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Patient School as a Way of Creating Meaning in a Contested Illness: the case of CFS

Pia H. Bülow

Department of Communication Studies

Linköping University

581 83 Linköping

Sweden

Email: piabu@tema.liu.se

Lars-Christer Hydén

Department of Communication Studies

Linköping University

Abstract

Creating meaning in a situation of contested illness like Chronic Fatigue Syndrome (CFS) is an interactive process. As an example of how meaning is created, a CFS patient school organised by a hospital clinic in Sweden is discussed. This school can be seen as both a school and a medically oriented activity. The presence of different frameworks provides an opportunity to use different perspectives to understand CFS. It makes it possible for the participating men and women to regard the illness both from the outside as a social object; from the inside through personal experiences, and to put the diagnosis and suffering in a larger 'sickness' perspective. Consequently, a number of different interpretations are brought up and used to create meaning in a situation of illness. The patients/students are thus learning to discursively manage the illness at the same time as they examine different ways to interpret their experiences through this discursive activity.

Keywords: contested illness; interaction; CFS; discursive management

Creating meaning in a situation of chronic illness is commonly considered to be an individual process. By reflection and adaptation the sick person is supposed to understand and grasp changes in life trajectory, life history or personal identity all by him/herself. This is thought to happen through biographic reconstruction, identity work or other similar processes. Social research concerning these processes usually draws on interviews with chronically ill persons (e.g. Charmaz, 1983; Corbin and Strauss, 1988; Williams, 1984). There are, however, few ethnographic studies of how meaning is created together with others in the same situation, in which the creation of meaning is considered to be a social interaction process (cf. Cain, 1991; Karp, 1992).

The creation and reconstruction of meaning becomes even more problematic when it comes to a chronic condition that has a controversial and disputed status as a disease. This is the case with Chronic Fatigue Syndrome (CFS) – a condition consisting of severe, prolonged fatigue that cannot be explained by any other disease, either physical or psychiatric. Hence, in medicine as well as in health care practice, CFS is treated as a contested disease and medical encounters have been described as ‘de-legitimizing’ for sufferers (Ware, 1992), as ‘micro-political struggles’ (Banks and Prior, 2001) and as negotiations between the sufferer and the physician (Hydén and Sachs, 1998). From interviews, CFS seems to be a diagnosis that physicians regard as disabling whereas patients see it as enabling (Woodward, Broom and Legge, 1995). In the same vein, Horton-Salway (2001: 247) has shown how ‘attributional stories and identity formulations’, told in interviews with sufferers, are linked together to construct a diagnosis of CFS/ME ‘as a physical disease while countering potential accusations of malingering or psychological vulnerability’. However, another part of her study shows that General Practitioners’ case narratives about patients suffering from CFS/ME also were constructed to justify the diagnosis as either physical or psychosocial (Horton-Salway, 2002). Confrontation with CFS is therefore difficult for health care personnel as well as for patients. Because of this we would like to call it a contested illness.

In the early 1990s a patient school based on a patient education program was started at an immunology clinic in a large hospital in Sweden. This patient school is the focus of this article and has been studied with an ethnographic approach. The aim is to explore how people suffering from an unexplained and contested illness like CFS make sense of their illness mutually. The patient school is interesting since the ‘school’ setting provides encounters between health care professionals and sufferers as well as among sufferers. Especially interesting is the ways patients, staff and lecturers talk about CFS and how the participating

‘pupils’ and patients use the lectures and the educational program in order to jointly create meaning in their suffering, illness and social situation.

The school as metaphor

Educating patients about their illness and how to best manage it has a long history that is possible to trace back to the era of Hippocrates (Bartlett, 1986). The contemporary development of patient education, though, is partly due to the general problem in the industrial world with an increasing number of chronically ill persons who require long-term contacts with the health care system (Deccache and Aujoulat, 2001). It is also partly due to ‘concerns about the inexorable rise in medical care costs’ (Bartlett, 1986: 141). The major part of patient education (compared to health education, which is concerned with the asymptomatic individual or population (Skelton, 1998)) seems to concern the practical management of chronic illnesses like diabetes, hypertension and rheumatoid arthritis (RA) and to help patients to help themselves (cf. Bartlett, 1986; Lorig, Konkol and Gonzales, 1987). However, even if many different professionals are involved in patient education (see e.g. Bartlett, 1986), educating patients about their illnesses, from Hippocrates to the present, appears to be something that is an integral part of health care activities. It is thus primarily something between, for instance, the physician and the individual sufferer as a ‘part of the routine, everyday fabric of the medical encounter’ (Skelton, 1998: 97).

This, however, leaves out the creation of meaning of illness and the problematic situation connected with contested illnesses for which no generally accepted treatments exist. The patient school that we discuss in this article was nevertheless started to support patients recently diagnosed with CFS or related diagnoses, offering them available knowledge about their illness as well as the possibility to meet other sufferers. A patient school, though, collectivise and ‘pedagogicises’ that which commonly is individualised and given as instructions or advice.

To name an activity within the health care sector ‘school’ is not that strange in the Swedish culture and not particularly unusual. Group education for patients with chronic diseases like diabetes has developed from the popular Swedish study circle tradition, which educates the general public in a variety of areas (Rosenqvist, 2001). In Sweden there are, for instance, ‘schools’ for RA patients and pain sufferers, accordingly called ‘pain schools’; these can be organised in many different ways (cf. Kogstad and Hintringer, 1993; Lindroth, 1996).

What seems to be unique for the studied patient school is that it deals with a contested illness surrounded by uncertainty as well as ambiguity and that it is organised by a hospital clinic as a group activity for patients where health care professionals act as lecturers. The criticism that has been directed at self-help groups is that they are too closely connected to medical professionals and their views. According to Williams (1989) they do not provide sufferers with the possibility to pose questions about the meaning of the illness since that is already settled from a medical point of view. All of this makes the patient school and what it might do for the patients even more interesting.

