It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors

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Abstract

In various studies during the last decade, women with medically unexplained disorders have reported negative experiences during medical encounters. Accounts of being met with scepticism and lack of comprehension, feeling rejected, ignored, and being belittled, blamed for their condition and assigned psychological explanation models are common. Women patients exerted themselves to attract the doctor's medical attention and interest, and were anxious to be considered as whiners or complainers. Here, we explore the nature of "work" done by the patients in order to be believed, understood, and taken seriously when consulting the doctor. 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 main outcome measures were descriptions reflecting the patients' activities or efforts invested in being perceived as a credible patient. We focused on the gendered dimensions of the experiences. The women patients' accounts indicated hard work to make the symptoms socially visible, real, and physical when consulting a doctor. Their efforts reflect a subtle balance not to appear too strong or too weak, too healthy or too sick, 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 most important activities or efforts varied. However, the informants were not only struggling for their credibility. Their stories illustrated a struggle for the maintenance of self-esteem or dignity as patients and as women. The material was interpreted within a feminist frame of reference, emphasising the relationship between dignity and shame, power and disempowerment for women patients' with medically unexplained disorders.

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Keywords: Doctor–patient relationship; Medically unexplained disorders; Chronic pain; Gender; Norway

Introduction

During a follow-up study of a group-based treatment programme offered to women with chronic muscular pain, we noticed that the participants often reported negative experiences from previous medical encounters. Studies from the last decade support these findings (Garro, 1992; Jackson, 1992; Johansson, Hamberg, 1996; Lilleaas, 1995; Raymond & Brown, 2000; Söderberg, Lundman, & Norberg, 1999; Ware, 1992; Östlund, Cedersund, Alexanderson, & Hensing, 2001; Asbring & Närvärinen, 2002). Accounts of being met with scepticism and lack of comprehension, feeling rejected, ignored, and being belittled, blamed for their condition and assigned psychological explanation models are common. Research indicates that the women patients have exerted themselves to attract the doctor's medical attention and interest, to be believed and taken seriously, and not to be considered as whining and complaining (Garro, 1992; Jackson, 1992;
Johansson et al., 1996; Lilleaas, 1995; Ware, 1992). We were interested in how these women manage these challenges in medical encounters.

Medically unexplained disorders, mostly occurring in women, are chronic and disabling conditions, presenting with extensive subjective symptoms, although objective findings or causal explanations are lacking (Malterud, 2000). These disorders challenge medical care and knowledge, because effective methods for diagnostic procedures, treatment, and prevention are lacking (Nativg, Nessiøy, Bruusgaard, & Rutle, 1995). Moreover, conditions classified as medically unexplained, including fibromyalgia, have been attributed low prestige in the cultural medical hierarchy of diseases (Album, 1991).

Doctors find consultations with medical uncertainty, interpersonal difficulties, chronic and so-called unexplained disorders difficult to manage (Hahn et al., 1996; Mathers, Jones, & Hannay, 1995; Reid, Whooley, Crayford, & Hotopf, 2001; Schwenk, Marquez, Lefever, & Cohen, 1989; Sharpe et al., 1994; Steinmetz & Tabenkin, 2001; Wileman, May, & Chew-Graham, 1992). They find it problematic to handle distrust, and to demonstrate their own shortcomings when carrying out medical consultations (Arborelius, Brembreg, & Timpka, 1991; Mathers & Gask, 1995; Skelton, Murphy, Murphy, & O’Dowd, 1995).

Behaviour and communication often imply frustration and difficulties in the consultation. Women consult more frequently, they report a higher number of health problems, they often have long-lasting and/or mental symptoms as well as symptoms which are difficult to diagnose (Malterud, 2000). The difficult patient, mostly portrayed as a woman, fits neatly into a historical tradition (Johannisson, 1996, 2001).

The objective of the present study was to explore the nature of “work” done by the patients in order to be believed, understood, and taken seriously when consulting the doctor. We concentrated on the patients’ activities or efforts invested in appearing as a credible patient, and we focused the gendered dimensions of the women’s experiences. We intended to explore how pain and illness is shaped in accordance with specific, normative expectations of disease, and how it is dealt with.

