

‘I am not the kind of woman who complains of everything’: Illness stories on self and shame in women with chronic pain

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Abstract

In this study, we explore issues of self and shame in illness accounts from women with chronic pain. We focused on how these issues within their stories were shaped according to cultural discourses of gender and disease. A qualitative study was conducted with in-depth interviews including a purposeful sampling of 10 women of varying ages and backgrounds with chronic muscular pain. The women described themselves in various ways as ‘strong’, and expressed their disgust regarding talk of illness of other women with similar pain. The material was interpreted within a feminist frame of reference, inspired by narrative theory and discourse analysis. We read the women’s descriptions of their own (positive) strength and the (negative) illness talk of others as a moral plot and argumentation, appealing to a public audience of health personnel, the general public, and the interviewer: As a plot, their stories attempt to cope with psychological and alternative explanations of the causes of their pain. As performance, their stories attempt to cope with the scepticism and distrust they report having been met with. Finally, as arguments, their stories attempt to convince us about the credibility of their pain as real and somatic rather than imagined or psychological. In several ways, the women negotiated a picture of themselves that fits with normative, biomedical expectations of what illness is and how it should be performed or lived out in ‘storied form’ according to a gendered work of credibility as woman and as ill. Thus, their descriptions appear not merely in terms of individual behaviour, but also as organized by medical discourses of gender and diseases. Behind their stories, we hear whispered accounts relating to the medical narrative about hysteria; rejections of the stereotype medical discourse of the crazy, lazy, illness-fixed or weak woman.

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Linda speaks on behalf of a group of women with chronic muscular pain:

It was obvious that some of the girls in the [treatment] group were very frustrated and felt that they were almost not believed by doctors and health services. Some of them were the sort of people who poured themselves out in the group, telling everyone how much pain they had and how fed up they were

with their men. Very often when I left the group I thought ‘thank goodness I’m not that ill; things aren’t quite so bad with me!’ Telling absolutely everyone how much pain one has is not very smart! It is boring to listen to, and I think it is very negative to make this into a big problem. This would only hit back on me. In fact, I’ve also tried to tell others when I’m in great pain. However, you feel that you are exposing yourself, and that you are boring others, and then you get a feedback that they also have pain. I think there is an essential difference between my pain and theirs, but as long as I’ve a somewhat doubtful diagnosis, the only difference is that I

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complain more: I become the person who has pain because I need or want to have pain: It becomes my own fault that I'm ill. However, it is difficult to accept that I can't do everything that I want to do, and to abandon hope of being the kind of person who never gives up, which I've always considered myself to be. I've always been so strong and robust, but I feel very much alone with these things; like a neurotic, whining woman. In the end you wonder whether the others are right and that it's you that there is something wrong with: But my back will never be cured by going to a psychologist.

Linda's story is constructed from illness accounts from 10 different women who participated in a study on chronic muscular pain. Below, we present the background and findings from this study.

Introduction

Chronic illness has been looked upon as biographical (Bury, 1982) or continual (Honkasalo, 2001) disruption of a person's ongoing life, touching the individual's sense of self or even causing a loss of self (Charmaz, 1983; Eccleston, Williams, & Rogers, 1997; Lillrank, 2003; Woodward, Broom, & Legge, 1995; Åsbring, 2001). They struggle to find identity and meaning; to reconstruct their personal life histories.

In various studies during the last decade, woman with chronic muscular pain such as fibromyalgia, and chronic fatigue syndrome have reported negative experiences during medical encounters: They repeatedly find themselves being questioned and judged either to be not ill, suffering from an imaginary illness or given a psychiatric label (Garro, 1992; Jackson, 1992; Johansson, Hamberg, Lindgren, & Westman, 1996; Lilleaas, 1995; Lillrank, 2003; Ware, 1992; Åsbring & Närvänen, 2002).

When we previously examined the nature of 'work' done by 10 women with chronic muscular pain in order to be believed, understood, and taken seriously in medical consultations, we found they were not only struggling for their credibility: Their stories illustrated how they struggled for self-esteem or dignity as patients and as women (Werner & Malterud, 2003). Several studies support that illness is experienced as a moral event, concerning shame and blame, responsibility and stigmatisation: The patients strive to legitimize their chronic illness and to achieve a sick role (Eccleston et al., 1997; Glenton, 2003; Good, 1994; Jackson, 1992; Lillrank, 2003; Kugelmann, 1999; Ware, 1992; Åsbring & Närvänen, 2002).