Studying the school

The most appropriate way to study the patient school seemed to be an approach by means of ethnographical methods. The analysis presented in this article draws on four kinds of data: field notes, audiotaped school interactions, interviews and texts. The various types of data reflect the context of the participants (the professionals as well as the patients/students and later on interviewees) through what they brought up and elaborated in the taped conversations; the observer's context reflected by phenomenon which was identified and selected as important to understand the observed situation and accordingly noted down as field notes; and finally, the researchers' context through the use of theoretical frameworks and analytical concepts. Field notes from the observations, informal interviews during the school as well as more extended formal interviews after the school was completed and texts (e.g. invitation letters to participants) form the background for the interpretation of the audiotaped, and later transcribed interactions.

The study was designed in such a way that one of the authors (PB) participated in different classes in the patient school as an observer sitting together with the participants during school-time (cf. Atkinson and Hammersley, 1994). The ethnographic approach also included the time in the waiting room before each lesson as well as, when the opportunity was given, short conversations with the participating men and women on their way out from school or on the way to buses or trains. In order to get the professionals' view of the patient school and its history, the observer had a number of contacts with the physician in charge of the special unit for CFS patients and the nurse who was responsible for practical arrangements and for group discussions in the patient school in the early phase of the study. In all, various contacts with the CFS unit concerning the study of the patient school continued from December 1998 until May 2000. During this time the researcher attended two complete classes and a few separate meetings in other classes as well as one meeting for family

members and others whom the participants had invited. Added to the data were some written materials, e.g. the invitation letter, and some other written information about the school.

The school meetings (lectures and group discussions) were audiotaped and later transcribed verbatim by the observing researcher. In addition to the recordings, notes were taken during time in the 'classroom' on such things as who was speaking to whom, and things that happened in the room but could not be heard on the tape, e.g. nodding gestures and other non-verbal communication. Conversations in the waiting room were not taped but were noted down soon after the meeting ended. Impressions of the meeting as a whole were noted at the same time. The audio-recorded material together with the observations, interviews, and field notes make it possible to go beyond a mere discursive analysis and to place the in-school discourse in its context. This method, as Hak (1999) writes, thus considers both 'text' and 'con-text.'

The two complete classes, from which all of the examples presented in this article originate, consisted of 8 and 11 participants, respectively, though in the former there was one dropout after the first meeting. (Neither the dropout nor those who rejected participation in the first place were contacted by the researchers.) With this exception the majority of participants attended all meetings, or all but one. The women dominated in number, and there were only two men in each class. This, however, corresponds by and large to the generally reported gender distribution for CFS (cf. Evengård, Schacterle and Komaroff, 1999). Ages in the two classes varied from nearly 30 to about 60 years old. The degree of work, sick leave and reported illness durations also varied considerably between the participants. The shortest time with this illness was less than a year, but commonly they talked about several years of suffering.

When each class had completed the school all seven participants in the first class and about half of those participating in the second class (six persons) were interviewed, usually two or three times. In addition, a participant from a third class volunteered to be interviewed. All of the first interviews took place between six and nine months after the end of school for that class. In total 34 interviews were conducted between November 1999 and December 2001.

The analysis was conducted on the Swedish material and translated to English later. At this time the transcripts were simplified to facilitate reading. All names have been changed to protect the anonymity of the participants.

In the following, we intend to discuss this school as an unfolding ‘sense-making’ process. The analysis and the present text are divided into three sections. The first section is an ethnographic analysis concerning the CFS school as a social setting, its structure and how it is socially organised using different frameworks. In the second part, we turn to an analysis of the school interaction during lectures primarily concerned with the illness and to some apparently underlying questions that seem to be important for the creation of meaning in an illness like CFS. In this section, examples from the completed classes will be an essential part. These two sections lead up to the third section, an extended discussion about contested illness and meaning concerning what participants might learn in this particular patient school and in what way this kind of activity can be of any help for those suffering from contested illnesses.

Frameworks of the patient school

The background of the school is that in the beginning of the 1990s, physicians at the clinic individually noticed that each of them was facing patients with similar but unclear symptoms that they as physicians tried to examine and treat. A research project was started, comprising a CFS unit and the patient school. The original name used for this school was the ‘ME school’, ME standing for ‘Myalgic Encephalomyelitis’. This diagnosis, which is used in the UK, is similar to CFS and is treated as largely synonymous in the professional literature (Wessely, Hotopf and Sharpe, 1999). However, since the criteria for diagnosis used at this unit correspond with that described for CFS (Fukuda, et al., 1994) the school in this paper will be termed the ‘CFS school’ to avoid mix-ups. In reference to the original name, participants as well as lecturers interchangeably used ME or CFS, or the Swedish word-for-word translation for CFS when talking about the illness and persons suffering from it.

Since the school was started its organisation was continuously changed, but at the time of this study the school was organised around five two-hour meetings or ‘lessons’, arranged as a series of lectures by different professionals, followed by a group discussion that concluded each lesson. Between the lecture and the group discussion there was a coffee break. All three activities took place in the same room, around a conference table. The boundaries between these different parts of the lessons were marked discursively as well as by physical actions, such as someone (the nurse or a lecturer) entering or leaving the room.

In addition to the five lessons consisting of lectures and group discussions, participants from the two ‘schools’ that usually were conducted each term, were invited for two more lectures. These special lectures were held only once every six months. No group discussions

followed these lectures and due to the differences in participating persons these meetings are excluded from the detailed analysis of school interaction.

Coming to the CFS school

In understanding what participation in this particular school might mean for the participants, two things seem to be of importance. First, one has to put the decision to attend school into the individual history of illness and suffering. That is, one has to understand the school from the point of view of the participant's pilgrimage of suffering (Reid, Ewan and Lowy, 1991). Sometimes stories about how they come to attend the patient school were told in school. This was also a recurring theme in the ethnographic interviews.

