

Suffering, hope and diagnosis: on the negotiation of chronic fatigue syndrome

Lars-Christer Hydén
Stockholm University, Sweden

Lisbeth Sachs
Karolinska Institute, Sweden

ABSTRACT The medical interview has a central place in the transformation of suffering into disease. The focus in this article is on patients with suspected chronic fatigue syndrome (CFS). Central to the diagnosis of CFS is the absence of a clear medical pathology causing symptoms. To patients it is of central importance to present themselves in the medical interview in a way that makes a diagnosis of CFS possible, which provides both hope for a cure and a social legitimization of their suffering. To doctors it is important that they maintain their position as a medical authority and gatekeeper. This means that in a medical examination the doctor and the patient together must explore the patient's suffering to define symptoms enabling a diagnosis of CFS. The central issue in this article is how doctors and patients in medical interviews *negotiate* symptoms and diagnostic criteria in search of a *legitimate* diagnosis and illness, and how this constitutes the central concern in the patient's and doctor's collaborative *diagnosis work* in the medical encounter.

KEYWORDS *chronic fatigue syndrome; chronic illness; doctor-patient interaction*

ADDRESS Lars-Christer Hydén PhD, Associate Professor, Department of Social Work, Stockholm University, 106 91 Stockholm, Sweden. [Tel: + 46 674 73 76; fax: + 46 674 73 98; e-mail: LC.Hyden@socarb.su.se]

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Illness is one of many possible forms in which suffering can appear and take shape in western culture. Suffering induces an individual to try to understand and do something about what is happening, by seeking the help of a doctor to establish it as the result of disease. Other cultures do not always

link suffering with illness. One difference between our own western, post-modern culture and others is probably that institutions for disease dominate in the West and have crowded out many other forms of expressing and relating to suffering.

To express one's suffering in terms of illness means that it must fit into and fulfil certain criteria and preconceptions about disease and its treatment, as found chiefly within institutional medicine. This means that, to have suffering recognized as disease and to obtain relief, patients must *transform* their suffering in a way that enables them to seek help and be accepted as patients for medical care.

When individuals present with chronic fatigue syndrome (CFS), pathology often cannot be discerned, even though they suffer from several severe chronic symptoms, especially fatigue. CFS is similar to several other so-called modern diseases, such as multiple chemical sensitivity syndrome, myalgic encephalomyelitis (ME), and several others where no clear-cut pathology can be identified (Ware, 1997). These modern diseases present patients with several problems. In general it is difficult both for patients and health-care professionals to pinpoint an explanation for the symptoms and suffering. That means that it is difficult for patients to receive a diagnosis and, as a consequence, a legitimization of their suffering and problems.

CFS is a relatively new and unknown syndrome, so patients in general are not aware of exactly which symptoms they are expected to exhibit if the doctor is to be able to diagnose this condition. This means that, in the examination context, the doctor and the patient together must explore the patient's complaint to determine what part of the patient's suffering can be established as symptomatic of CFS.

The central issue in this article is the analysis of how patients with suspected CFS and doctors at a special CFS unit transform suffering into a disease through the verbal interaction in the medical interview. Of special interest is how symptoms are defined as relevant and negotiated and the diagnosis received.

The study

At a large hospital in Stockholm, Sweden, a special CFS unit was created in 1992 to receive patients referred from other doctors. The requirement was that the referring doctor suspected the occurrence of the CFS syndrome or that there could be reason to examine the patient especially for this, even if only to rule out the suspicion of CFS.

A patient's first contact with the special unit is a medical interview with one of the four female medical doctors at the unit. This medical interview consists of anamnesis and a physical examination as well as information about CFS and the various treatment options that could be administered.

This means that a patient who comes to her or his first medical interview has not yet been diagnosed with CFS. The purpose of the interview is to perform an initial evaluation of the patient.

Two-thirds of the patients coming to the special unit are middle-aged women (35–65 years of age), of whom most have some form of higher education (high school or college). Of all the incoming patients about 50% receive a diagnosis of CFS. If the patients are diagnosed as suffering from CFS they are invited to take part in the patient activities at the clinic, including information and educational programmes about CFS, support groups, physiotherapy, etc.

The material for the present study consists of 15 consecutive audio recordings of the first medical interviews with the patients at the special unit, occurring once a week over a period of nine months. This material was collected as part of a research project on CFS as a disease without pathology. In addition, all patients in the study were interviewed by one of the researchers (LS) before and after the medical interview. This researcher also made observations during the medical interviews and at the clinic, as well as carrying out informal interviews with the doctors involved. Both the research and medical interviews were transcribed and served as the basis for the analysis reported here. All of the patients were informed about the study and agreed to participate. The material includes patients who were later diagnosed with CFS as well as those who did not receive that diagnosis. The latter were given referrals or, in some cases, allowed to participate in some of the unit's activities.