We were interested in how these women managed challenges to identity caused by disruptions of life and personal identity, and deligitimation of illness. The objective of the present study was to explore issues of

self and shame in illness accounts from women with chronic pain, focusing on the impact of cultural discourses of gender and disease. We concentrated on which purposes the stories served for the narrators, and which larger structures organized their accounts.

Theoretical framework

From focus on the told/experience to the storytelling/narrative

'Reality is not something out in the universe to be discovered, but rather is contingent upon people who construct it,' Scheurich (2000, p. 461) writes. Thus, what is said in the interview or answered in surveys cannot be treated unproblematically as a direct expression of the true or private self (Miczo, 2003).

Initial studies of the illness experience explored the patients' 'subjectivity' and the meanings that individuals gave to their illness experience through for example metaphors and images, often centering on the concepts of stigma, sense of shame and loss of self (Pierret, 2003). For several years now, research in this field has been using 'illness narratives'.

The concept of narrative has been used in a variety of ways and contexts: It can be defined as an entity that is distinguishable from the surrounding discourse and has a beginning, a middle, and an end (Hydén, 1997). The narrative is one of several cultural forms available for expressing or formulating experience of illness and suffering. It is also a medium for conveying shared cultural experiences. Narratives have gained importance in the study of chronic illness as a means of understanding the attempts of patients to deal with their life situations and the problems of identity that illness brings with it.

Then what do we hope to learn about the way people live when we interpret interview transcripts from the perspective of narrative or storytelling? Ochberg (1994, p. 113) replies that 'broadly, we see how individuals make sense of their lives'. He emphasize the relation between lived life and the telling, arguing that 'individuals do not merely tell stories after the fact about their experience; instead they live out their affairs in the form of stories'. Like a story, a life also is a kind of argument: It is a way of claiming that one construction of experience should be privileged and that other, negative alternatives should be dismissed.

Self, shame, and social structures in a gender perspective

We will return to findings in an earlier article (Werner & Malterud, 2003) as a background for understanding the stories and material presented here. The accounts of the women indicated that hard work was needed to

make the symptoms socially visible, real, and physical when consulting a doctor. Their efforts reflected a subtle bodily and gendered balance not to appear too strong or too weak, too healthy or too ill, or too smart or too disarranged. Attempting to fit in with normative, biomedical expectations of correctness, they tested strategies such as appropriate assertiveness, surrendering, and appearance. The various strategies illustrated how they organized pain and gender, aiming to reflect illness in a credible way, preventing their illness and (woman) body from being used against them as a diagnostic check on disease and morbidity—and perhaps also femininity. The work of credibility might be understood as compliance to hidden rules of the medical encounter; as ways of handling dignity.

Chronic muscular pain and other medically unexplained disorders are characterized by somatic symptoms without diagnosable organic disease (Malterud, 2000). Other clinical terms used to describe this kind of pain are functional or somatoform disorders or somatizing patients. Although some disagree (Malterud, 2002; Epstein, Quill, & McWhinney, 1999), many (doctors) interpret functional disorders or somatisation as psychopathology, i.e. that underlying psychological factors have a central place in the development of symptoms. The biopsychosocial model is used as the reason for focusing attention on the patients' personality traits and life circumstances.

Fibromyalgia and other functional disorders have also been described as 'new psychiatric disorders', modern forms of 'hysterical epidemics', and the 'new hysteria(ns)' (Ford, 1997; Scheurich, 2000; Shorter, 1992; Showalter, 1997). Although hysteria has also been registered in men, the relation between hysteria and the woman(body) has been striking. At the beginning of the 19th century, the diagnosis hysteria 'manifested the very horizon of expectation to femininity' and the woman: She was seen as (needing to be) 'sickly, weak, and delicate' (Johannisson, 2001, p. 100).

Many of the women in our material described themselves as people who did not want to talk very much about pain and illness and who regard themselves as both strong and ill. This may be expression of something more than purely thematic observations. It can also be interpreted as discourses that may be both general and special; as the way in which we are expected to talk about ourselves, and how one is expected to be and to understand oneself in the modern (Widerberg, 2001, p. 138).