Secondly, one has to consider what meaning the physical location and organisation of this school might have for the men and women who decided to attend it. In the health care system in Sweden, one usually has to be referred to the hospital clinics unless the symptoms indicate that this is an emergency case. Since the patient school was part of a specialist clinic at a university hospital, to gain access to it sufferers had to be referred to the CFS unit by their GP or some other specialist. This was for the majority of the participants quite a long and painful process, 'a pilgrimage' to have the experience of illness recognised (Hilbert, 1984; Ware, 1992). Many of the participants described this 'pilgrimage' as long periods - sometimes years - of searching for answers and credibility and for physicians who believed in the symptoms they described.

Due to the referral process as well as the pilgrimage, coming to school was for the individual a real effort. This personal effort was demanding, since practical arrangements for coming to each single meeting in school involved for many participants several hours of travelling by cars, buses, trains or taxis and for some even ferries.

The decision to attend the patient school, however, was for most of the participants preceded by a medical assessment, including an extended interview carried out at the CFS unit where the CFS diagnosis was either confirmed or rejected. After this, those patients diagnosed as having CFS or related diagnoses were invited to attend a body-awareness training program and/or the CFS school as the only treatment alternatives. On completion of either one or both of these activities, the contact with the CFS clinic was over and patients were assumed to be returning to their GPs or other medical contacts outside the hospital.

The CFS unit is just a limited part of one of all the clinics and departments at this modern and very large hospital. Like all hospitals, it is arranged so that there are both public

spaces and professional spaces to which persons due to their social and professional status have different access. The waiting room at the clinic to which the participants by the invitation letter were instructed to come can accordingly be compared to Goffman's (1959) concept 'frontstage' – a public space within the clinic. To reach the waiting room the participants could either use the hospital's main entrance and from there walk through the hospital corridors – 'a network of public spaces and connecting pathways [which] interlaces the network of professional spaces' (Young, 1997: 12). Or, especially if coming by car, they could reach the waiting room almost directly from a small parking place outside the clinic. It is by moving through these sequentially ordered spaces that persons undergo 'a series of transformations in the course of which they become patients' (Young, 1997: 14). People are not just turned into patients, but are actively transformed into a new and different status.

The social organisation of lectures

The first lesson started when the nurse entered the waiting room, assembled the participants and guided them down the corridors to the 'classroom' downstairs, which normally was counted as professional space. After about twenty minutes of information about practical arrangements, such as what participants should do if they could not attend one meeting, one of the physicians at the CFS unit arrived and started the first lecture. This lecture focused on the history of CFS and reviewed the medical research on CFS. A week later, an official from the social insurance office and in charge of rehabilitation presented the second lecture. This considered the public health insurance system in general, and how this system works regarding chronic illnesses. At the third lecture a physiotherapist talked about muscular tension and stress, and about techniques for relaxation and exercise in a theoretical way. No time was allowed here for practice or detailed descriptions. The fourth lecture, given by a psychologist, focused on psychological aspects of CFS, particularly emphasising the sufferer's personality as one possible contributory factor to the illness. In the concluding lecture a recovered CFS patient was invited to tell his story about suffering and recovering. (The order of the third and fourth lectures differed between the two studied classes.)

The organisation of each lecture could be compared with what Mehan (1979) has described for lessons in 'ordinary' schools. That is, a sequential organisation which divides lectures into an opening, an instructional and a closing phase. The opening phase in the patient school consisted of the introduction each lecturer framed his/her lecture with, presenting him/herself, and describing the essential content of the lecture. In the instructional phase, lecturers first presented the rules for interaction during the lecture, e.g. invited the

patients to ask questions or contribute in other ways, and then gave a talk presenting their views of the illness from a certain perspective like the ex-patient's or the psychologist's. During this talk about the illness and the diagnosis the lecturer acted as the primary speaker for twenty minutes to half an hour. The lecturer then held the floor and talked without any interruption except for responses to rhetorical questions such as 'Do you recognise this?', or when participants occasionally asked for some kind of clarification.

In the latter part of the lectures, however, the participants took part more actively and got involved in discussions about various topics. The closing phase usually started when the nurse came into the room with coffee. The lecturer then summarised the talk, finished the lecture and left the room.

The participants contributed to lectures by asking questions that developed the discussion or introduced new aspects, by supporting the lecturer's arguments or by objecting to them. The contents of these contributions were often examples that were more or less apparently rooted in personal experiences. The examples were sometimes given as elaborated narratives, but more often as short narrated examples that could be hypothetical as well as general or habitual (Riessman, 1990). When introducing new aspects the participants sometimes referred to, for instance, treatments they had heard about or things they had read about in newspapers or on the Internet.

Frames and roles in the CFS school

As mentioned earlier it is not that unusual in Sweden to name an activity within the health care organisation 'school'. Nevertheless the word 'school' might constrain the way people regard such activities. 'Schools' usually do indicate that there is something to learn and consequently that someone has a certain amount of knowledge about this particular subject. In addition to the name of the school, the invitation letter and some other texts concerning the school, which were handed out during school-time, in several ways revealed the view of this activity as a school setting. In these texts words and concepts such as 'school', 'course', 'lectures', 'lessons', 'subject', 'schedule', 'lecturer' and 'classes' were used repeatedly. This terminology was reflected in school-talk as well.

However, simultaneously both in texts about the CFS school and in school another vocabulary more connected to the health care and the medical sphere was used. Thus the same person was both lecturer and, for example, doctor or physiotherapist and the participating men and women could be addressed as either students or patients. As patients for instance, the

participants, like all other patients at the clinic, paid the ordinary patient fee at the reception desk when arriving at school. Likewise, the participants gathered in the waiting room until (usually) the nurse ‘called for’ them, as before ordinary medical consultations. In other words, many factors indicated that the CFS school could be regarded as a health care activity, at the same time as being a school.

Nevertheless, in the ‘classroom’, most participants acted as if it was a school after all. For instance, at the beginning of the lecture, the patients/students waited for the lecturer to begin the lesson. In the same vein, they sometimes raised their hands to indicate that they wanted to say or ask something, and almost everyone had paper and pens ready to take notes. In other words, they used behaviour that is usually associated with schools rather than with health care consultations.

