

Breathtaking practicalities: a politics of embodied patient positions

Jeannette Pols*

Academic Medical Centre (AMC), University of Amsterdam, Department of General Practice, Section of Medical Ethics, Amsterdam, The Netherlands

(Received 22 December 2009; accepted 16 April 2010)

By declaring biomedicine as its apolitical counter-discourse, social theory, including disability studies, experiences problems discussing bodies and their ailments. This paper explores possibilities to 'bring bodies back in' in politically relevant ways, while avoiding reducing bodies to singular, natural 'givens'. This is done by exploring some of the practices in which people with severe Chronic Obstructive Pulmonary Disease (COPD) attempt to live with their chronic disease and together with others. It becomes clear that what they experience as important physico-social problems are the *invisibility* of their disease, combined with the *visibility* of the aids used to deal with its problems. This combination leads to behaviour that is incomprehensible to others. It is demonstrated that some form of *presence* of the disease is needed to create social positions that allow patients to live with others in an acceptable way. The paper continues by exploring ways in which bodies are made present in useful ways. These are found where the people with COPD: (1) create communities of *shared bodies* that allow for a multitude of visible and invisible presences of COPD; (2) develop ways to *educate* their bodies in different ways to create new presences; (3) use their bodies as *sources of knowledge* about living with breathlessness; and (4) create *transportable* bodies to take COPD presences elsewhere, by using the argument of 'demonstration by numbers', the workings of time and by playing out the exceptional characteristics of their bodies and situations. The paper concludes with a discussion of the relatively unexplored possibilities for creating and sharing 'patient knowledge' and the areas this opens up for a new politics of social inclusion.

Keywords: body; social theory; disease/illness; ethnography; politics

Introduction

Defining which individuals are patients and what their concerns are is a political matter. Social theories such as medical anthropology, medical sociology and disability studies have been concerned with the articulation of the subjective experiences of patients as well as with analysing 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 opposition to medical discourse. Medical discourse and practices are suspect because they are seen as oppressive, individualizing, de-politicizing and objectifying patient bodies. Disability studies is opposed to biomedicine because it aims to play out a radical political agenda:

*Email: a.j.pols@amc.uva.nl

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 and Walker, 2003, emphasis added)

By placing disability outside the body and inside social arrangements, a biomedical or individual model of disability is effectively replaced by a social model and a politics of societal (rather than bodily) change. Handicaps should not be attributed to dysfunctional bodies but are characteristics of a socially and materially 'handicapping situations' and a social unwillingness to do modify these (Barnes, Mercer, and Shakespeare 1999; Davis 1997; Oliver 1996; WHO 1980).

However, the declaration to stay away from biomedicine as a theoretical repertoire is also questioned by disability theorists (Hughes and Paterson 1997; Shakespeare 2006; Hughes 2009; Moser 2009). The opposition to biomedicine makes it difficult to think about (handicapped) bodies in social theory other than in terms of *culture*. The *physical* body, on the contrary, remains the object of biomedical science and practices (Mol and Law 2004). In this model, disease is separated from illness, like nature from culture, and knowledge and facts from beliefs and meanings (Moser 2009; Mol 2002; Mol and Pols 1996).

I will discuss two major problems that follow from this division of labour. The first is the idea of the 'natural body'. By leaving medical definitions and bodies unquestioned, critics reinforce the idea that bodies are singular and natural entities about which social theory has nothing relevant to say. The second problem is that a disembodied 'patient politics' may suggest unrealistic or even dubious patient positions because they gloss over embodied positions that may be politically relevant because they provide people with disabilities or chronic disease ways to live together with others (Pols 2006). In this paper I will delineate patient positions that are embodied as well as politically useful. I will do this by presenting an ethnographic analysis of the practices of people suffering from Chronic Obstructive Pulmonary Disease (COPD), formerly known as lung emphysema. These people struggle to live together with others as well as with their chronic condition. I will explore the problems of living with COPD that are encountered by individuals who have this disease in their practical attempts to live with others and with their disease. What useful patient positions can be articulated from these specific patient practices?

