Bringing bodies - and health care - back in. Exploring practical knowledge for living with chronic disease

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Jeannette Pols

Social theory about people with disabilities or chronic disease mostly steers clear from medical practices and theories. This is how research is framed that is deemed relevant for the emancipation of people with disabilities: by providing a counter-discourse to assumed individualizing, oppressive and objectifying medical ways of approaching people with handicaps. In this paper, it is argued that the shrugging off of medical discourse comes at too high a prize: medical practices and physical bodies are 'given away' as objects of social theory. Ironically, this may lead to a strengthening of medical discourses, because they are not challenged by alternative concepts of living disabled or diseased bodies. Moreover, the knowledge of people with disabilities and chronic diseases have about their daily lives remains under-studied and under-valued, cutting off ways towards interesting social positions and strategies for the improvement of these positions. This paper explores the knowledge of people with disabilities or chronic disease as practical knowledge. What this practical knowledge might entail in daily life is illustrated from the practices of people with COPD, a severe and chronic lung condition.

[practical knowledge, social theory, medicine, ethnography]

Biomedicine or activism?

Social theories such as medical anthropology, medical sociology and disability studies have been concerned with the articulation of the subjective experiences of people with disabilities and chronic diseases, as well as with a critical analysis of their position in society. Although there are great differences between and within the disciplines and schools that I here lump together as 'social theory', they broadly share their refusal to critically engage with medical practice and theory.[1] Medical theory and practices are thought of as suspect because they are seen as oppressive, individualizing, de-politicizing and objectifying patient bodies. Disability studies oppose biomedicine by leaving it well alone, in order to play out a radical political agenda:

> Disability Studies refers generally to the examination of disability as a *social, cultural, and political phenomenon*. In contrast to clinical, medical, or therapeutic perspectives on disability, Disability Studies focuses on how disability is defined and represented in society. From this perspective, disability is not a characteristic that exists in the person so defined, but a construct that finds its meaning in social and cultural context (Taylor, Shoultz & Walker 2003, emphasis mine).

By placing disability outside the body and inside social arrangements, a biomedical or individual model of disability is separated from and replaced by a social model and a politics of societal (rather than bodily) change. In the social model, disabilities are not attributed to dysfunctional bodies but are characteristics of socially and materially 'handicapping situations' and a social unwillingness to do modify these (Oliver 1991; 1996; Barnes, Mercer & Shakespeare 1999; Davis 1997).

The social model has put the social position of people with disabilities firmly on the agenda, influencing policies for people with disability world-wide (WHO 1980; UN 2006). However, the declaration to stay away from biomedicine and its practices is also questioned, both within disability theory and science studies (Hughes & Paterson 1997; Mol 2002; Mol & Law 2004; Shakespeare 2006; Hughes 2009; Moser 2009; Suyata 2009; Pols 2010a). The implication of staying away from biomedicine seems to be that both biomedical knowledge and practices as well as questions about physical bodies cannot be addressed within social theory. This paper explores what it implies to 'leave bodies out' of social theory and considers the possibilities for 'bringing them back in' (Frank 1990; Zola 1991). The paper proposes a theoretical position that allows for an analytical framing of knowledge that people with chronic disease or disabilities have and may develop together. I will demonstrate that a concept of *practical knowledge* provides a useful tool, by analyzing some examples from the knowledge practices formed by people with COPD (lung emphysema). In the conclusion, I will return to the significance of such an analysis for the position of people with disability in society.

Social concerns within biomedical practices

Why would the turn away from biomedicine be a problem, and how would it implicate the bracketing of bodies? A first problem is that a split is created between what appears as the natural (-ly handicapped) body, which is the object of biomedicine, and the cultural (-ly disabled) body, which is the object of social and political sciences. Nature becomes opposed to culture, disease to illness, and knowledge & facts become separated from beliefs & meanings, each to be studied in different ways (Mol & Law 2004; Mol 2002; Moser 2009; Pols 2010a; Mol & Pols 1996).

The problem with such a division of labor is that biomedical practices are seen as homogeneous bulwarks that, even though they are oppressive as bulwarks and modes of knowing, do not have internal politics, struggles and conflicts. The bulwarks are assigned a singular mode of knowing that generates objective (and objectifying)

knowledge. This knowledge may be oppressive, but its truth-claims (or in a rather more constructivist vein: its ways of creating realities) are not contested. As a consequence, bodies and diseases may be conceived of as singular natural entities can only be known by the experts: doctors or medical scientists (M'charek 2010; this issue). There seems to be only one story about the body: a coherent medical story. Framing biomedicine in this way, paradoxically, gives the biomedical sciences an authority doctors may not even want to claim. It glosses over its internal conflicts and contradictions of which there are plenty, as social students of medicine have demonstrated (Mol 2002; Pols 2010b).