**Theoretical framework**

There is extensive literature on the relationship between doctor and patient. Many of these studies have focused on the doctors’ perspectives on features and management of “difficult consultations” or so-called ‘heartsink’ patients, aiming to help the doctor achieve a greater understanding of, and ability to cope with, these patients (Hahn et al., 1996; Mathers & Gask, 1995; Reid et al., 2001; Schwenk et al., 1989; Sharpe et al., 1994; Steinmetz & Tabenkin, 2001; Wileman et al., 2002). However, there is a growing research interest taking the patients’ view into account (Hunt, Jordan, Irwin, & Browner, 1989; Johansson et al., 1996; Mathers et al., 1995; Skelton, Murphy, Murphy, & O’Dowd, 1996; Östlund et al., 2001; Ashbring & Närvänä, 2002), and also how the patients influence the consultation (Fisher, 1993; Salmon & May, 1995). With few exceptions, among them Johansson et al. (1996), gender perspectives are missing in studies of “difficult” consultations. Furthermore, heterosexuality, in the sense of “doing” gender in an appropriate feminine or masculine manner, has not been problematised in studies of medical encounters.

“Doing” gender—‘doing’ pain within heterosexualised organised encounters

In sociological and feminist research, gender and illness have been viewed as not merely something we “are” or “get”, but also as social practices that we “do” or “express” in social encounters (Haug, 1992a; Kugelmann, 1999; Lorber, 1997; Smith, 1990; West & Zimmerman, 1987).

West and Zimmerman (1987, p. 126) have developed an understanding of gender as “a routine, methodical, and recurring accomplishment” as opposed to a strict distinction between sex as ascribed by biology, and gender as an achieved status. Viewing gender as a social performance means that our attention shifts from matters internal to the individual, and focuses on interaction and institutional arenas. According to West and Zimmerman, participants in interaction organise their activities to reflect or express gender.

Furthermore, gender has to be understood not merely through work, but also through sexuality, or more precisely heterosexuality, which has been perceived as the norm, and as an organising principle for gender socialisation (Haug, 1992a; Hearn & Parkin, 1995; Kolnes, 1995; MacKinnon, 1979; Widerberg, 1999).

Haug (1992a) has been occupied with how women learn to be women through social structures directed towards their bodies. According to Haug, socialisation

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1Fisher and Groce (1985) have explored how cultural assumptions (norms) about patients as “good” or “bad” women emerge, develop, and are negotiated and displayed as doctor and patient communicate over the course of an initial medical interview. Their study illustrate how (hetero)sexuality, i.e. the women’s attitude to or how they have managed their body and sexuality, is an important contribution in the doctor’s constructed view of them as “good” or “bad” women. However, they do not explicitly refer to heterosexuality as theoretical perspective.
of, and control over women centres on disciplining through their body and sexuality in a broader sense, i.e. as desirable. She argues that morality also has two genders: in men the central element is property; in women it is her relationship to her body and sexuality. Her point is that to be considered as moral beings, different behaviour is required from women than from men. The same behaviour is interpreted differently depending on the gender of the acting person. Thus, a woman considers that the shameful and the immoral are related to their bodily and sexual attitudes and practices, i.e. her attitude to, or how she manages her body and sexuality. However, women are not merely passive objects, Haug (1992a,b) argues. They themselves take an active part in their own socialisation process. Keeping to the rules of the game therefore represents the power they have, and consequently, they help to maintain both rules and subordination.