Drawing on the work of Ochberg (1994), we read the women's stories as a self-idealized version, aiming to reflect a positive image of self to a public audience of doctors, health personnel, and the general public—in addition to the interviewer. However, Haug's (1992) concept of the gendered moral can be fruitful for understanding the informant's illness accounts not

merely as strategic uses of narratives (Riessman, 1990) to legitimate an idealized version of the story (Ochberg, 1994): Their stories can also be seen as a work of credibility, i.e. as methods for handling dignity in an appropriate moral way, both as women and as being ill (Werner & Malterud, 2003). According to Haug's study of morality, the moral also have two genders: In men the central element is property; in women it is her relation to her body. Haug's point is that to be considered as moral beings, different behavior is required from women than from men. Moreover, the same behaviour by women and men is interpreted differently depending on the gender of the acting person.

Douglas (1999) regards the body as the starting point for different culture's understanding of 'purity', 'danger' and 'pollution'. This enables us to explore what is said or denied in the women's illness accounts as an expression of the culture's taboos, i.e. a social prohibition against making visible or talking about the tabooed. Leira's (2002) concept of tabooed trauma illustrates that the tabooed becomes hidden and invisible and leads to an invalidation of the experienced trauma.

The perspectives of Haug (1992), Douglas (1999), and Leira (2002) can provide access to an understanding of the structure and function of society at large, making the women's stories appear not merely in terms of individual behaviour, but also as organized by medical discourses of gender and diseases.

Method

The constructed illness story and the participants

Linda's story, presented initially, is drawn from qualitative interviews with 10 women with chronic muscular pain. We applied a purposeful sampling of 10 women of varying ages, backgrounds, medical history, and experiences. They were 26–58 years (average age 42½ years); one in her twenties and three from the next three decades of age (i.e. thirties, forties, and fifties). All except one, who was an Asian immigrant, were Norwegian. Five of the informants were living in marital relationships. Six had children—three of who were adults, and three of who were younger children. Three of the women had college degrees, and seven had education below this level. Five of the women had paid work (full- or part-time), and six received social benefits such as rehabilitation support and disability pension. The women were at present or previously working in professions providing service, care, office work, teaching, or academic jobs on various levels. The symptom duration in each individual ranged from 1 to 20 years (average duration 9 years); three between 1 and 5 years, four between 5 and 10 years, and three between 15 and 20 years.

All the women had taken part in different short treatment programmes with varying success. Six of them had taken part in a 1-year group-based treatment programme for women with chronic muscular pain (see Werner, Steihaug, & Malterud, 2003): They were recruited among participants from two treatment groups, and had been referred to the programme by local primary care providers (see Steihaug, Ahlsen, & Malterud, 2001). Four of the informants were recruited from a primary health care centre in Oslo, Norway. In spite of the fact that half of them had been given a diagnosis, chiefly fibromyalgia, they had all long-lasting pain that doctors often interpret as unexplained.

Data collection and analysis

Data were obtained from semi-structured, audio taped in-depth interviews based on Kvale's (1996) principles. The interviews (average duration 2½ hours) were carried out by the first author, a sociologist (AW), in the women's home, at the workplace, or at the treatment centre during 1997, 1999, and 2000. The study was introduced to the informant as part of a study on women's medically unexplained disorders. Finding out more about the quality of women's experiences of medical encounters, we hoped to offer women with chronic muscular pain the best possible health help in the future. The interviewer emphasized that the study was independent of the general practitioners and group leaders of the treatment programme.

The interview included questions about the informants' experiences of being a woman patient with chronic muscular pain in medical encounters and everyday life. We sampled step by step, covering a broad range of dimensions. The interviewer transcribed the conversations. The analysis was inspired by narrative theory and discourse analysis. However, we did not follow these methods strictly in the presentation of the findings. We began with standard modes of data analysis such as coding and categorizing, looking for emerging themes and patterns according to Giorgi's phenomenological analysis through the following four stages: (a) reading all the material to obtain an overall impression, and bracketing previous preconceptions; (b) identifying units of meaning representing different aspects of the women's experiences, and coding for these; (c) condensing and abstracting the meaning within each of the coded groups; and (d) summarizing the contents of each code group to generalize descriptions and concepts reflecting the most important experiences from the voices of the women (Giorgi, 1985; Malterud, 1993). We then constructed an illness story on the basis of some themes and patterns that emerged within the illness stories of the 10; i.e. common ways of talking about illness in terms of strength in various contexts,

and the negative talk of illness of others in contrast to their own accounts.

Linda's story is not a portrait of a person, nor is it completely fair to the informant's total illness descriptions. It is a summary of remarks that recurred in different forms in several of the interviews, and provides an important background to the results and analysis presented here.

