The meanings of pain: an exploration of women’s descriptions of symptoms

Eva E. Johansson, Katarina Hamberg, Gøran Westman, Gerd Lindgren

Department of Family Medicine, Umeå University, S-90178 Umeå, Sweden
Research Programme for Gender and Work, Stockholm University, S-10691 Stockholm, Sweden

Abstract

A grounded theory study with repeated semi-structured interviews was conducted to explore the meaning of the illness experiences of women patients, impaired by biomedically undefined musculoskeletal pain. Twenty female patients were recruited at an urban primary health care centre in northern Sweden, where two of the researchers work as family physicians. In this paper we focus on considerations of patient pain and analyze the findings from aspects linking together body, gender, and society.

Four categories of symptom description were identified: bodily presentations, explanatory models, consequences of pain for the patient’s activities, and consequences for her self-perception. The bodily symptoms signaled loss of control. The explanatory models consisted of physical damage and strain injuries, but were also psychological and self-blaming. The consequences of pain were described as negative consequences for the women’s everyday life that challenged their self-perception as women. The participants’ search and need for legitimization of their illness experiences, and the expectations placed on doctors as legitimizing agents was evident. To achieve the desired shared understanding in consultations, doctors must be aware of and consider not only physical signs and symptoms, but also the patients’ gendered concerns and psycho-social circumstances.

Keywords: Musculoskeletal pain; Women patients; Illness experiences; Symptom descriptions; Gender

Introduction

Pain: between biology and culture

The experience of pain lies at the intersection of biology and culture (Kern, 1987; Morris, 1991). Part of the problem in pain management is that scientific medicine has reduced the experience of pain to ‘an elaborate broadcasting system of signals, rather than seeing it as molded and shaped by the individual and their particular socio-cultural context’ (Bendelow and Williams, 1995). The ‘medicalization’ of pain has resulted in a split between body and mind.

The problem of medical knowledge appears when making pain operational. The main difficulty is that it is a person’s private experience, to which no one else has direct access. Physicians shape their pain theories ‘by constructs, by intellectual categories that both depend on but also generate the codes for perceiving illness’ (Baszanger, 1992). Baszanger describes two poles of pain management; one aiming at ‘curing...
through techniques', the other at 'healing through adaptation'. These poles of pain-managing attitudes are also recognized in consultation research. In the 'doctor-oriented approach' disease and biomedical skills are significant, and in the 'patient-oriented approach' the patient's experiences, expectations and worries are the focus (Byrne and Long, 1976; Pendleton et al., 1984; Tuckett et al., 1985). There is consensus in family medicine that the patient-oriented approach is preferable. It results in more patient satisfaction, compliance, and improved health (Bass et al., 1986; Stewart et al., 1989).

Pain is widely recognized as a complex phenomenon. Nevertheless, medical models often end up in reductionism and medico-centrism, since they look for expert explanations in biological facts (Armstrong, 1987). Baszanger showed that for physicians there was a hierarchy of explanation levels. A common view when concluding the results of investigations and consultation was to consider cellular pathology as 'something', whereas illness-provoking, psycho-social circumstances were 'nothing'.

Although pain is the experience of the sufferer the voice of the subject is often lost. There have been attempts to reclaim the experience of pain from exclusive biomedical jurisdiction. How pain beliefs are shaped in social interaction, and how emotions, perceptions of pain and social characteristics are embodied, has been focused on by social constructionists, anthropologists as well as phenomenologists (Kern, 1987; Morris, 1991; Delvecchio Good et al., 1992; Turner, 1996). Kleinman asserts that illness for the individual always has a meaning (Kleinman, 1988), and Stacey expressed it: "People's ideas are logical and valid in their own right, although they may not be consonant with biomedical science or with any other organized healing system" (Stacey, 1988).

One way to examine these issues is by a qualitative exploration of the patients' own experiences. Illness narratives can give access to aspects of suffering that are obscured in biomedical curricula (Kleinman, 1992b; Shapiro, 1993; Garro, 1994). The multidisciplinary approach, anthropological, sociological, psychological and philosophical attempts to understand pain, has bridged the gap between biology and culture. However, the impact of gender on pain is only beginning to be acknowledged in medicine (Bendelow, 1993).

**Gender perspective**

In the feminist discourse there have also been tensions between biology and culture, objectivism and relativism, essentialism and constructivism. The separation of 'sex' and 'gender' served the purpose of moving away and distinguishing them from views which explained differences between the sexes and also social norms as biologically and physiologically caused, and 'natural'. This distinction was problematic, and more recent theories conceive of gender as both biologically and socially constructed (Butler, 1993).