Here is an example from my research on telecare (Pols 2010b). In this paper I compared the differences between using a monitoring device or a webcam by way of supporting daily living with a chronic disease. The monitoring device was part of a practice in which developments considering the disease of the patient were objectified with the help of measurements (blood pressure, weight, heart rate) that were taken by the patients, and interpreted by professionals. The measurements indicated the condition of the body, even if the patients did not experience symptoms themselves. Hence, a disease 'inside the body' was constructed which was inaccessible to direct experience from those suffering from it. Professionals kept an eye on the developments of the numbers and suggested treatment when a set threshold was passed.

The people using a webcam, on the other hand, were stimulated to communicate about their problem, whenever they felt the need, regardless of the shape in which their concerns might show up. To this end they could contact professionals (by appointment), but also fellow patients they knew. In this configuration, to establish if there is a problem, was the responsibility of the patient, same as the construction of possible solutions. The patients experience was hence crucial for the naming of problems and the shaping of the remedies.

In both settings, the body and the disease of the patients were shaped differently, and so were their activities and responsibilities. This had not much to do with their diagnosis, but rather with particular ways to live with chronic disease, and the use of one medical device rather than another. Which device is to be preferred, however, is not – or should not be – the object of medical authority alone. Ways of living with a chronic disease concern the people whose life it is. Medical interventions interfere in patient lives – and as such they deserve social theory's scrutiny.

Disability politics

Apart from the problem of leaving biomedicine unchallenged, my other concern is the problem of a 'disembodied politics' for people with disabilities or chronic disease. Modern patient politics emphasize the *autonomy* of people with disabilities or chronic diseases, as an assumed characteristic of all citizens. If only the social and material obstacles are taken away, people with disabilities or chronic diseases will function same as everybody else. The exclusion mechanisms of claims for autonomy and equality are, however, also well known. There is the literature on 'normalization'

(see e.g. Moser 2000; Winance 2007; Goffman 1968) arguing that imposing norms of health and normality on people with disabilities puts to them a standard they can only fail to achieve. It is impossible to live up to norms that were made without taking disabilities into account.

Claims for autonomy and equality push handicaps and diseases away from the public debate, by turning them into matters belonging to the private sphere – or to bio-medical practices (Pols 2006, 2010).[2] 'Patients' may only become public or political actors when (temporarily) not demented, comatose or chronically exhausted, but are capable of acting as active consumers, legal subjects or expert patients. Hence, individualist images abound, making connections with psychologies and rationalities of a consumerist, legalistic or biomedical flavor. This may fit some people with disabilities and their struggles, but is often at odds with actual practices in which 'disabilities' become a matter of concern. A disability politics that does not relate to differences in disabilities and diseases runs the risk of becoming sterile – and even discriminatory.

So here is my wish list. I am looking for a politics and research of disability and chronic disease that includes bodies and medical practices, without essentialising the body as a singular, natural given that can be known in only one – (supposedly) medical – way. These politics I am after are a politics of 'naming, knowing and practicing bodies and handicapping situations'. They are about knowledge, about the development of knowledge by people with chronic disease or disabilities, about the characteristics and legitimacy of this knowledge and about the social positions in our society it may lead to.

For developing these politics and research, I suggest, an ethnographical engagement with daily practices. Many of the theoretical (op)positions described above, loose their meaning when one studies *practices* in which people and the objects and devices around them enact disabilities and disabling situations on a day to day basis. Bodies and knowledges can be studied as outcomes of – and actors in – particular practices, medical and other. The 'nature' of a disease is not a question that medical specialists are able to answer once and for all – they may rather articulate or help to enact some *versions* of it. Biomedical practices do not show up as 'the other' to 'patient perspectives', but are part and parcel of the daily life practices of people-with-bodies. And so is knowledge about bodies. I want to learn what knowledge may turn out to be when it is practical knowledge that is articulated from the practices of people with disabilities or chronic disease, including their encounter with medical practices.