The heterosexualised power dimension within medical encounters

The theoretical approaches of Haug (1992a,b), and West and Zimmerman (1987) enable us to explore the nature of activities and efforts made by women patients in encounters, considering them as social practices, accomplishments or performances organised to reflect both illness and gender. Haug’s perspective provides access to an understanding of the structure and function of society at large, making women’s work appear not merely in terms of individual behaviour, but also as relational, structural forces of power or disempowerment within a medically, heterosexualised organised power structure of gender and disease. At a micro-level, efforts to be perceived as a credible patient in medical encounters may be interpreted as enacting relational power. However, in a macro-perspective, the same strategies can be regarded as adjustments to a normative, biomedical template of disease, which also appears to be gendered. Thus, Haug’s (1992a) concepts of dignity and shame highlight women patients’ management of gender, body, and sexuality in a broader sense, when consulting the doctor. Her perspective enables us to explore the patients’ work not merely as strategies for legitimising their pain and illness, but as methods for handling dignity in an appropriate moral way, both as women and as patients. Furthermore, her theory makes it possible to render established templates for illness and patient behaviour as having some implicit and gendered aspects that need further investigation. Awareness of this work may provide new insight into the structures and mechanisms related to illness, rules of the game in medical encounters, the welfare state, and the living conditions for women with chronic pain in our society.

Method

Participants, data collection, and analysis

The empirical data consists of in-depth interviews of 10 women patients with chronic muscular pain. Four of the informants were recruited from a primary health care centre in Oslo, Norway. Six of the informants were recruited among participants from two treatment groups for women patients with chronic muscular pain (see also Steinhaug, Ahlsen, & Malterud, 2001). The women had been referred to the treatment programme through local primary care providers. We applied a purposeful sampling strategy covering women representing different backgrounds regarding illness experiences, consultation experiences, employment market connections, and civil status. The women were 26–58 years (average age 42 1/2 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 born. Five of the informants were living in marital relationships. Six had children—three of whom were adults, and three of whom 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-time or part-time), and six had social benefits such as rehabilitation support and disability pension. 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.

Data were obtained from semi-structured, audio-taped in-depth interviews based on Kvale’s (1996) principles. The interviews (average duration two and a half hours) were carried out by the first author, a sociologist, in the informant’s home, workplace, or at the treatment centre during 1997, 1999, and 2000. The study was introduced to the informants 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 hope, in the future, to offer superior health care to women patients with chronic pain. The interviewer emphasised that the study was independent of the general practitioners and group leaders of the treatment programme.

2 Even though shame is the central topic in Goffman’s book “Stigma”, he deals mostly with embarrassment without connecting it to shame (Scheff, 1999, pp.157–162). His idea of impression management made the avoidance of embarrassment a central motive of interpersonal behaviour. However, like other labelling theorists who have discussed stigma, he focuses on the behavioural aspects of stigma, paying too little attention to emotions, particularly the emotion of shame, Scheff argues.
The interview included questions about whether the patients’ experiences of encounters had been positive or negative, how they had prepared, their activities during the consultation, and challenges related to living with chronic pain. The last question is not discussed in the present study.

We sampled step by step, covering a broad range of dimensions. These included both negative and positive experiences of medical encounters, the women’s description of their activities or efforts before and during the consultation, as well as the consequences of the work they had done in order to receive help with their health, everyday lives, and self-esteem.

The interviewer (the first author) transcribed the conversations. Analysis was performed according to the principles of 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) summarising the contents of each code group to generalise descriptions and concepts reflecting the most important experiences from the voices of the women (Giorgi, 1985; Malterud, 1993).

Analysis focused on the nature of work done by the women patients in relation to encounters. Our attention was directed towards the activities or efforts they used to appear as a credible patient, and focused on the gendered dimensions of the experiences. The material was interpreted within a feminist frame of reference (Haug, 1992a,b; West & Zimmerman, 1987) emphasising the relationship between dignity and shame, power and disempowerment for women patients’ with medically unexplained disorders.

Findings

The women patients’ accounts indicated that they had invested much work, time, and energy before or during the encounters in order to be perceived as a credible patient. By trying out various strategies such as appropriate assertiveness, surrendering, and appearance, they attempted to fit in with normative, biomedical expectations of what was “just right”. The most important activities or efforts varied. However, the informants were not only struggling to appear credible. Their stories illustrated how they struggled for self-esteem or dignity as patients and as women. Below, we elaborate on the patients’ descriptions of their social practices when consulting the doctor. The following quotations are assigned a letter and the age of the informant.

