

# The role of chronic pain and suffering in contemporary society

Tidsskrift for Forskning i Sygdom og Samfund

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# Tidsskrift for Forskning i Sygdom og Samfund

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## Aims and scopes

*The Journal for Research in Sickness and Society* is an interdisciplinary journal which has a theoretical background in medical anthropology. The aim and purpose of the journal is to promote and develop research in the borderland between the health sciences and the humanities/the social sciences. The goal of the journal is to function as a forum in which these disciplines may meet and inspire each other – epistemologically, methodologically and theoretically. The journal conveys the debate and theoretical development which takes place in the growing collaboration and research initiatives emerging from this borderland. The journal addresses all with an interest in research in sickness and society and especially health professionals working with education and/or research in interdisciplinary institutions.

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# The normative and epistemological status of pain experiences in modern health care

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*This article explores the concept of 'pain' and the relation between abstract, detached knowledge and patient experiences and 'first person perspectives'. Pain can be handled as the correlate of a neurological finding (for example in a professional practice) and as an experience in a patient's life. Sometimes patients articulate experiences impossible to link to an objective trace. In such situations it is often claimed that we are left with a choice between dealing with pain and suffering as abstract, detached public conceptions or as private inaccessible entities. In this paper I argue that this is an unappetizing choice, and that we can develop a better understanding of 'first person perspectives' if we look at them in the light of contexts, stories and practices regulated by public exemplars. Discourses for handling pain as a phenomenon in a person's life exist, and it is an epistemological as well as a normative problem if such perspectives are not recognized. The argument is elaborated through a discussion of, amongst others, Martha Nussbaum, Marx Wartofsky, Amartya Sen, and Ludwig Wittgenstein.*

## Introduction

In contemporary clinic, understanding and dealing with concrete situated, local standpoints and knowledge are both necessary and underconceptualized. As clinicians turn increasingly to evidence-based medicine (EBM) to improve medical practices (moved by both scientific arguments and the exogenous pressure of policymakers in the public and private sphere), the need to conceptualize and understand local standpoints is even more pressing. Since EBM is especially concerned with clinicians testing their decisions against state-of-the-art testing of therapies that happens on an international scale, the threat arises that local standpoints will be swept away by a 'cookbook' approach to medicine. This would surely not lead to best practice health care.

Scientific knowledge is of course a crucial element in handling clinical problems in modern medicine. However, some interpretations of EBM-like strategies associate up-to-date scientific clinical practice with suspicion about concrete situated perspectives, which is conflated with unsupported clinical judgement. And it is true that particular standpoints and perspectives could be based on interests, belief, opinion, and bias that are resistant to testing. If the right knowledge is applied, according to EBM principles, then our practices will be improved (Schwandt, 2005: 97) by the test of better outcomes. However, I share Thomas Schwandt's worry:

What I worry about is that science-based or evidence-based approaches to practice are too readily becoming an ideology that aims to instill scientific rationality as authoritative for everyday practice, that threatens to eclipse practical knowledge and reasoning, and that comes dangerously close to regarding the practitioner as a judgmental dunce, who if left to his or her own way of doing things will inevitably be inefficient, ineffective, and squander precious social resources. We are at risk in believing in a false dichotomy: that the only legitimate knowledge for practice is scientific, for all else is unreliable intuition, habit, custom, or mere belief (Schwandt, 2005: 99).

The problem of situated and local knowledge has been one of the most intensively discussed problems in evidence-based medicine (Greenhalgh, 2002). A common EBM move is to claim that, by some yet undeveloped calculus, the skills and the doctor's experience must be added to scientific knowledge and taken into account in making therapeutic decisions (Sackett et al., 1996).

Yet this suggestion, which is not only vague but seems to operate as an afterthought in EBM-influenced protocols, is not just a problem relative to the diminishment of the respect one should have for the professional's experiences and judgement, but seems, as well, to threaten another aspect of contemporary health care practice: respect for the contribution of the patient's standpoints and perspectives (Juul Jensen, 2007). The latter is, according to Richard Horton (2003), one of the most important problems in modern medicine. While the institutional understanding of basic disease entities and the use of objective quantitative methods, particularly random testing, may have grounded clinical practice in science, there is (according to Horton) some reason to suspect that this has come at the cost of encouraging medicine to backslide into an old authoritarian pattern of disrespecting the perspectives of patients. From the point of view of rational clinical practice, can the patient, emotionally fraught, in pain, and heavily invested in his or her attitudes towards medical conditions, really be trusted to direct the course of their therapy? Are they even telling the truth about their health condition?

Modern health care thus faces a profound normative and epistemological challenge. Can the effort to improve abstract and detached knowledge be synthesized with recognizing and respecting concrete and particular perspectives, such as those expressed by the clinician and the patient? In this paper I discuss the uneasiness and suspicion in the EBM movement about particular perspectives. I claim that it is closely linked to the epistemological model of monological knowledge dominant in Western epistemology. There is a widespread tendency to undervalue first person perspectives (the way a condition is perceived, experienced, and understood from 'my' perspective in contrast to an external or third person perspective) in terms of treating them as an inner private mental entity, without real public status. If the search for the best practice relies on a statistical testing basis, how can the EBM clinician not feel uneasy about the untested and untestable particular standpoints and experiences of the patient? If experiences or first person perspectives are just an inner private entity, how can they then be trusted?

