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AN ILLNESS OF ONE'S OWN: POWER AND THE NEGOTIATION OF IDENTITY AMONG  
SOCIAL WORKERS, DOCTORS AND PATIENTS WITHOUT BIO-MEDICAL DIAGNOSIS

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# AN ILLNESS OF ONE'S OWN: POWER AND THE NEGOTIATION OF IDENTITY AMONG SOCIAL WORKERS, DOCTORS AND PATIENTS WITHOUT BIO-MEDICAL DIAGNOSIS

## ABSTRACT

In modern, neo-liberal societies like Denmark, social welfare and medical treatment are provided to individuals who 'take ownership' of their problems. Thus, sickness benefits are given to people who suffer from their 'own illnesses,' not to people with diffuse, chronic pains 'of the whole person.' This article presents findings from a qualitative research project into how power relates to identity negotiations among social workers and medical doctors who are dealing with patients who lack a bio-medical identity. The analysis shows that social workers and doctors have swapped roles in their negotiation with patients and that the new roles can be related to structural elements such as the law and discursively produced understandings of what it is to be a 'patient.'

Keywords: neo-liberalism; discursive power; structural power; identity; diagnosis; illness

## AN ILLNESS OF ONE'S OWN: POWER AND THE NEGOTIATION OF IDENTITY AMONG SOCIAL WORKERS, DOCTORS AND PATIENTS WITHOUT BIO-MEDICAL DIAGNOSIS

Chronic pain is a self-sustaining, self-reinforcing, and self-regenerating process ... It is not a symptom of an underlying acute somatic injury but rather, a destructive illness in its own right. It is an illness of the whole person and not a disease caused by the pathological state of an organ system. (Kang 2003, abstract)

Patients who suffer from what are called 'chronic widespread pain' (CWP) or 'medically unexplained symptoms' often find themselves caught in a no man's land defined by the underlying assumptions of medical science and social policy. Modern medicine assumes that disease and health are states of the individual body; the welfare state assumes that power and freedom pertain to the conduct of individuals. But what characterizes CWP is indeed the diffuseness of the symptoms, that is, the difficulty of locating them in the dysfunction of any particular organ or set of organs. The illness lacks a proper medical 'identity', we might say, making it difficult for doctors to diagnose. This has consequences for the civil status of the sufferer who, despite being what some doctors refer to as 'functionally ill,' that is, unable to work and enjoy social life, lacks a diagnosis, and consequently a medical identity, and is not quite worthy of the status of a 'patient'. The sufferer, then, resists the categories that both the bio-medical and state-welfare discourses need to apply in order to, respectively, initiate treatment and allocate benefits. In order for the sufferers to become medical patients and welfare clients, there must be something, some thing, wrong with them, and that thing recedes from view in 'diffuse' and sometimes 'idiopathic' pain symptoms, forever in danger of been dismissed as psychosomatic. The putative patient is here someone who may (or may not) need treatment, but does not quite deserve it.

In a phrase that Michel Foucault would no doubt have recognized the salience of, chronic pain has been called ‘an illness of the whole person’ (Kang 2003). In this domain, medical and welfare power is exercised through identity negotiations among social workers and doctors who together define what it means to be an ‘ill’ person. What determines the reality of a disease is here the patient’s ability to make the illness his or her own as stipulated in the Danish law of sickness benefits. The law’s request for the patient’s personal ownership of his or her illness can be approached as what Foucault and other scholars working in the tradition of governmentality studies call a ‘technology of the self’, that is, the ability of individuals to work with themselves. Our understanding of illness has, like many other topics, been shaped by the neo-liberal discourse of personal responsibility, individuality and freedom (Foucault 1980, 1983, Dean 2002).

If power is seen essentially as domination (theorized here as a patient’s ability to subject themselves to neo-liberal ‘truths’ on what it takes to be ill), it is the relationship of domination that is the paper’s focus (see Hearn 2008, p. 37). I want to demonstrate how a neo-liberal discourse on responsibility and governing through the social figure of the responsible, free citizen (Dean 2002) stimulate particular understandings of illness among doctors, social workers and people that suffer from diffuse pains, and hence influence the formation of identities among all three groups. Defining the social identity ‘an ill person’ is precisely a social process that leads to the development of particular self-perceptions for sick people captured by and involved in the categorization process.

I am interested in the dual character of power. There is no opposition between power/domination and individual freedom/subjectivity (Dean 2002, p. 37). The individual patients/clients, doctors, and social workers are both created/shaped by dominant bio-medical discourses on illnesses and by structural elements such as the law and creating/shaping the bio-medical discourses on illnesses and the law by their everyday actions. Put differently, I am looking at how subjects (doctors, social workers, clients/patients) act on an object (the body of a sick

person) (Foucault 1983). Here, the chronic pain sufferer surely has a subject position as well, albeit an importantly precarious one. The lack of a diagnosis is tantamount to the incomplete construction of an object of discourse (whether medical or pastoral) and this in turn creates a problematic or incomplete subject position for the would-be patient. The sufferer needs such a position ('patient', 'client') in order to deal with the pain, but the reported 'diffuse pains' ultimately fail to indicate an object (a truly 'sick' body), which is to say, diffuse pains fail in their role of 'symptoms.' With no organ to trace the pain back to, medical discourse is at a loss to come up with a diagnosis, and the welfare discourse has no place for 'sick' people who are not, properly speaking, 'patients'.