I will analyze *patient positions* as practical subject positions that are the result of specific relations between the heterogeneous elements that are part of a particular practice: bodies, technologies, language, activities, buildings (Pols 2010a; Moser and Law 1999; Mol and Law 2004). These positions include *observed* as well as *experienced* elements (Mol and Law 2004; Pols 2005).¹

Body politics in medical practices

What can be gained for social theory when biomedicine – and the bodies within it – is opened up for social analysis? From the perspective of the social studies of science biomedicine is studied as *a set of practices*. This work demonstrates, first, that there is no singular story articulated or enacted about disease and diseased bodies within the diversity of medical practices. For example, in her exemplary book *The body multiple*, Annemarie Mol shows that atherosclerosis is a different disease when it is observed

in the *clinic* or in, for example, the *surgical ward*. In the clinic, atherosclerosis is *pain while walking* (claudicatio intermittens), whereas in the operating theatre on the angiogram, it is a *clogged up blood vessel*. These different forms of atherosclerosis, Mol demonstrates, do not always coincide neatly; an angiogram may show a still-clogged-up vessel at the same time that pain-free walking distance had increased from walking therapy.

This type of analysis turns the question of the nature of bodies and diseases into a political question rather than into a matter of nature and its neutral observers. Bodies and diseases are no longer conceived of as singular, natural entities, but are viewed as the outcome of – and as actors in – practical arrangements, medical and other. Mol shows that the surgical version of atherosclerosis often ‘wins’ from the clinical version of it. When going to a Dutch hospital with severe claudicatio complaints, the odds are that one will receive an operation rather than walking therapy, even though the latter is effective according to state of the art clinical research. Whatever the reasons are for this situation, for the patients concerned both therapies are interventions in their lives that have very different and far-reaching effects, which raises the question as to which of the atheroscleroses and its concomitant treatment is the preferable one. The nature of a disease is not a question that only medical specialists are able to answer – it is a political issue as well (see Pols 2010a for different examples of ‘lives with chronic disease’).

The consequences of studying practices and the different ways in which disease is – and may be – enacted, is promising, but far from finished (Barbot and Dodier 2002; Moser 2006; Hendriks 1998; Mol and Law 2004; Pols 2005, 2010a, 2010b). In this paper I hope to take a next step, by exploring different practices in which disease is enacted, taking *the practices of patients* as the starting point of my analysis. Which different enactments are revealed in this way? Do these enactments lead to new and helpful political positions for living together with others?

Political bodies

Recent *social* representations of patients have emancipatory characteristics that make them *active* (Barbot 2006) but, at the same time, often make their diseased bodies invisible or unspecific. Modern patients have been granted *rights* by newly designed laws such as the Dutch law on the medical treatment contract. They have also received preferences, choices and power on the (Dutch) health care market to behave as *consumers* demanding value for money (Trappenburg 2008). They are granted a *patient perspective*, different from a professional medical one, and this perspective is organized to influence medical research and to evaluate services.² In the UK, there is a policy on the *expert patient*, individuals who manage their own live and disease using up-to-date medical knowledge and technologies (Department of Health 2001).

What these characterizations of the political patient share is an emphasis on autonomy. Patients are just like other citizens, they have rights, they can make decisions and choices, and they are capable of managing their own affairs. This emphasis on autonomy has provided some important political strategies to counter exclusion, improve the position of people with disabilities and guarantee accessibility, particularly in the United States. The backdrop of autonomy and equality are, however, also well known.

First, there is the critical literature on ‘normalization’ (see e.g. Moser 2000; Winance 2007). The argument is that people with a handicap – or ‘spoiled identity’

or stigma (Goffman 1968) – will have to act ‘as if’ they are just like other people. Hence, even if one manages to conceal one’s handicaps, one is at a disadvantage anyway. It is impossible to live up to norms that were made without taking handicaps into account. The emphasis on autonomy and equality, and hence normality, excludes particular handicaps and diseases from the public debate by referring them to the private sphere – or to biomedical practices (Pols 2006). A patient may only become a public or political actor when (temporarily) not demented, comatose or chronically exhausted.

As a consequence, differences *between* people – and between diseases – are no longer a matter of public debate or concerns for social theoretical analysis. Whether people in wheelchairs need a different social policy, or different technological adjustments when compared to people with schizophrenia, is not analysed. The trope of the expert patient, critics argue, creates an *individualist* and *rationalist* image, with the rationality being a biomedical rationality (Greenhalgh 2009; Edgar 2005). This may fit some people with disabilities, but not others.