In this paper I will challenge this model by emphasizing the contribution that can be made to the health care decision, to the whole course of therapy, and to improving quality of life results by particular situational standpoints and perspectives. I will argue that first person perspectives and experiences need not be seen entirely as private and mental events, and that this model is historically linked to empiricism and positivism that has been largely replaced in the scientific worldview. Instead, we can see first person perspectives in terms of a linguistic practical situated context, which gives us a better understanding of how they function.

Different kinds of first person experiences will be included in the paper, but the main focus will be on 'pain' due to the large role it plays in the literature and its illustrative value in delineating the challenges we are facing.

## Approach

This illustrates why it is necessary to put contemporary health care discourse in relation to philosophical analysis. It is primarily by addressing the philosophical premises, presuppositions, and implications of EBM and health care reforms that we see why medicine holds a special social place, straddling the gap between abstract scientific knowledge and the particular perspectives of all non-trained agents, such as patients. Unfortunately, philosophy of medicine, especially applied ethics where different philosophical positions (deontology, utilitarianism, etc.) are applied to problems in medicine, does not get to the heart of health care practices. Indeed, from the point of view of medicine, the subdisciplinary boundaries in philosophy – between, say, epistemology and ethics – seem arbitrary and limited.

The line of thought encompassed by philosophy of practice is not just a matter of applying philosophical positions and concepts developed outside practice, but develops concepts that emerge from studying specific practices, with an emphasis on how presuppositions and concepts are instantiated in these contexts. The tradition is inspired by Aristotelian practical reason and the late Wittgenstein; its contemporary thinkers include Marx Wartofsky, Martha Nussbaum, and Amartya Sen. It is to this group I turn in this paper, since among them is a sense that the orthodox approach of applied ethics does not give us enough scope to study the philosophical problems in practices as they emerge in real time. Moreover, tools have been developed in this tradition to clarify first person experiences and perspectives.

## Pain and suffering – a human tragedy?

In the Greek tragedy *Trachinian Women* by Sophocles, which is based on Heracles's tragic death from a robe woven by Heracles's wife, Deianira, which she unwittingly poisoned with the centaur Nessus's blood. Hyllus, Heracles son, in describing Heracles's agonizing end, states that Zeus and the other gods lack understanding of the way humans feel under these conditions. The gods live in a transcendent and abstract world and are therefore unable to understand the struggles and misery that are often part of a human life.

Hyllus: Take him up, servants, showing your great fellow-thought-and-feeling with me concerning these events, and knowing the great lack-of-thought-and-feeling of the gods concerning the events that have taken place – they who, having engendered us and calling themselves our fathers have overseen these sufferings.

Chorus: Do not you, young woman, remain at home – for you have seen great recent deaths, you have seen many newly inflicted sufferings, and there is not one of these things that is not Zeus (Quote from Nussbaum, 1990: 375).

The distance between the gods, who live in a different and detached world, and the mortals, who are finite, is most poignantly symbolized by pain. The gods cannot suffer, while, by their physical constitution, mortals are doomed to. Given this gap of physical sensibility, the gods are unable to really feel empathy or compassion with another person because they do not understand the human conditions of pain and misery. For this reason, gods can look unmoved upon the suffering of human beings without empathy – shared feeling. In human life, tragic events happen, but this is not part of the life of gods.

The essential difference that defines the mortal is that we are subject to pain and suffering and thus we understand these experiences. As Martha Nussbaum has argued in her interpretation of *Trachinian Women*:

Human beings are in a sense worse off than the gods because they suffer; but they also know how to deal with suffering, and their morality is a response to the fact of suffering (Nussbaum, 1990: 375).

Human life is limited; we are vulnerable, we suffer, and we feel pain, and in order to meet these challenging conditions we have developed human practices. Morality, for example, is a human response to vulnerability and mortality. Vulnerability, mortality, pain and suffering are the background against which morality makes its appeal and becomes meaningful.

There is a close link between the epistemological capability and normative reactions in this description of the human situation. Human beings are social creatures. We are involved in concrete and particular situations and relations and under these conditions we see, feel, and understand certain things, things that would be invisible if they were observed from a detached standpoint or perspective. From a 'god's eye perspective' the sociality and particularities of human life disappear. When the conditions disappear, the meaningfulness of our moral feelings and normative responses disappears as well. Observed from a 'god's' eye perspective, there can be no compassion, empathy, care, and moral feelings, since

there is no basic experience of the shared feeling – empathy – that grounds them. Nussbaum is using Sophocles’s play as an analogy of the level on which our efforts to handle pain, suffering, and human misery draws the epistemological and the normative into a close contact.