The analysis focuses on what the women told about themselves; how or who they see themselves as today in relation to past and future, and in relation both to others with similar pain, and to healthy persons. We have not tried to categorise the women regarding self-image or personality traits. Our attention focuses on how issues regarding self and shame within the illness stories were shaped according to cultural discourses of gender and disease.

Findings: (Telling) stories about strength

A common feature of many of the illness stories of the women are descriptions of their own strength (both physical, mental, and emotional) and a negative attitude to the talk of illness as 'whining and complaining'. Their presentation of strength in spite of illness seems to contrast with their accounts of disabilities, which often limited their ability to participate in social and work activities, and practical everyday life. Thus, there are some apparently paradoxical contradictions in the informants' stories. This applies to how they talk about their own health and illness in terms of strength (both past and present), in various contexts, encounters or relations. On the one hand, they tell how hard they have had to work to be taken seriously, believed, and understood in medical encounters, and also in relation to their closest family and friends when having chronic, but invisible pain. On the other hand, several of the women express negative images of encounters with other women with similar disorders. The contradictions that appear can be understood as a type of meaning construction that has emerged in an interview situation, referring to various contexts and discourses, rather than as lies, holding back information or as personality disturbances.

Below, we elaborate on the women's descriptions of their own (positive) strength and the (negative) illness talk of others. What the women meant by 'strong' varied depending on the context, encounter, or relation they referred to. Here, we focus mainly on illness stories from everyday life (i.e. themselves in relations to husband, family, and friends) and medical contexts (i.e. themselves in contrast to other women participating in various group-based treatment programmes). The following quotations have been assigned a letter (A–J) and

the age of the informant. The interviewer is assigned the letter R.

Stories about strength in daily life: 'I've always been so strong and robust'

Two women pointed out their strength when talking about disabilities in everyday life. Looking back on previous health, one of them emphasized her capacity for work or efforts for husband and children throughout the years, telling how strong she had been:

'Of course I've always been strong and arranged and fixed most things. But I gradually became unable to do this, as even if I just carried two bags up and down to the car and to the cottage, I had to lie down all Saturday' (C, 53 years).

Since her (physical) capabilities were reduced by her chronic pain, her husband was now responsible for carrying luggage during holidays, and groceries in daily life. Another woman had a similar story about strength in spite of disabilities, but she also emphasized her present emotional strength:

'He [the husband] is extremely good in the house, and he is at work all day. He does the shopping—as I can't carry anything home—and he does the cooking. I can't wash floors. I can't wash windows. I can manage to vacuum clean though! But there are obviously lots of things that I can't manage, and much is left to him, and he has a responsible job. (...) It is obvious that he has to do an *awful* lot (R: 'Does he think that this is tiring?') He says that he is tackling it, but I don't really think he is—not as well as he thinks. (R: 'That's probably what you see in retrospect?') Yes, but I see that I'm much stronger than he is—emotionally' (I, 37 years).

After having specified all her limitations related to housework and also social gatherings, clarified the few tasks she is capable of doing, she paradoxically ends up by concluding that she still perceives herself as emotionally stronger than her husband. Later in the interview, she let us know that her husband now has to phone the Social Security Office for her, as her last call ended in tears after having her application for disability benefit refused. However, when relating to different situations and persons during the interview, she still holds on to the first version of her picture of herself as 'fundamentally a strong person—emotionally'.

Despite disabilities or limitations, some of the women emphasize that they have been persevering and 'quite tough' even though family and friends might disagree or disbelieve this:

'I'm rather easily upset if I try to do more, because as I've said, I've been exhausted and burnt out, and for

several years I've been living like a stretched piece of elastic; at the maximum of my capacity. And I have so little to go on, and when you have been like this for a long time, then... I consider that I've really been rather tough, though not many of those who know me now would believe it. But when you have been like this for a long time, you reach the stage when you would like to avoid the stressful things' (E, 31 years).

These women both highlight their strength in everyday life, emphasizing earlier working capacity, emotional strength and perseverance, referring to both an inner world of previous health and present illness and an outer world of relations to husband, family, and friends. Simultaneously, we also hear about practical disabilities such as not being able to do housework, shop, or cook. On an emotional plane, we hear about difficulties such as not managing to phone the Social Security Office, and also the more psychological consequences of living with chronic pain, with the desperation, sorrow, and bitterness that this entails (Werner et al., 2003). They also tell about people who either do not understand or have other explanations of their pain than they have themselves (Werner & Malterud, 2003).

