

A watercolor illustration of a window looking out onto a green landscape. The window frame is grey and slightly open. Outside, there is a bright green field, a large green tree on the left, and a yellow sky. The overall style is soft and painterly.

# **Making sense of contested illness**

*Talk and narratives about chronic fatigue*

**Pia Bülow**

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- Full reference to Paper D has been added to the list of papers.
- The Post-print version of Paper B has been included instead in line with the publisher's guidelines.
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# MAKING SENSE OF CONTESTED ILLNESS

Talk and narratives about chronic fatigue

*Pia Bülow*

***Linköping Studies in Arts and Science***

In the Faculty of Arts and Sciences at Linköping University research is pursued and research training given within ten broad problem areas known as themes, in Swedish *tema*. These are: Child Studies, Ethnic Studies, Gender Studies, Health and Society, Communication Studies, Food Studies, Culture Studies, Technology and Social Change, Water and Environmental Studies and the Institute for the study of Ageing and Later Life. Each tema publishes its own series of scientific reports, but they also publish jointly the series Linköping Studies in Arts and Science.

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Pia Bülow

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*For Linnéa and Evelina*



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Jönköping, September 2003

Pia Bülow

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## **PART II: PAPERS A - D**

## THE FOLLOWING PAPERS ARE PRESENTED IN PART II:

### PAPER A

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### PAPER D

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# PART I

## Introduction



## Prelude

### A story about illness

*It was almost three years ago when Susan, then thirty-four, first went to see her general practitioner about feeling tired in a way she had never felt before. She felt as though she had lost all her stamina and even after a long night's sleep this tiredness remained. This was unlike her. She had always been on the go, energetic and ambitious, working hard at home as well as at work. At the district health centre they took extensive blood tests and did various kinds of examinations, but nothing indicated that she had any specific disease. Yet she felt anything but well. She was constantly tired, her body ached, and she felt as if she was going to get a nasty flu.*

*For a long period various diagnoses were discussed as she was referred to different medical specialists. New tests were done, and everything looked just fine. Despite the relief of not having any of the suspected diseases, it was frustrating always to be told that everything looked fine when she still felt terrible. In some of these encounters, she got the feeling that the physician suspected her illness to be psychological, and some of them even told her that they thought so.*

*At the beginning she tried to work as usual but when that became impossible, her GP sick-listed her for a couple of weeks. Since the tiredness did not disappear, the time on sick leave was lengthened for another period. However, she still did not improve. Instead, there were many visits to the district health centre and new sick-listings.*

*The lack of answers about what was wrong together with the feeling of being misunderstood made her feel worse. Added to this was the difficulty of explaining that what she felt was something totally different from ordinary tiredness. She even began to wonder if she was imagining the whole thing. The only person who seemed to understand better was her husband. He saw how completely exhausted she could be although she did almost nothing.*

*At one of her many visits to the district health centre she met a new physician who listened carefully to her story and then said that he thought that she might be suffering from a disease called chronic fatigue*

*syndrome, or CFS. The physician did not know much about this diagnosis, but he sent her to a specialist. Some months later, when visiting the specialist at the hospital, Susan's problem was confirmed to correspond to the criteria for CFS. After more than two years of searching, she finally got some kind of an answer.*

*The diagnosis was a turning point for Susan. Having a name for her illness gave her a certain degree of redress. At the same time, it was a tricky diagnosis since it lacked a generally accepted medical explanation. No cure or any kind of medicine was known to help. Nor could anyone tell for how long she would continue to feel the way she did and whether she would ever get well. All this made it hard to tell other people about the illness or how she was feeling. Her ordinary GP, who continued to sick-list her, seemed to know very little about her diagnosed condition, and appeared to be frustrated about the fact that she did not improve. She felt it hard to explain to other people why she was still on sick leave after all this time. Many people seemed to have difficulties in understanding an illness that they could not see, one in which the main symptom was as common a feeling as fatigue. "Everybody feels tired nowadays," she was often told.*

\* \* \*

Susan's story is not a single person's story about his/her illness. It is a story that I have put together from many different people's descriptions of how it is to suffer from chronic fatigue. In that respect, Susan is not any one identifiable person. She has, however, similarities with all of those men and women whom I have met during my study and whose stories I have had the privilege to listen to in different ways. This thesis is about these men and women and about their talk and narratives of suffering from a medically unexplained illness.

## Introducing the problem

In recent years, long-term sickness in general has been frequently discussed in Swedish public debate. The increase in numbers of persons on sick leave has been described as galloping – as something increasing rapidly and uncontrollably. In the last part of the 1990s this increase was largely accounted for by women, and particularly by younger women suffering from “psychological disorders” (*Social Insurance in Sweden 2002: Ideals and Reality in Disability Policy*, 2002). The economic consequences of the increase in the number of long-term sick have become an important issue on the political agenda. After the Swedish general election in 2002, the new Minister for Working Life was assigned the explicit responsibility of reducing the high numbers of absences from work (Statsrådsberedningen, 2002). For the first half of 2003, the central questions in this general discussion have concerned how to spread the costs for sickness benefits between the state, the employers and the sick individual.

Increases in long-term absences from work do not necessarily mean that people have become “sicker.” Illness has always been part of people’s lives. However, over time the image of illness has changed. Before medical discoveries like those of bacteria and penicillin, infections such as the plague and cholera spread fear among humanity. Afflictions like these were considered to be the beginning of collective death and the price to be paid for sinfulness (Herzlich & Pierret, 1987). They gave rise to social turmoil in the way they struck rapidly and apparently blindly. However, as the authors write, “it was not, as illness has become in our time, the foundation of a special way of life and of social integration” (*ibid.*, p. 22).

One reason for these different meanings is related to what kinds of illnesses are dominant in a particular society. Thanks to knowledge about contagion, vaccinations and penicillin, a gradual change in the landscape of sickness has appeared. In the wake of medical successes in curing and preventing a range of infectious diseases, chronic diseases have become more common since more people are reaching more

## Chapter One

advanced ages. The American physician Ernst P. Boas worked for several decades, starting in the 1920s, to make these diseases more visible. He writes in his book *The unseen plague – chronic disease* (1940, p. 4) that “we escape the invasions of micro-organisms to succumb at a more advanced age to diseases obscure in origin and chronic in character.” “Seventy years ago,” Boas writes in 1940, “these chronic diseases caused only one-fifteenth of all deaths; today they are responsible for as many as one-half.” Like today’s Swedish debate about increased costs for long-term sickness, Boas considered chronic diseases, aside from the personal suffering, to be a large economic problem for society, the family and the individual sufferer. Chronic diseases have not just turned out to be a more common cause of death; usually they also implied years of sickness and reduced capacity to earn a living.

### *Illness, disease and sickness*

Prolonged suffering with its most apparent social and economic consequences has made social scientists interested in chronic diseases – perhaps chiefly from the perspective of the suffering individual (cf. Cooley, 1951; Goffman, 1963; Kleinman, 1988; Schneider & Conrad, 1983; Strauss & Glaser, 1975). One important point of departure for these researchers, mostly sociologists and anthropologists, is that diseases do not mean the same thing for those who are sick as they do for medical professionals (Twaddle, 1993). This difference is usually described by the terms *disease* and *illness* (Eisenberg, 1977) for which the simplest definition presumably is Eisenberg’s now classical one that “patients suffer ‘illnesses’; doctors diagnose and treat ‘diseases’” (p. 11). In other words, diseases are based on the physician’s scientific striving to sort and categorise, to define and correctly diagnose symptoms while illness stands for the individual experience and what illness means in an individual’s own life. From a communicative perspective Elliot Mishler (1984) illustrates this difference as different voices – *the voice of medicine* and *the voice of lifeworld*.

This distinction of two voices and the division between the personal experience of illness and the medical striving for classification means that situations sometimes arise when these two perspectives of suffering disagree. This might happen, for instance, when the illness the suffering person experiences does not correspond to a medically definable disease (Radley, 1994; Sachs, 1987; Young, 1982). This means that the sufferer may have difficulties in the medical encounter in convincing the

physician that something is wrong. The physician on the other hand might have a problem understanding and defining the sufferer's experience as symptoms of a certain disease. In the absence of measurable and unambiguous biological marks, medicine deals with this problem by creating *syndromes* predicated on clusters of symptoms (criteria), all of which can be more or less impossible to observe and measure. Chronic fatigue syndrome and fibromyalgia are examples of such syndromes based on the individual feeling of tiredness and pain.

In addition to the terms illness and disease, a third concept *sickness* includes the image a certain disease gives rise to within a specific culture and how people think and talk about this ailment. In that respect, sickness describes both the pattern for how a certain kind of suffering can be understood as a disease as well as an administrative way to handle the disease by referring the ill person to a particular status or role in society (Eisenberg, 1977). Sickness is thus a process for socialising disease and illness (Twaddle, 1993; Young, 1982) and as the Swedish medical anthropologist Lisbeth Sachs (1987) expresses it, the communication of the meaning of illness and disease. Although having different "conceptual focuses" – the body, the individual experience and society – the three terms are commonly mixed up and need to be distinguished between in order to understand more about what labels people as "healthy" or "ill" (Radley, 1994). This is of particular importance when focusing, as I will do in this thesis, on diagnoses that are based on personal suffering – from illness.

### *Medically unexplained illnesses*

People suffering from long periods of fatigue and pain are not unique to our time. A description of a disease called *febricula* or "little fever" from 1750 is considered to be one of the earliest evidences of a condition similar to CFS (Demitrack, 1998). Since then, new names and diagnoses have appeared, of which many have declined in use after a while and disappeared or have been included in other diagnoses (Berrios, 1990; Shorter, 1993; Straus, 1991). Sometimes problems of fatigue and pain have been given a physical explanation, in other periods they have been explained as psychogenic. Both medical historians and medical scientists have tried to understand and describe the unexplained illnesses of our own time by relating them to those of earlier periods, like colitis, hysteria, paralysis, spasmophilia and neurasthenia (e.g. Cathébras, 1994; Shorter, 1993; Showalter, 1997; Straus, 1991; Wessely, 1990).

For diagnoses that are “medically unexplained,” there are often various understandings among medical scientists and clinicians. Especially if these unexplained conditions are based on sufferers’ personal experience of illness, like the cases of CFS and fibromyalgia, such differences in views of the illness seem to make the diagnosis controversial. Consequently, the individual suffering might be contested and called into question in the medical encounter. This “contestedness” probably increases when the problem remains for months and years and requires prolonged sick leave and sometimes a temporary or permanent disability pension. Added to this, the comparison with an historical predecessor like neurasthenia contributes to the image of a diagnosis that is provisional and uncertain as a medical category.

Such diagnoses, which are founded on strongly experienced illness at the same time as their status as real diseases is debated, also risk becoming contested as sicknesses since the cultural readiness to regard them as legitimate diseases is low. For this kind of suffering, I will use the term *contested illness*. My choice is based on the double meaning of the word contested, including both that which is debated and that which is questioned.

### *The focus of the study*

As my point of departure and as an example of a contested illness, I have chosen chronic fatigue syndrome (CFS). For reasons explained later, other syndromes of chronic fatigue like idiopathic chronic fatigue syndrome are included in my empirical work. Because of this I will use the indefinite term “chronic fatigue” interchangeably and synonymously with CFS throughout this text.

What makes CFS especially interesting to study from a communicative perspective is the simultaneous lack of medical explanation and that of observable signs of illness. This means that illness has to be put into words to make it tangible for others. Since the fact of illness has to be communicated to exist outside the sufferer, there is always a risk that others misjudge the meaning of the personal experience described. It may be that it is “forgotten” or that others even doubt the existence of the illness since it cannot be linked to what people recognise as a disease.

When the personal suffering cannot be located within a common framework for what is considered a disease, a range of problems that has to do with how suffering is understood and communicated easily

arise. As shown in the introductory illness story, it can be problematic for the individual to claim illness when the personal experience of being ill is not confirmed by tests and medical examinations. This can lead to feelings of being misunderstood and doubted but also to questions about the veracity of one's own feelings. The vagueness about what kind of illness it is – and if it is a disease at all – means that it becomes difficult to explain why one needs to be on sick-leave and how one lacks the strength to do many of the things one could do earlier. This might be especially difficult in a time when the cost of long-term sickness is being publicly debated – a debate that includes voices asking whether malingering may be behind the increased numbers of sickness. All this means that CFS is the kind of illness for which the individual needs to create meaning by him/herself, and for which communication about suffering turns out to be of particular significance in making the illness “visible” as well as comprehensible for others.

Why then did I choose CFS? There are two answers to that question – one simple and one more detailed – but like most things in life, they are intertwined. The simple answer is that there already existed a project initiated by Lisbeth Sachs and the social psychologist Lars-Christer Hydén (1997) to which I applied and later was accepted as a PhD student. The more complex answer is that in my former work in occupational health care, for ten years I took part in a company's programme for work rehabilitation. From the end of the 1980s and the first half of the 1990s, I apprehended that many of the long-term sick were on sick leave because of partly unexplained pain or that they spoke of themselves as burned-out. In meetings with employees, employers and the social insurance office I became aware of the special difficulties connected with being on sick-leave for diagnoses that were medically vague and therefore less legitimate. From time to time questions arose about whether it really was a disease that caused the incapacity to work, or if the employee really could not work.

When I later as a doctoral candidate started my study of chronic fatigue and in different situations told people about my work, I noticed how “chronic fatigue” often gave rise to funny (and sometimes sceptical) remarks. Just as the people I met in my fieldwork told me, I was met by comments like “Aren't we all tired?” This gave me a hint about the dilemma those suffering from chronic fatigue syndrome might experience. Even though chronic fatigue is an illness that has to be described in words to be “visible,” it seems to be problematic to meet

these descriptions as those of a legitimate disease. Noticing this communicative dilemma I started to understand something I think is important about suffering from a contested illness like CFS. An episode that intensified this impression occurred when one of my interviewees told me how she tried to explain to the taxi drivers why even though she was not looking ill, she still had the right to state-funded transport service. She used to say that she was suffering from “MS” (multiple sclerosis), one of the diagnoses she had been examined for, instead of CFS. For this woman a diagnosis like MS appeared to be more accepted and legitimate as a cause of invisible suffering than CFS.

Before continuing with the theoretical base for my work, I will briefly present the CFS diagnosis. It is not my ambition to give a complete medical presentation of CFS here, but rather to sketch an image of the diagnosis most of the persons in my study have received – a diagnosis I will refer to as a contested illness.

## Chronic Fatigue Syndrome (CFS)

Chronic fatigue syndrome (CFS) is quite a new diagnosis. It was named and defined as a syndrome in Atlanta, USA in 1988 by a group of medical experts and scientists gathering at the Centers for Disease Control (CDC) (Holmes et al., 1988). They were discussing a cluster of problems that clinicians saw among their patients, of which the main symptom was an unexplained fatigue. At the same time, people in Australia and in Great Britain were working according to partly different criteria to define similar problems. This called for some kind of unification (Natelson, 1998). In a subsequent revision of the diagnostic criteria for CFS an international group of physicians was included (Fukuda et al., 1994).

This international case definition of CFS allows a certain degree of overlapping with other diagnoses such as fibromyalgia, nonpsychotic or nonmelancholic depression and anxiety disorders (Fukuda et al., 1994). Aside from a medically unexplained fatigue that is persistent or relapsing for at least six months, four or more of the following symptoms should be reported: headache, sore throat, painful lymph glands, muscle pain, joint pain, unrefreshing sleep, post-exertion malaise, and problems with short-term memory or concentration severe enough to cause a considerable decrease in activity. For those having less than four of these concurrent symptoms but still exhibiting a medically

unexplained chronic fatigue, the diagnosis of idiopathic chronic fatigue was introduced. In Great Britain, where the diagnosis Myalgic Encephalomyelitis (ME) had been used earlier for unexplained fatigue, the government advocated via the Royal Colleges' Report on Chronic Fatigue Syndrome (published in October 1996) the use of the internationally agreed-upon guidelines as well as the diagnosis of CFS.

Even if CFS is a quite recently defined diagnosis, chronic fatigue has a much longer history as a medical problem, going back more than a hundred years (Abbey & Garfinkel, 1991; Shorter, 1993; Straus, 1991; Wessely, 1990). Then as well as now, no apparent explanations are given. However, just as it was for neurasthenia at the end of nineteenth century, chronic fatigue has been connected to conditions of a certain time and culture (Abbey & Garfinkel, 1991; Rabinbach, 1992; Showalter, 1997; Ware & Kleinman, 1992a).

What is perhaps most striking in the research on CFS is the number of different explanations and hypotheses that have been discussed. Research extends to fields like virology, immunology, the central nervous system, and psychiatry as well as more biopsychosocial influences like theories about stress and personality as contributing factors (e.g. Evengård, Schacterle, & Komaroff, 1999; Moss-Morris & Petrie, 2000; Wessely, Hotopf, & Sharpe, 1999). Despite this, medical scientists still cannot agree upon more than that they do not know what causes the fatigue or what the processes of the illness are. Benjamin Natelson (1998), one of the members of the international study group and a practitioner himself, writes that "without any definitive biomedical marker, our diagnostic capabilities remain at the *clinical syndromal level*" (p. 66, my italics). He describes four major groups based on different opinions about CFS: those who think of CFS as one kind of depression, those who believe that it is a functional illness (e.g. somatisation disorder), those who think it is a medical disease and those who believe that it is a combination. Demitrack (1998), who seems to represent the last group, argues that since CFS and other similar medically unexplained syndromes like fibromyalgia are impossible to classify as either physical or mental illness. They seem to end up in between. This probably explains the interest in a multifactorial, or a biopsychosocial model among both medical scientists and practitioners (e.g. Elliott, 1999; Wessely et al., 1999).

Different opinions concerning the cause of illness are reflected in treatments as well. There is no specific treatment for CFS, but reviews

and guidelines present a range of treatments that have been tried. These treatments have been as varied as low-dose hydrocortisone, vitamins, antidepressive medication, acupuncture, tai chi, rest, gradually increased exercise and cognitive behaviour therapy (CBT) (cf. Evengård et al., 1999; Natelson, 1998; Wessely et al., 1999). The obscurity about what causes the illness and the lack of any single medication or treatment have resulted in an emphasis on the encounter between physician and patient (Deale & Wessely, 2001; Sachs & Evengård, 2000; Sharpe, Palmer, & Wessely, 1997).

The prognosis for chronic fatigue in most studies is rather poor. Even if many sufferers improve, only about 10 % return to the same functional level they had before illness (Joyce, Hotopf, & Wessely, 1997). Thus most sufferers are ill for a very long time. At the same time, CFS does not cause progressive deterioration as do multiple sclerosis (MS), Parkinson's disease, and rheumatoid arthritis (RA). Nor is CFS a fatal illness. However, according to one study, the impact CFS has on reported quality of life is worse than, for instance, the impact on the reported quality of life of sufferers from multiple sclerosis (Schweitzer et al., 1995).

Long-lasting fatigue is a common problem. It is one of the most frequent reasons people give for seeking help at district health centres and the like. In a review about the use of formal and informal care among those suffering from "prolonged fatigue," Elliott (1999) refers to estimations of population prevalence rates at between 9 and 30 % for fatigue lasting for more than one month. Estimating the number of people suffering from chronic fatigue syndrome can be tricky since the criteria have been changed over the years and because many clinicians reject the diagnosis as a legitimate disease (Jason et al., 1997). What seems to be clear, though, is that CFS diagnosis covers only a small part of all those suffering from chronic fatigue. In community-based population surveys the prevalence of CFS is estimated to be between 0.07-0.2 % (Jason et al., 1997). However, in a larger study of English primary care the prevalence of CFS range from 0.8 to 2.6 % depending on the use of definitions from 1988 or 1994 on whether recognised psychiatric conditions are included or not (Wessely et al., 1999). There is a predominance of women both in the larger group seeking medical care for prolonged fatigue and the group diagnosed with CFS. The distribution according to gender commonly described in reports from hospitals or special units caring for people suffering from CFS is about

70 % women and 30 % men (Evengård et al., 1999)<sup>1</sup>. Whether this difference depends on the fact that women more often seek care or on other things like working conditions and quality of everyday life is not clear. Even if CFS seems to occur among people of various ages, the average age in many studies indicates that CFS is a diagnosis more often given to people still of working age. The range between the youngest and the oldest can, however, be large. The diagnosis also occurs among children and teenagers (cf. Wessely et al., 1999).

A particular difficulty for CFS and related problems is that fatigue as a phenomenon is impossible to measure “objectively.” Like pain, fatigue is something we can tell about and in different ways describe to other people. To a certain extent, it is also possible to express tiredness and pain through one’s face, bodily movements and by changes in how we behave, what we do and so on. It is, however, hard for others to know *how tired* someone is or *how much pain is felt*. Elaine Scarry (1985, p. 7), an American professor of English has described this difficulty in communicating pain by the words: “to have great pain is to have certainty; to hear that another person has pain is to have doubt.”

There is no diagnostic test to prove CFS. Instead, what physicians have to do is to exclude every other possible explanation for the fatigue. This means that CFS is a diagnosis of exclusions. However, to reach the diagnosis of CFS by the criteria described earlier means that the physician also has to consider the sufferer’s descriptions of his or her illness. Diagnosing someone as suffering from CFS is therefore largely a question of the sufferer’s ability to tell his/her story and of how the physician interprets this. This means that CFS is a diagnosis reached through interactive processes rather than based on traditional medical procedures. Consequently, even if CFS is described in various documents like guidelines and working case definitions and thereby can be said to have an official status as a diagnostic category, it is still in the encounter between each single physician and his or her patient that illness has to be recognised and interpreted to be CFS.

## Foundations for my work

Phenomena like illnesses are most of the time investigated within the medical field, by medically based theories and categories. This is also the

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<sup>1</sup> This majority of women is likewise reflected in most social scientific studies concerning CFS.

most reasonable approach when searching for the cause of illness and for effective treatments. The medical field is, however, not the only one able to describe and explain illness. This is shown by the difference between illness and disease presented previously. In my own research, based on people's experiences of illness and suffering, illness is regarded as a human problem and as a personal as well as a social experience. Because of this, I have been interested in the way illness can be understood by other principles than medical ones. Instead of thinking about illness as being directly related to a medical diagnosis understood within medical thought, I have based my research on the works of some social scientists. These cannot be said to be members of the same "school" or tradition. Instead, the problems and phenomena that I have encountered during my empirical work have guided me to search for useful theoretical methods of reasoning. My choices are thus pragmatic and above all problem-governed. At this point, I will present three concepts and themes particularly important for this thesis and for which I needed to find "answers" in order to continue. These are the concept of *chronic illness*, issues about *identity and the self* in relation to chronic illness and, finally, *time in illness narratives*.

Quite early in my research, I realised that I had to understand more about the concept of chronic illness, both generally and in relation to my own work about contested illness. I needed especially to understand it from a social scientific perspective, i.e. to understand chronic illness from a cultural, historical and experiential perspective. The American medical anthropologist and psychiatrist Arthur Kleinman's (1980) description of illness experiences and explanatory models in the People's Republic of China and in Taiwan opened my eyes to a more complex view of illness and how and what experiences are regarded as diseases. From this, his later works about chronic pain with collaborators including Byron Good (M.-J. D. Good et al., 1992) and about CFS with Norma Ware (Ware & Kleinman, 1992a, 1992b), created a link to how a contested illness could be understood from a cultural perspective. In a similar way, Claudine Herzlich and Janine Pierret's (1987) *Illness and self in society* helped in understanding how the meaning of illness has changed during history.

However, the two fields of research most important for my work are what the medical sociologist Peter Conrad calls *the sociology of illness experience* (Conrad, 1987, 1990; Gerhardt, 1990) and the increasingly growing field of *illness narrative* (e.g. Bell, 2000; Bury, 2001; Hydén,

1997). These two intersecting fields constitute the foundation for my own theoretical reasoning as well as the more practical fieldwork. These researchers' genuine scientific interest for people's experiences of chronic illness influenced my choices of methods for collecting data as well as how to analyse data (e.g. Bury, 1982; Charmaz, 1991; Corbin & Strauss, 1985; Frank, 1995; Hydén, 1995a; G. H. Williams, 1984). However, as I previously indicated, my work came to focus on people's narratives and narrating about illness. I was interested not only in the stories people told but also in the storytelling, regarding it as a meaning-creating and interactive process. During my last year of this work, this made me approach the tradition of discourse analysis through concepts such as *life story* (Linde, 1993), as well as *storytelling* and *co-narrating* (Blum-Kulka, 1997; Norrick, 1997; Ochs, Smith, & Taylor, 1989).

The issue of identity and self frequently recurs in this work even if it is not always in the foreground. The work of Elliot Mishler (1992; 1999) about identity as dialogic and relational has nevertheless governed much of my own work when analysing the narratives as co-produced by, for instance, chronic fatigue sufferers and myself in the interviews about their illness. For my analysis of the patient school as a place for creating meaning in illness, the social anthropologist Cheryl Mattingly (1994; 1998) and her descriptions of how people jointly make sense by telling stories not just about what has happened but also about what might happen gave me important impulses to see how stories worked in the patient school. This joint creation of meaning and of identity seemed to me to be related to George Herbert Mead's (1934/1967) theories about taking the role of the other, which I have come to understand in a somewhat new way via Hans Joas' (1985) reinterpretation and the concept of practical intersubjectivity. Philosopher Charles Taylor's work *Sources of the Self* (1989) eventually turned out to be a key to my quest for understanding the moral dimension in the interviewees' narratives, which I had been struggling with for a long time. Taylor's concepts "moral space" and "moral frameworks" became of great importance in my analysis of how what is contested is dealt with in the interview narratives.

Finally, though not last in the work process, the literary historian Gary Saul Morson's (1994) book *Narrative and Freedom: The Shadows of Time*, as well as the work about backshadowing in narratives about the Holocaust by his colleague Michael Andrew Bernstein's (1994),

became important when I started to realise the meaning of time in narratives about chronic fatigue.

### The aim of the thesis

The primary aim of this thesis is to study how people who have been diagnosed with chronic fatigue (usually CFS) make sense of and bring some order to their long-term, invisible suffering. Their suffering is medically unexplained and has no specific treatment – a kind of suffering that I call contested illness.

More specifically, I intend to study this from a communicative and interactive perspective by focusing on how people suffering from chronic fatigue make use in an educational situation of what medical professionals as well as other sufferers tell about CFS. I will also focus on how a number of these sufferers in recurring interviews tell about their own suffering. How do people suffering from chronic fatigue narrate their own experiences of illness and how do they use narratives of others? What kinds of questions about illness seem to be problematic in the way sufferers tend to give accounts for their actions or other things? How are matters like identity and morality brought up and managed in narratives about contested illness? In what way is time and temporality used in narratives about this kind of long-term illness?

The very name chronic fatigue syndrome underscores with the word chronic that the problem of fatigue is expected to last for a long time. It seems therefore reasonable to assume that suffering from chronic fatigue in at least some respects resembles that which is described for other chronic illnesses. Another plausible assumption, when dealing with an illness that at least from a medical perspective is invisible, is to consider people's narratives. What people tell about their illness and how they shape their illness narratives seem to be of significant importance for how to make sense of the illness. From these two assumptions, an interactive, communicative perspective seems to be a useful way to study how people make sense of an illness like CFS.

My purpose is to shed some light on processes that help to make sense in contested illnesses like CFS from the perspective of the sufferers. I hope my findings will be a contribution to an increased comprehension of what this sort of suffering means, and thereby increase understanding of chronic illness from the point of view of medical sociology as well as from a communicative perspective.

## Disposition of the thesis

This thesis consists of two main parts. The first is an introduction to my own empirical study and includes six chapters, which I will soon present briefly. The second consists of four papers describing different aspects of how people make sense of their chronic fatigue. All of the papers are written for international scientific journals and are presented in their entirety.

The first part of my thesis starts here, in Chapter One, in which I have already introduced the problem, presented the aim of the thesis and explained the foundations for my work.

In Chapter Two, I describe the field of research usually called the *illness experience perspective* and how chronic illness has been studied within this from the suffering individuals' point of view. The chapter begins with a description of the concept of chronic illness and ends with a section about time and self in chronic illness. This also functions as a link between the illness experience perspective and illness narratives on which the third chapter focuses.

In Chapter Three *illness narratives*, the other field of research used in this thesis, are described from three analytical perspectives appropriate to my goals.

Chapter Four consists of a description of the empirical study and its different parts and analyses. This chapter presents an overview of the empirical material on which the analyses presented in the papers in the second part are based, and ends with a description of ethical considerations during the work. These four papers are briefly presented in Chapter Five.

In Chapter Six, finally, I discuss in what way the empirical analyses presented in the papers, taken together, can shed some light on such a complex phenomenon as contested illness. I also discuss what making sense of such an illness as CFS means and in what way this study can be understood in a larger context. I discuss, in other words, how the study might be useful for clinical practice with people suffering from contested illnesses, and how this kind of empirical work contributes to the scientific fields of illness experience and illness narrative.

## Chapter Two

# Experiencing chronic illness

In the first chapter, I introduced the concept of contested illness as a type of chronic illness and briefly described the diagnosis of CFS as an example of a contested illness. In this chapter, I will review those parts of the social science field called the illness experience perspective that are appropriate to the aim of this thesis – how people make sense of contested illness like chronic fatigue. Through empirical work of people's descriptions of their experiences of illness, this field has become of great importance for the understanding of chronic illness from the sufferers' perspective. I will use works by Michael Bury (1982; 1991; 2000), Peter Conrad (1987; 1990), Uta Gerhardt (1990), Arthur Kleinman (1988) and Anselm Strauss and his colleagues (1984; 1985). Moreover, I will sketch the typology for chronic illness that Peter Conrad (1987) put forward more than fifteen years ago as a platform for future research in this field. Finally, I will explore some aspects of illness experience that seem to be particularly significant for those suffering from a contested illness like CFS. My purpose is to explore, from a communicative perspective, what it means to suffer from a contested illness and in what way this might be a specific kind of chronic illness. Let me begin with the concept of chronic illness from the perspectives of both medicine and social science.

## Chronic illness as a medical concept

The word *chronic* originates from “chro'nos,” a Greek word for time. This indicates that chronic illness has to do with time, or perhaps more correctly with duration of time. As a medical category, chronic illnesses are the opposite of acute and temporary conditions. However, within medicine, the emphasis is on disease. This becomes obvious for everyone who tries to use “chronic *illness*” as the subject heading in databases like Medline, since this promptly will be transformed into “chronic *disease*.” Diseases belonging to this group are rheumatoid arthritis (RA), diabetes, multiple sclerosis (MS), ulcerative colitis, Chron's colitis,

epilepsy, psoriasis, Parkinson's disease, cancer, heart and vascular disorders as well as some psychiatric diagnoses like schizophrenia. Some of these chronic illnesses are visible to other people, while some are more hidden, although they may still affect the individual's everyday life. Some start abruptly with an acute phase, e.g. a stroke, while others have an insidious onset that can last for many years, as can be the case in RA and MS. Some appear early in life and remain throughout the individual's life. Others appear later in life. A common description, though, is that the risk of chronic illness increases with age. Consequently, many elderly people suffer from chronic illnesses.

Compared to illnesses of short duration, chronic illnesses are often thought of as relatively stable. Yet it is well known that many chronic illnesses vary with the situation, for instance with the weather for those suffering from vascular spasm or severe asthma. Chronic illnesses can also become more noticeable in certain periods as with psoriasis, or recur intermittently as in manic-depressive psychosis. Others entail gradual deterioration, as is the case with RA, or require careful medication in order not to become acutely life-threatening, like diabetes. They can be evident as with epileptic seizures or "invisible" as diabetes or CFS.

There is variation in what diseases are considered chronic. Medical successes constantly alter the list of what kind of diseases that cannot be cured (at least not permanently) but can be managed medically (sometimes for a very long time). Examples are certain forms of cancer as well as conditions like HIV and AIDS. The development of new treatments has also made "classical" chronic diseases curable in some cases. Recent research has for instance shown that it may be possible to cure diabetes by transplantation, and that an immediate start of medication can completely prevent permanent brain damage due to stroke. From a medical perspective, it is difficult to say if an illness will remain or if it can be cured. In this increasingly shifting group of so-called chronic conditions, medically unexplained illnesses characterised by long-term fatigue and pain are included by diagnoses like CFS and fibromyalgia. Though unexplained, such syndromes still include the possibility of recovering.

When to determine what is chronic depends on the illness. Diseases like Parkinson's, MS and RA are usually considered chronic illnesses as soon as they are defined, while other illnesses like pain and fatigue do not become "chronic" until they have been shown not to be temporary.

Within the medical nomenclature and in manuals for classification of diagnoses, time is used for practical reasons to define what is no longer temporary but chronic and what is to be considered as cured. For instance, some illnesses must last for three, six or in some cases twelve months to be categorised as chronic (Nordenfelt, 1995). Correspondingly, time concepts like five- or ten-year survival are used in the medical field to measure the relative cure of cancer.

### Chronic illness in social science and philosophy

When social scientists began in the 1950s and 1960s to study chronic illness from the perspective of the ill, the need arose for a definition of chronic illness on other grounds than purely medical. One of the pioneers in this work was the American sociologist Anselm Strauss (1916-1996). From the middle of the 1970s Strauss has, together with different colleagues (Gerson & Strauss, 1975; Strauss et al., 1984; Strauss et al., 1985; Strauss & Glaser, 1975) described chronic illnesses, aside from being long-term and connected to uncertainty, as typically: requiring proportionately large efforts at palliation, tending to be multiple diseases, being disproportionately intrusive upon the lives of the ill and their families, requiring a wide variety of conflicts of interpretation and authority among patients, health workers, and funding agents, mainly requiring primary care, and finally being expensive to treat and manage. This description bears traces of the medical view of chronic illness but includes the experiential perspective of illness and its social consequences in pointing out the interactive difficulties as well as the financial effects chronic illnesses often have on people's lives.

Similarly, medical anthropologists define chronic illness as incurable but manageable from a medical perspective, and hence as illnesses that must be endured (Heurtin-Roberts & Becker, 1993; Kleinman, 1988, 1992). Because of the time it lasts, chronic illness affects in principle all of the social roles the individual is engaged in. This means that the patient role is just a small part of being chronically ill and that, as the British social psychologist Alan Radley (1994) expresses it, chronic illness implies "having to live with illness in a world of health" (p. 136). That chronic illness is more than the sum of events related to the course of illness from a medical perspective makes it inseparable from life history (Kleinman, 1988). The inclusion of such a time-scale makes it

important to view illness within a temporal framework. As the medical sociologist Michael Bury (1991) writes, we must “bring into the picture a view of the illness in terms of both the stages it passes through and their interaction with the individual’s age and position in the life course” (p. 452).

Another step away from the medical concept is taken by the Swedish philosopher Lennart Nordenfelt (1995) when he discusses, in relation to the concept “quality of life,” a conceptual framework for chronic illness by distinguishing two dimensions of suffering – direct and indirect. From a distinction similar to the one I described earlier, between the concepts of disease and illness, Nordenfelt states that “chronic illness does not presuppose the existence of any chronic disease” but is entirely connected to suffering (*ibid.*, p. 291). According to his line of argument, suffering can be the result of an earlier injury or earlier disease causing disability and distress. It can also be caused by an existential crisis without being linked to a psychiatric diagnosis, or connected to symptoms for which no underlying pathology can be found (that is, contested illness). The typical example of direct suffering is pain while indirect suffering is that “which is not really part of the illness but a consequence of illness” (*ibid.*, p. 292). Suffering caused by uncertainty about what kind of illness one is suffering from or what the future prospects are for a certain chronic disease are thus examples of indirect suffering that do not take chronic disease for granted. Indirect suffering can also be the “suffering from lack of mutual understanding between the subject and the carer” (*ibid.*, p. 293).

The description of chronic illness by sociologists, anthropologists and philosophers has brought to the originally medical concept a view that takes the sufferer’s perspective as its starting point. Suffering is not confined here to the existence of a medically defined disease. Even if time is important to both perspectives of chronic illness, different dimensions of time seem to be used. The medical concept appears to be governed by an objective view of time – clock time (cf. Adam, 1995) – while the illness experience perspective seems to be predicated on the experience of time.

Before continuing with the sociological and anthropological alternatives for studying chronic illness, I will explain the way I see contested illness in relation to the broader concept of chronic illness, and why this makes a good starting point for a thesis about contested illnesses like CFS.

## Chronic illness and contested illness

What chronic illnesses have in common and what make them chronic is the lack of remedy. The typical reason for this is an insufficient knowledge about the cause, or the *genesis* for illness. Despite this insufficiency, the *pathophysiology*, or what happens in the body during illness, is rather well known for a number of chronic illnesses, and becomes for some, like for RA, Parkinson's disease and MS more visible during the course of the illness. This lack of medical explanation for the genesis of illness is also one of the problems for illnesses like CFS. In this way, CFS and other contested illnesses resemble many other chronic illnesses.

However, for a contested illness like CFS knowledge about the pathophysiology of illness is lacking as well. What kind of processes that make people feel tired, have difficulties with concentration and memory, experience stiffness in their muscles as though flu might be on its way, just to mention some of the symptoms commonly described for CFS, are as unclear as the genesis of the illness. Added to this is the difficulty of suffering from something that is invisible and immeasurable.

Also typical for many chronic illnesses is the vagueness of the onset. This makes them hard to define and quite a long time can pass before an illness is recognised as a certain kind of disease. This means that many chronic illnesses, before they are known as a certain well-established chronic disease, may be perceived and experienced in a similar way, as is the case with contested illnesses. However, when the diagnosis is reached, well-established chronic illnesses legitimate suffering even when still invisible; you do not ask, for instance, "Are you sure it is diabetes?" Though incurable, many chronic illnesses may be possible to treat in some way, for instance by preventing impairment, reducing pain or in some cases like AIDS trying to slow down the process of the disease.

For a contested illness like CFS the lack of medical explanations for genesis as well as insufficient knowledge about its pathophysiology does not just make it difficult to find an efficacious treatment. It will also lead to questions about what kind of an illness CFS really is (and if it is a chronic illness at all). This means that it will be problematic to locate the personal suffering within a certain framework for illnesses. Part of these difficulties is that fatigue, like pain, is impossible to measure in the same way that one can, for instance, measure the level of blood sugar. This makes fatigue invisible medically as well as in most everyday situations. Unlike many other chronic illnesses for which the diagnosis

legitimizes suffering, a diagnosis like CFS, even if offering relief in some sense, still does not legitimate illness. In many contexts, chronic fatigue continues to be disputed and doubted even after the illness has been given a name. Is it a physical disease or does it originate in lack of mental strength or perhaps from people's emotional lives? Such questions, emanating from the problem of classifying this kind of suffering within the prevailing system, attract attention in scientific contexts as well as in everyday life, in meetings among scientists and in clinical encounters between those who suffer and those expected to provide relief or at least some answers. The same is described for diagnoses like repetitive strain injury (RSI) (Arksey, 1998; Arksey & Sloper, 1999) and fibromyalgia (Henriksson, 1995).

Nevertheless, similarities as well as differences make it reasonable to take studies about chronic illness as a starting point in the question of how people suffering from a contested illness like chronic fatigue make sense of their illness. I have three purposes for my choice to start with the illness experience perspective. The first is to describe the growth of a research field that uses the perspective of sufferers. Secondly, I intend to locate contested illnesses among the sociological types of chronic illnesses Peter Conrad (1987) suggests. My third aim, which constitutes the main part of the chapter, is to explore the experience of contested illness from the results presented in different studies on illnesses that could be called contested, primarily CFS or chronic pain. With this, I will emphasise difficulties of particular significance for those suffering from a contested illness and the meaning these might have for how people make sense of their illness.

## The illness experience perspective

The incipient interest in social science for exploring the meaning of chronic illness the way ill people experience it started, as previously mentioned, in the 1950s. One early example is Carol Horton Cooley (1951), who in a textbook for student nurses examines in great detail the social aspects of illness.

What is special with Cooley's book is that she emphasises "the chronically ill" as a special group of patients. Since Cooley argues that the meaning of illness is unique to the individual instead of being associated with a certain diagnosis, her book is dedicated to these social aspects and meanings of illness instead of focusing on diseases and

diagnoses, which is the most common direction in this kind of text. Her purpose is to show the social aspects of illness for, as she writes, “helping the student nurse to better understand the patient as an individual so that she may give him more effective nursing care” (p. V). Cooley gives a number of examples showing the social meaning of chronic illness for the ill and their families. What she primarily deals with is a kind of illness experience that someone else (maybe Cooley herself) has noticed with patients. Thus it is not necessarily the patients’ own experiences of being ill that Cooley describes.

Even if Horton Cooley’s book from the early 1950s is a textbook for student nurses, and thus part of the medical realm, it indicates a growing interest in ill people’s experiences of illness and the importance this might have for the care of the chronically ill. Such an interest in people’s experiences of illness is noticeable in social science as well, especially within sociology, producing a number of studies in the late 1950s and in the beginning of the 1960s. One of the earliest, still frequently cited, is Erving Goffman’s (1961) study of mental hospitals and how the inmates became mental patients as a result of institutional routines and the separation from their ordinary social world. Other examples are Julius Roth’s (1963) work on the timetables TB sufferers created while spending long periods in hospitals and Fred Davis’ (1963) study of families with a child suffering from polio. Unlike the work of Horton Cooley (1951), these are clearly sociological analyses by social researchers drawing on data from observations in institutional settings and interviews with sufferers and their families. Still, these early works show the same interest in chronically ill people’s experience of illness, as did Horton Cooley. Sociological studies like these form the basis of the social scientific research on chronic illness that in the middle of the 1970s seems to constitute a small but growing field of research (Bell, 2000; Conrad, 1987) and in the 1980s rapidly increased (Bury, 1991; Conrad, 1990).

Another prominent figure, whose work on chronic illness started in the 1960s with a study about dying (Glaser & Strauss, 1968), is the sociologist Anselm Strauss, mentioned earlier. As did several other researchers in the preliminary stage of the illness experience field, Strauss combined observations with interviews with health care staff as well as with chronically ill and their close families. For more than one decade, he worked together with a group of researchers on a project

unified by the concept *illness trajectory*, to which I will return later. (For an overview of his work within this field, see Conrad & Bury, 1997.)

During the 1980s, the field around chronic illness rapidly grew with the works of a range of researchers from different disciplines. These included for instance the medical sociologists Michael Bury (Anderson & Bury, 1988; Bury, 1982), Peter Conrad and J.W. Schneider (1983) and medical anthropologist Arthur Kleinman (1980; 1988). Together with the works of several other researchers these constitute the field within medical sociology and anthropology that has been called *the illness experience perspective* (Conrad, 1987). According to “the standard history” as Susan Bell (2000) calls it, three main reasons can be found for the emergence of this field of research considering illness experience. These are the distribution of disease, (which I wrote about earlier as the growing problem of chronic disease), changes in medical practice with a (new) attention to “the whole person” and, finally, changes within the field of medical sociology from a “study of sociology *in* medicine to a study of sociology *of* medicine” (ibid., p. 187). Even if there are different lines within this field, like grounded theory, phenomenology/narrative analysis and biographical research (Gerhardt, 1990), the essential question for researchers has always been the personal experience of chronic illness. They started by taking a critical attitude opposed to medicine and to the classical sociological outsider framework represented by Parsons’ concept of *sick role* (1951), examining the insider’s view of illness (cf. Conrad, 1990; Gerhardt, 1990).

In their empirical work, researchers in the illness experience perspective have usually studied people suffering from the same disease (Conrad, 1987). Bury (1982), for instance shows in an often-cited study how people diagnosed with rheumatoid arthritis experienced illness as biographical disruption. Schneider and Conrad (1983) as well as Scambler and Hopkins (1986) have studied people suffering from epilepsy in connection with concepts like stigma. Strauss (1984; 1985), as I mentioned before, has with different colleagues studied a range of chronic diseases which they categorise as chronic illness but which emanate from medical diagnoses, e.g. stroke, heart disorders and diabetes. Other researchers have in edited volumes presented different studies of various chronic conditions under the common heading of chronic illness (e.g. Anderson & Bury, 1988; Roth & Conrad, 1987). Exceptions from this include Kathy Charmaz (1983; 1987; 1991), who

in her study of people suffering from various chronic illnesses takes as her object the meaning of chronic suffering *per se*, and studies about chronic pain (e.g. M.-J. D. Good et al., 1992; Hilbert, 1984).