This issue relates to the third problem of politicized yet bodiless patient positions, i.e. that concepts of disembodied patients might withdraw useful and interesting embodied subject positions for people with chronic diseases and disabilities from exploration (Zola 1991). A comparison of the experiences of different patient groups may be very instructive (Epstein 2008; Pols 2009). Radical disability movements (as opposed to academic disability studies) do explore different kind of subject positions, for example in writing about passionate downhill wheelchair racing (Moser 2005), or by provokingly showing disabilities in art and photography (Sherlock 1996). A good example is Marc Quinns’ statue of Alison Lapper as a naked pregnant woman: the body radiates strength and new life . . . and has no arms. These are particular ways of making disabilities visible as differences between people while at the same time challenging the category of disability. But there are many more subject positions possible, as I will show in this paper.

Through empirical analysis, I will demonstrate that political analyses that do not take the body and its ailments into account also ignore the knowledge and knowledge practices of individuals with disabilities. Patient knowledge is a type of knowledge that requires patient *collectives* rather than individuals who share and develop it. When this knowledge and ways of using and producing it are not made explicit, helpful knowledge for living with disease or handicaps, as well as related social roles, remain inaccessible to others. In the patient practices I analyse, biomedicine is not ‘the other’ to ‘patient perspectives’, but is part and parcel of the practices of individuals who use the health care system. Medical practices can provide ways of knowing about and dealing with disease next to other ways.

I will explore how a particular group of patients, i.e. patients suffering from COPD, shape their lives and their disease with others around them through the technologies they use. My analysis draws on six month fieldwork I did 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 webcam was used in follow-up care. When I questioned how this device fitted into the daily life of the patients,³ 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 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).

Socio-physical problems

COPD?

COPD patients are a ‘forgotten’ group of chronic patients: physicians have difficulty caring for them and patients do not often ask for help, but spend their days at home (Habracken et al. 2008). COPD is a chronic, progressive and invalidating lung disease for which there is no cure. The life expectancy of sufferers is reduced by about 10 years. Medical textbooks tell that, because of inflammation in the lungs, their elasticity and capacity to take up oxygen is diminished. For patients the manifest problem is that they get out of breath easily on exertion. Crises are scary episodes, where patients feel they may choke and need to be hospitalized to treat lung inflammations. Most of the patients I met in the rehabilitation clinic where I did my fieldwork were severely ill. They were there because their daily lives were significantly disturbed and their doctors’ repertoires were exhausted. They came to the clinic to see if they could find ways to live with COPD. The patients were in the rehabilitation clinic for three months (weekends off) and took part in an intensive programme in which different aspects of their lives and physical condition were scrutinized and improvements were suggested and practised. An interdisciplinary team supported the treatment. This team consisted of pneumologists, specialized nurses and physiotherapists, psychologists, social workers and activity therapists.

Invisibility

Which problems with living with their disease and with others did the COPD patients report themselves? Most prominently – and intriguingly – these were problems related to the *invisibility* of their disease. Because other people could not see that they were ill, they felt misunderstood and rejected. A poem the patients circulated amongst each other in the clinic illustrates the problem of having an invisible disease. Here is the first strophe:

COPD

A disease with a name, but without a face
From the outside it is invisible what it has done to you
The tiredness, the despair, the sadness and the pain
Are not understood in a world . . .
Where everything should be visible

The poet addresses the problem that when differences between people with COPD and others are ignored, loneliness for individuals with COPD ensues. It is implied that worries and miseries can only be recognized and cared for when they are visible. A broken leg immediately evokes sympathy and helping hands for the sufferer. But most people underestimate the problems of patients suffering from COPD or they do not understand these problems at all:

Group therapy session with a social worker: Mr Dijkstra tells that, on his weekend leave from the clinic, he met someone in the street who was very surprised to hear that

Dijkstra was in a clinic. He looked so well! Dijkstra had replied: 'I am just like the grocer: the stuff on top looks very nice, but what's underneath is rotten'. Dijkstra is visibly shaken by the encounter and he didn't enjoy his witty explanation at all. He says it is hard to acknowledge that his appearance does not show how he is doing.