An individual's acknowledgment of being categorized in either sex has vast implications for personal self-perception and behavior, and 'gender' is the accomplishment of social situations and doings, from early childhood and thereafter (Davies, 1989; Jones, 1993). Gender is consciously, unconsciously and continuously performed in interactions between individuals in different social, cultural and political settings (West and Zimmerman, 1987; West, 1993). For example, a female is sex classified according to her genes and reproductive organs. But for a woman performing her 'gender', it is both her body, the organs, hormones, anatomy and the lived experiences that interact; her expectations and her response, accepting or challenging, at home, at work and among friends. Her adjustment to womanliness and motherhood depends not only on her hormones, but also on circumstances of upbringing, media influences, social class, the labor market, insurance systems and the legislative system.

In most human societies there is a 'gender order' implying that women are subordinated to men. It is overtly displayed for instance in statistics concerning income, position and power (Doyal, 1995; Sainsbury, 1996), but it is also hidden and variable. For each individual, female as well as male, the lived experience shows how gender order is maintained, challenged, varied and/or changed. An individual might present and motivate certain behavior, as a matter of personal 'free choice', but the choice can in fact be a result of restricted circumstances dependent on culture, or on class or political legislation.

Instead of seeing empirical sex/gender differences as proof of different anatomical or psychological characteristics, for instance lower pain thresholds in women, a gender perspective could give the analytic starting point for questions about why they appear (West, 1993). Bendelow contributed to the understanding of pain, gender, culture and embodiment in an interview study on pain endurance (Bendelow, 1993). It was shown that in 'lay' understanding women were attributed superior capacities about enduring pain, often linked to their reproductive functioning. It is remarkable that women's great exposure to pain, for instance in birth labor, did not imply that women's pain experiences were to be acknowledged and taken seriously, but rather taken as a part of their 'nature' and duty.

**The challenging consultation**

The patient's presentation of symptoms is of course...
the starting point for the diagnostic process in the consultation. The physician deals with ambiguous representations of experiences, in the presentation of a history, during the examination, and in the interpretation of laboratory tests and technical results. There is a selection process, a medical bias as well as a gender bias, involved in the information exchange (Rudebeck, 1992; Salmon and May, 1995b; Hamberg et al., 1998b). One problem in the consultation is whether patient and doctor are talking about the same things and are sharing the same interpretative framework and conceptual worlds (Lunde, 1990).

Considering patients' perceptions a valuable source for understanding, we have interviewed a group of women and analyzed what they told us from a gender perspective. In a former paper we analyzed the consultation experiences and elucidated emotions of uncertainty and distrust. The physicians were perceived as masterful, and the women patients coped by using strategies such as somatizing, pleading, martyrizing, mystifying and condemning (Johansson et al., 1996). The analysis exposed a consultation arena framed by biomedical discourse, positional power and sex stereotypes.

The aim of this paper is to interpret the meaning in the women's descriptions of pain from a gender perspective. By letting the women talk freely in semi-structured interviews and by a qualitative analysis of the transcripts, the purpose has been to give voice to the everyday experiences of a group of women with biomedically undefined pain. We have explored the women's narratives, their experiences and expectations, and the theories they developed to account for their circumstances. We have tried to understand the beliefs about pain and how they are adopted in a societal context where sex segregation and inequalities are challenged.

Method

Participants

Female patients visiting a health care center in northern Sweden and sick-listed due to undefined musculoskeletal pain, were asked to participate in an interview study. The pain was regarded as 'undefined' when no clear-cut biomedical etiology was assigned to it, in spite of thorough examinations. The medical records stated different diagnoses such as idiopathic pain, neck-shoulder syndrome, chronic back pain, musculoskeletal disorders, myo-fascial pain. One woman had the diagnosis of fibromyalgia. The common thread was that investigations and treatments had reached a stalemate. To be eligible for the study the women had to have been sick-listed for at least two months. There was great variation in the duration of illness, from six months to four years.

Twenty-two women were invited, two declined. The participants received verbal and written information about the study. They were assured of anonymity. They had a chance to read through, correct and comment on their own interview transcripts, and to withdraw from the study if they wished to.

The participants were all born in Sweden. They were lower middle class, and had jobs such as nursing assistant, childminder, cleaner, barmaid, often employed in the public sector. About half were in full-time employment, the rest part-time. All except one had children, and all had been or were currently living with a male partner.