In the medical interview the patient and doctor together have the task of conducting a conversation (speaking from different positions) in which the suffering is presented, assessed, and summarized, and in which the patient finds out if he or she satisfies the criteria for CFS. At time of the study to qualify for a diagnosis of CFS, the patient had to have the two principal symptoms of abnormal fatigue, the absence of any other illness, and at least eight of the following 11 symptoms: mild fever, sore throat, tender lymph nodes, muscle weakness, muscle pain, fatigue after exertion, headaches, pain in the joints, neuropsychological complaints, sleep disturbance, and the sudden appearance of symptoms (Holmes et al., 1988).

The analysis of the material was carried out in two steps. First, the transcribed research and medical interviews, together with the observations, were scrutinized in order to understand the *background* for the medical interviews. Specifically, recurrent patterns and themes were identified concerning the way the patients described and reported their suffering and problems, and how they had coped in relation to health care. Thematic analysis was also made of how the doctors experienced and described their situation at the clinic. Second, the *medical interviews* were analysed in order to identify the ways in which the doctor and the patient jointly attempted to identify relevant symptoms in order to make a diagnosis, and the way that these diagnoses were delivered and received.

The patients: suffering, diagnosis and hope

In the observations and in the medical and research interviews three themes emerged as being especially salient. First was the way that suffering presented itself as *atypical* for the patients. Second, there was the problem of making suffering and often impaired work capacity *legitimate*, especially in relation to family members and work colleagues. Third, *the hope* for an explanation, a treatment and a cure for the extended suffering.

The patients had been referred either by their GP or some other specialist. From the research interviews with the patients as well from the medical interviews, it appears that, in all cases, the patients had considerable experience of various types of medical examination. In many instances these examinations were both comprehensive and invasive. A large number of patients (14 of 15) had been treated previously for various types of illnesses and ailments. Common complaints were goitre (three patients), stomach ailments (six patients), and gynaecological problems (two patients). Four patients had also replaced or were in the process of replacing all amalgam fillings in their teeth.

In the interviews all the patients described extensive somatic and psychological suffering which they could not explain, and which the health-care system had not managed to capture through successful diagnosis. For example, patients tormented by chronic fatigue had their lives marked by their symptoms and suffering. It is something that had obvious consequences for their everyday life, including family, professional and social aspects. A majority of the patients had been on sick leave for extended periods (sometimes several years) and felt themselves to be incapable of work. For these patients their suffering had been at the centre of their lives and they had been searching for an explanation, for a cure and for care.

For these patients, as well others with chronic illnesses (Charmaz, 1991), suffering and pain entail a tearing apart of the seamless link between the body, the self and the surroundings that characterizes much of everyday life. This contrasts with normal conditions where neither the body nor the self is manifested as an object for consciousness, thoughts, or attention; from a phenomenological perspective, the two constitute a seamless whole within individual experience.

In both the research and medical interviews the patients described, in various ways, and with different words how pain and suffering directed their attention away from this experienced whole and converted either body or feeling into an alien object (Leder, 1990; Kleinman, 1988; Good et al., 1992; Toombs, 1988). Pain and suffering represent something that is foreign and that threatens and invades the patients' subjectivity by fragmenting their life world (Scarry, 1985; Cassell, 1991; Hydén, 1997).

Initially the patients had tried to put up with the pain and suffering in their day-to-day interaction and practice by trying to ignore the torment or to do something about it, in a way similar to the process described by

Alonzo (1984). Usually, they hoped that pain and suffering would go away by themselves or by a simple self-administered treatment. When this did not happen, suffering and fatigue became something *atypical* (Hilbert, 1984), compelling them to search for relief through biomedicine (Kleinman, 1980).

An example of how suffering becomes atypical was shown in the presentation made in a medical interview by a middle-aged female patient. The following excerpt describes how her problems started, and how she searched for help from the health-care system. Her problems and suffering started slowly over a longer period of time. Her tiredness increased and appeared as something alien and atypical. After some time she contacted a doctor for a thorough examination.

Excerpt 1. Patient CA. 37–49

37 D(occtor): How do you see it (the current complaint)?

38 P(atient): Mm, it came rather stealthily, I think, it hasn't struck

39 like lightning ... Instead it began last summer, I think. At that time I had
40 a lot of stomach problems, later it became a bit better. But I got
41 tired and tired, then I had a slight cold, no major infection as it
42 were. And then I began to vomit, I didn't see a doctor, just carried on
43 and then the vomiting returned in the same way, like an attack [?] of
44 the spleen type to the right of the stomach and downwards, and that
45 made me go to Cityakuten (an emergency clinic). And there they
46 suspected bile, and so I had ultrasound of the liver, gallbladder and
47 [?] and they found nothing. And then the temperature came creeping in
48 October, and then in December I have had a temperature most of
49 the time, at most it is 38.5 (°Celsius).