The negotiation of sickness is an ongoing process, subtended by complex power relations. It can be reduced to neither a structural view that denies the existence of human agency (structural elements influence but do not determine identity formations) nor a voluntaristic view that denies the existence of structural elements, such as law, rules, and policies, and dominant discourses on what it takes to be ill, bio-medically speaking (Hayward and Lukes 2008, p. 5, 14). Instead, the concepts of power and identity must be approached in a constructionist perspective that brings to light the everyday practices of the people involved. Inspired by Foucault and more new governmentality studies, I try to understand the micro-political situation in which sick people that lack a bio-medical diagnosis find themselves. These are 'patients' that are defined by their lack of a diagnosis and are, therefore, normally patients in name only. Their 'lack'-identity (in an important sense, a lack of identity) accentuates how dominant bio-medical discourses on illnesses are expressed and produced, in present day Danish law, education, etc., and hence among social workers and doctors, and in that way also in the categorization practices that transform persons into patients, grouping them as either sick or not sick. When sickness is indexed to localizable physical problems in particular parts of the body, for instance, sick people are empowered in their meetings with their social workers. They receive external validation from their doctors by being given, to borrow a

phrase from Woolf (1989), an illness ‘of their own.’ When sickness is not subject to categorization and validation in this way and is perhaps even vaguely related to ‘psychological’ problems instead, the sick person instead suffers from an ‘illness of the whole person’, for which the bio-medical discourse, always in need of a dysfunctional organ to refer to, has no name (Foucault 1987). In this case, the illness is not something they have but something they are, and this often leaves them without either treatment or benefits, which their fellow patients, burdened with less exotic conditions, enjoy as a matter of course. To be a proper patient in our neo-liberal age, you need to ‘have’ your illness, to own it. It is not enough to merely ‘be’ sick.

#### POWER AND THE NEGOTIATION OF IDENTITY

As in other western countries, the Danish welfare state has undergone changes that reflect and reproduce power in various ways. ‘One of the prime effects of power’, says Foucault, ‘[is] that certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals. The individual, that is, is not vis-à-vis of power; it is, I believe, one of its prime effects’ (Foucault 1980, p. 98). The individual, though, is not only an effect of power; the individual is also ‘the element of its articulation,’ as Foucault puts it (1980, p. 98). The individuals that are constructed as persons that suffer from an illness of the whole person, that is, patients who lack an illness of their own, are constructed this way because of two related sets of conditions. Firstly, there is a dominant bio-medical discourse that equates proper illnesses with somatic pathologies tied to specific dysfunctional organs; secondly, there is legislation that stipulates that illness is a personal event. On this basis, I will make an analytical distinction between ‘discourse’ (e.g., dominant professional attitudes among doctors and social workers) and ‘structural elements’ (e.g., the Danish law on sickness benefits). My interviews with doctors, social workers, and clients/patients show that there is a strong discourse among all three groups about what it takes to

be (properly) ill and that this discourse conflicts with the precise definition on illness in the Danish law. This conflict requires that we analyze the power inherent in the relationship between dominant understandings of (proper) illnesses and the structural definition of illnesses found in present day Danish law.

Power has a dual nature, in which ‘the individual which power has constituted is at the same time its vehicle’ (Foucault 1980, p. 98). Once being categorized as a person that suffers from an illness of a whole person, the self-perceived ill person’s encounter with the health and welfare system reflects and reproduces the result of this categorization process that defined the person as not really (bio-medically speaking) sick. Although the person still has problems, they stem from a different discourse – the psychological discourse – that conceptualizes the ill person differently because of an explicit focus on the ill person’s (problematic) personality. Our concept of power must consequently not only pertain to concepts like oppression, domination, and control, but must also be applied in relation to dominant positive neo-liberal values like responsibility, individuality, and freedom (Rose 1999, O’Malley 2000, Dean 2002). In order to understand the situation of today’s patient-clients, we need a concept of power that suggests a multifaceted practice that includes both traditional techniques of control and repression (e.g., Dahl 1957, Lukes 1974) and subtler constitutive and relational aspects (e.g., Foucault 1983, Rose 1999, Dean 2002). As we shall see in the analysis of especially the doctors’ positions, power does not rule out resistance. It is, however, a resistance that is framed by the neo-liberal and bio-medical discourses, which makes social workers defer to doctors and doctors’ critique of or resistant to the law and social system in general.

Research on power, disease, and diagnostic practices is not new in the social sciences. Since the 1960s, sociologists have been investigating how diagnostic practices construe individuals and groups. In sociology, the interest in diagnostic practices evolved from work with historical



documents (e.g., Foucault 1990, Hacking 2000) and concrete empirical diagnostic practices (e.g., Goffman 1990, Becker 1997). In this article, I am not only interested in showing that a diagnosis can change the way individuals experience themselves (see Hacking's 'interactive classes') or showing how diagnoses/labels/stigma relate to dominant discourses in society (Goffman 1990, Becker 1997, Gubrium and Holstein 2001), I also want to focus on how lacking a bio-medical diagnosis becomes influential for the sick person's identity. In these cases, the sick person is understood through a psychological discourse that does not meet with bio-medical, psychiatric understandings of mental illnesses. Precisely, because we are dealing with a group that lacks a bio-medical diagnosis (they are, clinically speaking, neither physically nor mentally ill), the definition of them as persons who are sick or not sick becomes – as we shall see – very dependent on structural elements such as the definition of a sick person in present legislation.