Working for appropriate assertiveness: “I don’t give up unless I have to”

Several of the women in our study emphasised how they had actively worked to appear credible. They had consulted different doctors and looked for help and information from many alternative sources to identify the cause and treatment of their health disorders. Two of the patients had informed doctors and the Social Security Office about their chronic pain condition, by sending a letter before the appointment. One of them had also sent copies of earlier medical records before seeing a specialist. Both during the interview and in the letter as well, the patient explained how her concentration problems prevented her from remembering to tell the doctor all that she had planned to say about the other aspects of her disease. However, both she and several other women repeatedly pointed out another difficulty in medical encounters. They emphasised how “strenuous”, “complicated”, and “heavy” they found “having to explain over and over again” about their chronic, but socially invisible disorders. Even so, health care providers, husbands, and friends still did not meet them with comprehension, respect, or acceptance. Some mentioned, when consulting health care providers, being “tested”, “checked”, or “assessed” for mental rather than somatic factors. Hence, sending a letter before the medical appointment could be a way of telling the doctor that the pain is not the type of pain that disappears on resting, setting limits, or altering the focus:

Muscle pain is not merely caused by tension, mental disturbances, stress, how one tackles everyday life— or that one is a woman. There is more to it than that: it often has an organic cause, so I tend to feed people with research results and emphasise how real it is (D, 31 years).

Several of the medical investigations, referrals to specialists, and occupational rehabilitation had actually been carried out on their own initiative. Seven of the informants reported consultations where they had asked, suggested, or even begged for a referral for treatment, sick leave, or painkillers. However, in our material there are examples of more assertive behaviour by the patients during consultations. Three of the women emphasised how they had exerted themselves in order to be investigated properly. One reported how she had reacted after two consultations without being properly investigated, except for having her limbs flexed and extended:

On my third visit, I just stood up - because I was so angry - and said to the doctor “I expect you to write a referral to the hospital now, because I want a second opinion” - as my whole leg ached (G, 58 years).
Another women had a similar story:

I was sent to a number of investigations, and had to quarrel to get an X-ray. I had a hard time working against those doctors. It was certainly a struggle with that doctor (A, 52 years).

The youngest woman in our study reported a consultation where she had criticised examination methods used by the doctor. When asked to draw and cross off on a form where she had pain, she had answered:

Shall I put crosses everywhere on the form? You must tell me what you are looking for because I have pain everywhere. It is better if you ask me how my body reacts or obeys me when I am doing something—then you will discover how my body functions (H, 26 years).

She also mentioned how, in various medical contexts, she had expressed herself very frankly by reporting the negative experiences she had with a painkiller commonly prescribed for patients with fibromyalgia:

I’ve made it clear to most of the doctors and health personnel that I have had contact with that I don’t want so much treatment with painkillers. At the pain clinic they recommended Sarotex [amytriptylin] several times (H, 26 years).

Although the women emphasised how tired it had made them continuously having to “take the initiative”, persevere, be stubborn, and spend all their strength on struggling, quarrelling, and asserting themselves during consultations, some of them still pointed out that they would not give up. One said she wanted to show both herself and other people that she would not “give up that easily”, and another patient who had had the same general practitioner for several years, emphasised: “I don’t give up unless I have to”.

Working for achieving appropriate surrender: “You have to tread rather softly”

Despite all the numerous illustrations of the patients’ assertiveness previous to and during encounters, the answers from the women also included some examples of surrendering. Instead of asking, claiming, or talking frankly when consulting the doctor, some said they had simply calmly terminated the relationship. However, one informant pointed out that, even though her relationship with her regular general practitioner did not function very well, she thought that finding another doctor would be a great effort. Her doctor was neither willing to give her sick leave, nor to refer her to physiotherapy again, as she had already been referred twice without improving. Instead of challenging the general practitioner’s opinion she had consulted a private, expensive doctor, solely in order to ask for a renewal of her physiotherapy referral.

A woman on disability pension reported that she had been troubled by inflammation of her thyroid gland, which had not been diagnosed after double pneumonia. She was worried that these could be symptoms of cancer, as she had suffered from this when she was younger. The doctor had written a prescription for thyroxin, but had not investigated her more closely.

He [the doctor] could have investigated me by a simple blood test, but instead I had to wait for two years and become so debilitated, in addition to all the other pain. I haven’t done anything about it. I’m the kind of person who forgives and gets on with life. This is history. (G, 58 years).