Data collection

Repeated, semi-structured interviews (Britten, 1995) were conducted by one of the two researchers (KH or EJ). The only guideline was to cover broad topics: work and family life, health history, and experiences of health care. Each interview lasted 1–2 h. Most women were interviewed on three occasions over a two-year period. Two women were interviewed only twice, due to practical circumstances, and one withdrew after the first interview. The first interviews were conducted at the health clinic, but outside ordinary office hours. Later interviews took place at the clinic or in the participant's home.

The aim of the interviews was to let the participant describe her situation in her own words. The interviewer tried to ease the narrative flow with probing questions like, “Can you tell me more?” or, “Would you give an example of that?”

Data analysis

The interviews were audio-taped and transcribed. The interviewing researchers (EJ, KH) first examined and coded the transcripts openly and independently. The codes were thereafter compared, discussed, and categorized by the researchers together. The analysis of the transcriptions was conducted parallel to the interview process, in order to collect and interpret data, and identify emerging themes for further analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1990).
One of these themes, the focus of this paper, was the patients’ descriptions of symptoms.

At this point in the data analyzing process we were influenced by modes of narrative analysis, described by Riessman (Riessman, 1993). ‘Narratives’ and story metaphors, illustrating how the participants ordered the flow of experience to make sense of events and actions in their lives, were looked for in the data. Our methodological approach was to examine the women’s expressions and examples, and analyze how they were put together, and how they tried to persuade the medical researcher of authenticity. Our preconception was that narratives do not necessarily mirror the world out there. To describe and narrate is also a way to create ‘a self’, i.e. how the narrator wants to be seen and known by the listener.

A second step was to return to the original data and ask of the data questions such as: What is she describing? How does she tell her story? Which metaphors are used? Why is the story told that way? (Kleinman, 1988; Charmaz, 1990; Sandelowski, 1991). The final analysis was completed as different drafts were discussed by all the authors.

Methodological considerations

A qualitative approach was used to provide insight into the patients’ illnesses concerns, by analyzing descriptions of pain. Most respondents were willing to share their experiences with us. What they told us might have been influenced by several contextual settings considered below.

The participants were patients from the health center where the interviewers (EJ, KH) work as doctors. This could imply that the women withheld information that put them in an unfavorable light, or had consequences for management. Nevertheless, we were interested in how the women disclosed their experiences in this particular context, to a researching physician in the socio-medical culture of primary care. The women were encouraged to talk freely, and to express their worries and frustrations. The interview interaction did often turn towards medical rather than lay concepts. This was proof of the medical impact, but also that the women themselves were not expecting their everyday experiences to be of medical interest. For instance, one woman hesitated when talking about housekeeping: “But really, are you interested in this? What has this got to do with health care?” She was encouraged to continue her story. Thus the research setting, by imitating a consultation context, had advantages compared to interviews conducted by a layman or another professional interviewer. The limitations framing a consultation were thereby exposed; that is preferential right of biomedical interpretation, power asymmetry and the gendered positions in the doctor-patient interaction, all of which is discussed by the authors elsewhere (Hamberg et al., 1998b; Johansson et al., 1996).

In the following we present the main findings, grounded in data. The narratives and short quotations given here are chosen to present typical illustrations of the material. Codes, concepts and categories, induced in the analysis of data are set in italics and single inverted commas, the first time they appear.

Symptom descriptions

Open coding of the transcripts led us to realize that the descriptions of pain were intertwined threads of recurring themes. When exploring the text we could divide the content into four main categories: ‘bodily presentations’, ‘explanations’, ‘consequences for daily work’ and ‘consequences for self-perception’.

Bodily presentations

The following quotation illustrates the bodily presentations. It is from an interview with a woman who had experienced musculoskeletal pain since adolescence. Here she (Cleaner, 42 yr old) refers to the start of the actual sick-listing period.

Well, it began in the fingers. I was ill, incredibly ill. And then I got this cramp. I lay down for 10 or 15 minutes at work that night, which I never do. But I had terrible pains in the lungs. Fingers, too. I remember that when I was going to shift gears when I drove home I couldn’t get my fingers around the stick and had to push the gear like this. Then it moved to the neck, and here behind the shoulder blade. A lump was stuck there and hurt. Then it moved. Since then it has gone up and down, actually. The slightest bit of exertion and it hurts again. And lately I think it has become worse. Today I feel really good. I just have a little pain in the neck. But I have it in my ankles, I have it in my hips, I have it in my thighs. I have it everywhere! But the cramp is actually a little better now. Otherwise it is everywhere. Which is why I thought that I might have got that disease, fibro...? Because it moves around so much. From one place to another. And the pain is so intense. Like last weekend, in the back of the neck and the fingers, so incredible, incredible... then it goes up into the flesh itself, or however I should put it, and then in the back of the neck.