Stories about the other (whining) women—stories about self: 'Some people pour out their troubles...'

Whining and complaining is a subject that recurs in different guises in the informants' illness stories, chiefly when they are talking about conceptions of or encounters with other women with similar pain to themselves, in contrast to how they perceive themselves. Two of the women told how, during the 1-year group-based treatment programme, they were confronted with their own negative attitude to other women with chronic illness such as fibromyalgia. In an extract from an interview with one of the oldest women, we hear about her doubt about whether she wanted to take part in the treatment group:

(R: 'What made you start in the group?') 'I was in great doubt about whether to start. (...) I was very negative to a group of women who had a lot of pain, and I was very afraid that there would be whining and complaining. (...) To sit and talk with women who had pain, I regarded that as rather... (R: 'But this changed?') Yes, in fact they did not talk about how much pain they had' (A, 52 years).

The doubt was not related to the treatment programme itself: It was more that she did not regard it as particularly interesting 'to sit and talk with women who had pain'. Later in the interview, she elaborates by referring to illness talk as 'boring to listen to'. She had been 'very afraid' before she started that the discussions

in the group would be characterized by ‘whining and complaining’. Several of the women express similar opinions on illness talk, but without referring to other women with chronic muscular pain. Some had also experienced negative reactions from health personnel, family, and friends after telling about their illness.

Both she (A) and another woman (B) expressed their surprise that the discussion in the group turned out to be different and more interesting than they originally thought: What they talked about was the causes of the pain and how they could live with this rather than ‘how much pain they had’. Informant B said something that both differed from, but also amplified the picture of other women with chronic muscular pain. When telling that the group was ‘just right’ for her, she said:

‘It was wonderful to meet other women who had the same symptoms, whether they accepted them or not. (...) Meeting other girls who were just as resourceful as I regard myself, who sat and felt the same; that they were not interested in whining and complaining, but in breaking out of an evil circle (...) (R: ‘After being in the group, did you regard them as resourceful?’) Yes, and I regarded them like this as we went along too, but when I started, I thought ‘these women lack resources’. (R: ‘The myth that...’) The myth that chronic muscular pain is only connected with whining and complaining, and people who can’t cope, and that it’s not a real disease, and - poor me in a way’ (B, 43 years).

This quotation illustrates that the informants not only distance themselves, but also relate to the other group participants and women with chronic muscular pain (see Werner et al., 2003). Another example here is the following statement:

‘We often played roles [in a short treatment programme] and talked a lot about setting limits in order to make our everyday life easier. (R: ‘Did you experience this as positive?’) Yes, very! It was easier for me then, although I regard myself as strong, to say ‘no’ without having a bad conscience. Because this is often why we women become ill and have pain here and there; we work double and can’t say ‘no’ (I, 37 years).

Even though this treatment programme helped her to say ‘no’ without having a bad conscience, she, and also informant A, emphasize that setting limits is not one of her/their problems. She describes herself as a ‘positive person’ with the ability to make the best of the situation:

‘I always think that ‘OK, we’ll manage that, won’t we?’ while the other [participants] tended to say: ‘I don’t know’: They haven’t budged for thirty years, and thought it was the end of the world to do weight lifting or anything like that. (...) I’ve always been a

positive person, or so I believe. So I make the best of things, and do as well as I can’ (I, 37 years).

The informant had been actively engaged in sport since childhood, and achieved much better results in physical tests of strength and endurance than the other participants in a 3-month treatment programme. Besides, she described herself as more conscientious, performing as well as she could in the tests while the other women ‘dared to give a damn’:

‘But the other women were [10–15 years] older and things don’t matter so much: One no longer minds so much what people say and one becomes more self-confident, while I somehow tried to do everything exactly right.’ (R: ‘Did you feel that you minded more?’) No, but I tried to carry out the programme more seriously than they did. (R: ‘More conscientious perhaps?’) Yes, when one is older one is more self-confident and one says more what one means in a way’ (I, 37 years).

Paradoxically, she describes the other participants both as in poorer physical form than herself, and more hesitant, indecisive, and worried, but simultaneously also as more lazy, independent, and strategic than her—or perhaps with the wrong mental attitude compared to her.

Another woman said that, during the 1-year treatment programme she realized:

‘I’ve never had those long periods of sick leave like the other girls in the group had obviously had’ (C, 53 years).

