

The role of chronic pain and suffering in contemporary society

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Mette Bech Risør (ansv.), Forsningsklinikken for Funktionelle Lidelser, Århus Sygehus
Torsten Risør, Forskningsenheden for Almen Praksis, Aarhus Universitet
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Ann Dorrit Guassora, Forskningsenheden for Almen Praksis, Københavns Universitet
Susanne Reventlow, Forskningsenheden for Almen Praksis, Københavns Universitet

Gæsteredaktør:

Marie Østergaard Møller, Department of Political Science, Aarhus University
Lise Kirstine Gormsen, Danish Pain Research Center, Aarhus University Hospital

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Formål:

Tidsskrift for Forskning i Sygdom og Samfund er et tværfagligt tidsskrift, der tager udgangspunkt i medicinsk antropologi. Tidsskriftet har til formål at fremme og udvikle den forskning, der ligger i grænsefeltet mellem sundhedsvidenskab og humaniora/samfundsvidenskab. Tidsskriftets målsætning er at fungere som et forum, hvor disse fag kan mødes og inspirere hinanden – epistemologisk, metodisk og teoretisk – i forskellige forskningssammenhænge. Tidsskriftet formidler den debat og teoretiske udvikling, der foregår i de voksende faglige samarbejds- og forskningsinitiativer, der udspringer af dette grænsefelt. Tidsskriftet henvender sig til alle med interesse for forskning i sygdom og samfund og i særlig grad til sundhedsmedarbejdere i forsknings- og undervisningssammenhæng med forbindelse til tværfaglige miljøer.

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.

Contents

Marie Østergaard Møller & Lise Kirstine Gormsen

Introduction 5

Peter Conrad & Vanessa Lopes Muñoz

The medicalization of chronic pain 13

Lise Kirstine Gormsen

Pain as an object of research, treatment, and decision-making 25

Marie Østergaard Møller

Stereotyped perceptions of chronic pain 33

Claus D. Hansen

Making a virtue of sickness presence - reflections on the necessities of everyday workplace 'suffering' 69

Jane Ege Møller

Lack of motivation as suffering 89

Keld Thorgaard

The normative and epistemological status of pain experiences in modern health care 109

Anders Dræby Sørensen

The paradox of modern suffering 131

Lars Thorup Larsen

The circular structure of policy failure and learning 161

Abstracts på dansk 195

Authors 201

Vejledning til bidrag 205

Beskrivelse af nummer 14 208

The role of chronic pain and suffering in contemporary society

Marie Østergaard Møller and Lise Kirstine Gormsen

Department of Political Science, Aarhus University.
Danish Pain Research Center, Aarhus University Hospital
marie@ps.au.dk & lise.gormsen@ki.au.dk

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The structure and organization of health care is a salient political issue across nations and welfare states. It is important not only from an economic perspective, but also from a social and political perspective regarding the possibility of maintaining a proper qualitative level of health care as well as a system that is broadly accessible to the citizenry. Equal access to health care and social care is thus a key factor when the general quality of public life is discussed, not only in Denmark but also in many other welfare states. A common prerequisite for the existence of such a system is a strong general norm of reciprocity in social and political contexts. The norm states that everybody should contribute to our common welfare by working, paying taxes and participating in political institutions and in return be treated as equal members (citizens) of the state. However, not all citizens are capable of working, and far from everybody has equal access to health care and social care. In theory everybody should enjoy the same rights and access to common services, but in reality the boundary between being considered entitled to and deserving of public assistance and being perceived as responsible for one's condi-

tion is more a political than an objective measure (Stone, 1984: 26; Møller, 2009b: 235). In practice, the principle of equal access is interpreted and implemented by doctors who treat patients, health care professionals promoting health strategies, caseworkers who manage clients and schoolteachers teaching children and at the end of the day it is professionals like them who decide who is given access to services, transactions, preventive interventions and treatments.

In health care the diagnostic system works as a platform for deciding who should treat which citizens with what, but in social care such a system is more invisible. Instead the main criterion for access to services and transactions is a system designed to detect and measure the workability of every assistance-seeking citizen. The method of evaluating assistance-seeking citizens' workability seeks to differentiate between needs and claims because an absolute main reason why citizens cannot maintain a job and need to apply for public support is health problems such as chronic pain, for which they seek medical, psychological or therapeutic help. On an economic level this demand of public support is often seen as creating incentives to exploit the social sector to reduce labor costs; on a practical level it constitutes a difficult and paradoxical interplay between the role of the doctor, the social worker and the idea of the independent citizen, in theory, the equal member of the state. This volume focuses explicitly on the case of chronic pain in such different social and political contexts.