If we accept the premise that the diagnostic practices employed to define individuals that believe they are sick have a certain power, it is important to stress that they have such power, and exercise it, in different ways. Diagnoses mediate power in the sense that they give suffering persons the opportunity to describe and explain their suffering in such a way that the environment (spouse, job, welfare institution, etc.) understands them. Diagnoses mediate power because they make it legitimate for the diagnosed individual not to have to support him/herself for a period of time, letting the state take over instead. Diagnoses also mediate power as they reflect and link to prevailing understandings of what health and illness is in a given period; a diagnosis directs our gaze to certain characteristics that the group – qua the diagnosis – is assumed to have. A depressive person is assumed, in other words, to act in a certain way and may even have a specific (and different) personality structure, while people suffering from chronic fatigue syndrome are assumed to act in a different way and have a different personality structure (Johannisson 2007, p. 31).

Perceiving more psychologically oriented diagnoses as social constructs (Scheff 1994) is not identical to saying that diseases do not exist. Suffering and pain can be very real, but the point is that a diagnosis or a label is not just a neutral reading and translation of biological facts (bio-medical diagnosis); it is more than just a name for organic and functional problems in the body (Hallerstedt 2007, p. 22). Therefore, depression may be viewed as a ‘disease of the will’ (Valverde 1998), a pathological inadequacy of action; the depressed fundamental disturbance is the lack of ability to act, to be accountable, and take initiative (Petersen 2005, p. 74). Diagnosis is not just a problem for those seeking a diagnosis in response to the pain and suffering they are experiencing. A diagnosis can be a kind of answer to who you are – it can become the source of a new identity (Hallerstedt 2007). Hydén (2005), for instance, shows how a diagnosis brings together people with similar symptoms and helps them through social interaction with others in the same situation. This goes a long way towards explaining the growth of patients’ associations.

In Scandinavian countries, diagnoses that have been commonly used in the past, such as chronic fatigue syndrome, are being replaced with diagnoses that identify conditions such as stress, depression, and pains in the body (Mik-Meyer and Johansen 2009). Any society at any given time supports and develops specific understandings of symptoms which in that society and at that time appear as a meaningful way to understand certain illnesses and, through them, certain individuals (Foucault 1983, 1990). It is the dual nature of the sick identity, implying both a self and social structure such as law and dominant discourses on health and illness produced in educational systems, for example, that therefore becomes important to investigate.

The sick identity is understood as social and relational, that is, formed and negotiated in the presence of other social actors. To take a symbolic interactionist approach, identity is not construed as a substance or a core that human beings carry around (like the understanding of illness in bio-medicine as an essence, a specific entity that can be identified by the symptoms [Foucault 1987]);

rather, identity is seen as a social process undergoing constant change, making the social surroundings in which the identity negotiations evolve central in the analysis. Identity work involves the exchange of symbols accentuating both ‘specific others’ (e.g., social actors) and ‘generalized others’ (e.g., discourses on health and illnesses in society) (Mead 1959). The negotiation of identities is hence a process where external validation from either specific others and/or generalized others becomes central. Applying this anti-essentialist approach to identity work, I study both how doctors and social workers (specific others) and the legislation, dominant discourses on health and illnesses produces in the educational system, media, etc. (generalized others), have a powerful role in either validating or not validating the patient’s proclaimed identity as sick. I examine how the negotiation of illness and health by different actors is both constitutive of and constitutive for practice (Mik-Meyer 2009a).

## METHODOLOGY

The negotiation that defines persons as ‘really sick’ or ‘not really sick,’ that is, as patients and clients of various kinds, can be analyzed on different levels. On a macro-level, it is a negotiation between arguments stemming from bio-medical science (somatic pathology) and arguments relating to psychology (psychological pathology) (Foucault 1987) and the growing field of holistic medicine. On a micro-level, it is an identity negotiation in which the sick person’s perceived identity is either externally validated or not (Mead 1959, Holstein and Gubrium 2000, Jenkins 2000). It is a negotiation that can have severe consequences for suffering people, whose experiences of the situation cannot be accepted and validated externally by doctors and consequently social workers. In this way, it is also a negotiation between different hierarchically defined social roles, that is, doctors, social workers, and patients. Structural elements, such as legislation and educational background of professionals, do not, of course, determine action, but they do produce ‘predictable

patterns of action' (Hayward and Lukes 2008, p. 15). Taking the existence of predictable pattern of action for granted, however, we need to look at how power works empirically in order to see how the actual identity process develops where the definition of sickness is employed. In order to do so, I have developed a research design where the three relevant parties – the suffering people, the doctors, and the social workers – have been interviewed.

Apart from political documents used in the analysis, all data stems from interviews and is thus related to my research agenda and my role in the interview situation. Conducting a research project that mainly consists of interview material produces certain possibilities and limits for analysis. In this project I have had an explicit focus on how different groups define being ill when there is no bio-medical diagnosis. This theme, thus, naturally became the focus of the interviews. As such the interview material should be seen as a result of an active encounter between the interviewer (with her theoretically motivated research agenda) and the interviewee (confronted by this agenda) (Järvinen 2000). Because an interview is a social situation in which interviewer and interviewee collaborate to produce the story of the interview (Järvinen 2000, Gubrium and Holstein 2002), and because the interviewer may easily take the lead in the conversation by setting the agenda for the discussion, my research assistant and I conducted interviews with these sources of error in mind. The interviews were, consequently, conducted as semi-structured interviews, keeping the interviewee's perspective and subjective experience in focus. We paid close attention to the interviewee's involvement in the story, specifically by asking open questions. In the actual interview situation, for instance, we often listened to longer passages on illness and symptoms than we had prepared for because the interviewee kept bringing these issues up in the interview. This way our research design was also adjusted during our interview period to better reflect the issues of importance to our research subjects.