Practical knowledge versus scientific knowledge

Practical knowledge is a pragmatic knowledge aimed at helping people with chronic disease or disability to live with disease or handicap. It is also a type of knowledge that clinicians use for treating individual patients.[3] The validity of this practical knowledge lies in its (temporary) usefulness rather than its truth. Both doctors and patients may use scientific knowledge (this is called 'evidence based medicine' in these days) as well, but they will have to *translate* it into practical knowledge to make it useful in

practice. Scientific, statistical knowledge will have to be interpreted within the situation of a particular patient.

Practical knowledge is essential for medical practices to function, but it is understudied. It exists in tacit ways in the routines, technologies, experiences and reflections of professionals intervening in their patients' lives. It is a kind of knowledge that allows doctors and patients to draw heterogeneous elements together: does this person's wheelchair allow for the necessary exercises, and if not, how can we change the exercises while fitting the program in with his attempts to keep his job? Practical knowledge is hence sometimes understood as being characterized by a logic of 'tinkering' of 'bricolage'.[4]

Dick Willems (1992) gives a useful example of what this knowledge might look like. He stages a GP, Bob, and a patient, Susan. Susan suffers from asthma and Bob gave her an inhaler to help reduce breathlessness. Willems shows that Bob is expert on some matters, but a lay person in others. When compared to a lung specialist, Bob is a lay person. He does not have the sophisticated technologies and knowledge of the specialist to understand asthma. But there is also a difference in expertise between Bob and Susan. As a GP, Bob is perfectly able to explain to Susan how to use the inhaler. Susan, however, is the expert when it comes to the embodied skill of actually using the device, and in using it in every day life in an inconspicuous and convenient way. A distinction between levels of practical knowledge is made: there is the (explicit) knowing-about know-how (Bob), and the (tacit, embodied) know-how itself (Susan). One could say that the explicit 'knowing about know how' may be shared between patients and professionals. The actual embodied knowledge is, however, more specific for those living it.[5]

Illustrations from practice

I will now present a few examples from an ethnographic study into the practices of people suffering from Chronic Obstructive Pulmonary Disease (COPD), formerly known as lung emphysema. These people struggle to shape their lives and their disease with others around them and through the technologies they use. My analysis draws on a six months period of fieldwork in a rehabilitation clinic and on follow-up interviews with patients using webcams to stay in contact with each other and the clinic. I conducted fieldwork in the clinic to study the ways in which the webcams were used in follow-up care. When I questioned how this device fitted into the daily life of the patients,[6] I learned a lot about the strategies and obstacles of living with COPD on a day-to-day basis. In-depth interviews were conducted with nine patients who were dismissed from the clinic, two ex-patients who had become volunteers in the clinic, as well as well as with staff. I asked my informants not only for their opinions, but also to engage in auto-ethnographic observations, by asking them to observe their own practices and report what they did, adding this to my own observations (Pols 2010b). I will use examples from their practices of living with COPD using practical knowledge, introducing the concept of *know-now*, and *translation* as a way of creat-

ing this know-now. I will show how this practical knowledge *mixes up the distinction between professional and lay knowledge*. Note that the development of these concepts is particular to this practice; other practices may be analyzed differently, highlighting concerns and strategies of knowing for different groups of people with COPD (less severely ill individuals for instance) and people with different conditions.

From know-how to know-now

Among the COPD patients, practical knowledge, tacit and explicit, clearly showed the pragmatics of practical knowledge. They were in need of directives about 'what to do', to interfere with daily life to improve it or keep it stable. In the interviews with patients who had left the clinic, I asked them what they had learned in the clinic. I was only rarely treated (tough occasionally was!) with stories about the chemical composition of particular drugs or physiological workings of the lungs to get oxygen out of the air. Mostly, the answers to my question told about *practical arrangements* for allowing them to live their daily lives. Regardless of its im- or explicity, one could say that to 'know-*now*' is a more accurate term for what was going on here. Patients struggled to find out how to assess what is the problem and know what to do in a particular situation.

> *Mrs Smith*: What I learned [in the clinic] is that you should be focused on getting to know your limitations, and also learn that you have to make these limitations explicit. So when you are doing sports and you should stop: how can you make others know? And where do you notice you got to the limit, and how to deal with that? A lot of work in the clinic is aimed at that: that you recognize your limits, and learn what to do with those.

This practical knowledge provides pointers for Mrs. Smith towards the things she should become sensitive about. It is not a proposition about a state of the art, although such proposition might be derived from the story as well: limitations should be respected. However, what this proposition means, for example what a 'limit' is, is something that has to be assessed in any concrete situation. The 'limit' to become aware of when encountered is a temporary and situated one. It only makes sense in a particular situation, as a 'know-*now*'. The other day may bring different limitations. Mrs. Smith' practical knowledge provides a tool for identifying problems. These need to be assessed by checking the environment and ones' reactions to it.