These two different roles were also discernible in school-talk where the participants were addressed as patients, or the even more specific category of ‘CFS patients’ when they were supposed to relate the content of the lecture to their personal illness, for instance by responding to questions like ‘how many of you have ...?’. At other times the same participants seemed to be addressed primarily as students who were supposed to learn something about what the lecturer was saying in a more general sense. This could be the case, for example, when a lecturer concluded something with a question like: ‘Are there any questions?’. This categorisation as patients or as students was also reflected in the rules for talk and interaction in the patient school. At the information about the school, for example, the nurse emphasised the status of group/class by saying: ‘when you are here (at school) you are here as a group and not as individuals’. This was stressed even further by the instruction that there was no time for personal talk with individual participants during school-time. Personal messages (e.g. requests for appointments with the doctor) that the participants as patients wanted to convey to the nurse had to be written down and handed over as notes. All this means that the CFS school appeared as an activity that makes use of two different social organisational frameworks between which participants as well as professionals may alternate in order to organise and interpret the ongoing social interaction.

Considering this, the CFS school could presumably be regarded as an example of what Sarangi (2000) calls ‘interactional hybridity forms’. That is, when one kind of social activity (the school) is used within another organisational framework (the hospital) and thereby gives rise to something new, namely patient schools.

One important consequence of the possibility to shift between various social organisational frameworks is that particularly the patients' status as participants changed. That is, their identity in the CFS school varied. In relation to the health care system they were defined as patients, and as patients they sought care for and relief from their illness. However, at the same time they were students engaged in learning something about their own illness, and as students they were supposed to take part in the education program, contributing their personal experiences. That is, they were both working students and patients who should be treated. This ambiguous status is also reflected in this text, since we alternately use both these categories (student and patient) as well as the more neutral word participant, even if the last category might also include the medical staff.

'School-talk' about contested illness

So far we have been dealing primarily with the social organisational and interpretative frameworks of the CFS school. In the following section we will turn to a more detailed analysis of the interaction in the patient school, making use of the participants' contributions to the school-talk about CFS discussing how the participants discursively organised and explored the diagnosis they had recently received. However, as pointed out earlier in this paper, the development of the patient school has its roots in professional frustration as well as in the fact that many patients who present unexplained symptoms like long-term fatigue have been met with disbelief and doubt. Probably because of this the interaction in school about chronic fatigue was closely connected to the meaning of this contested illness.

The question of how to explain CFS was essential in the patient school and even when talking about treatments and the prognosis this question seemed to be the underlying issue. In one class, for instance, this question was explicitly raised as early as the time for the nurse's information about the school. From the very beginning of the school, however, it appeared to be true that many different, partly conflicting ideas about CFS existed and that there were no clear answers available. This ambiguity was reflected in lectures as well as in the nurse's talk about the illness and was something that the participants' dealt with in their contributions.

How this ambiguity was handled in interaction is illustrated in Example 1, from the first lecture in CFS school where the physician gave a talk about CFS as a diagnosis and as an illness, explaining the history from neurasthenia to today's research. During this first lecture the participants acted most of all as students – listening, making notes and occasionally asking questions connected to the lecturer's talk (Example 1).

Example 1 (ME/C:1)

Physician: /.../ and then immunological stress and if there is some virus after all that recently has been disturbing the physical stress. What level of ambitions you have and where you are at if you push yourself too hard. And then also psychological stress. And then there are also these big traumas cause then one needs more psychiatric help. To get over that difficult thing.

(1.2)

Myra: When you say trauma then it can be surgery too or?

(1s)

Physician: Yes, well, then it depends on the individual's experience of (Myra: okay) it all (Myra: hmm) What for one person is a trauma maybe isn't so for another. (Myra: no) So it's hard to say

Myra: Okay

(2.2)

Gwen: Do these traumas trigger, does it come immediately, this fatigue, or can it be latent and appear after several years then or? Does it have a direct link and as you sa- like the Estonia catastrophe then?

Physician: Yes, well, I don't have enough experience. I believe that you will have- that it com- can come after a while. (Gwen: hmm) It beco- (? : hmm) When the state of shock has gone and you get a depression [and then it just doesn't stop

Gwen: [Can that be years - years later and like that?

Physician: Probably it can. (? : hmm) That's why it's important to go through one's own history and see if there is something, 'cause I mean /.../

The lecturer/physician presents a number of different explanations of CFS, which are all related to the concept of stress. She talks about immunological, physical and psychological stress and of psychological traumas. Of all these possible explanations, one of the participants selects trauma. Together with one of the other participants she examines the meaning of this theme, asking the lecturer different questions about things like what sort of events might be regarded as traumas and how traumas are connected to fatigue. The physician answers these questions in rather guarded terms like 'it does depend on the individual', 'it's hard to say' and declares that she does not have 'experience enough'. Nevertheless, the lecturer gives an answer, though in a rather vague way, emphasising a general and almost vernacular explanation: 'it can come after a while /.../ when the state of shock has gone and you get a depression and then it just doesn't stop.'

In this conversation about CFS, the lecturer/physician as well as the participants primarily used a multifactorial framework for interpretation of the causes of CFS in combination with everyday reasoning. The illness is chiefly discussed from the pedagogical

point of view, and the verbal interaction resembles an educational situation about a certain illness rather than a doctor-patient meeting concerning the suffering patient. The participants take an active part as they seize upon possible explanations, asking questions and even propounding interpretations like ‘can that be years later and like that?’ while the physician/lecturer assumes a more cautious position, pointing out her own insufficient experience. The organisational structure of the school seemed in this way to allow the patients as well as the medical professionals to go beyond their traditional roles and limitations, in order to create meaning in suffering that eludes both patients and professionals. Accordingly, the conversation above has been analysed as one about CFS as a disease – a sequence where both lecturer and participants face the illness from the ‘outside’, so to speak.

According to what the two women in Example 1 told in interviews later on, the elements they chose to focus on in the example were of significance to their personal illness history. Nevertheless, neither of them referred to their personal experience in this particular situation. They just picked out elements in the lecture that made sense to them to explore the disease they happened to have contracted.