This is not to argue that moral feelings and compassion are simply our immediate or only responses to human pain and suffering. Over the course of human history other practices – notably, the techniques of medicine have been developed to handle these conditions as well. In medicine, systematic strategies and procedures are developed in order to take care of such aspects in human life. Medicine, according to Marx Wartofsky, is the most important practice in the human struggle against misery, pain, suffering, disease, and death (Wartofsky, 1976). Thus, it would be an epistemological as well as a normative problem for medical practice if it primarily perceived these conditions from a detached ‘god’s eyes perspective’ and is unable to relate to the concrete and particular conditions of human vulnerability, pain and suffering in human lives. In the words of Nussbaum:

Heavenly physics seems at least initially plausible. But medicine seems to be in its nature an engaged, immersed art, an art that works in a pragmatic partnership with those it treats. It takes very seriously their pains and pleasures, their own sense of where health and flourishing lie. Its aim is to help; that aim can never be completely separated from the patient’s own sense of the better and worse (Nussbaum, 1994: 19).

Marx Wartofsky has argued that the main tradition in Western epistemology since the seventeenth century has had a damaging effect on the doctor-patient bond and has led to scientific standards out of touch with the messiness of particular situations and particular experiences of patients that have pervaded clinical practice.

When abstract epistemological models dominate, they blur the link to the normative context of human vulnerability, weal, and woe. The problem with epistemological models of modern medicine is not just that they are abstract and detached and maybe even (without using this word) godlike, but that they tend to ignore a body of knowledge that arises out of the experience of that vulnerability that has imminent bearing on the course of any treatment. Wartofsky’s hope is for a medical practice in which knowing and caring are considered synergistically, and not as two easily separated realms (Wartofsky, 1976: 189).

This hope, however, seems utopian in light of the extensive struggles and disagreements that have defined current state of modern health care. Wartofsky wrote

before the full effect of the many different exogenous factors was felt in clinical practice, from the dominance of the pharmaceutical companies to the exigencies of political governance, the patient rights movement, the cost-benefit analyses, and, of course, the rise of EBM. Thus, the health care system has changed thoroughly at a clinical, managerial, institutional, and political level in recent years.

In consequence, the treatment of pain, suffering, and human vulnerability is determined by various factors that respond to expectations produced by different perspectives, making it difficult to locate the essential prototype of medical practice amidst this diversity of practices. The biomedical industry proffers multitudinous treatments and uses enormous sums on advertising, trying to influence the perceptions and understandings of professionals and patients. Different scientific conceptions — epidemiological, pathophysiological, genetic — contribute or compete in generating knowledge of pain and suffering. Patients articulate their conceptions and understandings in various contexts and organize networks (for example, the fibromyalgia network, pain relief network, etc.).

Instead of trying to effect reconciliation through rehabilitating a lost epistemological and normative sense of empathy in medical practice, I think it is more important to understand the different positions and perspectives struggling to define modern health care practices, most notably the patient's perspectives and standpoints.

## Epistemological models

The Editor of *The Lancet*, Richard Horton, argues that the extensive changes in modern medicine calls for a new philosophy of medical knowledge (Horton, 2003: 58). Tensions have arisen in the doctor-patient interface because doctors are encouraged to be hypersceptical about the patient's stories. Medicine has created powerful methods for acquiring scientific evidence in both the diagnostic and treatment stage, but the same effort has not been put into improving the clinical sense of evidence in the basic and structuring interaction between patients and doctors. Instead the patient's perspectives and experiences are often considered secondary and unreliable guides to diagnosis and treatment. If clinical practice is to improve, much depends on the better integration of the patient's perspectives in the clinical encounter. Horton is basically right to claim that "the consultation is a shared exchange of evidence" (Horton, 2003: 51). Too often, it is treated as a tiresome prelude to the real examination. Horton's diagnosis of the present situation is illuminative, but it is not clear what he means by a new philosophy of medical knowledge. By terming the

patients' perspectives and experiences kinds of evidence, is he elevating them to a status equal to scientific evidence in the clinical encounter? Is he suggesting that communicative skills should be developed in order to both understand the patient's narrative and to create patients who can give enriched narratives of their experience (for instance, patients who have had access to more and clearer up-to-date medical information)? It is not clear, but I do think the program of investigating the epistemology of medicine and patients' experiences and perspectives should be pursued.

### *Western Epistemology – the Inner-Outer Dichotomy*

As I pointed out in the introduction, Western epistemology has been dominated by the idea that knowledge is an inner representation of an outer reality since the early modern era. Rationalism and empiricism both accept this model, which has shaped the research project in epistemology: to describe and validate the establishment of the representation of outer reality. During springtime of early modern science, scientific breakthroughs seem to show that everyday thinking and experiences were no guide to physical reality. The heart's function is to circulate blood – not, as in popular belief, to operate as the seat of affections. Sense impressions and common beliefs were questioned as to whether they really represented outer reality, or some mix of traditional superstitions, mirages, and false conclusions. Locke, for instance, claimed that there is a distinction between primary and secondary qualities, and that primary qualities are really in the object while secondary qualities are made up in the mind. Locke's ideas exerted a tremendous influence during the Enlightenment, teaching us to regard first person accounts with some caution, in that they might involve subjective effects that could not be generalised or externalized. We think we know what the reality is, but it often turns out to be completely different from what we imagined when it is checked and inquired.

