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SHARING EXPERIENCES OF CONTESTED ILLNESS BY STORYTELLING

Pia H. Bülow

Department of Communication Studies

Linköping University

581 83 Linköping

Sweden

Email: piabu@tema.liu.se

Phone: +46 13 28 66 54

Fax: +46 13 22 99

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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 primarily is of 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: storytelling, co-narration, illness experience, narrative analysis, identity, chronic illness

INTRODUCTION

Sharing personal experiences with other people is a common phenomenon that we all engage in. This sharing of experiences is probably of importance since it corroborates others' as well as one's own experiences and contributes to a sense of belonging. Sharing experiences therefore becomes especially important when experiences like suffering, pain and other experiences 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 what this article will examine, 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 kind 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 where 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 particularly the function of co-narration 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 paper 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 since 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 since we are concerned with sharing, ethnographic studies from self-help groups focusing interaction and/or storytelling seem to be a relevant point of departure for the following discussion about venues for sharing.

What links these groups together, and what seems to make sharing experiences of suffering possible, is that each member does assume—and the group has to validate that—that the others have the same kind 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). Irrelevant 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 of 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. Since 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 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 still 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 above 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 is usually called oral narratives. This situation can be ordinary small talk

at the family dinner table (Blum-Kulka, 1997), or it can be 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 can be presented than what is possible to tell in a conversation with a colleague. Similarly, the repetition of familiar family tales can play a special role in the family circle (Norrick, 1997), while 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 individual narratives' structure to the 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 the group's 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).

Since 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 with 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 in time by one year. This patient school, organized and arranged by a clinic at a large hospital in Sweden, consisted of five meetings, or lessons, of about two hours once a week.¹ 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 consisted from the beginning of eight participants – two men and six women – though there was one dropout (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 nearly 30 to about 60 years old. The majority (15 persons) had received the diagnosis CFS, sometimes in addition to other

diagnoses like fibromyalgia and burnout, while the rest (3 persons) did not fulfil the criteria for CFS and had received the diagnosis of idiopathic chronic fatigue. In addition to the material from the patient school, 31 interviews with 13 of the participants from the two studied classes have been 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 have been conducted on the Swedish material and translated to English later. The transcripts (for which a key is provided at the end of the paper) 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 major part 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 completion of the school patients were supposed to return to their former medical contact.

The five two-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. Between the lecture and the group-talk there was a coffee break. All these three activities took place in the same room, around a conference table. Two additional lectures were presented as part of the school but since 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 where 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. Since 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 do 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* are possible to describe 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 kinds 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 kind 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 stories was shared with the others as ratified listeners only (Goffman, 1981), that is, by overhearing other participants’ stories.

Example 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
- 06 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.
- 12 Lecturer: [Did you do that?
- 13 Cornelia: No
- 14 Lecturer: No
- 15 ((chuckles are heard among the other participants))
- 16 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.
- 19 P: Yea.h
- 20 (.)
- 21 ?: °mhm°
- 22 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 3 and 5) and takes the form of a clearly defined narration (lines 6-11). 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 16), 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. Since 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 the example above 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*. Since 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. Example 2, below, 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 example these three sections are marked as different parts.

Example 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: Yeees

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))

and, um (.) yes of c- I want to extend the temporary disability pension now that the time’s up

30 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.

I like to [...] ((interests))

- 35 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
 38 Agnes: It's the same every *day*
 39 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.
 41 (.)
 42 Astrid: oh well
 43 Alison: (°doesn't sound so xx°) ((a whisper that probably only those sitting closest can hear))
 ((Part 3 Introduction to Astrid's introduction story))
 44 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's 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 example above 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 example above 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 40) mark the end of her introduction story and indicate that the next participant can continue.

Linkings to others' experiences are part of a pattern that reappears in this class's introduction stories. Alice does this four distinct times in the example above (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 [...]*” (line 37). 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.

Secondly, 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 where 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 the example above, 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. Except from 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 as well.

These co-narrated collectivized stories were collaboratively told either by constructing a joint story using several participants’ experiences, or by evaluating and elaborating another co-participant’s personal experiences. Although the topic 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 the following example 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 example starts with this story.

Example 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*
- 17 Clara: no. [(and then-)]
- 18 Carol: [because- then it gets so bothersome
(and) then you give up right [away. It just doesn't *work*.
- 20 Cathy: [mm
- 21 PP: no
- 22 Clara: this stress tol[erance, you know
- 23 Carol: [oh it's *very* important [that you get the people around you [to understand that.
- 24 Clara: [yes [mm
- 25 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.
- 31 Carol: [mm [mm
- 32 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.
- 38 Carol: [there is constant prioritizing
- 39 nurse: yes mm otherwise you get so disappointed (PP: yes) when that kick you got from ye- I did it
anyway.
- 41 Cindy: mm it's probably because-
- 42 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.
- 44 Clara: mm
- 45 nurse: so it- I think it's very important.
- 46 Clara: mm
- 47 Cindy: (yes) because then you have the energy for much more too because you know yes but I can
rest for two days later.
- 49 nurse: mm
- 50 Clara: mm
- 51 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

- 53 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
- 56 nurse: .h yes
- 57 PP: mm
- 58 Celia: the hours [around
- 59 Caroline: [() prepared (PP: mm) or you have to be
- 60 Clara: just that you have to be prepared. 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.

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). Secondly 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 25-30). It is followed by several contributions to the collective experiences; Cindy jumps into the narration with her "but then I think" (line 32), 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 37) 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 38). The nurse, in turn, uses this to comment "it makes you feel so disappointed" (line 39). 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 in what 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, since they also, as for instance Clara in the example above, 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 paper 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 has 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). Since 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 where 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.

Secondly, 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 was 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.

Thirdly, it appears to be as Norrick (1997) describes for twice-told narratives of family stories, that the active sharing of experiences involves in itself 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 the suffering that was earlier misunderstood and sometimes suspected in many contexts appears thus 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 where suffering brings people together and where 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

¹ The whole study also consists of observations and audio recordings from some other kind 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 since the study of the whole series of lectures seem to be a necessary condition for an analysis of the process of sharing.

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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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