Through examination, diagnosis, and treatment, the pain and suffering are encircled and transformed by the medical doctor into a biomedically defined disease, with an identity, cause, prognosis, and treatment. Pain and suffering are no longer foreign and unknown but identified and thus confirmed by someone with social authority. Through this recognition and confirmation, pain and suffering achieve an existence not only for the sufferer but also in a social context. In other words, these experiences are recognized socially, and in being confirmed for the individual, become *legitimate* (Kleinman, 1992; Ware, 1992; Cooper, 1997).

In this way, pain and suffering obtain a social, cultural, and psychological validity, they exist in the form of a disease and can be treated (Good, 1994). Thus it becomes possible to establish a relationship with the illness, based not on it being foreign, but 'something' with a history, meaning, and significance (Brody and Waters, 1980). As a consequence one's own self and life world can be kept intact, and the threat of fragmentation can be avoided or minimized.

Patients experiencing pain, fatigue, and general physical suffering for extended periods are present in relatively large numbers in the health-care system (Berrios, 1990). At regular intervals, various categories are created of which some are historically temporary, such as the diagnosis of neurasthenia

in the West, and others are more enduring because an underlying pathology can be identified. A central task for patients who seek to fulfil their hope for healing and relief in this way is to try to identify what, in different medical contexts, are perceived as symptoms confirming the presence of disease.

To continue to visit new doctors, new hospitals and clinics, to follow the debate about new diseases and treatments (and, not least, diseases that are 'recognized', such as fibromyalgia) in the mass media means continuously to be presented with hope, because the next doctor might be able to provide an explanation, a diagnosis, and thereby the possibility of healing.

CFS and health care

Historically and culturally, an array of syndromes fall into a grey zone between patients' suffering and the possibilities for the health-care system to identify, and to cure disease. Suffering in the form of chronic fatigue and pain in parts of the body is a historical and partly cultural syndrome recognized as chronic fatigue syndrome (CFS) (Aronowitz, 1992; Cathebras, 1994). Central to the concept of CFS is the absence of a medical pathology causing the syndrome; i.e. it has not been possible to identify the medical causes of the symptoms. This fact has several important implications.

It is not possible for the doctors to diagnose CFS without reservation, solely on the basis of an examination of changes or pathologies in the body. This means that differential diagnostics are important; it must be possible to rule out other conceivable explanations of the patient's symptoms. In general, this means that patients are forced to undergo a long series of examinations spread over time, which include a wide variety of tests (allergy, stomach and intestinal, infection, psychiatric, etc.).

A diagnosis of CFS is based on the patient exhibiting a number of symptoms that agree with the internationally accepted criteria for CFS (Holmes et al., 1988). This means that determining which symptoms are actually present is crucial because, for example, it is not possible to supplement an examination with tests of various values to arrive at a diagnosis. This type of examination can only exclude other explanations and diagnoses. Thus, the diagnosis of CFS can be made when certain symptoms are present and other possible explanations of the symptoms can be excluded.

Based on this evaluation, and sometimes certain additional tests for analysis, the diagnosis of CFS is made. If it turns out that the patient does not have any pathology but satisfies certain criteria for CFS, the doctor makes what can be called a *negative diagnosis* (a diagnosis in the absence of signs of pathology).

This negative diagnosis is problematic from a medical perspective because it is difficult to determine medically. There are no clear and unequivocal procedures for determining that the syndrome is present. In contrast to much else in modern health care, in the case of suspected CFS there are few or no possibilities for the doctor to find signs besides the patient's symptoms,

in the form of test values, cell changes, or the like. Thus, the doctor is almost completely limited to the patient's description of symptoms.

One characteristic of the patients under study who seek help at the clinic because they themselves or their regular physicians suspect that the patients may be suffering from CFS is that they all have relatively long histories of seeking medical help for their suffering and pain (Ware and Kleinman, 1992; Ware, 1992). In this study the mean duration was six years from the onset of the symptoms to the time of the interview.

The patients in the study, like others who have spent much time journeying through the health-care system, being examined but not being successfully diagnosed, find themselves in a special situation. For them, it is impossible to achieve the recognition of a doctor or 'society', so that their suffering and pain can be conceptualized as a disease and thereby become socially legitimate (compare the situation with certain types of chronic pain, (Reid, Ewan and Lowy, 1991)).

In a not dissimilar way, the doctors too are faced with a problem; namely, that of maintaining medical authority or, in other words, being able to legitimize their diagnosis within the framework of the medical community (Kirmayer, 1994). The doctor has to make an array of decisions pertaining to this issue: is the patient's problem relevant for somatic medicine or should he or she be referred to a psychiatric clinic or to a psychologist? Is the present clinic the one that should be responsible for the patient? Is the patient eligible for continued contact and treatment at the present clinic (e.g. receiving physiotherapy)? Should the patient be on sick leave?