Excluding personal information and personal experience of illness in a rather medical lecture and discursively objectifying oneself talking about CFS patients as others might, of course, be possible to explain from the fact that this was the first meeting and that the participants did not know each other. Another explanation is that personal experiences were avoided according to a general assumption that personal stories about suffering do not belong in medical discourse. However, it can also be compared to what Young (Young, 1997) has described for gynaecological examinations where patients refrain from telling stories to protect their personal integrity and how narrated personal experiences can ‘disrupt the dominance of medical discourse’. Young writes:

[S]hifting her focus of consciousness from medicine to narrative, as the realm in which to spin out a presentation of self, can disrupt the dominance of medical discourse over the voice of the lifeworld. (1997: 68)

CFS as illness

What then could possibly change this ‘outside’ position towards the illness in a situation of medical explanations? In another class during their first lecture held by the same physician and similar to the one analysed earlier, the following conversation appeared (see Example 2).

Example 2 (ME/A:1)

- Physician: At the same time it's like this – Several patients that I've met have said now I'm really healthier than I've ever been since I got chronic fatigue syndrome, except that I have symptoms so to speak. (Jenny: yes yes) But I never get infections any more. There are a few (Jenny: okay) there are several patients that say (that). (Jenny: oh gosh) And that can be true because it can be a sort of irritation that gives you high levels of interferon, which is another (Jenny: mm) thing like (Jenny: mm) cytokines which are our first defense against virus infections. And that makes you have such a high level that the viruses just bounce right off you. (Jenny: okay) Yes. Some patients say that. I wonder if any of you have had that experience?
- Mary: No, but I had two bad infection reactions in a very short period, and after that I had no problems for several months. [I think the whole thing was really odd.
- Jenny: [Yes, I've noticed that too I noticed that too.
- Mary: Then this came back. (Jenny: yes) (It) sneaked back. (Jenny: yes) I was fine for three months.
- Jenny: I was only fine for a week, but then I was really healthy, you know. Or I mean I was [very inf-
- Mary: [Yes, almost [healthy for three months.
- Jenny: [had a terrible cold but I had no other problems (then).
- Physician: Then it – was just the opposite of what I was saying.
- Jenny: Yes, it was. (Mary: yes) And that /.../

At the end of the lecturer's biomedical explanation about the immune defence system and cytokines she turns to the participants, explicitly requesting their personal experience in this area. With this invitation to tell their stories about infections, two participants start to tell their stories, which seem to be parallel. Their stories are followed by another story (not included in the example) built on the same theme.

The conversation that is presented in Example 2 starts with a question from one of the participants (Jenny) about immune defence. The lecturer's/physician's answer is divided into two parts. The first part is a kind of a narrative about what other CFS patients have told her as a physician. 'I' in the narration is therefore not the lecturer but other patients. In that sense it is an illness narrative but since it is told not from one specific patient's point of view but from that of many different patients', perhaps representing the typical patient, it becomes a narrative about illness (Hydén, 1997). Related to this narrative about illness and according to Hydén's terminology, the participants' simultaneously told stories, though short, are nonetheless illness narratives.

The use of personal experience of illness appeared to be important to answer the second question seemingly underlying the interaction in patient school, namely ‘Do I fit into this description?’.

‘Asking questions’ about in what way one’s own suffering might correspond with the descriptions of the illness that were discussed in the patient school means to face the illness from the inside. This is obviously what was accomplished when personal examples were compared to abstract descriptions of the illness and to the image of the typical patient that sometimes were conveyed through narratives about illness. We found many examples in the material of how the participants compared what the professionals described as common and typical symptoms among patients with chronic fatigue with their own personal experiences. In this way; the participants examined and tested their personal suffering from what is usually called an illness perspective (Kleinman, 1988).

The school format seemed to allow the participants’ real-life experiences of illness to be heard. We also found that the interaction between the medical professionals and the patients quite often implied that experiences from everyday life became the starting point for the lecture. The lecturers could then, for instance, ‘re-use’ parts of the experiences that the participants told about. Consequently, the border between medical explanations and experiences and explanations of everyday life were not always clear and unequivocal. One interesting example of this is how both psychological and physical factors were used in positive ways. Thus, for instance, the typical CFS patient was presented as being ‘very ambitious and achievement-oriented’, and physical symptoms were described as being ‘smart’ responses, and constituting body signals of being ‘overloaded’.

As an activity within the wider organisational framework of a hospital, the patient school was linked to the biomedical ways of interpreting and reasoning about diseases. But at the same time, and as shown in previous examples, this biomedical interpretative framework was far from unambiguous; it was rather very equivocal. During the physician’s lecture, for instance, where several of the large number of biomedical theories about the cause of CFS were presented, the physician also made use of the nowadays preferred multifactorial description of the disease invoked by the so-called biopsychosocial approach. And in conversations between one participant and the psychologist, both speakers used non-medical explanations of the disease when they describe the body as ‘smart’ and the body being about ‘to hold back’. They thus seemed to jointly reinforce the view that the body also communicates psychological overload. All of this implies that at least three different

interpretative frameworks were at use more or less simultaneously in the patient school: (i) the traditional biomedical framework, (ii) a broader biopsychosocial framework, and (iii) the framework of interpretation used in everyday life.

Making use of others' illness experiences

In the previous example we have shown how the participants faced the illness from inside by comparing their own experiences to what the lecturer lectured about as professionals. In the fifth and concluding lecture, however, others' personal experiences of suffering were used. The lecturer this time was an ex-patient who had recovered from CFS. This lecture took the form of an illness narrative (Hydén, 1997) or a pathography (Hawkins, 1984). It included the whole illness trajectory, describing the time from the onset of illness, his pilgrimage, the recovery and finally his return to full-time work. The presentation of this story makes this lecture very different from all the others; it deals with the lived experience of illness rather than with professional experience and medical knowledge. The resulting discussion between lecturer and participants after the ex-patient's story followed a similar pattern in both classes. It started as a kind of interrogation in which the participants seemed to try to understand in what way the lecturer's story could be relevant for them. What could they learn about their own illnesses from what the lecturer/ex-patient had described? Did the lecturer actually suffer from the same kind of illness as they do?

