult-to-diagnose illnesses might find themselves in problem situations with which they are not conversant. If a patient questions the doctor's medical knowledge, the situation surely can be regarded as a nonroutine problem situation. The authority of the doctor, the role of the doctor, and medical knowledge are regarded here as power resources, which means that they can be, but do not have to be, realized resources in a context, that is, resources that are treated as "situationally real" (Wentworth, 1980, p. 104). As Wentworth expressed it, "Authority cannot become a realized resource in the presence of sceptics" (p. 104). The recognition of qualities such as knowledge or authority has to be mutual. The patient's power, on the other hand, depends on the resources she or he is able to bring to the situation (cf. Wentworth, 1980). Wentworth also made a distinction between power and control, suggesting that control is used routinely, as opposed to power, which is used nonroutinely. Botelho (1992) stated the opinion

that control relates to regulating the use of power. Control can therewith be described as having the opportunity to use power, namely, making choices, implementing intentions, taking action, and affecting the actions of others.

Research on power and control in health care has focused above all on the power of the medical establishment (e.g., Haug & Lavin, 1979, 1983) and, on the other hand, on patient participation and empowerment (e.g., Anderson, 1996; Malterud, 1993; Sätterlund Larsson, 1989). According to earlier studies, the role of the doctor is central with regard to power within health care. The doctor, for example, holds a position of power in the encounter with the patient due to his preferential right of interpretation concerning diagnostics, putting the patient on the sick list, choice of treatment, and the prescribing of medicine (cf. Hammarström, 1997). Doctors thus have legitimacy and authority, based on their professional role, to exercise power and thereby also social control, deciding who is sick and who is not (Conrad, 1992; Freund & McGuire, 1999). The patient can thus be regarded as the weaker party. Studies that have highlighted the patient's weak position in relation to the health care provider are important for understanding the patients' situation in contacts with health care. However, other researchers have shown that the patients can also have influence in relation to the health care provider (e.g., Anderson, 1996; Sätterlund Larsson, 1989). Research on patient influence and empowerment has focused primarily on the course of action that should be taken to transfer more power to the patients and increase their influence over their health care process. Researchers have not, however, studied the power strategies that patients, according to their own perception, employ in encounters with health care providers.

Some studies have described the patients' possibilities of influencing health care providers' decisions (e.g., Hayes-Bautista, 1976). Haug and Lavin (1979) have shown that patients with extensive experience with health care in particular challenge the authority of their doctors. Cooper (1997), who studied patients with CFS, claimed that these patients are more likely to challenge their doctor than are those with legitimate and easily diagnosed illnesses. In a discourse analysis, Ainsworth-Vaughn (1998) has shown that both the patient and the doctor exercise power momentarily in their interaction. Through negotiation, both the patient and the health care provider have the opportunity to influence how the current situation is to be defined (Botelho, 1992; Hydén & Sachs, 1998; Scheff, 1987). Thus, the patients also have, according to earlier researchers, an opportunity to employ power strategies in the interaction with the health care provider and of influencing the definition of the situation in the interaction with the doctor (Perinbanayagam, 1974), such as defining the state of health as well as the need for interventions. A common definition of the situation can thus be created jointly in interaction (Närvänen, 1994). However, it might also be the case that participants in an interaction situation do not arrive at a common definition of the situation. The question is What happens if the patient and the health care provider do not arrive at a mutual understanding regarding the definition of the problem concerning, for example, the cause of the illness, the individual's status as patient, or the need for essential investigations and treatments? Lazare, Eisenthal, Frank, and Stoeckle (1976) described the possible consequences of a failed negotiation situation. The patient might then show dissatisfaction, not comply with the treatment recommendations, or change health care provider. The health care provider, on the other hand, might, for example, refer the patient to someone else or refrain from giving support.