Hence, the medical interview has a central place in the transformation of suffering into disease, and an important place in the illness trajectory of the patients concerned.

Presentation and initial examination

An analysis of the medical interviews shows that the meeting between the doctor and the patient is generally organized in six parts. The interview starts with (1) socialization, in which the doctor and patient exchange greetings, followed by the patient (2) presenting his or her current problems. After that, the doctor (3) examines the patient, partly by (3a) taking the patient's medical history and partly by (3b) the patient describing his or her current symptoms. The doctor (4) summarizes the results of the examination and provides a preliminary diagnosis. The patient (5) comments on the diagnosis and asks any additional questions he or she may have, after which the doctor (6) concludes the interview. What happens in parts two through five is pertinent to the following analysis.

After the initial socialization the doctor in all conversations asks how and when the patient's current problems or symptoms began, which results in stories of how they started. In what could be called *the debut stories*, the patients delineate a series of events which represent the start of their

current suffering and which precede their present situation. In these stories, the patients point out a number of events that they associate directly with their situation. These are defined against a background that indicates which events can be considered deviant in relation to the normal. In other words, these events indicate how suffering and pain came into focus as special objects for attention. The stories also show the patients' reactions to and evaluation of their ailments or symptoms. Finally, the stories set out the patients' attempts to relate to their ailments, either by 'containing' them, that is dealing with the suffering within the framework of the everyday, or by seeking some kind of medical help.

The debut stories are important in that patients define the topic relevant to the conversation, where they wish to start the examination, and how they want the conversation to continue after that point. Furthermore, in the debut stories patients not only present their symptoms and ailments but also what they consider relevant to understanding the symptoms, and how they themselves relate to their suffering and their troubles. They also indicate the subject for the next phase of the examination, specifically, anamnesis and current symptoms.

In this second excerpt a middle-aged male patient talks about the beginning of his problems and how he has coped with them.

Excerpt 2. Patient AA. 48–63

48 D: What is it that made you come here? Can you tell me.

49 P: It started seven eight years ago. It started with recurrent pains
50 in the heart.

51 D: This was in 1989 something?

52 P: Yeah, seven years ago, well something like that. And I also felt
53 that I started to become very tired, I had certain periods when I thought the heart
54 beat fast and I thought I had something wrong with my heart. So I
55 went to the hospital and told them how it was, and they took
56 some tests and a work EKG and so on, they told me that I wasn't especially
57 well trained physically, but they didn't find any major problems.

58 D: No, and nothing [?]

59 P: No, and after that I have been living with it. I have had that kind of work
60 that if I was tired I didn't have to work that day. And it worked that way
61 until three years ago. After that point in time I haven't been working at all.

62 D: Since 1992?

63 P: Since about 1992.

Among the symptoms presented in the debut stories, problems with chronic pain and fatigue are especially frequent. A common feature of the symptoms reported by the patients is that they resist all the normal everyday procedures for coping with these kinds of problem: the pain does not stop after a while or respond to medication, the feelings of fatigue cannot be related to excessive physical exercise or lack of sleep. The symptoms present themselves as problematic and atypical for the patients (Hilbert, 1984).

After the patient has presented the debut story, the doctor starts the

medical examination of the symptoms. This often long and comprehensive part of the conversation contains a medical history and a review of the current situation. The doctor's point of departure consists of two conditions: previous medical examinations that the patient has undergone and the current status of the symptoms.

The review of previous medical examinations, examination results, and medical history is aimed at excluding an array of alternative explanations of the current ailments. In this case, the review covers all the other types of examinations that the patient has undergone: allergy tests, stomach and intestine tests, tests of the immune system, rheumatism, etc. This process is simplified to a great extent by the doctor, in most cases, having received copies of the relevant examination records or journal extracts from other doctors. In some cases, the patients bring the relevant materials themselves.

What patients wish to emphasize about these previous medical examinations is that the results were negative or inconclusive. Thus, despite previous consultations, the patient's ailments and problems appear unexplained, providing a special justification for the current examination. As far as the patient is concerned this is the starting point for the present medical examination.

The doctor reviews the information to update his or her knowledge of examinations the patient underwent previously. In addition, patients are often able to provide supplementary information about examinations where nothing had been written down, about the results of examinations and which measures, especially medication, that may have been ordered by another treating physician.

Examination of symptoms: questions and answers

After the initial review, the doctor moves on to examine the patient's current ailments and problems. For this work, the doctor's point of departure is the question of the extent to which the patient satisfies the 11 different criteria for chronic fatigue syndrome. Sometimes this test for symptoms includes a physical examination.