She had gone to work although she had been ill. Two other informants (J, 49 and D, 31) also mentioned that they had seldom been ill, needed sick leave or consulted a doctor earlier, but without comparing themselves to the other group participants:

‘I had almost never been to a doctor before [the chronic illness]. There was no need’ (D, 31 years).

In contrast to the numerous stories about negative experiences when consulting doctors, two of the women emphasized that they had not experienced being disbelieved. One said: ‘I’ve received the help I’ve needed’ (C, 53 years), and the other said: ‘I didn’t have to fight for anything’ (G, 58 years).

All the women also mentioned medical encounters characterized by listening and caring doctors who provided good help, but without comparing their positive experiences with the negative experiences of other women patients.

Thus, the women described themselves in positive terms as having been or being strong in various ways, in relation to husband, friends, and other women with chronic muscular pain. How they defined ‘strong’ varied

depending on to whom they related and to which context they referred. Examples mentioned here were physical and emotional strength, positive mental attitude, being resourceful and not ‘whining and complaining’, having no problems with setting limits in relations with others, having seldom been sick or needing sick leave, or almost not having visited the doctor before the onset of the chronic pain.

Discussion

Gendered plots, performances, and arguments on the cultures of complaint

In narrative research, the focus is on how people talk about past and present events, and not only on what is said. What characterizes the oral narrative is that both narrator and listener are active participants in the creation of an emplotment, i.e. the activity of a reader of a story who engages imaginatively in making sense of the story (Good, 1994; Mattingly, 1994): Both are looking for a way to understand and articulate the illness (events) as a meaningful whole. Frank (2000) has defended the legitimacy of an interest in illness narratives that is therapeutic, emancipatory, and pre-occupied with ethics in response to Atkinson’s critique of this interest as a blind alley. The value of storytelling as complementary to story analysis is argued, and the importance of recognizing one’s own standpoint is emphasized. His conclusion considers how qualitative methods can inform changing relationships between illness, health, medicine, and culture.

According to Ochberg (1994), we live out the essence of the matter in ‘storied forms’. The lives we perform expose us to the same dangers of negation as the stories in the literary sense, and the attempts to rescue itself occurs at three levels: As a *plot* a story exposes its narrator to the possibility of defeat, as a *performance* a story risks the disbelief or disinterest of its audience, and as an *argument* a story risks being supplanted by an invidious alternative.

The illness stories in our material can be read as legitimation of illness, reflecting that this pain or illness must be explained and argued for both in encounters with the health services, in everyday life, and even in the encounter between the researcher and the interviewee. As a plot, the women’s (private) stories attempt to cope with psychological and alternative explanations of the causes of their chronic pain. As a performance appealing to a (public) audience, the stories attempt to cope with the scepticism and distrust these women report, and several studies have supported, that patients with fibromyalgia and chronic muscular pain are being met with, particularly by doctors (Johansson et al., 1996; Ware, 1992; Åsbring & Närvänen, 2002). Finally, as an

argument(ation) the informants’ illness stories attempt to convince us about their credibility as somatic patient with biomedical explanation of the pain.

However, every story presents a particular version of the events (Ochberg, 1994). Each version attempts to persuade us that it alone is credible, indicating a preferred reading, but at the same time hinting to us that this preferred reading is peculiar. According to Good (1994), the story can be told in a subjunctivized mode, i.e. in a format that agrees better with the reality that the narrator wants to stick to—even though it may be a strategic use of narratives (Riessman, 1990) or a self-idealized version of the story (Ochberg, 1994).

Plummer (1995) asserts that stories are generated by social and political conditions, which enables certain stories to be told and heard. Frank (1995) has shown that restitution stories are among the stories we all want to hear, whether we are patients, health personnel, or just members of society. He says that these stories reflect how we have learned to talk about illness from institutional stories that provide a model of how illness should be described in our culture. According to Haug’s (1992) theory, we may assume that the act of ‘saying’ pain in the genre of complaints (Kugelmann, 1999) would be interpreted differently, depending on gender and disease. Women who talk (too much) about illness might be in danger of having their complaints interpreted as groundless suffering from unreal pain caused by their inappropriate or maladaptive way of relating to their bodies and health disorders (Werner et al., 2003). Telling stories about their own (positive) strength and the (negative) illness talk of other (women) might be a way of living out their illness stories in an acceptable and (gendered) moral manner as woman with medically unexplained pain. However, our material also indicates that some forms of complaint may be better accepted than others and therefore appear as exchange of information rather than complaining. Talking about the causes of illness can be an example of this. Moreover, there may be some contexts where one should complain in order to appear open and honest, for example in group-based treatment programmes, while in other contexts one should remain silent about pain and conceal illness.¹

¹Album (1996) has written about the mandatory and forbidden rules between patients in hospital when they talk about illness: It is forbidden to complain, make a fuss, or boast. One should not talk about difficulties, or should only do this with a cheerful voice. One should not bother other people by telling them too much or by talking about anything that might be importunate or offensive. One should not be self-pitying or make remarks unless there is an opening for this, and even when not talking one should not appear to be making a fuss by being restless.