The above discussion shows that there is an asymmetry in the power relationship between health care provider and patient, at the same time as the patients might still be considered to have certain possibilities to exercise power and influence the decisions made by the health care provider. However, at present, there is relatively little research describing such strategies, and therefore a need exists for further research on these issues (cf. Ainsworth-Vaughn, 1998). In this article, we will give an account of the strategies the women with CFS or fibromyalgia describe using to gain control over their situation during the health care process.

## THE STUDY

Because women are in the majority, especially among fibromyalgia patients (Komaroff, 1994; Olin, 1995), the study sample consists only of women. We selected the sample in consultation with staff on care units at two Swedish hospitals providing health programs for these patients. A member of staff from each unit selected participants, according to instructions from the interviewer, to obtain a maximum variation of experiences among the women. The first few interviewees were selected without any specific criteria other than having the diagnosis. After a preliminary analysis of these interviews, we instructed the staff members to select a few more women with different characteristics (ages, professions, levels of education, and stages in the course of their illness) than those already interviewed. We repeated this procedure to obtain a breadth of the categories developed, that is, to maximize the finding of differences within categories. During the sampling procedure, we distributed a letter of invitation to the women, who thereafter decided whether to participate. Two women with CFS declined because of a lack of energy.

We employed interviews as a method of data collection, as our aim was to record the patients' accounts and definitions of their illness, and the encounters with health care providers. The interviews were semistructured and were carried out in conversational form using an interview guide covering basic interview themes. The themes analyzed here considered the patients' descriptions of encounters with their health care providers and possibilities of practicing patient power. (Other aspects of importance in the encounter between patients and health care providers have been described in previous publications, i.e., Åsbring, 2001; and Åsbring & Närvänen, 2003.) We carried out the interviews on various occasions from October 1995 to January 1998, usually in treatment rooms at the respective hospital (11) or at the home of the interviewee (11). We also conducted some interviews at the interviewee's place of work, a café and a local branch of the ME association. The interviewee selected the location for the interview. Generally, the interviews carried out in the interviewees' home were more open and had a greater depth. All interviews were tape-recorded and subsequently transcribed verbatim. The duration of the interview varied between 60 and 150 minutes, and each patient was interviewed once.

We interviewed 26 women, although 1 subsequently withdrew from the study. Thus, we analyzed 25 interviews, of which 12 were with women diagnosed as having chronic fatigue syndrome and 13 with women diagnosed with fibromyalgia. A saturation point was then reached with regard to the information collected. The age range of the participants is 32 to 65 years (average 46 years), and they reported having been ill for between 1 and 23 years (average 10 years). Mean illness duration

prior to diagnosis is 9 years (8 years for CFS and 10 years for fibromyalgia) and after diagnosis 2 years at the time of the interview. Most of the women (15) were on the sick list or in receipt of temporary disability or sickness pension at the time of the interview. The interviewees represent a wide range of educational levels and professional backgrounds. Six of the women with CFS have a college degree or equivalent, compared to 3 women with fibromyalgia.

We used the procedures developed by Glaser and Strauss (1967) and Strauss and Corbin (1990) in the collection and analysis of data. These procedures give an opportunity to discover categories, relationships, and so forth not foreseen by the researcher. As we have only limited knowledge of the informal strategies patients perceive that they can use to influence health care providers, this approach seemed appropriate.

In accordance with the grounded theory approach, (a) we made a preliminary analysis after each interview, (b) the results were used as a guide for further interviews and to indicate sampling size, and (c) data generation and data analysis proceeded simultaneously. The starting point in the analysis process was to read through the interviews once to form a general impression. A second reading served to identify and categorize central themes. After additional interviews had been read through, we revised some of these categories. The analysis process also included comparisons of similarities and differences between themes, as well as writing notes, that is, reflections and hypotheses, while reading the interviews. In addition, we analyzed the interviews systematically using the constant comparison method (Glaser & Strauss, 1967; Strauss & Corbin, 1990) by comparing one incident with earlier observed incidents. In the light of further reading, writing, and reflection, we changed slightly and refined the thematic finally identified in the material and matched the theoretical concepts that could describe and summarize the material with the categories found in the empirical data.