Then there is the point of finding out what to do when a limit is sensed and identified. Mrs. Smith then needs a strategy to deal with it. Explain people about your disease? Merely wave to signal you'll wait behind? Take extra medication? In Lucy Suchman's terms: situated action is called for. There is no plan other than the general proposition. Patients need to make improvisations within particular situations.

In the quote, the practical directives are questions: what is the limit *here*? How can you deal with it? These questions are specific and open at the same time. They ask for particular things, but do not provide a closed or multiple choice answer. They are

tools or methods for understanding a particular situation and finding out what to do. Practical knowledge is not a stable knowledge of facts, such as knowing the capitals of all countries in South America. It is a way of actively *knowing*, verb rather than noun. Every set of activities needs to be sensed and thought through in terms of energy, and fresh arrangements to best live them. The practical rationality needed here demands the persistent solving of new puzzles and calculations with ever changing sets of variables. Rather than information alone, it needs experience and skills for improvisation.

Technologies and translations

In order to develop methods to *know-now*, patients used the knowledge they got from their doctors and devices. This knowledge is often not 'ready to use' to improve daily live with disease. To develop these tools into useful *know-now*, patients need to make *translations*. What devices do is not something that hides somewhere within the devices. They are put to work by their users, who are being put to work in their turn. It is an interaction.[7] The directions the technologies provide will have to be translated to make them useful for daily life practices and daily life bodies.

> *Mrs Jarmus*: You see, what I had to learn is to walk slowly, right from the start, walk very slowly. And this is not what I naturally do. And then I used the saturation device and I noticed that after one minute walking, my saturation goes down. Or goes below 90, and then I will have to stop. So, well… One minute is not far.
> *Interviewer*: So you walk one minute and take one minute break.
> *Mrs Jarmu*s: Yes, that could be a possibility. But I find this so difficult to practice! You have to stop in front of every shop window. Look very interested at something, when there is nothing to see! Play with your car keys or whatever. And sometimes you just cannot even do that. I have days that I can hardly get from the kitchen to the sofa.

Mrs. Jarmus uses a saturation device. She was told that 90 is the clinically relevant threshold; below 90 saturation is too low to continue exercise without damaging tissues. But this fact in itself is not enough to learn. Mrs. Jarmus has to put it to use. She makes a first translation from *oxygen saturation* to *time*: after one minute of very slow walking, she should stop. 90 % Oxygen saturation then becomes 'one minute rest'. Then another translation takes place; one minute rest, becomes one minute of standing still. Standing still is an activity that takes place in a particular practice of everyday life where one walks, but hardly ever rests. It is in the streets.

The body performed by Mrs. Jarmus is a different body with each translation, as are its troubles and the solutions to be worked out. The first body is a body with oxygen in the blood that may sink to a level that is too low to keep moving without damage to tissues. This becomes a body that should rest after one minute walking. The body needing rest becomes a body that is visible to others and stands inexplicably inert in public places. This is a body that needs to learn how to stand in the streets inconspicuously. Any body that is too abstract needs to be adapted and crafted

to turn it into fitting *know-now*. This may be done in many different ways. The use of a mobility scooter would have lead to a very different series of know-now in Mrs Smith's situation.

Blurring the lay-expert divide

Patients have to somehow combine the knowledge generated by the different specialists with knowledge from other sources, such as advice from fellow patients, and knowledge inscribed in medical technologies. Often, the patients got tasks that were formerly the responsibility of their GP, such as the management of their medication. The next example shows how the knowledge about medication in a practice where patients take care of this medication themselves, cannot simply be described in terms of patients mastering medical knowledge.

> Mr. Hansen says he was regularly admitted to the hospital and he has a supply of prednisone and antibiotics in his closet, so he may start treatment quickly when it is needed. When he is admitted, he's put on a drip with corticosteroids and antibiotics immediately. He tells me his last admittance was January first in 2004, now three years ago. He says the most important thing is to deal with your panic when getting out of breath. That helps you a long way.