In focus group interviews, which we also conducted, the social context and the interaction between the participants interviewed has special importance for the story that is produced (Kitzinger 1994). Participants will inspire and stimulate each other during the interview and this may result in discussions on central themes and parting in disagreement, or the opposite. One of the advantages of this type of interview is that it generates a dynamic situation with room for discussions on various practices. It may, therefore, stimulate a more complex story about a given topic than is possible in interviews with one person only. Many factors influence the progress of a focus group interview. In our interviews, group dynamics and positioning, which are normal among colleagues who know each other, were particularly prominent. In these interviews (conducted separately with social workers and doctors), we experienced disagreement about how the clients'/patients' situation should be understood and how it could best be dealt with. The focus group interview method appeared to be an appropriate way of identifying implicit attitudes and apparent agreement about the client'/ patient' situation, which later proved to involve complex interpretations that varied significantly in the group of social workers/doctors. In the personal interviews with the people suffering from CWP, we also focused on the ambiguity of their medical description.

The dataset produced for the analysis in this paper consists of 15 focus group interviews with social workers (each lasting approximately two hours), 11 focus group interviews with doctors (each lasting approximately one and a half hours) and 41 individual interviews with people suffering from CWP. Each of these interviews took about one hour to carry out. All the interviews with social workers were conducted at their workplace; most of the interviews with doctors took place at the doctors' offices or at my research institution, and most of the client/patient interviews took place in their homes. All interviews were transcribed. For ethical reasons, the identities of the

interviewees quoted in this article have been concealed. Participants in the study were made aware in advance that they would participate anonymously.

I began the analytical work by reading the whole material and listing the themes that interviewees talked about. I then grouped themes and attitudes according to my research agenda (e.g., various definitions of illness), and according to themes, the interviewees brought up in the interviews and seemed to be very engaged in (judged by length of talk, eagerness, etc.). My aim was to find theoretically motivated patterns in the three interview groups and across interview groups that could help me answer my research questions on the relation between bio-medical diagnosis and different conceptions of illnesses. Afterward, I produced documents with quotes from the material, for example, descriptions of the welfare system and diagnosis (grouped in relation to client/patient, social worker or doctor). This organization of the material formed the basis for my investigation of illness and the prevalent logic of welfare and medical systems concerning clients/patients with CWP.

## THE DIAGNOSTIC PRACTICES AT THE SOCIAL AND MEDIAL SYSTEMS

The Danish welfare state, like many other western countries, has until recently had a long period of economic growth and, consequently, a low rate of unemployment. In Denmark, only 3.5 percent of the population was unemployed in 2008 (compared to 8.7 percent in the euro area) (OECD 2009). The number of people on sick leave, nevertheless, has also been rising during the years of economic growth and has, as a consequence, been an area of political interest. The cost of people on sick leave in Denmark has risen from £1.3 billion (11.3 billion DKK) in 2002 to £1.7 billion (13.8 billion DKK) in 2007 (Ministry of Employment 2008). It is particularly the number of people on sick leave lasting more than 14 weeks that has grown, which has led the Danish parliament to focus predominantly on this group and to focus on the reasons why this group often ends up not

reentering the labor market. Half of the people on sick leave suffer either from pains in the body (25%) or psychological problems (24%) (OECD 2009). From 2002 to 2007, there has been a doubling of people given early retirement because of psychological problems. It is on this background my research project was developed and funded.

According to Danish law (Sickness Benefit Act, § 7), people have a right to sick pay when they are unable to work due to illness. The law requires that the illness must undergo a ‘comprehensive assessment’, that it must be found to interfere with the person’s ability to work, and, crucially for our purposes, that it must be the patient’s ‘own illness’ (‘egen sygdom’ in Danish), that is, it must belong to (be directly suffered by) the patient, not the patient’s family, friends, or co-workers. To be eligible, one must have an ‘illness of one’s own’, as it were. Ill citizens are just like unemployed healthy citizens enrolled in job-searching program, which are specifically targeted to their perceived needs. In these Danish welfare programs, different self-regulating techniques are taught (Andersen 2003, Petersen 2005, Mik-Meyer 2006, 2009b, forthcoming, Karlsen and Villadsen 2008) so that the client/patient – sick or not – can take responsibility for his or her problems. These self-technologies have in many research projects – also outside Denmark – been related to the rise of neo-liberal policies in liberal democratic states (Dean 1998, Valverde 1998, Cruikshank 1999, Tulloch and Lupton 2005).

When professionals focus strongly, albeit in different ways, on how *the individual client/patient* can improve his or her health, and not much, for instance, on factors in society producing ill citizens, one can interpret this personal focus on the client’s/ patient’s body as an example of a political re-orientation towards a ‘self-regulating’ society – a society that governs through its appeal to the self-regulation of the individual (Foucault 1983). This individualization should not be understood as a de- politization of health issues but as an alternative politization, one that directs itself towards the individual body.