Mr Dijkstra has been in the clinic for two months now and is working hard to deal with a disabling and frustrating disease. All this hard work and harsh reality is glossed over by the passing neighbour. Mr. Dijkstra is not understood because his appearance does not provide any clue about the severity of his condition. His efforts and worries cannot be recognized and accommodated when they are not perceived. The effect generally is that patients are left to deal with their condition entirely on their own.

One suggested solution would be for patients to *explain* their worries to others. But this is difficult. It takes a breath of air to do so. But above all, people do not understand when what they see appears to contradict the account provided by the patient. When others do not notice that something is wrong, they find it hard to imagine that something is *really* wrong. It may all be 'in the head'. 'Dad, if you just got off that couch and got back to work', one patient's children commented. But dad could not walk unaided more than 100 metres. There is nothing to notice when you visit his house, apart from the oxygen tanks and warning stickers announcing their presence. This patient can walk to the front door and back, and when not strained he looks perfectly healthy.⁴ Indeed, patients must often feel that they are approached as a kind of disembodied persons, because the bodies perceived by others are so different from the bodies they experience.

In these examples, invisibility is a metaphor for the *absence* of disease in any form. When a disease or signs of it are not visible to others, the physical practicalities encountered by patients are excluded from social interactions. Interestingly, theories about exclusion of disabled people usually target visibility rather than invisibility (see e.g. Thomson 1997). Theories of stigmatization are about the presence and visibility of deviance or 'abominations of the body' that lead to social exclusion, or the unsuccessful attempt to hide these differences (Goffman, in Winance 2007). The stigma is a problem that, even if it can be hidden, cannot be lifted. In the experience of COPD patients, however, social exclusion is related to the absence of any visible reference to a life with disease. There is no shared world where differences may be accommodated. This problem is signalled more widely, and even a new symbol to mark this and allow people to get help is suggested (<http://invisibleillnessweek.com>; see Figure 1).

Visibility

If invisibility turns out to be troublesome, would 'visibility' be a solution? Apart from the feelings of exclusion by invisibility, the interviewed patients encountered problems when their disease or handicaps *were* visible. That is to say: they were seen or expected to be seen by others as handicapped individuals. This was not because their *disease* was visible (which it is not), but because their walking aids were. This did not lead to the desired presence of disease and recognition its problems, but rather to feelings of shame and misery connected with more classical – Goffmanian – forms stigmatization and social exclusion.



Figure 1. Emblem for person with invisible handicaps.

Mrs Clarke: And then this man [from the factory] came, with the mobility scooter. O, I'll never forget that! It didn't go through the front door, so it had to go around the back. And then I said to this man: 'Well, if you just drive around the corner, then I'll open the gate'. 'No!' he says. He says: 'Hop on, it's yours'. And then I had to drive in front of all these houses . . . ouch, terrible! So I drove around the block, really with red cheeks. . . . And I just dumped it in the shed. I took the keys out, and in the evening I said to my husband: I will *never* do this. People look at you, you feel so miserable, I really felt awful.

Mrs Clarke is so ashamed that she intends to keep the scooter locked up in the shed, even if this would profoundly diminish her mobility. Having people look at her is just too shameful. Mr Ferron explains why visibility is not equal to *transparency*. What one sees may be opaque, in need of explanation:

Mr Ferron: The trouble with my disease is, one day I can just walk with you for a bit. And then people see me walking. Well, and I think, this is just in the head, but then I enter the front door and go out at the back on the mobility scooter . . . [meaningful silence] Nobody understands that. And as I said: you look so healthy, that is the trouble with this disease. When you broke your leg, people notice at once: he broke his leg. But then, they all sit there staring at you.

Not only does the scooter signify that something is wrong and makes people stare. There is the unexplained visibility and invisibility of a body that walks at one moment and not at another as well. On top of that, because there are no visible signs that something is wrong with his body, people will judge that Ferron is mad. They do not know about bodies that are handicapped at one moment, but are fit the next. This turns COPD into an erratically visible-invisible disease.