In one of the very first reviews of the field, Conrad (1987) levels a certain degree of self-criticism toward the illness experience perspective, asserting that the choice to base sociological studies about people's experiences of illness and suffering on medical categories like a diagnosis could be problematic. There is, Conrad argues, a risk that social science by such methodological considerations is governed by medical categories rather than by empirically grounded data of the meaning of suffering. Even Cooley (1951) emphasised, as we remember, that the meaning of illness is unique to the individual and cannot (without being empirically proven) be connected to a certain diagnosis. Moreover, Conrad (1987) contends that attempts to go beyond diagnoses and like Strauss (1984; 1985) and Charmaz (1983; 1987; 1991) use chronic illness, or like Good et al. (1992) use chronic pain as a category, tend to be problematic, since these concepts are also used within medicine and thereby, according to Conrad, are quasi-medical. Instead, social science should work out its own categories, based on people's experiences of chronic illness. For this, he suggests a typology of different *sociological types of chronic illness*.

### A typology for chronic illnesses

According to the model suggested by Conrad (1987), there are three basic sociological types of chronic illness: *lived-with illnesses*, *mortal illnesses* and *at-risk illnesses*. Medical problems like diabetes and rheumatic arthritis belong to the first group. That is, chronic illnesses which are not (at least not usually) life-threatening but which have a strong influence on people's lives to which they have to adapt. The second type includes all kinds of chronic illnesses sufferers perceive as life-threatening. Conrad mentions cancer and cardiovascular diseases like heart attack and stroke. The third type – at-risk illnesses – are conditions not usually counted as illness in everyday contexts although they function as a medical category in that they are based on what is thought of as deviant from the normal. It is the experience of risk, though, which makes it interesting as a sociological type. At-risk illnesses can consist of predisposing conditions, exposure risks and heredity risks. From a medical perspective, conditions like high blood

pressure, obesity and work with different chemicals entail a risk of the individual becoming ill later even if the individual does not at first experience illness. (What we find here is thus another situation when illness and disease do not coincide but where illness might be created by the experience of risk (Adelswärd & Sachs, 1998; Sachs, 1995).) To make his sociological types more distinct, Conrad adds three sub-categories – *stigmatised*, *disabling* and *terminal illnesses* – to be used in combination with the three basic categories. This will increase the possibility of including more dimensions of what it means to suffer from chronic illness.

As I see it, the point Conrad intends to make with his sociological types of chronic illness is that illness and suffering should be possible to study, to compare and to name from the meaning empirical studies show it to have for those who are ill. Such empirically-based typology would neutralize the medical influence on sociological and anthropological studies since medical categories would not necessarily be the point of departure. Compared to a concept like chronic pain and to the ordinary use of chronic illness, the suggested model shows that long-term suffering can be described with greater variation when it is based on the meaning it has in people's everyday life and biography. This would facilitate the descriptions as well as the understanding of differences between various types of suffering. Another consequence of the sociological types of chronic illness is that not only those kinds of suffering that up to now were considered chronic illnesses could be included, but also other kinds of long-term suffering, like infertility and traumatic experiences. In fact, social scientists have been studying this kind of suffering in the same manner as chronic illnesses (cf. Becker, 1997; Riessman, 2000).

However, one obvious problem with the typology is that, as in most studies of chronic illness, it seems to be based on, and primarily suited to, medically well-established illnesses. In the given examples there are no diagnoses that could be described as contested. Instead, the illnesses focused on in this thesis seem to be placed within the group of lived-with illnesses – a group tending to be a very large and heterogenic category including illnesses of many different kinds and meanings. Well-established chronic illnesses such as epilepsy and rheumatoid arthritis, among themselves different but still legitimate diagnoses, belong to this group of illnesses as well as a range of “new” long-term syndromes like fibromyalgia, burn-out, Gulf War syndrome, CFS and many others

(Olin, 1999; Showalter, 1997). It does not even seem to be possible to distinguish these rather different illnesses by the complementary concept of stigmatised illnesses. A medically well-established diagnosis like epilepsy has been shown in different studies to be stigmatising (Scambler & Hopkins, 1986; Schneider & Conrad, 1983) just as CFS has, as we shall see. Yet there seem to be obvious differences between how life will appear when suffering from an legitimate illness such as epilepsy and what meaning it might bring to the sufferer compared to the meaning of suffering from chronic fatigue. The differences will at least become evident when regarded from a communicative perspective, when one is usually concealed and the other has to be communicated to become “visible.”

### Exploring illness experience

In his review of the illness experience perspective, Conrad (1987) uses what he calls a number of *conceptual hooks* to create a joint platform for future studies. These hooks originally emerged from empirical data, but thanks to publication, they have become “part of the sociological stock of knowledge” (ibid., p. 7). In the following, I will make use of a couple of such conceptual hooks and themes that seem to be highly relevant for the study of the experience of contested illness. My choices are based on empirical studies concerning CFS and other illnesses that might be called contested. The headings I will use are *uncertainty*, *stigma and morality in contested illness*, *“challenging medicine”* and *experiential knowledge*, and finally, *time and self in chronic illness*.

#### *Uncertainty*

Uncertainty is a key concept in the experience of chronic illness. Bury’s (2000) definition about chronic illness having an insidious onset, a fluctuating course and an uncertain outcome reminds us of this. This means that people suffering from chronic illness have to live with uncertainty in many different ways. Conrad (1987) mentions five. The first is the *uncertainty associated with a feeling of something unusual* raising questions like “could something be wrong?” At this first stage, it is the individual who experiences bodily or mentally sensations that he or she does not recognise, and therefore might think of as illness. The second type is the *medical uncertainty* linked to questions such as “What kind of disease do I have?” Sometimes this question is answered

rather quickly while at other times the medical uncertainty is prolonged. When this stage ends, typically when illness is defined as a particular disease, the diagnosis itself might constitute the third type of uncertainty including questions about *the meaning of the illness*. Why me? The fourth, called *trajectory uncertainty* has to do with the difficulty of planning for the future when suffering from illnesses that have an unpredictable outcome. The fifth and last, *everyday symptomatic uncertainty*, resembles what Charmaz (1991) calls “good days and bad days.” It is the uncertainty of not knowing what one will be able to do tomorrow or next week because the illness fluctuates.

The first three seem to form a series of uncertainties in which one follows another in a fixed order. When the individual finally decides to think about the strange feeling as an illness and because of this goes, for instance, to the doctor, the first kind of uncertainty is succeeded by the next, the medical uncertainty. When eventually the illness is diagnosed as a certain kind of disease, the medical uncertainty is followed by questions about what this particular disease means for the individual.

However, for a contested illness this series of uncertainties might turn out in a slightly different way. Being medically unexplained, diagnoses like CFS, building on subjective feelings of illness, do not end the medical uncertainty. Instead the uncertainty remains about what kind of disease this illness really is. Lesley Cooper (1997), who has interviewed people suffering from CFS, calls this the *scientific uncertainty*. Unlike the medical uncertainty, which is about the quest for a diagnosis and therefore ends at that point, the scientific uncertainty remains because the diagnosis provides just a name and no clear answers at all. As a result, even the first type of uncertainty – the strange feeling the individual finally considered as illness – might return when sufferers begin to wonder if they have misinterpreted their own perceptions after all (Ware, 1999). The scientific uncertainty about some illnesses and diagnoses is noticeable from the way some illnesses (which I usually call contested) are labelled *non-diseases* or *illegitimate illnesses* (Cooper, 1997), *nameless diseases* (Ziporyn, 1992), *disputed diagnoses* (Arksey & Sloper, 1999) and *ambiguous illnesses* (Honkasalo, 1999). All these names express in some way that the personal feeling and the illness connected to that are perceived as less legitimate and thereby less real.

*In the medical encounter*, the scientific uncertainty could lead to such situations as when a diagnosis like CFS is “negotiated” between physician and patient rather than having a decision made by the

physician alone (Hydén & Sachs, 1998). It can also lead to a micropolitical struggle of how to recognise illness as having a biopsychosocial genesis or a physical cause (Banks & Prior, 2001). The scientific uncertainty also means that these parties might hold different opinions about what it means to get a diagnosis like CFS (Woodward, Broom, & Legge, 1995). In interviews with general practitioners and CFS sufferers, Woodward and her colleagues found that persons suffering from chronic fatigue valued receiving the diagnosis that they described as *enabling*, providing a name for their illness that made it easier to talk about illness. The GPs, on the other hand, often described the diagnosis of CFS as *disabling* and a self-fulfilling prophecy that they accordingly stated they were reluctant to use.

The diagnosis means that the personal experience is classified in the medical system. Usually this implies some kind of explanation and treatment for the illness. A diagnosis therefore confirms personal illness and legitimates it (Sachs, 1987). Even if a diagnosis like CFS provides no answers about what kind of illness one is suffering from, how to cure it, how long it will remain and whether it will disappear at all, the diagnosis seems to be one of the most important things for those suffering from a contested illness (Honkasalo, 1999; Woodward et al., 1995; Åsbring & Närvänen, 2002). The diagnosis has helped people to make sense of their illness even if it has not provided social legitimacy in all contexts. According to Woodward et al. (1995), not having a diagnosis was connected, on the other hand, with experiences like fear, anxiety, bitterness and self-doubt. Woodward and her colleagues (ibid.) also found that an early diagnosis seemed to moderate the harmful social and psychological consequences connected with the suffering. The longer people went without a diagnosis, the more the suffering affected their social relations and their self-perception. Still, due to things like the scientific uncertainty, in several studies concerning various contested illnesses, the time before illness is diagnosed is described as extremely long, not seldom many years (cf. Cooper, 1997; B. J. Good, 1992; Henriksson, 1995; Hilbert, 1984; Honkasalo, 1999; Reid, Ewan, & Lowy, 1991; Åsbring, 2001).

However, for illnesses characterised by scientific uncertainty the legitimating function of a diagnosis does not always work as it does for many other illnesses. For instance, in a study about RSI the authors found that the interviewed women did not so much seek a diagnosis as they sought credibility (Reid et al., 1991). Even if the diagnosis provided

some relief, the illness continued to be contested in many contexts. In this way, the scientific uncertainty also plays a role for the stigmatising aspect of contested illness and the moral dimension of illness.

### *Stigma and morality in contested illness*

Concepts like stigma confront us with the meaning of illness (Conrad, 1987). It makes us ask questions like “Why me? What have I done to be stricken with this?”

Diagnoses most often considered to be stigmatising are usually visible illnesses like epilepsy and leprosy. However, less obvious illnesses like AIDS and cancer have also been described as stigmatising (Sontag, 1991). Chronic fatigue is similarly an “invisible” illness but still very different from the two just mentioned. Nevertheless, CFS as well as medically unexplained or poorly understood chronic pain have been described as stigmatising (Hilbert, 1984; Honkasalo, 1999; Åsbring & Närvänen, 2002). In this section, I will review studies discussing stigmatisation in relation to contested illnesses. My purpose is to point out what seems to make an illness like CFS stigmatising.

According to the classic Greek definition, stigma signifies bodily marks indicating that the stigmatised person was someone deviant or showed his/her blemished moral status (Goffman, 1963). Out of Goffman’s three types of stigma, two are of special importance to understanding illness as stigmatising. One is, just like the classical definition, based on clearly visible signs of illness. Goffman uses the term *discredited*. The other is less visible and Goffman calls this kind of stigma, which is more like “spots” on the personality, *discreditable*. Despite this, stigma according to Goffman is not some kind of characteristic tied to the individual but something arising in interaction. (This analysis has been criticised, though, as describing the sufferer as being too passive and as a person on whom stigma is just being imposed (Anspach, 1979).) As interactionally shaped, no single diagnosis is necessarily stigmatising for every sufferer. At the same time, most illnesses are probably *potentially stigmatising* (Conrad, 1987) or connected to *felt stigma* (Scambler & Hopkins, 1986) which means that sufferers act according to their experience of having an illness that would lead to stigma if anybody knew.

From different studies about CFS it is possible to discern two partly intertwined ways that seem to make CFS potentially stigmatised: an *historical comparison* and *stigmatisation through interaction*. Both

belong to Goffman's second type of stigma, the more hidden and discreditable, and seemingly based on the invisible suffering as well as in the scientific uncertainty. They also appear related to the division between psyche and soma, which dominate Western culture.

*The historical comparison* between CFS and neurasthenia is mostly theoretical and conveyed by the scientific literature (e.g. Greenberg, 1990; Ware & Kleinman, 1992b; Wessely, 1990). By pointing out similarities and by making assumptions about CFS as the modern neurasthenia, the two illnesses, separated by time, are linked. The potential stigmatisation of CFS might then be fuelled by the history of neurasthenia, which from first being thought of as a physical condition was transformed into a psychiatric diagnosis – illnesses that “remain as stigmatising as ever” (Wessely, 1990, p. 50), and later almost disappeared from Western nosology. The comparison with neurasthenia reinforces the opinion that CFS is a psychological condition (thereby potentially stigmatising) as does the suspicion that it is some kind of temporary phenomenon and not a genuine medical disease. It has been argued that CFS will meet the same fate as neurasthenia (Abbey & Garfinkel, 1991), “a decline in social value as it is demonstrated that the majority of its sufferers are experiencing primary psychiatric disorders or psychophysiological reactions” (ibid., p. 1638).

*The stigmatising medical encounter*, which is the second way stigma is discussed in relation to contested illness, is based on empirical data primarily from interviews with sufferers. It becomes obvious in these studies that stigmatisation seems to appear in interaction with persons important in a situation of suffering – usually physicians. What many sufferers describe are their experiences of being mistrusted when visiting physicians for feelings of persistent fatigue or pain, a feeling that is connected to what might be thought of as “felt stigma” (Cooper, 1997; Hilbert, 1984; Reid et al., 1991; Ware, 1992; Åsbring & Närvänen, 2002). This becomes the “spots on personality” Goffman (1963) describes.

However, just as Hilbert (1984) argues in the case of chronic pain, it is not the symptoms – like the fatigue or the pain – that seem to be stigmatic. It is how the fatigue or pain is communicated, emanating from the dilemma people are facing when suffering from something, which is “unfamiliar as a cultural object” (Hilbert, 1984. p. 373). Hilbert calls this dilemma *pain management* and describes it as a balancing act between the disclosure and concealment that sufferers

constantly have to manage. When disclosing too much or too often, the sufferer risks being seen as a complainer. Not disclosing the problem, on the other hand, implies the risk that others will have difficulty understanding why someone does something like withdrawing from activities in which he/she used to participate. A related problem is that invisible suffering is easy to forget for those not suffering.

By concentrating on the pain management, Hilbert emphasises the sufferers' part in the stigmatisation process. However, in more recent studies about both CFS (Ware, 1992; Åsbring & Närvänen, 2002) and chronic pain (Honkasalo, 1999; Reid et al., 1991) the potential stigmatisation is demonstrated by the way interviewees describe the action taken by their physicians, their own reactions to this and how they responded. Norma Ware (1992) distinguishes between two kinds of disbelief, *trivialisation* and *delegitimisation*. In the first case, the personal feeling of illness is rejected as symptoms of a disease; in the other illness is psychologised and stated to be "all in your head." When one's experiences of illness are distrusted or regarded as "normal for your age" the suffering person might feel doubt about his/her own feelings, or guilt for experiencing something which could not be explained (Henriksson, 1995; Hilbert, 1984; Reid et al., 1991; Ware, 1992). Ware argues that the delegitimisation might lead to feelings of shame, not for the illness but for "being wrong about the nature of reality" (p. 354). At the same time being "psychologised" means that people might feel responsible for their own illness (e.g. Kirmayer, 1988). This means that both trivialisation and delegitimisation could lead to questioning the sufferer as a moral person. In a recent Swedish study of women suffering from either CFS or fibromyalgia, the distress from being psychologised, especially by physicians, and the experience of having one's *moral character* called into question turned out to be two important aspects of stigmatisation (Åsbring & Närvänen, 2002).

In connection with the scientific uncertainty and invisibility outlined in a previous section, what Hilbert (1984) describes as *inadequate cultural resources* could be one reasonable explanation for stigmatisation in contested illness. His point is that illnesses like chronic pain are *culturally unfamiliar* because of the difference between "normal" pain, which we think of as temporary, and chronic pain, which we have inadequate cultural resources to understand. The same can probably be said about "*normal*" *fatigue* versus *chronic fatigue*. Almost everyone

can recognise the feeling of being tired, but few can imagine fatigue to be chronic.

*To resist stigmatisation* people try to maintain their dignity when openly stigmatised, and when not openly stigmatised they try to pass as “normal” by controlling information about their illness (Goffman, 1963). However, suffering from an invisible and contested illness like CFS means that those suffering, unlike what Goffman describes, must present their fatigue as “abnormal” to be able to claim illness. This corresponds with studies stating that suffering from an invisible illness intensifies the feeling of stigmatisation (Hilbert, 1984; Honkasalo, 1999; Reid et al., 1991). However, a diagnosis, even when it is an uncertain one like CFS, makes it in some sense “real” by confirming and naming illness, and this in turn reduces the potential stigmatisation (Honkasalo, Woodward, Åsbring & Närvänen). Consequently, the stigmatisation connected with contested illnesses like CFS is not possible to resist with the same strategies as Goffman describes (as do others after him, e.g. Conrad and Scheider (1983)). The dilemma of balancing disclosure and concealment means that people suffering from a contested illness like CFS or chronic pain have to use both. Because of previous experiences of stigmatisation in medical encounters, interviewees in Åsbring and Närvänen’s study (2002) described that they constantly consulted different physicians to avoid the risk of being seen as “problem patients” repeatedly seeking help. In the same study, sufferers avoided telling about their illness, and when they did choose to tell, they disclosed symptoms that they saw as more legitimate than fatigue. The authors argue that each woman’s status as a deviant made her develop a *situation consciousness* to assess the impression she made.

### *“Challenging medicine” and experiential knowledge*

“For people with chronic illness, information about their disorder is a significant resource for managing their lives,” writes Conrad (1987, p. 14). Such information about the personal illness could include everything from diagnosis to details about pathophysiological processes and treatments. However, for those suffering from a contested illness like chronic fatigue, the lack of answers makes it difficult or impossible to get this kind of information. In addition there is the problem of different views about the illness between physicians and patients (Banks & Prior, 2001; Cooper, 1997; Reid et al., 1991; Woodward et al., 1995).

The lack of established medical explanations as well as the experience of not being taken seriously when explaining one's illness or the feeling of being questioned as a moral person might lead to what Cooper calls "challenging doctors" (1997). This can happen when sufferers demystify their individual doctors and to some extent doctors in general or go outside traditional medicine to the "alternative paradigm," in which Cooper includes self-help groups as well as complementary medicine.

Joining groups in which members have a certain kind of suffering in common is not unique for those suffering from contested illnesses. As a phenomenon such groups are often described as being a response to the incapacity within health care to deal with the problems people experience from different kinds of long-term suffering (Jacobs & Goodman, 1989; Kelleher, 1994; Kronenfeld, 1986). By sharing experiences of illness and suffering, members of self-help groups and the like develop *experiential knowledge* grounded in the individuals' lived experiences (Borkman, 1990). With this term, Thomasina Borkman argues against the two-category system of professional and lay person commonly used within medical sociology. That simplified image makes no difference between, as Borkman writes, "knowledgeable and uninformed lay persons" (p. 4). The demystification Cooper (1997) describes, concerns the fact that the sufferers concluded that they had more medical knowledge of their condition than did their GPs. This can be noticed in actual meetings as well. In one study of a self-help group Schubert and Borkman (1994) describe how the experiential knowledge dominated over the professional. Information from invited professionals was validated by being compared to experiential knowledge and was sometimes disputed and considered incorrect.

On another level, interest groups like patient associations also seem to have a clearly political function (cf. Anspach, 1979). The issues of what is doubted and what is uncertain, and which are tangible parts of contested illnesses, partially explain the polarisation that has appeared in diagnoses like CFS in Great Britain (e.g. Banks & Prior, 2001) and for RSI in Australia (e.g. Arksey, 1998). The differences between the experiential knowledge and the professional have been described at this level as a battle between the medical establishment and patient associations (Banks & Prior, 2001). This polarisation has occasionally involved fierce discussions between the patient organisations and medical expertise about the reasons for, and indeed about the existence

of, the condition. This confrontational attitude can be reflected in meetings between physician and patient (ibid.).

### *Time and self in chronic illness*

Time and self are central aspects in the study of the experience of chronic illness. At least partly, they seem to be mutually dependent. The longer illness remains, the greater the influence on the way people think about themselves presumably will be. In a similar way, illnesses that have a strong influence on people's sense of self (like being stigmatising) might also affect their conception of time. Yet, few have discussed the interplay of these two aspects. One exception is the American sociologist Kathy Charmaz whose book *Good days, Bad days* (1991) is one of the most extensive single works focusing on time and self in chronic illness. Aside from that, it is possible to roughly group studies concerning illness, time and self into two main categories. The first one is primarily focused on the course of illness, that is, stages or phases in illness and the perceptions of self that occur as time goes by. The central focus for the other group of studies is on changes in the sense of self in relation to illness and suffering.

In the first group, we will find concepts like *careers* and *illness trajectory*. This use of the term careers originates from Everett C. Hughes' (1958) study *Men and their work*. Erving Goffman (1961) and his analysis of mental patients' moral careers, however, transformed career into a social psychological concept useable in relation to the gradual changes of the self due to hospitalisation because of mental illness. Later, career has been used by Julius Roth (1963) and by Fred Davis (1963) in their works on how people anticipate the time they had to stay in hospital. *Illness trajectory* then describes the course of illness from a sociological point of view and is closely related to another of Strauss' most important concepts, *work* (Corbin & Strauss, 1988; Strauss et al., 1985). Like the "moral career," illness trajectories are based on different phases connected to the particular disease. "Any trajectory," the authors write, "can analytically be broken down into phases which give it its shape" (Corbin & Strauss, 1988, p. 45). Accordingly, not until there is some certainty about diagnosis, can projections and planning necessary for the shaping of a trajectory start. For reasons that should be obvious by now, such concepts, based on division into phases, are difficult to use for contested illnesses like CFS, for which the course of illness is rather unclear. An alternative approach

to understanding the course of illness in relation to culture was presented by Arthur Kleinman and Norma Ware (Kleinman, 1992; Ware, 1999; Ware & Kleinman, 1992a) in their studies about CFS and chronic pain. With their term *the social course of illness* they argue that events in the social world influence illness at the same time as illness will “shape and structure the social world” (Ware & Kleinman, 1992a, p. 548). Like the view that “bodily distress has social roots,” illnesses also have a social course (Ware, 1999, p. 303). For those suffering from a contested illness like CFS this means that “standards for social life” for constant activity and expectations for speed “trigger social processes of marginalization” (Ware, 1999, p. 305). To maintain one’s position in one’s social world despite lack of stamina, different strategies or *processes of resistance* are required. Time is, however, rather unnoticed in the social course of illness.

In the second group, concerning changes in people’s perception of self in relation to illness and suffering, the key concept is probably Michael Bury’s (1982) widely used *biographical disruption*<sup>2</sup>, followed by variations like interruption (Charmaz, 1991) and disrupted lives (Becker, 1997). In his concept, Bury shows how people diagnosed with a chronic illness (RA) perceived a disruption of everyday life, of what they took for granted (such as a view of life that continued as usual), and the way they thought about illness and their social relations. Since the publication of Bury’s paper a number of social scientists have turned their (sometimes renewed) interest towards self and biography in relation to chronic illness (Carricaburu & Pierret, 1995; Charmaz, 1983, 1987; Estroff, 1989, 1993; Maines, 1983; G. H. Williams, 1984). For instance, Corbin and Strauss (1987) expanded their study of illness trajectory and biographical work to encompass the term *biographical body conceptions* or the *BBC chain*.

Despite the influence of Bury’s concept, the biographical disruption has been partly revised. In a recent paper, Simon Williams (2000) criticises the unreflected use of the concept without anchoring it in scrupulous analysis of empirical data. Instead, he argues in favour of a more nuanced use of the concept. Since this kind of experience cannot be prejudged as part of every chronic illness, “*timing* and *context*, *norms* and *expectations*, alongside our *commitment* to events, antici-

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<sup>2</sup> In a bibliographical study on the impact of papers published in the journal *Sociology of Health and Illness* Bury’s paper from 1982 is stated to be one of the most cited and still relevant to the field (Armstrong, 2003).

pated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow it" (ibid., pp. 51-52. Williams' own italics). Different kinds of illnesses probably also make a difference. As we will see, other studies confirm this assumption by terms like for instance "loss of self," "the reinforced self" and "the transformed self."

According to Charmaz (1983; 1987), chronic illness is essential for people's identity and sense of self, and a fundamental consequence of illness is the experience of *loss of self*. This changed perception of self partly originates from the loss of social contacts that is inherent in illness and partly from the way that other people seem to regard them and treat them. She describes how chronically ill persons struggle for a sense of self, and to *reconstitute a sense of self*, as optimal as possible due to illness (Charmaz, 1987).

Almost a decade later, Danièle Carricaburu and Janine Pierret (1995) introduce the concept of *reinforced self*. Through what is called the biographical reinforcement, these authors show that a diagnosis like HIV does not always involve a disruption. For those suffering from haemophilia prior to being diagnosed as HIV-positive, the diagnosis instead turned out to be a continuation of the illness they had already learned to live with. For the gay men in the study, the diagnosis at first lead to a feeling of disruption and then later on to a reinforced identity as homosexual. For this group of men, the diagnosis connected them to the collective history of homosexuality and AIDS.

A third type of an altered sense of self is *the transformed self*, or as in a recent paper the *radicalized self* (Clarke & James, 2003). One example is the work by the American social anthropologist Sue Estroff (1989; 1993) about identity and self in chronic psychiatric illnesses like schizophrenia. In an interesting analysis, she discusses the altered sense of self by the concept of *chronicity*. According to Estroff, chronicity is a fusion of identity and diagnosis, a transformation of the identity, which she regards as a social and interactional process. By this, she links her own work to Goffman's analysis of the moral career (which seemingly ends up in both groups). Another example of the transformed self comes from a Swedish study that I have mentioned earlier, and an analysis of the identity work among women suffering from CFS or fibromyalgia (Åsbring, 2001). According to this study, the interviewed women, although describing a feeling of disruption, often described another identity process as well, when coming to terms with their illness. This is

interpreted as a *partial* transformation of identity. This change in sense of self is described as at least partly positive through “illness gains” resembling the “gains” of the illness (CFS) Ware and Kleinman (1992a) discuss. In a time characterised by constant time pressure, illness provides a change in what people value in life. They get “time to think” or to “smell the roses,” as Simon Cohn (1999) was told by his respondents in an analysis about CFS similar to the one by Ware and Kleinman (1992a).

As shown in this section, many studies about the experience of chronic illness discuss identity work as some kind of reconstruction of an earlier identity, or the establishment of a new, (sometimes) partly transformed sense of self. When described like this, changes in sense of self appear primarily to be the response to the experience of illness as a biographical disruption. The sense of self thus becomes linked to the linear perception of time and change, according to which the identity work most of all seems to be a matter of going from one perception of self to another. However, the experience of illness as a disruption is not given. In the review just being completed, I have reported on studies showing how people suffering from CFS experienced the diagnosis as one of the most important events since they became ill and one that helped them to sort out their illness experience. This kind of description partly invalidates the meaning of diagnosis as a biographical disruption. Moreover, the uncertainty about the genesis of illness as well as the moral dimension, connected to an medically unexplained illness such as CFS, might lead to the need to regard life in retrospect by questions like “How could this happen?” Looking for answers behind the diagnosis and before that in time might result in various possible explanations, which in turn could influence the life history by providing several alternative courses of events. Restricting the analysis to the ordinary view of time as linear could mean an unnecessary limitation. In conformity with Simon Williams’ (2000) criticism, we cannot presume all chronic illnesses to be experienced in a certain way, and in extension not presume the way an identity work process due to chronic illness happens. We can learn more about this only through empirical studies of how people actually describe their experiences and what they do to make sense of and to manage a life situation that has been changed because of illness.

## Summing-up experience of contested illness

The central focus of this chapter has been the illness experience perspective. This field of research has been explored as a theoretical approach as well as by reviewing empirical works primarily concerning illnesses like CFS. With this, I have intended to outline aspects of significance for the experience of illnesses that might be called contested, like CFS. My purpose for this has been to show what kind of experiences people suffering from this kind of illnesses have to deal with when making sense of illness and suffering.

The key aspect has been the scientific uncertainty. Because of this, many difficulties remain even if or when the diagnosis offers some relief. Due to the scientific uncertainty, however, it could take quite a long time before illness has been diagnosed (if ever). The scientific uncertainty in combination with the invisibility of fatigue (or pain) tends to lead to a sufferer being called into question as a moral person. This has implications for the way people experience time and self. Why me? What made me become like this? Has it anything to do with the way I have been leading my life? The scientific uncertainty as well as the feeling of distrust could result in what has been described as challenging medicine and to the struggle between medical and experiential knowledge.

All this implies that the individual sufferer is the one who has to make sense of and bring order to the confused world he/she is living in due to illness. This coincides with the new focus in social science concerning chronic illness. In a recent work, Bury (2000) describes this shift in contemporary social science in the fields of chronic illness and disability. The conflict perspective, built up against Parsonian functionalism by emphasising the personal experience of illness, has been replaced by a new focus on the individual as well as on the collective agency. This shift has been called *the narrative turn* and is what I will concentrate on in the next chapter.

The shift from a problem perspective to one that stresses the active engagement of the person with his or her illness and disability suggests potential positive aspects of such experiences. Through battling with illness and through suffering may come a sense of gain as well as loss. Illness and disability are then turned into moral narratives, in which the person is no longer the victim or sufferer but presents himself or herself as a “wounded storyteller,” to use Frank’s ringing phrase. (Bury, 2000, p. 178)

## Chapter Three

# Illness narratives and narrating illness

Life stories express our sense of self: who we are and how we got that way. They are also one very important means by which we communicate this sense of self and negotiate it with others. (Linde, 1993, p. 3)

Creating narratives is characteristic for human beings and something that helps us to create coherence and meaning in our lives. Hence, narratives can be told about almost anything, and yet we do not tell stories about everything in our lives. The stories we tell are about things important to us – like illness. The Canadian medical sociologist Arthur Frank (1995) argues that serious illness is a *call for stories* in order to make one's life whole again and to provide answers for all those questions that other people ask the ill person.

However, narratives not only create meaning by telling about what happened. By our stories and the way we tell them, we express something about ourselves, about “who we are and how we got that way” as Charlotte Linde describes it in the quotation above. This makes it sound reasonable to study illness narratives as well as people's narrativisations about illness when trying to find out how people make sense of contested illness.

In this chapter, I will focus on the field of research now usually called *illness narrative*, which is intersectional to the illness experience perspective that played the central role in the previous chapter. My intention is to outline three different functions of illness narratives that also constitute different forms of narrative analysis, *the narrative reconstruction*, *narrative as performance*, and *shared stories*. These three are not clearly distinguishable; they partially overlap since all three are related to identity. They correspond in different ways to what in the previous chapter turned out to be important aspects of the experience of a contested illness such as CFS. That is, the scientific uncertainty which implies that questions about the genesis of illness remain even after diagnosis, thereby providing legitimacy to a lesser degree, and the

experience of being questioned as a moral person due to this uncertain and invisible illness.

I will start by describing how the study of illness narratives has obtained a place of its own in the broader field of illness experience and the relationship between these two fields. Thereafter, I will devote a few words to different ideas about what a story is and of what narrative contexts mean, before turning to the main section and the exploration of illness narratives from the concepts and themes already mentioned. As I did in the previous chapter, I will refer to different empirical studies in my discussion in this section. However, before all this I would like to say something about the relation between illness narratives and studies concerning communication of health and illness.

## Communication about illness and suffering

As indicated in the introduction to this chapter, narratives are important means for communication. By including storytelling as well as the content of the story, narratives in a more obvious way become part of a conversation (cf. Sacks, 1995). This counts of course for narratives about illness as well. However, research concerning communication about health and illness has for quite some time been based on the interaction between people who suffer and health care professionals. This is commonly called *institutional discourse* (cf. Agar, 1985; Drew & Heritage, 1992). In a review about studies concerning language and medicine, Lars-Christer Hydén and Elliot Mishler (1999) distinguish between four different groups of research on communication about illness. In accordance with the dominant perspective used in the reviewed studies, Hydén and Mishler name these categories: speaking *to* patients, speaking *with* patients, speaking *about* patients and, finally, speaking *by* patients.

With this typology, it becomes clear that most research within this field has taken the medical encounter as the point of departure and thus the role of the “patient” versus that of the professional – usually a physician. Since the role of the sufferer is confined to that of the patient, other aspects of communication about illness are left out. Even if, as the authors write, “patients’ stories are clearly a significant source of data,” they have mostly been studied within the group called speaking with patients and are thus “usually treated from the standpoint of the biomedical model” (Hydén & Mishler, 1999, p. 182). However, in the

fourth group, called “speaking by patients,” the stories examined are not really those of patients, but of people suffering. Such stories are either told by sufferers in autobiographies or revealed in research interviews. This fourth group illustrates studies in which sufferers are given a voice of their own (Frank, 1995). Writing the history of language and medicine the way Hydén and Mishler (1999) do, portrays the same shift within social science as Bury (2000) refers to when explaining how personal narratives have replaced expert discourse, and the right of the personhood to that of the patienthood. Janine Pierret (2003), in one of the most recent reviews of illness experience perspective, places studies concerning accounts about health and illness, like the one by Alan Radley and Michael Billig (1996), somewhere on the way to this contemporary shift. In a similar way, works on metaphors of illness (Radley, 1993; Sontag, 1991) are important to mention when dealing with communication about illness. In my text, though, I will stick to the illness narrative.

### Illness experience and illness narratives

One reason for the social scientific interest in narratives about illness is the power stories possess. Stories about illness provide us with a glimpse of the suffering we intend to study. Anthropologists have a long tradition of using people’s personal narratives as an important resource in their analyses, especially when examining things like illness and healing (Mattingly, 1998). The usefulness of people’s stories is the foundation for why researchers in the illness experience perspective, like Arthur Kleinman (1988), Michael Bury (1982) and many others, have turned to the stories ill people tell about their suffering. Yet it was not until the beginning of the 1980s that narratives *per se* became the focus of research in social science on a wide front (Riessman, 1993; 2001).

From this more general interest in narratives in social science, a particular interest in narratives about illness and suffering began to develop (e.g. Bell, 2000; Hydén, 1997). At the beginning, the interest in illness narratives was considered to be part of the criticism of the medical dominance in the encounter between patient and physician (e.g. Bell, 2000). According to Susan Bell, it was first when Elliot Mishler (1984) showed how the medical voice dominates over and interrupts the voice of the life world that attention was actively turned to the ill people’s experiences of illness through narratives. This change, allowing

room for the sufferer's own voice, is the same move as described earlier in the history of language and medicine (Hydén & Mishler, 1999).

Except for a shared interest in what ill people tell about their illnesses, the two fields of research – illness experience and illness narratives – intersect by, for instance, basing their research on everyday experience (Bell, 2000). In her argument, Bell quotes Conrad (1987, p. 4-5) who states that the sociology of illness experience “must consider people's everyday lives living with and in spite of illness” as well as Hydén (1997, p. 49) writing that “one of our most powerful forms for expressing suffering and experiences related to suffering is the narrative.”

Since the 1990s, illness narrative has “grown up” and more obviously stands out as a separate part of the sociology of illness experience. Before that, the relatively small numbers of narrative analyses concerning illness were thought of in medical sociology as part of the ethnomethodological school, together with studies of institutional discourse such as interaction between patient and physician (cf. Gerhardt, 1990). Aside from Mishler's book *Discourse of medicine* (1984), Gerhardt mentions Gareth Williams' (1984) now more or less classical paper on narrative reconstruction. In retrospect, though, both of these constitute in a sense the starting point for a definite interest among social scientists to collect and analyse illness narratives *as narratives*. They made this clear by pointing out the narrativising of experiences of illness as something that could bring new light to the way people made sense of their illnesses, saying that narratives seemed to have various functions in interaction about illness and suffering.

During the last few years, at least three reviews concerning illness narratives within social science have been published in international journals and scientific handbooks. The authors are Lars-Christer Hydén (1997), Susan Bell (2000) and Michael Bury (2001). These reviews are attempts to sort out and illustrate illness narratives as a unique and separate field of research, though intersectional to the illness experience perspective.

In the first-published review, Hydén (1997) typologises illness narratives from the relationship between the story, the storyteller and illness, into three different types of illness narratives. This means that not only narratives concerning the personal illness experience (*illness as narratives*) are considered but also *narratives about illness*, typically physicians' stories about patients' illnesses and diseases, e.g. Kathryn

Montgomery Hunter's *Doctor's stories* (1991). The third type, called *narrative as illness*, is defined as a situation when the narrative itself or the inability to tell a coherent story constitutes illness. According to Hydén, the first type of illness narrative, which is the one focused on in this chapter, can have several functions. Three of these are especially relevant for my work, namely the narrative reconstruction of life history, narrative as a strategic device and the transformation of individual experience into collective experience. I will come back to these later on in this chapter.

Bell (2000) focuses in her review on illness narratives as the narrative turn within the sociology of illness experience and on in what way the two fields of research intersect. According to her, identity as a common topic for research overlaps the two fields. Nevertheless, there are obvious differences between the two in how data is treated and analysed. Even if interviews are a basic method of collecting data in both fields, and even if sharing the view that local contexts shape the experience as well as the analysis, they differ in the way stories are treated as categorical data (grounded theory) or as narrative data. Instead of coding interview data according to themes or categories, narrative analysis focuses on "how a narrative unfolds and makes sense in the process of collection, transformation, and interpretation of data" (ibid., p. 192). However, despite differences and sometimes antagonisms between the two fields, Bell points out studies concerning aspects of identity that are often compared, and discusses similarities as well as differences in aspects, for instance stigma and biographical disruption.

Finally, in the most recent review, Bury (2001) presents a framework for the analysis of illness narratives that more clearly considers the temporal dimension of illness and its cultural meaning. For this, he suggests the use of three forms of narratives. The first, *contingent narratives*, "deal with beliefs and knowledge about factors that influence the onset of disorder, its emerging symptoms, and its immediate or 'proximate' effects on the body, self and others" (ibid., p. 268). By the second form, *moral narratives*, Bury introduces an "evaluative dimension into the links between the personal and the social," a dimension that includes accounts people give to justify themselves (ibid., p. 274). The third, *core narratives*, deals with different levels or functions of the narrative form such as heroic, tragic, ironic and epic, and reveals "connections between the lay person's experiences and deeper cultural levels of meaning attached to suffering and illness" (ibid., p. 263). With

these three, Bury links up as well as gives a narrative frame to different parts of his earlier works. These include biographical disruption (Bury, 1982), the problem of explanation and legitimation, the impact on treatment and the development and use of adaptive responses like coping, strategy and style (Bury, 1991).

The three reviews emphasise illness narratives as a separate field with its own methods of analysis to reveal the personal experiences of ill persons. This way, the “narrative turn” becomes a continuation as well as a differentiation of the illness experience perspective. However, the two are separated by the way narratives are analysed as individual stories and accounts. Because narrative analysis often brings forth a few individual narratives, the situational in the production of stories becomes emphasised in a way that differs from categorical analyses in which individuals sometimes “disappear” in themes and categories. When the single narrative is the unit for analysis, the question “Why was the story told that way?” (Riessman, 1993, p. 2) becomes highly relevant and salient.

## Narratives, storytellers and the storytelling context

Perhaps because narrative analysis has become common in many different disciplines and is not confined to a particular field of research, there is no precise definition agreed upon for what will count as a narrative and what distinguishes a narrative (cf. Riessman, 1993). However, according to the view that narratives have a beginning, a middle and an end, “scholars agree that sequence is necessary, if not sufficient, for narratives” (ibid., p. 17). What is analysed as narratives often has to do with disciplinary differences in methods and points of view (Riessman, 2001). Historians, literary historians, linguists, sociologists and anthropologists, to mention some, could define narratives differently but still claim that they are doing narrative analysis. The same can be said also about the study of illness narratives. In anthropological studies for instance, researchers commonly regard the whole interview as a narrative and emphasise cultural aspects in the stories about illness (cf. Early, 1984; Garro, 1992; B. J. Good & Good, 1994). Some medical sociologists have adopted a narrower definition offering the possibility to closely analyse more clearly defined stories (cf. Bell, 1988; Hydén, 1995a, 1995b; Langellier, 2001). One plausible explanation for this is a relatively closer relationship with research on

institutional discourse, something that I wrote about in the beginning of this chapter as communication about illness.

However, for differences in interpretations the individual researcher's own choice of what to count as a narrative is not the only thing that matters. Another thing that influences the narrative form is the *social context of storytelling* (Hydén, 1997). Hydén distinguishes three such social contexts for illness narratives, the institutional context: the everyday context and different forms of elicited context (such as interviews). Narratives about illness and suffering most likely look different and cannot be analysed in the same way when, for instance, elicited in research interviews as when found in published or unpublished autobiographical texts like much of Frank's works (1995; 1997; 2000). Narratives likewise will have different forms and functions if they are told in a medical encounter rather than in a group of people suffering from the same kind of illness, and if the narrators are sharing some other kind of experience, as in meetings of Alcoholics Anonymous (AA). This is shown by researchers like Carole Cain (1991) and Vibeke Steffen (1997). However, to regard all stories told in groups as one kind of narrative is of course too simple. The structure of such meetings will influence the story form; factors include whether there is someone who leads the discussion, if there are any rules on when and how long members will talk, or on what they will talk about.

Despite their differences, researchers in the field of illness narratives share the ambition to study people's own descriptions and explanations of their illnesses. It is a kind of analysis that restores to the sufferers their right to be heard in their own "voices." In the following, I will, however, not distinguish between studies using a narrow definition and those using a broader view of narratives.

## Exploring illness narratives

As already mentioned, the interest in illness narratives as a field of research is quite new. Nevertheless, there are by now a number of studies taking people's narratives or narrativising about suffering as their objects for research. Even if the word "chronic" is not included in the name of the field (just as is the case with illness experience), the majority of these studies seem to focus on chronic illnesses. In her comparison between the two fields of research, Bell (2000) writes that the study of the experience of illness has "from its inception /.../ for

practical purposes meant the study of the experience of *chronic* illness” (p. 188, my italics). The same seems to hold true for studies about illness narratives. These studies are usually based on personal experience of long-term illnesses like cancer or being at risk for cancer (Bell, 1999; Frank, 1995), stroke (Becker, 1997), rheumatoid arthritis (G. H. Williams, 1984), HIV (Ezzy, 2000), epilepsy (B. J. Good & Good, 1994), multiple sclerosis (MS) (Riessman, 1990; Robinson, 1990), psychosis (Hydén, 1995a), chronic pain (B. J. Good, 1992; Jackson, 1992), temporomandibular joint (TMJ) (Garro, 1994) and CFS (Horton-Salway, 2001).

Narrative research thus covers a great variety of medical diagnoses. Despite this, differences regarding the kind of illness the narrative concerns are hardly ever discussed, i.e. whether differences in the narratives can teach us something about differences between various types of chronic illnesses. One explanation is that a narrative can have many different functions, as the reviews presented in a previous section illustrate. Because of this, it is possible to analyse illness narratives from many different aspects. Accordingly, researchers working with narrative analyses on several different kinds of suffering can as likely focus on unifying aspects as on divergent ones. The medical anthropologist Gay Becker (1997), for instance, has discussed several of her own studies concerning people suffering from things like stroke, cancer, childlessness and ageing, and has described them from a narrative analysis as *disrupted lives*. When reviewing the field of illness narratives, Hydén (1997) as well as Bell (2000) calls attention to the lack of studies that investigate possible variations in illness narratives for people of different ages or those who suffer from different types of chronic illnesses.