The review of the status of symptoms is largely based on two different patterns of conversation. The first is the relatively traditional conversation patterns between doctor and patient. The doctor asks the patient about a group of complaints, the patient answers, and the doctor asks any follow-up questions, gets answers, then moves on to introduce the idea of a new ailment or symptom. The second consists of a negotiation of what could be counted as relevant symptoms, and how the symptoms could be interpreted. The central question here concerns to what degree the patient's symptoms could be fitted into and fulfil the established criteria of CFS.

In the more traditional form of conversation the doctor initially utilizes the symptoms and ailments that the patient presented in his or her debut story to move on to the examination of symptoms. In excerpt three, a middle-aged

woman is interviewed. The woman's main ailments are aches, weakness, and fatigue, and she has suffered from these problems for over five years.

Excerpt 3. Patient MM. 162–179

162 D: Did you find it easy to relax?

163 P: No, I don't think so.

164 D: But earlier?

165 P: Sure, earlier, well I have . . .

166 D: But it isn't so that your sleep is disturbed because of pain somewhere or...?

167 P: No, it's not like that really.

168 D: Do you snore?

169 P: No, I don't know.

170 D: Nobody complains about it?

171 P: I sleep alone so I don't know [laughs].

172 D: You have lived alone . . .

173 P: Right, but that's right, [?] in the country, that time there . . .

174 D: You have lived alone for many years or . . .?

175 you don't have a steady partner?

176 P: Sure, I've had a steady partner, but no one who has stayed with me at home.

177 D: Do you have a steady partner now?

178 P: No.

179 D: And your child, is it a boy or a girl?

Within the framework of an ongoing discussion about sleep and sleeping habits initiated by the doctor, the doctor formulates a specific, closed question about whether the patient can relax easily (line 162). To this question, the patient answers directly (line 163), whereupon the doctor follows up with questions for clarification (lines 164, 166, 168).

When the doctor considers the information to be sufficient, she moves on in the conversation by following up one of the patient's previous answers. When asked if she snores (line 168), the patient answers that she does not know because she sleeps alone (line 171). The doctor turns this bit of information into the subject of a question and asks the patient if she lives alone (line 172). The formulation of this question begs an answer: it is asked in an indirect form and with a rising tone at the end, which is characteristic of a question in Swedish. The purpose is to ask about a delicate subject where the doctor suspects there might be problems (Bergman, 1992; Jefferson, 1988; Adelswärd and Sachs, 1996). Thus the doctor formulates an open question for the patient that concerns her social relationships, especially her intimate relationships with men. The patient answers the questions vaguely and declares that she has steady relationships but that she lives alone and does not have any partner at the moment (173–8). The doctor is obviously satisfied with this information and introduces a new subject, the patient's child (179).

Throughout the consultation, it is the doctor who introduces the topics for the conversation or defines what subject in the patient's answer can become a new topic. The doctor's questions are, to a great extent,

formulated as closed questions and answered with short information by the patient. This pattern of interaction agrees with the traditional question–answer–follow-up question–answer pattern identified in conversations between doctors and patients (Frankel, 1984; Mishler, 1984).

During this process of symptom assessment, it appears that the patient is ‘at the mercy of’ the doctor: it is the doctor who decides the topic and when the answer is sufficient. Normally this is not problematic because both parties can cooperate in delineating the symptoms, as part of which the patient can resist the doctor’s suggestions (Stimson and Webb, 1975). In this case both the doctor and the patient are clear about what count as relevant symptoms and how to interpret and evaluate them (Maynard, 1991).

Examination of symptoms: negotiating relevance

In the medical interviews with the suspected CFS patients, an uncertainty arises on the part of the patient in some cases whether or not certain physical ailments should be interpreted as symptoms, or whether the absence of some symptoms means that there is no ailment or suffering on the part of the patient. This uncertainty in the patient is related to which symptoms can be counted as relevant to the diagnosis and what weight and meaning they have for the doctor in the work of arriving at a diagnosis. So the patient can have difficulty in determining the significance of the questions the doctor asks about symptoms. This uncertainty leads to a *negotiation* between the doctor and the patient about how certain aspects of the patient’s suffering and actions are to be counted as relevant symptoms or not. This is shown in excerpt four. The patient is a middle-aged women, suffering from aches, fatigue, swollen legs and arms. Her present symptoms made their debut one year before the present examination.

Excerpt 4. Patient GG. 414–437

414 D: But muscle pain like that and pain in your joints like that, it isn’t
415 something you think troubles you?

416 P: No.

417 D: Because what we were talking about that you get short of breath when
418 you climb stairs, but you, it’s not that you have a lot of trouble with your muscles
419 and that you can ... when you move like that, there’s nothing that you ...?