‘A threat’. Throughout the pain descriptions, as above, there were questions and worries about what the symptoms were implying. Pain was a threat of ‘something going wrong’ in the body.
Most of the time I got up and wandered around the house at nights and felt pain and it tingled and hurt... I really thought I had some sort of serious neurological disease. I thought I had better pay close attention before I became paralyzed and lost my sense of touch, so that I could commit suicide before I turned into a vegetable. (Nursing assistant, 60 yr old.)

‘Unpredictable’. The bodily symptoms were difficult to grasp and predict for the woman herself. The pain was out of her control, everywhere and nowhere, better and worse, moving around, up and down. It was described as if the body set traps for her, unpredictably.

‘Deconstructed’. Many informants described the body as detached into separate parts, not as a compound entity. “My fingers started” or “Suddenly my legs turned all crazy, I didn’t recognize them as mine” (child-minder, 33 yr).

‘A bizarre invader’. The pain was alien. Some women felt like victims, as if ‘it’ — the pain — was a constantly present but invisible enemy. “Then it moved, and now it is located in...”. It was an intruder, out of her control, reminding her whenever she felt a little better. “But the cramp is actually a little better now. Otherwise it’s everywhere” (nursing assistant, 49 yr).

‘From a distinct location to dispersed pain’. In the descriptions of pain there was often a minor accident in the background, a slip, a lift, a muscle stretch, a distortion, or an infection. These primary symptoms leading to the actual sick-listing period were localized and described in detail (nursing assistant, 60 yr):

This is how it happened... it began with a fall... lost my foothold and fell flat on my face, a violent fall. I was so totally shaken up. I landed on my left side... I managed to get to work and they helped me and I was at the X-ray department. But there was no fracture or anything. But it really hurt. Anyway, I drove myself home. It’s important to know that when I was sick-listed I thought: Thank God I was sick-listed, since I have such a painful back. I had been thinking about what I should do about my back.

However, most of the women described long periods of silent struggle against an insidious pain preceding the present situation. They described an event that was ‘the final straw’. When the emergency caused by that event had passed there was still that same old distressing pain in the background.

Explanations

The symptom descriptions contained different explanations for the pain.

‘A physical origin’. The informants were convinced that the pain had a bodily cause. Medical diagnoses were hinted at “Could it be fibro...?”, and further investigations were suggested, as if it was up to them to push and make a claim if anything at all was to be done. “There must be something concrete there”.

‘Work-related’. “I think it is job-related. I’m pretty sure of that”. An explanation near at hand was that the pain was caused by heavy and monotonous work, and was a result of repetitive strain injuries. However, overstraining also included housework responsibilities and chores (secretary, 58 yr):

I’ve done everything, I have, really. And managed all right. I have been janitor, mechanic, gardener and painter. So it’s really not so strange that I should have pains in my joints. One has to be so darned competent all the time.

‘External elements’. There were also ideas about other environmental influences causing bodily damage. These explanations were of the kind that are controversial within the biomedical framework, such as unfavorable effects of minerals or metals such as amalgam or gold, of magnetism and radiation, and the weather.

‘Tensions and worries’ had caused the strain. Examples including a stressful childhood, disagreements at the workplace, and marital conflicts, were given (home help, 37 yr):

While we were living together. When I was anxious I had headaches and shoulder pain. I knew exactly why. I worried about him... He might stay away at nights. He might come home drunk. It was not so bloody funny with him thudding about, falling on the bathroom floor perhaps...

‘Punishment’. Ideas about the pain emanating from wrong decisions, or even bad behavior, were presented. It concerned feelings of being insufficient, in relationships with parents-in-law, parents, husbands or children. The women talked about guilt, but also grief and shame. This might involve a period of addiction (alcohol or tranquilizers), having been sexually abused or beaten, or an abortion (teaching assistant, 49 yr):

I kind of believe in fate. In a way you want to think that everything has a meaning. And I have had these thoughts that I was punished for doing this abortion. I don’t think so any longer though; that it was God’s punishment that forced me to
stop knitting, and weaving, and that my world collapsed.

‘Predisposed’. There were ideas about being predisposed as a woman. “My mother, my grandmother and my sister, too” (cleaner, 25 yr) suffered the same. Whether the heritage was seen as a genetic disposition, a part of the socialisation process, or an aspect of women’s living conditions was not developed.