### *Experiences – caused by objective entities?*

The Lockean model can cause us some particular problems in understanding concrete particular experiences and perspectives when they intersect with our social structures. This is especially the case in medicine. Some experiences are caused by and linked to objective reality, for example in questions about illness and disease where we can trace a cause linking a specific disease entity to an experience in the mind of a patient. The cause of the experience can be located by a brain

scan, for instance, and give rise to a neurological finding. In another case, a person might have an experience, but it is impossible to link the experience to an objective trace (the chronic fatigue syndrome and fibromyalgia are examples extensively discussed). Does this mean that the patient is somehow deluded? Are we left with a private mental entity and an individual subjective experience that the person might or might not have, and where we are unable to check it and discuss it with anyone else? Is it necessary that we possess an exteriorized record that presents us with an explanation about the relation between the experience and the objective cause in order to diagnose the patient?

Values are also often interpreted with reference to the parameters of this model. They are (according to the proponents of the model) either properties in objective reality or a subjective projection upon the world. But where are they? According to, for example, John L. Mackie (1977), objective values in the real world would be queer things. They must arise within the mind and be projected upon objective reality. From this point of view, it is a small step to the argument of David L. Sackett (one of the most influential figures in evidence-based medicine) that patient preferences should be included in the clinical decision. Sackett's choice of the word 'preference' seems to indicate this reduction of the patient's perspective to that of the consumer of medical goods. Preferences are closely associated with utilitarian conceptions of value. Within this framework, preferences and values are considered a kind of private, subjective projection on the objective world.

The above account compresses a long history into a brief number of steps. First comes the conception of the first person perspective and experience as determined by and expression of private mental entities. Then comes an uneasiness and suspicion about basing material behaviour involving chemistry and physiology upon the subjective notions upheld by these perspectives. As a compromise, it is claimed that patients' subjective perspectives should be recognized and accepted, but they will continue to be strange phenomena, and discussions will continue about whether patients' experiences and perspectives are objective or private projections. What matters, finally, is that they are preferences, much like consumer preferences in other markets. In this way, the model ends up blocking the possibility of developing clinical practice as a shared exchange of evidence.

### *Position-dependency*

In the Wittgensteinian and neo-Aristotelian line of thought, this Lockean model is challenged. Rather, our perspectives are linked to the fact that we are engaged

in activities, in forms of life, and in social and linguistic practices. Instead of understanding human knowledge as a representation in the mind of an outer reality, the focus in the Wittgensteinian and neo-Aristotelian line of thought is on the way practical knowledge is constituted in different activities and practices.

Position-dependency is an important tool in the development of these analytical strategies. It has, for example, been argued that a view is more objective if it relies less on an individual's character and position in the world (Nagel, 1986), but that we often are most interested in the way an object appears from a certain position (Sen, 2002). In scientific activities, among others, we pursue knowledge about an object or a subject from a specific position. And it is often possible by specifying parameters about location, language, etc. to make the same observation as another person would under the same conditions.

As mentioned above, the importance of understanding illness, pain, and suffering from the first person perspective is widely acknowledged. There are several aspects that detached knowledge, manifest for example in medical statistics, cannot capture. The disinterested protocol for randomized controlled trials and scientific knowledge is imposed by the criteria for a valid experiment. In order to do a scientific study we have to exclude a number of aspects and features surrounding a specific problem and study it under very specific and abstract conditions. One of the unexpected results of this experimental condition is its projection on the particular and local understandings of a specific person or community. It is another way of excluding them, for experiences are not formed in relation to empirical testing of a statistical type, but rather ad hoc or under a certain unscientific structure. Given this variance in the provenance of the two streams that join together in clinical practice, we have to understand how detached knowledge can be used in a person's life, and we need to supplement scientific knowledge with concrete local and situated perspectives.

We live our lives under certain social, cultural, linguistic, and material conditions, and these aspects importantly specify the particular standpoint and the perspective of a person. But it would be sheer romanticism to think that this is all there is to the story. These conditions may well be limiting, blinding the person about options, possibilities, and forms of life. This is Amartya Sen's insight. He discusses problems about decision-making in health policy, equity, and development, but the discussions are also relevant in relation to first person perspectives in clinical practice and other decision-making practices. Sen importantly sees that first person perspectives are malleable, that people are teachable, that we use vo-

cabularies that we have learned sometimes inexpertly, and that our abilities can improve or decay.

First person perspectives are, according to Sen, conditioned by the social experience of the person. This large fact endows these standpoints and perspectives with meaning, but these conditions might also limit the perspective of the person. If a person lives in community where the disease frequency is very high, he or she may consider symptoms and conditions as normal even though they could easily be treated and cured. Illness and suffering may be considered unavoidable because the person does not have the medical knowledge necessary to see the problem: "The dependence on contingent social experience can be a very big limitation in the epistemology of the internal view" (Sen, 2004: 266).