In interviews with social workers and doctors, it became evident that the process of negotiating and categorizing symptoms unfolds in two different but equally important systems: the welfare system and the medical system. As we will see in the analysis below, the process either supports the sick person's experience of being sick by bio-medically validating the illness described by the sick person or challenges the sick person's experience of being sick by reframing the described physical pain in terms of 'psychological' problems. Interestingly, however, this reframing is not carried through to the extent of constructing a 'mental illness', that is, an illness of the brain. Rather, unable to locate the pain in a particular organ, the health of the 'whole person' is called into question and the relevance (seen at least from the patient's perspective) of a holistic medical approach is born. In the welfare system and bio-medical system, though, the illness has now become a diffuse object, and the subject, accordingly, is assigned an indeterminate position.

### The welfare system

The increased focus on procedures and rules in the social worker's contact with clients in Denmark can be related to the neo-liberal management strategy of new public management (Andersen 2003, Mik-Meyer and Villadsen 2007). Social workers' encounters with clients that are sick are regulated by the Danish law on sickness benefit that sets a number of rules for their contact with the clients. In this context, the definition of illness is of great importance. When social workers call for bio-medical diagnoses that can prove that we are actually dealing with a dysfunctional organ or set of organs, then, they are essentially enforcing the law in this area, and when social workers focus exclusively on the sick person's physical body and not on a series of possibly stressful situations in the sick person's life, this too can be traced back to the stipulations of the law. The narrow definition of disease in terms of some specific thing that is wrong with an individual body, then, simply reflects the legislation that is applied by social workers. According to the law, disease is a



personal event that can be evaluated bio-medically in the patient's body. Patients, again, are expected to 'own' their illness.

This creates a recurring problem for social workers. The task of the social worker is to match a claimed inability to work with a medical diagnosis that not only explains it but also assigns it unequivocally to the patient. The more general aim is to move the client from the category of merely 'feeling ill' to that of really 'being sick', but in the lack of a medical diagnosis (i.e., a description of the illness in terms that are tractable to the bio-medical discourse), the social worker is unable to constitute the client's body as the deserving subject of sickness benefits. 'As a counselor', one social worker told me:

You are in a difficult situation, because these people have some pain, although the pain cannot be medically documented. You would of course like to help them, but you also have a law that says that if you do not have a [bio-medical] diagnosis, we can deal with, well then we do not really believe fully in what you say.

The demand of a formal diagnosis fosters a suspicious attitude, which leads clients with CWP to 'fear' their encounters with the welfare system, as a social worker puts it. In the first meeting with social workers, clients worry, according to another social worker, that:

They will not be understood, because they do not have a diagnosis, so they want a diagnosis, so I will know they are (really) sick ... The first meeting becomes a situation in which the client tries to convince me that she is sick and that she has the symptoms that she describes.

Having the sick identity validated by the social workers becomes an important goal for clients suffering from CWP. This validation will clarify the economic situation of the client, just as the validation will be helpful for the client's ability to uphold the identity as sick in his or her social life (spouses, friends, family, colleagues, etc.).

'Even though it's our job to help these clients,' a social worker explains, 'we are still authorities as well and we need to employ the law, and the law is not made for this particular group. This particular group does not in any way fit the boxes that the law has made.' According to a different social worker there is 'a search for diagnosis in this system' so that the legal basis for sick leave can be complied with. 'We will not accept that there is no diagnosis, that there is nothing objective to be found ... we want proof that they are sick', as a social worker puts it. This specific understanding can be related to the social worker's particular roles related to the present legislation here explained by a social worker: 'The legislation suggests that in order for you to be sick so that you can get reimbursement from your employer there must be a documented disorder. That is how it works.' The search for diagnoses, thus, is built into the welfare system through legislation and may paradoxically lead to an increasingly unclear process for the client. Of course, this is the opposite of what was intended, as one social worker explains:

When they go through such a process, you know, having been to a psychiatrist, a rheumatologist, an orthopedic surgeon ... they have been so many places and nobody can agree on what the problem is, well, their situation cannot be said to be better defined, can it?

A common attitude among social workers is that clients that are on sick leave without a proper biomedical diagnosis suffer from merely 'psychological' problems. Two social workers (A and B) describe clients in the following way:

A: I don't call them 'whiners', that is not how I see them, but I really do not think they are happy with themselves, because their lives have been a struggle, and I think they are stuck with a problematical image, because what else can they do?

B: I think they have a kind of life crisis, if you can say that. They are experiencing a crisis in their lives, which they don't know how to handle.

A description like this, which focuses on the psychological aspects of the clients' lives, and which constitutes a challenge to the clients' focus on physical, bodily problems, is very common among social workers. Social workers understand it as their job to make clients who cannot get their symptoms supported by a bio-medical diagnosis 'realize that they may not be sick at all' and to understand that all they need is to regain control of their lives and develop a more responsible attitude.

In the social workers' talk about this specific group, one gets a very clear image that this group sees these clients as individuals whose main problem is that they do not take charge of their own lives and are, in general, irresponsible in their daily actions. This is, of course, an evaluation that departs from the viewpoint of a professional group that over the years has been more and more regulated by legislation and other well-defined procedures for contact between client and system (Mik-Meyer and Villadsen 2007). Social workers also complain about the many phone calls from clients who go on inventing new diseases. As a social worker explains about a particular client:

There is not a single place in her body she feels all right, but she can work 37 hours in a rehabilitation center, though not without hurting all over. And there is no bio-medical

evidence that the symptoms she describes are actually there. So I think that it's probably in her mind.