Ethical principles have been adhered to throughout the study. We provided participants with information about the study and informed them of their right to decide whether to participate. We have taken care to present the material with the greatest possible confidentiality. An ethics committee granted approval for the study.

## FINDINGS

The women described various strategies that they had used to gain control over their situation during the health care process and to influence its course in the encounters with health care providers. These strategies are presented below under the following headings: (a) gaining control through knowledge and (b) control through practicing patient power. As the role of the doctors is often central to the women's health care process, it is these encounters above all that are described in the interviews, even though descriptions of interaction with other health care providers are also given.

### Gaining Control Through Knowledge

Seeking knowledge about the illness, for example about causes and possible treatments, was described as an important strategy for gaining control over the

situation. The women sought this kind of knowledge primarily through reading daily and evening papers, weekly magazines, medical journals, and textbooks, and using the Internet. They described acquaintances, health care providers, and patient support groups as other important sources of information. Approximately two thirds of the women, in particular those with CFS, described actively seeking knowledge as characteristic for them. A third described themselves as less active. The women reported that the level of activity with regard to seeking knowledge varied over time. They regarded knowledge as a strategy for (a) clarifying the cause of the problems, (b) defining a diagnosis, (c) obtaining information about the diagnosis and its characteristics, (d) finding a treatment, and (e) being able to plan one's health care process.

The acquisition of knowledge, with the aim of finding an explanation for what might have caused the problems or illness, was described as having taken place both prior to and after the establishment of the diagnosis. The women often tested and subsequently incorporated or discounted a special theory about the cause of the illness. Pieces of accessible information that fitted in with the interpretation of a given situation were often selected and combined:

One of the bosses said that we had been going at breakneck speed and that was almost an understatement. Then I began to wonder about whether stress might have affected my immune defense. So I looked it up in this book and read, it may well have been that, I don't know, but in fact many of the books I found at home described the same thing, how one could lose vitamin B in particular. (FM)

Another aim of the knowledge seeking, according to the women, was to find a possible diagnosis. Five of the women with fibromyalgia and 6 of those with CFS, that is, 11 out of the 25 interviewed, considered themselves to have arrived at a diagnosis before the doctor did. In the present study, those who described having diagnosed their illness themselves had usually found out about the existence of the illness through the media: "I read everything that I saw in magazines about what it could be and I saw that it began to fit together very well." (FM). The pronounced pattern is that the women, after having established that information about the illness agreed with their symptoms, suggested to a doctor that they should be referred to a specialist able to establish a probable diagnosis.

Once the diagnosis had been established, the women sought more knowledge about the illness, especially as they believed such knowledge to be in short supply among health care providers. Directly after the diagnosis, most patients invested a great deal of time in acquiring knowledge about the illness and its characteristics. However, some of the interviewees described that their seeking of knowledge subsequently waned. One woman considered the information she had received through the diagnosis to be sufficient:

I don't think one should seek too much information. It's quite enough for me to know that it is fibromyalgia, how it works and possibly that there is a weakness in me which has brought it on. I know that there are lectures that people run along to, but for me it's not an issue. I feel reassured as long as I know what it is all about. (FM)

Seeking knowledge to find an adequate treatment that might lead to an improvement or cure is a fourth aim described in the interviews. According to the women's descriptions, they subsequently often developed a thorough knowledge

of the various treatments available. However, the efforts to find a helpful treatment could diminish after having lived with the illness for a long time, which resulted in less "doctor shopping."