When cross-examining the lecturer/ex-patient, the participants investigated with their questions the lecturer's experiences of those symptoms that are usually regarded as typical for CFS sufferers, and of symptoms and experiences that had been discussed previously in the class. Even when not saying so they seemed to ask questions to relate the lecturer's story to their own experiences, and ask whether they were actually talking about the same illness. In those interrogative episodes it seemed as if the participants struggled to find durable structures of meaning, and ways to understand their own illness as something that has at least a certain degree of stability.

That the interaction between the participants and the ex-patient not only concerned the lecturer's illness experience but the participants' as well, became even more obvious when the participants explicitly compared the lecturer's experience with their own. The participants thereby examined the CFS from an illness perspective even though if they did so by the means of somebody else's experiences, accordingly sharing experiences of illness (Bülow, 2002). Making use of the ex-patient's story became important when looking for an answer to questions concerning, for instance, the possibility of recovery. Did the lecturing ex-patient do

something special; did his type of personality have anything to do with his recovering? Were the lecturer's experiences unique or may the participants hope for the same kind of recovery? (Cf. Example 3.)

Example 3 (ME/A:5)

Mary: Your what should I say immune defence and so on, did that become exactly as it was before then?

Ex-patient: Yes it seems like that. I have anyhow (Mary: Yes) not. They have run tests on me and followed this up and so on, and then I haven't got any kind of proposals or restrictions in any way so that (Mary: hmm) I haven't got that.

Rita: If you compare yourself with the others in your group [the lecturer's class in the CFS school] are there, do you think that you are kind of different as a person in that way? That you are stronger and more stubborn and all that. That you had the strength to try all the time?

((some data omitted))

Mary: Yes, 'cause you got well in such a short time that (Ex-patient: Yes) I always think here's the message is that yeah you have to be prepared for four five years.

((some data omitted))

Ruth: Then you had great pain I don't know that /.../ but great pain like that in the body and that I haven't felt but /.../

The first question concerns whether the ex-patient really has recovered. When Mary asks if the lecturer's immune defence had 'become exactly as it was before', thereby indicating what in this context seemed to be regarded as a standard for recovery, the lecturer reinforces his own experience of a complete recovery by referring to the medical professionals and to the taking of tests. In a following question Rita airs a suspicion that the lecturer's experiences might be unique and, if this is so, not useable as a comparison. This is examined and tested as the lecturer's illness history is compared with that of other CFS patients as well as with one of the participant's own experiences. In this way the conversation between the ex-patient and the participants was about comparisons of many different kinds – between experiences that the lecturer had during his illness and his experiences after recovery, between the lecturer and those other CFS sufferers who joined the same class in the patient school, between the lecturer's experience and what has been said in the patient school to be typical for CFS patients, and between the lecturer and the participants in this particular class.

To explore personal illness from the outside as an abstract phenomenon and a medical subject, as well as from the inside by examining what is described as typical in relation to one's own experiences of illness, seemed to be important for creating meaning in an uncertain

and contested illness like CFS. However, closely linked to contested illnesses is the question of how other people comprehend the illness. Consequently, it seemed that CFS could not only be understood as a medical diagnosis or as a personal experience. In some way the participants had to deal with their illness in a larger perspective as a sickness (Kleinman, 1988).

How can we make sense of chronic fatigue?

The question of how to make sense of chronic fatigue concerns aspects of ‘school-work’ where the participants tested what they had learned about CFS. It concerns the sufferer and what he or she thinks about the future, but also how other people such as families, employers, and health care organisations view the chronic fatigue. This means that CFS is discussed from what might be called a sickness perspective. That is, the participants touch upon the meaning that CFS is given in different social contexts.

Chronic fatigue syndrome indicates in its name, as well as through diagnostic criteria, that it is an illness that can go on for a long time. This has consequences not only for patients’ social lives, but also for their financial situations. Talking about suffering from a sickness perspective can, for instance, mean discussing CFS in relation to the social insurance system with its rules and views on such things as working capacity and rehabilitation, and also the rights and duties of persons considered sick. Most of the participants had regular meetings or contacts with physicians, the social insurance office, and their employers. The participants spoke of these meetings as inevitable, yet nonetheless contacts that quite often implied that their experiences of illness and of suffering were contested by other persons who had power and influence upon their lives – who had the right to make decisions about things like sickness benefits or whether they got sick leave.

These sickness-related aspects of CFS were, for instance, discussed in the patient school with an official from the social insurance office. During this lecture the participants brought up their personal experiences of misunderstandings, and with a helping hand from the official they tried to interpret these experiences. In Example 4 it is apparent how the lecturer, through her knowledge of social insurance system regulations and of routines for sick leave and rehabilitation, tries to interpret and explain the encounters one of the participants did not understand.

Example 4 (ME/C:2)

Lecturer: And it might be that you can't make a plan for rehabilitation until the medical part is finished. (Tina: hmm) And it almost sounds like it was just such an evaluation (Tina: hmm) they had made (Tina: hmm) there at that time

(2.8)

Tina: Because you can- This is wha- This I think is a problem of interpretation [that time. What is what?

Lecturer: [Yes that's right, yeah. Here as you see the office had obviously made an evaluation then and then you had (Tina: hmm) you had of course the chance to talk with someone at the office

Tina: Yes I was at one such inquiry meeting.

((some data omitted))

Tina: But I never understood that, that my boss wouldn't come up with a plan for rehabilitation 'cause (Lecturer: That's right) 'cause that must still- I mean from that very day you fall ill and become sick for a long period (Lecturer: hmm) it must be of interest or you must try for rehabilitation (Lecturer: hmm hmm) And then you shouldn't have to wait for, yeah, maybe a year (Lecturer: hmm) before they start to rehabilitate a (Lecturer: hmm) person, [so to speak.