But how do we know that the presented version is not the whole story? Asks [Ochberg \(1994\)](#). We hear about doctors who considered that the symptoms as originating from the mind as opposed to the body, and family or friends who had their own explanation of the pain: They are not really ill, or at any rate not more ill than most people; they just complain more. Although several of the women regard mental strain as a precipitating cause of present health disorders, none of them viewed their pain as essentially psychological, nor could they be cured by discussion therapy. However, sometimes we hear that other people's versions gained a victory over the informants' own illness story. Findings from several studies agree well with this: The women developed uncertainty about their experienced bodily feelings of pain ([Johansson et al., 1996](#); [Lillrank, 2003](#); [Steihaug, Ahlsen, & Malterud, 2002](#); [Ware, 1992](#); [Asbring & Närvänen, 2002](#)). The (traumatic) illness experiences of the informants' seemed to be in danger of being denied or invalidated ([Leira, 2002](#)).

Making sense of a life—as who would I like to be seen as?

What we learn in a 'storytelling' perspective is 'how people go about making something of themselves', [Ochberg \(1994, p. 13\)](#) writes. We learn something about the informants' continuous efforts to maintain a positive self-image. Then who are the 'hero(ine)s' that the women relate to in their stories, and who are the audience?

Our informants knew that although they were talking to a researcher/sociologist in an interview context, the objective was to reach a larger public of doctors and health personnel, researchers and the general public.

Then what do the interviewed women (not) want to be part of? Their descriptions of themselves as (so) strong and their disgust of talk of illness can be interpreted as several ways of negotiating good morals as patients and women in various contexts, encounters and relations. It may be a way of managing their own identity and dignity; that are closer related to their management of the body ([Haug, 1992](#); [Frøberg, 1995](#)). [Johansson et al. \(1996\)](#) found that the women patients with chronic muscular pain up-held their self-respect by mystifying and martyring themselves and their symptoms.

In some of the stories, particularly of the older women, they referred to the other group participants as 'they' in such a way that neither the patients nor the pain had anything to do with them. According to [Widerberg \(2001, pp. 142–143\)](#), women as 'whiner and complainers' are an expression of women and femininity that is so generally implicit that women's talk of fatigue may often be interpreted as the expression of a women discourse of this type. They have to position themselves in relation to this to demonstrate that they represent

another type of femininity. Is it a woman collective ([Widerberg, 2001](#)) that the informants do not want to be part of?

The talk about illness as a private and forbidden subject, something rather negative that becomes whining and complaining, and something one does not want to participate in, may also be an expression of culture's marginalizing, disgust of and tabooing of illnesses such as medically unexplained disorders. [Lilleaas \(1995, p. 189\)](#) found that women with fibromyalgia experienced their bodily symptoms as tabooed, both in their closest surroundings and at work. As a result of the informants (gendered) internalising of the rules for telling about illness, and because breaking cultural taboos results in the individual herself becoming a carrier of the taboo ([Leira, 2002](#)), medical short-comings regarding diagnostic procedures, treatment, and prevention of chronic muscular pain remain invisible. Thus, their illness stories can be read as negotiating a picture of themselves that fits with normative, biomedical expectations of what illness is and how it should be performed ([Werner & Malterud, 2003](#))—or lived out in 'storied form'—according to a gendered work of credibility as woman and as ill to avoid stereotyped classifications of gender and disease.

The context of sharing stories

In line with earlier feministic interpretations including [Riessman \(1990\)](#), we have thought that, in their accounts of illness, the women relate themselves to a way of life that is legitimate in our culture today ([Ochberg, 1994](#)). We can therefore at last obtain contextual information about the matter under investigation through the way they tell us about their illness. We have looked behind the illness stories, drawing on indirect clues about both what is said, that which is explicitly or implicitly denied, and what seem to be paradoxical contradictions or wrong for various reasons when compared with other information from the informant, other interviews, or our previous knowledge. One of the young women in the material said for example:

'I've been offered so many jobs and said 'no' to them—and I could have earned masses of money there. This is not something I've chosen! It is what my life is like now' (H, 26 years).