The declining frequency of specific diagnoses, such as generalized rheumatism, whiplash injuries, chronic fatigue syndrome, and burnout, is taken to confirm this attitude. Social workers see the reduced rates as merely a change of names of conditions of clients who they assume are ultimately, or 'really,' just psychologically weak, not in control of their lives. Normally they are described with words like 'depressed' or 'stressed,' or with a combination of these, or in more ordinary terms that emphasize a general, everyday condition. 'They are just tired,' as one social worker puts it, 'that goes for "stress-depression" too. They are tired. They have no energy left. That's what is wrong with them.'

Another central point of the law is the labor market. Many social workers have adopted a language that implies that the best strategy for becoming well and staying healthy is to get reattached to the labor market. This type of language centers on concepts like 'being active,' 'demonstrating will power' and 'regaining control.' The strong focus on the labor market might relate to the political development of programs for the unemployed that we have witnessed in the Danish society since 1990s. The labor market has been a significant focal point for politicians resulting in a large industry of so-called activation programs for the unemployed and has as such made the labor market an important focal point for social workers also. The relation to relevant legislation is explained by a social worker: 'Okay,' she says, 'we have a law that works in a certain way; [it tells us that] our goal is to focus on their work situation. That makes things easier for us.' A common goal among social workers is, accordingly, to provide evidence for why people on sick leave are unable to work. Evidence is translated into bio-medical diagnoses that can serve as a proof that the person in question is in fact ill. Despite the fact that most social workers describe disease as

a general concept that may define many illnesses and types of suffering, they cannot act upon this generalized perception when deciding whether a person is entitled to sick pay or not. They have to act within the legislative framework and with a much slimmer concept of disease, that is, one that equates disease with distinct dysfunctions in the physical body. These dysfunctions, in turn, must be associated with practical incapacities, that is, the inability to work.

This narrow concept of disease is actually a departure from a professional ideal of social workers when they describe their work. They would normally take 'the complete individual situation' into account, and by getting diverted into hunting for diagnoses to satisfy the terms of the law and dominant political discourses in society that equates inability to work with bio-medically diagnosed illnesses, social workers not only work counter to their own professional ideals, they also inadvertently give doctors greater authority and power. Doctors are the only professionals who can supply clients with bio-medical diagnoses and in this way turn them into patients who are, properly speaking (or, simply, legally), sick. A diagnosis allows social workers to work efficiently with clients (now patients), and it also transforms clients (viewed as inactive, lacking control and will, untrustworthy) into patients (viewed as sick and trustworthy). It is clear that the negotiation that determines whether or not a client is 'sick' is a highly political process that involves a number of structural elements. But while dominant discourses on health and illnesses, as well as the educational backgrounds of the professional groups involved, would normally be assumed to carry the day in the struggle over categories, it appears here to be dominated almost entirely by the stipulations of the law, which assigns a prominent role to doctors. I will now turn to the question of how doctors respond to the power given to them by social workers and the welfare system.

### The medical categorization practice

Chronic widespread pain or medically unexplained symptoms play a role not only in the welfare system but also in the medical system (Rief and Broadbent 2007, p. 822). From my interviews, however, it is very clear that doctors do not feel particularly restricted by the letter of the law. This professional group is mindful of the focus on bio-medical diagnoses in the welfare system (on which their patients depend), and some doctors also explain that they sometimes opt to give particular patients the diagnosis ‘depression,’ precisely because, unlike ‘stress,’ it is a bio-medical description that will give the patient the status they need in the welfare system. The strong position of doctors in a bio-medical discourse, which is upheld in the legislative framework regulating the area of sickness benefits, provides doctors the ability to resist and – one could even say – manipulate the law. By having the power to label patient’s illnesses with bio-medical diagnosis even though the patient’s symptoms might not back up the label chosen, doctors can define the treatment plan they find appropriate. In this way, doctors conceal their resistance to the law through acts, that can be seen as upholding the law.

A widespread attitude among doctors is that patients with diffuse pain are ill whether a diagnosis can be provided or not. Though they believe that holding a job is often healthy for a sick person, most doctors see sick leave as a sometimes necessary break from work. From the doctors’ point of view, in other words, it is legitimate to be sick, even if there is no bio-medical diagnosis to describe the symptoms. The doctors, thus, apply a broader definition of ‘sickness’ than the social workers (who rely mainly on the definition that is found in the legislation). While the social worker distinguishes ‘real’ sickness from ‘psychological’ problems, the doctor includes the latter in the definition of the former. Doctors do stress the need for patients to attend scheduled meetings with their doctor, but besides this, and a concern to treat the patient and identify symptoms that might indicate a serious illness, there are few criteria to determine whether a person is rightfully ill.

Danish law concerning people on sick leave, in other words, does not restrict doctors in their daily contact with this group of patients in the same way it restricts social workers.

The doctor is normally the first professional that a patient suffering from CWP encounters. At this meeting, the doctor will give the patient a medical certificate that defines him or her as ill. For doctors, the result of this meeting will usually not be an accurate bio-medical diagnosis. From a medical viewpoint, a patient is sick if he or she cannot perform his or her normal daily duties. A doctor explains:

When you ask me what the criterion for sick leave without a diagnosis is, then the criterion is a functional one, and that does not necessarily mean a bio-medical diagnosis. The criterion is that they cannot act as they are accustomed to acting, and I have to believe that to be true.