Lecturer: [No and that is of-

Tina: And this is that- that understanding I didn't get but now- it is partly explained if you equate (Lecturer: hmm) training to work (Lecturer: hmm) with professional (Lecturer: hmm) rehabilitation (Lecturer: hmm) or (Lecturer: hmm) education

As an answer to the question of what a rehabilitation plan actually means, the lecturer describes some administrative rules that patients will usually confront in their contacts with the social insurance office, and what consequences these routines might have in the patients' everyday lives. Preceding this answer is a story from one of the participants (Tina). Tina tells about how different actors like her physician, her physiotherapist, her employer and the official from the social insurance office interpreted the regulations for rehabilitation in different ways. This confused her, and made her feel misunderstood and neglected. Although Tina viewed this event as problematic, the lecturer regarded these different efforts by those who make up plans for rehabilitation and those who deal with 'the medical part', as equally dependent – as something that explains the problem. The lecturer then explains the evaluation and decision-making routines at the social insurance office, as well as the specific concept of 'rehabilitation plan', and the principles applied when judging these cases. The participant then uses the same kind of reasoning to discuss her own situation and the difficulties she experienced in relation to her employer and the issue of rehabilitation.

When someone tells about personal experiences this particular narrator gets an opportunity to interpret various situations in which the experience have been contested, and the other participants can also make use of these narrated experiences by sharing experiences of illness and suffering (Bülow, 2002). All of the experiences discussed in the school contribute to the common collection of examples of different kinds of meanings at risk, as well as to know-how about ways in which these might be interpreted differently and also be handled differently in the future.

Contested illness and meaning

As stated at the beginning of this paper, creating meaning in a situation of chronic illness is commonly considered to be an individual process where the sick person by reflection and adaptation is supposed to understand and grasp changes in life trajectory, life history or personal identity all by him/herself. The study of the CFS school however, indicates, just as do studies of self-help groups (cf. Cain, 1991; Karp, 1992), that the creation of meaning might be considered to be a social interaction process.

From the CFS clinic's point of view, the patient school is at least partly an attempt to give recognition to CFS sufferers. Nevertheless, since it is organised as a school it seems to be an activity based on the idea of teaching patients how to manage their illness, i.e. it provides patient education. Schools are associated with learning, and usually there is a particular fund of knowledge or a specific subject incorporated into a defined course of study. Unlike patient education for those suffering from something like RA (e.g. Lindroth, 1996), there is no use in the CFS school of any clear-cut material, e.g. guidebooks. On the contrary, this study indicates that it is not just one way to understand and manage the illness that is discussed in the school. Instead, a number of different interpretations are brought up and used to create meaning in a situation of illness. The participants are thus learning to discursively manage their problem at the same time as they examine different ways to interpret their experiences through this discursive activity. Thus, a variety of possible perspectives, views and meanings of illness are created. All of this takes place in interaction with the professionals and as a reciprocal process among patients through sharing.

In a way, the CFS school constitutes a sheltered spot where the diagnosis and the symptoms are not contested as they are in many other social contexts. On the contrary, the school is a place where it is possible to talk about situations like experiences of mistrust and about the struggle to be referred to the CFS clinic. The school structure allows the

participants' everyday experiences and explanations to be heard and makes it possible for the patients/students to elaborate and test various kinds of interpretations as well as to compare their own experiences with others'.

Since several social organisational and interpretative frameworks are used in the CFS school, there is a mixture of different types of activities, and of discourses and shifts between them. The presence of different frameworks provides an opportunity for all participants to move about freely between different ways to talk about CFS, to bring different perspectives to each discussed issue and to switch focus within each framework. In this way, it becomes possible to regard the illness from the outside as a social object, as well as from the inside through personal experiences of the illness, and to examine experiences of how other people comprehend their illness.

During lectures the participants treated the lecturers as experts. This relationship reinforces the sense of legitimation and confirmation that the school intends to convey to the patients. At the same time the participants, in their capacity as students, carefully scrutinise the lecturers' presentations by testing the medical explanations against their own real-life experiences. Using the different frameworks of the school, participants will presumably get their experiences of illness and suffering legitimated in a number of ways. One way this is done is through the lecturers' showing interest in this particular diagnosis, which is emphasised by the fact that a hospital clinic gives priority to this kind of activity. That is, the school's biomedical frameworks contribute in an active way to the patients' creating of meaning in illness.

Secondly, the school provides the individual participants with the opportunity to hear other persons describing symptoms and difficulties that resemble their own experiences, which are sometimes doubted and contested. This means that both the diagnosis and the personal experiences are confirmed and made legitimate.

This kind of testing and examination of the meaning of illness and of the usefulness of different theories and ideas about CFS is all about interpreting one's own suffering by means of various established theories, views and diagnoses. As a consequence the participants are able to evaluate and test how they can use these theories and ideas to legitimate and talk about their own illness in various contexts. They also learn how to act towards others who make use of these ideas to contest the illness. However, this testing also represents an interesting example of how patients become discursively versatile in using different ideas and views.

They learn to move discursively between different ideas, and thereby not to be constrained to only one single interpretation; this makes them considerably less vulnerable (Radley and Billig, 1996). This is what we think of as learning to manage the illness discursively.

During conversations in the CFS school, patients and lecturers jointly form a kind of prototypical image of CFS patients and of experiencing CFS. To do this, the participants usually made use of examples or stories drawn from their personal experiences, while the lecturers' contributions were composed of prototypical, medical images of symptoms drawn from professional experiences. These latter images were usually based on the apprehension of the typical CFS patient 'considered as a group'. By means of these prototypical images the participants were able to compare themselves to what is conceived of as 'normal' for CFS patients, especially when it comes to matters like symptoms, duration of illness and what kind of everyday activities seem probable and reasonable to expect. Thus, they established a normal non-normality, which is used to interpret personal symptoms and experiences that in other contexts are characterised as deviant and different.

CFS is an illness with clear consequences for the relationships between patients and their families, as well as with employers, physicians and others. In these connections the ability to explain and legitimate one's own illness is important. Aspects central to this are knowledge about regulations and an ability to convince others by, for example, explaining the suffering in a very credible way. This means that the patients must become able to look at themselves from the outside and to regard themselves and their suffering in relation to things like various bureaucratic systems. They must also be able to consider their own illness from an 'outside' perspective, through, for instance, the health care system's or the social insurance system's point of view. That is, they must be able to consider how others might even perceive and describe the illness in critical terms.