Consequences for activities

The women described how the pain had consequences for their everyday capacities. They evaluated their resources in relation to former capabilities and present expectations (cleaner, 46 yr):

Well, you know. I wonder if I can ever go back to the job I had. I don’t think so. The problems with my fingers, which you’re so dependent on. I’ll give you an example. Yesterday, the sun shone directly into my kitchen so that you saw everything clearly, the doors and everything. So I got a cloth and started cleaning. But as soon as I did, my fingers started hurting. Completely exhausted. Just that little thing. So one starts to think, how would I be able to manage a job, when I can’t even do this? And I have to divide the apartment up into rooms when I vacuum. How then is one supposed to manage the heavy workload we have?

‘Housework’. In the example above the woman described a routine that she evidently executed automatically and regarded as trivial, “So I got a cloth and started cleaning”. From this example of her limited capacities in the home, she extrapolated to incompetence in her actual paid work as cleaner.

Domestic undertakings were core examples in many ways. They described the ‘lived everyday experiences’, illustrating that sickness certification did not liberate one from housework. Expressed as taken for granted, they gave glimpses of her ‘life world’ — what was expected from her, and what she expected from herself. They formulated her priorities. At the same time, they demonstrated that even the most elementary chores were hard to fulfill (kitchen maid, 33 yr):

I have my better periods, you know. That’s when I try and do everything that needs to be done.

Interviewer: Like what?

Well, I sew new curtains, I want to clean, and wipe out the cupboards and the things inside the cupboards... things I can’t do you know? And so as a result I feel ten times worse.

Being sick-listed full-time implied that the descriptions of restricted work capacities were taken from the domestic arena; however, the women characteristically interwove shortcomings in unpaid as well as paid work. They did not distinguish between the two.

‘Paid work’. The women had jobs such as cleaners, nursing assistants, kitchen maids, and child-minders. This particular part-time, sick-listed woman described her work in a bar. In fact, in most cases duties at the workplace were similar to those in the home (bar maid, 58 yr):

When I carry things and work hard, I have only one thought in my head: As soon as you have finished this, Elsa, made lunch and washed up, then you can go home! Otherwise, usually by the time lunch is finished, it’s almost two o’clock, because all the leftovers have to be put away. Then the afternoon snack has to be prepared. Then everything in the cafeterias has to be wiped off, snacks have to be put out, and coffee and tea have to be brewed. This is how it goes, all the time, all the time. We are always in a rush. From eight o’clock in the morning until half-past one, we never stop.

‘Caring’. The pain had consequences for the woman, as daughter, mother, wife or grandmother. One woman felt she could not help her parents mend their towels and linen, as she was expected to do. A mother of two children of school age accused herself for not having enough strength for playing and being pleasant to the children. Another described how the insistent pain made her irritable. She feared being seen only as complaining and nagging by her husband and daughter, when she asked them to take part in the household chores. One of the grandmothers experienced difficulties in finding acceptance for not involving herself in the grandchildren (nursing assistant, 60 yr):

The pain makes it hard to handle small children. They ought to, but they don’t accept it, in a way... my illness. I feel stung, because I know there are people saying that grand-children are the most wonderful experience on earth. I don’t have that feeling. Is that horrible? I don’t live up to the ideal grandma.

‘Relaxation’. The pain was an obstacle to different activities that formerly had given pleasure, for instance knitting, embroidering, berry picking, weaving or jogging (waitress, 34 yr):

Like I can never bake, it just exhausts me. Not bake and not sit and knit. I feel it when hanging up curtains and stretching and then I am exhausted. Little jobs are just as difficult. Like sitting and knitting or sitting and sewing.
Consequences for her self perception

‘Risks her good name’. The pain, and its consequences, was an obvious menace to her reputation. To be suffering from something that did not show and could not be medically diagnosed was a delicate issue to handle. A recurring theme was the uncertainty of how to interpret and deal with lowered working capacities in private life, at the workplace, and officially in terms of insurance rights. The women wanted ‘to do’, to be active and respected. However, in most circumstances they perceived themselves as exposed to doubt and mistrust in the eyes of others. This was a dilemma. Being at home and sick-listed, they felt expectations from others to take on ‘extra responsibilities’ and have a perfect home. At the same time, if they were active, went out shopping, cleaned windows, it could make neighbors suspicious: If she was that effective, why couldn’t she manage to go to work?

‘Womanliness’. Betty, a 38-year-old barmaid, had been sick-listed for a year for widespread pain. Many work-trials had failed, and she considered herself incapable of taking part in the labor market. As far as the pain went, she was reconciled to living with it the rest of her life. In this situation she began planning to adopt a child. The adoption bureau needed a doctor’s health certificate. She was utterly astonished, and insulted, when the agency hesitated to recommend adoption because of her decreased working capabilities. In this speech, she tried to object to the illness being held as ground for disqualifying her as a woman (barmaid, 38 yr):

Although I’m sick-listed full-time for pain disorders, I’m a totally healthy woman and I would be a perfect mother.