In theories distinguishing expert from lay knowledge, Mr. Hansen may be seen to have obtained professional knowledge, and become a proto-professional, using the knowledge and know how of professionals.[8] In a perspective of practical knowledge, however, Mr. Hansen learns to develop a practical know-now that is specific to his situation and those to come. When he understands what the meds are for, he needs to find out *when* he has to take them. This starts with sensing his condition. Is his breathlessness the result of inflamed lungs, or does it have other causes? To be able to establish this, Hansen first had to learn not to panic. Panic would hinder him to *sense* what is wrong with his body and think of what he should do and is a source for breathlessness in itself. He has to *feel* his lungs and combine what he feels with other things, such as the weather condition, the presence of vapors, or the analysis made together with fellow patients. Maybe he has a peak-flow meter to help him assess his situation.

Next, Hansen has to decide what to do: take the medication or do something else. If 'something else' would be better, he will have to find out what this something else might be. Obviously, the distinction between expert and lay looses its salience here, although one could say that Hansen possesses the practical knowledge that, in its explicit form, used to be the area of expertise of his doctor. For Mr. Hansen it has become *embodied* knowledge that he actively uses. The explicit propositional knowledge that 'antibiotics cure inflammations' is turned into an embodied, lived practical knowledge.

This example only concerns the knowledge of the *GP* that Hansen had to make his own. The many different expertises he encountered in the clinic each provided different knowledge repertoires and know-now to master. There was the physiotherapist,

the psychologist, there were activity therapists, and so on. When this is added to the know-now needed to deal with all the other tasks in life, such as looking after children or parents, going to school or work, keeping one's marriage going, people with chronic disease can be regarded as users of *interdisciplinary* practical knowledge. The illness ran through different arrangements in life, showing up in the shape of the need to take pills, a confrontation with grief and a suddenly appearing loneliness. Mrs. Yildrim tells how she had been doctoring with her norms of cleanliness to help her cope with COPD.

> *Interviewer*: What did you learn in the clinic?
> *Mrs. Yildrim*: Well, my family, eh. [laughs] To divide my energy, particularly with the kids, and also the domestic work. Because, you see, I always love tidy and clean, *too* tidy and clean sometimes. And I know that, that when I have a bad day, that I should say: just look through the mess. And not the next day, when I feel well again, do everything, but keep dividing the work into small chunks. And with the kids too, make it clear to them: this is what mum can do. And yes: now mummy's short of breath, and then mummy just cannot do it.

Here, it is not Mrs. Yildrim's body that is the object of doctoring. It is the love for 'tidy and clean', and the tireless kids wanting to play. The household had to be re-arranged, and so was the bringing up of the children. Again, a straightforward professional-lay, or medical-non-medical distinction does not do justice to the complicated mixtures of relevant variables to be combined and reorganized. Lungs, children and norms all play their part. This mix of variables also there for the remedies and their effects.

> *Mr. Gregory*: The most difficult was to accept it, which was really, back then in 2003, I had had enough. I did not see the need to go on anymore. I had had that many diseases, really, if there was this one tiny little virus around, I was sure to get it. Really. And then one of my daughters came with that picture [he points to the picture on the table, showing three kids]. This is a holy picture. These are three of the four grandchildren I have. She came with that pic: if I didn't know at all what the meaning of life is, I would have to just look at that picture. That would remind me about it. I don't know if it was this that helped me trough, but it still is a very important picture [laughs]. That's why it so proudly stands on the table!

The picture 'works' for Mr. Gergory, and helps him not to give up on his life and drown in despair. The picture is 'effective', even though it would make no sense at all to organize a clinical trial around putting pictures on tables, even if this proved to be a life saving remedy in Mr. Gregory's case. Disciplinary boundaries are useful for professionals, and in that way they are useful to patients as well. Nobody would want the doctor to give them a pill that has not been thoroughly checked for its workings, or an operation that is a mere experiment of a creative surgeon. The patient, however, faces the task to coordinate the different inputs from the different disciplines in a meaningful way, even if they are contradictory. Is it despair or inflammation? Will it need a pill or a picture? How to combine lungs that are written off with a perspective that allows

one to move in daily life? From the position of the patient, is not the coherence within the medical disciplines, but all the different relevant elements that come together in a daily life practice that is fussy, incoherent and changing. Indeed this demands an impressive kind of know-now!

Conclusion

Talking about bodies and medical practices made it problematic to put professionals and patients in opposition to each other as experts and lays. Neither would it make sense to make their knowledge 'the same', or only viable when relating to medical science, as is done in the policy on expert patients and studies of patient movements (Callon & Rabéharisoa 2003; Callon 2005; 1999). Instead, the extrapolation of the differences between laboratory and clinic such as they are designed by Canguilhem to distinguish between scientific knowledge and practical knowledge seems promising, and helps to develop insights into knowledge used and developed by people with chronic disease or disability.