The patient did not want to complain as she thought this might create more problems for herself. Another informant referred to the strategy she had used to help herself tolerate comments, and other instances of being badly treated by health care providers:

You have to tread rather softly; because once you antagonise them it’s not certain that you are any better off. So there are in fact some comments and events that you just have to accept (D, 31 years).

Finally, one woman, whose application for disability benefit had been refused because she was too young and had had too little occupational rehabilitation, said that her husband had phoned the Social Security Office for her, as her last call ended in tears.

Working for achieving appropriate appearance: “I feel I should look groggy”

After having received comments from doctors and other health care providers about their appearance, apparent strength, and age, some of the patients gradually started to wonder what impression they made in medical encounters. Statements like “You don’t look ill!”, “You always look so healthy!”, or “You are so young!” had made them feel irritated, sad, and frustrated, rather than flattered. Some of them said such statements indicated little understanding for how much pain they really had.

Before [the consultation]—though I actually rather regret this now—I had been to a solarium. I hadn’t actually remembered that I was going to visit the doctor the following day. I had put on some make-up, and I was wearing a pair of jeans and a completely normal, long-sleeved pullover. The weather had been quite sunny. I had slept quite well that night, and I actually did look pretty healthy. And when I arrived, he [the doctor] remembered the
letter I had sent him about my pain, and said: “You’re not ill!” I didn’t answer—because what
could I say? After a while he said: “You certainly
don’t look ill! And I remember I was thinking,
goodness, am I the only healthy-looking person with
this disease? (D, 31 years).

The doctor’s message had made her assume that the
solarium, the sunny weather, the make-up, and a good
night’s sleep had made her appear too healthy to be
perceived as ill. Another patient had a similar account.
She had begun wondering whether her daily walks in the
forest and her subsequent healthy-looking complexion
had made her look “too strong” when she consulted the
doclor:

Sometimes I feel that I should look groggy, my face
should be grey, and I should wear no make-up; that I
perhaps appear to be too strong (I, 37 years).

This woman reported that she tried to avoid looking
“too strong” by refraining from wearing too smart
clothes. Moreover, she connected her physical fitness
with the risk of looking “too strong” when consulting
health care providers. She had been actively engaged in
sport since childhood. After having achieved much
better results in physical tests of strength and endurance
than the other participants in a treatment programme,
she had come to the conclusion that:

I could have refrained from trying so hard in the test,
but they [the health care providers] wanted max-
results, so I went ahead until I tasted blood, and the
other [participants] didn’t do that. Besides, they were
all more than 20 years older than me (I, 37 years).

Finally, four of the patients mentioned age as some-
thing that had been “used against” them in different
ways. Two claimed that their young age had been a
disadvantage when finding causes, making a diagnosis,
or suggesting a treatment programme, as well as sending
an application for disability benefit. But two of the
oldest informants also thought that being a middle-aged
woman was also a disadvantage when requesting a
proper investigation. According to them, doctors either
regarded their symptoms as menopausal, to be tolerated,
or, the menopause was used to interpret the symptoms
as mental rather than somatic.

Discussion

The medical encounter described as a legal court case

Lackoff and Johnson (1980) have written about the
persuasiveness of metaphors in everyday life, not just in
language, but in thought and action as well. The patients
in our study use not only a war metaphor, but a legal
metaphor as well, in their descriptions of the encounters.
They use concepts from a legal court case to label their
experiences, activities, and efforts in the consultation. In
their reports, the doctor has the role of the enemy or
protector of the welfare state rather than being the
patients’ lawyer in the battle for receiving diagnosis,
help, and treatment. The women said that they regarded
their experiences of the medical encounter as credibility
tests where their psyches were “tested”, “checked”, and
“assessed”.