Despite doctors usually work with bio-medical diagnoses and diagnostic tools, diagnostic tests and objectivity are replaced with trust and confidence with this group of patients, fostering a different kind of encounter. As in the case of social workers, this sets up a tension in the self-image of the professional doctor. Here explained by two doctors:

Benedict: I think this patient group is difficult to grasp, because we must give an objective assessment of their situation. And when there is a discrepancy between the patient's perceived symptoms and our objective findings, it becomes difficult. Should we act as an advocate for the patient, or for the municipal authorities, or what? The ideal of objectivity becomes hard to realize. Because you can only say: 'The patient will have pain sitting

down, going to school, standing up as a cafeteria worker or something.’

It is subjective; you cannot be objective.

Charlotte: You have to take what the patient says at face value.

Benedict: Well, it’s what the patient says is wrong with her that matters, even though we know she recently worked a 37-hour/week job. I think it is difficult to comment on their description. We are doing our best of course.

Charlotte: It is indeed a balancing act for us because those who think it’s great to go on sick leave when it is not reasonable, they should not go on sick leave. But those who are sick should be able to go on sick leave.

In Benedict’s words, the doctor’s job becomes difficult when there is a discrepancy between the medical examination and the patient’s description. The ideal of objectivity is challenged. One doctor puts it this way: ‘My job is to try to diagnose and treat. Categorize, put their pains into boxes.’ Or as another doctor explains:

I am trained for success. I am schooled to treat the broken leg: I put it together ... Or the one with cardiac arrest: I make him well again. And their family brings chocolate and flowers for me ... Success is when we cure people and they do not come back.



It is hard to play the usual part in a ‘success story’ with this group of patients, however. They are hard to ‘cure’ and they do come back, which explains why many doctors find working with this group demanding. ‘This group can really put a doctor to work,’ as one doctor says. They are difficult or impossible to cure, the treatment options are often inadequate or absent, and they require a lot of energy and time.

Nevertheless, many doctors share the opinion that even though the group is challenging, one must ‘take them seriously, because one is always afraid to miss somatic illness. ‘We are always afraid that we may have overlooked something,’ as one doctor says. The doctors’ role changes from diagnosing and curing to supporting, guiding, and ruling out serious illness. The professional basis of objective assessments as the most important part of a doctor’s work is expanded to include elements such as making a relationship of trust with patients. Many doctors see this new role as the opposite of the role of social workers. The doctors become the patients’ savior in their ‘struggle against the welfare system’, as one doctor puts it. Or in the words of another doctor: ‘We tell the patients that we are cooperating with them: we are their man, we are not the government’s man, the municipality’s man, or the employer’s. We are theirs.’ Or as yet another doctor explains: ‘Our role is to protect them. Quite simply. We protect them against pressure from the welfare system.’

Ironically, the doctors protect these patients from the legislation that takes its departure from the bio-medical discourse. Doctors see themselves as ‘the safety net’ for this group of patients. One doctor thinks that social workers are ‘caught between the law and the client – between the Danish parliament on one side and the social client on the other’. The doctor’s position, as one of them explains, is that ‘we cannot say “you are a hypochondriac!” We can’t. We have to get this patient group to cope with their situation.’

Despite the fact that the law (and, consequently, social workers) give all power to the bio-medical discourse in defining what constitutes an illness, we see how doctors – the prime actors in

reproducing and defining the bio-medical discourse – decide to found their encounter with this particular group of patients using a social–psychological discourse where trustworthiness becomes more important than measuring symptoms bio-medically. But because doctors represent the bio-medical discourse, they still hold a powerful position in the negotiation of sick identity. Thus despite the fact that doctors might not define sickness using techniques from the bio-medical discourse (but still choose to validate the illness described by the patients), the fact that they represent the bio-medical discourse makes their judgment of whether a person is ill or not more accurate than the social workers’ and patients’ own descriptions.

Doctors and social workers appear to swap roles when dealing with people with CWP. Doctors may employ a broader concept of illness including social factors such as life-crises, stressful psychosocial conditions of patients, etc., while social workers, because of the legislation that frames their work, use a much narrower concept of illness, equating it with bio-medical problems in the individual client’s body. This narrow concept works opposite to a professional ideal among social workers, which demands consideration of the social situation of clients in need of help.

Many of the clients’/patients’ stories reveal how the social context, structural, regulative elements in their encounter with either social workers or doctors influence whether their experience of sickness can be validated externally or not. Viewed from the sick person’s perspective, it is not enough to be identified as a CWP sufferer by the social worker if their doctor does not validate the illness in bio-medical terms. The symptoms need to be re-described in a bio-medical diagnosis in order to be recognized by the welfare system, which allocates sickness benefits. If you do not succeed in having your own illness validated bio-medically then you are not really sick and, consequently, not eligible for welfare benefits. Although some diagnoses (like depression) are not popular among chronic pain sufferers because of the connotations of a problematic psychological

situation, sick persons may nevertheless wish to receive these diagnoses in order to secure understanding from their social surroundings and economic benefits from the welfare system.

Receiving a bio-medical diagnosis provides a useful explanation for the sick person. But it also has the power to define the person who is diagnosed, despite the fact that the new identity can be in conflict with the person's self-perceived identity. The lack of an important identity marker one could say, is worse than receiving a diagnosis of an illness. Here exemplified by a woman:

I am actually hoping ... well, I am not hoping that I have arthritis ... but on the other hand if they say it is arthritis then I almost think it could be cool because then I have a real diagnosis. It sounds completely stupid to hope for an illness, and as I said I don't really hope either, but it is still ... well then I would have a real diagnosis and that would be sufficient for my case to develop and for me to get on in life.