Practical knowledge for patients relates to the variety of the situations people with chronic disease or disabilities move through, which calls for improvisations. Also, they have to juggle and improvise aims in life, and negotiate these with their physical condition. They used practical knowledge, or know-now that needed to travel from one situation to another, providing footholds for any new kind of problem that came within a particular situation. Added to this variety was the variety of the different scientific disciplines and their relations to different kinds of practical knowledge. Physiotherapy had to be combined with medication management, the entanglements of peak-flow meters and embarrassments needed to be sorted, panic needed to be negotiated with breathing techniques. Next to these were domestic worries, demanding yet other forms of know-now to engage with. One could argue that the household situations also had their varieties of 'disciplinary knowledge': of norms for when a house can be called clean, about excusing oneself to ones children when out of breath, or juggling problems together with ones spouse.

Why is the articulation and development of this practical knowledge a *political* matter? I belief that explicating and developing the knowledge practices of people with disabilities or chronic disease holds promises for interesting social positions. There is no systematic collection and development of this knowledge or of the practices in which it is made and used. As a type of knowledge that is aimed at finding ways to live with disease in daily life practices, there is an enormous potential for improving ways of living with chronic disease by sharing knowledge, or jointly produce it when needed. And this is already done by local groups, but this knowledge is not shared with others than those directly involved.

Developing patient knowledge also provides potentially interesting positions for participation in the wider community. People with chronic diseases or disablties can be teachers who may also be employed as professionals in the heath care system. Rather than trying to be a good citizen without a body, living the body as a source of

knowledge provides opportunities to be a good citizen without trying to erase chronic diseases or disablities. This has, for example, been achieved among fellow patients in long-term mental health care. Patients have organized themselves to develop what they call 'knowledge of experience', which is a form of the practical knowledge specific for their situation. Some of these patients became professionals with paid jobs in mental health care institutions where they support patients and educate staff. This movement started out of discontent with modern psychiatric knowledge that was not experienced as very helpful in living daily lives with chronic psychiatric trouble (see Boevink 2006 a, b; Mead et al. 2001; Mowbray et al. 1998; Dixon et al. 1997). This practice may provide interesting models for other patient groups as well.

A next step in this politics of patient positions and knowledge would be to translate these insights to and from other patient groups (see also Epstein 2008; Whelan 2007). What potentials do they use for living with chronic disease or disability? Which ways are good and why? What may different patient groups learn from each other? There is no singular 'language of nature' to speak the final word about disease and disabilities, but there are multitudes of practices. Breathlessness is typical for COPD, but how and if it could be countered, differed between patients. Other differences may be shared over the 'disciplinary' boundaries of a disease category, such as difficulties with relinquishing work. There is not much known about how the practical knowledge of people with chronic disease or disabilities may benefit others. High time to breach disciplinary boundaries of any kind and find out!

Notes

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1   For an extensive discussion on this subject: see Pols 2010a.
2   For a comparable argument – but without the medical practices – made within feminism, see Pateman 1988; Mouffe 1995.
3   Polanyi (1966) analysed practical knowledge as 'tacit knowledge', or maybe rather as the activity of tacit knowing (Polanyi 1966). The distinction between scientific knowledge or the 'laboratory' with practice or the 'clinic' is proposed by the French philosopher Georges Canguilhem (1966) and is here extended to the practices of people with handicaps or chronic disease.
4   The term is from Lévi-Strauss 1966, but see also: Charmaz 2000; Prior 2003; Barbot & Dodier 2002; Hester 2005; Mol, Moser & Pols 2010).
5   The expertise in embodied know-how by professionals may vary according to disciplines (nurses and GP's may demonstrate using an inhaler) and their experience as patients or carers for patients.

6   In this paper I want to foreground bodies and illness, hence, I will boldly speak of 'patients'.
7   We described this interaction in terms of the 'taming' and 'unleashing' of both devices and users in Pols & Willems 2010.
8   To talk about medicalisation here would miss the point, because that critical term points to the treatment of problems that are not medical as if they are medical problems. Treating an inflammation of the lungs as a medical problem escapes this criticism, when one considers that constructing this problem differently would lead to a certain death of the patient.