We have heard here, as is also often heard in cases of
rape, that women’s clothes and appearance have been
taken into account when assessing their credibility. The
patients said that by making use of appropriate
assertiveness, surrendering, and appearance they made
an effort to turn themselves inside out. When meeting
the doctor they made their outward appearance
harmonise with their internal experience of pain. In
other words, there seems to be an underlying fear that
their body will be a traitor, by appearing from the
outside to be much healthier than the patients’ internal
experience of pain. There also seems to be an underlying
fear of incorrectly being found guilty as ‘traitors’, and
disclosed as healthy or mentally unbalanced. This
implies a suspicion of having tried to swindle the doctor
or the health personnel into making a diagnosis or
illegally granting National Insurance benefits. The
question is, will the woman patient be allowed to
witness her own case, will she be believed or will she be
sentenced to treatment by a psychologist, or will her case
(i.e. symptoms) be dropped?

Credibility strategies—the making of gendered dignities?

To sum up the findings, the women patients’ activities
during or before the consultations demonstrate that they
have worked hard to make the symptoms socially
visible, real, and physical when they consult a doctor.
Their efforts reflect a subtle balance not to appear too
strong or too weak, too healthy or too sick, or too smart
or disarranged. This applies both to what they say and
do, and how they appear through clothes, body, and
manners when they consult the doctor. A common
feature of their strategies or methods in medical
encounters is their effort to appear as what they hope
is “just right” under the scrutiny of the biomedical
authority. They have struggled to be perceived as
somatically ill, whilst simultaneously avoiding appearing
mentally unbalanced.

Findings from Johansson et al. (1996), Ware (1992),
and Åbring and Närvänen (2002) agree well with our
results: women patients with chronic fatigue syndrome
and fibromyalgia repeatedly find themselves being
questioned, particularly by doctors, and judged to be
either not sick or suffering from an imaginary illness.
These studies explore strategies patients use to attract
the doctor’s attention and interest (Johansson et al., 1996), to avoid enacted stigma (Åsbring & Närvänen, 2002), and to challenge the definition of the symptoms as being “not real” (Ware, 1992).

The women in our study seem to organise pain and gender, aiming to reflect illness in a credible way. Consequently, the activities or efforts made by the patients during the medical encounter can be understood as a credibility work, i.e. work invested in appearing as a credible patient, which includes a subtle bodily and gendered balance.

Apart from attempts to appear as a credible patient to attract the doctor’s medical attention and interest, what do all the different methods employed by the women patients indicate?

Hahn et al. (1996) describe how doctors felt being manipulated by the so-called difficult patients, and Salmon and May (1995), claim that by reporting subjective symptoms, suffering, and coercion (i.e. implicit threats) patients with “unexplained” pain acquire power over the doctor at the outcome of the consultation. At the end of the 19th century women’s “unexplained” health problems, which included migraine, hysteria, and neurasthenia, were interpreted as a demonstration of power rather than a disease (Johansson, 1996, pp. 252–253). There were many myths surrounding the woman patient. She has been suspected of exaggerating, pretending to be ill, not wanting to recover, and of using the medical encounter to seduce the doctor. Hence, women’s power potentials are tied to gender and sexuality.

Could possibly overdoing morbidity and femininity work as a power strategy for women patients for whom objective findings or causal explanations are lacking when visiting the doctor? Changing doctor, demanding referral or treatment, or receiving information about their condition are examples of relational power held by the patient.3 However, those who complained too much or had their own opinion regarding examination methods and treatments, risked and being perceived as quarrelsome, whining, or mentally disturbed, getting no further help. Presenting with only minor complaints did not facilitate interest on the part of the doctors. By appearing ill and disarranged and therefore weak, women risked being perceived as unable to manage.

However, those who appeared as too healthy and smart, or in other ways as too strong, risked being assessed by the doctor as someone functioning well in their everyday life. Overdoing both illness and femininity, the patients might subsequently be disempowered as less credible patients according to normative, biomedical standards. Showing drive and determination nevertheless also seemed to conflict with the image of an ‘ill’ patient.

Perhaps their activities and efforts connected with the medical consultation can be understood as negotiations regarding both morbidity and femininity in an attempt to avoid stereotype classifications of gender and disease. How assertive can patients be without appearing too strong to pass as somatically ill? What is suitable assertiveness for women with long-lasting pain (although objective findings or causal explanations are lacking) and when should they be assertive? Can they be assertive when healthy, but not when sick, or perhaps only when acting on behalf of other people in the role of mother or a relation? What may the consequences be of taking on an incorrect role as patient and woman? And does a woman’s credibility increase when her husband phones the Social Security office to check on her case?