For my purpose of studying how people make sense of a contested illness like CFS, I will in the following text concentrate on three aspects of illness narratives: *reconstructing the story of life*, *narrative as performance* and, finally, *shared stories*. These three are based on empirical research and some, like the first, is a classical concept within medical sociology (cf. Armstrong, 2003). They have similarities to the functions of illness narratives that Hydén (1997) described earlier – the narrative reconstruction, narrative as a strategic device and collectivised experience – as well as to the three forms of illness narratives Bury (2001) suggests as bases for future analyses. All three are strongly linked to aspects of identity, but as we will see in different though overlapping ways. In this way, they also correspond to those aspects which in the

previous chapter were revealed to be connected to the experience of a contested illness like CFS – the uncertainty, invisibility and morality.

*Reconstructing the story of life*

“Why do you think you got arthritis?” Gareth Williams (1984) asked the interviewees in a study about RA. The way people responded to this rather abstract question by telling him stories about their lives showed how people suffering from chronic illness made sense of their illness by giving it a particular place in their life story. In doing this, the interviewees not only explained illness from the horizon of their personal lives (thus shaping rather different explanations of the same disease). They also reconstructed their own stories of life by including illness as a comprehensible part. By Williams’ own definition, such a narrative reconstruction is “an attempt to reconstitute and repair ruptures between body, self and world by linking up and interpreting different aspects of biography in order to realign present and past and self with society” (ibid., p. 197).

The question Williams asked his respondents might indicate that the narrative reconstruction is simply some kind of explanation of what caused the illness. However, as we are about to see, there is more at stake when people reconstruct their experiences of illness by narrating them. By using Williams’ concept, I return in this section to some of the issues about time and self introduced in the previous chapter. With this concept, I will discuss two questions essential to the purpose of this thesis: the function of narrative reconstruction in contested illnesses and the shape such reconstructions might have in stories about medically unexplained and less legitimate illnesses. For this, I will use empirical studies concerning the narrative reconstruction for chronic illnesses like chronic pain and psychosis.

The narrative reconstruction is thus about creating coherence in life by connecting the present to the past, thereby making the story of life comprehensible and a meaningful whole. In narratives, we can weave the threads together from many different events so they form a meaningful and coherent story even if those events did not seem to be related at the time they occurred. The emphasis on reconstruction and the genesis of illness imply a central focus on what has happened from the perspective of personal experiences in the sufferer’s life. In narratives shaped by questions like “Why me?” the present life, living with a chronic illness, is linked to the past and the way life was before illness.

The narrative reconstruction makes assumptions about the experience of biographical disruption (Becker, 1997; Bury, 1982) caused by, for instance, the information that one is suffering from a chronic illness, and about the “unmaking of world” caused by the long-term medically unexplained pain that Byron Good (1992; 1994) describes. The way the narrative reconstruction works to link present experiences to those of the past, it seems to be strongly related to issues of time and biography. It becomes a question of “remaking the world” (ibid.). This allows the body image, the self in a social context that was interrupted by the illness, to be repaired. In this way, the narrative reconstruction in some sense overcomes the uncertainty about the cause of illness that is often connected with chronic illnesses and is particularly salient in contested illness.

However, the narrative reconstruction also has implications on the sense of self, and particularly the moral self (Taylor, 1989). Like Williams (1984), Hydén (1995a) discusses the narrative reconstruction as a means of explaining the genesis of, in this case, psychosis. However, Hydén emphasises the moral dimension embedded in the narrative reconstruction (which Williams also mentions). Through the analysis of a former mental patient’s narrative about his illness, Hydén shows how the man elaborates with several possible explanations for his illness. Hydén argues that the narrative reconstruction thus becomes a *moral quest* for which the central goal is “to find out to what extent the illness event is a result of the kind of life the person has led” (Hydén, 1995, p. 82). What appears clear in this analysis is that the narrative reconstruction not only creates a coherent story by connecting different aspects of time in a person’s life. The way illness is explained by the narrative also affects questions about the narrator’s responsibility for the illness. Including different possible explanations for illness the narrator is given the opportunity of taking different stands towards illness as well as towards himself as a moral person.

Related to this discussion, Good (1992) argues, in an analysis of a narrative about chronic pain, which after many years of unexplained suffering became diagnosed as TMJ, that diagnoses have different meanings depending on whether they are connected to the body or thought of as mental. Naming illnesses like pain (or fatigue) thereby becomes “a critical step in the remaking of the world” (p. 45).

The naming of illness, or (usually) the diagnosis, is a critical point when discussing different functions of narrative reconstructions for

different kinds of illnesses. However, just as the diagnosis does not always function as a point of disruption (S. J. Williams, 2000), narrative reconstruction does not always concern only the genesis of illness. For those women who were exposed to a chemical drug (diethylstilbestrol, DES) prenatally and because of this are at risk for ovarian cancer and infertility, the narrative reconstruction might look different. In a close analysis of an interview with one of these DES daughters, Bell found that a series of linked stories together constituted the narrative reconstruction. This, however, concerned not only the genesis of illness and its consequences. This woman's stories also show a change in attitude towards her illness, from taking almost no interest and distancing herself from the illness to becoming a "political woman."

Nor does the narrative reconstruction in Linda Garro's (1992) analysis of narratives about temporomandibular joint (TMJ) point only backward in time, but appears instead to be an ongoing narrative. That TMJ, which is connected to chronic pain, in many ways seems to be a contested illness since "perhaps the most striking feature of TMJ is the lack of consensus on just about any aspect of the disorder" (*ibid.*, p. 100) could be one possible explanation. In interviews about TMJ, Garro found that narratives about the illness were told according to a certain pattern. These stories typically started by establishing a genesis for the illness but went on with a story about the time before the illness was recognised as an illness, a point which when it arose was described as a disruption and a turning point. After this, the story continued with the long search for a name for the illness, providing legitimacy, and finally, when a diagnosis was made, with the search for treatments. As Good describes it, the diagnosis, by naming the illness, seems to give rise to a new story in which the pain is reinterpreted as part of TMJ. In this way, past events were "reconstructed in a manner congruent with current understandings" (Garro, 1992, p. 101). The narrative pattern that Garro describes shows that the narrators (just as Good and Good (1994) have shown) consider themselves to be in the midst of the story they are telling. Thus, neither the narrative nor the reconstruction have an ending. Garro writes that "the present is explained with reference to the reconstructed past, and both are used to generate expectations for the future" (p. 101).

The narrative reconstruction appears as significant for creating meaning in personal suffering. This is especially true for someone who suffers from an illness that is medically unexplained and thereby less

legitimate in many contexts. The narrative reconstruction seems to comprise time and biography as well as issues concerning illness and the moral self. Empirical studies show that not only the link between present and the past, but also changes during the time of suffering as well as expectations for the future, become part of the reconstruction – expectations that vary depending on the different possibilities for interpretation that the story includes.

#### *Narrative as performance*

In the previous section, the meaning-making aspect of the narrative was considered by the reconstructive function of narrativising experiences. However, when we are telling stories about our personal experiences, we express at the same time something about ourselves. We can do this in many different ways.

That narratives are so intimately related to the telling of stories makes it possible to analyse them not just as stories about something (or as reconstructions) but as performances as well (Langellier, 2001; Riessman, 2001). That is, they are something people do in front of others, like an audience, which can be a single listener or an interviewer. According to Riessman (2001), such an analysis makes the story a means by which the narrator presents him/herself as a particular kind of person, as for instance a woman, a mother, a chronically ill person or a professional. To do this, a range of performative means of expressions is available to the narrator. By emphasising some words, for instance, more than others, by adding more details to some part of a story or using the body to show something important or salient in the narrative, the narrator can bring special meaning to the story. Likewise, a narrator can base his/her story on dramatised meetings with other people who are present only in the narrative, and by positioning him/herself as well as other persons in the story, to let different actors stand out as different kinds of persons (Harré & Langenhove, 1999).

Considering narratives as a means by which we perform our identities means that we take the stories and the way they are told as the starting point in understanding something about the narrators, and about the way they see themselves, their own lives and what it is to lead a good life. For instance, Gareth Williams (1993), in an analysis of the story by a woman in her sixties, chronically ill with RA, shows how this woman strives to present herself as a capable person when she tells the interviewer about her everyday life. From the way she presents herself,

Williams interprets the story to be a *pursuit of virtue*. In a similar way, Catherine Riessman (1990) shows how a man suffering from MS, in a research interview about his divorce, chose to present himself from a healthy perspective, as a competent father and a caring husband. By doing this, he constructs a positive masculine identity despite the visible illness from which he suffers.

Kristin Langellier (2001) distinguishes between two dimensions of the performative in narratives. She reasons that the narrative as well as the narrating appears as two intertwined but still discernible narrative paths. Langellier argues that the interplay and the reciprocal interdependence of the narrator and listener (audience), as well as that of the story told and the narration as an event, are central to the analysis of narratives as performances. Quoting Maria Maclean (1988), she describes this as some kind of a “two-way narrative contract between teller and audience” (Langellier, 2001, p. 150). This “contract” includes both here and now (the situation of storytelling) as well as there and then (the situation that the story describes).

In an analysis of an illness narrative about suffering from a contested illness like CFS, this implies that both the story told about being mistrusted, or delegitimised as Norma Ware (1992) describes it (see above, Chapter Two), and the way this particular story becomes part of the interview, are important in understanding the narrative as a performance about illness and suffering. This concerns not just what the story tells us about what happened in the encounter with, for instance, a physician. The act of telling this particular story in this particular way will also show us something about what is going on between the narrator and the listener, and thus something about the illness. From Langellier’s two dimensions, the narrative becomes more than merely the narrator’s choice to present him/herself as a certain kind of person. Instead, the presentation of self, which is carried out by the narrative, also has to do with how the narrator interprets the current situation and what kind of person he or she thinks that the listener (possibly an interviewer) might perceive him/her to be. Langellier’s emphasis on the narrative as an act makes the relation between listener and storyteller as important for the analysis as the content of the story being told. In this way, the performative aspect of narratives has to do with the question mentioned in the beginning of this chapter, “Why was the story told that way?” (Riessman, 1993, p. 2) and “why at this time?” Thus, the performative analysis of narratives has similarities to analyses of

accounts about health and illness such as that by Radley and Billig (1996), and to the function of narratives that Hydén (1997) calls *strategic devices*.

Analysing narratives as performances could be of special interest in connection with contested illnesses. In this kind of analysis, the invisible suffering as well as the moral implications of the scientific uncertainty and invisibility can be made clear by the way the narrators present the illness, their encounters with physicians and themselves both as ill and before illness. Consequently, analysing narratives as performances can illustrate something about the contestedness in illnesses like CFS. For instance, in an analysis of a story about CFS, co-narrated by the suffering woman and her husband, Mary Horton-Salway (2001) shows how the couple construct their story in the interview situation in a way that lessens the woman's personal responsibility for becoming ill. By portraying themselves prior to illness as active and healthy persons, and by showing a readiness to resist illness, this image evolves in the meeting with Horton-Salway as an interviewer. The presentation also indicates similar strategic devices in studies not using narrative analysis. One instance of this is when Woodward and her colleagues, in a study I have reported on earlier, describe how many interviewees had told them how they resisted the CFS diagnosis in different ways when first presented with it. By doing this, the interviewees presented themselves as being people who did not easily accept this label. From the two dimensions Langellier (2001) describes for narratives as performances, studies like these show that what happens in the interview can be as helpful in understanding a contested illness as the stories told about being mistrusted.

In the following section, my focus will remain on storytelling but will now highlight, more specifically, stories about illness and suffering among sufferers.

#### *Shared stories*

Some of the reconstructed function as well as of the performative in narratives can be seen as being connected with the *formulation* of our experiences and the fact that we narrate our stories *for* someone. Thus the narratives are a part of a social context consisting of both the narrator and the listener<sup>3</sup>. In some situations, like those of research

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<sup>3</sup> They do not, however, need to be present at the same time; the "listener" can for instance be a reader and it happens (maybe quite often) that we tell our stories to

interviews or therapy sessions, it is quite clear who has the primary listener's role and who is expected to provide the narration. Even when the narratives are regarded as co-produced, it is usually the person who has the role of narrator who "provides" the experiences. In other situations where the suffering is something all those present can be expected to share, the narration can be different and can also include other functions, e.g. what Hydén (1997) calls the *collectivising of experience*. What I intend to do in this section is to continue the discussion about sharing experiences that I started in the previous chapter, but this time from a narrative perspective.

By formulating our stories for someone, we can make something that happened to us appear in a much more comprehensible form than it seemed to be in our own thoughts. When we hear ourselves tell about them, the events and our experience of them can suddenly appear in a new, clearer light. The other person's questions, his/her attentive listening and even his/her mere presence leads the narrative on in directions that we may not earlier have considered or seen as a part of this special narrative (cf. Sacks, 1974). This is one of the basic theses for conversational therapy of various kinds, for example group-analytic psychotherapy (Foulkes, 1975). It is also the history behind, and one of the fundamental stories in movements like Alcoholics Anonymous (AA) (cf. Cain, 1991; Steffen, 1997). Storytelling is thereby to a large extent a social activity and, as Catherine Riessman (2001) writes, "a relational activity that encourages others to listen, to share and to empathise" (p. 697).

In studies of illness narratives, storytelling has received relatively little attention. Those who bring out the narration usually do so in an interview context, and then as accounts or performances, or in institutional interactions (Clark & Mishler, 1992; Mattingly, 1994). Storytelling within groups of so-called lay persons is primarily found in studies of conversations between family members and what is called "dinner-talk" (cf. Norrick, 1997; Ochs et al., 1989; Ochs et al., 1992). There are few studies of storytelling about illness and suffering in keeping with Hydén and Mishler's (1999) typology of communication about illnesses – those that can be called "speaking *among* sufferers." The ones that do exist describe self-help groups (Cain, 1991; Karp,

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someone we imagine as a conversational partner. In this section, though, I have chosen to concentrate on narrativising in so-called face-to-face interaction within groups whose members have some kind of suffering in common.

1992; Maines, 1991; Steffen, 1997) and, although under different conditions, narrative therapy in groups (Krietemeyer & Heiney, 1992; Laube, 1998) or a group activity within a therapeutic community (Wootton, 1977).

If both narrators and listeners (or more accurately co-narrators) can be assumed to have had similar experiences and it is these that have brought them together, the narrative function can be to try to understand something about one's own suffering by talking about suffering with others. It is done, in that case, in order to reach an intersubjective understanding of the suffering. Such a mutual exchange of experiences means that one person's narrative can also say something about the "listener" and about his/her suffering. The narrative interaction between listener/narrator and co-narrator/listener can rather be likened to what Mead (1934/1967) described as taking the other person's perspective. In other words, it is like each trying to understand him/herself through the other person. From an analytical point of view this means that, just as with analyses of narratives as performances, an analysis of the relational act of storytelling could focus on the shared stories (Cain, 1991) as well as meaning-making (Karp, 1992).

In the previous chapter I described, via experiential knowledge, what could be called the *learning function* of the sharing of experiences. Seen from a more clearly narrative perspective and through studies that emphasise the narrative and the narration, it is especially the function of a *joint construction of the meaning* of illness and suffering that becomes apparent. In studies of AA meetings, for example, several researchers have shown how one's identity as an alcoholic, or rather as a sober alcoholic, is formed by the joint narrative (Cain, 1991; Steffen, 1997). It is a matter, so to speak, of adopting a role by learning to tell the right story. This is a relatively structured form of narration in which the form of the common narrative, the time it takes to tell it, and the context in which it can be told are more or less given. In ethnographic studies of groups with more open structures, the creation of meaning also becomes "freer." This has been described both as a conversation in which participants compare experiences and give each other advice (Karp, 1992; Kelleher, 1990) and a sharing of experiences through actions (Blauner, 1991), which can be described as enacted stories.

## Summing-up contested illness in narratives

Throughout this chapter, I have concentrated the discussion on illness narratives as a field of research intersecting with the illness experience perspective, but still separated by its focus on ill people's narratives and narrativising about illness and suffering. I have presented three approaches to narrative analysis: the narrative reconstruction, narrative as performance and shared stories. These correspond to the experiences of contested illness like CFS that were emphasised in the previous chapter – the scientific uncertainty and the morally questioned – and to the aim of the thesis, the investigation of how people make sense of contested illness.

When the narrative reconstruction connects biographic time and re-establishes the relationship between the body, the self, and society, such a narrative seems to some extent to compensate for the scientific uncertainty associated with contested illnesses like CFS. When we explain it from a life perspective, however, it means that the responsibility for suffering can weigh heavily on the person who is ill. The narrative reconstruction thus becomes significant for people's ways of understanding their suffering from a moral dimension and offers the opportunity to try out different explanations. Being able to name one's contested illness means that a platform can be created on which a narrative reconstruction can be based.

Analysed as strategic devices or as performances, the narrative as well as the narrating situation becomes a stage on which the narrator performs identities as well as illness in front of and together with the audience (often the interviewer). Stories thus become a means for the sufferers of restoring or maintaining themselves as moral persons, and of telling something about illness, such as about contestedness. Performative analyses show how ill persons try with performed identities to counteract, or at least mitigate, negative images of themselves that they might assume others to have or that they have experienced through stigmatisation.

By using shared stories and storytelling, I have shown an analytical approach in which the creation of meaning takes place between people who have a certain kind of suffering in common. Being able to narrate oneself and hearing others' narratives are the cornerstones of this creation of meaning. Compared to the learning function of sharing experiences I described earlier, it is here more a question of the joint

### *Chapter Three*

construction of how the illness and the suffering are to be understood. Thus, it is a matter of a collectivising function in the narration.

With these three themes or analytical approaches, I have first wanted to demonstrate that narrative analysis is a feasible path to use in studying how people make sense of a contested illness like CFS. Secondly, I have wanted to show how different narrative analyses bring out different dimensions of such suffering. I have shown the significance of the creation of identity that in a contested illness is marked by uncertainty about the illness, as well as by the questioning of the ill person as a moral person.

One of the things shown so far in this thesis is that a contested illness like CFS must be made visible. It has to be described in words or through stories to become noticeable and tangible for others than the person suffering from fatigue, pain and difficulties in concentration. This is true for the clinical encounter as well as for a research situation and has implications on the methodological consideration. To merely observe how people manage chronic fatigue and concentration difficulties is impossible. In the following chapter, I will present my empirical study as well as the methods used.

## Chapter Four

# A patient school and its participants

Somewhere underneath the prose of social science lies some human contact. Before the clatter of the typewriter begins, some person (a social science researcher) collaborates with another person (usually called subject, respondent, or informant) to create a social relationship within which an exchange of information occurs. (Agar, 1980, p. 1)

My study is primarily based on contacts with people suffering from CFS and on their talk and narratives about illness and suffering. As the quotation from Agar indicates, these contacts are the foundation for the analysis and understanding of how people make sense of a contested illness. However, the collaborative relationship that Agar describes as prior to analysis includes a range of methodological questions and choices. These are of great importance for the understanding of what happened in different situations during the fieldwork as well as for understanding the analysis.

In this chapter, it is my purpose to provide a closer description of how the study developed and how the situations that I have been studying were shaped. I will show here the planning and final “design” of the study, my methods for collecting data, and how I continued to work with data. Finally, I will discuss some ethical considerations raised by the study and how I handled some of these. I will start by once more referring to the two intersecting fields of illness experience perspective and illness narrative that were discussed in previous chapters, and methods used within these. I will thereby state the reasons for my choices of both data and analysis methods.

## Studying meaning-making in chronic illness

In the two previous chapters, I have presented and discussed studies in which illness and suffering have been researched by collecting and analysing people’s personal experiences of suffering. For instance, illness experiences have been “collected” through narratives. Sometimes these experiences/narratives have emerged in research interviews. At other

times, experiences consist of published or unpublished narratives or of what people tell someone other than the researcher, in a situation that is part of research by, for instance, observation. From the way researchers generate their material, the studies that have influenced my own study most are primarily based on four different kinds of data: interviews, tape-recorded interactions, texts and ethnographical observations (such as fieldnotes).

Each of these types of material has its advantages as well as disadvantages, and each type has its limitations when it comes to what can be studied. Interview materials can answer the question of how people reason about a certain question but will not provide answers for how people really act in such situations. Ethnographical observations, on the other hand, can answer questions about what people do but offer answers to a lesser degree for the line of arguments that lie behind their acts. A published text like an autobiographical illness narrative provides the researcher with elaborated reasoning, but since it is edited (usually in part by others than the author) it differs from an oral story (Linde, 1993). While material limits what is possible to study, every research project limits how much detail could be included in the study due to limitations in time, financial resources and focus of research. No matter what kind of material one chooses to start from, each piece of material offers the opportunity to explore many more aspects than what is feasible in most cases. This means that each researcher in every study has to make a number of choices about what to include and what to eliminate as not being in the focus of the study. Because of the aim of the study, the researcher who works with interview data, which by itself could contain a great number of stories, might choose to concentrate on what kind of experiences the respondents tell rather than on how they narrate their experiences.

To make clear the reasons for my choices and at the same time relate my own work to that of other researchers who like myself discuss meaning-making in chronic illness, I choose here not to restrict the discussion exclusively to the question of how material is created. Instead, I will take as a starting point the kind of material those researchers have been using and what it is in this kind of data that actually constitutes the focuses of the studies. I want to find out if the focus is on people's experiences of chronic illness, their narratives about experiencing chronic illness or if the essential things to explore are the situations in which people talk about chronic illness and suffering.

In many studies based on interviews, the essential aspect is people's experiences of suffering from a chronic illness. By creating categories and themes in an analysis founded on the descriptions of several interviewees, researchers show how people experience illness (Becker, 1997; Bury, 1982; Charmaz, 1991; Karp, 1996; Ware, 1999; Yoshida, 1993). This produces an image of the collected suffering connected to a certain kind of diagnosis or, as for instance with Charmaz (1983; 1987; 1991), of chronic illness. However, this kind of analysis makes it impossible to discern how the individual sufferer makes sense of his/her illness.

In a number of studies, though, also based on interviews, it is instead people's narratives and accounts about chronic illness that become central to the analysis (Bell, 1999; Horton-Salway, 2001; Hydén, 1995a; Radley & Billig, 1996; G. H. Williams, 1984). When the central unit of analysis is the narrative, data can also consist of texts like published autobiographical narratives about illness, as in the works by Arthur Frank (e.g. 1995). The majority of studies, however, are based on narratives elicited in research interviews designed to facilitate storytelling (Mattingly & Lawlor, 2000; Riessman, 2001). The emphasis on the personal story means that several researchers make use of quite a small number of personal stories, or sometimes just one, in a *case-centered study* (Mishler, 1999). The individual's story and his/her explanations will then appear, providing a glimpse of how people make sense of their experiences. However, in studies based on published narratives, the stories might differ from those told in everyday situations or in interviews, because published stories are edited.

Research that studies how people talk *about* chronic illness and suffering in ordinary social settings, i.e. situations not designed by the researcher, is usually based on ethnographical observational data and fieldnotes (Blauner, 1991; Cain, 1991; Karp, 1992; Mattingly, 1998; Steffen, 1997). It can also be based on tape-recorded interactions (Banks & Prior, 2001; Hydén & Sachs, 1998). Some of these researchers have studied the interaction between physicians and those suffering from chronic illness (Banks & Prior, 2001; Hydén & Sachs, 1998; Mattingly, 1998). Others focus on the interaction among people sharing some kind of illness experience, like meetings in self-help groups (Blauner, 1991; Cain, 1991; Karp, 1992; Steffen, 1997). In studies of self-help groups, there have been certain difficulties in being allowed to tape-record meetings, since these, unlike medical encounters, are more often perceived as private meetings. Such circumstances make it hard to write

down the ongoing interaction in detail. The more persons involved, the harder this will be. Consequently, fieldnotes from observations will be of a different kind than the detailed transcriptions that can be produced from tape-recorded interactions. At the same time, ethnographical fieldnotes could offer a lot of information about contextual facts concerning the situation as well as about the individuals involved. However, observational studies provide researchers with material that is personally controlled to a lesser degree by the researcher, whether a tape recorder is used or not, compared with interviews.

Since the material influences what is possible to investigate, the choice of method for collecting data is a way to operationalise the questions the study is meant to answer. What has dictated my choices of methods for collecting as well as working with data is the question of how people make sense of a contested illness like CFS. From my recent arguments about advantages and shortcomings of different kinds of material, the optimal choice would be a combination of different materials if possible from different kinds of situations.

My opinion, that making sense of chronic illness largely concerns talking about illness with other people, who might suffer something similar or who might not, is important for this ambition. This will presumably hold true especially for illnesses that are invisible and contested. As a result, I decided to focus primarily on the interactive process of meaning-making. Because of this, I did not wish to confine myself exclusively to interviews, but also looked for opportunities to study people interacting about CFS. That is, I looked for some kind of social setting that was not designed by my research questions and myself. Since I was interested in people's talk and narratives, I wanted to find a situation that gave me the opportunity to tape-record these interactions. Such recorded material would give me the possibility to examine the studied interaction in detail as well as to transform it into a text. A transcription like this would provide still more details for the analysis. To find situations of importance for people trying to make sense of their illness, and that at the same time are well-defined enough to be studied within a reasonable space of time, could be difficult. So when the opportunity came to study an educational activity within health care, which I have called a *patient school*<sup>4</sup> for those suffering

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<sup>4</sup> The official name for the studied activity was, in conformity with other "patient schools" as for instance pain schools, a combination of the word "school" and the diagnosis or problem that most participants had in common – that is to say CFS/ME.

from CFS or other related diagnoses like idiopathic chronic fatigue, I thought this to be a good point with which to start my study.

Being both an educational activity, containing lectures by primarily health care professionals, and a place where people suffering from similar illnesses could meet and talk, this patient school seemed to be a unique possibility to study the interaction between professionals and sufferers as well as the interaction among sufferers. Because of this structure, the patient school could be perceived as a hybrid (e.g. Sarangi, 2000). It was a mix of, on the one hand the clinical encounter between the professional and the patient or client and, on the other, meetings in self-help groups, support groups, patient associations and similar arenas where people sharing a certain kind of suffering gather, usually without the presence of professionals. I therefore judged the patient school to be a social context that could be of importance for sufferers in making sense of their illness, and as one that could give valuable insights into the process of meaning-making. To increase my understanding of how these people tried to make their illness comprehensible, I continued my contacts with two thirds of the former participants in the patient school with recurring interviews some time after the school had finished.

With a procedure like this, my study was to consist of a combination of three main types of data: ethnographical data, tape-recorded interactions and interviews. Conducted this way, the study became based on two separated parts. These, however, are closely linked, since they mostly include the same individuals and are based on the same research question. The first is the observational study of the patient school, and the second is a series of interviews with 14 of the 18 participants<sup>5</sup>.

The final design of the study was, as indicated in my description, not defined from the beginning. On the contrary, it was allowed to develop in relation to the experiences I had during the work. Its definite form, with two main parts for which the methods for generating data differ, is the reason for separating them in the following when this seemed to be needed.

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<sup>5</sup> In the patient school, the participants were interchangeably called students and patients. Since my interest in how people create meaning and comprehend a medically unexplained suffering does not specifically focus on how this happens within a medical context but rather in a broader sense, I have chosen to avoid the concept of "patient." I base my argument on Arthur Frank's (2000) distinction between *patient* and *ill person*. Instead, I have chosen to use the term "participant" throughout this work when I am referring to the "patients" in the patient school. I do so even if this term might be misleading since the professionals as well as I, to some extent, participated in the studied school.

## The patient school study

### *Planning and design of the study*

The empirical study was thus instituted by the observational study of the patient school, a group activity for people diagnosed to suffer mostly from CFS but in some cases from idiopathic chronic fatigue. This activity is organised by a specialist clinic at a large hospital in Sweden. Like many other activities within health care that use educational elements, e.g. lectures, this activity is called a “school” (cf. Kogstad & Hintringer, 1993; Lindroth, 1996; Rosenqvist, 2001). The reason for my decision to call this activity a patient school throughout this text is that the men and women who participated were also patients at this clinic. They paid, for instance, the ordinary patient fee for each meeting/visit and at the conclusion of the patient school they were offered a personal meeting with the physician.

Aside from what I have described so far, the choice to study the patient school became a natural continuation of the larger research project of which my own is a part<sup>6</sup>. Other researchers in this project had earlier studied the medical consultation at the same clinic as the patient school (Hydén & Sachs, 1998). Since the patient school usually follows these kinds of encounters, a study of the patient school seemed to be a reasonable continuation from the perspective of the structure of the clinic, as well as from the patients’ point of view. Even if the individual sufferers are not the very same persons in the two studies, the two kinds of institutional settings usually have much in common.

That the patient school had an educational form for groups of sufferers made it particularly interesting for a study of meaning-making in a medically unexplained illness. By its form, the patient school probably has some similarities with patient associations, self-help groups and support groups (cf. Karlsson, 2000; Sallerberg, 1993). At the same time, the patient school probably differs from these kinds of groups due to elements like being based on a limited number of meetings, consisting of a small number of participants, having an educational form and finally by having the presence and guidance of health care professionals. There is also the obvious connection to a medical clinic.

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<sup>6</sup> This project, “Lidande utan patologi: fallet kroniskt trötthetssyndrom” (Suffering without pathology: the case of chronic fatigue syndrome), SFR 98-0024:1B (Sachs & Hydén, 1997) is financed by SFR and headed by Professor Lisbeth Sachs.

Thanks to the earlier study by Hydén and Sachs (1998), contacts with the clinic were already established. This facilitated the part of approaching the field and cleared away most of the difficulties usually described when attaining access to activities in, for example, the health care system (Hammersley & Atkinson, 1995). During preparations, the chief physician and the nurse in charge contributed to the study by providing important information about the patient school. They also contributed in a more practical way before the study and were in some sense part of it when acting as lecturer and conversational leader in the patient school.

### *The structure of the patient school*

The patient school started as a project in the beginning of the 1990s. Since then, there have been continuous changes in order to develop the activity. At the time of my study, a new school, including about ten participants, was set up twice each half year. Each school continued for about five or six weeks. During this period, the class met on five plus two occasions. The first five “ordinary” meetings consisted of a lecture and a time for group conversation, while the two “supplementary” meetings consisted of lectures only (see Figure 1). Each of the five ordinary meetings lasted, according to schedule, about two hours, and the two supplementary meetings about one hour each. Participants from the other class from the same “term” were invited to the two supplementary lectures. Thus, those participating in the first school each term had to wait a couple of months for the supplementary lectures. One evening during the period of each patient school, a meeting for persons close to the participants was arranged. Each participant had the opportunity of inviting to this meeting someone with whom he or she had a close relationship. It should also be someone that the participant wanted to receive information about the illness. This meeting, to which the participants themselves were not invited, was led by the nurse and the physiotherapist.

Since the patient school only takes place at particular times, on specific days and during limited periods, it is impossible to speak about this school as a certain place, such as a building or a room. Instead, the patient school seems to exist only on those occasions and at the place where a defined group of people happen to be, according to schedule or other kinds of instructions. From the participants’ perspective, the time in the waiting room could count as part of school as well. From the

second meeting (see Figure 1), when they were able to recognise each other, the group gathered around one of the tables in the waiting room as they arrived. This meant that at least some of them had about ten or fifteen minutes together, a time usually filled with conversations about the illness and sharing of experiences. The scheduled activities took place outside the clinic, in a conference room in a part of the hospital to which patients usually do not have access.

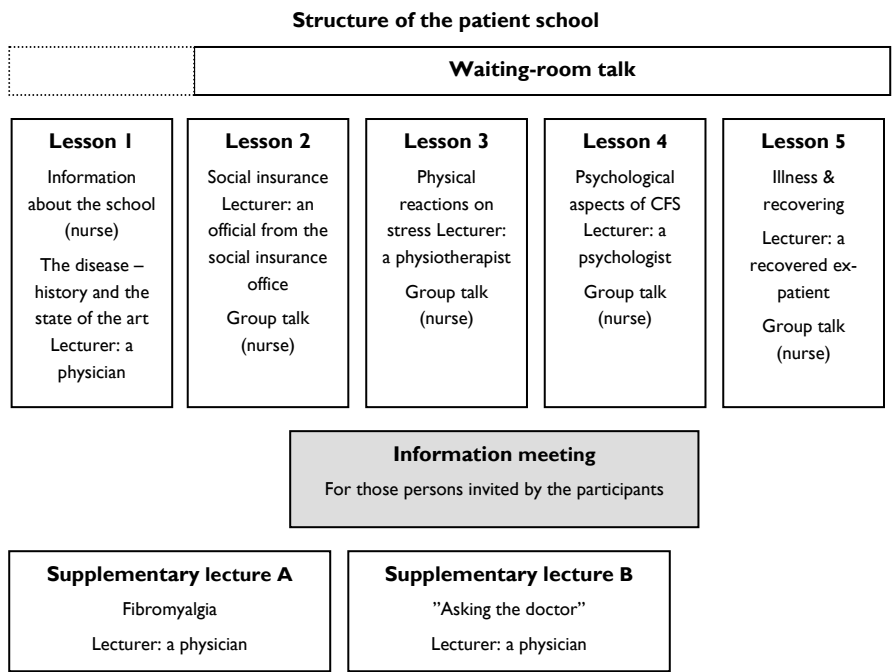


Figure 1. The figure shows the structure of the patient school consisting of a series of five lectures followed by a group conversation. The part marked with grey shows a meeting that is part of the school but does not include the participants. The two supplementary lectures were usually held in a lecture room and were not, unlike the five first lessons, followed by a group conversation.

Participants as well as professionals usually spoke of the group as the patient school. To speak about “classes” became relevant only on those occasions when participants from another class temporarily joined the group (for instance because they had missed this particularly lesson in their “own” class) or at the supplementary lectures when participants from two different classes were routinely invited. This means that in my text it is more correct most of the time to describe the two studied

groups as different patient schools rather than as two different classes in the school. However, both of these definitions occur.

### *Collecting data*

The selection of the classes or groups of patients to be included in the study was dictated by practical circumstances. That is, my study was scheduled according to when it was possible for me to participate, provided the clinic as well as the local ethical committee had approved the study. That the two studied patient schools are separated by one year therefore depends on practical and personal circumstances rather than on strategic choices. Which individuals were included in the study depended on which persons were in turn to be invited to the patient school, and on who accepted this invitation. Thus, participation in the study is governed by organisational procedures and by the participants' own choices. It is therefore impossible to comment on to what degree the studied patient schools are representative of all "classes," or even if they are typical of this particular activity. Rather, they are case studies in which the "case" is not an individual patient but a group of sufferers who together form a class in the patient school (cf. Mishler, 1999).

Data from the patient school were collected in two main stages separated by one year. Methodologically, the study is based on an ethnographical approach and consists of several different kinds of data, such as observational data, fieldnotes, texts about the school, informal interviews and audiotaped interactions that were transcribed verbatim. The study includes lessons one to five in both studied patient schools, the two supplementary lectures in one of the schools, one information meeting for people invited by participants. It also includes a couple of occasional school meetings in some other "classes" (see Figure 1). I usually arrived about half an hour before the start of the lesson, which often made me one of the first. This arrangement gave me the possibility to observe the group gathering and to hear what they talked about when no professionals were present. It also made it possible for me to talk to individual participants.

Ethnographical studies usually involve a long-term contact with a group of people. The patient school study was confined to relatively few hours due to the school structure; each series of meetings took place for only a couple of weeks, spread out over between five and seven meetings. Nevertheless, I have chosen to talk about an ethnographical approach. I base this choice on Hammersley and Atkinson (1995),

according to whom ethnography is mostly a set of methods to participate in people's everyday lives either openly or covertly. The "everyday life" I chose to study was only part of people's lives for a short time. In that way my study concerns what could be seen as the "special" rather than the ordinary ways of life. The way it was organised, the patient school constituted just a small slice of the participants' lives during the days and weeks when the school went on. This small slice of life is what the patient school study focused on. Agar (1980), who usually describes ethnographic work as long periods of fieldwork, emphasises that the time needed depends on what kind of setting researchers intend to study and on the purpose. If the study intends to capture something rather specific concerning a separate group, the time can be reduced a great deal. Similarly, doing research in a field to which contacts already are established might reduce the time needed for the study. It was my intention to study the school from the participants' point of view, rather than to study it as part of the organisation of this particular clinic and the clinical work with patients. Therefore, limiting the study to comprise only two patient schools or classes in the patient school seemed to be justified.

Limitations in time as well as space (the waiting room and the "class-room") made it reasonable to tape most of the activity. This means that the study also consists of the kind of data that conversational analysts usually call "naturally occurring" conversations (Duranti, 1997). I used double microphones placed on the oval conference table (see Figure 2).

Just as in many school situations, the patient school was primarily an activity where the participants were sitting down, listening, making notes, asking questions and so on. They usually returned to the same place at the table each time, but since not everyone turned up at every session, the positions around the table could change slightly. I made a practice of starting each meeting in the school, by doing a quick sketch of the room and of how the participants were seated (like the one in Figure 2). This gave me an image of the whole situation and helped me to remember things like which participants were present and which were missing, and what was happening in the room at different times. Knowing who was seated where at each single meeting also facilitated the work of transcribing the interactions, since I could sometimes identify a speaker from the direction of the voice.

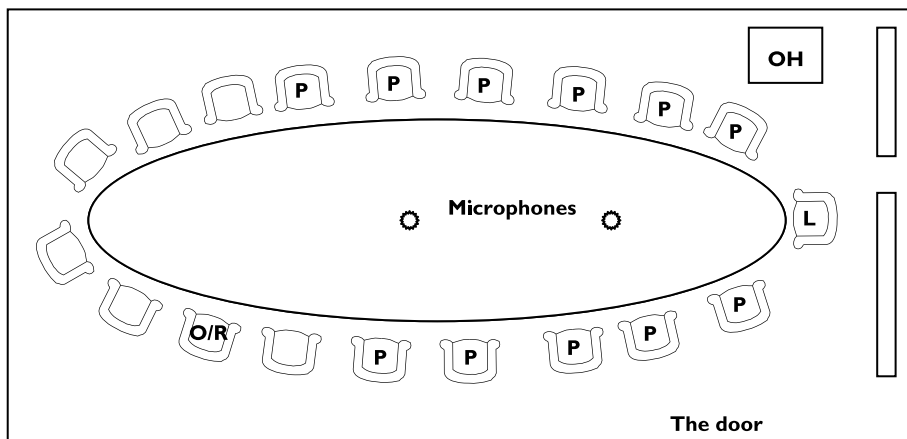


Figure 2 Sketch of the “classroom” where the five first lessons were held and how the participants (P) usually were seated, the lecturer’s/nurse’s (L) place at the table and my own as observer/researcher (O/R).

Thanks to the tape recorder, I could concentrate on the situation I was observing and curtail the fieldnotes of the verbal interaction to some keywords in order to facilitate the transcribing. I also took short notes on who was speaking. This was not always easy when several persons were speaking at the same time and when the conversation became animated. To the extent that I could follow what happened in the room, I made notes on such things that would not (at least not sufficiently) be captured by the tape recorder. I made notes, for instance, of things like the scratching sound when a number of participants took notes on what the lecturer was writing on the flipchart, when participants answered a question from the lecturer by raising their hands, or when they gestured for permission to speak. Using a coding system (cf. Richardson, 1998), I separated notes about the observed situation, my interpretations of the school, ideas for analysis and methodological or technical problems (like what I had to remember for the next time). However, my own place at the table made it difficult to see the participants sitting on the same side of the table without leaning forward. This of course restricted the possibility to follow the non-verbal communication in a satisfactory way. This choice of place at the table had to do with the role as a *participant-observer* (Atkinson & Hammersley, 1994).

*The participant-observer*

Like what Duranti (1997) describes for many ethnographical studies, my own degree of participation, that is to what extent I was involved in the ongoing activity, shifted between different situations in the patient school. In the waiting room, for instance, I was part of the conversation even though I participated in a limited way. In the classroom, during lectures as well as group conversations, I was more obviously the silent observer. During the coffee break, I again shifted my role to that of a person who was part of the activity. However, even when my role was the observer's, I would be sitting together with the participants, on their side of the table, so to speak. Deliberately, I chose a chair down the table, far away from the door, and if not all of the participants had arrived, I left the chair next to me empty. I did so since I was careful not to make any belated participant feel forced to take a seat to the left of my own (see Figure 2). Most of the time, this chair did not remain vacant. My reason for choosing a place at the side of the table instead of right down at the end, which would have given me a better view of the situation, was a wish not to become too "visible" or too "deviant" from the participating men and women.

In addition to the degree of participation, the degree of openness is relevant to discuss in an ethnographic study. Even if I, as I have just described, tried not to interfere too much, my role as an observer and researcher was evident to all in the room. The microphones on the table as well as the tape recorder I was running always reminded the others of my specific role. Nevertheless, I was in some respects regarded as less different than I had expected. Because of the school situation, most of the participants, like me, had pens and paper on the table in front of them. Occasionally they made notes about what was discussed. On one occasion, a female participant asked her neighbour at table about some notes from a meeting she had missed. Her neighbour had only very brief notes from that time but made a gesture towards me, saying something like "ask her, she's always writing." When the question was posed to me, I had to explain that my notes were more about who was speaking and what happened in the room than what the lecturer was saying. Without any sign of being surprised, the two women said, "Oh yes, of course."

Even if my role as an observer was well known to everyone (though sometimes forgotten in some respects), I was more restrictive about my own background as a health care professional. In the information letter

as well as when I presented myself and my study before starting the tape recorder at the first lesson in each school, I chose to emphasise my role as a researcher. My reason was that I did not want to risk that the participants would see me as connected to the health care organisation or as a professional nurse. As much as possible, I wanted to avoid questions about medical issues, something that could make it more difficult for me to act as a curious researcher. This could otherwise have given me a more ambiguous role. At the same time, I was aware of the fact that a professional background could inspire confidence and legitimacy for taking part in conversations about personal suffering. However, despite this, I chose to attract less attention to my medical background, although I did not conceal it.

### *The participants*

Who then were the participants? What they had in common was their suffering from chronic fatigue. As for the rest, the groups were rather heterogenous (see Table 1). The youngest in each class were in their 30s, and the oldest were between 55 and 60 years of age. Most had been diagnosed as suffering from CFS; some of them, though, had one or several additional diagnoses such as burn-out, fibromyalgia and depression. Some of the participants did not fulfil enough criteria to receive the diagnosis CFS, but had been diagnosed as suffering from idiopathic chronic fatigue.

One kind of information that is usually discussed in summaries like this one is for how long people have been sick. This, however, appeared to be a difficult “variable” for the participants in the patient school since most of them found it difficult to answer this kind of question. It was also possible for them to provide different answers, depending on whether they were answering the question of how long they had been on sick leave, or if the question involved how long they had been feeling ill. Other variations included their identification of early signs of illness or of when they first started to perceive their fatigue as illness. The span between these different kinds of answers could sometimes be a matter of several years. What is clear, however, is that those who defined the onset of their illness to be less than a year before the patient school started described themselves as newly ill. Several of the participants, on the other hand, described how they had been ill for several years, some of them for ten years or more.

Table 1. The participants in the patient school at the start of the study.

	Class A	Class C	Total
Number of participants	7 <sup>a</sup>	11	18
Number of men	2	2	4
Number of women	5	9	14
Percentage of men/women	29/71	18/82	22/88
Estimated <sup>b</sup> average age	41	38	39.5
Diagnosis CFS <sup>c</sup>	5	8	13
Unexplained chronic fatigue excluding CFS	2 <sup>d</sup>	3	3
Sick leave <sup>e</sup> 100 %	4	9	13
Part time on sick leave	1	1	2
Working 100 %	2	1	3

<sup>a</sup>At start, they were eight but one participant decided not to continue the school after the first lesson. <sup>b</sup>Usually the participants told the group about their age when giving their presentation in the school or told me when I asked them in the interviews. In a few cases, when such information is lacking, I have estimated the age from what these persons have been telling about themselves. <sup>c</sup>In some cases the participants presented, in addition to CFS, at least one more diagnosis relevant for the patient school such as fibromyalgia, burn-out or depression. <sup>d</sup>One participant was uncertain whether the diagnosis of CFS was confirmed. <sup>e</sup>In the presentation, I have not separated those different types of benefits that are part of the Swedish social insurance. This means that "sick leave 100 %" could also stand for the same level of temporary or permanent disability pension.