Knowledge was also described as important for planning the health care process, including obtaining an assessment from specialists and other health care providers to whom one should turn. This could be described as "detective work," as various doctors, examinations, and treatments were tried and assessed continually. However, a minority of the women described being simply sent off by the doctors to various examinations without feeling that they had any knowledge about, or influence over, what was happening, which indicates a lower degree of control over their own health care process:

So then he [the doctor] sent me for various tests, one here and one there and I had no idea what it was all for. I just trotted off and did what I was supposed to and then he got the answers, and that's how it went on. (CFS)

### Consequences of Enhanced Knowledge

Many of the women in this study defined themselves as experienced patients, which means that they considered themselves to be competent regarding their illness and the health care system. Experienced patients have become familiar with the arena, the system, the rules of the game, and the values, and know how they should behave to attain the best possible results for their own part (Clarke, 2000; Skau, 1993; Steinholtz Ekekrantz, 1995). As the women's "patient-career" proceeded, more knowledge was obtained about the health care system and the illness. The women described this knowledge as advantageous for maintaining control, influencing health care providers, and wielding power. In becoming an experienced patient, the time aspect was therefore perceived as important: "But it might be the case that over the years one becomes . . . not tougher but perhaps one knows more what one wants and can make demands more easily" (FM).

Through enhanced knowledge, many of the women considered themselves able to assess the doctor's competence, and this sometimes led to dissatisfaction. Several of the women reported that they considered their knowledge to be superior to that of the health care provider. They could therefore sense that they were shouldering an increased amount of responsibility for both the illness and improving the health care providers' knowledge of the field. One woman said, "I have to work very hard and inform and talk and sort of be responsible for stuff that is actually too much." (CFS). The women also described themselves as having a great responsibility concerning seeking care and help. Criticism was leveled at the doctors in particular: "One has to seek the contacts oneself. And to ask for referrals instead of the doctor doing the work. After all it is their job." (FM).

The women who perceived themselves as having planned the health care process clearly knew what they wanted help with even before coming to the consultation. The consultation was described as a matter of influencing the health care provider to act in accordance with this wish, often with success. In these accounts, GPs in particular were regarded as resources for obtaining what was wanted, for example, a certain referral or a prescription.

However, it should also be pointed out that some patients in this study accepted the health care providers' definition of the situation or the fact that they did not have

an exhaustive knowledge of the illness. These patients were satisfied with the knowledge that was available and with the support they felt they received from the health care providers.

### **Control Through Practicing Patient Power**

As discussed in the previous section, the women regarded themselves as having succeeded relatively often in influencing the health care providers in accepting a definition of their condition and need of care, which in time might lead to their acting according to the women's wishes. However, the women also described that using power strategies was sometimes necessary to affect and gain influence in the interaction, and thereby gain control over their health care process. The women described using six power strategies in interaction with the health care providers, in particular doctors: (a) exiting, (b) noncompliance, (c) confrontation, (d) persuasion/insistence, (e) making demands, and (f) demonstrative distancing. Exiting was described as the most common strategy, followed by noncompliance and, thereafter, confrontation. The women with CFS described a greater number of types of power/counterpower strategies than did those with fibromyalgia, who described a smaller repertoire of these strategies per person. Noncompliance, exiting, demonstrative distancing, and confrontation can all be designated as counterpower strategies, as they entail resistance. Counterpower refers to a resistant force and a resistance to the intentions of the power (Albinsson & Arnesson, 1997; Mathiesen, 1982). A majority (approximately three out of four) of the interviewees described various power-counterpower strategies. However, the power strategies appeared with differing degrees of frequency among the interviewees. More often, these strategies were expressed in relation to male doctors because of less patient satisfaction. The power strategies, which are subcategories to the main category Control Through Practicing Patient Power are described in more depth below.

#### ***Exiting***

Exiting is a counterpower strategy described by the women in terms of changing health care provider when dissatisfied, that is, if he or she did not act according to expectations regarding prescriptions, examinations, treatments, referrals, and so forth. It was also important to feel believed, understood, and respected. Some women reported having "tested" the doctor during the first appointment and only then making a decision about continued contact. The uncertain illness trajectories, the difficulties of treating the illnesses within the framework of textbook medicine, and the desire to be healthy resulted in a clear majority of the women's turning to some form of alternative medicine. This might also be regarded as a type of exiting. However, the interviews do not reveal whether the women continued to see their former health care providers within biomedicine at the same time as they sought alternative medicine. According to Freund and McGuire (1999), people often use alternative healing systems simultaneously with biomedicine. Seeking alternative medicine could be a way of attempting to alter the illness trajectory by finding someone who might provide alternative pictures of it (Milliken & Northcott, 1996; Strauss et al., 1984), as, for example, a hope of improvement. Our study also reveals such pattern: "It felt so pointless to run along there and be given penicillin time after time. It was that that made me turn to this anthroposophist doctor" (CFS).