It is useful to begin an analysis of the health care situation by specifying the particular position occupied by the person who perceives a certain problem whether that problem is physical pain, mental distress, or fear of causing pain or distress to others. It can help us explain how an experience or perception might be objective under certain specified observational parameters and at the same time be illusory. These are, in Sen's words, 'objective illusions'. Kant, in *The Critique of the Pure Reason*, refers to the 'necessary illusion' which befalls all onlookers on the shore of the sea, where the "sea appears higher at the horizon than at the shore." This illusion "cannot be avoided" (Kant, 1998: A297).

The observation is right (under the specified parameters), but it is also obviously wrong. The belief is not just a subjective illusion, but the product of a position-dependent perspective in which one of the criteria of objectivity – substitution between observers – would fail to disperse it. Kant's sea shore illusion is easily explained by means of the properties of the light. By seeing and judging a belief, experience, and perception from a more inclusive position, we often disclose the flaw in a particular perspective by finding the conditions that make it an objective illusion (Sen, 2002).

There is for example a widespread tendency to claim that what is a normal health condition for a woman and what is a normal health condition for a man differs significantly (Sen has studied women's health in India and stresses this point). A woman living in a specific community might not see or understand that she is actually ill and that something can be done about it. Getting out of the community frame of reference might help us observe the stress of the woman's condition from another position, and as we adjust our 'gaze', we may discover, as well, the factors making it impossible for her to realize her illness.

This situation impinges on the ways we act, according to Sen. The health workers who know about treatments and potentials for the woman should enlighten her about this. They should take on the role of making her see from a different frame of reference, thus shifting her understanding of normality, health, disease, pain, and suffering. This is the path of liberation from her positional objective (but illusory) perspective.

### *Legitimate and illegitimate first person perspectives*

Even though Sen's examples come mostly from India, we can transpose the formal lesson to Western epistemological and practical contexts of clinical practice. Particular, situated, socially contextualized experiences and perspectives are the basic human material that health care deals with, and are, similarly, the starting point for its normative and epistemological projects.

But saying this, we must be well aware that this human material is not immutable, and that there is a mutual interdependence between the clinician and the patient in the course of therapy. The person who comes to the doctor with a problem comes with certain limits and blindnesses, some of which the doctor can see. The doctor's dialogic task is to show the patient these limitations, and to dispel the patient's blindness. For example, in the U.S., between the time the connection between cigarette smoking and cancer was proven epidemiologically, and the time when smoking declined, there was actually an increase in smoking. Listening to advertisements, modeling oneself on one's peers, and other kinds of social pressures made the population incautious about a habit that led to lung cancer only after decades of smoking. From 1965, when the prevalence of smoking was at 42 percent of the American population, smoking then declined to 25 percent in 1993 (Haustein, 2002: 19). During this time, the medical profession had an educational task to perform. Still, the downturn came only when the results of heavy post-war smoking fad – lung cancer and cardiac problems – spiked to a previously unknown prevalence.

How do we distinguish between situated, social, contextualized first person perspectives as a resource and as a limitation? When do they represent important and necessary epistemological knowledge and when are they illusory? When does the experience of the person give the health care professional a normative reason to act, and when should the therapeutic strategy be revised from having been grounded in a more inclusive position? Is there one single criterion that can help us make this distinction?

Pain and suffering, according to Sen, has a certain privilege in being, among all human feelings, one that should command *de facto* respect by the clinician and the health care official. Several other experiences and perspectives are affected and sometimes limited by the social conditions and experiences, but:

No mechanically observed medical statistics can provide an adequate understanding of this dimension of bad health, since pain – as Wittgenstein had noted – is a matter of self-perception. If you feel pain, you do have pain, and if you do not feel pain, then no external observer can sensibly reject the view that you do not have pain (Sen, 2004: 265).

Sen correctly points to Wittgenstein's claim here as an important transformation of the previous Lockean notion of pain that assimilated its feeling to the subject to the realm of inscrutable privacy. Skepticism about a person's pain experience is, Wittgenstein thinks, absurd for the most part. He gives an example of a person lying on the road twisting and turning. The person has been involved in an accident, and Wittgenstein argues that in this case we would not ask, or at least it would be absurd to ask, "Is this person really in pain?" The situation, the activities, the reaction tell us that this person is in pain, not the presence (or not) of a private mental entity. It is not necessary to 'see' the pain in itself (for instance, by a brain scan showing neurons firing) in order to tell whether the person is really in pain or not (Wittgenstein, 1953). Pain, according to Wittgenstein, is linked to our activities and reactions. The example is part of his famous argument against the idea of a private language where our utterances are understood as denotations of private mental entities (Wittgenstein, 1953: §§243-315).