As this quotation exemplifies, clients/patients are well aware of how important bio-medical diagnosis – or their doctor's validation – is for external validation in the welfare system.

## DISCUSSION

In modern, neo-liberal societies, such as Denmark's, both social welfare and medical treatment are provided in the context of assumptions about the need for individuals to 'take ownership' of their problems. Therefore, sickness benefits are given to people who suffer from their 'own illnesses,' not to those whose entire bodies are suffused with symptoms, people who have 'illness of the whole person,' people, as some have said, whose 'lives hurt' (Ehlers 2002). In these cases, medical science registers 'diffuse' or 'widespread' pains that remain 'unexplained,' and the welfare system shunts the patients into a group of clients with (likewise undiagnosed) 'psychological' problems.

(This can explain the growing number of patients' associations targeted at specific exotic illnesses as described in this article and the growing field of holistic medicine.)

In these situations, power can be registered as dominant discourse in which certain acts and understandings (produced by the legislation, educational background of staff, particular social roles, etc.) modify and shape other acts and understanding (Foucault 1983). The paper's three agent groups – doctors, social workers, and clients/patients – occupy social roles that I found existed in a relationship of domination, especially to structural elements such as legislation, but also the bio-medical discourse on what it takes to be genuinely sick. Even though I found that all three agents groups – for different reasons – opposed the logic of the bio-medical discourse's proper diagnosis and the dominant individualization in western societies that locates illness in the physical body, all three groups still reproduce, as a response to legislative demand, these discourses through the creation and reproduction of the social figure 'the genuinely sick person.' Such people have illnesses of their own; they have appropriated their disease, we might say; or, better, they have an appropriate disease.

The diagnosis of diffuse pains is clearly part of 'the conduct of conduct' (Foucault 1983). The appropriate understanding of a sick person is shaped by doctors and social workers and accepted and reproduced by clients/patients, doctors, and social workers. Power is therefore not processes of confrontation and/or domination (how A dominates B, see Dahl 1957); power can be seen in how the acts of individuals or groups are voluntarily governed by other individuals or groups, or even by themselves (Foucault 1983). Power is transmitted through acts that try to shape another person or group's acts or their view of themselves.

Surprisingly, perhaps, I found that structural elements, such as the law regulating this area, almost ruled out the development of strong professionally founded independent discourses among social workers on what it takes to be genuinely sick, which could be used in the social workers'

meeting with clients. Power in the name of structure thus seems still to bear some analytical weight when understanding peoples' contradictory actions. I found that the discourses on neo-liberalism and bio-medicine that places the individual and the individual body in the forefront (Rose 1999, Novas and Rose 2000, Dean 2002) permeate legislation in the local practices in social workers' and doctors' encounters with the client/patient. I found that doctors, who are also governed by the Hippocratic Oath, accepted a patient's experience of being ill even though this experience could not be validated bio-medically. The social role of doctors as representatives of bio-medical discourse gave them a powerful position or greater authority in the welfare system. Even when doctors' acts did not stem from medical logic, they were still empowered by the bio-medical discourse.

Many studies (e.g., Goffman 1990, Becker 1997) have showed that diagnosing illnesses, and by this means providing individuals with names and labels for use in social life, is an instrument of power for professionals such as doctors and social workers. I have tried to demonstrate that withholding a diagnosis also constitutes an act of power, not least because of the general mistrust generated in the welfare system by anyone lacking a bio-medical diagnosis (and still claiming to be sick). This particular group of patients is constructed, understood, and acted upon differently in the two systems I have focused on in this paper. The clients suffering from CWP are positioned in the welfare system as persons that social workers should not (necessarily) trust and take seriously, whereas the same group in the medical system is positioned as persons that doctors can trust and take seriously. One might argue that social workers' less formal power or less authority (than doctors) makes them more suspicious of clients' stories about problematic, painful bodies, and by contrast, the formal power/authority doctors hold gives doctors the ability to create positions of trust within their encounter with patients suffering from the same diffuse pains in the body (and doctors' strong authority also gives this group the ability to bend or even manipulate the law).

If your illness cannot be documented bio-medically in your body – then your social role as an ill person cannot be validated. Ultimately, your existence as a person is threatened. Furthermore, on the standard neo-liberal assumptions, backed up by current Danish legislation, this is ultimately your problem: you must appropriate your symptoms; you must make your illness your own. These citizens cannot count on welfare benefits from the state but can hope for compassion and pity from their surroundings. Or they can turn towards the growing area of holistic medicine for which they seem to fit perfectly:

Holistic Health is actually an approach to life. Rather than focusing on illness or specific parts of the body, this ancient approach to health considers the whole person and how he or she interacts with his or her environment ... With Holistic Health people accept responsibility for their own level of well-being, and everyday choices are used to take charge of one's own health. (Quote from Suzan Walter, President for American Holistic Health Association, Holistic Health. Available from: <http://www.ahha.org/rosen.htm> [Accessed 10 March 2010])

As we can see, the neo-liberal assumption of taking ownership and responsibility flourishes in holistic medicine as well. As the quotation illustrates: to become a whole person in holistic health one needs to accept responsibility for one's well-being. Michel Foucault would probably also have recognized the salience of holistic medicine's social figure of the whole person accepting responsibility for his/her own health resembling Kang's (2003) concept of 'an illness of the whole person'.

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