Doctors and social workers see citizens who experience chronic pain and express a need for help as 'hard cases' for at least three reasons: (1) the objective evidence of pain is non-existing even though (2) the citizen experiences the pain as real, and (3) public empathy towards non-visible and undocumented chronic pain is at a minimum (Østergaard, 2005: 27; Malleon, 2002: 267; Barker, 2005: 126-129). This is the case even though very few citizens with 'hard case diagnoses', e.g. fibromyalgia, apply for public support compared to citizens with other diseases (Møller, 2009a: 10). Furthermore studies in welfare state policies indicate that social casework on eligibility for social benefits is based on a general mistrust toward citizens with 'unexplained' chronic pain, because the chronic pain patient is stereotyped as lazy and malingering incapacity to work (Møller, 2009a: 24; 2009b: 183; Østergaard, 2005: 44).

Basically our welfare policies decide who is entitled to help and why. In practice the social authorities determine who receives public support. The political objective to solve the questions of entitlement is far from new. Several examples from different welfare states (US, Holland, UK) show similar attempts to answer the question of entitlement by using medical knowledge as objective measures. Some

30 years ago in the US, doctors were induced by the Administration to assist social workers in the process of determining entitlement to public support because of their clinical and diagnostic practice. This practice was interpreted by the political system as a way to justify through 'medical objectivity' the procedures and evaluations of entitlement made by the social authorities. Even though American doctors objected that medicine is far from an accurate science capable of separating the 'worthy needy' from the 'non-worthy needy' applicants, they ended up as central tools in this political matter (Stone, 1984: 82).

Until 2003, Danish doctors had a similar central function in the public support system, but after a policy shift in 2003 a new law explicitly forbade doctors to make social evaluations of entitlement to public support. Doctors no longer had the right to recommend pension or other kinds of public support and were, technically speaking, reduced to consultants for social workers in matters of social services, transactions and insurances. The public perception of the medical profession seemed to have changed, and doctors were no longer seen as professionals offering rational and objective knowledge but were suddenly framed as 'uncontrollable', political and always on the 'patient's side' in discussions of entitlement to public support. The public discourse on welfare services portrayed doctors as striving to increase their political power to decide which patients should receive public support. They were even accused of putting healthy people on permanent welfare deliberately by (mis)using clinical diagnosis as an instrument to do so on behalf of legal authority (Bang, 2002; Ehlers, 2005).

But where does that leave specialized medical and psychological knowledge with respect to diagnoses that are still unclear and poorly defined among lay people, for example unexplained chronic pain? What happens when chronic pain patients are asked to document their pain as part of a request for public support? Without clinical experience or training to understand what different diagnoses mean for the individual's cognitive and physical capacities and hence also for his workability, the evaluation is likely to be based on lay knowledge and moral judgment reflecting social stereotypes of malingering people and free-riders (Møller, 2009b: 318). It remains an open question how these judgments are made, but studies indicate that social workers develop a kind of 'lay understanding' of the client's diagnosis to be able to evaluate entitlement. The discretion and accountability used in casework are apparently reduced to a matter of sympathy with certain diagnoses and mistrust towards others. This practice puts some ailments at a disadvantage, since some diagnoses are publicly well known and accepted as illnesses. Other diagnoses, e.g. fibromyalgia, do not activate any kind of empathy

in the social worker, who therefore sees them as 'common' discomforts that they expect clients to tolerate instead of using health issues as a malingering tool to gain public support.

Based on this interest in exploring how society, reflected in e.g. social worker, pain doctor and employer practices, relate to, tolerate and manage 'other people's pain', the main question in this special edition is: How and to what extent does society expect the individual to tolerate pain? The volume features social, political, philosophical, psychological and medical reflections on ailments, pain and suffering and asks how we should study these phenomena and, not least, how they can be treated. What do the medical professions say about pain, and when do pain and suffering go from being a personal problem to a problem society should recognize as a malfunction, affording the patients public recognition and support?

This special edition was launched with an interdisciplinary symposium at Aarhus University, Aarhus, Denmark, May 21-22, 2008. Besides the political dimension of the public administration of pain, a variety of psychological, philosophical, and sociological aspects were discussed. This issue sets forth the above-mentioned perspectives on pain and suffering in the welfare state as well as other related political themes on health and health care promotion regarding management of chronic pain.

American sociologists Peter Conrad and Vanessa Lopes Muñoz start this special edition with the article "The Medicalization of Chronic Pain". They present an initial analysis of the medicalization of chronic pain, focusing on past decades' definitions and treatments of chronic pain. They argue that the increased attention to chronic pain as a discrete medical category as well as innovations in chronic pain treatments have contributed to the medicalization of chronic pain in ways that suggest there may be benefits to society and pain sufferers, in contrast to many other cases of medicalization.