Sen agrees with Wittgenstein, yet it is unclear whether his argument, that some first person perspectives are limited by social experience while others are informed "by knowledge to which others do not have access" (Sen, 2004: 266), is in line with Wittgensteinian thinking. Is he, after all, implying aspects of the model mentioned above?

It is not important here to decide whether Sen retains aspects of an 'older' epistemology and metaphysics or not; yet Sen's confusion concerning the genuine character of first person perspectives, and the remnant of a link to the inaccessible and private, illustrates a widespread paradox in practices and theories dealing with such perspectives. Inaccessibility is often used in arguing that they are legitimate and genuine because they are distinct from social standpoints and perspectives, yet at the same time this conception is the source of the uneasiness and suspicion aforementioned, in that what is structurally hidden can be faked. In

childhood, most of us learn the game of pretending to be hurt – and we also see actors performing as though they were hurt. Diderot in *The Paradox of Acting*, wrote:

Do not people talk in society of a man being a great actor? They do not mean that he feels, but that he excels in simulating, though he feels nothing” (Quoted from Sennett, 1977: 110).

The ability to simulate pain, to act, has more than theatrical consequences. It is, for instance, one of the constant themes in the courtroom where doctors testify in suits for damages due to injury. The paradox was the origin of Freud’s theory of neurosis, in which he dismissed the idea that neurotics were ‘faking’, instead shifting the source of the pains and conditions they felt to another realm of pain-making – that which occurs over time in relation to trauma. Even the Wittgensteinian concedes that pain behaviour can be faked. In fact, that it can be faked tells us that pain is understood under the aspect of various behaviours, gestures, and responses. Yet, this ought not to lead to a general suspicious attitude. We just have to accept the expression of pain unless we find some break in the practices that make us suspect that here we are not dealing with pain.

I wish to stress that the legitimacy of first person perspectives should not – and in fact, in ordinary life, is not - decided by using the privacy and inaccessibility of certain experiences as the sole criterion for treating them as real. This is important in order to understand first person perspectives in general, and because essential aspects of the pain experiences are lost if they are only interpreted as private mental entities.

## Pain and social experience

The idea that inaccessibility and privacy of certain first person perspectives must be respected by making a distinction between genuine and pure first person perspectives and others that are subjective, biased, impure, colored, and limited by social experience leads us down a philosophical cul de sac, I think.

Elaine Scarry argues, in her influential book about torture victims *The Body in Pain – The Making and Unmaking of the World*, that it is as an essential characteristic of pain that it is resistant to language:

...a problem that originates much less in the inflexibility of any language or in the shyness of any culture than in the rigidity of pain itself: its resistance to language

is not simply one of its incidental or accidental attributes but is essential to what it is (Scarry, 1987: 5).

Scarry's example of acute pain in torture is frightening and she may be right in this context that acute pain shatters language. Nevertheless, we need to be careful here not to confuse the inability to find a vocabulary sufficient to express the sheer intensity of the feeling with the inability to find a vocabulary to express the feeling at all.

It may be that the voice of the sufferers is numb and without life. This is how Veena Das in her empirical work describes several of the persons involved in the Partition in India in 1947 and the massacre of Sikhs in 1984. She narrates the lives of persons and communities embedded in the violence taking place in relation to these events. The persons speak, but their voices (in Stanley Cavell's suggestive phrase) are frozen (Das, 2007: 8).

However, this is not the same as arguing that "resistance to language...is essential to what it [pain] is" (Scarry, 1987: 5). According to Das, it is not an 'essential' feature of pain that it is resistant to language, but the voices of the victims freeze and they are unable to articulate their pain and suffering because of their experiences.

I want to challenge, then, the distinction between (a) health problems that persons do not see because they are necessarily limited by the limits of their social situation and (b) first person perspectives like pain and suffering where we have to rely on the patient's description of something inaccessible. This distinction cannot guide us to treat the health problems where we ought to do something, and where doing something in terms of health care is not called for. Pain and suffering are closely linked to the social experiences, as are all moods, emotions, and feelings. There are cultures, for instance, in which gender determines how the agents assess health risks and the very definition of illness. In Western culture, there has been much discussion of the 'medicalization' of 'normal' human occurrences. For instance, historians have pointed to the way menstruation has been differently treated over the past two centuries (Scrambler & Scrambler, 1993: 1-25). Or one might live in a community where one has experienced massive violence and pain, and where the voices are frozen and limiting the articulation of these problems. A community where you do not say 'ouch' or 'I am in pain' seems to be no different from a community where other aspects of first person perspectives are unarticulated, and are variants of Sen's example of women who have accepted a version of normality that makes them blind to the fact that certain of their health conditions are curable. The reverse of that is the idea that any pain – for

instance, grief at the death of a loved one – is a medical matter, to be ‘cured’ by the administration of pharmaceuticals. Inaccessibility is not a reasonable criterion for making a distinction between legitimate and illegitimate first person perspectives.