### *Noncompliance*

Noncompliance is defined as an individual's not following medical advice (Lowry, 1998; Playle & Keeley, 1998), and also appears in the women's descriptions. Patients have their own ideas about treatment that only partly originate from their doctor and that, according to the women, affect their actions. Noncompliance might be a way for the patient to gain control over the patient-doctor relationship (Conrad, 1985). The women described noncompliance in situations in which the doctor's advice did not seem to make sense: "I have been given enormous amounts [pain-killer, tablets], that I have not taken out. Because I don't think you should take tablets as long as you don't know what it's about." (FM).

### *Confrontation*

The counterpower strategy of confrontation is distinguished by manifest aggression toward the health care provider. A confrontation can arise for many reasons. For example, confrontation was described in situations when there was a conflict between the patient's wishes and the doctor's actions (cf. Freidson, 1961). Staging a confrontation was described, particularly when the health care provider expressed a questioning attitude concerning the veracity of the woman's experience of her illness, meaning that they were unable to agree on a mutual definition of the problem:

"You'll have to trust me," I say. "After all, I'm not sitting here paying a lot of money because I think it's fun and to pretend, but because I'm ill. I need help dammit!" Then you have to say, "Don't you get it?" Then they take you more seriously. (FM)

Furthermore, the women reported that a confrontation was sometimes necessary to gain attention for their own standpoint, for example, in the case of noncompliance. Confrontation is also described on occasions when the woman subsequently discovered that the doctor had made an incorrect medical assessment of her condition.

### *Persuasion/Insistence*

The interview responses show that the patients sometimes perceived difficulty in having their wishes met during the consultation. On these occasions, according to the accounts, some patients used the power strategy of persuasion/insistence, which is distinguished by stubbornness on the part of the patient to get her own way in interaction with the health care provider. According to the participants, persuasion could make it easier to obtain satisfaction concerning treatment wishes, although the strategy might also be used for other purposes. One woman described, for example, how she succeeded in becoming a patient of a doctor who was thought to be particularly competent: "I sort of pleaded and begged, so she took me on even though she was actually full up" (CFS). Another woman described how, through repeated letters to her doctor, she tried to get him to take action on her behalf, namely, write desired referrals to various specialists. However, this succeeded only when she also confronted the doctor aggressively. Insistence does not, however, always yield results and might, according to the respondents, even have the opposite of the desired effect, as, for example, in the case of lobbying the doctor too intrusively.

### *Making Demands*

Making demands involves pressing the health care provider to carry out various interventions, such as conducting tests, prescribing medication, or writing referrals. Making demands, in relation to doctors, could be expressed relatively strongly in the interviews: "Then I went to him and gave him an order and said, 'Now you have to refer me to the [specialist unit]!' and so he did it." (CFS). Such action often, but not always, entails an indirect questioning of the doctor's judgment. According to the interview responses, making demands can be either negotiable or absolute. In the case of an absolute demand, there was no negotiation between the health care provider and the patient (see the above quotation). Instead, it was the patient alone who defined the situation. Negotiable demands were described more often.