However, if Mr Ferron's audience did *know* about his disease, they would be able to understand his behaviour and would not think of it as irrational. In the case described, the neighbours and strangers *not* knowing about the disease (its absence) are again more problematic than in case they *would* know. Another woman jokingly said: 'Oh, I can do everything, when I don't do anything!' She referred to the fact the she is not bothered by complaints if she is not moving or exerting herself. Living with COPD shows the fluidity of a body variable over time and in different situations, differing from one day to another, from one hour to the next or between activities pursued. In daily practice it is not constant or consistent. Nothing is wrong when one quietly sits on the couch, whereas one is completely handicapped when the tiniest amount of shopping needs to be done.

What Ferron and the woman who can-do-everything-when-doing-nothing seem to suffer from is a lack of explanation or some form of 'presence' of their disease that would make their behaviour understandable to others (for presence, see also Sörensen 2009; Law 2002). Apparently, assumed characteristics of disease are that it produces stable defects or displays gradual improvements, like fractures, amputations or flues, whereas COPD does not. The seemingly erratic behaviour is perfectly understandable and rational when it is explained as an effect of COPD. This brings a more fluid understanding of 'how bodies behave'. Again, some form of presence is needed to accommodate COPD within a situation. This is difficult because of the poor visibility and the trouble of explaining. Are there alternative forms of 'good presence' of COPD? What are these and why, when and where are they good?

Good presences, helpful positions

How do people with COPD enact helpful presences of COPD and hence, helpful positions for living with others? One position is to *reduce differences*. One way to do this is to change the décor by moving from the home to the clinic. In the clinic, the buildings are far apart. The patients are expected to do sports and go to meetings, and if they would walk to the facilities, they would have exhausted themselves, or would not be able to go at all. Hence, there are many mobility scooters around. Most of the patients use them. In this scooter-filled environment, it is much easier to drive one yourself than it would be at home. As a scooter driver one does not stand out, and the gaze of the others is the gaze of 'people seeing one scooter among many'. They probably drive themselves. The scooter disappears as a difference between people. Mrs Jones observes:

Well, you know, in the clinic everyone races around on these things [mobility scooters]. That helps you over the threshold. Because, if they would have brought a scooter to my house, I really wouldn't have considered using it. No. Positively not. I find it, yes, how to say it in a decent way, such a failure [afgang]! Devastating, to sit on this thing like an old hag. No, I don't believe I would have done it.

Making COPD visible and present, in this case, means *being part of a community of mobility scooter drivers*. Apart from the décor, the *audience* is different as well. Fellow patients are in the same boat (or on the same scooter) and share habits that may be frowned upon by ignorant others.

Mr Vanderbilt: And not a soul looks at you [in the clinic]. When you are walking and you suddenly stop to lean against a big tree, heavily breathing through your nose, nobody will look at you. Because they know what you are doing. But if you do this in the street, people will say: 'Did you see, mad Vanderbilt was leaning against a lamppost!' You will have to conquer that.

In an environment where most individuals have trouble breathing and need breaks while walking, one doesn't stand out. So presence of COPD in the clinic takes the shape of the use of scooters and struggling for breath. Together with their tools and habits, these patients enact new expectations in patterns of visibility and new routines that create a community of 'individuals with COPD'. Verbal explanations are not

needed; there are signs everywhere, and everyone is familiar with the invisible workings of COPD as well.

I hasten to add that, among the many differences between people, only some are reduced in the clinic: those having to do with a life with COPD. This leaves many other differences to be negotiated and fought over. There is class, gender, education, preference for one kind of TV programme or another, conversations to be had, table manners, temperaments and so on. To some, life in the clinic was much more about living with differences than with similarities; they did not meet people they could connect with. But roughly one set of differences is reduced: everyone admitted to the clinic has to deal with COPD, and everybody else knows about the difficulties of living with COPD.

So, by the omnipresence of COPD, the clinic becomes a place where COPD is turned into a *public* presence; it is visible, present and shared with others, even if this is in the protected, semi-private sphere of the clinic.⁵

Fieldnote: The next point on the programme of 'The Day's Start' physiotherapy is 'huffing'. Slime in the lungs that has loosened after the former exercise of o-ing and humming [singing O's and hums], should be coughed up. This is done by strongly breathing out and pushing the hands in a short movement towards the midriff while uttering a sound like 'huf!'. Some of the participants succeed in coughing up slime and these productions are warmly applauded by the others.