## First person perspectives - public or private?

Even though there are contexts in which the language of pain and suffering is frozen and numb, in other contexts the articulations about the experience of pain and suffering are varied and profound. For example, there are many different networks and groups in America and Europe for chronic pain sufferers. The American anthropologist Byron Good has done fieldwork among chronic pain patients and he observed how:

for many pain patients, language is far from shattered in a literal sense. Brian was frighteningly articulate, though language at times seemed inadequate to express the subtle sentient quality of his suffering (Good, 1994: 121).

This is also the fact that Wittgenstein finds both puzzling and important in his arguments against a private language. The stereotypical scene of ‘learning a language’ is one in which a parent or teacher points at an object and says the word that denotes it. We learn the name ‘table’ because we are involved in a practice wherein our parents and other persons use this word. They point at a table and say ‘table’. By learning the exemplar we learn to distinguish between tables and chairs. This seems impossible with ‘pain’. We cannot point at a ‘pain entity’, say pain, and hereby teach each other what the word means. If I twist a person’s arm in order to explain how a certain pain feels, could I then be sure that he feels the same pain? There would seem to be no certain public exemplars (Harre & Tisaw, 2005: 184).

Yet, even though it is ‘me’ that experiences a certain pain, we do share a language, and not only a verbal one but also a pictorial one (think, for instance, of Jesus on the cross, depicted hundreds of thousands of times in Western Europe) about pain conditions. We have literary genres – for instance, tragedy – that are based on shared expectations about pain. We do inform the doctor about our pain with the expectation that he will not be puzzled when we use the word. We may qualify our description of pain by explaining that it is sharp or itchy. And other persons do respond and react to other persons’ feelings. We do talk about it in publicly meaningful ways. How is this possible?

By conceptualizing the language of feelings, pains, and first person perspectives as denoting entities, states, and events in a mental immaterial world, the suspicion about the existence of these phenomena seems unavoidable. If our pain language referred to or was a denotation of private mental entities, it is hard to imagine how we would be able to learn this language. Understanding 'I am in pain' as a representation, a report, and a denotation of a pain entity in my mind is misleading. Which entities do the language denote?

It is not irrational to try to detect and localize pain in the body in order to treat it. Nor is it irrational to use a brain scan or find means of recording the neurophysiological process we think is associated with pain. But this is hardly the doctor's first response to the patient's phrase 'I am in pain'. There exists a longstanding language and discourse in which pain is understood and handled as a phenomenon in a person's life, and made sense of as part of the life of all others as well – pain has a social life. When judging or interpreting myself and my own situation, I am not engaged in a quest for the truth – whether I am in pain or not. Something other than truth is at stake here. In most cases of pain, we do not discuss with ourselves whether the pain is really there or not.

And when I say the phrase 'I am in pain' out loud, my purpose is not to alert my fellow human beings of the presence of certain 'mental entities'. A person who has been involved in a car accident might, for example, describe what happened in the accident and his experience and perspective in this situation. Furthermore, he might link these circumstances to other experiences and activities in his life. He could articulate how he normally feels and interpret the painful situation in light of these conditions. Such discourses are not just private experiences and they do depend on social experiences, practices, and narratives.

When I describe the circumstances and the situation to my family, my friends, or a network, I link my story to situations and conditions that others might be familiar with. And my condition can be understood and judged in light of such contextual circumstances and situations. They are publicly accessible exemplars that I use in understanding and explaining my condition and making it accessible to other persons as well.

When I articulate my situation in a narrative and link it to publicly accessible situations, I am presenting some facts about how it is to be me. This is, however, also a normative claim. It is the reason why I think somebody should help me. And it is the reason why I, for example, go to the doctor. I explain how I feel, how it is different from my normal condition, and how my life has changed. In such a narrative,

the epistemological and the normative dimensions are so intimately connected that separating them to an abstract rationality would result in irrational practice.

The language of pain is part of social experience, activities, and reactions. Therefore, instead of trying to detect a certain class of first person perspectives that are inaccessible and legitimate because they are untouched by social experience, we would do better – and come closer to the ordinary sense of pain in everyday life – to explain and understand the particular and concrete social practices, contexts, and communities. Certain circumstances and conditions will always limit our articulating and describing the first person perspective of our life story. What is it exactly that makes these circumstances and conditions blinding and limiting? Here, it is a good idea to have a sense of more than one community and context, in order, by comparison, to understand what limits are blinding on first person articulations in a given community. To look, for instance, at the way menstruation has been medicalized in the West, we need to see other ways in which menstruation is understood in other communities and times. To understand how a woman in a given Indian village might take a certain condition as a given instead of a correctable health risk, we need to look at communities where that condition is treated. Instead of searching for a standpoint beyond these conditions, an explanation of the specific situations and conditions is essential in determining whether it supports or limits first person perspectives.

## The McIver case

This is no easy task. In modern Western health care systems, several conflicts and struggles are present. Different methods, strategies, and perspectives clash. New technologies and biomedical therapies are developed. Drug-based therapies are promoted by laboratory medicine and the pharmaceutical industry. Patients' rights are promoted and patients demand to have a say in questions about health and disease. Patient networks, where patients collaborate with each other and sometimes with medical experts and researchers as well, are established. They fight for the needs and interests of the group.