### *Demonstrative Distancing*

Demonstrative distancing is a matter of refusing to cooperate with the health care provider and can, for example, express itself through the woman's "clamming up" during the consultation and not providing any more detailed information about herself. This was described as being staged primarily when the health care provider defined the woman's health problems in psychological terms, this being experienced as an infringement of her integrity, and also if she felt that the doctor did not want to incorporate her view of the problem:

When they stop listening altogether then there's no point in talking to them, it doesn't matter who I talk to . . . I don't talk then either if they don't listen. It's like pointless. Why should I sit there and say things only to be misunderstood. (CFS)

### **Possible Consequences of Having Used Patient Power in the Interaction**

It was especially when the doctors' medical competence was questioned that the patients' power/counterpower strategies evoked negative sanctions from the health care providers, which, according to the interviews, included expressions of irritation, reproof, direct reprimand, or making it clear to the woman in some other way that she was a difficult patient. Negative sanctions can be seen as a punishment system that aims to normalize a person's behavior according to the health care provider's values about what is appropriate. Such sanctions might arise as a consequence of the women's using power/counterpower in the interaction, but also, for example, when they have proffered their own suggestions regarding the cause of the illness or interventions.

The following quote shows how a woman, according to her own description, was exposed to negative sanctions by a doctor after she had used the power strategy of noncompliance. The discrepancy that she suggests exists between her and the doctor's definition of the problem appears to contribute to the conflict:

I did not feel depressed, but she thought that I should try Cipramil [antidepressant]. And so I tried it for 14 days and felt terrible so I just stopped taking them and then she was furious, not furious but she thought that I was resisting and doing the opposite. (CFS)

As has been described, the women often tried to achieve control and influence over their health care providers in different ways. However, this was described as difficult and burdensome, as the women lived with both an uncertainty regarding what was happening with their body and a reduced capacity to take action as a consequence of the illness: "When you're that sick, then you don't always have the strength as it were to assert yourself and contradict and make demands" (FM).

There are those who felt that they had relied on their doctor's assessment regarding their complaints during their illness episode, and this was suggested by one woman as a possible reason for not having received a diagnosis until a late stage. Self-blame can arise as a consequence of not having taking own initiatives:

You know I reckon I have had it for 10 years, so they should have been able to work out what it was. But it's partly my own fault. Because one was happy to accept it when the doctors said that they also had a pain in the back or knee or shoulder or whatever it was. (FM)

## DISCUSSION

The women included in this study described how, through the acquisition of knowledge about their illness, they tried to gain control over their situation during the health care process and influence it in their interaction with health care providers. Some described having used their knowledge primarily to create their own sense of control (cf. Fitzgerald Miller, 1992), and others to influence health care providers. The women thus defined knowledge as an important power resource (cf. Närvänen, 1994; Wentworth, 1980). Knowledge seeking could be described as a classic coping strategy, an "effort to manage stressful demands, regardless of outcome" (Lazarus & Folkman, 1984, p. 134). However, the knowledge-seeking strategies described in this study are also perceived as purposeful activities (e.g., finding a diagnosis or cure), like the power strategies described by the women, and therefore different from traditional coping strategies (cf. Bury, 1991; Radley, 1994).

Most of the women in this study used active power strategies to some extent. Those with CFS described themselves as being more active in their quest for knowledge than did those with fibromyalgia, and they also used a greater number of power strategies. The women with CFS seemed, then, to be more in control than the women with fibromyalgia did, but this issue requires further research. This difference might be due to the fact that the women with CFS had a somewhat higher level of education than those with fibromyalgia and thereby might be considered to have had a greater possibility of acquiring knowledge and exercising power. Social background, position in professional life, income, level of education, and so forth are of significance regarding the possibility of influencing health care providers (Beisecker, 1990). A high level of education, for example, gives the patient a higher status, putting her on a more equal footing with the doctor. Social class as well as gender can in all contexts constitute power resources. Malterud (1987) has stated that communication between female patients and male doctors can be complicated by gender incongruence. The women in the present study expressed less satisfaction with male doctors and used more power strategies in interaction with them. Freund and McGuire (1999) have suggested that female doctors' communicative

abilities are focused more on cooperation, which reduces some of the social distance between the patient and the doctor.