'Huffing' is certainly not something one can do just everywhere. Patients mention embarrassment doing their exercises at home with their spouse at hearing distance. But here they get applause. In the clinic, a physical and social world is created where COPD is shared and present in a lot of physical detail. By organizing the physiotherapy groups, not only techniques for breathing and other practical strategies are practised, but a community is created in which behaviours that would not be possible elsewhere becomes present, acceptable and trainable.

So instead of *individualizing* patients' troubles, the disease here is made part of a shared set of experiences and activities. All patients struggle with 'stuff' that gets stuck in their lungs. All patients know what it means to be out of breath in the morning. This is a first way of enacting a position with helpful presence of bodies and disease, i.e. an embodied position that does not lead to social rejection but to ways of living together. The position is one of creating a community in which differences that are problematic elsewhere are shared and self-evident concerns of many.

Practising new bodies

In the clinic, helpful presence is also about finding new repertoires for living a body with COPD. In the conversations with patients, I was told that they find it difficult to see themselves as someone-with-COPD. They have trouble 'accepting that they have a disease', as they and their carers called it. This 'accepting' is about the presence of COPD for the patients *themselves*. They told me that they keep 'forgetting' they have problems with their lungs when they have a good day. On this good day they will slip into their pre-disease routines and overburden their bodies. All patients I talked to describe this; everyone had experienced it in one form or another.

'Accepting' that one has a particular disease, however, turns out to be much more than a mental act of 'facing the facts'. It implies new ways of behaving, observing varieties in one's condition and abilities, learning how to react to these changes and negotiating with oneself about the activities one deems important to do notwithstanding these difficulties. The patients have to get to know and enact themselves and their possibilities anew. This is something they may learn in the rehabilitation clinic as well: to acquire new repertoires of doing things, when their old routines have let them down. This is a tough learning process of active re-interpretations and training of the body. This is not 'merely' a psychological matter, but something the *body* has to learn as well:

Mr Charles: You see, you get out of breath, and you think that everything happens to you, you think that you die, you think this, you think that. But you should try to synchronise your breathing with your mind. And then you are OK again.

Simply breathing and getting out of breath sends the wrong signal, explains this informant. It leads to panic and an acute fear of dying. What Charles had to learn was to 'synchronise his breathing with his mind', that is to say, to breathe, not automatically, as-ever-before, but in new ways, ways that need reflection and practice before they may become routines. In this case it would be to 'talk back' to the body ('you are not dying') and teach it a different reaction ('sit down, don't panic, try to breath normally, and check if you need to take medications'). It is to re-educate and re-socialize the body. Bodies do not 'speak' transparently or in one voice: they are educated and trained to allow them to routinely react in certain ways. Routines are not given by 'nature':

Caregiver: The green park is meant to invite people to go out. People move less, because they get short of breath. And that is wrong. You should move in the right way.

To go for a walk leads to bodily signals indicating that this is not a good idea, even though it is supposed to be good for you according to the carers. But it is only good if you move and breath 'in the right way', which means that one should take breaks; many breaks, and preferably *before* one starts to get out of breath. The routine interpretation of signals from the body may be unproductive and needs to be re-shaped; this also applies to the routines. Elias (1976) shows how bodies learn to enact 'shame' by the face turning red. It is a cultural-physical reaction to turn red when particular events occur. There is no singular form of 'natural' here and different alternatives may be experimented with.

The patients have to create new norms and routines in which, to them, their sick body may be a *deviant* body (it is different in comparison to the one they had before, and not in the happiest of ways), but it is also a body that acts and reacts, and also *should* act and react according to particular new norms and routines, be they physically enforced or creatively designed. These are not individual norms or therapeutic regimes, but different combinations of strategies, routines, advice that may be valid for a collective of people suffering from breathlessness. It implies an active creation of presences:

Physiotherapy session: The exercise is to pick up a small sandbag that lies on the floor while standing. Not putting the feet right next to each other helps: taking a step is much

more stable. Then move the upper body down, bend through the knees, use support of a wall if possible. Two women grumble that support is not often readily available. 'You can also ask somebody to pick up something for you', the physiotherapist says brightly. The women snort: 'They will look at you: are you crazy?!' 'It's not written on your head that you have COPD'.