As I mentioned earlier, it is impossible to say anything about to what degree these persons are representative or even typical of participants in the patient school as a whole or for the larger group of people suffering from chronic fatigue syndrome. Since each of the studied patient schools consists of a relatively small number of individuals, it becomes difficult to make comparisons like the distribution according to gender. What seems to be obvious, though, is that the number of women in my material was considerably higher than that of men. This is consistent with other social science studies (cf. Cooper, 1997; Ware, 1999).

### *Transcription and analysis*

To study any kind of social situation completely is of course impossible. There will always be aspects and perspectives that one has to ignore to make others more visible (Duranti, 1997). Defining concepts like *setting* and *case* as Hammersly and Atkinson (1995) suggest, might help to make the focus of research more clear.

A setting is a named context in which phenomena occur that might be studied from any number of angles; a case is those phenomena seen from one particular angle. (Hammersley & Atkinson, 1995, p. 41)

By these definitions, the patient school as a social event might constitute a “setting,” while for instance the use of different frames of references, patterns of the participants’ narratives about their problems, or the forms for sharing experiences, become a “case.” That is, a special angle from which different kinds of forms for meaning-making as a phenomenon can be viewed. One setting can thus consist of many different cases, and one kind of case can be collected from many different contexts. The meaning of “a case” here is consequently another than that referring to the number of participants or classes in the study. What becomes a case in the meaning used here is instead an empirical question. In the anthology *What is a case?* (Ragin & Becker, 1992), Charles Ragin expresses a similar opinion about what is a case and how cases are created.

The various kinds of data from the study of the patient school allowed both an ethnographic analysis of the school and a microanalysis of the interaction in the school. This data included observations, fieldnotes, tape-recorded spontaneous interactions, texts about the school, short incidental interviews with the participants and different contacts with the professionals before and during the course of the study. The latter in turn can be separated into two analyses, one of the interaction between participants and the professionals/lecturers and one of the sharing of experiences among the participants. The first has, however, important differences as well as some similarities with analyses of medical encounters and the meeting between the voice of medicine and the voice of life world as described by Elliot Mishler (1984). However, by its structure it also resembles analysis of educational situations (cf. Mehan, 1979). This analysis focuses on the encounters between different types of knowledge (cf. Borkman, 1990) as a way to make sense of illness and suffering. The second analysis of interaction in school bears a resemblance, in some respects, to studies of groups of people sharing some kind of suffering, like studies of self-help groups and support groups (Cain, 1991; Karp, 1992). The phenomenon that is analysed is the sharing of experiences. Central in this analysis for understanding this meaning-making activity are narratives (Labov, 1972; Labov & Waletzky, 1967), storytelling (Ochs et al., 1992; Polanyi, 1985; Sacks, 1995) and co-narration (Blum-Kulka, 1997; Mattingly, 1998; Norrick, 1997; Ochs et al., 1989).

Even if part of the analysis is carried out when data is collected, written down as fieldnotes, the greater part of the work remains to be

done after the observations. In my case, transcribing the tape-recorded interactions, reading the texts produced by this rather time-consuming work, as well as testing different analytical “models,” constituted an essential part of the analysis. The work of transforming the recorded lessons from the patient school into a text became my first attempt to understand the interaction in the patient school. The transcriptions also made up the necessary part of a microanalysis of interaction in the school that I outlined earlier.

I started to transcribe as soon as possible to facilitate the work of transcribing material consisting of many different speakers. Usually that meant that I transcribed one tape-recorded lesson during the week before the next lesson, and so on. Each form of transcription has implications on how to interpret material and on what kind of analysis will be possible. I allowed myself some experimentation time but soon arrived at the conclusion that my visual impression of the interaction was important for the analysis. By this, I mean that a narrow transcription with a great many details, like the kind used in conversational analysis (CA) on my kind of material, which sometimes consisted of as many as twelve persons, produced a confusing number of line shifts. The fragmentation produced by such a wealth of details made it difficult to perceive things like a single person’s relatively connected speech, which was otherwise possible to discern by listening, since a number of persons simultaneously may have contributed supporting back-channeling. I therefore chose a model in which more or less overlapping talk that I interpreted to be so-called back-channel signals (Gumperz, 1982) is represented within the turn of the main speaker (cf. Linell, 1994).

This model of transcription helped to bring out larger features and moves in the interaction, like narratives and the sharing of experiences. It also made it easier to discern episodes when the participants verbally contributed to the lectures with questions and examples. In conformity with my purpose of studying how people suffering from CFS make sense of their illness, the parts of the interaction that were focused on are when the participants either verbally take part by interacting with the lecturer (or nurse) or interact among themselves.

However, the transcriptions became important for the ethnographic analysis as well, by the way the social organisation of the patient school stands out both in the written texts and during the work of transcribing. For the ethnographical description of the school from the perspective of the participants, though, I made use of all the kinds of data collected –

text as well as context, as Tony Hak (1999) puts it. Accordingly, I used data as varying as written information about the school, which was sent to participants before the start, my own fieldnotes from the observational study as well as the transcriptions from the school situation. With the fieldnotes were included descriptions of the school as well as my own reflections of the situation in school from the time of the observations. I also included things that the participants told each other or me in the waiting room or, occasionally, on the way from school. I gained part of my understanding of the patient school and its meaning for the individual participant from the interview study to which I now will turn.

### The interview study

The interview study was partly conducted parallel with the study of the patient school, since the series of interviews with former participants of the first patient school studied had already begun when the second patient school started. This intensified my impression that the two separate studies, despite some differences, were closely connected. In accordance with the way Elliot Mishler (1986; 1995; 1999) describes interviews as co-produced by interviewee and interviewer, data from interviews could be analysed as interactions. Such a view, which I share, means that data from the interview study also becomes part of the way illness and suffering is presented and made sense of in social interaction.

### *Planning and design of the study*

Quite soon, it became clear to me that personal interviews with the participants in the patient school would make up a body of material that could increase understanding for how people make sense of contested illness in many ways. This would be the result of giving each person more time to tell his or her story. As mentioned before, interviews are a common way to collect data about people's experiences of chronic illness. Researchers' ways of getting in contact with their interviewees can, however, differ greatly. Some take advantage of contacts the health care system has with people suffering from a certain illness or diagnosis. For instance, those individuals Norma Ware (1992; 1993; 1999) interviewed for some years are part of a larger group of patients with CFS included in a medical study about CFS. Other social scientists have tried to find their interviewees without any help from the health care system. One reason for this is to reach those who have not sought help

within the traditional health care system. Another reason is to create an interview situation in which it becomes easier to criticise medicine, doctors and the like, something that could be difficult if the study seems to be part of the health care organisation or at least closely allied with it. Lesley Cooper (1997) found, for instance, the respondents for her interview study about CFS from the list of members of a self-help organisation. In a study about suffering from depression, David Karp (1996) chose to turn to people he already knew to have this illness, and in addition to advertise for sufferers.

The way the researcher gets in contact with interviewees and whether each person is interviewed on one occasion or several times during a longer period of time has of course implications for how these interviews will turn out, as well as for the relation between the interviewer and interviewee. My choice of a series of interviews with persons I had already met in the patient school meant that the interviewees in my study knew about me and my project from the very start. Our earlier contact also implied that we shared a certain experience, namely that of participating (though under different conditions) in the same patient school.

### *Selection*

Who took part in the interview study depended primarily on who accepted the offer to participate in the patient school in the first place. At the end of both patient schools, I asked all participants about a possible interview about half a year later. All participants accepted. From the school first studied, all seven former participants were interviewed on two or three different occasions – six months after finishing school, after another six to ten months and (when a third interview was conducted) about six to fourteen months after the second interview. Due to limited time resources, I had to restrict the number of interviews as well as the number of interviewees. The restriction meant that I met about six of the former 11 participants for two interviews except for one person, whom I met for one extended interview. Since the patient school was organised by a specialist clinic its catchment area was large and could occasionally extend beyond the boundary of the county. As a consequence, the interviewees were spread over a large geographical area. Because of this, I also took practical considerations of factors such as where people lived when I had to restrict the number of interviewees from the second school. In the end, I had to choose those

living fairly near or at least not very far away from each other. Despite this, people from several municipalities were included. I chose to include both of the men in the study in order to attain the distribution according to gender usually described in studies about CFS. Except for that, my purpose was to include persons of different ages and those who had been sick for a long time as well as those who had been sick for a short time, i.e. between six months and one year. I met these six interviewees from the second school for a first interview (for one person the only interview) about five to eight months after the patient school and for a second interview about three months after that (four persons). I met the sixth person for a second interview about one year after the first. The reasons for certain differences in time between interviews were in all cases practical or in response to an explicit wish from the interviewee. Beside these thirteen interviewees already presented, one person from the class invited to the same supplementary lectures as the participants from one of “my” classes was included in the interview study and was interviewed on three occasions. The whole study thus includes 34 interviews.

### *Collecting data*

The interview study followed as a consequence of the study of the patient school and the contacts with the sufferers there. However, according to the choices I have just described, the interview study was not an obvious part of the study of the school since not all those who participated in the school took part in the interview study. Neither did the interviews primarily concern the patient school and the experiences from participating there. Since one person from another class also consented to join the interview study, as just described, it was possible to participate in just one of the two studies. The number of interviews, neither with each person nor in total, was decided from the beginning. Instead, I asked at the end of the first interview about the possibility to contact them later for another interview. In the same way, I got the opportunity to meet a number of persons for a third interview.

To facilitate for the interviewees, I let them choose the place for the interview by offering to either meet them at their homes or at a public place of their choice. I suggested places like cafés, a park (in summer-time) or a library. Four interviewees then chose a public place. At the time for the second interview, the situation had changed for two of the interviewees so that they now were working part-time and full-time

respectively. One chose then to meet me at her workplace at the end of the day. The third interview for the other person was arranged as a telephone interview for practical reasons. In Table 2 below the choices of place for the interviews are shown.

Table 2. Type of place for the interviews.

	Interview			Total
	First	Second	Third	
In the interviewee's home	9	9	4	22
Public places <sup>a</sup> (cafés etc.)	5	4	1	10
At the interviewee's workplace	0	0	1	1
Telephone	0	0	1	1
Total	14	13	7	34

<sup>a</sup>On one occasion, the “public place” was a seminar room at the university where the interviewee was a student at that time, although not at this department.

Usually the same kind of place was chosen for the following interviews, but in some cases there were changes for different reasons. In one case, the first interview was conducted for practical reasons at a public place while the second was carried out at the interviewee’s home. Except for this one occasion, changes only happened in those cases that I described earlier, when the interviewee had begun to work and chose his/her workplace for the interview.

I felt that letting the interviewee choose the place for the interview was important because the interviews should be done on the interviewees’ terms to as great an extent as possible (Mishler, 1999). The place that was chosen came to some extent to reflect the circumstances under which the individual interviewee was living at that particular time and gave me a glimpse into his/her everyday life. It happened that we agreed on a certain place to meet and then together took a bus or car to the place for the interview, usually the interviewee’s home. Sometimes we had lunch or coffee together before or during the interview. It also happened that I accompanied the interviewee to the nursery to pick up their children or that I met their children with or without playmates in the home of the interviewee. Occasionally, I was introduced to husbands or partners. The amount of time that I met each interviewee was thus in most cases significantly longer than the time for the tape-recorded interview, which on average lasted just under an hour. However, there were differences between different interviewees as well as between

different interviews with the same person. The longest interview lasted for one and a half hours while the shortest lasted for half an hour.

The time before and after the tape-recorded interview bore similarities to an everyday chat about all sorts of things, both connected to their illness and other things, like studies and children, or about nothing in particular. In some cases, these chats, which were not recorded, lasted for just a couple of minutes, at other times the small talk constituted half of the time together with the interviewee. When the tape recorder was turned on, the conversation became less mundane and more focused on the experiences of illness, which was in accordance with the aim of the interviews. I had no pre-formulated questions, but I did have an idea of what kind of issues I wanted the interview to cover. Thus the tape-recorded parts of the interviews also had the character of *conversational interviews* (Herman, 1999) because of the manner in which I encouraged the interviewees to tell their stories rather than to give their answers to well-formulated questions in a reporting style (Mishler, 1986; Riessman, 2001). In this way, the interviews came to deal with the interviewee's illness and what had happened to them since we met at the patient school, or since the last interview. Their contacts with the health care services and the social insurance office were covered in the interviews, as well as how people around them reacted to their illness. We also talked about how they managed difficult situations like when someone questioned their illness, their right to reject certain activities like driving, or their right to be on sick leave. We talked, too, about occasions when they for different reasons did more than they really had the strength to do and thereby acted opposite to the image of themselves and their illness that they had tried to explain to other people. Despite this rather open approach to the interviews, I had a clear idea about how to start the interviews. At the beginning of the first interview with each person, I referred to earlier meetings such as in the patient school, and I encouraged the interviewees to tell their story using the patient school as some kind of starting point. See Example 1.

*Example 1 Introductory question in one of the first interviews*

- PB: .hh well, I thought that we could start there, when we met last. When we met, so to speak, at the patient school. (Karen: mm) Because there I could- there I could be with you and listen to what you told each other. (Karen: mm) But of course that meant that I don't know much about each one of you. (Karen: mm) So what I know about you and your problems and how or why you – why you were there at the patient school. Would you tell me about that?
- Karen: Yes, how it happened that - ((short pause))

## *Chapter Four*

hhh Well, yes, it's what was offered, somehow.  
I had of course been sick for two years by that time ((continues to talk))

This first “question,” or invitation to tell a person's story, in most cases led to an extended and sometimes very long story. The question was shown to be “open,” in the meaning that different interviewees chose completely different starting points for their stories. They could start at almost any point from childhood or early adulthood to the specific meeting with the physician leading to the referral to the clinic that organised the patient school.

All interviews were tape-recorded. In addition, I made notes about the situation after each interview. One of the things I noted was if something had occurred during the interview that seemed to have disturbed either the interviewee or me as an interviewer. No matter whether the interviews were carried out at the interviewee's home or in a public place, things happened that, for instance, made the sound recordings difficult, interrupted the interview or made one of us, or both, lose concentration for a moment. Such “disturbing” things could be almost anything from a noise in the environment such as the use of a lawnmower nearby, or dishes clattering in the café where we were sitting, to “disturbances” when other people, such as a child, came into the interview room. In the fieldnotes, I also wrote down things that I noticed during the interview but which, for different reasons, were not touched upon in the interview, for example when someone looked especially tired. I also wrote down things that I was told before or after the tape recorder was turned off.

### *The interviewees*

All fourteen interviewees were, as I have already described, former participants in the patient school. Thirteen of those in the classes were included in my observational study, as was one from another class in the same patient school, whom I met at the supplementary lecture for both “my” class and the class this person attended. When I introduced the study as well as myself on that occasion to the participants from the class unknown to me, I asked for permission to participate as an observer and invited them to the interview study. One out of approximately five persons then volunteered and was thus included as the fourteenth interviewee. The interviews with this person were excluded, however, from the analysis of sharing of experiences in the patient school. Of the thirteen former participants from the classes I followed

through the patient school, seven were from the first class studied and six from the second class. The average age of the interviewees at the beginning of the study, that is when we first met at the patient school, was 41.5 years in three distinct groups. Those in the largest group (seven persons) were between 30 and 39 years of age. The second largest group (five persons) were all about 45 years old and two persons were older than 55. See Table 3.

Table 3. Some figures concerning the interviewees at the start of the study, i.e. when they began the patient school.

	Number of persons
Number of men	4
Number of women	10
Percentage of men/women	29/71
Average age at the beginning of the study	41.5
CFS	12
Idiopathic chronic fatigue	2
Sickness benefit, temporary or permanent disability pension 100 %	10
Sickness benefit or permanent disability pension < 100 %	2
Full time work	2

Since the time between the first and last interview with an individual interviewee in many cases was relatively long, it sometimes happened that there were changes in the degree and form of sickness benefit they achieved from the national social insurance system. For instance, compared with the situation at the time of the first interview, there was one person less on full-time sick leave at the last interview. In Table 4 below, changes in degree and form of sickness benefits reported by the interviewee are shown.

Table 4. Changes in degree and form of sickness benefits and/or temporary or permanent disability pension received by the interviewees from the national social insurance system, between what was reported in the first interview and in the last interview (the second or the third interview).

Changes in degree and form of sickness benefits	Number of persons
From sickness benefit to temporary or permanent disability pension	3
From higher to lower degree of sickness benefits	3
Unchanged degree and form of sickness benefits, temporary or permanent disability pension	8

*Transcription and analysis*

The tape-recorded interviews were transcribed verbatim. Just as I did with the data from the patient school, I tested a couple of different models for transcribing this material. I started with the same model that I finally had decided to use for the school material. This was a model of turn-taking in which minimal supportive utterances like “mm” or “yes” were put in brackets within the turn of the present speaker. Since I encouraged the interviewees to narrate their experiences, this model became cumbersome (and almost impossible to analyse) when the interviewee’s turns tended to be very long. There were sometimes several pages of text. Instead I experimented with a model developed by the American sociolinguist Jim Gee (1986; 1991) for analysing narratives and structures for narrativising from a linguistic perspective. This model is based on rhythmic markers in spoken language and on how the speaker connects certain parts of his/her narration and defines differences with others. As a result, the transcribed text resembles a poem with relatively short lines joined into groups of lines or stanzas, which together constitute a story or an account about something. Interviews transcribed according to the turn-taking model were retranscribed into this somewhat simplified version of Gee’s model.

Despite the simplifications, the Gee model made it easier to disclose narratives and narrative structures like abstracts and evaluating clauses within the interviewees’ speech (Labov, 1972; Labov & Waletzky, 1967; Mishler, 1999; Riessman, 1993). For instance, it became obvious how different periods of time were opposed to each other in different stanzas and how a narrative thus could oscillate between now and then but also between different places and situations.

As Mishler (1999) points out, the Gee model is well suited for analyses of clearly defined narratives, as in, for example, a Labovian structure (Labov & Waletzky, 1967) as well as for those parts of less-structured narratives that often occur in interviews. I saw this as a great advantage. In my analysis of the interviews, I have not confined the analysis to the narrow view of narratives, i.e. being stories in the strict Labovian sense including abstract, orientation, complicating action, evaluation and in some cases a coda. Narratives about illness and suffering could sometimes be such well-defined stories, but most of the time the experiences the interviewees were telling about were of a different kind. Because of this I chose to analyse the narratives and the narrating in a broader sense and to regard the interviews as a whole as

some kind of *life stories* (Linde, 1993). That is, I regarded them as stories that express something about the narrator and his/her view of things that happen or have happened earlier in their lives. This means that different narrative genres (Riessman, 1993) are included in the analysis.

Considered as life stories, illness narratives are not just a way for researchers to analyse personal experiences. Arthur Frank (1995) writes about storytelling as a way to give voice to the body and to illness experience. In accordance with this, narrative analysis also becomes a way of lending voices to people whose own voices have sometimes been weakened by illness itself, or by the fact that the credibility of their suffering has been questioned. This involves, however, a series of ethical questions and dilemmas, especially when a researcher chooses certain narratives and thus lends voices to certain individuals in presentations of the material. I end this chapter by presenting important ethical considerations in this work and a discussion about ethical dilemmas connected to research using a narrative approach like the one I have used.

## Ethical considerations

According to the rules for studies within the health care sector, the local committee for research ethics at the medical faculty where I was working on my project gave permission for the study. Following these rules, all prospective participants received an information letter about the study when they were offered a chance to participate in the patient school. The information letter was sent by the nurse who was in charge of the invitations for the school. Those who decided to accept the invitation contacted the same nurse. At this contact, the nurse, who is accustomed to ethical questions concerning research from her work at the clinic, made sure that each person who accepted the offer of attending the patient school was also aware of the observational study and consented to being part of this. All of those who decided to participate in the patient school also consented to being part of the study. Of those who decided not to attend the patient school, no one gave the study as a reason for their decision. At the beginning of the first lesson, I introduced my interests and myself before turning on the tape recorder. I had contacted the lecturers in advance to inform them of the study and to ask permission to attend their lecture and to tape-record it.

Even though my purpose was to study the patient school from the participants' perspective, the lecturers were also asked about their "participating" in the study. This was because the interaction between them and the "patients" presumably was important to the understanding of how the participants might use the school to make sense of illness. This was also made clear in the application to the local committee for research ethics.

The interview study was based on the same ethical principles, i.e. those compiled by *Humanistisk-Samhällsvetenskapliga Forskningsrådet* (HSFR) (the Swedish Council for Research in the Humanities and Social Sciences). In accordance with these, all participants were asked individually whether they would like to take part in an interview some months later. All of them agreed. A couple of weeks in advance, I sent a letter about the aim of the interview to each intended interviewee. In the letter, I wrote that I would phone them within about a week, to agree upon the time for the interview. By doing it this way, each of the intended interviewees was given some time to think about the conditions for an interview. My purpose here was to facilitate for those who did not want take part. When I later phoned each of them, I once more asked if they consented to being interviewed, and gave them another opportunity to refuse. All accepted, however, and signed an agreement to this effect when we met later for the interview. At the end of the interview, I asked for permission to contact them for another interview later, which all accepted. Except for the letter, I followed the same procedure before the second interview as I have described for the first, and in the case of a third interview, for that one too. All consented to being interviewed all the times they were asked.

To protect the integrity of the individual participant as well as the interviewee, all names have been changed. This common way to fulfil the responsibility of guaranteeing confidentiality was part of my agreement with the interviewees. To increase the protection of the individual, the same person has usually been given different names in different analyses. The reason for this is twofold. First, it has to do with the fact that studies of group activities like the patient school provide a somewhat lower degree of anonymity since all participants at a certain meeting may be able to recognise themselves as well as others. Secondly, when personal experiences in the form of narratives from different kinds of material, i.e. from the patient school as well as from the interviews, are brought together as they are here in this thesis, a more detailed

picture of a person is sometimes created. To change names in different analyses minimises the risk of a single person being identified.

Unlike many other kinds of qualitative studies of illness experiences, narrative analyses have a special way bring of bringing to the fore the personal and the unique. This is their strength but also something that “entails extensive ethical obligations” (Frank, 2002, p. 16). Narrative analyses involve the use of more extensive examples. Despite the efforts to depersonalise the material from my study, which I have just described, the analyses are based on the individual participants’ and interviewees’ narratives about themselves and their illness. This has required other forms of ethical considerations than just changing the names. Instead, I have always asked myself what in a particular story is needed to depict what I intend to show in the specific analysis, what in a story seems to be too personal to be used as an example and which of the stories I should present at all. Other considerations are about the way a certain analysis portrays a person. The acts of renaming a person, changing or just dropping identifiable details also mean that I as a researcher modify the narrator’s “voice.” Those who consented to participate in the study presumably did so because they had something to say, something they wanted other people to hear. To be working with data that is so strongly linked to people’s lives means that you always have to ask yourself, “Whose story is it anyway?” as Sue Estroff (1995) has so expressively titled a chapter discussing ethical dilemmas in analyses of illness narratives in terms of authority, voice and responsibility.

Catherine Riessman (2002), who has reflected in a similar way on her own narrative analysis done some years ago, writes about “doing justice.” She calls attention to the fact that interviewees do not just give information *about* themselves in their narratives; “they present dramas involving themselves to an audience” (2002, p. 204). This means that by analysing a narrative the narrator is presented as a certain kind of person, without taking into consideration that the interviewee in the next moment may show a different side of himself or herself. It is certainly so that my interpretation of the narrator and his/her story will not be the same as the individual’s own interpretation of the same situation. Still, my interpretation is the one that dominates in the analysis. In only a few cases have I let the interviewees read and comment on the analysis. My choice not to involve the interviewees more is based on my purpose of studying how people make sense of their illness. Unlike

research focusing on *what* people are telling, this *how* means that what I am looking for is usually impossible for most people to describe and explain, or indeed sometimes even to have a clear conception of.

The audience for which the interviewee is telling his/her story is another aspect of voice, authority and responsibility. Even if I as the interviewer am the person in front of the interviewee, I need not be the only person or kind of person included in the audience. From a performative perspective there is always what Kristina Minister (1991) calls a *ghostly audience* for an oral narrative. In my study this means that GPs, officials from the social insurance agency as well as researchers and other persons the interviewee thinks “ought to know” might all be part of the audience together with me. The question then is what meaning words like authority, voice and responsibility have.

In his text about the ethics of research into stories, Frank (2002) describes how the reciprocal relationship between researcher and storyteller does not always mean the acceptance of the morality of the story as it is told. “The moral impulse of telling any story includes taking the risk that the listener, who may be a researcher, may not offer the recognition that the teller seeks” (ibid., p. 16). However, since I have consented to these ethical considerations, I have to answer the question posed by Sue Estroff regarding whose story it is. I have to say that it is my story about many different persons’ stories. Nevertheless, my intention in analyses and texts has always been to depict the stories I have become part of as an observer, listener and interviewer with respect. This includes respect for all these storytellers and for the suffering several of them have not earlier been able to express in a voice strong enough to be heard.

In the next chapter, the papers included in the thesis will be summarised.

## Summaries of the papers

### *Paper A: Chronicity and the moral quest: Sense-making and self-making in narratives about CFS*

This paper draws on data from the interviews with people suffering from chronic fatigue. The analysis takes as its starting point the moral quest that seems to be connected to long-term illness due to contested illness. This becomes evident in the interviews by the way the interviewees appear to try to account for things like still being on sick leave, that they have not tried to go back to work, and in what way the illness confines them in everyday life. In this paper, I discuss the meaning of presenting oneself as chronically ill from an illness that is medically unexplained. A central point in the analysis is that of how people portray themselves in their narratives as moral persons in relation to their illness. Starting from a close analysis of the stories by two interviewees and the storylines, which come forward in these narratives, I discuss how the narrator seems to relate him/herself to a moral framework for what it is to lead a good life under the circumstances of illness. The analysis of the two personal narratives shows that this could be handled in different ways, either by describing a shift in the moral framework, or by describing the rejection of the common moral framework and living life in accordance with a more restrained moral framework. The two narratives are not homogeneous categories or types of stories but simply two examples of how people make sense of a medically unexplained illness for which no end seems to be apparent. The conclusion is that stories about a contested illness like CFS have both a reconstructing and a constructing meaning. This twofold meaning seems to occur as a result of a narrative reconstruction that includes the future by projecting a future story as well, and through the meaning of illness narrative as a way of presenting oneself as a moral person in the interview.

*Paper B: In dialogue with time: identity and illness in narratives about chronic fatigue*

The second article is also based on data from the interview material. Here two intertwined problems that have to do with the organisation of time in narratives about illness are discussed: the interviewee's attempt to create an interview narrative and the researcher's need to create a temporal order and coherence properly founded in research in the interview material. With a foothold in the literary scholars Morson's and Bernstein's theories about *shadows of time*, the interview narratives about chronic fatigue are analysed according to the way the narrator uses time as a discursive tool when telling about illness and identity – here called temporalizing. Using different forms for temporalizing means that we can negotiate and change the meaning of the relationship between events, and thus both the meaning of the course of events and the narrator him/herself as a character in his/her narration. What is argued in the article is that this possibility makes it important to let the narrator's choice of temporalization become visible in the analysis and to be treated as valuable data in illness narratives.

Although this article primarily discusses a methodological problem for analysing illness narratives, the analysis on which the arguments are built also shows that temporalizing illness might be of special significance in illness narratives about a medically unexplained illness like CFS. Telling other people about one's chronic illness often involves an attempt to understand the origin of the illness. The use of time shadows can be a way to tell about and to explain illness. What has occurred up to the present can be seen as something unavoidable, something that one should have understood a long time ago, or as something that was just one possible result among many different ones. The analysis of the narratives about CFS shows various ways time can be used as a discursive tool to temporalize illness and suffering. This includes temporalities that frequently go outside linear time perceptions by the use of "sideshadowings." Especially when touching on issues like the genesis of illnesses, the various ways of temporalizing illness influence aspects like questions of responsibility and freedom of action. Findings like these indicate the importance of including the interviewees' own temporalizations in the analysis of illness narratives in social science.

*Paper C: Patient school as a way of creating meaning in contested illness: The case of CFS*

This paper draws on the material collected from the observational study of the patient school for people suffering from CFS. The aim of the paper is to show the meaning-making in a situation of contested illness as an interactive and discursive process. In the paper, an ethnographical analysis of the patient school is presented together with an analysis of the interaction between, primarily, participants and lecturers. The ethnographical analysis shows how this school is an amalgam of at least two different kinds of institutional settings, both well known to the participants: the health care organisation and the school setting. Being an activity within health care and at the same time constituting an educational situation means that several different frameworks of interpretation are created, frameworks that the participants as well as the professionals can make use of. For instance, the participants could act as both patients and students. Through the possibility to move between different frameworks, illness could be investigated from various perspectives. This makes it possible for the participating men and women to regard illness from the outside as a social object that they as students want to learn about. It can be regarded from the inside through personal experiences, which are compared to professional knowledge, and finally, by putting the diagnosis in a larger sickness perspective, from which their illness might be seen by others in a broader social context. As a result, a number of different kinds of interpretations are used to create meaning in a situation of illness. Since the patient school most of all is an activity based on talk and narratives, and since CFS is an illness that has to be spoken of in order to exist for others than the sufferer, verbal communication and discursiveness become central in this interactional hybrid form of activity. The conclusion is that participants in the patient school learn to manage their illness discursively at the same time as they, by this discursive activity, investigate various ways to interpret and understand their own experiences of illness.

*Paper D: Sharing experience of contested illness by storytelling*

The fourth paper focuses on sharing the experience of illness among CFS sufferers participating in the studied patient school from the perspective of storytelling and co-narrating. The analysis is based on the observational study of the patient school as well as on the tape-recorded interactions from the observed interactions. Through an analysis of the

interaction among the sufferers, a pattern of mutually shared experiences from the stories and the telling of stories appeared. The analysis shows that this sharing was not restricted to the part of the school presented as “time for sharing” but happens through the whole activity. The participants were sharing experiences in the waiting room before school, during lectures as well as during group-talk.

However, the sharing of experiences appeared to have different forms, partly depending on the school structure and its two main parts, lectures and group-talk. The analysis brings out three different forms of narratives and narrating which seem to constitute the foundation of sharing in the studied patient school: *self-contained personal stories*, *orchestrated chained personal stories*, and *co-narrated collectivized stories*. These three are possible to distinguish by form and content, but also according to the extent that the shared experiences are individual or collective experiences.

In the paper, I also discuss the function of sharing experiences of illness through which three things seem to happen. First, by sharing experiences the participants form joint experiential knowledge, which creates an image of illness and of suffering. Secondly, each participant had the possibility to test this image and to compare his/her own experiences in accordance with the jointly created picture. Thirdly, the sharing of experiences seems to confirm the individual suffering, whether this corresponded to or diverged from the jointly created image of illness. The conclusion is that two parallel transitions seemed to occur: the transformation of personal experience into shared collectivized experiences and the transition when the individual sufferer perceives his/her private suffering through sharing experiences with co-sufferers.

## Conclusions

The aim of this thesis has been to study how people suffering from chronic fatigue make sense of their illness, one that is both medically unexplained and invisible. As I stated at the beginning, the vagueness and indefinable character of chronic fatigue make it an illness that has to be put into words to exist outside the individual sufferer. Because of this, a communicative and interactive perspective was proposed as the most appropriate choice for the study. Making the basic assumption that narratives are important means for making sense of experiences like illness, I have mainly adopted a narrative approach when analysing the interaction in a patient school and illness narratives told in research interviews. Different aspects of long-term illness associated with the contestedness, like uncertainty, time, invisibility, doubt and responsibility for becoming ill, gave rise to the following questions: In what way can participating in a patient school for sufferers help people make sense of their illness? How do people narrate their own experiences of suffering from chronic fatigue and how do they use narratives of others? In what way are matters like time, identity and morality brought up and managed in narratives about a long-term and often doubted illness like chronic fatigue?

### Making sense of chronic fatigue

The analyses from the empirical study show that those who suffer from chronic fatigue make sense of their illness in and through interaction with others. Making sense of illness seems to come about in the joint encounter with the professionals in the patient school as well as in the social interaction with other participants in this school and in the interview situation with me as a researcher. One may say that meaning-making in a contested illness like CFS is about trying to understand one's personal suffering while at the same time making sense of the illness, to others and in interaction with others. The analysis emphasises different ways this can happen in different kinds of social contexts. I will

discuss two principal ways indicated by the thesis; these are narrative reconstruction and sense-making as an interactional process.

*Reconstructing narratives: moral quests and temporalizing illness*

The narrative reconstruction is especially emphasised in the analysis of the interviews but is also, of course, part of the narrativising in other studied contexts. Similar to earlier research about illness narratives, this study points out the significance of narratives and narrativising when people try to make sense of their illness experiences. The narrative reconstruction as a means of explaining and understanding illness and suffering from a biographical perspective and of making illness part of the personal story of life becomes especially imperative in an illness that lacks a generally accepted explanation, and which because of that is conceived of as a less legitimate illness. Two aspects of the narrative reconstruction appear as particularly essential to making sense of a contested illness like chronic fatigue, *the moral quest* and the use of time (*temporalization*).

*The moral quest* describes people's striving to find what the good life is and thereby how to lead one's life. Due to illness, this is something that those suffering from chronic illness have to renegotiate. The moral quests that appear in the interview narratives show changes in the moral frameworks people use to orient themselves in moral space, as the philosopher Charles Taylor (1989) writes. What seem to be important for such a reorientation in moral space are the narrative reconstruction and the anchoring of illness in the personal life story. This means that the *moral quest* is not only related to how people try to understand their own suffering from a life perspective, but also to how they create meaning in their lives with illness by reformulating the moral frameworks for what it is to lead a good life. In that way, the future is included in the narrative reconstruction as well as the past and the present.

Closely linked to the moral quest are those questions about morality and reliability raised by the contestedness of illnesses like CFS. This means that those suffering from such an illness also have to deal with how other people think about their illness from a moral perspective. Making sense of a contested illness like CFS is therefore something that involves not just the ill person. It seems to be equally important to make sense of the illness in front of others by remaining a moral person oneself. By considering the narratives as performances and as strategic

devices in the interaction, this other dimension of the moral quest is brought to the fore in the analysis. As shown in the analysis, these two dimensions of the moral quest go hand-in-hand through the narratives and the narrativising. Thus, the narratives at the same time work as reflective considerations of the person's own life story and as strategic devices to maintain him/herself as a moral person

*Temporalizing illness* is the other aspect of the narrative reconstruction that appears as particularly significant when making sense of an unclear and contested illness like chronic fatigue. From the way time is used in the narratives about illness and suffering – by so-called *shadows of time* (Bernstein, 1994; Morson, 1994) – the narrators deal with questions like responsibility, freedom of liability, blame and guilt. By using different timeshadows, illness can be presented as something unavoidable that one could not have foreseen, or as something one should have recognised and understood a long time ago. It can also, by the use of shadows thrown from the side (sideshadowing), be presented as something that was one possible course of events among many possible stories. One result of this is that by including possible courses of events, people can negotiate and change the meaning of the relationship between events that explain why they became ill. This means that time becomes less something that the narrators try to adapt to, and more of a resource they can use to help them make sense of illness.

Thus, the moral quest as well as the temporalizing concerns biography and the personal life story; both of these aspects are closely linked to issues about identity in chronic illness.

However, the moral quest and the way people temporalize their illness are also important factors for how we as researchers understand sufferers' experience of a contested illness like CFS. By putting one's finger on how people renegotiate in their narratives what is important in life, how they strive to maintain themselves as moral persons and how by temporalizing illness and suffering they deal with questions about responsibility makes the contestedness in chronic fatigue come to the fore. Methodologically, this speaks for an even greater interest in how people narrate their illness and suffering. By illuminating narrative structures and processes, our knowledge about illness experience and about how people deal with their illnesses will increase. Analyses like the one concerning time shadows stress the importance of the narrator's own choice of temporalizing illness to understand how people in and through their narratives about illness and suffering deal with things like

hope, guilt, blame and regret. Accordingly, the risk of disregarding the narrator's way of temporalizing in analysis of illness narratives is emphasised as well. This can be compared to studies about psychotherapists who organise and reformulate their clients' stories through first session notes made during the psychotherapeutic session, and later through the initial assessment which becomes part of the client's records (Ravotas & Berkenkotter, 1998). In both cases, leaving the narrator's own way of telling his/her story out of the analysis means that valuable knowledge about how people experience illness and various kinds of suffering is lost.

### *Sense-making as an interactional process*

The importance of social interaction in people's processes of making sense of chronic fatigue appears to an even greater degree in the analyses from the patient school. It can be seen in the structure of these meetings and from what is described as the *discursive management and sharing of experience*.

In the encounter with the professionals, the ill can examine their own suffering (as well as the diagnosis) in relation to the various explanations the professionals present. This gives them the opportunity to "choose" the kind of explanation that corresponds to the personal experience of illness and the individual life story. At the same time, by being a verbal activity, the testing can lead to a greater ability to manage discursively an illness that must be explained and accounted for in many contexts. Thus, the study of the patient school shows that knowledge about chronic fatigue is created in the meeting between the professional's expert knowledge and the participants' experiential knowledge, and in the movement between different *frames of references* (cf. Borkman, 1990). However, this is not a description of participants passively receiving information given by professionals. The different frameworks of interpretation offer the possibility of taking on different roles. A participant can one minute act as a student questioning what the professionals describe in a general sense, and the next minute ask for advice about personal matters, like pain and how they as individuals should exercise etc. At the same time, the professional does not need to have answers for all the questions. Considering this, the patient school, even if it is organised and run by a medical clinic, contributes by its very structure to some kind of *demedicalisation* of suffering (Jeppsson

Grassman, in press). Here a great deal of the meaning-making is about the ill and their understanding and experience of illness.

Allocating time for sharing among sufferers is part of this demedicalisation. The sharing is constituted of personal stories as well as co-narrated collectivised stories. By sharing personal experiences with others in a similar situation, the participants seem to make sense of their own suffering in a process similar to the sense-making described in self-help groups. By sharing, a joint image of the illness is created to which each person can compare his or her personal experiences and according to which they can judge their own suffering to be similar to or different from the picture created jointly. In this way, a transformation of personal experiences into shared collectivised experiences occurs (cf. Hydén, 1997) at the same time as the individual sufferer perceives his or her private suffering through the social interaction of sharing experiences with others.

### Contested illness a sociological type of chronic illness?

Throughout this thesis, I have called CFS a contested illness. However, according to the arguments I have used for this and from the reviews of the two fields of research – illness experience and illness narratives – a number of other illnesses appear to be contested in a similar way. Comparable descriptions of distrust and doubt as well as similarities in narrative structure in studies concerning CFS and other controversial diagnoses like RSI, TMJ, unexplained chronic pain and fibromyalgia are indications of this. From an experiential perspective, these illnesses seem to constitute a sociological type of chronic illness that could be called contested illness.

To point out contested illness as a particular sociological type of chronic illness would contribute to the study of the contestedness in a helpful way without confining the research to a certain diagnosis, bringing new knowledge about similarities as well as differences in contestedness. Likewise, it could provide motivation for studies of possible changes in the contestedness connected to a certain condition or diagnosis. That is, how and in what respects a contested illness ceases to be contested, or becomes contested to a lesser degree. The difference between the experience of a diagnosis like fibromyalgia and of CFS, commented upon in a recently published study (Åsbring & Närvänen, 2002), indicates that such a transformation occurs. One possible way to

come closer to an understanding of such changes might be by comparative studies between different countries concerning what illnesses are considered to be contested illnesses, and how they are considered to be such. Another approach could be to do comparative studies from the perspectives of the different contested illnesses.

## Future research

From my study of how people make sense of chronic fatigue, a number of new questions about the meaning of chronic illness seem to emerge. I will point out three aspects concerning meaning-making in chronic illness that seem to be important to explore further. This exploration will be important if we wish to increase our understanding of what it means to suffer from chronic illness in general and from contested illness in particular, and of how people make sense of illness.

*Time* in chronic illness is one such important aspect that needs more attention. Usually time in chronic suffering has been discussed from a chronological point of view, when for instance the present is understood by the past. This view of time seems to be taken for granted in many studies of chronic illness without asking what time means for those suffering. My study has shown that time can be used in different ways and that illness narratives also include what could have happened and what might happen. This opens up the view of time in illness and gives rise to new questions concerning time and illness. What might happen, for instance, to our understanding of illness as a biographical disruption? Could people's temporalization of illness be a useful analytic approach to illuminate what Simon Williams (2000) has described as a nuanced use of Bury's concept? However, to learn more about the experience of time in chronic illness and people's temporalization of illness, we have to take their narratives about suffering into account and allow the narrators' own way of using time to appear in analysis.

*Morality* is another aspect of illness and suffering that needs further research. For contested illnesses, morality seems to be of particular importance due to the obvious risk of sufferers being called into question. However, chronic illness in general might be connected to questions about morality as well. At a time and in a part of the world where health is taken for granted most of the time, and where illness when it nevertheless strikes is presumed to be curable by medicine, incurable illness easily becomes a moral question linked to lifestyle and

personality. The fact that biopsychosocial explanations for medically poorly explained illnesses seem to be gaining ground might also turn the experience of illness into a moral issue. All of this makes morality an important aspect of chronic illness, one that will not be explained by concepts like stigma alone. Research addressing the relation between morality and stigma would be welcomed.

The *pedagogisation* of illness and suffering is the third issue I will point out for future research. Plausible explanations for the growth of new forms of care like patient schools and educational programs include shrinking resources for caring for the chronically ill, combined with the biopsychosocial explanation model. Another possible explanation is a more commonly expressed opinion within medicine that those who are ill must be involved in the management of their own illness. This development of alternative forms of care for the chronically ill, one that seems to be increasing in health care, is important to follow in social scientific research. In what way does this development concern contested illnesses? Is it primarily an alternative for illnesses that are poorly explained medically and thus a way for medicine to handle the problem? What will a continuous pedagogisation of health care mean for sufferers as well as for health care professionals? How do these new forms of care work for the sufferers, and in what way will collective forms of caring influence the relation between medical experts and sufferers? Will activities like patient schools be complementary to self-help groups, perhaps even replace the need of self-help groups, or be something that encourages sufferers to establish self-help groups? Will further pedagogisation, for instance by patient schools, bring about a medicalisation of suffering like fatigue and pain, or as I suggested above, a demedicalisation?

Although this wide range of questions makes up a field that waits to be explored, I will conclude by saying a few words about what a study like mine could bring to clinical practice.

### What can the study bring to clinical practice?

There will most likely always be a group of patients in health care whose suffering medicine cannot explain. From the professionals' point of view, the encounters with these patients are often experienced as problematic. Not being able to provide any clear answers for what is troubling the patient is often frustrating for the individual physician as

well as troublesome for the patient. From my study, I conclude that activities like the patient school seem to be one possible way to meet these patients. A foundation for the meaning-making processes that I have described from participation in the patient school, is recognition of the personal suffering. The fact that a medical specialist clinic organises and runs the school contributes to this recognition of personal illness. The devotion to the school the individual health care workers show by their commitment similarly seems to confirm the suffering people are experiencing – suffering which in many other contexts has been doubted. Added to this, the possibility of meeting others suffering from similar illnesses means that the personal suffering becomes more “real.” This can be an incentive for arranging this kind of pedagogical practice within health care.

The empirical study from the patient school confirms other studies of the physician-patient relation in contested illnesses by emphasising that the role of the physician should not necessarily be that of the expert. As the study of the patient school shows, sufferers do not seem to have any problems dealing with various and sometimes contradictory explanations. On the contrary, for illnesses that lack clear answers the openness to different explanations seems to be something that sufferers can use as a resource when they try to make sense of their personal illness. Hence, in such encounters it is probably important that the “role of the expert” be shared between the physician and the patient. This role distribution is most likely facilitated if the meeting takes place outside the ordinary clinical situation, in a more “neutral” setting like a patient school. This means, though, that medical professionals have to respect ill persons as active agents who make their own choices about how to deal with their problems, but who will need, especially at the beginning, support and guidance to help them become active agents.