420 P: Sure, but it’s obvious it does ... why sure, I’m out walking every
421 day. I haven’t been doing it since I’ve been like this, because I just haven’t been
422 up to it lately, just walked around town, walked downtown, but that takes about
423 10 minutes. I mean, you have to, for one thing everybody
424 has errands to run, but usually, when I’m out and walking so to speak,
425 then I’m just out ... depending on the weather, too, but I’m usually out about
426 an hour each day walking.

427 D: Uh-huh.

428 P: And I do that because, partly for prevention and partly because I also just
429 basically like to keep active.

430 D: Sure, physical activity [?] . . .

- 431 P: Sure, I do that now too . . . I don't let this get me down,
432 because I'm going to . . .
433 D: You're going to stick it out.
434 P: Sure, gee. You only live once, and you've got to have a little fun, too.
435 D: Yes.
436P: This isn't any fun, for sure.
437D: No. How do you find the energy to socialize with people around you . . .?

The doctor starts with a specific question about pain in muscles and joints (lines 414–15). Thus, the doctor indicates this indirectly as a possible and relevant symptom. The patient answers briefly that she has not been in pain (416). The doctor makes the question more precise by linking the muscle aches and physical movement (417–19), with the understanding that it could be a relevant symptom.

By introducing the question of muscle pain, the doctor indicates that this symptom is relevant to the diagnostic work. The patient answers 'no' to this question. The doctor emphasizes the relevance of the question by repeating the question in a verbose manner. In this way an uncertainty is produced: for the patient the doctor apparently views the muscle pain as important, although she does not state why and how. As a result the patient appears to become unsettled and starts to negotiate her symptoms by starting to describe and frame them in different ways.

She does this by answering the doctor's repeated question about muscle pain by saying that she moves around physically every day (420). However she responds with hesitation by saying in the next sentence that she has not been up to it 'lately' (421–2), which is a reference to an earlier remark that currently she has acute ailments. The patient says that, despite this, she has been out walking (422). However, through modifications in her talk the patient restricts the meaning of this walking, first by indicating that she only walks a short distance that can be covered quickly (422–3), then by saying that she 'has to' take that walk because she has important errands to attend to (423–4). Through these two modifications, she minimizes the significance of her walking, while giving it the character of an obligation. The patient adds that she usually walks one hour a day (425–6). She immediately redefines this information as a 'preventive' activity and an expression of her preference to keep active (428–9). The doctor suggests that her walking can be defined as 'physical activity' (430), which the patient accepts (431). The patient provides an additional frame for her physical activity, specifically that she won't let her ailments 'get [her] down' (431–2). The doctor confirms this framing of events by commenting in a supportive way and confirming that the patient will 'stick it out' (433). The doctor and patient conclude discussing the subject of muscle pain by saying that it is not fun to be in pain (434–6). After that, the doctor introduces a new topic, socializing (437), and drops muscle pain and physical activity. This is a signal to the patient that the doctor is satisfied with the received information, and a new topic is broached.

When the doctor insists on the relevance of the muscle pain by repeating the question, the patient has to relate to the repeated and reframed question. An uncertainty is produced that starts off a negotiation about how to interpret a symptom that is very important for the diagnosis of CFS in relation to the actual behaviour and experiences of the patient. The patient tries to minimize the significance of behaviour which does not corroborate a symptom. She does this with the help of reframing, and by indicating that she does not get around right now. The doctor follows her in this task and helps provide a frame of interpretation. The patient minimizes the importance of her movement, redefines movement as physical activity, and reframes it as struggling against her ailments.

By reframing, the patient tries to remain with her suffering (in this case the difficulty of moving as much as she would like to) which obviously does not fit into the desirable symptom criteria as discretely indicated by the doctor. She does this by reframing her action so that it can fit into a possible sign of reduced functional capacity and show that she is suffering from her ailments but taking an active approach to her problems.

Negotiation about what part of the patient's suffering can be defined as relevant symptoms is based on the fundamental question-answer format of the conversation: the doctor starts with a question, which the patient answers; the doctor is not satisfied with the answer and thus repeats the question and indicates its further relevance. This leads to an answer from the patient in which the current problem is placed in various frames that provide the doctor with different options for interpretation; the doctor accepts one of the interpretations and then concludes the subject by asking a new question.

However, a central problem for the doctor is that the only information she can rely on is what the patient tells her, as no other sources of information are available. In other types of cases the doctor can use information from other sources, such as the results from clinical tests or investigations, in order to help to come to a diagnosis. This kind of information only has a negative relevance in CFS cases. It means that one of the few methods to which the doctor has access is a verbal investigation of the patient. It is primarily through conversation that the doctor can define relevant symptoms and finally reach a diagnosis. Questioning about symptoms and negotiating the patient's reports of suffering are thus central devices for the doctor.