What Betty exemplified applied to other women as well. When describing their incapacity and shortcomings in a way that made them understandable and legitimate, these women risked being labeled, not only as malingerers, hypochondriacs or psychological deviants, but also as insufficiently womanly. Their identities were being questioned.

‘Sexuality’. A few informants gave spontaneous information about the problems the pain caused in their sex life. In doing this they choose to describe their insufficiency towards their partner rather than their own expectations. This woman described her wish ‘to do’ as a wife, to be accessible for her husband’s needs (industrial worker, 40 yr):

And these pains affect sex life, too. It consumes a whole lot of the desire. And men are, well, like, they don’t function the same way. If they have pain they still can function sexually. But I don’t so it can be a problem. But I see what it does to him — it puts him in a bad mood.

Discussion and analysis from a gender perspective

To sum up the findings, the women in this study described their pain by intertwining bodily presentations, explanatory models and negative consequences in their everyday life. The meaning of the bodily presentations — with the pain being a threat, unpredictable, deconstructive, invasive, alien and dispersed — was expressed as a ‘lack of control’. The explanatory ideas presented by the women designated them as ‘victims of an undiscovered disease’, caused by repetitive strain injuries, overstraining, predisposition, violence and abuse. The causal agents were perceived as being beyond change. The damage was done and persistent. These were external causes they could not be responsible for. Still, since the agents they proposed were not recognized as causal agents by the physicians, the women also displayed ‘self-blaming ideas’. Furthermore, the pain, the lack of control, and the deadlock induced shortcomings that threatened self-perception, and ‘risked their identities as capable women’. They were not sufficiently capable to take full part in the labor force, nor to live up to expectations, as daughters, wives and mothers.

Analyzing data from a gender perspective implies consideration of cultural contingencies and how the status of the sexes in society influences embodiment, expressions, and social cognition (Blaxter, 1983; Ruda, 1993). In the following the different meanings are compared to other research findings but also interpreted from a perspective of subordination and gendered demands. The women’s descriptions of symptom, their explanations as well as the consequences, are shown to be dependent on the social interaction — with family members, friends, neighbors, work-mates, and doctors.

Lack of control

Pain as an enemy, something coming from outside and invading, has many cultural and historical expressions in literature and art (Kern, 1987). In a recent Swedish study of female fibromyalgia, patients symptom descriptions were similarly displayed — pain as an aggressive physical torture, a threat without a distinct location (Söderberg and Norberg, 1995). In our study we tried to find a deeper meaning in the women’s pain experiences and found ‘lack of control’ to be a common attribution.

‘Control’ is a central concept in cognitive therapeutic models (Crisson and Keefe, 1988; Buckelew et al., 1990). Coping theories focus on the individual’s cognition, his or her personality, and capacity to take con-
trol. For instance, people with high ‘self-efficacy beliefs’ are more successful than those with low beliefs, as they perceive fewer shortcomings in life. Strategies with low control, such as ‘helplessness’, and ‘relying on others’, enhance suffering and medical help-seeking (Jensen et al., 1991).

In this perspective women’s poor outcome in pain treatment programs is explained by their ‘catastrophizing’ modes, ‘pain behavior’ (Jensen et al., 1994), or even ‘pain prone’ personalities (Engel, 1959). As Lazarus in his later work, we want to point to the risk in confounding origin and outcome and missing the context of women’s pain experiences (Lazarus, 1994). There is certainly not a simple cause-effect relationship, but a complex pattern of interrelated factors, involved in the sources and consequences of pain. Our analysis demonstrates that medical and institutional frameworks, and cultural and social relational factors such as gender and power, interact in forming the women’s meaning of pain, i.e. their lack of control.

The women in this study experienced, suffered, and described bodily and emotional sensations that were ‘undefined’ within the medical framework. Delegitimation (Kleinman, 1992a) awoke feelings of mutual mistrust (Johansson et al., 1996). The pain experience was alien, threatening, and hard to control for the physician also. In the ‘medical room’, designed and conducted by health care, can women make their experiences understood and acknowledged before a physician? Adapting to the medical world, by extensive symptom descriptions and pleas for help, is considered as ‘pain-prone’ and ‘somatizing’. Dissociating from the medical knowledge, by mystic ‘lay’ descriptions, self-blame or condemning physicians, are modes that are considered as unsuccessful coping strategies (Jensen et al., 1991; Rotter, 1966). However, ‘success’ is valued here from a medical standpoint.