# References

- Abbey, S. E., & Garfinkel, P. E. (1991). Neurasthenia and Chronic Fatigue Syndrome: The role of Culture in the Making of a Diagnosis. *American Journal of Psychiatry* 148(12), 1638-1645.
- Adam, B. (1995). *Timewatch: The Social Analysis of Time*. Cambridge: Polity Press.
- Adelswärd, V., & Sachs, L. (1998). Risk Discourse: Recontextualization of numerical values. *Text* 18(2), 191-210.
- Agar, M. H. (1980). *The Professional Stranger: An Informal Introduction to Ethnography*. London: Academic Press.
- Agar, M. H. (1985). Institutional Discourse. *Text* 5, 147-168.
- Anderson, R., & Bury, M. (Eds.). (1988). *Living with Chronic Illness: The Experience of Patients and their Families*. London: Unwin Hyman.
- Anspach, R. R. (1979). From stigma to identity politics: Political activism among the physically disabled and former mental patients. *Social Science and Medicine* 13A, 765-773.
- Arksey, H. (1998). *RSI and the experts. The construction of medical knowledge*. London: UCL Press.
- Arksey, H., & Sloper, P. (1999). Disputed diagnoses: the cases of RSI and childhood cancer. *Social Science and Medicine* 49, 483-497.
- Armstrong, D. (2003). The impact of papers in *Sociology of Health and Illness*: a bibliographic study. *Sociology of Health & Illness* 25(Anniversary Issue), 58-74.
- Atkinson, P., & Hammersley, M. (1994). Ethnography and Participant Observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 248-261). Thousands Oaks: Sage.
- Banks, J., & Prior, L. (2001). Doing things with illness: The micro politics of the CFS clinic. *Social Science and Medicine* 52, 11-23.
- Becker, G. (1997). *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Bell, S. E. (1988). Becoming a Political Woman: The Reconstruction and Interpretation of Experience Through Stories. In A. D. Todd & S. Fisher (Eds.), *Gender and Discourse: The Power of Talk* (pp. 97-123). Norwood, NJ: Ablex Publishing Corporation.
- Bell, S. E. (1999). Narratives and lives: women's health politics and the diagnosis of cancer for DES daughters. *Narrative Inquiry* 9, 347-389.
- Bell, S. E. (2000). Experiencing illness in/and narrative. In C. E. Bird & P. Conrad & A. M. Fremont (Eds.), *Handbook of Medical Sociology*. New Jersey: Prentice Hall.
- Bernstein, M. A. (1994). *Foregone Conclusions*. Berkeley, CA: University of California Press.

## References

- Berrios, G. E. (1990). Feelings of Fatigue and Psychopathology: A Conceptual History. *Comprehensive Psychiatry* 31, 140-151.
- Blauner, M. L. (1991). Self-help groups for the chronically ill: Different structures, varying processes. *Dissertation Abstracts International* V52 (8-A), 3094-3095. (UMI No. 9202257).
- Blum-Kulka, S. (1997). *Dinner Talk: Cultural Patterns of Sociability and Socialization in Family Discourse*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Boas, E. P. (1940). *The Unseen Plague: Chronic illness*. New York: J.J. Augustin.
- Borkman, T. J. (1990). Experiential, Professional, and Lay Frames of Reference. In T. J. Powell (Ed.), *Working with self-help* (pp. 3-30). Silver Spring, MD: NASW Press.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness* 4(2), 167-182.
- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness* 13(4), 451-468.
- Bury, M. (2000). On chronic illness and disability. In C. E. Bird & P. Conrad & A. M. Fremont (Eds.), *Handbook of Medical Sociology* (pp. 173-183). New Jersey: Prentice Hall.
- Bury, M. (2001). Illness narratives: fact or fiction? *Sociology of Health & Illness* 23(3), 263-285.
- Cain, C. (1991). Personal Stories: Identity Acquisition and Self-Understanding in Alcoholics Anonymous. *Ethos* 19, 210-253.
- Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health & Illness* 17(1), 65-88.
- Cathébras, P. (1994). Neurasthenia, Spasmophilia and Chronic Fatigue Syndromes in France. *Transcultural Psychiatric Research Review* 31, 259-270.
- Charmaz, K. (1983). Loss of Self: A Fundamental Form of Suffering in the Chronically Ill. *Sociology of Health & Illness* 5(2), 168-195.
- Charmaz, K. (1987). Struggling for a self: identity levels of the chronically ill. *Research in the Sociology of Health Care* 6, 283-321.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick: Rutgers University Press.
- Chronic fatigue syndrome, report of a Joint Working Group of the Royal College of Physicians, Psychiatrists and General Practitioners. (1996). London: Royal College of Physicians, Royal College of Psychiatrists, and Royal College of General Practitioners.
- Clark, J. A., & Mishler, E. G. (1992). Attending to patients' stories: reframing the clinical task. *Sociology of Health & Illness* 14(3), 344-372.
- Clarke, J. N., & James, S. (2003). The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine* 57, 1387-1395.

- Cohn, S. (1999). Taking time to smell the roses: accounts of people with Chronic Fatigue Syndrome and their struggle for legitimisation. *Anthropology & Medicine* 6(2), 195-215.
- Conrad, P. (1987). The Experience of Illness: Recent and New Directions. *Research in the Sociology of Health Care* 6, 1-31.
- Conrad, P. (1990). Qualitative Research on Chronic Illness: A Commentary on Method and Conceptual Development. *Social Science & Medicine* 30(11), 1257-1263.
- Conrad, P., & Bury, M. (1997). Anselm Strauss and the sociological study of chronic illness: a reflection and appreciation. *Sociology of Health & Illness* 19(3), 373-376.
- Cooley, C. H. (1951). *Social Aspects of Illness*. Philadelphia: W.B. Saunders.
- Cooper, L. (1997). Myalgic Encephalomyelitis and the medical encounter. *Sociology of Health and Illness* 19(2), 186-207.
- Corbin, J. M., & Strauss, A. (1985). Managing Chronic Illness at Home: Three Lines of Work. *Qualitative Sociology* 8(3), 224-247.
- Corbin, J. M., & Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care* 6, 249-281.
- Corbin, J. M., & Strauss, A. L. (1988). *Unending work and care: managing chronic illness at home*. San Francisco: Jossey-Bass.
- Davis, F. (1963). *Passage through Crisis: Polio Victims and Their Families*. Indianapolis: The Bobbs-Merrill.
- Deale, A., & Wessely, S. (2001). Patients' perceptions of medical care in chronic fatigue syndrome. *Social Science & Medicine* 52, 1859-1864.
- Demitrack, M. A. (1998). Chronic Fatigue Syndrome and Fibromyalgia. Dilemmas in Diagnosis and Clinical Management. *The Psychiatric Clinics of North America* 21(3), 671-692.
- Drew, P., & Heritage, J. (Eds.). (1992). *Talk at work. Interaction in institutional settings*. Cambridge: Cambridge University Press.
- Duranti, A. (1997). *Linguistic anthropology*. Cambridge: Cambridge University Press.
- Early, E. A. (1984). The logic of well being. Therapeutic narratives in Cairo, Egypt. *Social Science & Medicine* 16, 1491-1497.
- Eisenberg, L. (1977). Disease and Illness: Distinctions Between Professional and Popular Ideas of Sickness. *Culture, Medicine and Psychiatry* 1, 9-23.
- Elliott, H. (1999). Use of Formal and Informal Care among People with Prolonged Fatigue: A Review of the Literature. *British Journal of General Practice* 49(439), 131-134.
- Estroff, S. E. (1989). Self, Identity, and Subjective Experiences of Schizophrenia: In Search of the Subject. *Schizophrenia Bulletin* 15(2), 189-196.
- Estroff, S. E. (1993). Identity, Disability, and Schizophrenia: The Problem of Chronicity. In S. Lindenbaum & M. Look (Eds.), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life* (pp. 247-286). Berkeley: University of California Press.

## References

- Estroff, S. E. (1995). Whose Story is it anyway? Authority, Voice, and Responsibility in Narratives of Chronic Illness. In S. K. Toombs & D. Barnard & R. A. Carson (Eds.), *Chronic Illness: From Experience to Policy* (pp. 77-102). Bloomington: Indiana University Press.
- Evengård, B., Schacterle, F. S., & Komaroff, A. L. (1999). Chronic fatigue syndrome: new insights and old ignorance. *Journal of Internal Medicine* 246, 455-469.
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science & Medicine* 50, 605-617.
- Foulkes, S. H. (1975). *Group-Analytic Psychotherapy: Method and Principles*. London: Gordon & Breach.
- Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- Frank, A. W. (1997). Illness as moral occasion: restoring agency to ill people. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 1(2), 131-148.
- Frank, A. W. (2000). Illness and Autobiographical Work: Dialogue as Narrative Destabilization. *Qualitative Sociology* 23(1), 135-156.
- Frank, A. W. (2002). Why Study People's Stories? The Dialogical Ethics of Narrative Analysis. *International Journal of Qualitative Methods* 1(1), 1-20.
- Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M., Dobbins, J. G., Komaroff, A., & 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(12), 953-959.
- Garro, L. C. (1992). Chronic Illness and the Construction of Narratives. In M.-J. D. Good & P. E. Brodwin & B. Good & A. Kleinman (Eds.), *Pain as Human Experience: An Anthropological Perspective* (pp. 100-137). Berkeley: University of California Press.
- Garro, L. C. (1994). Narrative representations of chronic illness experience: cultural models of illness, mind, and body in stories concerning the temporomandibular joint (TMJ). *Social Science & Medicine* 38(6), 775-788.
- Gee, J. P. (1986). Units in the Production of Narrative Discourse. *Discourse Processes* 9, 391-422.
- Gee, J. P. (1991). A Linguistic Approach to Narrative. *Journal of Narrative and Life History* 1(1), 15-39.
- Gerhardt, U. (1990). Qualitative research on chronic illness: the issue and the story. *Social Science of Medicine* 30(11), 1149-1159.
- Gerson, E., & Strauss, A. L. (1975). Time for living. *Social Policy* 6, 12-18.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago: Adline Press.
- Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Anchor Books.
- Goffman, E. (1963). *Stigma*. Englewood Cliffs, NJ: Prentice-Hall.
- Good, B. J. (1992). A Body in Pain - The Making of a World of Chronic Pain. In M.-J. D. Good & P. E. Brodwin & B. J. Good & A. Kleinman (Eds.), *Pain as Human Experience: An Anthropological Perspective* (pp. 29-48). Berkeley: University of California Press.

- Good, B. J. (1994). *Medicine, rationality, and experience*. Cambridge: Cambridge University Press.
- Good, B. J., & Good, M.-J. D. V. (1994). In the Subjunctive Mode: Epilepsy Narratives in Turkey. *Social Science and Medicine* 38(6), 835-842.
- Good, M.-J. D., Brodwin, P. E., Good, B. J., & Kleinman, A. (Eds.). (1992). *Pain as Human Experience: An Anthropological Perspective*. Berkeley: University of California Press.
- Greenberg, D. B. (1990). Neurasthenia in the 1980s: Chronic Mononucleosis, Chronic Fatigue Syndrome, and Anxiety and Depressive Disorders. *Psychosomatics* 31(2), 129-137.
- Gumperz, J. J. (1982). *Discourse strategies* (Vol. 1). Cambridge: Cambridge University Press.
- Hak, T. (1999). "Text" and "con-text": Talk bias in studies of health care work. In S. Sarangi & C. Roberts (Eds.), *Talk, Work and Institutional Order* (pp. 427-451). Berlin: Mouton de Gruyter.
- Hammersley, M., & Atkinson, P. (1995). *Ethnography: Principles in practice* (2 ed.). London: Routledge.
- Harré, R., & Langenhove, L. v. (1999). *Positioning Theory: Moral Contexts of Intentional Action*. Oxford, UK: Blackwell.
- Henriksson, C. M. (1995). Living with Continuous Muscular Pain - Patient Perspectives. Part I. Encounters and Consequences. *Scandinavian Journal of Caring Science* 9, 67-76.
- Herman, D. (1999). Toward a Socionarratology: New Ways of Analyzing Natural-Language Narratives. In D. Herman (Ed.), *Narratologies: New Perspectives on Narrative Analysis* (pp. 218-246). Columbus: Ohio State University Press.
- Herzlich, C., & Pierret, J. (1987). *Illness and Self in Society*. London: The John Hopkins University Press.
- Heurtin-Roberts, S., & Becker, G. (1993). Anthropological Perspectives on Chronic Illness: Introduction. *Social Science & Medicine* 37, 281-283.
- Hilbert, R. A. (1984). The Acultural Dimensions of Chronic Pain: Flawed Reality Construction and the Problem of Meaning. *Social Problems* 31, 365-378.
- Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Straus, S. E., Jones, J. F., Dubois, R. E., Cunningham-Rundles, C., Pahwa, S., Tosato, G., Zegans, L. S., Purtilo, D. T., Brown, N., Schooley, R. T., & Brus, I. (1988). Chronic Fatigue Syndrome: A Working Case Definition. *Annals of Internal Medicine* 108, 387-389.
- Honkasalo, M.-L. (1999). What is Chronic is Ambiguity. *Souomen Antropologi* 4, 75-92.
- 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(2), 247-259.
- Hughes, E. C. (1958). *Men and Their Work*. Westport, Connecticut: Greenwood Press.

## References

- Hunter, K. M. (1991). *Doctors' Stories*. Princeton, NJ: Princeton University Press.
- Hydén, L.-C. (1995a). In Search of an Ending. Narrative Reconstruction as a Moral Quest. *Journal of Narrative and Life History* 5, 67-84.
- Hydén, L.-C. (1995b). The Rhetoric of Recovery and Change. *Culture, Medicine and Psychiatry* 19, 73-90.
- Hydén, L.-C. (1997). Illness and narrative. *Sociology of Health & Illness* 19(1), 48-69.
- Hydén, L.-C., & Mishler, E. G. (1999). Medicine and Language. *Annual Review of Applied Linguistics* 19, 174-192.
- Hydén, L.-C., & Sachs, L. (1998). Suffering, Hope and Diagnosis: on the Negotiation of Chronic Fatigue Syndrome. *Health* 2(2), 175-193.
- Jackson, J. E. (1992). "After a While No One Believes You": Real and Unreal Pain. In M.-J. D. Good & P. E. Brodwin & B. Good & A. Kleinman (Eds.), *Pain as Human Experience: An Anthropological Perspective* (pp. 138-168). Berkeley: University of California Press.
- Jacobs, M. K., & Goodman, G. (1989). Psychology and Self-Help Groups: Predictions on a Partnership. *American Psychologist* 44(3), 536-545.
- Jason, L. A., Richman, J. A., Friedberg, F., Wagner, L., Taylor, R., & Jordan, K. M. (1997). Politics, Science, and the Emergence of a New Disease: The Case of Chronic Fatigue Syndrome. *American Psychologist* 52(9), 973-983.
- Jeppsson Grassman, E. (in press). Undflyende och styrande. Om kropp och delaktighet hos människor som har Multipel Skleros [Avoidance and control. About body and participation in people having Multiple Sclerosis]. In E. Jeppsson Grassman & S. Antonsson & R. Stål & L. Svedberg (Eds.), *Att drabbas och forma sitt liv. Om strategier bland funktionshindrade och arbetslösa*. Lund: Studentlitteratur.
- Joas, H. (1985). *G.H. Mead A Contemporary Re-examination of his Thought*. Cambridge: Polity Press.
- Joyce, J., Hotopf, M., & Wessely, S. (1997). The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *The Quarterly journal of medicine* 90, 223-233.
- Karlsson, M. (2000). *Delade erfarenheter: om självhjälpsgrupper i Sverige [Shared experiences: about self-help groups in Sweden]*. Stockholm: Sköndalsinstitutet.
- 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(2), 139-170.
- Karp, D. A. (1996). *Speaking of Sadness: Depression, Disconnection, and the Meanings of Illness*. New York: Oxford University Press.
- Kelleher, D. J. (1990). Do self-help groups help? *International Disability Studies* 12, 66-69.
- Kelleher, D. J. (1994). Self-help groups and their relationship to medicine. In J. Gabe & D. Kelleher & G. Williams (Eds.), *Challenging medicine* (pp. 104-117). London: Routledge.

- Kirmayer, L. J. (1988). Mind and Body as Metaphors: Hidden Values in Biomedicine. In M. Lock & D. Gordon (Eds.), *Biomedicine Examined* (pp. 57-93). Dordrecht: Kluwer Academic.
- Kleinman, A. (1980). *Patients and Healers in the Context of Culture: An exploration of the Borderland between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press.
- Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Kleinman, A. (1992). Pain and Resistance: The delegitimation and Relegitimation of Local Worlds. In M.-J. D. Good & P. E. Brodwin & B. Good & A. Kleinman (Eds.), *Pain as Human Experience: An Anthropological Perspective* (pp. 169-197). Berkeley: University of California Press.
- Kogstad, O., & Hintringer, F. (1993). Patients with Fibromyalgia in Pain School. *Journal of Musculoskeletal Pain* 1, 261-265.
- Krietemeyer, B. C., & Heiney, S. P. (1992). Storytelling as a Therapeutic Technique in a Group for School-Aged Oncology Patients. *Children's Health Care* 21(1), 14-20.
- Kronenfeld, J. J. (1986). Self-help and self-care as social movements. *Advances in Health Education and Promotion* 1, 105-127.
- Labov, W. (1972). The Transformation of Experience in Narrative Syntax. In W. Labov (Ed.), *Language in the Inner City* (pp. 354-405). Philadelphia: University of Pennsylvania Press.
- Labov, W., & Waletzky, J. (1967). Narrative Analysis: Oral Versions of Personal Experience. In J. Helm (Ed.), *Essays on the verbal and visual arts* (pp. 12-44). Seattle: University of Washington Press.
- Langellier, K. M. (2001). "You're marked" Breast cancer, tattoo, and the narrative performance of identity. In J. Brockmeier & D. Carbaugh (Eds.), *Narrative and Identity: Studies in Autobiography, Self and Culture* (pp. 145-184). Amsterdam: John Benjamins Publishing Company.
- Laube, J. J. (1998). Crisis-oriented narrative group therapy. *Crisis Intervention* 4(2-3), 215-226.
- Linde, C. (1993). *Life Stories: the creation of coherence*. Oxford: Oxford University Press.
- Lindroth, Y. (1996). *Development and evaluation of patient education in rheumatoid arthritis*. Lund: Lunds universitet.
- Linell, P. (1994). *Transkription av tal och samtal: teori och praktik [Transcription of speech and conversation: theory and practice]* (Arbetsrapport 1994:9). Linköping, Sweden: Linköpings universitet, Tema Kommunikation.
- Maclean, M. (1988). *Narrative as performance: The Baudelairean experiment*. London: Routledge.
- Maines, D. R. (1983). Time and biography in diabetic experience. *Mid-American Review of Sociology* 8(1), 103-117.
- Maines, D. R. (1991). The Storied Nature of Health and Diabetic Self-Help Groups. *Advances in Medical Sociology* 2, 185-202.

## References

- Mattingly, C. (1994). The Concept of Therapeutic 'Emplotment'. *Social Science and Medicine* 38(6), 811-822.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge: Cambridge University Press.
- Mattingly, C., & Lawlor, M. (2000). Learning from Stories: Narrative Interviewing in Cross-cultural Research. *Scandinavian Journal of Occupational Therapy* 7, 4-14.
- Mead, G. H. (1934/1967). *Mind, Self, and Society. From the Standpoint of a Social Behaviorist* (Charles W. Morris ed.). Chicago: The University of Chicago Press.
- Mehan, H. (1979). *Learning lessons: Social Organization in the Classroom*. Cambridge: Harvard University Press.
- Minister, K. (1991). A Feminist Frame for the Oral History Interview. In S. B. Gluck & D. Patai (Eds.), *Women's Words: The Feminist Practice of Oral History*. London: Routledge.
- Mishler, E. G. (1984). *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ: Alex Publishing Corporation.
- Mishler, E. G. (1986). *Research Interviewing: Context and Narrative*. Cambridge: Harvard University Press.
- Mishler, E. G. (1992). Work, Identity, and Narrative: An Artist-Craftsman's Story. In G. C. Rosenwald & R. L. Ochberg (Eds.), *Storied Lives: The Cultural Politics of Self-Understanding* (pp. 21-40). New Haven, CT: Yale University Press.
- Mishler, E. G. (1995). Models of narrative analysis: A typology. *Journal of Narrative and Life History* 5(2), 87-123.
- Mishler, E. G. (1999). *Storylines: Craftartists' Narratives of Identity*. Cambridge, MA: Harvard University Press.
- Morson, G. S. (1994). *Narrative and Freedom: The Shadows of Time*. New Haven, CT: Yale University Press.
- Moss-Morris, R., & Petrie, K. J. (2000). *Chronic Fatigue Syndrome*. London: Routledge.
- Natelson, B. H. (1998). *Facing and Fighting Fatigue: A practical approach*. New Haven, CT: Yale University Press.
- Nordenfelt, L. (1995). On Chronic Illness and Quality of Life: A Conceptual Framework. *Health Care Analysis* 3, 290-298.
- Norrick, N. R. (1997). Twice-told tales: Collaborative narration of familiar stories. *Language in Society* 26, 199-220.
- Ochs, E., Smith, R., & Taylor, C. (1989). Detective stories at dinnertime: Problem-solving through co-narration. *Cultural dynamics* 2(2), 238-257.
- Ochs, E., Taylor, C., Rudolph, D., & Smith, R. (1992). Storytelling as a Theory-Building Activity. *Discourse Processes* 15, 37-72.
- Olin, R. (1999). "Nya diagnoser" - en förklaringsmodell till neurosomatiska sjukdomar ["New diagnoses" - an explanatory model for neurosomatic diseases]. Stockholm: Nationella folkhälsokommittén.
- Parsons, T. (1951). *The Social System*. Glencoe, IL: Free Press.

- Pierret, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health & Illness* 25(Silver Anniversary Issue), 4-22.
- Polanyi, L. (1985). Conversational Storytelling. In T. A. van Dijk (Ed.), *Handbook of Discourse and Dialogue* (Vol. 3, pp. 183-201). London: Academic Press.
- Rabinbach, A. (1992). *The Human Motor: Energy, Fatigue, and the Origins of Modernity*. Berkeley: University of California Press.
- Radley, A. (1993). The role of metaphor in adjustment to chronic illness. In A. Radley (Ed.), *Worlds of Illness* (pp. 109-123). London: Routledge.
- Radley, A. (1994). *Making Sense of Illness The Social Psychology of Health and Disease*. London: Sage.
- Radley, A., & Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of Health & Illness* 18(2), 220-240.
- Ragin, C. C., & Becker, H. S. (1992). *What is a case? Exploring the foundations of social inquiry*. New York: Cambridge University Press.
- Ravotas, D., & Berkenkotter, C. (1998). Voices in the text: The uses if reported speech in a psychotherapist's Notes and Initial Assessments. *Text* 18(2), 211-239.
- Reid, J., Ewan, C., & 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.
- Richardson, L. (1998). Writing: A Method of Inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and Interpreting Qualitative Materials* (pp. 345-371). Thousand Oaks: Sage.
- Riessman, C. K. (1990). Strategic Uses of Narrative in the Presentation of Self and Illness: A Research Note. *Social Science and Medicine* 30(11), 1195-1200.
- Riessman, C. K. (1993). *Narrative Analysis* (Vol. 30). Newbury Park: Sage.
- Riessman, C. K. (2000). "Even If We Don't Have Children [We] Can Live" Stigma and Infertility in South India. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the Cultural Construction of Illness and Healing* (pp. 128-152). London: University of California Press.
- Riessman, C. K. (2001). Analysis of Personal Narratives. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of Interview Research: Context & Method* (pp. 695-710). Thousand Oaks (California): Sage.
- Riessman, C. K. (2002). Doing justice: Positioning the Interpreter in Narrative Work. In W. Patterson (Ed.), *Strategic Narrative* (pp. 193-214). Lanham, MD: Lexington Books.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine* 30(11), 1173-1186.
- Rosenqvist, U. (2001). Patient Education: new trends in Sweden. *Patient Education and Counseling* 44, 55-58.
- Roth, J. A. (1963). *Timetables*. Indianapolis, Indiana: The Bobbs-Merrill.

## References

- Roth, J. A., & Conrad, P. (Eds.). (1987). *Research in the Sociology of Health Care: the Experience and Management of Chronic Illness* (Vol. 6). Greenwich, CT: JAI Press.
- Sachs, L. (1987). *Medicinsk antropologi [Medical anthropology]*. Stockholm: Liber.
- Sachs, L. (1995). Is there a pathology of prevention? The implications of visualizing the invisible in screening programs. *Culture, Medicine and Psychiatry* 19, 503-525.
- Sachs, L., & Evengård, B. (2000). Speciell patient-läkarrelation vid kroniskt trötthetssyndrom [Special patient-physician relation in chronic fatigue syndrome]. *Läkartidningen* 97(3), 176-181.
- Sachs, L., & Hydén, L-C. (1997). *Lidande utan patologi: fallet kroniskt trötthetssyndrom [Suffering without pathology: the case of chronic fatigue]* (Projektansökan SFR). Linköping, Sweden: Linköpings universitet, Tema Kommunikation.
- Sacks, H. (1974). An analysis of the course of a joke's telling in conversation. In R. Bauman & J. Sherzer (Eds.), *Explorations in the ethnography of speaking* (pp. 337-353). New York: Cambridge University Press.
- Sacks, H. (1995). *Lectures on conversation*. Oxford: Blackwell.
- Sarangi, S. (2000). Activity types, discourse types and interactional hybridity: the case of genetic counselling. In S. Sarangi & M. Coulthard (Eds.), *Discourse and Social Life* (pp. 1-27). Harlow, England: Longman.
- Scambler, G., & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health & Illness* 8, 26-43.
- Scarry, E. (1985). *The Body in Pain. The Making and Unmaking of the World*. New York: Oxford University Press.
- Schneider, J. W., & Conrad, P. (1983). *Having Epilepsy: The Experience and Control of Illness*. Philadelphia, PA: Temple University Press.
- Schubert, M. A., & Borkman, T. (1994). Identifying the Experiential Knowledge Developed Within a Self-Help Group. In T. J. Powell (Ed.), *Understanding the self-help organization: Frameworks and findings* (pp. 227-246). Thousand Oaks, CA: Sage.
- Schweitzer, R., Kelly, B., Foran, A., Terry, D., & Whiting, J. (1995). Quality of Life in Chronic Fatigue Syndrome. *Social Science of Medicine* 41(10), 1367-1372.
- Sellerberg, A.-M. (1993). *Handikapp och organisering - en sociologisk tolkning [Disability and organization - A sociological interpretation]* (Research Program in Medical Sociology 1993:7). Lund: Department of Sociology Lund University.
- Sharpe, M., Palmer, I., & Wessely, S. (1997). Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management. *General Hospital Psychiatry* 19, 185-199.
- Shorter, E. (1993). *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era*. New York: The Free Press.
- Showalter, E. (1997). *Hystories - Hystorical Epidemics and Modern Culture*. London: Picador.

- Social Insurance in Sweden 2002: Ideals and Reality in Disability Policy.* (2002). Stockholm: Riksförsäkringsverket (The National [Swedish] Social Insurance Board).
- Sontag, S. (1991). *Illness as Metaphor and AIDS and Its Metaphors*. London: Penguin Books.
- Statsrådsberedningen. (2002). *Press release 21 October 2002: Prime Minister Göran Persson presents new government.*  
[http://www.regeringen.se/galactica/service=irnews/owner=sys/action=obj\\_show?c\\_obj\\_id=46943](http://www.regeringen.se/galactica/service=irnews/owner=sys/action=obj_show?c_obj_id=46943) (Acc: 2003-09-24).
- Steffen, V. (1997). Life stories and shared experience. *Social Science and Medicine* 45(1), 99-111.
- Straus, S. E. (1991). History of Chronic Fatigue Syndrome. *Reviews of Infectious Diseases* 13(Suppl 1), 2-7.
- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D. R., Suczek, B., & Weiner, C. L. (1984). *Chronic Illness and The Quality of Life* (second ed.). St. Louis, MO: Mosby.
- Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1985). *Social organization of medical work*. Chicago: The University of Chicago Press.
- Strauss, A., & Glaser, B. G. (1975). *Chronic Illness and The Quality of Life*. St. Louis, MO: Mosby.
- Taylor, C. (1989). *Sources of the self. The making of the modern identity*. Cambridge, UK: Cambridge University Press.
- Twaddle, A. (1993). Disease, Illness, and Sickness Revisited. In A. Twaddle & L. Nordenfelt (Eds.), *Disease, Illness and Sickness: Three Central Concepts in the Theory of Health* (pp. 3-18). Linköping: Linköping University, Department of Health and Society.
- Ware, N. C. (1992). Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome. *Medical Anthropology Quarterly* 4(6), 347-361.
- Ware, N. C. (1993). *Society, mind and body in chronic fatigue syndrome: an anthropological view*. Paper presented at the Chronic fatigue syndrome, Ciba Foundation Symposium 173, Wiley, Chichester.
- Ware, N. C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *Culture, Medicine and Psychiatry* 23, 303-331.
- Ware, N. C., & Kleinman, A. (1992a). Culture and Somatic Experience: The Social Course of Illness in Neurasthenia and Chronic Fatigue Syndrome. *Psychosomatic Medicine* 54, 546-560.
- Ware, N. C., & Kleinman, A. (1992b). Depression in Neurasthenia and Chronic Fatigue Syndrome. *Psychiatric Annals* 22, 202-209.
- Wessely, S. (1990). Old wine in new bottles: neurasthenia and 'ME'. *Psychological Medicine* 20, 35-53.
- Wessely, S., Hotopf, M., & Sharpe, M. (1999). *Chronic Fatigue and its Syndromes*. Oxford: Oxford University Press.
- Williams, G. H. (1984). The genesis of chronic illness: narrative reconstruction. *Sociology of Health and Illness* 6(2), 175-200.

## References

- Williams, G. H. (1993). Chronic illness and the pursuit of virtue in everyday life. In A. Radley (Ed.), *Worlds of Illness* (pp. 92-108). London: Routledge.
- Williams, S. J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness* 22(1), 40-67.
- Woodward, R. V., Broom, D. H., & 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.
- Wootton, A. J. (1977). Sharing: some notes on the organization of talk in a therapeutic community. *Sociology* 11, 333-350.
- Yoshida, K. K. (1993). Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health & Illness* 15(2), 217-245.
- Young, A. (1982). The anthropologies of illness and sickness. *Annual Review of Anthropology* 11, 257-285.
- Ziporyn, T. (1992). *Nameless diseases*. New Brunswick, NJ.
- Åsbring, P. (2001). Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing* 34(3), 312-319.
- Åsbring, P., & Närvänen, A.-L. (2002). Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia. *Qualitative Health Research* 12(2), 148-160.

# PART II

## Papers A – D

### PAPER A

Bülow, P. H. (2003). *Chronicity and moral quests: Sense-making and self-making in narratives about chronic fatigue*. Manuscript submitted for publication.

### PAPER B

Bülow, P. H., & Hydén, L-C. (2003). In dialogue with time: Identity and illness in narratives about chronic fatigue. *Narrative Inquiry* 13(1), 71-97. <https://doi.org/10.1075/ni.13.1.03bul>

### PAPER C

Bülow, P. H., & Hydén, L-C. (2003). Patient school as a way of creating meaning in contested illness: The case of CFS. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 7(2), 227-249.  
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### PAPER D

Bülow, P. H. (in press). Sharing experiences of contested illness by storytelling. *Discourse & Society* 15(1) 33-53.  
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Paper A



# Chronicity and moral quests: Sense-making and self-making in narratives about chronic fatigue

Pia H. Bülow

Department of Communication Studies  
Linköping University, Sweden

**ABSTRACT** This article discusses how moral questions raised by an illness like Chronic Fatigue Syndrome (CFS) become part of people's illness narratives. Drawing on the writings of the philosopher Charles Taylor (1989), about moral quests and identity, two individual sufferers' illness narratives are analysed concerning how they try to make sense of life with respect to morality and how to maintain oneself as a moral person in and through narratives. The analysis shows that the narrative reconstruction and the anchoring of illness in the personal life story seem to be of significance for orienting oneself in a moral space. This orientation, or sometimes re-orientation, also included the question of where they were heading, that is the future. One example is the shift in moral frameworks about what it means to lead a good life. The analysis also shows that people through their narratives resist threats against their sense of self by striving to maintain their views of themselves as moral persons. This was for instance done by presenting themselves as trustworthy persons and as persons with dignity.

**KEY WORDS:** *illness narratives, narrative analysis, morality, identity, contested illness*

## Introduction

Long-term and 'invisible' illness that medicine cannot explain is problematic for the sufferer in a special way. It is a type of suffering that is often trivialised and psychologised in medical encounters as well as in everyday life (cf. Henriksson 1995, Hilbert 1984, Reid *et al.* 1991, Ware 1992). Even when given a name, such types of suffering tend to be less legitimate and less accepted as real diseases. Chronic Fatigue Syndrome (CFS) is such a *contested illness*. The combination of vagueness and the attack on the sense of self resulting from the way others treat them and their illness often leads sufferers to experiences of being questioned as

moral persons. They can feel that they are suspected of malingering, of complaining unnecessarily or of having lost touch with reality (Cooper 1997, Ware 1992). Sufferers thereby not only have to struggle against illness. They also have to deal with those moral questions that illness seems to raise, questions concerning responsibility for becoming ill and for not getting well. They ask themselves, for example: What kind of person am I? Has this illness anything to do with the way I have been leading my life? How does this illness influence how I should view my life and how do others see me? Suffering from a contested illness like chronic fatigue means being constantly prepared for such threats against the sense of self and finding ways to maintain oneself as a moral person.

This article discusses how moral questions raised by an illness like CFS become part of people's illness narratives in two different ways. First, how do people suffering from chronic fatigue make sense of their lives with respect to morality? Secondly, how can they maintain themselves as moral persons in and by their narratives?

For the philosopher Charles Taylor (1989), morality is not confined to what is right to do or what we ought to do. Morality also concerns what it is good to be and what is valuable to us. According to his line of argument, we always act and reason in accordance with some kind of moral framework. This means that we ask questions about what is good in life and that we orient ourselves in relation to the answers we find. Accordingly, the self, as Taylor describes it, exists in a space of moral issues – in a *moral space*. From this perspective, an illness narrative might be understood as an orientation in moral space – a *moral quest*.

The moral dimension of CFS usually described in social science is the question of the genesis of the illness – whether it has a physical or a psychological cause (cf. Banks and Prior 2001, Horton-Salway 2001). These studies show how the unanswered question about the cause of illness becomes central in conversations about CFS by being closely related to the question of what kind of person the sufferer is. However, other aspects of morality are usually not discussed, like what happens when the ill person continues to be sick for months and years.

The following analysis draws on a series of interviews with people suffering from CFS. In a close analysis of the interviews with two of the interviewees, I intend to show how their illness narratives about chronic fatigue work as an orientation in moral space. It is my purpose to discuss this in relation to both what is usually called the narrative

reconstruction (Williams 1984) and to morality in interaction, regarding narratives as strategic devices (Hydén 1997).

## Illness and morality

From a functionalistic view of the roles of physicians and patients, morality can be regarded as the patient's obligations to be a 'good patient', one who is trying to become well by following the physician's advice (Parsons 1951). Such a view is a long way from that of Taylor (1989) and others who write about morality. However, during the 1990s some researchers, most of them medical sociologists, emphasised morality as an important aspect in understanding how people experience and narrate their chronic illnesses. Gareth Williams (1993), for instance, emphasises dignity when he shows how an elderly woman's story about her chronic illness can be understood as a *pursuit of virtue* by the way she struggles to present herself as capable and competent despite her illness. Also in relation to dignity, Mildred Blaxter's (1993) analysis of the stories told by middle-aged women who were economically deprived, at least as young mothers, shows how each of these women presented a moral identity as someone who would not 'give in' to her illness. In an analysis of a former psychiatric patient's story about his illness, the social psychologist Lars-Christer Hydén (1995) interprets the man's different explanations of why he became ill as a moral quest.

The medical sociologist Arthur Frank (1997) describes *illness as a moral occasion*. According to Frank, morality and illness are linked to identity by the question of what kind of person one has to become to get well. In this way, his paper also concerns the moral quest. Frank writes about the sociology of the morality of illness and about the need to restore moral agency to the ill by giving them the right to be successfully ill too. That is when people 'become engaged in their own process of healing' (p. 136). This, however, is not the same as to comply with medical advice or instructions. In some cases it can be entirely the opposite. Frank argues that from what he calls a medicocentrism, the moral issues raised by illness have become marginalised. One way to restore the power over the moral questions to the ill is by recognising people's stories about their illness. The task for the ill, Frank writes, is 'to use illness as a medium for the creation of a new relationship to self and others' (p. 137).

## Morality and selfhood

To know who you are is to be oriented in moral space, a space in which questions arise about what is good or bad, what is worth doing and what not, what has meaning and importance for you and what is trivial and secondary. (Taylor 1989: 28)

Taylor describes three axes for people's moral thinking in a general sense. These are the respect for other people's lives and the understanding of what makes a good life. The third axis, then, concerns issues about dignity. Taylor describes the axes as 'the characteristics by which we think of ourselves as commanding (or failing to command) the respect of those around us' – and how we practice and express dignity. The foundation for our moral assumptions according to these three axes varies between different times and cultures. People's subjective right to choose their own life and to come to a personal decision about moral questions distinguishes the modern view of morality from the prevailing opinion to obey the law and other authorities (like the Church), above all in earlier periods. What likewise differentiates today's views from the classical appraisal of 'higher' activities like contemplation is that 'the higher is to be found not outside of but as *manner of living* ordinary life' (ibid. p. 23, Taylor's own emphasis). This makes the moral frameworks of our own time more problematic in that they largely value people's own choices and opinions instead of being based on a joint horizon such as religion.

From the quotation above, we learn that selfhood and morality are inseparably intertwined for Taylor (1989), in that we must be oriented in moral space to know who we are. This moral space is about learning what a good life is and how to lead a good life. As a guide for our moral orientation we use frameworks that can be universally human (e.g. thou shalt not kill). Or we can use those that are more socially and thereby culturally bound (e.g. the virtue of working), or not giving in to illness and suffering (cf. Blaxter 1993). This does not necessarily mean that we always succeed but that we always strive to understand our lives in relation to a certain view of what the good and desirable way of living is. By describing the relation between our sense of the good in life and our understanding of self, Taylor links morality and selfhood. An identity crisis then becomes more a question of *loss in moral space* than of loss of self, which is a common description of the influence that illness has on identity. The question of what kind of person one is is transformed to questions like: How did I get to this point and where am

I heading? Thus, it is about what kind of person I am, have been and must become. Fundamental to such an understanding, Taylor writes, is the creation of stories about life – of seeing one's life as an unfolding story. The concept of *moral quest*, which Taylor and others have borrowed from McIntyre (1981), can be seen as all that people do in their endeavour to attain the right way of living one's life. This also includes their search for understanding their own lives in relation to what is considered the good, and how they narrate that.

## The study

The following analysis is based on an interview study with people suffering from chronic fatigue syndrome. This study was preceded by an ethnographic study of a patient school for chronic fatigue sufferers (Bülow in press, Bülow and Hydén 2003b) which was followed up in a series of interviews with 14 former participants in this school (see also Bülow and Hydén 2003a). The opening interview took place in most cases about half a year after the school was finished. Half of the former participants (seven persons) were interviewed on three occasions, six of the interviewees twice and one person was interviewed at length on one single occasion. The interviews were usually conducted at the interviewee's home. They were tape-recorded and lasted for about one hour. The longest period to elapse between the patient school and the last interview was two and a half years. The youngest person was about 30 and the oldest about 60. Four of the interviewees were men. The study comprises 34 interviews in total.

The interviews were open-ended and were narratively oriented so that the interviewees were encouraged to narrate their experiences rather than responding reportorially (Mishler 1986, Riessman 2001). Because of this approach, the separate interviews turned out differently. Some consisted of long, complex narratives such as 'my way to the patient school,' narratives composed of a number of storied episodes like how the visit to Dr X turned out. Other interviews were more like conversations in which the answers to my questions sometimes resulted in a narrative about a certain event and at other times in the interviewee's accounting for acts and thoughts in relation to illness.

The interviews were transcribed verbatim in accordance with a sociolinguistic model for narrative analysis based on rhythmic markers in the spoken language, represented in lines, stanzas (clusters of lines) and strophes (e.g. pair of related stanzas). This model offered the

opportunity to analyse the structure of the narratives as well as the content (Gee 1986, 1991). It also allowed the analysis of well-bounded stories as well as more loosely narrated stories that are commonly part of unstructured interviews (Mishler 1999). In the analysis, both of these types of narratives and narrating have been considered. This means that stories could be either clearly defined stories of the Labovian type about a specific event (Labov and Waletzky 1967), like when an interviewee visited the GP who referred him or her to the CFS clinic. Or it could also be a chain of short stories marked by an abstract at the beginning of the chain and a resolution or a coda at the end, or linked by some kind of refrain or narrative structure. Added to this, I considered the interviews with each subject as part of his/her *life story* (Linde 1993: 219-20) to be ‘a discontinuous unit, consisting of a set of stories that are retold in various forms over a long period of time and that are subject to revision and change as the speaker drops some old meanings and adds new meaning to portions of the life story.’

An important basis, theoretically as well as methodologically, is that interviews are understood as the result of the interaction between the interviewee and the interviewer (Mishler 1986). Thus, narratives about, accounts of and descriptions of illness and the suffering person, of which the interviews consist, are interpreted based on how they contribute to making a contested illness like CFS intelligible for the sufferer as well as for the interviewer. The narratives have therefore been analysed on the basis of the content of the stories as well as on the basis of how they work as a performance (Riessman 2001). That is, from the way the interviewees tell about and portray themselves – what Goffman (1959) writes of as the *presentation of self*; Mishler (1999), in interview data calls this self-description.

Following Mishler (1999), I have chosen a ‘case-centred model of analysis,’ analysing each interviewee’s illness narrative separately. Nevertheless, as Mishler has commented, ‘the Gee model lends itself well to a thematic approach, since grouping lines into stanzas depends on their being about the same “topic”’ (Mishler 1999: 153). This allowed me to find certain points of view of content that appear throughout all the material, as well as to follow a theme of one interviewee through the whole series of interviews with him or her. The moral quest, the case in point for this article, is one such general ‘topic’ that is more or less salient in the interviews with all interviewees. The illness narratives of two interviewees presented in the following were

collected on two and three occasions, respectively, over a period of one year and one and a half years. The moral quest was the focus of the analysis, which seems to be one way to make sense of the ‘contestedness’ connected with chronic fatigue. All names have been changed to protect the individual interviewee’s personal integrity. For the same reason, some personal details have been modified.

## Interview narratives about chronic fatigue

Identity and transformations of identity appear throughout the narratives in the entire interview material. They manifest themselves in sufferers’ stories describing the difference between the kind of person they are now, compared to the kind of person they used to be before the illness. These narratives commonly cover several years of the interviewees’ lives. In some cases, this means that episodes from childhood are included in the illness narrative. Nevertheless, only few speak explicitly of the story as a narrative about identity. One example was a woman who started her narrative in the first interview with the words: ‘I believe that one has to start from the person one really is, for when one has CFS one is not really oneself.’ Even if few expressed in their stories such a clear concern about identity as this woman did, questions about what kind of person they have become and were before are recurrent themes in the narratives and something the interviewees tried to answer with their stories. Sometimes the question is posed in and through narratives about how the narrator has been called into question by someone like a physician or a friend. Sometimes the question is answered by the way the narrator presents him/herself as a responsible person who shows ability to take action regarding the illness. Many of these narratives have a moral dimension, or maybe rather a moral foundation, by the way they seem to arise from questions concerning how life has been led and is lived. In this manner, the narratives constitute some kind of accounts in relation to questions posed from a certain moral framework. Using Taylor’s (1989) figure of thought about identity and morality in a spatial dimension, the interview narratives in my material can be understood as quests for both explanations for illness and directions for lives that now can be seen as good ones – that is, a moral quest. Such a moral quest can be found in the data as a whole. However, in what way these quests are manifested and what they result in varies between different interviewees.