What used to be a very simple task has become a difficult one. There are different ways to deal with these difficulties, each bringing new complications. To get something off the floor may demand agility, but one could also ask for a helping hand, implying very different ways to deal with a situation. These are among the different technical and social abilities and routines one has to learn in order to 'synchronise one's breathing with one's brain'. Patients perform different positions one may take in order to deal with the situation; they may demand help from different resources, or they may train different skills, such as bending down in a better way, or asking other persons for help.

The presence of COPD enacted in the clinic does not (only) create an individual body, and it certainly does not create a consistent, medical or natural body. COPD is present here as a varied and shared set of practical arrangements and routines that may be selected, learned and trained to allow people to live with a body with COPD. It is a position of actively educating and (co-)shaping one's body.

Knowing COPD in practice

Sharing difficulties with fellow patients helps people to develop knowledge about their condition and new repertoires of behaving. This entails a type of knowledge that does not take the shape of abstract theories or established facts, nor does it take the shape of scientific medical knowledge. It is the skill to live daily life with COPD in a good way.⁶

Mr Johnson: I think the contact with fellow patients is really nice. Because there is always a night when you wake up, and you are short of breath, and things do not work out, and ... And then you think: is this me, is this my illness, or what? But if you can talk to another patient, and he or she feels just as bad, than you think: well, I am not the only one suffering today. And then it may turn out that there is a storm-depression coming or something like that. That has the same effect as going into the mountains. The air pressure diminishes and when your breathing is bad, and when there is less oxygen in the air, you notice it right away, definitely. And then you see: it is not only me.

The kind of knowledge creation in this fragment is not to be found in textbooks of medicine, although Mr Johnson does articulate a law of physics that he uses ('less air pressure makes for less oxygen, which makes breathing more difficult'). But it is not the formulation of this fact that is the aim here, but the way it may be used to diagnose a particular situation and find ways to act upon it. Mr Johnson and the person he is talking to try to find out what their bodies are doing at a particular time. They are not sure *why* they are getting out of breath. But being out of breath when thunder is coming is something that may be *sensed*; it is a reaction to be expected when one's body is susceptible to it. To find out if this is what is happening, they had to check with each other if their bodies were behaving like barometers, or if something else was taking place. Hence this type of practical, embodied knowledge is created to identify the nature of day-to-day problems and to think of appropriate strategies to deal with them. The patient's bodies are both the problem as well as the

instrument to diagnose the nature of the problem. They produce knowledge about the atmosphere – and hence about themselves – at a time when they need it.

Johnson and his fellow patients create this knowledge together: they need the other bodies to check what they are dealing with. However, one has to establish whether this is the case at a specific moment by talking to others. Hence, this creates a shared, practical and fluid way of physically being in the world, a knowledge to be created by bodies with sensitive lungs. The illness here connects people, not primarily through a disease category, but within a community of people who share a set of physical, emotional and practical capabilities, interests and difficulties, and knowledge about ways of dealing with these.

These kinds of things are what fellow patients know *about* and *through* their bodies and from sharing this knowledge with each other. They are valuable *sources of knowledge* to each other, and enact a useful presence of the disease by turning it into understandings and explications of how bodies with COPD may react, in order to establish if they do so *now* and how they should deal with that.

Apart from these practical and situated meteorological diagnostics, patients may also provide a large repertoire of suggestions for getting things done:

Mrs Petterson: It's the same with vacuuming; sometimes I ask others, other times I do it myself. And then I take the front of the room first, and then I sit down, to have a cup of tea, and I take a book and read for an hour. After that I'll do the back part. It doesn't have to be all done at once. Same with cleaning the windows. I would do the front, and then do the back a few days later. Or I don't do it. Or the rain does it. Or my husband does it. You have to learn this. I used to do the kitchen in one day: now I take one kitchen cabinet every now and then, and it gets done too.

To balance one's activities, to ask others or to change standards are all strategies one may develop to get things done. Patients learn this in the clinic but also develop their own tricks or learn these from others. Having COPD may therefore take the shape of 'having knowledge about how to live with a chronic disease on a daily basis'. This is a powerful position for patients. It may provide knowledge that is different from that of doctors, or may be about things the doctor never thought of. Empathic others may passively gain this experiential knowledge (Pols 2005; Mol 2008), but they cannot produce and develop it, because it is embodied in skills and activities. As Willems (1992) shows, professionals may *explain* the workings of an inhaler, the patient is the one able to use it on a daily basis, in different circumstances.