The women’s ‘lack of control’ in this study indicated individual unease and frustration, but it also included positional powerlessness in the medical interaction. From a gender perspective patient’s lack of control can be considered as medical failure. Furthermore, the so called unsuccessful strategies, from the point of view of the position of women patients as inferior, might also be interpreted as trials to assert power, and control, in the consultation situation.

Extensive empirical data and theory describe the power asymmetry in the doctor–patient relationship (Ainsworth-Vaughn, 1995). The focus has usually been on ways in which doctors exert authority (Meeuwesen et al., 1991). The ways patients influence the consultation have been neglected. However Salmon and May illustrated in a single-case study that patients can exert power on the doctor to determine the outcome of consultations by including the presentation of emotional and social distress around a biomedical model (Salmon and May, 1995a).

The bodily descriptions in our study exposed tension between the women’s descriptions and the medical agenda. The women used tableaux and metaphors that communicated general norms, e.g., pain as an invasion by an unpredictable intruder calls for aid for the victim. They also took advantage of socially-ascribed feminine behavior, such as help-seeking, and challenged the doctor’s authority to conduct control (Johansson et al., 1996). Peters et al. claim that the ‘patient’s sense of authority over doctors derived, not from facility with medical language and ideas, but from contrasting their own sensory and therefore infallible experience of symptoms with doctors’ indirect and fallible knowledge’ (Peters et al., 1998). Kleinman discusses the ways that suffering can be a form of resistance against oppressive relationship and delegitimation of experiences (Kleinman, 1992a).

**Victims of an undiscovered disease**

Not being legitimated with a clear-cut diagnosis had consequences for the women’s interpretations and strategies. This analysis shows that the women lived with many different explanations, but they usually ended with the question of disease and physiological damage (shop assistant, 32 yr):

> I don’t think it is merely psychological, as I feel it in my body, and that frightens me.

Health and illness are socially constructed notions which mean different things to different people. When there are discrepancies between diseases and illness behavior there are disputes both among lay and professionally-trained people. Eccleston et al. found that patients contest the reality of the pain and its physical origin, while physicians tend to see chronic pain as a dysfunctional reaction (Eccleston et al., 1997). In society the notion of the biophysical facts has primacy over humanistic interpretations. This false dichotomy of soul and body has great impact on the misunderstanding and mistrust uncovered in our study. One woman said: “I was stressed, but I didn’t talk about that with the doctor, he might have considered me a psycho” (cleaner, 34 yr). This dualism permeates not only lay beliefs but also, as described in the introduction, physician’s beliefs, politicians and the legislation.

In Sweden a medical diagnosis must be in hand before a sick certification can be granted. The almost exclusive dependence on the medical model makes it understandable why a diagnosis is utterly important for the patient to perceive themselves as justified and taken seriously. As discussed above, and also shown elsewhere (Johansson et al., 1996), it was essential for...
the women to get a credible explanation: “I was willing to be cut in pieces to figure out what was wrong with me” (nursing assistant, 60 yr). They tried to uphold self-respect, by securing a name for the disorder and be able to collaborate against it, also shown in Peters study (Peters et al., 1998).

Still, in the long run, focusing merely on diagnosis, labeling is a deadlock. High levels of investigations and treatments, including surgery, that are carried out on the technical track of Western medicine, can only give the physician and patient reassurance for a short time. New approaches to patient intervention, reassurance and empowerment are needed to extend traditional models. For the physician’s awareness it is important to understand how women’s illness perceptions and illness behavior are shaped in cultural and social mounds of subordination. Pain is a lived experience in daily life undertakings. To legitimize this experience, to give the right information, and reinforce the self-appraisal of the patient, the everyday life conditions must be made visible. As Mechanic states: “sickness in a social sense could be a vehicle of power and influence making new adaptations possible” (Mechanic, 1995).

Risks identities as capable women

In our data expressions such as ‘one should and would’ pointed to the social norms that guided the women. Conditional conjunctions such as ‘if only... I would’ and the use of the indefinite pronoun ‘one’ demonstrated the gaps between the women’s actual circumstances and societal ideals, between their personal capacities and what they felt was expected of them. By referring to the standards of housewives and mothers, the women themselves assigned their main arena, and its delimitation. Examples given from child caring, knitting, vacuuming and mopping up formulated ‘female undertakings’ that were taken for granted. The subtle utterance “The sun shone directly into my kitchen...” signaled a world of ‘having an eye for fundamental duties’, that might be invisible for some, but which were mandatory for the initiated woman. Through pictures of this kind, the women also reflected that their deficiencies were not matters of idleness or omission. Rather, they revealed their eagerness to qualify for an intact ‘womanliness’. This woman articulates her goals and attempts, inhibited by bodily pain: “What I’d really like to do... sew curtains, clean out the cupboards...”.