Three questions seem to be of central importance for this moral endeavour. First, to what kind of questions are these narratives a response? That is, what is happening in the interview and what underlying questions concerning morality can be discernable through the narrative? Secondly, how are these questions answered? That is, how are these narratives shaped and what storylines come to the fore? The third question concerns dignity and the relation between the self and suffering. That is, how can a narrator maintain him/herself as a moral person through the narrative?

### Morality in narratives about chronic fatigue

As I have already mentioned, questions about morality and selfhood are recurring themes in the entire material and in principle every interview can be understood as a moral quest. In a close analysis of two interviewee's narratives, I will show how this quest for what is a good life is created in the narratives and in what way the interviewees seem to orient themselves according to different moral frameworks. The analysis concerns how the narrators, here called Jack and Judy, present themselves as well as their view of what a good life is and how this view is transformed or adjusted to a situation including a contested illness like CFS. The reason for choosing the narratives of these two interviewees is not that they represent different kinds of moral quests, but because their narratives illustrate in different ways what can be a moral quest in a situation of contested illness. In that respect, these two narratives represent the material as a whole. I chose Jack's narrative since he is a very good storyteller and therefore puts a lot of what others also told in a concrete way. Judy's story is chosen because it constitutes in several ways an interesting contrast to the narrative Jack tells, and thereby shows that the moral quest can be different.

The illness narratives of Jack and Judy have thus been analysed from the way they strive to make sense of a contested illness like CFS by orienting themselves in a moral space. The analysis shows how conflicts between different frameworks become visible and how the narrators by their quest seem to solve these. The two narrators, however, come to different conclusions. For Jack the quest seems to lead to a reformulation of the moral framework, while for Judy it is more some kind of restricted moral framework embracing fewer people as well as fewer social situations. Jack's narrative will start the analysis.

### *Jack's illness narrative*

Jack is in his late thirties and has been on sick leave for one and a half years at the time of our first interview. He has a university degree in health care and had been working in this field for several years before his illness. When he became acutely ill, two and a half years before the interview, he was in the middle of an educational course that would have given him new working opportunities and a partly new career. The two interviews with Jack were separated by thirteen months, and taken together they are possible to understand as a moral quest by the way he tells his stories. That is, how he at the beginning of his illness tried to behave towards illness in accordance with the same moral framework by which he had managed his life before illness, and how he later reworks these moral frameworks.

In the first interview, Jack responds to my initial question of how he came to participate in the patient school with a ten-minute long narrative. It is a complex story that ends with the words 'so that- that was the long way I have taken.' These words create a *coda* (Labov and Waletzky 1967) and at the same they provide the story with a title. 'The long way' is constructed from several short stories linked together by the way each single story in the chain constitutes one step on the way to the diagnosis of CFS and to the patient school. Although each storied event is possible to consider as a separate short story with its own plot, they are linked by a joint *storyline* (Schafer 1992), positioning Jack as a responsible and trustworthy person.

In his narrative about 'The long way,' Jack tells me about his active role in the search for answers, from the time ten years back when he began to 'feel this tiredness' to the medical encounter about a year prior to the interview when his illness was diagnosed as CFS. In the first part, Jack describes his visits to the district health care and how he was told that there was nothing to worry about. He continues by telling an acute illness episode, which is described as a turning point in his illness story. This point leads on to an extended period of medical investigations when several medical specialists at different clinics examined Jack for a range of physical diagnoses. During this period, Jack describes how he has to force the investigation and thus take an active role vis-à-vis the physicians – something that is illustrated in the narratives. For instance, Jack describes how he during the latter part of the investigation period raises the question of whether the illness can be 'something psycho-

logical.' In the related dialogue between Jack and the neurologist who examined him at the time, the latter strongly rejects this suggestion.

However, the result of all those medical examinations is that Jack is declared to be well. He then tells me how he 'looked back' and noticed for himself how he 'had been working very hard,' that he, as he says had 'pushed' himself 'over many limits.' He continues, telling a story of how he went to see a psychiatrist but was met by 'the same thing' again when his problem did not fit into the psychiatric frame either. He even tries antidepressant medication 'in a diagnostic effort.' At the end of 'the long way,' Jack describes how he remembered having heard about the diagnosis of CFS and how he mentions this diagnosis to his physician, who immediately refers him to another specialist. As an epilogue, Jack retells parts of the visit at the CFS clinic and how the physician 'already at the first consultation' told him 'that you have this chronic fatigue syndrome.'

The division between physically and mentally caused diseases common in Western society and the different moral values connected with them (Kirmayer 1988) is obvious in the story Jack tells. Throughout the whole narrative, Jack deals with this division. For instance by the balancing act Jack performs when he on the one hand presents himself as taking an active part in the investigation by 'pushing' and on the other describes how he respects the medical order by acting as a good patient taking advice from the physicians seriously. By showing openness towards a psychological explanation, he takes the sting out of the suspicion he himself presents and at the same time prevents the trivialisation and delegitimation that are described in encounters between physician and a patient suffering from CFS (Ware 1992). He stands out instead, through the narration, as a responsible and trustworthy person. This counteracts the threatening image that seems to lie behind the narrative of himself as a hypochondriac or malingering person.

Considering its place in the interview, the first complex narrative creates a platform (cf. Hydén 1995) from which Jack can describe changes. As an opening story it becomes especially important because of the image it creates of Jack as a person who takes on the responsibility of trying to understand his illness in every possible way. This image seems to be connected with and reinforced by the recurring presentation of self Jack gives when describing himself as a person who was almost never on sick leave before this illness, and who managed to work at the

same time as he was studying. From such a platform, it becomes possible for Jack to tell of his altered view of work for instance, without breaking down the picture of himself. The story below about the plan for his work rehabilitation is an example of this. It is a story about different moral frameworks and about how these frameworks, in accordance with which Jack up to now has judged his life, seem to crumble because of his illness. A key for the transcription is provided at the end of the paper.

#### *THE MORAL FRAMEWORK OF WORK*

01 But eh I- I don't believe in that that much.

*The common moral framework of work*

02 I feel that- that both physicians, and the social insurance office (and) my employer they have some kind of overconfidence in this well work training<sup>1</sup> and so.

That you- I've been told so many times that eh well that's no good to stay home from work

and (that) you have to get back in your eh ordinary social situation like that otherwise you'll never get well.

Cause one becomes too much or well identified with one's sick role and so.

*The resistance*

06 .h (.) eh but sure hh that- that's probably true for many ((people)).

But- but I've not- Now.

#### *FORMER FRAMEWORK CRUMBLES*

*How it was before*

08 It was like that for me before that I found it very difficult to stay home from work cause I- I felt worthless

and I eh lost a great part of my- my life so to speak cause I had- lots of good friends there too or still have.

*How it is now*

10 .hh but eh now I've come- now I've started to feel that that e:h that I well I'm not getting any better by working you know.

On the contrary that's eh partly what's contributed me feeling the way I do.

.hh and I will not get well by working e:: hm

#### *QUESTIONING THE SOLUTION OF THE PROBLEM*

*The official plan*

13 .h so the plan now (I guess) is that eh it will work fairly well and then I will increase my hours of work

and then I will be doing full time again and so.

and- and I will be fine.

*Jack's opinion*

- 17 But I feel that .hh that's not what eh what eh what the solution is of- of e:hu: how  
I'll get well you know.  
I- I don't know what the solution is but it's not that anyway.

From the very beginning, Jack starts by positioning himself in relation to someone else or towards some view by stating that he does not 'believe in that that much.' With this, he indicates that he will talk about a conflict between different moral frameworks. To understand his story as a narrative about a moral conflict it is, however, important to know something about the situation in which it is told. Like many other stories in the interviews with Jack, this one is a part of a whole chain of short stories – a chain that starts when Jack (on a question from me) specifies the time for how long he has been ill. To my question 'have you been able to work during this time?' he replies: 'first I did- .h you know I've always been that kind of person who never stayed home from work.' By the way Jack responds, the question turns out to be a moral issue about what kind of person he is and how he has been leading his life. He continues his account with a report of his attempt to go back to work, about his current situation of work training and about the many ways of getting better that he has tried. In this way, the story in the example is a link in a chain of storied events that all seem to concern moral issues about responsibility and the way he has been leading his life – thus it is about moral frameworks.

The short story above is divided into three main parts. In the first one, Jack describes the moral framework for which work is also the primary goal for those struggling to recover from illness. This is presented as the commonly accepted moral framework – a framework that is well-known to Jack. By emphasising that his physician, the official from the social insurance office and his employer – all of whom together make up what can be called an institutional voice (cf. Mishler 1984) – have 'overconfidence' in work, Jack shows disagreement and that he considers their view unrealistic. In the second part, Jack tells me about the beginning of some kind of change in his thoughts about what it is good to be ('now I've started to feel') and how his former moral framework seems to crumble. This transformation is represented in two stanzas in which Jack compares what he believed in before (lines 8-9) with the way he is reasoning about work and illness now (lines 10-12). In accordance with his new way of reasoning, the third part of the story describes how Jack calls into question the solution of his problem. This

part is also divided into two stanzas seemingly representing two opposing moral frameworks. In the first (lines 13-16), Jack reports on *the official plan* and its goals, and in the latter (lines 17-18) he expresses his own hesitations about the same. The official plan, which he obviously does not regard as his own, is rejected by his words 'I don't know what the solution is but it's not that anyway.'

Up to this point, Jack has described through the chain of stories, of which this example is just one, how he has been trying to use the common moral framework by struggling against fatigue and his unexplained illness. His attempt to do so is also manifested in the epilogue of the story when Jack tells me that even if he has his doubts, he will go on with the plan he has agreed on. His reason for this is that he will avoid the risk of being thought of as 'work-shy.'

The rehabilitation issue recurs in the second interview a year later. The story Jack tells this time is partly another story, but it is also a continuation of the one he told me in our first interview. Now, one year later, my first question concerns what has happened to him since last time and Jack responds to this by saying: 'spontaneously I think it has been quite good.' He moderates his answer by adding: 'at least things have been going in the right direction for some time.' His answer indicates that my question brings up moral issues concerning expectations for recovery and change. Soon after this, Jack starts the new story about work training and rehabilitation. The conflict between the culturally valid moral framework about work and the doubts he felt about that, a conflict which was at the centre of the narrative a year earlier, gets a different conclusion this time. Jack has made a decision not to 'go back to work until,' as he says, 'I feel completely recovered.' He tells me how he expressed this decision at a meeting with his physician, employer and an official from the social insurance office. When he stood up for this conclusion, the formal decision about putting him on temporary disability pension was made.

Compared to the way Jack told me about the rehabilitation plan a year earlier, the second narrative shows a change. Jack describes a feeling in the first interview that work training was not the right solution to his problems, but he does not express then to the physician and the others this insight that he stands up for a year later. The formal change with the temporary disability pension accentuates the chronic nature of his illness. At the same time, however, his way of telling it by describing himself as taking on an active role and being the person who

makes the important decisions in his life, shows agency (even if this decision can be said to be in conflict with what is culturally most desirable). In this way, too, the two stories about work training and rehabilitation differ. This also makes the shift in moral frameworks that was possible to discern in the first interview become much more obvious in the second one. The altered way of considering illness as in a way chronic becomes a theme Jack develops throughout the second interview. Differences between then and now turn out to be variations between different moral frameworks. Halfway through the second interview, he summarises this as a crossroads and says that he now follows a different path.

that would be crazy that I- if I did that ((would go back to his old job))

Because then I might end up here (once) again.

In the same state.

But (I mean) that even if I- even if I really had the possibility to do that in every way so to speak .h the question is if I would want that you know

I eh I feel that now I follow another eh path in some way (PB: °mm°)

and that- and this is a path that I eh I don't know if I can stop walking on this path

At least for now.

The narrative from which the example is drawn evolves from a longer description in which Jack talks about what he thinks of his own illness. He describes how he exceeded his limits partly because of a particular sensitivity and partly because he was unaware of his personal limits. He demonstrates this by presenting himself as a person that 'made a point of being the kind of person who never complained.' Even if Jack says, when I ask him what illness has meant to him, that illness has ruined his life, he continues with the story of which the above is a part. In this story, Jack elaborates with changes by comparing his life before illness with how it is now, as well as with what might happen in the future. He describes this as a successive transformation and as a shift in moral frameworks: 'I have different values (now).' The choice to, as he says, 'follow another path' paradoxically means that his former moral framework becomes a risk. What earlier in the interviews turned him into a moral person, by presenting himself as a hardworking, ambitious man who did not give in to illness, is now in this new moral context given another meaning. He argues that if he would end up in the same situation again, that is to go back to his old work; he would probably become ill once more. He formulates this shift as a crossroads he has

come to, and as a choice he has to make, a choice that means that he now follows 'another path.' It is interesting that Jack's revaluation of his former life also has general validity by including how he looks upon other people's ways of leading their lives. He describes how he now can see how people close to him run the risk of becoming ill in the same way as he did by the way they are leading a stressful life similar to his own.

### *Judy's illness narrative*

Judy is in her forties. We met for three interviews conducted with an intervening space of about a half-year. She has a university degree in the same field as that where she is employed. However, Judy has been sick for quite some time and has had a temporary disability pension for a couple of years. She considers her fatigue as one part of a range of different but related health problems that she has been suffering from during the last six or seven years. Most of all, she associates the chronic fatigue with a surgical operation she underwent about five years earlier. This operation is usually considered to be uncomplicated, but in Judy's case there were severe complications.

Judy describes herself as depressed and seems to have accepted a psychiatric label for her suffering as well as one of chronic fatigue. According to Judy, a psychiatric diagnosis could be easier to live with, in some cases, than CFS. She describes the depression as being a consequence of CFS and says that she cannot cope with all the things she did before. Her various health problems have also led in different ways to several negative experiences of the health care system. In several ways, her illness narrative differs from the one Jack tells. She is more resigned and her confidence in the health care system is low; she feels that too much has happened. Judy's situation with a temporary disability pension (which in the interim between the two interviews has been reviewed and extended for another period) means that she has no pressure from her employer, the physician or the social insurance office to go back to work. On the contrary, she describes how these people told her it was too early to think about rehabilitation when she brought up the issue herself. She assumes that she will get another period of temporary disability after this one. This, however, does not mean that Judy has no plans for a future career. At the two first interviews, she tells me about her plans for the future and about her work to realise these plans – efforts that at times are actively pursued. These plans

include re-education and a totally different kind of job 'later when I'm well.'

However, work and rehabilitation are not central themes in the interviews with Judy. Instead, most of her stories are about her family and about social relations with more distant family members and with friends. The illness as a moral occasion, as Frank (1997) writes, becomes in Judy's narratives first of all a question about being ill for a very long time with an illness that is relatively 'invisible.' It is also about how she deals with a type of suffering that because of its invisibility is easily forgotten by others. She shows how issues about morality are constantly raised in her everyday life by habitual narratives (cf. Riessman 1990). In these narratives she lets 'the others,' those who 'also become tired' of her always being fatigued, to be heard in comments like 'why don't you just cheer up a little?' or 'come on now!' The moral framework that becomes noticeable in the interviews is thereby one which is chiefly linked to Judy as wife, mother, daughter, sister or friend. In that way, the moral framework Judy deals with in her narratives is confined to people close to her in some way and to everyday moral questions like having the strength to do things for herself and for those nearest to her. The manner in which Judy has chosen to manage her illness as a moral question seems to be to confine herself and limit herself in different ways.

The second interview with Judy starts as well as ends by her describing that nothing has really happened with her illness since we last met. She has not become worse and has not improved but is maybe a bit more resigned. Judy describes her situation as her 'little life'.

I have well I have my temporary disability pension, and I have my mobility service, and I have my- my little life.

The only difference she brings to the fore is that she has become more used to her illness and thus can handle it in a better way. This means that she sometimes can force herself to do things if, as she says, 'I have to.' To do such things implies that she 'fights very hard,' and afterwards she feels exhausted. Her statement at this point in the interview turns out to be important for what happens later on and for the understanding of the moral dilemma that such actions might entail.

The interviews were spread over a relatively long period, and this most likely contributed to the fact that moral questions related to prolonged illness, improvement and recovery became topics in our meetings. In a similar way to what the interviewees told me about their

contacts with physicians, the social insurance office as well as the family and friends, the recurring interviews seem to give them reasons for giving accounts of why they were still ill. Thus the method shows, from still another dimension, a glimpse into the particular difficulty many chronically ill find themselves in – dealing socially with their continued illness by facing moral questions. In the interview situation, and particularly when I met the interviewee for the second or third time, there seemed to be a need to explain why one had not become well, had not started to work, or had stopped the work training one was engaged in when we met before. They also seemed to feel an urge to explain different methods they used to make the illness more tangible, by pointing at what they could or could not do. The moral work performed through the narratives to handle all this is some kind of justification. For Judy, this seems to be about the balancing act between what others wish from her, and about choosing the situations when she ‘struggles’ to do more than she actually feels that she can handle.

Some time into the second interview, Judy tells a story about such a special occasion. Introduced by her initial words ‘yes, and what else has happened?’ a story follows that seem to be told in response to my opening question about what has happened to her since we saw each other last time. The narrative is about a particular party for her adult son. By giving this party, Judy fulfils a wish her son has expressed for many years. However, this is not something that Judy says when she introduces the story. Instead she tells the story as an example of a situation when she has to ‘pull herself together.’ Important to understanding the narrative is the fact that the party was held in the area where Judy grew up, and that this place is far from the city where she and her son now live. This means a number of difficulties like how to find a suitable place to stay, since Judy has to rest a lot more than most people do, how and what to cook etc. Judy describes how she and others solve problems like these. Through her narrative about the party, we gain insight into another difficulty – the fact that her relatives seldom see Judy because of the distance between the city where Judy and her own family live and the place where her relatives live. Instead, they had been getting reports on how she was feeling by telephone contacts with Judy herself or, when she is too tired to speak for herself, with her husband. The meeting with her kin at the party for the son therefore leads to a moral dilemma for Judy. At the same time as Judy fulfils her son’s wish by arranging the party, she shows an ability to take action.

This counteracts all that she has been trying to explain to her relatives for a long time about her illness. The dilemma thus consists of the problem that Judy cannot both act as a good mother and show the ‘true picture’ of herself and her illness that she wants her relatives to understand. When Judy returns to this story a bit later into the interview, she seems to do so to explain to me something about her illness.

#### PULLING ONESELF TOGETHER

- 22 But it’s not something that you manage to do very often.  
.hh you just do it now and then  
but then you have to pay the price, and, well  
for many days after that I’m just exhausted and like that.

#### THE DILEMMA

- 26 .h and that’s why my relatives, for example, they .h they think that it wasn’t so  
bad, since I got there, didn’t I  
and then they can’t understand.

*((I ask whether her relatives in her hometown know anything about her illness, and Judy describes how and what she has told them.))*

PB: Was there anyone who said anything?

Judy: They were surprised

#### THE ILL

- 52 and eh and like if they compare when they call me and so on  
and eh sometimes I say myself that I don’t feel well  
and haven’t had the strength to do something or something like that  
or else my husband says that Judy isn’t doing so well.

#### THE CONFUSION

- 56 .hh and then I show up and I’ve like  
and eh (I’ve) bought new clothes and everything  
and now it’s going to be  
59 And eh I guess I did a little extra for the way I looked since it was such a party  
then and .hh everything  
60 So it was – they were really very confused.

#### A NEW PROBLEM

- 61 So now I don’t know how I’m going to get them to understand that it was one of  
these .h well, it-  
or else I just don’t give a damn.  
They can think whatever they want to.

Judy summarises the story about the party by describing it as an extraordinary situation when she had to pull herself together – something that she explains to me ‘it’s not something that you manage to do very often.’ Her evaluation works as an introduction to the second version of the story in which she presents the problems that arise from her attempt to fulfil her son’s wish. Considered from a moral dimension the story emphasises the dilemma Judy finds herself in. By taking her role as a mother seriously and putting aside her own suffering to live up to her son’s dream, she puts herself in an unfavourable and doubtful light in front of her relatives. At the same time, the story Judy tells becomes a way to present herself as a good mother and as someone who does everything she can for her children even though she is chronically ill. In this way, it is a story about illness as well as about morality.

The contradiction between the images conveyed over the telephone and by the way she looks in her new clothes and makeup confuses her relatives. Judy says that ‘they were really very confused.’ The problem Judy expresses in the rhetorical question ‘now I don’t know how I’m going to get them to understand’ is solved by withdrawing herself and simply not bother about the consequences that these contradictory pictures lead to (‘or else I just don’t give a damn’). Just as she describes herself doing in other situations, Judy says that people who are at a distance from her (geographically and/or relationally) ‘can think whatever they want to.’ In relation to her husband and her children, however, she describes how she tries to fulfil their expectations in different ways even though she is not always able to carry this out. In this way, the moral frameworks Judy uses are confining due to the illness.

### **Illness narratives as moral quests or as moral questions**

Viewed from the perspective of what Taylor (1989) writes about identity and morality as intertwined in a spatial dimension, the analysis of the two interviewees’ narratives illustrates how illness narratives can be understood as a search for what a good life is and how to lead a good life despite illness – a moral quest. In Jack’s story, the shift of moral frameworks is at the centre of the narrative while Judy’s narrative most of all seems to reveal a struggle to maintain parts of her old moral framework by confining herself. In his new moral framework, Jack no longer sees work as the most important thing in life and he describes this shift as if he is now ‘following another path.’ The new way to consider

life and its value – the shift of moral frameworks – makes it possible to lead a ‘good life’ despite his illness and his new more chronic status due to the temporary disability pension. In Judy’s narrative, the moral quest means that she prioritises certain social relationships that appear to be more valuable and important while she chooses to leave other more distant relationships out of her daily life. This can be interpreted as a kind of a reformulated framework for what is a good life. However, it is a transformation when the new frame has become more limited and narrow, not because of a new moral framework but as a result of a necessary prioritisation due to illness. In that way, this narrative describes a retreat with reduced goals for living rather than being about new and different ones. Yet, Judy tells me about a distant goal by describing her plans for a new kind of career later when she is well.

All of the interviewees in the study seem to involve some kind of moral quest in their narratives about illness. This tells us something about chronic fatigue as an illness that raises questions about morality. However, in order to be able to reorient oneself in a moral space it seems as if the illness has to be linked to the personal life story by a narrative reconstruction. Unlike what has been shown in the narratives told by Jack and Judy, the quest in one other case in the study seems to stop at the question of what kind of illness one is suffering from. For this question, posed by others as much as the sufferer, the individual sufferer could find no answers by searching for an explanation in his personal life history. That is, the suffering could not be explained within the biographical frame of how his life has been led. Thus, illness remains as something inconceivable and inexplicable in accordance with his life story as well as from a medical perspective. The moral quest then becomes restricted to the ‘moral question’ – why me? Without an explanation that makes it possible to understand one’s illness from the perspective of one’s own life, one also lacks an anchorage that can orient one in moral space. Without knowing how one has come to the place where one is now, it becomes difficult to define a future path.

## Conclusions

In the narratives about chronic fatigue, the narrative reconstruction and the anchoring of illness in the personal life story also seem to be of significance for orienting oneself in a moral space. These are furthermore significant as guidance tools for how the person should proceed in life in order to live it in a ‘good’ way, and for what a ‘good life’ is when

one is suffering from a contested illness. As in earlier studies (e.g. Blaxter 1993, Hydén 1995, Williams 1984), this means that the narrative reconstruction is important to understanding and dealing with chronic illness. However, most of these studies emphasise how people explain the genesis of their illness through narratives. This means that they, according to Taylor's arguments, ignore the question about where they are heading. The analysis presented here shows that alongside the moral quest, the narrative reconstruction also includes this question. One example is the shift in moral frameworks. What also becomes possible to see in the analysis is that an explanation in other contexts, when presented by others than the sufferer him/herself, might be perceived as face-threatening and offensive. It could be so because it places the blame on the ill person. In their own illness narratives, though, the same kind of explanation can be used as a resource with which to reformulate the frameworks for what a good life is. It can help to answer the question of where one is heading. In that way, the shift of moral framework through reformulating one's aim in life could be an example of what Frank (1997) calls being successfully ill. A situation when continuing illness with physical as well as psychological limits not only turns out to be something the ill person tries to manage, but which also becomes a starting point for a re-orientation in life. In studies about CFS, this has been described as identity work and as the 'partly transformed self' (Åsbring 2001) and the 'radicalized self' (Clarke and James 2003).

The 'new' or modified moral frameworks that the individual can adopt do not always agree with what usually is conceived of as a 'good' life. Williams (1993: 92) argues that when they narrate their experiences of illness in relation to everyday life, people 'elaborate moral discourses based on their own biographical experiences which often stand counter to the dominant rhetoric of both professionals and politicians.' To turn down suggestions for work training, for instance, can be such a moral discourse that contradicts the prevailing view of work, illness and morality. As a consequence, what in one respect can be viewed as an example of being successfully ill, in another respect might be thought of as a case of chronicity (Estroff 1989) – a fusion of identity and diagnosis. What this analysis has shown is that people resist threats against their sense of self by striving to maintain their views of themselves as moral persons in at least two different but intertwined ways. They try to orient themselves in the moral space, and by presenting

themselves as trustworthy persons and as persons with dignity. Both of these presentations can be seen as part of the moral quest.

## Transcript key

(once)	uncertain interpretation
((comment))	transcriber's comments or non-verbal activity
underlined	emphasis
-	sharp cut-off
°quiet°	noticeably quieter than surrounding talk
*laugh*	with laughter in voice
.h .hh	audible intake of breath
(.)	short pause

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<sup>1</sup> Work training is an occupational rehabilitation activity that the ill person usually undertakes at his/her own workplace. The ill person can then do some adjusted 'work' for a few hours a day. During work training, the individual will receive a rehabilitation allowance from the social insurance office, as compensation for lost income instead of sickness benefit.

## References

- Banks, J. and Prior, L. (2001) Doing things with illness: the micro politics of the cfs clinic, *Social Science and Medicine*, 52, 11-23.
- Blaxter, M. (1993) Why do the victims blame themselves? In Radley, A. (ed), *Worlds of illness*, London: Routledge.
- Bülow, P.H. (in press) Sharing experiences of contested illness by storytelling, *Discourse & Society*.
- Bülow, P.H. and Hydén, L-C. (2003a) In dialogue with time: identity and illness in narratives about chronic fatigue, *Narrative Inquiry*, 13 (1), 71-97.
- Bülow, P.H. and Hydén, L-C. (2003b) Patient school as a way of creating meaning in contested illness: the case of CFS, *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7 (2), 227-49.
- Clarke, J.N. and James, S. (2003) The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome, *Social Science & Medicine*, 57, 1387-95.
- Cooper, L. (1997) Myalgic encephalomyelitis and the medical encounter, *Sociology of Health and Illness*, 19 (2), 186-207.
- Estroff, S.E. (1989) Self, identity, and subjective experiences of schizophrenia: in search of the subject, *Schizophrenia Bulletin*, 15 (2), 189-96.
- Frank, A.W. (1997) Illness as moral occasion: restoring agency to ill people, *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 1 (2), 131-48.
- Gee, J.P. (1986) Units in the production of narrative discourse, *Discourse Processes*, 9, 391-422.
- Gee, J.P. (1991) A linguistic approach to narrative, *Journal of Narrative and Life History*, 1 (1), 15-39.

- Goffman, E. (1959) *The presentation of self in everyday life*, New York: Anchor Books.
- Henriksson, C.M. (1995) Living with continuous muscular pain - patient perspectives. Part i. Encounters and consequences, *Scandinavian Journal of Caring Science*, 9, 67-76.
- Hilbert, R.A. (1984) The acultural dimensions of chronic pain: flawed reality construction and the problem of meaning, *Social Problems*, 31, 365-78.
- 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 (2), 247-59.
- Hydén, L-C. (1995) In search of an ending. Narrative reconstruction as a moral quest, *Journal of Narrative and Life History*, 5, 67-84.
- Hydén, L-C. (1997) Illness and narrative, *Sociology of Health & Illness*, 19 (1), 48-69.
- Kirmayer, L.J. (1988) Mind and body as metaphors: hidden values in biomedicine, In Lock, M. and Gordon, D. (eds), *Biomedicine examined*, Dordrecht: Kluwer Academic.
- Labov, W. and Waletzky, J. (1967) Narrative analysis: oral versions of personal experience, In Helm, J. (ed), *Essays on the verbal and visual arts*, Seattle: University of Washington Press.
- Linde, C. (1993) *Life stories: the creation of coherence*, Oxford: Oxford University Press.
- MacIntyre, A. (1981) *After virtue. A study in moral theory*, Notre Dame, IN: University of Notre Dame Press.
- Mishler, E.G. (1984) *The discourse of medicine: dialectics of medical interviews*, Norwood, NJ: Alex Publishing Corporation.
- Mishler, E.G. (1986) *Research interviewing: context and narrative*, Cambridge: Harvard University Press.
- Mishler, E.G. (1999) *Storylines: craftartists' narratives of identity*, Cambridge, MA: Harvard University Press.
- Parsons, T. (1951) *The social system*, Glencoe, IL: Free Press.
- 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, 601-12.
- Riessman, C.K. (1990) *Divorce talk: women and men make sense of personal relationships*, London: Rutgers University Press.
- Riessman, C.K. (2001) Analysis of personal narratives, In Gubrium, J.F. and Holstein, J.A. (eds), *Handbook of interview research: context & method*, Thousand Oaks (California): Sage.
- Schafer, R. (1992) *Retelling a life*, New York: Basic Books.
- Taylor, C. (1989) *Sources of the self. The making of the modern identity*, Cambridge, UK: Cambridge University Press.
- Ware, N.C. (1992) Suffering and the social construction of illness: the delegitimation of illness experience in chronic fatigue syndrome, *Medical Anthropology Quarterly*, 4 (6), 347-61.
- Williams, G.H. (1984) The genesis of chronic illness: narrative re-construction, *Sociology of Health and Illness*, 6 (2), 175-200.

- Williams, G.H. (1993) Chronic illness and the pursuit of virtue in everyday life, In Radley, A. (ed), *Worlds of illness*, London: Routledge.
- Åsbring, P. (2001) Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia, *Journal of Advanced Nursing*, 34 (3), 312-19.

## Paper B



# IN DIALOGUE WITH TIME: IDENTITY AND ILLNESS IN NARRATIVES ABOUT CHRONIC FATIGUE

Pia H. Bülow and Lars-Christer Hydén

*Department of Communication Studies,  
Linköping University, Linköping Sweden*

When we are stricken with an illness or some other affliction, the temporal frameworks that we take for granted in our everyday lives are overturned. Thus suffering and illnesses raise questions associated with temporality: were the past events necessary and unavoidable, could anything else have happened, and what will happen next? In this article we will discuss two intertwined problems that have to do with the organization of time in narratives about illness: the interviewee's attempt to create an interview narrative and the researcher's need to create a temporal order and coherence in the interview material properly founded in research. With a foothold in the literary scholars Morson's and Bernstein's theories about shadows of time we base our argument on an analysis of narratives given in interviews by people affected by Chronic Fatigue Syndrome (CFS). The analysis shows various ways time can be used as a discursive tool to temporalize illness and suffering including temporalities that frequently go outside linear time perceptions by the use of "sideshadowings". These various ways of temporalizing illness influence, for instance, factors like issues of responsibility and freedom of action. Findings like these indicate the importance of including the interviewees' own temporalizations in the analysis of illness narratives in social science.

*Keywords: Illness Narratives, Interviews, Narrative Analysis, Responsibility, Temporalization*

## INTRODUCTION: THE PROBLEM OF TIME IN INTERVIEW NARRATIVES

Every suffering and illness has a history – a past, a present, and a future. Thus suffering and illnesses raise questions associated with temporality: were the past events necessary and unavoidable, could anything else have happened,

and what will happen next? When we are stricken with an illness or other affliction, the temporal frameworks that we take for granted in our everyday lives are overturned. Thus we have problems with one of the foundations for organizing our lives and ourselves, namely temporality. One way to make sense of and to order our life is by narrativizing our experiences of illness, a narrativization and temporalization which often is asked for by, for instance, consulted physicians and social researchers (Bury, 2001; Hydén, 1997).

The issue of time in suffering and illnesses is often brought to the fore in studies of experiences of illness and narratives about illness. In this article we would like to discuss a problem that we feel to be central specifically in studies of different forms of illness narratives that are based on use of interview material. Our thought is that we as researchers are confronted with two intertwined problems that have to do with time. The first is the interviewee's attempt in the interview situation to use time to create a narrative based on a balancing act between personal responsibility and liability, between hope and despair, and between the possible and the actual. The second is the interviewer's need to impose research-based temporal order and coherence on the interview material. This means that there are at least two different kinds of temporal orders which are to be put together. There is therefore a risk that a certain temporal order – perhaps chiefly the researcher's – will dominate, at the expense of other possible temporal orders. The problem is that we are then in danger of losing the issues of responsibility for actions and destiny, possibility and necessity, which are linked to the sufferer's narrativization, and thus an action-related plurality that presupposes active use of a whole series of *different* temporal frameworks.

In our view, it is possible to shed new light on how time is used in interview subjects' narratives about their illnesses, based on discussions of temporality by two literary historians, Gary Saul Morson (1994) and Michael André Bernstein (1994). They examine examples from Russian literature (Morson) and narratives about the Holocaust (Bernstein), based on the idea that temporality concerns issues of conduct, freedom, determinism, responsibility, destiny, and choice. They are especially critical of the "utopian temporality [that] satisfies a hunger for certainty" (Morson, 1994, p. 1). It does not offer any opportunity of reflection or individual action, since life is seen as being predetermined by a temporal pattern that the individual cannot influence, but to which he or she must resign himself. By the same token, they say, there is a tendency in all sciences – social science, as well as the humanities

and the natural sciences – to reduce time to *one* type of time, and thus to describe and perceive human existence within a framework that is far too narrow. Morson and Bernstein argue instead that we need “multiple concepts of time – multiple ‘chronotopes’, as Bakhtin would say – for diverse purposes and circumstances” (Morson, 1994, p. 3). We argue that their emphasis on the diversity of temporality – by their concept *shadows of time* – can provide new perspectives on studies of narratives about illness.

If, like Morson and Bernstein, we proceed from a view of time as being closely associated with central human questions concerning hope, guilt, blame, and regret, then the conception of time also becomes significant to how we interpret and thus narrate our own experiences, and to how we interpret others’ narratives. While a research interview is a tool with which researchers collect data as well as an opportunity for the interviewee to try to describe and explain his/her experiences, it is also a meeting between two people who create an interview narrative together. Thus the significance and function of different temporalities that are used will influence this meeting and also the interpretation of what is told. And if a greater role is given to the different temporalities that are expressed in the interview, this should have implications for the analysis regarding factors like issues of responsibility and freedom of action.

There are two points that we want to make in this article. The first is to show how interview subjects use various forms of temporality for various purposes and the second is to argue for the importance of letting the narrator’s temporalization of his or her illness narrative appear in the analysis. We start by discussing the general matter of time and narrative and the relation between narrativizing and temporalizing. After this an overview of how the issue of time and illness has been described and analyzed within social science will be presented, especially concerning studies of illness narratives. Then Morson’s (1994) and Bernstein’s (1994) alternative for analyzing temporalizations as *shadows of time* is introduced, followed by our own study based on an analysis of narratives given in interviews by people affected by Chronic Fatigue Syndrome (CFS). By proceeding from what people tell about themselves and their illness, with a foothold in Morson’s and Bernstein’s theories, we attempt to describe the various ways time can be used as a discursive tool to tell about illness and identity – what we call *temporalizing*.

## NARRATIVIZING AND TEMPORALIZATION

All narration is based on our selection of certain events as “reportable” (Labov, 1972). Telling about these events can cast a special light on one’s life, for example, or on one’s current situation (Bruner, 2001). The *selecting* of events, the *organization* of them and the description of the *relationship* between these events are thus basic elements in narratives. The construction of the order and the relationship between events involves asking questions about factors including the result of one’s own action or lack of action, about necessity and externally-originating constraints, about what might have been possible but never occurred. It connects the way we choose and narrate events to issues that deeply affect our own moral evaluations of our lives. This is something that has the greatest significance especially in connection with illness (see, for example, Hydén, 1995; Williams, 1993).

Creating an inner order and relationship between events involves the narrator’s use of time; events are organized within themselves, which is tantamount to some form of temporal relationship and order. If two events happen at different moments of time one thing has to be said to happen earlier and the other consequently occurs later. Thus we often visualize time as being linear; it moves in only one direction from the past to the future. Linear time is often compared to an arrow or an axis. This view, however, of time as merely linear has lately been rejected by social theorists like Barbara Adam (1995) and Alberto Melucci (1996), who both plead for a complexity of times (consisting of different aspects of time) and for a view of time as simultaneously linear and circular.

According to Jens Brockmeier’s (2000) analysis of autobiographical narratives narrated time can also be given other forms than the arrow. Brockmeier states that “autobiographical time” from the straight line “only needs a small shift” to be ordered into a circle, a cyclical wave shape, or a spiral. Regardless of the linear time’s form, it seems to give a time that moves “forward” with, as Freeman describes it, “each moment unique and unrepeatable” (Freeman, 1998). As we know from fiction, temporality can, however, assume many forms; we have possible and virtual times, events that develop backwards, and so on. As narrators we are often adroit at using just these different forms for *temporalization*.

## ILLNESS AND TIME

In research about illness experience and time it is, somewhat simplified, possible to identify three different ways that sufferers' temporalization of illness has been interpreted and analyzed. First, there are studies that are based on a linear comprehension of time, in which the illness is analyzed as *a disruptive event* that marks the temporal distinction between "before" and "after". Secondly, there are studies based on the same linear perception, but in which analyses primarily take the *direction of time* as departure. Thirdly, there are studies that build on the fact that there can be different *types of temporal orders*, and that interviewees and/or their narratives can conform to these temporal orders. We briefly discuss these different ways of interpreting and analyzing the temporalization of illness experience.

The first way to describe illness, and primarily chronic illness, as an interruption – a "biographical disruption" is rather common in social science since the publication of Michael Bury's (1982) well-known article. According to this view the medical diagnosis and the illness achieve the status of something that divides life into a "before" and an "after". For the individual this leads to the perception of a "disrupted life" (Becker, 1997) in which falling ill is a sort of "turning point" interviewees describe (Charmaz, 1991). That is, life is seen with a linear perception and the illness is therefore placed into that time line.

In the view of the illness as a disruption, it is the break and the gap between then and now that must be handled in some way. Narrating then becomes a question of creating a coherent life story bridging the gap between life before the illness and the life that the illness and the diagnosis involve. Williams (1984) describes in an often-cited article how narratives about chronic illness create such a coherence via a reconstruction of the life history – and thus of the individual identity – in which the then and the now are joined together. Mark Freeman (1993), the American psychologist who has been interested in the relationships between memory, narrative, and self, describes similarly how the retelling in the form of autobiographical texts is a kind of "rewriting the self".

Analyses which are limited in this way to linear time become problematic in understanding narratives that fall outside the culturally prevalent figure of time, i.e. when the narrator's temporalizing is not in linear order (or for that matter falls outside the researcher's choice of temporal direction). In

Brockmeier's (2000) analysis, for example, this results in two categories of "timeless" models – what he calls "the static" and "the fragmentary" models – in which he describes the former as common when people tell about illness, bereavement, torture and other traumatic experiences. In Davies' (1997) breakdown of her interviewees' temporalizations, the category of "living in the empty present" similarly represents a way of temporalizing one's experiences that rejects the linear view of time by simply ignoring it. The same can probably be said about Charmaz' (1991) category "existing from day to day", and about Frank's (1995) chaos narrative.

The second way of analyzing temporality is likewise based on the linear time axis with the illness as a turning point and a disruption, which causes the issue of the temporalization's direction to appear. Time and the temporal dimensions are usually studied and analyzed in a forward direction from the present toward the future, or based on the question of how the present can be understood in light of the past. An example of the aforementioned is Charmaz' (1991) analysis of "how ill people's thoughts, feelings, and actions toward [the present] shape their time structure and reshape their perspective" (p. 170). Asbring (2001) makes a similar description of CFS as a disruption in life that is handled in a forward direction. Similarly, several researchers have, after the recent development of new medicines for HIV-infected and AIDS patients, studied how people with these diagnoses regard their uncertain but more positive futures (Davies, 1997; Ezzy, 2000; Pierret, 2001) in the same kind of forward direction of time.

One interesting example of how illness and identity can be temporalized in different ways backward in time is brought out in an analysis by Orona (1990). She describes how people who care for an Alzheimers-afflicted spouse or parent use temporal dimensions in order to be able to understand their relative's identity change, to describe a changed perception of time (compared with earlier), and to oppose the identity loss brought by the illness in order to retain memories of the relative as he or she was before the illness.

The problem with these analyses of temporality is that they exclude descriptions based on what could have happened, but did not happen, i.e. the trials and tests that the narrator can make of various possible courses of events and assumptions of responsibility in the past (for an example of this, see Hydén, 1995). Not allowing the past just to cast a shadow forward, but

rather testing the possibilities of other courses of events, demonstrates the possibilities of the past.

The third way of analyzing the temporalization by sufferers is based on researchers' thinking in terms of a number of models for temporality and time sequence in which whole narratives are reduced to a certain type of illness narrative. Ezzy (2000) describes this as "identifying the dominant narrative structure around which each interview was formed" (p. 608). Similarly, many researchers have identified and categorized different kinds of illness narratives that are formulated in relation to time (Charmaz, 1991; Davies, 1997; Frank, 1995; Orona, 1990; Pierret, 2001; Robinson, 1990). Robinson (1990), for example, using an analytic model developed by Gergen and Gergen (1986), described a number of different kinds of biographical narratives based on how people afflicted with MS employ written autobiographical accounts to formulate their illness narratives in relation to time and to their own goals.

The problem with typologically classifying narratives and categorizing them is that, in principle, it is only possible to describe one way in which the individual temporalizes his illness, while other types of temporalizations end up outside the analysis or remain unobserved. Thus the narrator is forced into one type of the researcher's gallery of types, and the hesitations and trials that may remain in the narratives risk being lost.

The problem of time, which we as researchers are confronted with, is connected with the interview and how we analyze it. In the interview situation two different temporal frames meet: the interviewer's and the interviewee's. Analyzing the interview later on the researcher adds a third temporal frame, namely the analytical/interpretative. In analyzing, writing and reading temporalizations in illness narratives it is sometimes difficult to distinguish between these three frames. This is sometimes found in the overview of research presented here as well. However, despite the different ways that interviewee's narrativizations about illness have been interpreted and analyzed few researchers have discussed the possibility of many different ways of temporalizing in a single illness narrative. Likewise few researchers have discussed what meaning the use of different kinds of temporalizations have in illness narratives. In order to be able to adopt a multiple view of temporality it is necessary that we as researchers use a broader concept of temporality. We need one that will give us the opportunity to ensure that interview subjects can use and alternate between different forms of temporality in their narratives and that these will be reflected in the analysis. For this, it is important

to discuss and distinguish between different temporal frameworks for interview narratives. This means that it is of interest to us to search for authors who present analytical instruments that can shed light on different forms for temporalization. The Bakhtin tradition (Bakhtin, 1986), as it is presented by Morson (1994) and Bernstein (1994), is just such an interesting example.

## SHADOWS OF TIME

Narrating and narratives can, by describing other times and other places, be seen as a way of transporting both the narrator and the listener in both time and space (Young, 1989). It can also be seen as a way to try to form the future by initiating a narration about what could happen (Mattingly, 1998). Morson (1994) and Bernstein (1994) attempted to describe different forms of temporalization. They worked, sometimes in parallel, with three different forms of temporalization which they call “shadows of time”, based on the fact that they were particularly interested in the relationship between possibility and necessity in the novel and in historiography.

The concept *shadows of time* means that events cast their shadows over the narrator’s present. These shadows of time can come from the front (foreshadowing), from the back (backshadowing), or from the side (sideshadowing). Based primarily on Russian literature (especially on Dostojevsky and Tolstoy), Morson (1994) describes how the shadow of what is expected to happen, what has happened, and what might happen – or even what might have happened, gains significance in the narrative of a novel in the use of different types of shadows that can open and close time.