Next, pain doctor Lise Kirstine Gormsen discusses the challenges of working with chronic pain both as a researcher and as a clinician. Her essay "Pain as an Object of Research, Treatment, and Decision-Making" explains why it is problematic when the social and health care system sees **pain as a mere physical phenomenon**, because pain has a fundamental mental side embedded in a complex biological, social, and psychological context. By recognizing this, pain medicine is in a position to develop a research tradition that integrates different views and methods that will benefit patient treatment and strengthen the position of chronic pain patients in health care and the social system.

Following this line of thinking, political scientist Marie Østergaard Møller's article presents a qualitative experiment in which social workers were exposed to different stories about chronic pain patients. Her analysis illustrates how social workers hold very stereotyped perceptions of pain and tend to estimate the degree of reality in a patient's pain by comparing cases to previous cases. The comparative analysis illustrates why this way of comparing pain stories results in very biased approaches to the same case and the analysis shows how this difference can be explained with reference to the previous case presented. The article interprets the meaning of this finding as a matter of degree of institutionalization and collective orientation. The more a diagnosis is associated with a negative category of malingering and poor standards, the harder is the evaluation strategy used towards the citizen and vice versa.

Shifting the perspective from the social worker to the labor market, sociologist Claus Hansen's article asks the fundamental question of this special edition both empirically and theoretically: How much pain should an employee be prepared to accept when carrying out her job? Are symptoms of illness at work sufficient reason to take sick leave, or simply a normal condition of everyday life that you have to put up with (even if this means pain or discomfort while carrying out your job)? Claus Hansen argues that the answer depends on social class, and more specifically on the extent to which members of different classes find it 'necessary' to show up for work even when ill. For some, going to work ill is preferable to taking sick leave because the consequences of the latter will be severe. Bourdieu's notion of 'making a virtue of necessity' helps explain why manual workers take a more restrictive view of when it is legitimate to take sick leave than professionals, who are more likely to look at the question theoretically.

Philosopher Jane Ege Møller introduces the concept of motivation especially in relation to health promotion and sickness prevention. Her article "Lack of Motivation as Suffering" investigates how the concept of motivation functions in health promotion practices. It analyzes the understandings and articulations of motivation at the levels of the state, of health professionals, and of citizens. The article concludes that motivation must be seen as the latter: a relational concept, relating to concrete, social and situational contexts rather than an instrumental, psychological entity within the individual.

Returning to the basic concept of pain, philosopher Keld Thorgaard's article "The Normative and Epistemological Status of Pain Experiences in Modern Health Care" explores the concept of 'pain' and the relation between abstract, detached knowledge, patient experiences and 'first person perspectives'. The argu-

ment is elaborated through a discussion of, amongst others, Martha Nussbaum, Marx Wartofsky, Amartya Sen and Ludwig Wittgenstein.

Continuing in the philosophical dimension of pain and suffering, philosopher Anders Dræby Sørensen introduces the historical perspective of what pain and suffering have meant for society and the individual. His article "The Paradox of Modern Suffering" elucidates the paradox of existential suffering in Western modernity from the perspective of an existential analysis of culture. The main discussion of the article shows that modern mankind has become engaged in an existential strategy to achieve happiness in this life. This notion involves a life with pleasure and self-satisfaction that is free of suffering and discomfort.

Finally, political scientist Lars Thorup Larsen discusses his comparative policy study of three decades of Danish and American public health programs. The article "The Circular Structure of Policy Failure and Learning. Danish and American Public Health Policy 1975-2005" shows how two very different health care systems experienced a similar pattern of policy failure. While both systems continually experience that citizens fail to live by what they know is healthy, public health policies always seem able to generate strong optimism for each new policy program, because the values responsible for policy failure are associated with the medical treatment paradigm that the policies depart from, but never with prevention itself. The article illustrates how the literature on policy learning has focused our attention on how governments 'puzzle' over society's great problems and foster solutions based on experiences from previous policies as well as new knowledge and ideas. While policy learning is often seen as a linear process, this article shows how the learning process is influenced by previous policy in a circular sense because a given new policy is being constructed over and over, instead of being built upon the actual experiences of the past policy. While downplaying the belief in traditional medical treatment technology, most Western nations shifted their health policy objectives in the mid-1970s in order to get into 'the business of modifying behavior', i.e. to counter lifestyle diseases by getting citizens to exercise more, but eat, drink, and smoke less.

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