The various strategies used by the women patients illustrate how they conduct their bodily and gendered practices to prevent their pain and gender from being used against them as a diagnostic check on disease and morbidity—and perhaps also femininity. Hence, through a subtle balance to appear “just right”, the women patients seem to take on responsibility for their pain and illness being interpreted within a biomedical frame of reference rather than as mental problems. How can we understand this?

Negotiating dignity and shame

According to Johansson et al. (1996), the women patients with medically unexplained disorders describe a vulnerable position being exposed to the doctor’s interest and power. Several studies emphasise how not being believed, understood, or taken seriously affects one’s honour, individual integrity and human dignity (Howell, 1994; Lilieas, 1995; Sharpe et al., 1994; Söderberg et al., 1999). Being met with recognition has been reported by participants in a treatment group as of vital importance (Steinhaug, Ahlén, & Malterud, in press), and makes the rehabilitation process easier (Östlund et al., 2001). Illness has been shown to be experienced as a moral event, concerning shame and blame, responsibility and stigmatisation (Eccleston, Williams, & Rogers, 1997; Jackson, 1992; Kugelmann, 1999; Ware, 1992; Åsbring & Närvänen, 2002), but without discussing the impact of gender and power.

Ware (1992) and Åsbring & Närvänen (2002) claim that women patients with “unexplained” pain experience the illness as delegitimising and stigmatising in two ways:
Firstly, because they experience their moral characters being called into question in interaction with others. Secondly, because they experience distress from being psychologized by others, doctors in particular.

The women patients we interviewed described symptoms unsuitable to fit the biomedical frame of disease, saluting objective findings more than subjective symptoms and internal pain being compared to external signs. According to Haug (1992a), women develop a feeling of guilt if their bodies are not as they should be, compared with normal standards. In this perspective, feeling rejected, disregarded, and ridiculed might function as effective mechanisms of medical and social control of the behaviour of the women. Comments on body and age, appearance and strength may strike out in both directions in these women patients. Their power is therefore limited to the framework given in the context of the consultation, which requires them to perform as a credible patient within a normative, biomedical frame of reference. Trying to appear as “just right” under the scrutiny of the normative, biomedical authority might be a possibility (albeit limited) women patients have when consulting the doctor. This is also emphasised by Johansson et al. (1996). Thus, the subtle attempt to find a balance might be understood as compliance to hidden rules of the medical encounter in a western society. Here, we discuss an extended understanding of compliance, (i.e. whether patients comply with advice offered by doctors). However, our aim here is not to present the medically unexplained disorders of women patients as to originate from emotional problems. Skelton (1998) has explored the implicit learning that occurs in the doctor—patient relationship conceptualised as the “hidden curriculum” that the patients learn through the encounter; i.e. the knowledge, values, norms of behaviour and attitudes that learners experience in and through educational processes. According to Haug’s approach, the patients’ work may be interpreted as an expression of bodily and gendered attempts to live up to hidden norms of the encounter, both because they are patients, and because they are women with so-called unexplained disorders. Paradoxically they contribute to maintaining both rules and subordination. But if living up to the rules leads to social integration—i.e. becoming a credible patient who therefore receives treatment—why should the women then want to change the rules? Haug (1992a) asks.

The question of credibility: What are the patients’ stories valid about?

Many women with medically unexplained disorders receive satisfactory health care. Our study indicated that there are also many examples of listening and caring doctors who follow up their patients. However, not all medical encounters turn out as the patient had hoped. In this article, the women’s negative experiences of consultations were our points of departure, rather than the many accounts of encounters characterised by mutual trust and respect. We aimed to transcend descriptions of the negative experiences themselves, which have previously been extensively presented (Johansson et al., 1996). Our intention was to take a closer look, from the perspectives of the women patients themselves, at the nature of work done in relation to the medical encounter.