*Foreshadowing*, or the shadow that future events cast over characters in films or novels without the character himself knowing what we as audience or readers think we understand, is hardly ever found in narratives of life experiences that people give in interviews. This is a sort of “backward causation” that, outside literature can almost exclusively be equated to a belief in omens as prospects of what will happen. However, to understand in retrospect how an event should have been foreseen in different signs and omens, which once something *has* happened are reinterpreted as signs of what later on actually *did* happen – “*backshadowing*” – can very well be included in people’s narratives about their lives. The shadow comes in both cases before the fateful or important event, but in the latter case could not be under-

stood until afterwards, when something has already happened. Regardless of whether a catastrophe can be predicted ahead of time (as by the reader of a novel), or retrospectively is judged as something which should have been predicted, both the foreshadowing and the backshadowing presuppose a predestined event, something that cannot be changed. Time closes.

Morson (1994, p. 238) states that both of these two time shadows can be related to what is needed for “good storytelling”. In other words, with these time shadows a more “tellable and effective” structure can be created, with a certain order between different events. “Loose ends” are eliminated, and a structure with a beginning, a middle, and an end becomes a narrative technique that we use almost “automatically”. What Morson calls “loose ends” consist of alternative courses of events and possibilities – “*sideshadowing*”, shadows cast on the present from the sides. These “sideshadows” tell what could happen or what could have happened. Sideshadowing opens time. At the same time as a description is given of what happened, the picture of what could have happened becomes apparent. In sideshadowing, that which has happened becomes not the only possible outcome, but rather one of at least two possible alternative developments of events. Thus the sideshadows counteract the tendency to interpret what is happening now as an unavoidable consequence of earlier events. The sideshadows entice us instead to investigate “the other possible presents that might have been and to imagine a quite different course of events” (Morson, 1994, p. 118). Questions like “if only this or that had not happened, what would my life look like now; what would have happened?” become both possible and reasonable to ask.

A fourth time concept that Morson works with is *vortex time* – in other words, regarding time as a whirlpool or as a black hole. Vortex time is the opposite of sideshadowing – where sideshadowing divides itself into branches of a number of different courses of events, vortex time converges several different reasons and events into one single point, a catastrophe. Morson compares this to “a hidden clock [which] seems to synchronize this diversity so that, even though causal lines seem unrelated to one another, they not only lead to the same result but also do so at the same moment.” (p. 163).

Even though Morson and Bernstein developed their concepts of time shadows based on written fiction and historical novels in which a story always has some sort of an ending, we suggest that it is reasonable to use some of these concepts to describe and understand how interviewees tell about their illnesses. The concept of time shadows and the various ways of temporalizing

make it possible to understand how interviewees tell how events have influenced their lives in different ways, how they could have influenced them, and even how they can influence them in the future. The shadows of time, and primarily sideshadowing, make a more open view of use of time possible, by presenting an alternative to the otherwise quite closed temporality that linear narratives have. This will be of our concerns when we now turn to the study and to the analysis of narratives about CFS.

## THE INTERVIEWEES AND THE ANALYSIS

The examples that we will discuss are excerpts from interviews with 14 people, each of whom has received a diagnosis of CFS or a related diagnosis in which unexplained fatigue makes up a significant part of his/her suffering. These people earlier constituted two “classes” in a patient school organized by, and carried out at a specialist clinic in a large hospital in Sweden. After each class completed the patient school in which one of the authors of the article (PB) took part during an observation study (Bülow, 2002; Bülow & Hydén, 2003), contact with several of the participants continued.

Except for one person who was interviewed only once, all of the interviewees were interviewed on at least two different occasions, and half of these (seven people) were interviewed on a third occasion. All interviews lasted for about an hour. The first interview took place in most cases about six months after completion of the patient school. An additional period of between three months to a year elapsed between the two first interviews. The third interview was done with six subjects about 1½ years after completion of the patient school. The third interview of one of the subjects was done after a lapse of 2½ years after completion of the patient school. Most of the interviews were conducted in the interviewee’s home while the rest took place in public places like libraries or cafés that the interviewee suggested or at the interviewee’s work place. The analysis presented here is based primarily on the 14 initial interviews.

The interviews were transcribed using a sociolinguistic model for narrative analysis that is based on spoken-language, rhythmic markers represented in lines and stanzas (Gee, 1986, 1991). Each line is organized around one central “idea unit” in what Gee (1991) terms “argument”. Lines then tend to be clustered into series of lines that have a similar structure, concern the same

topic or are matched in content. These series of lines, called stanzas, are “the basic blocks of extended pieces of discursive language” (Gee, 1991, p. 23). Important for the analysis is the prosodic use of language where, for example, the length of a pause tends to indicate the end of line, or, if it is a longer pause, a major transition like the end of story (Gee, 1986). This model thus allows analysis of both the narratives’ content and structure. It expresses oral narratives in writing, making it possible to capture both the clearly defined stories with a distinct narrative structure and those parts of less-structured narratives that often occur in interviews (Mishler, 1999).

In a first analytic phase, the transcribed interviews were labeled according to the temporal placement that the narrator assigned to events and experiences. Thus it became apparent how the interviewees oscillate between different time perspectives in their narratives. They switched back and forth between the times before their illnesses, the times of searching for answers about the unexplained suffering, how their lives were going at present, and so on. The individual narratives or narration episodes were then analyzed with regard to how the interview subjects made use of various temporalizations of their illnesses and their suffering in their narratives.

## THE INTERVIEWS AND TEMPORALITY

Interviews can be said to make up a complex discursive event in which a whole series of different time perspectives are presented by the interviewee in such a way that it becomes possible for the listener (the interviewer) to draw conclusions about how these events were played out in real time – what is sometimes called the told (in contrast to “the telling order”) (Goodman, 1981; Mishler, 1992). At the same time the interviewer can by his/her way of questioning suggest for instance a certain time as the starting point or as the endpoint for a narrative. What is said and narrated in interviews is thus based in the interview situation’s here and now. The speakers sit opposite each other, in a focused situation (Goffman, 1961), which makes it necessary for both of them to relate to the time of the narration. In other words, when the speakers move to other times and places, each must indicate to the other what he is doing. Thus it becomes possible for the second speaker to move along with the first, and at the same time to gather the different pieces together into a temporal whole. Temporalizations of illness events are therefore based

on the interview situation's here and now, which thus makes up one of the points over which a shadow is cast.

The common starting place and the initial question in all interviews in our study concerned the patient school where the researcher/interviewer had first met the interviewees. How did they come to the patient school, and what had caused them to be there? From a point that in most cases was about six months back in time, the interviews were then developed into narratives starting from several different junctures in the interviewees' lives.

The interviewee as narrator and the interviewer as questioner and listener created jointly the order of what was said in the interview. The interviewer's questions and interposed comments sometimes led a narrator to continue, or caused him/her to diverge in some other direction. At other times the interviewee seems to have continued with the story that he/she started before the question.

Even though the narration time is constructed simultaneously by the interviewee and the interviewer and is partly controlled by a series of assumptions, the interviewees temporalize their experiences, thoughts, and explanations about their chronic fatigue in several different ways. They talk alternately about things that have happened recently, and of things that happened many years ago – in their childhoods, or when they started working at a certain job. The narration time thus shifts both listener and narrator from the present to the past and back to the present, which at the time makes the narrative seem quite fragmented.

By classifying the parts of the interview in the analysis by their temporal placement in relation to, for example, when the person became ill, when the diagnosis was made (or in some cases not made), and the “present”, and by distinguishing the narration sequences, it becomes clear how the interview and the “telling order” are configured. The narratives in the interviews are not always concluded with a new question from the interviewer and a question from the interviewer does not always immediately initiate a narrative. Instead, a narration can be initiated as a digression from an answer to a question, and a narration that has been concluded can be followed by a new narrative episode that follows chronologically the latest story told. The new narrative can also digress, as explanation or insertion of what is told in a larger context.

## TEMPORALIZING CHRONIC FATIGUE

By starting out from the narrative time and how time is used in the order that the narratives follow in the interview, it becomes possible to see how the interviewees try to understand and describe something about their illnesses and their lives by switching between different temporalizations. In our material the use of various types of temporalizations thus seems to reveal something about responsibility for the illness as well as freedom of responsibility. A similar situation is seen in their choices of where in their life narratives they place their illnesses.

In the following we will discuss how the interviewees in our material operate with four different types of temporalizations in their narratives about chronic fatigue. The first way of temporalizing presented is the turning point. This is followed by three ways of temporalizing that correspond to Morson's concept of backshadowing, vortex time, and sideshadowing. However, we did not find any instances of foreshadowing, which according to Morson (1994, p. 7) "appears as the most artificial" of literary devices. We will however come back to this in our discussions about the examples of backshadowing.

### Turning Points

Turning points, as the concept has been described by for instance Charmaz (1991) as a special kind of time marker, are also used by the interviewees in our material. According to the view that a person's life biography could be described as a linear time axis Charmaz explains how a meaningful chronology can be created by inserting several different events and situations – "time markers" – on the linear time axis. For this a number of different kinds of time markers can be used to sort out and divide up life experiences but only certain significant events attain the status of "turning points" (Charmaz, 1991) or "existential coordinates" (Orona, 1990). What makes a time marker be also a turning point, says Charmaz, is that it does not just mark a point in a life biography, but that it *constitutes a shift* both in the sequence of events and in self-understanding. These are moments of what Aristotle in his *Poetics* called "peripeteia" (Nussbaum, 1986).

By constituting a shift the description of an event as a turning point divides time into a "before" and an "after", a past and a future. In the interview with one woman, here called Gwen, one such turning point is described in the

following story where each line has been numbered and where the spaces indicate a new stanza.

### Example 1

01 well, I was at X Square  
02 or maybe it was Y Plaza  
03 and I was going to go up  
04 and the escalator wasn't working. (I: mhm)  
05 I had to walk up the escalator then to-  
06 everyone else was walking, of course - everyone  
07 you just do it. You walk up, right? (I: mhm)  
08 But you see, I couldn't.

09 I wasn't strong enough to walk up those stairs, y'know  
10 I'd been rushing around and was carrying shopping bags and stuff.  
11 And just that I would suddenly have to walk up a huge, long stairs  
12 and it was just too much.  
13 And then I understood that something was not quite right here. (I: mhm)  
14 So then I began to think that something was wrong.

The story is told in connection with an episode in which Gwen is telling about the time she was diagnosed with CFS, a condition that she previously had been reading a little about. She thus frames her story about the turning point to be similar to the stories of other sufferers that she had been reading. Interpreted as that, this story is about the accuracy of the diagnosis she has got. What is important in our analysis at this moment however is to show how she by telling about a specific event ("I was at . . ."), which she describes in considerable detail, forms a story that ends up with the point that this was a moment when she realized something new about herself and her fatigue. That is, the turning point. After presenting the scene (lines 1–4) she continues to describe the problem she is facing when the escalator does not work and that she will have "to walk up the escalator". She tells about how other persons present at that specific time acted in the situation ("everyone else was walking"), what she perceives to be the expected thing to do in such circumstances ("You just do it. You walk up, right?") and then concludes the comparison by stating "But you see, I couldn't". In the third stanza (lines 10–12) she takes a step back and explains the situation that after rushing around the challenge of having to walk up the escalator "was just too much". Finally the turning point becomes the coda (Labov, 1972) of the story by marking a

shift in her self-understanding (“And then I understood that something was not quite right here”).

Several of the interviewees used this kind of temporalization to point out, as in the example above, a specific time when they first perceived their illness as something really wrong or when they got some important answers like a diagnosis and a name for their illness. These events became turning points since they marked a shift in how the interviewees interpreted their illness.

### Backshadowing

When the illness is viewed from the common point in time – the present – that the interview constitutes, significant events like being diagnosed or suddenly experiencing fatigue as illness are possible points of departure, or even, as in Example 1, described as turning points. However, this kind of time markers is far from the most obvious points that the interview subjects choose to expose. In the initial question about what made them come to the patient school, as well as during the rest of the interview, the interviewees often related their illnesses and suffering to other times, situations, and events which unlike turning points were more vague. In these descriptions the diagnosis or being taken ill suddenly does not form a clear break between a “before” and an “after”. Instead the illness is depicted as something that revealed itself far earlier, but was perhaps not comprehended clearly at that early stage. What the interviewees describe is the shadow of what became the illness, rather than the actual illness. The shadow is one that the interviewee him/herself did not perceive as a sign of illness or even of approaching illness at the point of time at which it occurred. In retrospect, however, and in the light of what has happened up until now, these events, vague symptoms, and other experiences seem to be interpreted by the teller as signs that the interviewee him/herself or (sometimes) others should have understood much earlier.

When John (Example 2), at the start of the interview is asked about how he got to the patient school and how it all started his answer becomes a long story. However, almost immediately he interrupts himself and takes his story back to a much earlier time.

### Example 2

- 01 Well, it started out that I about-
- 02 or to be honest it was really so that I felt a little of that fatigue for many many years, actually.

03 But it sort of sneaked up on me  
04 and it really wasn't really so eh it wasn't so dramatic at that time.  
05 I really went to the doctor a few times for that but-  
06 And they did like in outpatient care then, at my family doctor's and such those  
quick examinations.  
07 And they couldn't find anything wrong really so  
08 And then I felt a little better about it  
09 and just continued on  
10 even though I still had the fatigue  
11 and it came and went sort of in waves, but  
12 So it was really about ten years ago that I first felt it.  
13 But um then about two and a half years ago now,  
14 I- so um then I had a little increase in the fatigue  
15 um and I guess I thought it was just another of those little periods again  
16 that I'd had earlier like that

The story that John chooses to begin with concerns a time quite long before his diagnosis of CFS and even before an acute illness that he later on describes as the starting point of an extended medical inquiry. Instead of using a clear time marker he starts to tell about a time that continued for “many many years” (line 2). It is a time which is rather vaguely described as “at that time” (line 3) and which beginning later on in an “evaluative clause” (Labov, 1972) is settled as “about ten years ago” (line 12). Even though John emphasizes that he “really” had gone to his doctor for his fatigue, he also tells how he accepted the answers he received and “felt a little better about it”. The symptom of fatigue sneaking up on him wasn't interpreted as especially alarming either by John or by the health care system. In the light of what happened after that – his falling suddenly ill and then having a residual, increased fatigue – his earlier fatigue is interpreted in a different way. In retrospect the period of fatigue that started about ten years earlier becomes a sign – a shadow – of the illness that appeared later. It was, however, a shadow that he didn't notice at the time. He didn't even perceive it as a shadow when the fatigue became accentuated shortly before his acute illness. At that point he interpreted it as being “just another of those little periods again” (line 15). At the time of the interview, however, the time shadows are very evident to him. This can be seen in the way John introduces his earlier fatigue as an important part of his illness narrative, even though it reflects a time long

before his falling suddenly ill and long before the diagnosis was made, “or to be honest it was really so ...”.

Time shadows like the one John is telling about in Example 3, which do not become evident until afterwards – backshadowing – means that not only experiences in the past can be reexamined, but also actions. In the interview with Tina (Example 3), she describes her life situation as she remembers it from the time when she began to feel ill. Her narrative develops successively between the interviewer’s questions. In describing her work as rather stressful, she tells about negative changes in the organization of work, and also about her ambition to do a good job as well as about the feeling of responsibility that partly stopped her from “getting out of there”. How her working situation, in combination with her “personality”, had an effect on her and on the illness that developed later, she summarizes with the words:

### Example 3

Because that I really should have seen much earlier.  
And left.

When Tina reflects on the time before and during her falling ill and of the stresses that eventually led to her illness breaking out she too uses a kind of backshadowing. The illness thus becomes a given result of her life as she has lived it. It is a shadow that she in retrospect thinks that she “should have seen much earlier” and also should have acted upon by leaving. Considering both John’s story and Tina’s the shadow of the future illness is made up not only of early signs of the disease in the form of symptoms, but can also be memories of traumas, life crises, or periods of intensive burdens that in retrospect can be understood as “omens” of illness and suffering. However, since it cannot be perceived ahead of time, it cannot be prevented but rather becomes something unavoidable. Yet backshadowing by no means implies freedom from responsibility but rather poses questions about responsibility and about whether alternative actions might have been possible. This relationship between foreshadowing and backshadowing is reflected in Bernstein’s (1994, p. 16) description of backshadowing as a kind of “retroactive foreshadowing”. That is, what seemed to be impossible to foresee becomes in retrospect something that *should* have been foreseen. Thus backshadowings seem to have to be handled within the narrative that discloses them as in the case of John declaring that that he in fact “**went**” to a doctor to check on his fatigue. By this statement as well as the one describing how he trusted

the medical examinations which did not indicate any disease, he presents himself as a person who already at that time he is telling about showed great responsibility, which counteracts some of the questions that might be posed about possible actions. In a similar way what Tina tells about her feelings of responsibility towards her work might be interpreted as an answer for why no action was taken; why she did not leave.

### Vortex time

A special way to explain and coordinate events backward in time is to relate them to each other, and to show in one's narration how several episodes and events that are separated in time and space finally converge at the point that something like a chronic diagnosis can be. This corresponds to what Morson (1994) calls "vortex time". He describes vortex time as relentless and as ineluctable. In being likened to a whirlpool, vortex time appears to be an inverted variant of Brockmeier's (2000) "spiral model" of autobiographical time. In contrast to Brockmeier's spiral, however, which directs itself outward in ever-widening circles, vortex time is not based on one single time line. It can rather consist of a whole series of different events that do not necessarily need to be related to each other but nonetheless converge in a central point. It is this centripetal, center-seeking force that characterizes vortex time and that distinguishes it from "pure" backshadowing.

In the interview with Gwen a series of different narratives from different times in her life form a totality by converging in, or linking together in the illness as an unavoidable result of many different events in her life story. Gwen herself initiates the longer narrative without any new question being posed, when she reflects about her life with the words, "but a lot has happened, too/. . .there's a lot, I think, that this is due to". After that she begins to tell about a series of different episodes having to do with her growing up, her husband's death, the development of a new family, tensions between generations, and problems in relationships with the children. The narratives are each concluded with a kind of refrain in which Gwen declares that "this isn't what has brought on this (CFS), but a lot has gone on in my life". After telling about a series of different events that she in a similar way declares cannot be said to have caused her chronic fatigue, Gwen summarizes these narratives about her life and the relentless unavoidable movement toward the illness (Example 4).

#### Example 4

- 01 I don't think about this so often  
02 but when I sit and talk and try- (I: mm)  
03 then of course it appears that it can happen that like my life in total then.  
04 Maybe it'll finally be like this.  
05 Maybe it's just too much so that it becomes like this. (I: yes)  
06 Then there's some safety valve then  
07 so that you can sort of survive and live through it. (I: mhm)  
08 It's like that.

The ineluctable, what simply will “finally be like this”, that Gwen in her narration calls a “safety valve” is described there as a result of what has happened in her life “in total”. It was a series of different events that in themselves did not cause her illness, but which in combination converged in a fixed point – i.e. the chronic fatigue. The structure of vortex time is seen both in Gwen's summation of her narratives (Example 4) and in a narrative structure in which several events come together via the common refrain. The result of vortex time does not become evident until afterwards. In this case it is similar to backshadowing. Compared to the discussion in relation to backshadowing however, the structure of vortex time does not seem to raise any questions about responsibility and thereby does not in the same way call for accounts for not foreseeing the catastrophe. Unlike what was shown for backshadowing the refrain Gwen repeats after each single event she tells about stresses that this particular event or experience could not be blamed for causing the illness. That is, she could not have prevented the coming catastrophe by acting differently. This freedom of liability might be explained by the structure where the ineluctable consists of many different, unrelated but still concurrent working events that are connected in vortex time become almost impossible to see through. Not until afterwards when in these narratives the illness is a fact, will the vortex pattern appear.

The feeling of catastrophe brought on by the relentlessness in vortex time can to some extent be compared to what Arthur Frank (1995) calls “chaos narrative”. But in contrast to the anti-narrative structure and the non-self-reflecting trait that Frank describes for the chaos narrative, a narrative from vortex time involves a reflection in which earlier events and experiences are associated with illness and suffering that appeared later. Despite this difference, some of the interviews contain narratives that, observed from the narrative time, describe experiences in vortex time. However, in these the

narrator still does not have the ability to describe any connections between different events by, for instance, converging in one central point. These narratives seem chaotic (to both the narrator and the listener), both because there is a lack of conceivable explanations for a narrated event and because the narration contains a structure in the form of vortex time. In this vortex time events are added to each other and thus appear to drag the person toward the catastrophe (the illness) and yet reject this kind of explanation. By not relating the events in time, these narratives are more similar to chaos narratives and to the type of timeless model for autobiographical time that Brockmeier (2000) calls the static model.

### Sideshadowing

The exact opposite of vortex time is constituted by shadows from the side – sideshadowing – which instead of indicating a single point gives an image of several different alternative courses of events (Morson, 1994). By opening time sideshadowing thereby also oppose the closure of backshadowing and foreshadowing.

By restoring the presentness of the past and cultivating a sense that something else might have happened, sideshadowing restores some of the presentness that has been lost. It alters the way we think about earlier events and the narrative models used to describe them. (Morson, 1994, p. 7)

That which might have happened and that which perhaps can happen is compared to a shadow from the side in Morson's concept of time shadows. It is a shadow that opens the door for other alternative courses of events both in the past and in the future. In Morson's analysis, he states that Dostojevsky, for example, who frequently employed sideshadowing, used the opposites of sideshadowing and vortex time to create effects in his narratives, and to make it possible to conclude his fictional narratives despite the open time he aimed at.

When Jenny (Example 5) tells, like Gwen in Example 4, about the combinations of reasons she sees to explain the chronic fatigue syndrome that afflicts her, the narrative does not stop at the inevitability (and the vortex time) where it starts. Jenny includes in her narration what also could have happened.

## Example 5

- 01 But then I think it was a combination of um partly that I was already rundown be-  
fore from lack of sleep, a lot of infections,  
02 and then one serious infection that I then never recovered from (I: mm)  
03 and then eh that eh job  
04 and the stress.
- 05 And I think that I could have managed each of those factors  
06 If it had been the only one. (I: mm)  
07 If I had been in great shape and worked that much then it might have been OK.  
08 Or if I'd just been sick but didn't have to work so much. (I: mm)
- 09 .h and then the lack of sleep I think too  
10 I think lack of sleep effects people more than you understand  
11 But then I guess there's also an inherited component.
- 12 That it's- eh but I mean If I'd been- if I'd had another inherited component  
13 Maybe I would've had a heart attack instead.  
14 I mean now I'm very young for a heart attack  
15 but of course it- it could have been that instead. (I: mm)  
16 But then I got this.

The two opposite-acting time shadows of vortex time and sideshadowing are both found in Jenny's narration. When the relentless and, because of the conditions of her life, inevitable result in the form of fatigue has been fully described as a sort of vortex (lines 1–4), Jenny switches to sideshadowing by opening the door to a series of other alternative courses of events (lines 5–8). In lines 9–11 however, she switches back to adding things to the list of difficulties that she believes have contributed to her illness. But then in line 12–15 she goes back to sideshadowing one of these (“if I'd had another inherited component”) before she closes by ascertaining what her “fate” has been. As a result her story is not just about what did happen and why but also about what might have happened. If the conditions at different junctures had been different, then something else could have been the result. The sideshadows that Jenny uses concern several different possible courses of events, which in part could have led to a completely different illness (like a heart attack) or in part didn't have to lead to any illness at all. If she had had to confront each of the stress factors by itself, then she might not have become ill. By opening the door to other possibilities, Jenny opposes the inevitable result that the series of different stress factors she described earlier seems to lead to, at the same time as she accepts what has happened. The

shadows from the side do not allow the only possibility to stand unopposed, but weigh in many others.

Including sideshadowing in narratives about experiences of illness and suffering means often that the narrator is stating the conditions for events in an “if only” model (Morson, 1994), expressing wishes, thoughts, and assumed possibilities in statements like “if only . . . then this could have happened”, “if not only . . . then it might have been OK”. In the example above it is obvious how Jenny switches in her sideshadowing from the indicative mode in past tense to describe how something was (“I was already run down”), to a subjunctive mode: “If it *had been* the only one”; “If I *had been* in great shape”; “if I *had just been* sick”.

Even without explicitly expressing what might have happened if this or that had not occurred, or if this or that had not been the case, sideshadowing is a way to open up time. Sometimes in our material sideshadowings occur in the way a narrative is told about things that have happened. By for instance telling about dead ends a story almost automatically includes sideshadowing represented by all that might have happened if the way had not been blocked. This kind of unspoken sideshadowings occur, for example, in descriptions of the individual path to a diagnosis. Different diagnoses involve different courses of illness, and therefore different time images. To be confronted with many different possible diagnoses, as is the case for many who suffer from unspecified symptoms, therefore also includes being confronted with different pictures of the future and of time. Without explicitly discussing what could have happened if another diagnosis had been made, or if the diagnosis had been made on another occasion, the narratives about the different alternatives that have been blocked in various ways still make up a kind of sideshadowing of what could have happened. As Morson (1994) writes, it is telling about what happened that makes the picture of what could have happened become obvious.

Thoughts and reflections about the future also operate as a kind of sideshadowing in which a possible route is determined. However, it is not described as the only possible one but rather as one of several plausible continuations. Viewing the future as a special type of sideshadowing causes neither the future nor the time up to the interview to form a single long line. A cluster or a braid of different future threads is created instead; these can all materialize, but can just as easily remain what could have happened “if only . . .”

Including sideshadowing in a life narrative involves entering a dialogue with time and operating with various possibilities. In oral narration, hypothetical narratives (Riessman, 1990) and narrating “in the subjunctive mode” (Bruner, 1986; Good & Good, 1994) can be examples of ways to present sideshadowing. Labov (1982) discusses how adult storytellers often use “evaluative clauses” to tell about events that did not occur rather than those that did. However, according to David Herman (1999) these evaluative clauses tend to be regarded as comments on the evolving story and not as a part of it. Herman argues, just as we do about timeshadows, that these kinds of evaluations are important for the understanding of the narrative and thus has to be included in the analysis of the story. The tension that Mishler (1992) describes between on-line choices and off-line choices about profession and career can for instance show how people handle choices retrospectively and thus use a kind of sideshadowing when they tell about their lives. Certain events and choices can be seen as sidesteps that might have led to a completely different story than the one now being told. The life narrative thus becomes a more open story, in which the players are given responsibility for the events and choices presently being made.

## CONCLUSION

Telling about one’s chronic illness often involves an attempt to understand the origin of the illness in a life perspective, and as Williams (1984) describes it, to “reconstruct one’s life narrative” so that the illness can be seen in the light of, and be explained by what happened earlier in life. However this might, as we have mentioned, involve the question about responsibility. In our analysis based on Morson’s and Bernstein’s concept of shadows of time we have shown how the interviewees use both time markers as turning points and different kinds of time shadows to tell about their chronic fatigue. These two kinds of temporalizations are however, as the analysis shows, rather different in their significance and function. Unlike turning points, whose function as significant time markers simply implies that specific events are marked out on a time line, time shadows bring to the narrative a depth by allowing time to be hazy and by the use of shadows cast from many different directions. This vagueness connected to time shadows makes them very usable in illness

narratives, especially concerning the origin of the illness and questions about responsibility.

For the person who has a contested diagnosis like chronic fatigue, it appears that the affliction does not only lead to a reconstruction of the life narrative in the perspective of earlier experiences and life events. The fact is that the illness and suffering are firmly established in the ongoing life narrative so that they become a part of life, not only backward in time, but also in the present and in a possible future. The chronic fatigue becomes a shadow over earlier life events as well as over what is happening in the present and what the person believes will happen. It is, however, a shadow that the interviewees work with, and one they can perceive in several different ways; even things that could have happened exist there as shadows from the side. The use of different time shadows appears to have consequences for how issues like responsibility and freedom of liability emerge in the narratives. In that way the narrators can approach matters about blame, alternative actions, and hopes that can be of special significance in chronic illness that is contested.

Using different forms for *temporalization* means that we can negotiate and change the meaning of the relationship between events, and thus both the meaning of the course of events and the narrator him/herself as a character in his/her narration. The meaning and the significance in their own lives can thus be negotiated through temporalization by the interviewees who describe their lives from the perspectives of their illnesses. We argue that this makes it important to let the narrator's choice of temporalization become visible in the analysis and be treated as valuable data. If we neglect to regard the narrator's way of temporalizing his or her illness we will lose an important opportunity to understand specific aspects of the meaning of chronic illness.

Moreover, our analysis shows that people actually do also consider what could have happened. They use sideshadowing, not just in fictional works and historical novels, as shown by Morson and Bernstein, but also when people tell their own narratives of suffering. When what could have happened but never actually did happen is also pointed out in a narrative, it stands out in contrast to a more linear view of time and thus in contrast to the inevitability of backshadowing. However the question is if we, as researchers, tend to ignore in our analyses some of the sideshadowing that interviewees show in their narratives about illness, and are perhaps inclined to eliminate all the "loose ends" and create instead a neat, well-plotted story based on our own time concepts?

The interpretation of life experiences differs when time is seen as being predestined, or when, on the contrary, time is something that develops and can be influenced. For the person who receives a diagnosis for which there is a lack of images and narratives, the story is not a closed chapter but rather an ongoing one. Good and Good (1994) write that narratives about illness can, because of their structure, give an impression of incompleteness. Even though each narrative is organized into a beginning, a middle, and an ending, the narrator finds himself right in the midst of his/her own narration. The use of “time shadows” can be a way to tell about and to explain his/her illness. What has occurred up to the present can either be seen as something unavoidable that one should have understood a long time ago, or as something that was a possible result among many different ones.

In this way, time becomes less something that the narrators try to adapt to, and more of a resource they can use to help them understand and place their illness and suffering in a life perspective that is not limited solely to what has happened. Being still in the middle of one’s own narrative, say Good and Good (1994), means that the end of the story is not given. It may possibly be so that the sideshadowing becomes more distinct because it is used to a great extent in ongoing narratives where shadows of what could have happened make it possible to keep the story open for several kinds of endings, and for handling questions of guilt and responsibility, of possibilities and hope.

## REFERENCES

- Adam, B. (1995). *Timewatch: The social analysis of time*. Cambridge: Polity Press.
- Asbring, P. (2001). Chronic illness – a disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312–319.
- Bakhtin, M. M. (1986). *Speech genres and other late essays*. Austin: University of Texas Press.
- Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley: University of California Press.
- Bernstein, M. A. (1994). *Foregone conclusions*. Berkeley, CA: University of California Press.
- Brockmeier, J. (2000). Autobiographical time. *Narrative Inquiry*, 10(1), 51–73.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Bruner, J. (2001). Self-making and world-making. In D. Carbaugh (Ed.), *Narrative and identity: Studies in autobiography, self and culture* (pp. 25–37). Amsterdam: John Benjamins Publishing Company.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182.

- Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health & Illness*, 23(3), 263–285.
- Bülow, P. H. (2002). *Sharing experiences of contested illness by storytelling*. Manuscript submitted for publication.
- Bülow, P. H., & Hydén, L. C. (2003). Patient school as a way of creating meaning in contested illness: The case of CFS. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7(2), 227–249.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick: Rutgers University Press.
- Davies, M. L. (1997). Shattered assumptions: time and the experience of long-term HIV positivity. *Social Science & Medicine*, 44(5), 561–571.
- Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science & Medicine*, 50, 605–617.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: The University of Chicago Press.
- Freeman, M. (1993). *Rewriting the self: History, memory, narrative*. New York: Routledge.
- Freeman, M. (1998). Mythical time, historical time, and the narrative fabric of the self. *Narrative Inquiry*, 8(1), 27–50.
- Gee, J. P. (1986). Units in the production of narrative discourse. *Discourse Processes*, 9, 391–422.
- Gee, J. P. (1991). A linguistic approach to narrative. *Journal of Narrative and Life History*, 1(1), 15–39.
- Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 22–44). New York: Praeger Publishers.
- Goffman, E. (1961). *Encounters. Two studies in the sociology of interaction*. Indianapolis: The Bobbs-Merrill.
- Good, B. J., & Good, M.-J. D. V. (1994). In the subjunctive mode: Epilepsy narratives in Turkey. *Social Science and Medicine*, 38(6), 835–842.
- Goodman, N. (1981). Twisted tales; or, story, study, and symphony. In W. J. T. Mitchell (Ed.), *On narrative* (pp. 99–115). Chicago: The University of Chicago Press.
- Herman, D. (1999). Toward a socionarratology: New ways of analyzing natural-language narratives. In D. Herman (Ed.), *Narratologies: New perspectives on narrative analysis* (pp. 218–246). Columbus: Ohio State University Press.
- Hydén, L. C. (1995). The rhetoric of recovery and change. *Culture, Medicine and Psychiatry*, 19, 73–90.
- Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19, 48–69.
- Labov, W. (1972). *Language in the inner city*. Philadelphia: University of Pennsylvania Press.
- Labov, W. (1982). Speech actions and reactions in personal narrative. In D. Tannen (Ed.), *Analyzing discourse: Text and talk* (pp. 219–247). Washington, DC: Georgetown University Press.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge: Cambridge University Press.
- Melucci, A. (1996). *The playing self: Person and meaning in the planetary society*. Cambridge: Cambridge University Press.
- Mishler, E. (1992). Work, identity, and narrative: An artist-craftsman's story. In R. L. Ochberg (Ed.), *Storied lives: The cultural politics of self-understanding* (pp. 21–40). New Haven, CT: Yale University Press.

- Mishler, E. G. (1999). *Storylines: Craftartists' narratives of identity*. Cambridge, MA: Harvard University Press.
- Morson, G. S. (1994). *Narrative and freedom: The shadows of time*. London: Yale University Press.
- Nussbaum, M. C. (1986). *The fragility of goodness. Luck and ethics in Greek tragedy and philosophy*. Cambridge: Cambridge University Press.
- Orona, C. J. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science & Medicine*, 30, 1247–1256.
- Pierret, J. (2001). Interviews and biographical time: The case of long-term HIV nonprogressors. *Sociology of Health & Illness*, 23(2), 159–179.
- Riessman, C. K. (1990). *Divorce talk: Women and men make sense of personal relationships*. London: Rutgers University Press.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine*, 30(11), 1173–1186.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175–200.
- Williams, G. (1993). Chronic illness and the pursuit of virtue in everyday life. In A. Radley (Ed.), *Worlds of illness* (pp. 92–108). London: Routledge.
- Young, K. (1989). Narrative embodiments: Enclaves of the self in the realm of medicine. In K. J. Gergen (Ed.), *Texts of identity* (pp. 152–165). London: Sage.



## Paper C



# Patient school as a way of creating meaning in a contested illness: the case of CFS

Pia H. Bülow & Lars-Christer Hydén

*Linköping University, Sweden*

**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 organized 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 *discursively to manage* the illness at the same time as they examine different ways to interpret their experiences through this discursive activity.

**KEYWORDS** *CFS; contested illness; discursive management; interaction*

**ADDRESS** Pia H. Bülow, Department of Communication Studies, Linköping University, 581 83 Linköping, Sweden. [e-mail: piabu@tema.liu.se]

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 (see 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 et al., 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 programme 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 are the ways patients, staff and lecturers talk about CFS and how the participating ‘pupils’ and patients use the lectures and the educational programme in order jointly to 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 (see Bartlett, 1986; Lorig et al., 1987). However, even if many different professionals are involved in patient education (see, for example, Bartlett, 1986), educating patients about their illnesses, from Hippocrates to the present, appears to be something that is an integral part of other 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, collectivizes and 'pedagogicizes' that which commonly is individualized 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 organized in many different ways (see 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 organized 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 a 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 (see 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 eight 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

(see Evengård et al., 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 organized 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 et al., 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 article 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 organization was continuously changed, but at the time of this study the school was organized 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 et al., 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.

Second, one has to consider what meaning the physical location and organization 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 recognized (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 programme 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 walk from there 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 organization 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 20 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 emphasizing 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 organization of each lecture could be compared with what Mehan

(1979) has described for lessons in 'ordinary' schools. That is, a sequential organization 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 20 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 recognize 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 summarized 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 obviously 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 organization '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 categorization 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 emphasized 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 organizational frameworks* between which participants as well as professionals may alternate in order to organize 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 organizational framework (the hospital) and thereby gives rise to something new, namely patient schools.

One important consequence of the possibility to shift between various social organizational 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 programme, 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 organizational 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. We discuss how the participants discursively organized and explored the diagnosis they had recently received. However, as pointed out earlier in this article, 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).

In the following examples numbers in brackets, like (1.2) etc indicate pauses in seconds, '[' indicates overlapping or beginning of simultaneous talk, '-' a sharp cut-off and a sound of interruption, and '/. . ./' that some words have been omitted.

#### **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 . . . ?

(1)

Physician: Yes, well, then it depends on the individual's experience of (Myra: okay) it all (Myra: mm). 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: mm). It beco-. (?; mm) 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. (?; mm). 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 'enough experience'. Nevertheless, the lecturer gives an answer, though in a rather vague way, emphasizing 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 organizational 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 shown previously 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 (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 (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 defence 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 was 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 organizational 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; rather it was 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 jointly to 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: (1) the traditional biomedical framework; (2) a broader biopsychosocial framework; and (3) 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 professional. 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 lecture's experiences unique or may the participants hope for the same kind of recovery? (See 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: mm) 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.)

*health: 7(2)*

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 organizations 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: mm). And it almost sounds like it was just such an evaluation (Tina: mm) they had made (Tina: mm) 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: mm) 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: mm) it must be of interest or you must try for rehabilitation (Lecturer: mm, mm). And then you shouldn't have to wait for, yeah, maybe a year (Lecturer: mm) before they start to rehabilitate a (Lecturer: mm) 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: mm) training to work (Lecturer: mm) with professional (Lecturer: mm) rehabilitation (Lecturer: hmm) or (Lecturer: mm) 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 experiences has 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 article, 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 (see 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 organized 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 manage their problem discursively* 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 organizational 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 scrutinize 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 emphasized 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.

Second, 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 characterized 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 discursively to 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 manage discursively, and 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 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. 248–61. Thousand Oaks, CA: 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, 135–49.
- 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, 210–53.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168–95.
- Corbin, J.M. and Strauss, A.L. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco, CA: 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, 455–69.
- 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, 953–9.
- 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. 427–51. Berlin: Mouton de Gruyter.
- Hawkins, A. (1984). Two pathographies: A study in illness and literature. *Journal of Medicine and Philosophy*, 9, 231–52.
- Hilbert, R.A. (1984). The acultural dimensions of chronic pain: Flawed reality construction and the problem of meaning. *Social Problems*, 31, 365–78.

- 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, 247–59.
- Horton-Salway, M. (2002). Bio-psycho-social reasoning in GPs' case narratives: The discursive construction of ME patients' identities. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6, 401–21.
- Hydén, L.C. (1997). Illness and narrative. *Sociology of Health and Illness*, 19, 48–69.
- Hydén, L.C. and Sachs, L. (1998). Suffering, hope and diagnosis: On the negotiation of chronic fatigue syndrome. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 2, 175–93.
- 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, 139–70.
- 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, 261–5.
- 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, 207–52.
- 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 and Illness*, 18, 220–40.
- 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, 601–12.
- 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, 55–8.
- 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 and 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, 347–61.
- 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 and Illness*, 11, 133–59.

- 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, 325–9.
- Young, K. (1997). *Presence in the flesh: The body in medicine*. Cambridge: Harvard University Press.

### ***Author biographies***

PIA H. BÜLOW, is a PhD student at the Department of Communication Studies, Linköping University, Sweden. She is currently working on a dissertation about communication among people suffering from Chronic Fatigue Syndrome. She has particular interest in illness narratives, co-narrating, identity and chronicity.

LARS-CHRISTER HYDÉN, PhD (psychology) is Professor at the Department of Communication Studies, Linköping University, Sweden. He is a social psychologist with a special interest in language and social interaction. He has done research on interaction in medicine and social welfare agencies, and on illness narratives.



## Paper D



# Sharing experiences of contested illness by storytelling

Pia H. Bülow

Department of Communication Studies  
Linköping University, Sweden

**ABSTRACT** Based on audiotaped conversations from a patient school for adults suffering from chronic fatigue syndrome (CFS), this article examines *sharing experiences of illness* as a mutual activity. The analysis shows that sharing experiences in this context is primarily of the narrative kind. Three main types of narratives were found: *self-contained personal stories*, *orchestrated chained personal stories*, and *co-narrated collectivized stories*. Through sharing three things seem to happen: (1) the participants jointly created experiential knowledge and a mutual image of the illness, (2) the individual sufferers could compare themselves to the jointly constructed image, (3) the active sharing of experience bestows a mutual confirmation of suffering irrespective of whether the individual's experiences correspond or deviate from the common picture. Two parallel transitions seemed to occur: the transformation of personal experience into shared collectivized experiences and the transition when the individual sufferer perceives his/her private suffering through sharing experiences with co-sufferers.

**KEYWORDS:** *chronic illness, co-narration, identity, illness experience, narrative analysis, storytelling*

## Introduction

Sharing personal experiences with other people is a common phenomenon that we all engage in. This sharing of experiences is probably of importance because it corroborates others' experiences as well as one's own and contributes to a sense of belonging. Sharing experiences, therefore, becomes especially important when experiences like suffering, pain and others that are not immediately shared threaten the intersubjectivity of our relations (cf. Frank, 2001).

In many contexts sharing experiences is a powerful resource in troublesome situations, leading, for instance, to desirable changes like sobriety for alcoholics who join groups such as Anonymous Alcoholics

(AA). Considering the proliferation of groups for people sharing the same kind of suffering or diagnosis, i.e. self-help groups (Jacobs and Goodman, 1989), this power of sharing seems to hold true for the sharing of experiences of illness and suffering more generally. Although ‘sharing experiences’ can be used both in the sense of *having something in common* and of sharing something *with* someone else neither of these meanings necessarily implies the other and both can be true for groups like self-help groups. However, to understand what is shared it seems important to focus on sharing as an interactional and mutual activity (cf. Graumann, 1995). This social process, which appears to be closely constituted by stories and storytelling, is examined in this article, although the subject is not self-help groups but a ‘school’ for patients.

Sharing experiences with someone who has similar experiences becomes especially important in cases of illnesses which are contested, like chronic fatigue or chronic pain (Bülow and Hydén, 2003a, 2003b). In most situations, this type of illness can be very difficult to explain, especially in encounters with physicians, and this frequently leaves the individual sufferer with a sense of being mistrusted or delegitimized (Hilbert, 1984; Ware, 1992). Situations where those suffering from a contested illness share experiences of illness with each other might, therefore, be of interest as a situation in which people try to make sense of their illness by sharing. The analysis is based on audiotaped conversations from a group of sufferers constituting two different classes in a patient school for adult persons suffering from chronic fatigue syndrome (CFS). The analysis of sharing will be done from a narrative approach, using theories about storytelling in conversation and co-narration, and addressing the following two questions: in what way do people share experiences of illness, and what is the function of the sharing of experiences in a situation of contested illness?

In the first section, self-help groups are discussed and compared as instances of venues for sharing experiences of illness. In the second section, storytelling in conversations, and the function of co-narration in particular, is presented as a theoretical background. The third section begins with a presentation of the study and consists of an analysis of sharing experiences in the patient school. Finally, the article concludes with a discussion of the meaning of sharing experiences in contested illness.

## Venues for sharing

Self-help groups, support groups, patient associations, patient education and group therapy – there are many different venues for people who have some kind of suffering in common. In the literature, these groups have been distinguished and classified in many different ways, within each category as well as between the main types of groups (Bartlett, 1985; Keefe et al., 1996; Levy, 1979; Schubert and Borkman, 1991). Despite differences and sometimes blurred distinctions, it is what these groups have in common – that they assemble people who suffer in one way or another and that these groups, in some respect, focus on that suffering – that is of concern for this article. I do not claim that the patient school is the same as any of those venues, but because sharing experiences of suffering is a possibility within all groups gathered around illness and suffering, they do seem to have some aspects in common which might be important for the understanding of the patient school. The research concerning these different groups is quite extensive, but because we are concerned with sharing, ethnographic studies from self-help groups focusing on interaction and/or storytelling seem to be a relevant point of departure for the following discussion about venues for sharing.