References

Barbot J.
    2006   How to build an 'active' patient'. *Social Science & Medicine* 3: 538-51.
Barbot, J. & N. Dodier
    2002   Multiplicity in scientific medicine: the experience of HIV-positive patients. *Science, Technology & Human Values* 27: 404-40.
Barnes C., G. Mercer & T. Shakespeare
    1999   *Exploring disability.* Cambridge: Polity Press.
Boevink, W.
    2006b   From being a disorder to dealing with life. *Schizophrenia Bulletin* 1 (2): 17-19.
Boevink, W. (red.)
    2006a   *Stories of recovery. Working together towards experiential knowledge in mental health care.* Utrecht: Trimbos-Instituut.
Callon, M.
    2005   Disabled persons of all countries, unite! In: B. Latour & P. Wiebel (eds), *Making things public. Atmospheres of democracy*. Karlsruhe: ZKM, Center for Art and Media, Cambridge (Mass) and London: The MIT Press, pp. 308-13.
Callon M. & V. Rabeharisoa
    2003   Research 'in the wild' and the shaping of new social identities. *Technology in Society* 25 (2): 193-204.
Canguilhem, G.
    1989   *The normal and the pathological.* New York: Zone Books [1966].
Charmaz, K.
    2000   Experiencing chronic illness. In: R. Fitzpatrick & S.C. Scrimshaw (eds), *Handbook of social studies in health and medicine*. London: Albrecht G.L., pp. 277-92.
Cohen, M.Z. et al.
    1994   Explanatory models of diabetes: Patient practitioner variation. *Social Science & Medicine* 38 (1): 59-66.
Davis, L.J. (ed.)
    1997   *The Disability Studies reader.* New York: Routledge.
Dixon L, A. Hackman & A. Lehman
    1997   Consumers as staff in assertive community treatment program. *Administration & Policy in Mental Health* 25 (2): 199-208.
Edgar, A.
    2005   The expert patient. Illness as practice. *Medicine, Health Care & Philosophy* 8: 165-71.

Eisenberg L.

1977 Disease and illness. Distinctions between professional and popular ideas of sickness. *Culture, Medicine & Psychiatry* 1 (1): 9-23

Epstein, S.

2008 Patient groups and health movements. In: E.J. Hacket et al. (eds), *The Handbook of science and technology studies.* Cambridge: MIT-Press, pp. 499-539.

1996 *Impure science. Aids, activism and the politics of knowledge*. Berkeley: University of California Press.

Frank, A.W.

1990 Bodies back in: A decade review. *Theory, Culture & Society* 7: 131-62.

Goffman, E.

1968 *Stigma*. Harmondsworth: Pelican.

Greenhalgh, T.

2009 Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal* 338: b49.

Hart, A., F. Henwood & S. Wyatt

2004 The role of the Internet in patient-practitioner relationships: Findings from a qualitative research study. *Journal of Medical Internet Research* 6 (3): e36.

Henwood, F. et al.

2003 'Ignorance is bliss sometimes': Constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health & Illness* 25 (6): 589-607.

Hester, J.S.

2005 Bricolage and bodies of knowledge: Exploring consumer responses to controversies about the third generation oral contraceptive pill. *Body & Society* 11: 77-95.

Hughes, B.

2009 Wounded, monstrous / abject: A critique of the disabled body in the sociological imaginary. *Disability & Society* 24 (4): 399-410.

Hughes, B. & K. Paterson

1997 The social model of disability and the disappearing body. Towards a sociology op impairment. *Disability & Society* 12 (3): 325-40.

Kivits, J.

2004 Researching the 'informed patient'. The case of online health information seekers. *Information, Communication & Society* 7 (4): 510-30.

Kleinman, A.

1980 *Patients and healers in the context of culture.* Berkeley: University of California Press.

Lévi-Strauss, C.

1966 *The savage mind.* Chicago: University of Chicago Press.

Lupton, D.

1997 Consumerism, reflexivity and the medical encounter. *Social Science & Medicine* 24 (3): 373-81.

M'charek, A.

2010 Fragile differences, relational effects: Stories about the materiality of race and sex. *European Journal of Women's Studies* 17(4): 1-16.

2011 When whiteness becomes a problem: (Un)doing differences in a case of neo-natal care. This issue.

Mead, S., D. Hilton & L. Curtis

    2001   Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal* 25 (2): 134-41.

Mol, A.

    2002   *The body multiple. An ontology of medical practice.* Durham: Duke University Press.

    2008   *The logic of care.* London: Routledge.