The breadth of power strategies that the patients perceive having used in the interaction with health care providers has, to our knowledge, not been shown in earlier studies of patients with a diffuse symptomatology, such as CFS and fibromyalgia. Hammarström (1997) proposed adjustment, exit, and protest as patient power strategies, although these suggestions are not based on an empirical study. Muir-Cochrane (2000) found that patients controlled the encounter with community mental health nurses by, among other things, using noncommunicative or aggressive behavior. Johansson, Hamberg, Lindgren, and Westman (1996) have reported that patients with fibromyalgia sometimes use persuasion in their interaction with health care providers. However, the majority of earlier studies have focused primarily on empowerment. To be able to transfer more power to patients, it is essential to understand which power resources these individuals experience themselves as having.

The contribution of this study is the empirical findings that show a broad spectrum of power strategies employed by patients with regard to health care providers. The theoretical frame of power as a resource makes it possible to identify power resources connected with formal position (e.g., authority). However, it is also possible to observe informal resources that seem to be associated with the persons in the interaction situation in question, such as using emotions and cognitive capabilities as power resources. As the results of this study indicate, a patient's social and cultural capital might be important with regard to opportunities to negotiate and gain control in interaction with health care providers (cf. Bourdieu, 1991).

Peters, Stanley, Rose, and Salmon (1998) stated that patient power strategies are above all the product of health care providers' having rendered explanations of the patients' problems that have involved questioning the veracity of their condition. The diffuse nature of the symptoms might provide health care providers with grounds for invalidating the experiences of these women. The results of this study indicate that the women resist social control from doctors and also question their legitimacy and authority, both implicitly and explicitly. This, in turn, means that the power resources of the doctor are not always realized (cf. Wentworth, 1980). Peters et al. (1998) have also proposed that knowledge seeking among patients might be a way to compensate for an experienced lack of knowledge in the health care provider and medical science as a whole, and a way of protecting oneself against possible mistakes having been made by health care providers (cf. Freidson, 1961). However, even if some patients are satisfied, it is possible to conclude from the results that many patients would benefit from having access to health care providers with more expert knowledge, as this would result in more support in managing their health problems (cf. Deale & Wessely, 2001; Tang & Anderson, 1999). Expert knowledge can be described here as knowledge in a broad sense, that is, about the research front, the illness and its characteristics, treatment possibilities, management regimens, and, in addition, a holistic way of thinking about the problems. Furthermore, expert knowledge includes some insights into patients' experiences of living with the illness and, most important, according to the women, taking the patient and her illness seriously.

Lack of faith in the doctor's knowledge and in medical science might result in the woman's shouldering a large responsibility for her illness, as with time, she has gained a more thorough knowledge of it. Nevertheless, many of the women

included in this study expressed the wish that the doctors would take a greater responsibility for them (cf. Coyle, 1999), that is, not leave them alone with their worry and efforts to find a solution to their problems. However, this is a complex issue, because responsibility, as Scheff (1987) has pointed out, is a construction of reality by those involved. Nevertheless, the findings in this study imply that the border between lay and expert responsibility is fluid and that the patients with CFS and fibromyalgia take over some expert responsibility.

## TO CONCLUDE

This study has revealed that the patients perceive knowledge to be an important way of attaining control, to be able to influence health care providers as well as to increase the possibility of using power in the interaction with the health care provider. Power, as discussed in this study, in interaction is relative; it means an opportunity for mutual influence related to action as well as being associated in particular with nonroutine problem situations (cf. Wentworth, 1980). The interaction between patient and health care provider is described as problematic when the two parties do not arrive at a mutually acceptable definition of the situation, and this can result in action, that is, power/counterpower strategies from the women's side and negative sanctions from that of the health care providers. Both doctors and patients desire control, autonomy, and power in the interaction (Beisecker, 1990; Stimson & Webb, 1973) and therefore use various strategies to reach these goals.

The aim of this article has been to find out how patients with CFS and fibromyalgia view their possibilities to influence their health care process and health care providers. Light has been shed on the patients' accounts and their definition of the various strategies that they consider themselves to have used to attain their goals. Concerning the patients' perceptions of their situation, it is apparent that they believe that they can influence their health care providers by employing various strategies, that is, they perceive themselves to have a certain amount of power and control in relation to the health care providers.

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