What links these groups, and what seems to make sharing experiences of suffering possible, is that each member assumes – and the group has to validate this – that the others have the same types of experiences as they have. This implies a homogeneity that gives ‘a sense of symmetry and a willingness to disclose deeply personal feelings’ (Jacobs and Goodman, 1989: 538). Irregardless of differences in organization and what kind of illness/suffering ties members of a self-help group together, ethnographic studies of various self-help groups show how members do find their ways to share experiences. This can happen through a *formalized narrative structure* as in AA meetings (Arminen, 1998; Cain, 1991; Steffen, 1997), or in more freely organized *group conversations* (Karp, 1992), or, as shown by Blauner (1991) in his ethnographic study of members in a self-help group for Parkinson’s disease, in a *performative* way. Here members used the stairs instead of the elevator to demonstrate their personal degree of independence and ability to the group.

### *The power of sharing*

In a broad sense, the function of sharing experiences in self-help groups and the like is one of mutual support and of the possibility to learn about one's illness. Kelleher (1990), for instance, found that the interaction in self-help groups for diabetics turned out to be a mix of sharing of experiences and giving practical advice. By providing its members with a venue, self-help groups become an opportunity to make friends, as well as to learn more about the illness and how to manage everyday life from others in the same situation. Because the knowledge that is shared and developed in self-help groups is based on personal experiences of the particular difficulties around which the group is gathered, social researchers like Borkman (1990) use the term 'experiential knowledge'. This makes members of self-help groups 'experientialists' and the groups 'experiential learning communities'. One important aspect of this experiential knowledge is the special understanding people who have been through similar experiences claim to have of each other. Other aspects of this learning process include learning from living examples and by communication about one's illness. Blauner (1991) argues that this kind of learning, in contrast to formal training, is the basis of self-help groups.

Other described functions of self-help groups are self-identity and meaning-making aspects like the acquisition of an identity as a non-drinking alcoholic through the formalized narrative structure in AA groups (Cain, 1991, see also Holstein and Gubrium, 2000) or the creation of meaning and identity by jointly establishing a coherent image of the illness (Karp, 1992).

It does not seem to matter if researchers have been interested in what kind of knowledge is developed in self-help groups through sharing of experiences, or in what way and to what extent this sharing of experiences is applied. One cornerstone in the process of sharing of experiences seems to be stories and storytelling.

### *A narrative approach of self-help groups*

As indicated in the previous section on sharing experiences as the means of developing experiential knowledge and for creating meaning, sharing is based on communication about one's illness experiences. Even though most of the sharing of experiences thus seems to be founded on stories and storytelling this is rarely discussed in detail in studies of self-help

groups. However, several researchers focus on the social process of sharing in self-help groups (Arminen, 1998; Blauner, 1991; Denzin, 1987a, 1987b; Karp, 1992; Kelleher, 1990), and some specifically in connection with storytelling and narratives (Cain, 1991; Maines, 1991; Steffen, 1997).

Maines (1991) points out that the social organization of storytelling in self-help groups aids in enhancing the group structure. In a self-help group for diabetics he found that 'core members' had the ability to tell the 'right' shared story while peripheral members could not tell the group story in an adequate way. For Cain (1991) it is the process of learning to tell the story according to the appropriate structure that helps an AA member to understand him/herself as an alcoholic. In this process, newcomers learn from old-timers to tell the story in the right way. Steffen (1997: 99), who has investigated similar groups in Denmark, argues that it is the use of different genres of personal narratives (life stories, anecdotes, case stories and myths) that allows individual and collective experience to merge 'into the same therapeutic process'. Although not explicitly using a narrative analysis in his ethnographic study centered on the role of conversation in a self-help group for people suffering from depression or maniac depression, Karp (1992: 166) found that even if members could not resolve important questions concerning the illness, 'there was something powerful for individuals in learning that others shared their confusions.' Through conversations these individuals 'came to understand their situation in collectively shared ways' (Karp, 1992: 167).

Emphasizing stories and storytelling, these studies contribute in various ways to the understanding of the act of sharing experiences in self-help groups. However, the question that remains open for investigation in self-help groups as well as in other venues for sharing is how people share experiences through narratives and narrating. This article will use micro-analytical methods, building on theories about storytelling in conversation (Polanyi, 1985; Sacks, 1995) and on co-narrating (Blum-Kulka, 1997; Norrick, 1997; Ochs et al., 1989). The studies of self-help groups mentioned earlier will, however, be of importance for the analysis of the patient school, which to some extent shows similarity to self-help groups but at the same time is something very different.

## Storytelling and co-narrations

Sharing experiences in self-help groups, as well as in everyday situations, is employed through the medium of what are usually called oral narratives. This situation can be ordinary small talk at the family dinner table (Blum-Kulka, 1997), an interrogation associated with a medical consultation (Young, 1989) or a research interview (Mishler, 1986). Different situations, however, involve different kinds of narratives as well as different kinds of narrating. For example, in the self-help group personal testimonies of a completely different kind to what is possible in a conversation with a colleague can be presented. Similarly, the repetition of familiar family tales can play a special role in the family circle (Norrick, 1997), whereas a narrative in other situations must be unique and contribute something new if it is to have a sufficiently great narrative value – or *reportability* (Labov, 1972). In certain situations narratives can also constitute a more or less clearly requested form of discursive action, as in ritualized forms of sharing in *show and tell* or *sharing-time* in the lower grades in school (Michaels and Cook-Gumperz, 1979), or in correspondingly formalized actions that are part of an AA meeting (Arminen, 1998; Steffen, 1997).

Considering narratives to be part of a conversational situation means that focus is partly shifted from the structure of the individual narratives to narration seen as a social activity. Here the interaction between an individual narrator and his/her conversational partners becomes important to analyze in order to understand the significance of both the narrative and the narration. Blum-Kulka (1997: 101), who has studied family dinner conversations from a cultural perspective, says, for example, that ‘to capture the unique nature of family narratives one needs an approach that accounts simultaneously for family storytelling as an event, a social action unfolding in real time, and (at the discourse level) a text about other events’. These narrative events include three dimensions: the telling, the tales, and the tellers – which means that a narrative cannot be seen as something produced by the ‘teller’ alone, but rather as something co-produced. At the very least, this means that a narrative as a part of the ongoing interaction may need to be defined and accepted interactionally in order to be admitted (cf. Sacks, 1995). Thus narratives always become more or less co-narrated. Such a co-narration can occur in various ways. The whole narrative may be co-produced by two or more narrators, or the narrative develops via

sequences of questions and answers, or it develops through sporadic but meaningful contributions from the audience (Blum-Kulka, 1997).

Partly depending on the various contexts in which narration plays a role, different researchers have seized upon partially different functions of co-narration. For example, co-narration of well-known family tales can be said to confirm membership in the group, as well as to reinforce the bonds between members by reviving memories of pleasant common experiences. Co-narration can also confirm the long-term bonds between group members with the feeling of belonging that the act of co-narration itself creates (Norrick, 1997). The problem-solving function studied by Ochs et al. (1989: 242) similarly involves a two-directional meaning in that 'the activity of co-narration stimulates problem-solving, while the activity of problem-solving stimulates co-narration'. Mattingly (1998), who does not use the concept of co-narration but rather that of *storytelling episodes*, emphasizes a view of narration that does not stop at a glance backwards. She describes instead how the members of a team who share their individual experiences by storytelling 'try to construct a collectively shared story about what was going on and, within that story, what their role [...] should be' (1998: 4).

Because co-narration is important to the understanding of what is happening, and experiences can be made common through narration, storytelling and co-narration also become important resources in more casual groups, such as the patient school.

## The study

The analysis draws on a study using an ethnographic approach through an observational study of a patient school for people suffering from chronic fatigue syndrome or related diagnoses. The researcher participated as an observer in this school in two different classes divided by a period of one year. This patient school, organized and arranged by a clinic at a large hospital in Sweden, consisted of five meetings, or lessons, each of about two hours, once a week.<sup>1</sup> Each meeting included a lecture as well as time for 'group-talk'. These five meetings in both classes were audiotaped and later transcribed verbatim. In total, the transcribed data used for the analysis presented here consists of about 20 hours of 'naturally' occurring interaction. In addition to the recordings, field notes were taken during the observations. These notes on things impossible to capture by audiorecording enriched the analysis and facilitated the work with transcription and interpretation. The

ethnographic approach included the conversations that occurred in the waiting room before each lesson from the second meeting and on. These interactions were not recorded, but brief notes were taken afterwards.

The first class initially consisted of eight participants – two men and six women – although one person dropped out (a woman) after the first meeting. In the second class two men and nine women participated. Most of the participants attended all meetings or all but one. The ages of the participants varied from almost about 30 to about 60 years. The majority (15 persons) had received the diagnosis CFS, sometimes in addition to other diagnoses such as fibromyalgia and burnout, whereas the rest (three persons) did not fulfill the criteria for CFS and had received the diagnosis of idiopathic chronic fatigue. In addition to material from the patient school, 31 interviews with 13 of the participants from the two studied classes were consulted as far as they concerned the school. These interviews, which started about six months after the last meeting in the school, were not designed as follow-up interviews to evaluate the school but rather to explore the interviewees' experiences and views of their illness.

All analysis and interpretations were conducted on the Swedish material and translated to English later. The transcripts (see Appendix for key) have, in some cases, been simplified after the analysis to facilitate reading. All names and some other personal details have been changed to protect the anonymity of the participants.

## The school setting

The studied patient school started in the early 1990s within the framework of a research project (see also Bülow and Hydén, 2003b). The majority of the patients participating in the study came to the organizing hospital clinic, referred by their GP or some other specialist, for a medical assessment as a first step. They were then invited to the patient school as one of two possible activities offered by the hospital after medical assessment. (The other opportunity is to attend a body-awareness program led by a physiotherapist.) After completing the school, patients were supposed to return to their former medical contact.

The five 2-hour meetings were arranged as a series of lectures by a physician, a physiotherapist, a psychologist, an official from the social insurance office in charge of rehabilitation, and at the concluding lecture, by one recovered ex-patient who had attended the patient school some years earlier. In addition to these lectures, approximately one hour

of group-talk, guided by a nurse, followed the lecture from the second meeting onwards. Between the lecture and the group-talk there was a coffee break. All three activities took place in the same room, around a conference table. Two additional lectures were presented as part of the school but as these were not followed by any time for group-talk they are excluded from the analysis. Before each meeting the participating men and women gathered in the waiting room at the clinic just as other patients do. The room in which the meetings were held was, however, outside the clinic in an area usually used by hospital staff.

The participating patients were encouraged to share their experiences, and a lot of stories were told there about living with an illness like CFS. Because this kind of illness is usually connected to a long history, many of these stories had a form that differs from stories about a specific event. Instead, several stories were told about experiences extended in time including how they were diagnosed, periods of contacts with doctors, how they experienced their illness during its course, and what they usually do to manage their illness – such as treatments and strategies. Various narrative genres (Riessman, 1993) like habitual- and topic-centered stories are therefore common in the material even though there are stories concerning specific events as well as hypothetical ones.

## Forms of sharing

The social process of sharing experiences was noticed during the observational phase of the study when the participating men and women occasionally turned to each other and shared experiences. Instances included: comparing various symptoms, telling each other what they usually did to manage the illness, medical treatments they had tried, and so forth. However, as the analysis continued it became apparent that the participants were sharing experiences in at least three different ways. These *forms of sharing* can be described as three different types of narratives that I call *self-contained personal stories*, *orchestrated chained personal stories* and *co-narrated collectivized stories*. These three main types of narratives partly coincide with different types of interactional situations in the patient school. They are interesting, not only in terms of different kinds of narratives, but also in terms of different forms of sharing experiences. All this indicates that the process of sharing is not just one type of interaction but something rather complex and diversified. In the following each of these three types of

narratives will be discussed on the basis of what kind of interactive event they usually occurred in and of how sharing of experiences was accomplished through each particular type of narrative.

### *Self-contained personal stories*

Typically self-contained personal stories were told in interaction with the lecturer or the nurse, leaving the role of the other participants to that of an audience. These personal stories were related to a specific event in the recent past (like yesterday or last week) or topic-centered stories usually told in the past tense. They had a beginning and an end and resembled in this sense the personal experiential stories described by Labov and Waletzky (1967). Most of these stories were told during lectures, sometimes to contextualize a question posed to the lecturer/nurse, but more often they appeared to be told as examples or personal illustrations of elements of the lecturer's talk. Other participants did not get involved in this kind of storytelling except with minimal responses or receipt tokens like 'mm' and the narrator did not link his/her story to any other participant's experiences. Thus, this kind of personal story was shared with the others as ratified listeners only (Goffman, 1981), that is, by overhearing other participants' stories.

#### *Extract 1 'I can just tell you how it was for me' (C4:1)*

- 01 Lecturer: [...] I don't know if it's a coincidence. Very many who have chronic fatigue syndrome are very ambitious and achievement-oriented and can't give up, because this limit where one psychologically gives up doesn't exist, right. But the body is smart. The body says no, now it's enough. I can't go on like this any longer. (P: mm) And this is then something you have to manage to understand that the body, like the body may be smart. And- yes
- 08 Cornelia: Or I can just tell you how it was for *me* before. I also got an infection but before (L: yes) I got this infection it was like my eyes were smarting so incredibly. Just like you know when you are so terribly tired and haven't slept. (L: mm) That you just want to keep your eyes closed and that was what I had as a signal actually (L: mhm) from the body. That now, now you have to go into reverse. Now you have to hold back. (L: mm) But I did[n't] do that.
- 15 Lecturer: [Did you do that?
- 16 Cornelia: No
- 17 Lecturer: No
- 18 ((chuckles are heard among the other participants))
- 19 Lecturer: And it is here I mean if you look back. (P: .hmm) You maybe have to go quite a long way back. Were there any signals? That you perhaps (Cornelia: yes) should have listened to, that you didn't listen to because you are so (PP: hmm) damn stubborn.

- 23 P:           Yea.h  
24 (.)  
25 ?:           °mhm°  
26 Lecturer: .h and that is ((continues lecturing))

The experience that Cornelia shares is presented as an illustration of what the lecturer had just been talking about ('the body is/may be smart', lines 4 and 7) and takes the form of a clearly defined narration (lines 8-14). This is indicated in the words 'or I can just tell how it was for *me*'. In this way Cornelia's narration becomes an example of how it can feel in the initial stages of the illness, and indirectly also an example of the way people with CFS typically act, as described by the lecturer. Cornelia, as the narrator, chooses herself to tell about her personal experience on this occasion. The narrative is thus unexpected, which is shown when the lecturer understands that Cornelia wishes to say something, interrupts herself, and offers Cornelia the floor ('And- yes'). The lecturer then encourages the narration with continuers like 'mm', thus further reinforcing Cornelia's right to tell about her experience at this juncture. At the conclusion of Cornelia's story, and partly overlapping the point that Cornelia makes in her narrative, 'but I didn't do that', the lecturer asks the corresponding question, 'did you do that?'. The overlapping can be interpreted as the lecturer's attempt to show that this was the point of the story, as well as to conclude the story in order to resume her position as the main speaker. Cornelia reinforces her own words with her 'no', at the same time as she answers the question asked by the lecturer. The lecturer in turn echoes this answer, and then continues to lecture ('and it is here I mean...', line 19), but now with a certain support from the example Cornelia contributed with the use of the word 'signal' and the reference to '...look back'.

What is special about self-contained personal stories is thus that they are about personal experiences that individual participants bring out, and they actually resemble what Labov and Waletzky (1967) call personal experiential stories. By volunteering as a narrator, a participant can share his/her personal reflections about the disease and suffering that have been stimulated by the lecturer's or nurse's words. Thus, this type of clearly defined personal narrative becomes an illustration for the professional knowledge about the illness that is given precedence, or at least special attention, through the lectures. At the same time, this is a form of sharing in which individual experience becomes the figure by which the professional frame of reference (cf. Borkman, 1990) can be

either reinforced or reduced, depending on what the personal example demonstrates.

Even though the narratives develop to different extents from an interaction between the narrator and the lecturer/nurse, there is no obvious structure for how these narratives should be told or what they should be about. Because they appear spontaneously and as a response to what happens in the particular situation rather than having been requested, these narratives are partly unanticipated. Their position in the lecture must therefore be negotiated, as Sacks (1995) described for narratives in conversations, i.e. the narrator must request and be given the floor. It is obvious in the demeanors of other participants that these are personal and clearly defined narratives; they mostly continue to play the listening roles they assumed before the narrator volunteered and was given the floor. They may, however, demonstrate by low-key laughs as in Extract 1 or by other sporadic conversational affirmations that they recognize the situation and also that they are attentive to and empathizing with the narrator's experiences.

### Orchestrated chained personal stories

The second kind of narrative and narrating – orchestrated chained personal stories – is the least common form of sharing found in my material. At several meetings it did not happen at all, which probably has to do with the structure of the patient school. In this form of sharing, all participants take part by presenting their personal illness narratives. Thus, they take a relatively long portion of the meetings at which they are told.

In orchestrated chained personal stories, the personal experiences of different participants are linked together by means of a model supplied by the nurse for both content and structure of the narration/sharing. This form of narration occurs only during the portion of patient school intended for participants' sharing of experiences – the group-talk. This is a narration that is initiated and steered by the nurse. These stories are based on regular chaining rules (Sacks, 1995), but achieve their own special form by being orchestrated by the nurse. The linked-together personal stories can also be described as themes of rounds, and in that way are similar to what Tannen (1984) calls *story rounds*. Because this form of dividing stories up into chains is based on having each story 'formally' requested and on having the chain orchestrated by the nurse, they make up a kind of formalized story round. Thus they also resemble

the ritualized form of sharing that is described in school (Michaels and Cook-Gumperz, 1979) and in the AA movement (e.g. Arminen, 1998). It is a form of sharing that has a pattern for how and what should be shared, and in which each person's conversational turn is dictated by the sharing structure, and thus also by the conversation leader (the nurse).

The conditions for orchestrated chained personal stories are that at least two participants' personal experiences must be linked to the collected story chain by having the nurse ask the same question of several participants, one after the other, or that the nurse provides a pattern and a specific order for the narration. A typical example of the latter are the introductions that each one of the participants is expected to give at the beginning of the first group conversation. In the introduction stories some of the narrators choose to relate separate parts of their stories to what others have said earlier, by directly referring to someone else ('as you said...') or by suggesting similarities/differences more indirectly ('I've also...' or 'I don't know either...'). It is typical, however, of this form of sharing that participants do not take part in each others' narration to any greater extent than through sporadic back-channeling and/or by minimal comments as they take turns. Extract 2, which concerns three different participants' contributions, is initiated when one of the participants concludes her introduction story and thereby her part in the chain. In this extract these three sections are marked as different parts.

*Extract 2 'I also watch ...' A2: 8:6*

((Part 1 Conclusion of Agnes' introduction story))

01 Agnes: [...] now I won't say any more. Now we'll stop.

02 Nurse: yes

03 Alice: °are you through?°

04 Agnes: Yees

05 Nurse: (((laughs)))

06 Agnes: [well, yes

07 Nurse: completely

08 (.)

((Part 2 Alice's introduction story (abbreviated)))

09 Alice: Yes, my name is [...]

And um (.) if I tell you about myself, I mean, um, my life situation first

\*I'm\* (.) I've (.) I'm [...] ((profession and position))

Then at home we have a daughter who is [...] ((child's age and some details)).

And um (.) I have a temporary disability pension.

I've been sick (.) for many years.

- I don't know really when this illness began either  
 15 but I believe [...] ((describes a medical problem))  
 and after that I tried to work for a while.  
 It didn't work.  
 I was very sick and very strange.  
 And of course all the doctors believed that it was caused by [...]  
 20 I went to the doctors all the time [...] ((describes changing doctors))  
 and he ((a doctor)) saw to it that I could come here  
 and understood that this fatigue and everything.  
 He had been to a lecture.  
 [...] ((evaluates contacts with the medical system))  
 25 → sure, I'm depressed just like you are  
 and you get depressed from all this, ahem, when you have an ill- and don't  
 understand,  
 and nobody believes you  
 and (.) you don't have strength for anything and so on.  
 [...] ((introduces more medical problems))  
 30 and, um (.) yes of c- I want to extend the temporary disability pension now  
 that the time's up  
 but I (.) would really like to work sometime at something completely  
 different.  
 I just want to get rehabilitation and start to live again someday.  
 \*I don't want to be like this\* ((laugh/sob)) my whole life.  
 I suffer a lot from not being able to concentrate [on] anything.  
 35 I like to [...] ((interests))  
 I can't do anything  
 → I lie on the sofa too (Agnes: mm)  
 → I also watch [...] ((the same TV program that Agnes mentioned in her  
 introduction)) and uh  
 39 Agnes: It's the same every \*day\*  
 40 Alice: Yeess so that I- oh well, it's not much of a life and it's not worth living, you  
 know that.  
 That's it.  
 42 (.)  
 43 Astrid: oh well  
 44 Alison: (°doesn't sound so xx°) ((a whisper that probably only those sitting closest  
 can hear))  
 ((Part 3 Introduction to Astrid's introduction story))  
 45 Astrid: My name is [...] (.) I'm forty years old, married, and I have two children  
 who are eight and fourteen. I'm a [...] ((profession)) at [...] ((workplace))  
 in [...] ((town)). (.) I got sick [...]

By first introducing herself, the nurse has presented a pattern for the introduction stories' form and content. After that both the participants and the nurse contribute to the pattern being followed and developed. As more of the participants make their introductions, variations and

additions to what may be included in the pattern appear. Thus different themes for sharing are created in the two studied classes.

Alice's introduction story in the earlier extract is the sixth and the penultimate in this class. This means that she has already heard five other co-participants' illness stories, and can link her own introduction to them. The shift in conversational turns becomes, however, a little confusing. The formal structure in which one person at a time tells his/her illness story, taking turns by the order in which they are sitting at the table, means that the participants must agree when and how the shift in speakers is to take place. In the extract the shift takes place partly at Agnes' metacomment that she isn't going to say any more and partly at Alice's question of whether Agnes is finished talking. After a short pause Alice starts her narrative, which follows in most respects the given pattern of name, family situation, length of illness, degree and type of sick leave, and the story of her illness. Alice closes her story with a look at the future, telling about things she wishes would happen and comparing these with how she feels at present. Her words, 'That's it' (line 41) mark the end of her introduction story and indicate that the next participant can continue.

Links to others' experiences are part of a pattern that reappears in this class's introduction stories. Alice does this four distinct times in Extract 2 (marked by →), by comparing her own experiences to others' stories: '*I don't know* really when this illness began *either*' (line 14); '*sure, I'm depressed just like you are*' (line 25), '*I lie on the sofa too*' and '*I also watch [...]*' (lines 37-38). The latter two links are answered by Agnes (to whom they seem to be directed), first with an 'mm' and after naming the TV program, with a comment about the program, 'it's the same every \*day\*'. For the greater part of Alice's introduction story, however, there are neither comments nor audible receipt tokens.

This kind of orchestrated story involves first giving each participant a turn to tell his/her story. This avoids the competition for the floor that can otherwise occur to make it more difficult for some participants to be heard. This also means, however, that anyone who doesn't wish to narrate has a hard time avoiding it. Even though the nurse points out that each participant can tell as much or as little as he/she wants, it can be difficult in practice. Whoever breaks the pattern and thereby the framework of this form of orchestrated telling/sharing by, for example, forgetting to give his/her name can be interrupted by the question from both co-participants and nurse, 'and who are you?'. Similarly, the nurse

sometimes asks questions at the end of an introduction that prompt elaboration on what a narrator has chosen to tell.

The orchestrated sharing involves the juxtaposition of a long series of personal illness stories, rather like an AA meeting (e.g. Steffen, 1997) or other kind of meeting at which confessional stories are told (Stromberg, 1993). This simplifies comparisons between different individuals' experiences, and the possibility of discerning patterns in the linked narratives. The results become especially apparent in one of the classes when a participant later asserts to the lecturer that most of the other participants in the class seem to have had experiences that differed from hers. Other participants protest immediately and offer a correction; 'there were only two'.

The direct and indirect links that individual participants make with the others, as in Extract 2, indicate that orchestrated storytelling is a basis for collectivizing experience, even though the interaction between participants is relatively controlled by the form of the sharing. Instead, this type of direct and indirect links to others' experiences constitutes a kind of interactive sharing within the framework of the formalized.

## Co-narrated collectivized stories

Characteristic for co-narrated collectivized stories is that individual experiences are played down whereas what is or might be common is pooled. At the heart of this type of narrative is the collectivizing of experiences (cf. Hydén, 1997). It is therefore no longer meaningful to speak of anybody's personal story in isolation. Instead, by sharing experiences through co-narration a jointly produced story appears. Sometimes a joint story is build up around what Sacks (1995) has described as 'second stories' or 'clumped stories'. However, most of the time each person's contribution is less than what could count as a full story. In order to be counted as a co-narrated collectivized story, the story is collaboratively told by at least two of the participating sufferers, sharing experiences in a manner where both contribute by more than back-channeling or receipt tokens like 'mm', 'oh yeah', and 'of course'. This third type of narrative turned out to be the most commonly used, especially during segments of the school allocated for the participants to share experiences. In addition to being used in this kind of group-talk this was a common way to share experiences in the waiting room but occurred occasionally in a limited form during lectures.

These co-narrated collectivized stories were told collaboratively either by constructing a joint story using several participants' experiences, or by evaluating and elaborating another co-participant's personal experiences. Although the topics for these stories are serious matters like illness and suffering, the storytelling contained laughs and jokes about, for instance, people who did not believe in their illness. Co-narrated stories could be triggered by questions from the lecturer/nurse but were mostly exclusively between the participants. One interesting detail is that when the nurse got involved in such collaborative storytelling she sometimes acted almost as a 'co-participant' contributing in a general way, 'otherwise you get so disappointed when ...'. In Extract 3 several of the women in one of the classes co-narrate a story about how it is possible to do things despite their illness, provided that they are done in a certain way. This co-narrated story originates from the personal story in which Clara has been telling how she nowadays chooses not to do things that she feels are too much. The extract starts with this story.

*Extract 3 'You can do things' (C2:11)*

- 01 Clara: sometimes my husband says he is [...] .h shall we do this or that?  
What about going to the movies today?  
No but I can't *go* see a film today.  
No but why not?
- 05 No but I- today- I *can't*.  
It's like a *huge* effort for me (Carol: mm) to go see a movie.  
Oh- yes. So I don't *do* that.
- 08 P: °No°
- 09 Clara: I did that before.  
And then I felt *terrible* (P: °mm°) of course. Now I don't *do* it.
- 11 Cathy: but that's probably the important thing.
- 12 Clara: yes, it's important. (PP: mm) I think so.
- 13 Carol: and then like you say, too, you- .h if you're going to do something,  
you can *do* things anyway. (Clara: yes) like babysitting.  
.h (Clara: yes) but it's just that you have to plan (it) (Clara: yes) because  
you can't stand to have it be a *must*
- 16 Clara: no. [(and then-)
- 17 Carol: [because- then it gets so bothersome  
(and) then you give up right [away. It just doesn't *work*.
- 19 Cathy: [mm
- 20 PP: no
- 21 Clara: this stress tol[erance, you know
- 22 Carol: [oh it's *very* important (Clara: yes) that you get the people  
around you (Clara: mm) to understand that.
- 23 Clara: .h yes but you can do a lot.  
(you know) I can wash the windows, and everything.

- And I- I can clean.  
 I think that things like that are fun to do at home.  
 .h but I have to do it at my own speed, you know. (PP: mm) peace and  
 quiet, like .h (Carol: .hm) (.) not so that somebody comes oh now let's do  
 this. [and oh: no [God.
- 28 Carol: [mm [mm
- 29 Cindy: but then I think that it also feels a little like if you're really going to do  
 something that you know is going to take- require a lot of energy. .h then  
 it's usually very important too to plan the coming hours then and the days  
 (PP: mm) afterwards there I'm free. (PP: mm yes)  
 then I don't do *anything*. (PP: mm yes mm) ((many voices at the same time))  
 then [I just lie down and sleep.
- 32 Carol: [there is constant prioritizing
- 33 nurse: yes mm otherwise you get so disappointed (PP: yes) when that kick you got  
 from ye- I did it anyway.
- 34 Cindy: mm it's probably because-
- 35 nurse: it makes you feel so disappointed (Cindy: yes) when you have to give it up  
 or not (Cathy: mm) could do the things you .h wanted to do (PP: mm) on  
 other days then.
- 36 Clara: mm
- 37 nurse: so it- I think it's very important.
- 38 Clara: mm
- 39 Cindy: (yes) because then you have the energy for much more too because you  
 know yes but I can rest for two days later.
- 40 nurse: mm
- 41 Clara: mm
- 42 Cindy: I'm not going to do anything (nurse: mm) for the next two days. So I'll have  
 the energy to do this (nurse: mm) (P?: yes) today or [this evening
- 43 Caroline: [yes (because) you see  
 to it that you have the next day free you (nurse: mm) (PP: mm) that you're  
 going to stay up late. (nurse: mm) (PP: yes) if you have guests and then yes
- 44 nurse: .h yes
- 45 PP: mm
- 46 Celia: the hours [around
- 47 Caroline: [( ) prepared (PP: mm) or you have to be
- 48 Clara: just that you have to be prepared.
- 49 Now I'm going to yes- our oldest son [...] ((starts to tell another story))

The starting point for the common story of how one can handle fatigue is thus Clara's story (lines 1-10). When Cathy (line 11) evaluates Clara's personal story with the words 'but that's probably the important thing', a shift takes place in the meaning of the point. At the point when Cathy reaffirms Clara's story, the point is transformed into having a common validity. Thus the point of the story becomes valid for more than the narrator (Clara), and for more situations than the one just described. With that a co-narration starts, in which the collection of experiences

forms a partially new collectivized story. This co-narrated story is a direct collaboration between five female participants. The nurse even takes part, to some extent, in the narration.

First, Carol (line 13) is the one who starts the collaborative narration. She does this in a way that neither challenges Clara nor deprives her of her role as the initial teller by first creating a link to Clara's story, both with the words 'as you say' and by using one of Clara's earlier-mentioned themes in her hypothetical example 'like babysitting' (line 14). Second, Carol uses a general 'you' as a personal pronoun (by the Swedish word 'man' which is a different word than the form of 'you' (Sw. 'du') that she used in the first part linking her words to Clara's story). Together with the partially hypothetical form, this makes the story become general and valid, as is Cathy's evaluation, for several participants. At the same time it is a direct continuation of Clara's story. Both Clara and Cathy affirm and reinforce the alternative continuation, and Clara contributes her own examples of what she can manage to do provided she acts as Carol has just suggested (lines 23-27). It is followed by several contributions to the collective experiences; Cindy jumps into the narration with her 'but then I think' (lines 29-31), a contribution that the nurse interprets and develops. Caroline uses it to continue, '(because) you see to it that you have the next day free'. Celia also makes a little contribution by filling in spaces in Caroline's story.

The collaborative narration of experiences of how one manages and what one can or should do to handle the illness is collaborative in that it is based on several different individual's contributions, and also because the narrative structure makes it co-produced to a great extent. Various overlaps, as well as evaluating what others have narrated and filling in spaces in others' stories, demonstrate this co-narrated structure. An example of this occurs when Cindy's description (line 31) of how she lies down and sleeps as a part of her planning is overlapped by Carol's evaluating sentence, 'there is constant prioritizing' (line 32). The nurse, in turn, uses this to comment 'it makes you feel so disappointed' (line 33). Sharing experiences thus becomes in this type of narration even more perceptibly interactive, and the way in which the sharing works is by co-producing stories where the personal experiences are made general and collectivized.

As Norrick (1997) describes for twice-told narratives in families, the repetition of experiences in the patient school seems to be rather desirable. Here, however, it is not the same story that is told over and

over again, but rather similar narratives/experiences that, by being retold together on the same occasion, form a sort of collectivized narration of the illness and its significance in different contexts. This occurs when participants move on from others' contributions with their own similar experiences, which are often told in such a way that they are less personally linked and thus more general and easier to share. In this way, the co-narration in the patient school resembles the meaningful storytelling episodes that Mattingly (1998) describes. The collectivized co-narrated stories are also future-oriented, at least in part, as they also, as for instance Clara in Extract 3, include legitimate refusals that spouses might question, and thus it becomes a matter of how the illness can be understood and managed.

Involved narration, indicated by the overlapping and conversational support, means that sharing of similar experiences are apprehended as being significant. The double meaning of co-narration, as described by Norrick, in which the common stories as well as the common narration reinforce the feeling of belonging and legitimacy, seems also to be valid for co-narration in the patient school. The patient school thus has multiple functions – to collect similar experiences, and in turn to reinforce participants' experiences.

## Different stories – different forms of sharing

It is important that the sharing of experiences considered in this article concerns a long-term illness that is contested. Suffering from chronic illnesses is usually regarded as having an influence on the self. Changes in chronically ill people's self-perception depending on such things as limitations in bodily functions, as well as mental and social difficulties due to the illness, have been described as giving rise to a sense of *loss of self* (Charmaz, 1983). A particular aspect of this is the delegitimization connected with illnesses like chronic pain and CFS (Hilbert, 1984; Ware, 1992), an aspect which commonly leads the individual sufferer into self-reflecting questions like 'Have I gone mad?' Or 'Is all this a figment of my imagination?'. When what we experience no longer seems to be intersubjectively shared storytelling becomes imperative (Frank, 2001). We must then tell our experience both to ourselves to re-establish coherence and to others 'as a means to of seeking new terms of intersubjectivity' (p. 233) (see also Bülow and Hydén, 2003a). Considering this, sharing experiences becomes a key factor for understanding the

significance of participating in activities like the patient school studied here.

The significance of sharing experiences of illness and suffering in self-help groups has been emphasized by different researchers (Cain, 1991; Karp, 1992; Steffen, 1997). Because the proliferation of these kinds of groups has been partly explained by reasons such as that people's needs have not been adequately met either by the health care or by changing lay networks (Jacobs and Goodman, 1989; Kelleher, 1990) it is interesting that sharing experiences was found to such an extent in the patient school. Moreover, as shown by the analysis, sharing became evident even at times in school when this was rather unexpected and not requested – like self-contained personal stories during lectures.

Three things seem to happen in sharing experiences of illness and suffering in the patient school. First, the participants, by taking active parts and collectivizing, create a common fund of experiences and knowledge about their illness. This kind of mutual creation through sharing experiences can be compared with what Borkman (1990) describes for self-help groups as experiential knowledge. Analysis of the narratives and the narration shows how this can occur by creating a picture of the illness, its significance, and different ways of managing the suffering. The picture that is created, however, is not distinct but rather reflects the pool of varying experiences to which the group contributes. As one interview subject later expressed it, a picture does emerge, although not a focused one.

Second, the process of sharing of experiences means that all of the individual participants had the opportunity to compare themselves and their personal suffering with the image of the illness that was created through sharing. Each person thus had the opportunity to either regard himself/herself as being similar to this image or as being different in some way. Consequently, the active process of sharing experiences also means that the image of the illness and its meaning were modified and developed during the school period. One interesting thing that was revealed in some interviews was that this possibility to compare oneself to the jointly created image seemed to continue after the school had finished as well. This happened when an interviewee compared his/her experiences with another specific participant's or with collectivized experiences emphasizing similarities or stressing differences between their own experiences and the others'. The 'others' were described either

as being in better shape than the interviewee himself/herself or as a frightening picture of what one was afraid of becoming.

Third, it appears that, as Norrick (1997) describes for twice-told narratives of family stories, the active sharing of experiences itself involves a mutual recognition of distress, whether the individual's suffering corresponds to the common picture or deviates from it in any way. Reinforcement through sharing of experiences was also the function of sharing pointed out by most interview subjects. Sharing suffering that was earlier misunderstood and sometimes suspected in many contexts thus appears in itself to confirm that the suffering is real. If others suffer in similar ways, an individual's own suffering becomes more credible. Thus, the sharing of experiences of a contested illness can be considered to contribute to a reduced sense of loss of self. This may be the motive that can be discerned behind sharing experiences, one that appears not only during the time allocated for this purpose, but also one that is a significant component of the entire patient school itself.

The intersubjective understanding of the illness that might be said to arise from sharing thus seems to result in two different, but parallel, transitions. On the one hand, there is the transition in which experiences of illness and suffering that were once private become mutual and shared; that is when personal experiences are collectivized. On the other hand, there is the transition in which the individual sufferer perceives and understands his/her situation in a new way through sharing experiences with other sufferers. Both transitions are part of the meaning-making context that the patient school constitutes. They are thereby also examples of how the individualistic and the collectivistic – what Williams (1989) calls Janus-faced in reference to self-help groups – co-exist and co-operate in groups in which suffering brings people together and suffering is actively and mutually shared. Sharing experiences of illness in this sense is more than just sharing the same diagnosis or the same kind of illness experiences. Instead, sharing experiences of illness consists of those social acts that form the intersubjective relations through which the participants, at least for the moment, create and sustain a common world.

## Transcript key

[...]	some data omitted
P	unidentified participant
PP	several participants in chorus
((comment))	transcriber's comments or non-verbal activity
[	start of overlapping talk
?	rising inflection
.	a conclusive fall in tone
,	a 'continuing' intonation
<i>italic</i>	emphasis
-	sharp cut-off
°quiet°	noticeably quieter than surrounding talk
*laugh*	with laughter in voice
.h .hh	audible intake of breath
(.)	short pause
→	points to specific parts of an example discussed in the text

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## Biography

PIA BÜLOW is a doctoral candidate at the Department of Communication Studies at the University of Linköping, Sweden. Her present research focuses on sense-making processes in a contested illness like Chronic Fatigue Syndrome (CFS) with particular interest in illness narratives, co-narrating, identity, and chronicity. In her dissertation she examines the interactions between experts and groups of sufferers, among sufferers, and in research interviews with individuals suffering from CFS.

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<sup>1</sup> The whole study also consists of observations and audio recordings from some other types of meetings in this school. Additional lectures without being followed by a group conversation as well as solitary lectures in other classes are however excluded as the study of the whole series of lectures seem to be a necessary condition for an analysis of the process of sharing.

## References

- Arminen, I. (1998) *Therapeutic Interaction. A Study of Mutual Help in the Meetings of Alcoholics Anonymous*. Helsinki: The Finnish Foundation for Alcohol Studies, vol 45.
- Bartlett, E. (1985) 'Patient Education. Eight Principles from Patient Education Research', *Preventive Medicine*, 14, 667-669.
- Blauner, M.L. (1991) 'Self-Help Groups for the Chronically Ill: Different Structures, Varying Processes', *Dissertation Abstracts International*, V52 (8-A), 3094-3095. (UMI No. 9202257).
- Blum-Kulka, S. (1997) *Dinner Talk: Cultural Patterns of Sociability and Socialization in Family Discourse*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Borkman, T.J. (1990) 'Experiential, Professional, and Lay Frames of Reference', in T.J. Powell (ed.) *Working with Self-Help*, pp. 3-30. Silver Spring, MD: NASW Press.
- Bülow, P.H. and Hydén, L-C. (2003a) 'In Dialogue with Time: Identity and Illness in Narratives About Chronic Fatigue', *Narrative Inquiry*, 13(1), 71-97.
- Bülow, P.H. and Hydén, L-C. (2003b) 'Patient School as a Way of Creating Meaning in Contested Illness: The Case of CFS', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7(2), 227-249.
- 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(2), 168-195.
- Denzin, N.K. (1987a) *The Alcoholic Self*. Newbury Park, CA: Sage.
- Denzin, N.K. (1987b) *The Recovering Alcoholic*. Newbury Park, CA: Sage.
- Frank, A.W. (2001) 'Experiencing Illness through Storytelling', in S.K. Toombs (ed.) *Handbook of Phenomenology and Medicine*. Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Goffman, E. (1981) *Forms of Talk*. Philadelphia: University of Pennsylvania Press.
- Graumann, C.F. (1995) 'Commonality, Mutuality, Reciprocity: A Conceptual Introduction', in I. Markovà, C.F. Graumann and K. Foppa (eds) *Mutualities in Dialogue*, pp. 1-24. New York: Cambridge University Press.
- Hilbert, R.A. (1984) 'The Acultural Dimensions of Chronic Pain: Flawed Reality Construction and the Problem of Meaning', *Social Problems*, 31, 365-378.
- Holstein, J.A. and Gubrium, J.F. (2000) *The Self We Live By: Narrative Identity in a Postmodern World*. New York: Oxford University Press.
- Hydén, L-C. (1997) 'Illness and Narrative', *Sociology of Health & Illness*, 19(1), 48-69.
- Jacobs, M.K. and Goodman, G. (1989) 'Psychology and Self-Help Groups: Predictions on a Partnership', *American Psychologist*, 44(3), 536-545.

- 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(2), 139-170.
- Keefe, F.J., Beaupré, P.M. and Gil, K.M. (1996) 'Group Therapy for Patients with Chronic Pain', in R.J. Gatchel and D.C. Turk (eds) *Psychological Approaches to Pain Management: A Practitioner's Handbook*, pp. 259-282. New York: The Guilford Press.
- Kelleher, D.J. (1990) 'Do Self-Help Groups Help?' *International Disability Studies*, 12, 66-69.
- Labov, W. (1972) 'The Transformation of Experience in Narrative Syntax', in W. Labov (ed.) *Language in the Inner City*, pp. 354-405. Philadelphia: University of Pennsylvania Press.
- Labov, W. and Waletzky, J. (1967) 'Narrative Analysis: Oral Versions of Personal Experience', in J. Helm (ed.) *Essays on the Verbal and Visual Arts*, pp. 12-44. Seattle: University of Washington Press.
- Levy, L.H. (1979) 'Processes and Activities in Groups', in M.A. Lieberman and L.D. Borman (eds) *Self-Help Groups for Coping with Crisis*, pp. 234-271. San Francisco: Jossey-Bass.
- Maines, D.R. (1991) 'The Storied Nature of Health and Diabetic Self-Help Groups', *Advances in Medical Sociology*, 2, 185-202.
- Mattingly, C. (1998) *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press.
- Michaels, S. and Cook-Gumperz, J. (1979) 'A Study of Sharing Time with First Grade Students: Discourse Narratives in the Classroom', *Berkeley Linguistics Society*, 5, 647-660.
- Mishler, E.G. (1986) 'The Analysis of Interview-Narratives', in T.R. Sarbin (ed.) *Narrative Psychology: The Storied Nature of Human Conduct*, pp. 233-255. New York: Preager Publishers.
- Norrick, N.R. (1997) 'Twice-Told Tales: Collaborative Narration of Familiar Stories', *Language in Society*, 26, 199-220.
- Ochs, E., Smith, R. and Taylor, C. (1989) 'Detective Stories at Dinnertime: Problem-Solving through Co-Narration', *Cultural dynamics*, 2(2), 238-257.
- Polanyi, L. (1985) 'Conversational Storytelling', in T.A. van Dijk (ed.) *Handbook of Discourse and Dialogue*, Vol. 3, pp. 183-201. London: Academic Press.
- Riessman, C.K. (1993) *Narrative Analysis* (Vol. 30). Newbury Park: Sage.
- Sacks, H. (1995) *Lectures on Conversation*. Oxford: Blackwell.
- Schubert, M.A. and Borkman, T.J. (1991) 'An Organizational Typology for Self-Help Groups', *American Journal of Community Psychology*, 19(5), 769-787.
- Steffen, V. (1997) 'Life Stories and Shared Experience', *Social Science and Medicine*, 45(1), 99-111.
- Stromberg, P.G. (1993) *Language and Self-Transformation: A Study of the Christian Conversion Narrative*. New York: Cambridge University Press.
- Tannen, D. (1984) *Conversational Style: Analyzing Talk among Friends*. Norwood, NJ: Ablex Publishing Corporation.

- Ware, N.C. (1992) 'Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome', *Medical Anthropology Quarterly*, 4(6), 347-361.
- 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(2), 133-159.
- Young, K. (1989) 'Narrative Embodiments: Enclaves of the Self in the Realm of Medicine', in J. Shotter and K.J. Gergen (eds) *Texts of Identity*, pp. 152-165. London: Sage.

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