The struggle and clash between different discourses, practices, and perspectives in modern health care sometimes make it difficult to distinguish between legitimate and illegitimate first person perspectives. Is it reasonable in contemporary Western societies to distinguish between pure first person perspectives and first person perspectives determined by social experiences, for example, tho-

se influenced by the pharmaceutical industries promotion of drug-based therapies?

The widely discussed trial against Ronald McIver is illustrative of this clash (Rosenberg, 2007). Ronald McIver worked at a pain therapy center. He administered different kinds of therapy. In his work he wrote many prescriptions for high doses of opioid drugs like OxyContin. McIver was an unusually aggressive pain doctor. He recommended therapy with high doses of drugs. Some of his patients became addicted to the medicine, and some of them even started selling the pills. And furthermore, one of McIver's patients died. He had great amounts of opioids in his blood; opioids prescribed by McIver. McIver was charged and convicted for drug distribution.

Even though McIver was an unusually aggressive pain doctor, he did not sell drugs. He prescribed higher doses than other pain doctors, but does this make him a criminal or is he just meeting the 'needs' of his patients?

Some of McIver's patients confessed that they cheated him to get more drugs than they needed in order to sell them. Yet, other patients said, during the trial, that McIver was the only doctor who understood their needs and how it is to be a chronic pain patient, and he was the only doctor who ever brought them relief (Rosenberg, 2007).

The case has led to a fiery debate. Was he an innocent doctor cheated by his patients? Was he the only person understanding the patients and their pain and suffering? Was he a simple criminal?

This is of course a tragic story. Yet, it is not only a story about an immoral doctor, about patients cheating, about patients taking advantage of a naive and trustful doctor. It is also a story about the difficulties for medical doctors, health care managers, and patients in reaching an agreement and common understanding in a specific situation.

Does this story tell us that because pain is private, we will forever be uncertain whether a patient is telling the truth or not? The strong conclusion would be that we cannot rely on first person perspectives, and thus must disregard the pain reports of the patient. But this seems like an over-excited response to the fact that it is possible to find patients who cheat, who are strategic and abuse the doctor's trust – just as it is possible to find persons in the scientific community who cheat. However, the facts in the McIver case do not support a general suspicious attitude towards patients' perspectives and pain experiences, but point, instead, in the other direction. A report gains its sense only in light of the patient's history, their life, and his practices. We want to know what the specific situation of this person

is like, and how it has changed over time. Is there information available in the patient narrative? Are there signs telling us that the patient is selling the drugs? It also illustrates that although, as claimed in this paper, first person perspectives are an important resource in clinical decision making, they are influenced by numerous discourses. In the media sphere in which news and PR releases are often conflated, information about new drugs is being broadcast all the time, making an impact on the perceptions of the patients and the doctors. Patients get information from different sources (the internet, relatives, professionals, etc.). It is only through concrete analysis by the patients, doctors, and health care researchers that the constitution of the specific perspective can be judged.

## Conclusion

In theory and practice we often face a choice between taking an abstract and detached perspective or observing as participants in an ongoing particular and situated perspective. The recognition of first person perspectives in relation to health care practice and theory is an important epistemological and normative challenge. The analytical model of position-dependency is a better model of understanding the therapeutic situation inasmuch as it allows that certain phenomena are only accessible from certain perspectives. On the other hand, this does not lead to the conclusion that privacy and inaccessibility to other persons characterize the phenomena referred to in genuine first person perspectives. We need to understand the practices and circumstances within which the patient and the clinician are both participants. We should see it both as an enabler, helping persons give voice to their experiences, and a limiter, censoring and filtering experiences and understandings. From this perspective, there is convergence between private and public perspectives, which will mean that whether social experiences are limiting or enabling for patient perceptions and first person perspectives can only be seen after making a thorough analysis of the specific practices and contexts involved.

Pain is handled and treated as an entity in professional practices: it is understood as the correlate of a neurological finding or a picture in a brain scan. However, long before this technology was available, there was pain. As long as humans have existed as language-using animals, they have developed discourses for handling and treating pain as a phenomenon in a person's life. It is an act of misprision to reduce pain to a private experience, when it is a socially mediated one. I articulate and explain the conditions and circumstances of my experience. If we do not recognize such perspectives, it is an epistemological as well as a normative problem.

This is not the same as arguing for a naïve acceptance of the patient's word. Diderot's paradox of the actor is true for all people who are familiar with a language game. Faking pain is possible – but the possibility is grounded in the fact that pain is subject to certain expectations, exhibits itself in certain behaviors, etc. The existence of counterfeits of pain should not move us to find some more 'objective' criterion of pain, but to pay closer attention to the life history in which the pain is manifest. Sometimes they cheat (as like in the McIver case) and sometimes their perspectives are blinded by their social experiences. Yet, first person perspectives are not inscrutable. They are neither totally private nor, in the social sense, totally inaccessible. Explanation and understanding of specific practices, activities, and reactions are a promising path for treating and understanding pain.

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