Considering that she had no education after secondary school, together with our knowledge of how difficult it can be to get a job, it sounds peculiar when we read that the informant has 'been offered so many jobs' where she 'could have earned masses of money', but which she even so refused. The message seems to appear in the sentence: 'This is not something I've chosen': The object seems to be to legitimize and defend the

credibility of her pain as real and somatic rather than imagined or psychological. The moral of this and many of the other stories in the material can be read as an attempt to negotiate that in spite of the medical uncertainty of these pain symptoms: I am a good (woman) patient too!

Despite a table showing the characteristics of those being interviewed would help making it clearer who the women are, we have chosen not to include this since the number of informants are few.

Our point of departure has been illness stories of women with chronic muscular pain. Nevertheless also men with similar pain or women with other symptoms may present accounts similar to those presented above. According to Paulson, Danielson, and Norberg (1999), men with fibromyalgia report not being believed by health personnel. Paulson et al. have explored nurses' and doctors' narratives about men with fibromyalgia and non-malignant, unexplained pain (SFM). The men were reluctant to be given a medical diagnosis that indicated a psychological problem and pointed to a 'woman's disease'. Thus, the doctor's were cautious when giving them this diagnosis because it could be preconceived as being unmanly. The men did not spontaneously communicate their feelings: They were seen as having greater difficulties coping with pain than women, expressing their pain as more intensive, and as having an urgent need of confirmation.

Findings from Paulson et al. (1999) and our earlier article indicate that the combination of pain and gender demand specific forms of expression if women with medically unexplained disorders are to be perceived as credible patients (Werner & Malterud, 2003). The work of the women in our material indicate an adequately performed womanliness regarding appearance and assertiveness to neither appear as too healthy-looking, wearing too smart clothes and make-up or in other ways appearing as too strong, nor too ill and disarranged or in other ways as too weak. Overdoing both illness and femininity, the patients might subsequently be disempowered as less credible patients according to normative, biomedical standards.

Whispering voices

Let us finally move beyond the story levels of the idealized version or the continuing work of maintaining a positive self-image (Ochberg, 1994; Riessman, 1990); beyond psychological explanations of the assumed benefits of narrative constructions (Miczo, 2003). Then what can we learn from these and other stories in our material about the context of the matter under investigation? Which discourses of illness and gender do the women draw upon when presenting their illness?

Behind the informants' stories about their own strength and the others (negative) talk of illness, we hear whispered accounts relating to the medical narrative about hysteria: A medical discourse with a simple cause-effect understanding of underlying psychological disorders behind these pain symptoms. We hear whispered rejections of the stereotype medical account or cultural perceptions of the crazy, lazy, illness-fixed or weak woman patient. Various studies support this interpretation (Wood & Wessely, 1999; Woodward et al., 1995; Åsbring & Närvänen, 2003). According to the patients', the chronic pain is not caused by individual weakness, personality or attention seeking, nor is it psychological, habitual, a plea for sympathy, an excuse to avoid work or something they could have mastered if they only would (Eccleston et al., 1997; Lillrank, 2003). A moral discourse that is also echoed in the medical history, i.e. the beginning of the 19th century: 'There were women who seemed to need to be ill, to compensate for the lack of another role in life, to affirm their femininity, to counteract their feelings of dissatisfaction, or to escape from married life and repeated pregnancies' (Johannisson, 2001, p. 100).

We have read the illness stories of 10 women with chronic muscular pain as a moral plot and an argument about biomedical causes and reality of their pain, appealing to both the interviewer, and a medical and general public. Our material demonstrates that by stories about their own strength and by distancing themselves from other women with similar pain to themselves and their illness talk as 'boring' or 'whining and complaining', they try to convince us about the credibility of their version of the illness story. They argue for their morality as patients and women by convincing us about their innocence as regards the development of their health disorders. They also reveal that they know about alternative ways in which their pain symptoms can be and often are interpreted. Through their accounts they both relate to and try to avoid the medical discourse about 'unexplained' pain, which some have described as 'fashionable diagnoses' or 'the present-day answer to hysteria' (Ford, 1997; Scheurich, 2000; Shorter, 1992; Showalter, 1997). This is a subject that we will return to in more detail in forthcoming study.

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