Each individual woman’s pain experience was compounded by comparisons and considerations concerning her former and present capacities and her emotional state, and was related to normative conditions: What can I do at home? How shall I expend my resources? Am I capable of working, or entitled to be sick-listed? How am I considered in the eyes of family members, neighbors, and doctors? What was taken for normal and natural, and what was considered as illness? For instance feeling pain, being weak, dizzy or having backache, were not always considered to be illness (nursing assistant, 48 yr):

I had a backache for a long time. We were short of people at the ward. Everyone was suffering. Having a backache became quite natural.

The consequences of pain for women, in work and family life, has been thoroughly described by Henriksso (Henriksson, 1995a, 1995b). Our analysis of meanings demonstrates the strong impact of gendered norms in the women’s emphasis. Inability to do housework, and difficulties in fulfilling family commitments were the salient themes. The pain created personal and social gender-related troubles for the women in the study. As social expectations of ‘womanliness’ were very much related to cleaning, caring and accessibility for others’ needs, the difficulties were double-edged. To be respected they had to live up to the norms, and when doing so they risked being mistrusted as not ‘really ill’. Thus the concepts of Borkan et al were confirmed: limitations and delegitimation in the lives of patients (Borkan et al., 1995). In this balancing act the women had problems in prioritizing their own needs, and also in following recommended training and rehabilitation programs. They had a ‘marriage contract’ in their marital relationship, characterized by segregated duties, female subordination, and a restricted action potential (Hamberg et al., 1997).

These were findings in a group of women belonging mainly to the working-class and lower middle class. The strong ‘family orientation’, and a concealed subordination was also exposed in a study by Friberg, who described it as ‘the employee life-form’ in Sweden (Friberg, 1993). Although about 80% of women take part in the labor market, women still take on the main responsibility for home and family (Hall, 1992; Lagerlöf, 1993). For women with a career however, work benefits might exceed home commitments as sources of self-esteem. However, this cannot not be concluded from our study, especially as the women had jobs with similar caring and cleaning tasks to those at home.

When explaining pain and describing their shortcomings the women also disclosed how gender-related circumstances, self-perceptions and self-esteem had an impact on the pain. Tensions and worries, shame and guilt, were not only examples of self-blame but also features of an exposed position. As Friberg demonstrated these women, too, concealed or reformulated their subordination. For instance, when the first interview was conducted two women were known to have
experiences of abuse. However, by the time of the third interview as many as half of the women had disclosed experiences of physical abuse (Hamberg et al., 1998a).

For the women in the study physicians were, apart from their tasks as medical advisers, also very important legitimizing agents. The legitimization question is well-recognized in medical sociology and psychology (Telles and Pollack, 1981; Miles, 1991; Reid et al., 1991). Are physicians aware and prepared for this task, when it concerns women patients with undefined pain disorders? A purely diagnosis-oriented approach is not enough, and an attitude of healing through adaptation must be completed with a gender perspective on women’s actual circumstances. The medical encounter ought to provide possibilities for the patients to express psycho-social problems. Physicians have a chance to listen, voice concern, discuss solutions and offer remedies such as counseling as well as medication to empower the patient. Yet, in general, medical discourse tends to marginalize the contextual issues of greatest concern.

The origin of the pain might be physical and psycho-social, but its persistence might be due to life conditions, norms and gender-related tasks, which have been disguised in research (McDonough, 1996). The dilemma in consultations is that often the only legitimate expression is the somatic. Thus the interaction with health care can even have negative effect on curing. Understanding illness begins with an understanding of illness as it is lived (Merleau-Ponty, 1962; Singer, 1990). The encounter between physician and patient could be the start of the healing process, although it is only a small part of the patient’s total life situation or ongoing suffering. A physician showing respectfulness towards patient’s experiences and circumstances, instead of merely referring to biomedical diagnoses and paid-work standards, is certainly contributing to the patient’s experience of legitimation. Insurance norms and recommendations ought to consider women’s unpaid duties and everyday life circumstances, as well. The sick certification system in Sweden at present, based on purely medical criteria, is a contribution to a medico-centrism which is not tangible for understanding patients, as it neglects and/or medicalise gendered conditions.

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