    2010   *The ability to taste. The eating body between laboratory and clinic.*

Mol, A. & J. Law

    2004   Embodied action, enacted bodies. The example hypoglycaemia. *Body & Society* 10 (4): 3-62.

Mol, A., I. Moser & J. Pols

    2010a   Care: Putting practice into theory. In: A. Mol, I. Moser & J. Pols (eds), *Care in practice. On tinkering in clinics, homes and farms.* Bielefeld: Transcript Verlag, pp. 7-26.

Mol, A, I. Moser & J. Pols (eds)

    2010   *Care in practice. About tinkering in clinics, homes and farms.* Bielefeld: Transcript Verlag.

Mol, A. & J. Pols

    1996   Ziekte leven: Bouwstenen voor een medische sociologie zonder disease/illness-onderscheid. *Kennis & Methode* 20 (4): 347-61.

Moser, I.

    2000   Against normalisation: Subverting norms of ability & disability. *Science as Culture* 9: 201-40.

    2009   A body that matters? The role of embodiment in the recomposition of life after a road traffic accident. *Scandinavian Journal of Disability Research* 11 (2): 81-96.

Mouffe, C.

    1995   Feminism, citizenship and radical democratic politics. In: L.J. Nichols & S. Seidman (eds), *Social Postmodernism. Beyond identity politics.* Cambridge: Cambridge University Press, pp. 315-31.

Mowbray, C.T., D. Mosley & M.E. Collins

    1998   Consumers as mental health providers: First person accounts of benefits and limitations. *Journal of Behavioral Health Services & Research* 25: 397-411.

Oliver, M.

    1990   *The politics of disablement.* London: Macmillan.

    1996   *Understanding disability: From theory to practice.* Basingstoke: Macmillan.

Pateman, C.

    1988   *The sexual contract.* Stanford: Stanford University Press.

Polanyi, M.

    1966   *The tacit dimension.* New York: Doubleday.

Pols, J.

    2003   Enforcing patient rights or improving care? The interference of two modes of doing good in mental health care. *Sociology of Health & Illness* 25 (3): 320-47.

    2006   Washing the citizen: Washing, cleanliness and citizenship in mental health care. *Culture, Medicine & Psychiatry* 30 (1): 77-104.

    2010a   Breathtaking practicalities. A politics of embodied patient positions. *Scandinavian Journal of Disability research.* DOI: 10.1080/15017419.2010.490726 (Oct 2010).

2010b   Telecare: What patients care for. In: A. Mol, I. Moser & J. Pols (eds), *Care in practice. On tinkering in clinics, homes and farms.* Bielefeld: Transcript Verlag, pp. 171-94.

Pols, J. & D. Willems

2010   Innovation and evaluation. About taming and unleashing telecare technologies. *Sociology of Health & Illness*. In press.

Prior, L.

2003   Belief, knowledge and expertise. The emergence of the lay expert in medical sociology. *Sociology of Health & Illness* 25: 41-57.

Schermer, M.

2009   Telecare and self-management: Opportunity to change the paradigm? *Journal of Medical Ethics* 35: 688-91.

Shakesepare, T.

2006   *Disability rights and wrongs.* London: Routledge.

Struhkamp, R., A. Mol & T. Swierstra

2009   Dealing with in/dependence: Doctoring in physical rehabilitation practice. *Science, Technology & Human Values* 34: 55-76.

Suyata, V.

2009   The patient as a knower. Principle and practice in Siddha Medicine. *Economic & Political Weekly* 44 (16): 76-82.

Taylor, S., B. Shoultz & P. Walker (eds)

2003   *Disability studies: Information and resources*. http://thechp.syr.edu/disability_studies_2003_current.html.

United Nations

2006   *Convention on the rights of persons with disabilities.* http://www.un.org/disabilities/default.asp?id=150

Whelan, E.

2007   'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community. *Sociology of Health & Illness* 29 (7): 957-82.

WHO

1980   *International classification of impairments, disabilities and handicaps* Geneva: WHO.

Willems, D.

1992   Susan's breathlessness. The construction of professionals and lay persons. In: J. Lachmund & G. Stollberg (eds), *The social construction of illness,* Stuttgart: Franz Steiner, pp. 105-14.

Winance, M.

2007   Being normally different? Changes to normalisation processes: From alignment to work on the norm. *Disability & Society* 22 (6): 625-38.

Zola, I.K.

1991   Bringing our bodies and ourselves back in: Reflections on a past, present and future 'medical sociology'. *Journal of Health & Social Behavior* 32: 1-16.