The patient strives to fit her complaints into the doctor's latticework of concepts, and when the doctor shows interest in a symptom, the patient tries to negotiate her suffering (not primarily for it to fit into the overall depiction of symptoms but so that it will be recognized as an ailment and symptom). What happens otherwise from the patient's point of view is that the doctor leaves that symptom and moves on, by which time the patient runs the risk of the current ailment not being taken up as a relevant symptom. This means that it may not be recognized by the doctor as

suffering, and ultimately the claim that it is symptomatic of disease is discredited.

In conclusion, the examination part of these medical interviews alternates between two conversational formats: question–answer and its modification as symptom negotiation. Through this alternation, the patient attempts to maintain his or her hope by being able to present relevant symptoms, and the doctor tries to maintain his or her medical authority by restricting discussions to the symptoms she considers relevant to the diagnosis.

Doctors' diagnoses and patients' reactions

In all but a few of the meetings, the doctor summarizes the examination and attempts to convey to the patient whether or not the patient satisfies the criteria for CFS. After the doctor has presented her diagnosis, the patient comments on it. In some cases, when the patient is not considered to have satisfied the criteria for CFS, the doctor asks the patient what he or she thinks could explain the ailments. The patients tend to comment regardless of the diagnosis they receive. Even patients who satisfy the criteria for CFS sometimes begin to talk about how difficult it is not to have a diagnosis. Some patients bring up additional symptoms or other physical ailments after the doctor has pronounced the diagnosis.

Of the 15 patients in this study, the doctors in the conversation judged that six persons satisfied the criteria, four did not, and five were of uncertain diagnostic status. In a few cases, the doctors also offered, in this context, certain treatment measures at the health-care unit, such as relaxation, group activities, or physical therapy.

The ways the doctors present their diagnoses are relatively uniform with respect to how the presentation is made and what it contains. The presentation of the diagnosis follows directly on the examination of symptoms, and the doctor consistently takes the initiative to begin the presentation by concluding the examination and introducing the diagnosis as a new topic. After that, the doctor discusses the extent to which the patient fulfils these criteria, as illustrated by excerpt five.

Excerpt 5. Patient GG. 679–684

679 D: If I look at these, look narrowly at these criteria, I could say that
680 you do not have all the symptoms we describe for someone to . . .

681 well, satisfy these criteria.

682 P: No.

683 D: But then, naturally you have a fatigue syndrome, that seems clear
684 from your description of your situation.

In this excerpt the doctor informs the patient of her conclusion directly in relation to the criteria that must be satisfied (lines 679–81). The conclusion of the doctor is that the patient does not have all the symptoms needed for a diagnosis if you 'look narrowly at these criteria' (679). Quickly the doctor

says that despite everything the patient 'has a fatigue syndrome' (683) based on what the patient has conveyed in the examination. That is, although the patient does not meet the criteria for a CFS diagnosis, she apparently suffers from something similar, that the doctor calls a 'fatigue syndrome'.

This move from the doctor indicates an elasticity in the CFS diagnosis: the diagnosis or a version of it, can be stretched to at least partially cover symptoms that are close to being sufficient for the CFS diagnosis.

In presenting the diagnosis the doctor has to consider several different aspects. She maintains her position as a medical authority and gatekeeper by insisting that, in order for the CFS diagnosis to be made, more criteria than were actually established in the investigation will have to be fulfilled. At the same time, the doctor is trying to endorse the patient's suffering by presenting a form of minimal CFS diagnosis, 'fatigue syndrome'. A further consequence of giving the patient this diagnosis (which is seen later on in the conversation) is that it gives the patient access to some of the treatment facilities of the unit, e.g. physiotherapy.

Gaining a diagnosis locates the patient's suffering and pain unambiguously within the framework of medicine. And yet, to receive a diagnosis that places one's suffering in a medical context can be both a confirmation and a disappointment for the patient.

Excerpt 6. Patient GG. 693–700

693 D: So you have ended up in the right place, you could say.

694 P: Yes, well it feels very good, in fact, also just because of ... it's
695 no big deal but it is something that no one has to think that.

696 D: Uh-huh.

697 P: All the time you have to struggle because I have to, you know, tell them
698 what it's all about, because this fatigue I have, there's no one
699 who cares about it. They don't understand it, they don't believe
700 in it.

The patient acknowledges with gratitude the diagnosis she has received from the doctor (694). She explains this by saying that it has been difficult to explain to others that she is tired, because she had not been diagnosed, and no one could find a medical explanation for her fatigue (697–700). Directly after this episode, however, the patient returns to the question of the diagnosis when the doctor comments on the patient's ailments related to her immune system.

Excerpt 7. Patient GG. 737–741

737 P: I have of course read about these criteria and all that and I
738 have noticed myself that it's not exactly the same in any case. That I'm
739 tired and that sort of thing, I understand all right that because I never get
740 well then neither can I ... I'm just so tired sometimes but
741 at the same time I'm basically a realist so ...