Creating meaning of suffering associated with a contested illness is an interactive process accomplished in many different ways. These include the patients' use of the school's institutional frameworks as well as of different participant statuses, and especially of learning to discursively revise and restrain the illness. Consequently, the patients will not obtain just one idea about, or one description of their contested illness. Rather, they will gain the ability to discursively manage, and to discursively make use of a number of different theories, thoughts, and ideas about CFS. This will give the patients a versatile competence to interpret as well as understand their own illness in relation to more or less established – though not generally accepted – ideas about CFS, which might come up in various social settings. They

will also have a readiness and a capability for arguing for their illness, for the diagnosis and for different explanations of the illness, in meetings with people like family, employers, and the authorities. This discursive competence to control parts of the rhetoric of CFS increases their capability to handle meanings at risk, since they are not restricted to just one single view, but can move freely about between several different opinions and interpretations. Consequently, they can constantly create and recreate the meaning that is contested.

References

- Atkinson, P. and Hammersley, M. (1994). Ethnography and participant observation. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research*, pp. 248-261. Thousands Oaks: Sage.
- Banks, J. and Prior, L. (2001). Doing things with illness: The micro politics of the cfs clinic. *Social Science and Medicine*, 52, 11-23.
- Bartlett, E. E. (1986). Historical glimpses of patient education in the united states. *Patient Education and Counseling*, 8, 135-149.
- Bülow, P. H. (2002). *Sharing experiences of illness and suffering: Identity work and collectivised experiences*. Manuscript submitted for publication.
- Cain, C. (1991). Personal stories: Identity acquisition and self-understanding in alcoholics anonymous. *Ethos*, 19, 210-253.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168-195.
- Corbin, J. M. and Strauss, A. L. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Deccache, A. and Aujoulat, I. (2001). A european perspective: Common developments, differences and challenges in patient education. *Patient Education and Counseling*, 44, 7-14.
- Evengård, B., Schacterle, F. S. and Komaroff, A. L. (1999). Chronic fatigue syndrome: New insights and old ignorance. *Journal of Internal Medicine*, 246, 455-469.

Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M., Dobbins, J. G., Komaroff, A. and Group, t. I.

C. F. S. S. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121, 953-959.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Anchor Books.

Hak, T. (1999). "text" and "con-text": Talk bias in studies of health care work. In S. Sarangi and C. Roberts (Eds.), *Talk, work and institutional order*, pp. 427-451. Berlin: Mouton de Gruyter.

Hawkins, A. (1984). Two pathographies: A study in illness and literature. *The Journal of Medicine and Philosophy*, 9, 231-252.

Hilbert, R. A. (1984). The acultural dimensions of chronic pain: Flawed reality construction and the problem of meaning. *Social Problems*, 31, 365-378.

Horton-Salway, M. (2001). Narrative identities and the management of personal accountability in talk about me: A discursive psychology approach to illness narrative. *Journal of Health Psychology*, 6, 247-259.

Horton-Salway, M. (2002). Bio-psycho-social reasoning in gps' case narratives: The discursive construction of me patients' identities. *Health*, 6, 401-421.

Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19, 48-69.

Hydén, L. C. and Sachs, L. (1998). Suffering, hope and diagnosis: On the negotiation of chronic fatigue syndrome. *Health*, 2, 175-193.

Karp, D. A. (1992). Illness ambiguity and the search for meaning: A case study of a self-help group for affective disorders. *Journal of Contemporary Ethnography*, 21, 139-170.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*.

New York: Basic Books.

Kogstad, O. and Hintringer, F. (1993). Patients with fibromyalgia in pain school. *Journal of*

Musculoskeletal Pain, 1, 261-265.

Lindroth, Y. (1996). *Development and evaluation of patient education in rheumatoid*

arthritis. Lund: Lunds universitet.

Lorig, K., Konkol, L. and Gonzales, V. (1987). Arthritis patient education: A review of the

literature. *Patient Education and Counseling*, 10, 207-252.

Mehan, H. (1979). *Learning lessons: Social organization in the classroom*. Cambridge:

Harvard University Press.

Radley, A. and Billig, M. (1996). Accounts of health and illness: Dilemmas and

representations. *Sociology of Health & Illness*, 18, 220-240.

Reid, J., Ewan, C. and Lowy, E. (1991). Pilgrimage of pain: The illness experiences of

women with repetition strain injury and the search for credibility. *Social Science and Medicine*, 32, 601-612.

Riessman, C. K. (1990). *Divorce talk: Women and men make sense of personal relationships*.

London: Rutgers University Press.

Rosenqvist, U. (2001). Patient education: New trends in sweden. *Patient Education and*

Counseling, 44, 55-58.

- Sarangi, S. (2000). Activity types, discourse types and interactional hybridity: The case of genetic counselling. In S. Sarangi and M. Coulthard (Eds.), *Discourse and social life*, pp. 1-27. Harlow, England: Longman.
- Skelton, A. (1998). The hidden curriculum of patient education for low back pain in general practice. *Sociology of Health & Illness*, 20, 96-111.
- Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly*, 6, 347-361.
- Wessely, S., Hotopf, M. and Sharpe, M. (1999). *Chronic fatigue and its syndromes*. Oxford: Oxford University Press.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness*, 6, 175-200.
- Williams, G. H. (1989). Hope for the humblest? The role of self-help in chronic illness: The case of ankylosing spondylitis. *Sociology of Health & Illness*, 11, 133-159.
- Woodward, R. V., Broom, D. H. and Legge, D. G. (1995). Diagnosis in chronic illness: Disabling or enabling the case of chronic fatigue syndrome. *Journal of the Royal Society of Medicine*, 88, 325-329.
- Young, K. (1997). *Presence in the flesh: The body in medicine*. Cambridge: Harvard University Press.