But can we actually rely on what these women told us in the interviews? Have they really had to persevere so much in order to be investigated, and receive help and treatment? Is what they have reported true, for example not being taken seriously, believed, or understood in encounters with doctors and health personnel? Or perhaps the patients’ behaviour is an expression of a personality trait and vulnerability, something for which the doctor can neither be blamed nor do anything about. What conclusions are we justified in drawing when we have only interviewed one part of the encounter, i.e. the patient?

We will look at things from a slightly different angle here, and argue that an assessment of what these patients’ experiences are valid about, is more relevant than asking whether they are true or false (Malterud, 2001).

An accepted theoretical principle when using qualitative methods is that many different versions of reality exist, and they can be valid simultaneously (Malterud, 2001). We will never know exactly what happened; only what the patient perceived in their encounters with the doctors and health personnel. In other words, we only see events through the eyes of the narrator. The stories appear or are created in the dialogue between the interviewer (a woman sociologist) and the informants (women with chronic muscular pain). We have researched what the patients say that they have done during or before the consultation, and not what has actually happened, or the experiences or actions of the other part, i.e. the doctor.

We have looked in the interview data for explanations given by the women patients of why they have acted as they have in encounters with doctors and health care providers. Some of these explanations indicate that there are implicit rules of the game, related to pain and gender in medical encounters. We do not know who has made the rules or how strictly they apply, and we are not going to try to speculate how “true” they are. We have been interested in the dimension of the rules of the game concerned with “doing” pain and “doing” gender as prerequisites in order to appear credible, and thus be met with respect in a medical context. Our findings of the physical and gendered work that our patients performed in order to appear as “just right” under normative, biomedical eyes may therefore be valid.
descriptions about the women patients’ enacting a gendered and bodily patient competence of the rules of the game when, seeking medical care as patients and as women.

Hunter (1991, p. 123) has described the differences between the patient’s story about illness and the doctor’s medical version of the patient’s account as being “fundamentally, irreducibly different narratives”. In the same way, we could say that interviewing doctors about so-called difficult consultations with many conflicts would have given a different view of both the encounters and the behaviour of both the doctor and the patient. We did not intend to compare the patients’ descriptions with how general practitioners’ experienced the activities of the patients during the consultation. Nor did we intend to compare the illness or pain performance in different groups of patients during encounters. Instead, we aimed at a descriptive approach where reports by the women patients were taken at face value.

The question therefore becomes: In which situations can our findings be applied, beyond the context where we discovered them? The accounts presented above could indicate that women patients with other symptoms, or men with similar symptoms of pain may also exert themselves in different ways during medical encounters in order to be taken seriously, believed and understood. However, our findings 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.

Implications

A (heterosexualised) gendered work of dignity—then what?

Medical theory and practice has historically been developed by men and still reflects the hegemony of health disorders; mostly striking men. The women patients’ chronic pain and ill-health behaviour break with normative, biomedical expectations of what illness is and how it should be performed. This makes the medical encounter difficult for both patient and doctor, and these difficulties have gendered dimensions related to dignity and shame, power and disempowerment.

If access to health care and welfare benefits actually requires an extensive, yet subtle and gendered work of balance to be perceived as credible patients—then what?

Our findings indicate potential for alterations. Reproducing social patterns of gender and power, where women have little influence and talking space within the medical encounter, can be counteracted (Borges & Waitzkin, 1995; Waitzkin, 1979). This requires an awareness of gendered power-structures of imbalance which strengthen and reproduce women’s experience of impotence and suppression (Waitzkin, 1979). For women with long-lasting medically unexplained disorders, the work needed to appear as a credible patient may detract energy from the battle to adjust or reconcile oneself to a life with chronic pain. The responsibility of health care providers is to recognise the suffering of women patients, their strength, and to prevent further disempowerment (Malterud, 2000). Then the patients can concentrate on dealing with a painful life and the subsequent illness instead of struggling to maintain their dignity (Söderberg et al., 1999).

Acknowledgements

Thanks to Sissel Steiaug, MD, the director of the treatment programme from which this study started. Additional thanks to Lise Widding Isaksen, Ph.D., sociologist who gave valuable advice and comments, and Merete Undeland, MD, who provided helpful suggestions later in the writing process.

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