Although the diagnosis of CFS explains much for this patient, it does not explain everything: for example it does not account for the fact that she never recovers from her infections (737–40). She comments on this by saying that she is a ‘realist,’ and it is understood that she must live with her problem of infectious illnesses (741). In other words, for this female patient, the diagnosis has elicited recognition from the medical establishment for part of her suffering and her ailments, the fatigue, but not for all. It is as if there is a remainder of the suffering that is not caught up or covered by the diagnosis.

Discussion: suffering outside the life world

To formulate one’s suffering as a disease, it must be possible to present it as symptoms that fit into the relevant biomedical criteria for that disease. This requires subtle collaboration between patient and doctor: the patient must be able to formulate his or her suffering as relevant symptoms, and the doctor must be able to assess these symptoms within his or her framework for biomedical interpretation.

This collaboration becomes especially difficult when what counts as symptoms is unclear at least for the patient, and when the doctor cannot corroborate the verbal reports of the patient with independent test results.

Patients want to understand their suffering and their pain by having it confirmed in terms of medical diagnosis, and consequently to receive treatment that can heal or alleviate their suffering. Applying diagnostic and interpretive strategies, the doctor endeavours to maintain this medical authority in the face of suffering for which it is impossible to determine a pathology.

Within the framework of this tension the doctor and patient examine together the possibilities for transforming physical suffering into symptoms and disease, within certain institutional limits. Patients bring before their doctors the question of whether their suffering can be interpreted and understood within the framework of biomedical language and practice, expressed specifically in terms of a diagnosis of CFS. For their part, doctors serve as ‘gatekeepers’ in that they test to see, first, if their patients fulfil the criteria for receiving a diagnosis of CFS, and second for receiving certain types of treatment, although no cure for the condition has yet been found. This *negotiation* of symptoms and diagnostic criteria in search of a *legitimate* diagnosis and illness, constitutes the central concern in the patient’s and doctor’s collaborative *diagnosis work* in the medical encounter.

In social psychological terms, this can be expressed as patients trying to get confirmation and recognition of their suffering from the doctor who is empowered to sanction it, e.g. in the form of a diagnosis and doctor’s certificate of disease. Recognition in the form of a diagnosis also opens up the possibility of treatment and the hope of relief from the suffering that threatens to fragment and perhaps disintegrate his or her own self.

The doctor must maintain medical authority in the form of diagnoses legitimized by the medical establishment. Therefore, an important task for the doctor is to serve as a gatekeeper: patients who do not satisfy the relevant criteria do not get the benefit of social recognition (the diagnosis and treatment). This means that to define suffering in the form of chronic fatigue syndrome, medicine must pay the price of surrendering one of its cornerstones, namely being able to identify a physical pathology. As a result, the diagnosis must rest on the exclusion of possible explanations (a negative diagnosis) and an organization of the patients' descriptions of their symptoms.

To obtain social recognition of his or her suffering, the patient must, in turn, interpret and define his or her life of suffering using categories that are relevant for biomedicine but not necessarily relevant in a life-world perspective (Mishler, 1984). As a consequence suffering is severed from its links with the life world and obtains its relevance and significance only in relation to an institutional context, in this case the biomedical. For patients, this can threaten their suffering when it is transformed by this process of medicalization into a phenomenon that is separate from the person's self and life. On the other hand, suffering is not only located in the biomedical world, but also attains a new meaning within this sphere. In this way, patients can obtain recognition for their suffering, but at the same time it has become foreign by being transformed into symptoms of disease, lacking a direct relationship with one's self. The medical recognition of suffering thus threatens to reinforce further the patient's feeling of fragmentation and hopelessness, something which is underlined for patients with CFS by the lack of a specific healing treatment.

In their search for hope these patients appear as representatives of a general tendency in modern industrialized society. Advances in medical technology infuse a hope that medicine is able to alleviate troubles, pain and suffering. In order to gain these benefits patients, as well as medical professionals, must interpret somatic or psychological suffering and disturbances in terms of medical diagnoses. In this way a tendency emerges to medicalize life experience and thereby translate social signs into bodily dysfunctions. The diagnosis becomes an emblem for hope while at the same time turning suffering into something medically and socially legitimate.

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Author biographies

LARS-CHRISTER HYDÉN PhD, associate professor, social psychologist, senior researcher at Department of Social work, Stockholm University, and at Department of Communication Studies, Linköping University. Main interest are illness and identity and narrative.

LISBETH SACHS PhD, associate professor, anthropologist, is senior researcher at the department of Public Health Sciences, Karolinska Institute, Stockholm, and the department of Communication Studies, Linköping University. Her main interests are prevention, medical technology and the body, genetic information, hereditary cancer, the 'new' sicknesses; chronic fatigue syndrome and chronic pain.