For some, assisting their fellow patients with knowledge and advice becomes a mission in itself:

Mrs Forestier: Aw, there are more than enough people who think: the pneumologist is right [by yearly measuring lung function with the message that nothing can be done about it]. And then they are really in the dumps. And oh, I would really want to give them a shake-up. I could scream and say: Wake up! Do something with your life! Don't always point at what does not work. See what you *can* do. You cannot run a marathon. But you can go to the shopping mall. You can go swimming with your grandson. Enjoy that! Enjoy the garden and other things. It is very important to be optimistic. Of course there are off days, days that you think: shit. But then there is always a phone call or little thing that cheers you up.

Indeed, Mrs Forestier has come a long way: she felt that her pneumologist had given up on her because she has a very bad lung capacity compared to what was to be

expected for her age. He gave her five more years to live and could not do much for her in terms of treatment. Indeed, the lungs could not be cured. In the rehabilitation clinic, however, interventions were not only aimed at her lungs, but at her daily life. Thus she gained ways of living with COPD and, at the time of the interview, she had happily outlived the prognosis of the pneumologist by 15 years. It is an impressive example of making COPD present in helpful as well as unhelpful ways. It is helpful when it is approached as a condition that can be dealt with in order to allow individuals to pursue daily activities and finding ways of living with disease and with others. It is unhelpful when COPD is merely made present as an irreversible condition characterized by a progressive loss of lung function. The lungs will not improve – but daily life can.

Fellow patients provided an evolving repertoire of this type of practical knowledge about living daily life. This allowed patients to take the position of being users and producers of knowledge, offering a source of expertise that is useful for others.

Transporting differences

An obvious conclusion so far is that whether a certain form of presence of COPD may be helpful or not, much depends on the situation and the commonality of other presences. One may huff and cough together with fellow patients in physiotherapy class, whereas with others, elsewhere, one may not. Knowledge from bodies with COPD is helpful for fellow patients, but may not be useful to others. Within the clinic and by working with fellow patients, these presences are shown, known, invented, made more permanent, experimented with ('try using a scooter'), facilitated (everyone drives a scooter) and practiced ('never mind the occasional door-crash'). New sets of norms and routines are practiced; new repertoires for living with COPD were tried out.

But this is not enough. The new positions and presences have to be transported to other environments, outside the clinic. How did the observed COPD patients tackle this? They used three strategies to create *transportable* bodies. The first strategy was to do it together. Argue by demonstration, and present visible and numerous presences instead of explanations. For example, the patients went with the mobility scooters outside the terrain of the clinic. Mrs Jansen tells how this happened:

Well, there was a person who had been in the clinic already for a longer period. And she said: 'Let's go to the city [on the mobility scooter]!' Well, never, not for a million euros will I go out of that fence! [Ironically] 'Okay, than *you* stay here and sit nicely. *We* are going to enjoy the market'. And then I thought: 'Aw, I would also like to go to the market'. And then I thought: 'What do I care!' And we went to the market with a whole bunch of people on scooters. And we had a lot of fun. Because you bump into one another, you have to brake, the market is crowded. And then you are over it.

These patients took their new décor, in which mobility scooters were in the majority, to places where they were not. In this way they supported each other and challenged the world to get used to persons using mobility scooters. When organized in groups, one may introduce new behaviours as new norms: this is how we do it. It is not an individual, but a collective way of living.

However, fellow patients are not available to get help everywhere. In these cases, the advice I gained from a patient who worked as a volunteer in the clinic, was to let *time* do the work:

Mr Jansen: I go to a café once a week, and then we have a beer with a few guys. And when I came in with the scooter for the first time, they stood up and looked at me. And now, when I come in: Did you bring your scooter, or did you take your car? [laughs] Delicious! Other people are ashamed that you have to sit on such a scooter thing, the whole neighbourhood talks about it. Well, they do. For three days. 'Gosh, did you see that, Jansen is in such a . . . Phew, that is . . .' And after three days, they don't talk about it anymore. You just drive around. [laughs] They started to keep a free space for my scooter in the café!

Mr Jansen's friends got used to it quickly; the wheels became part of Mr Jansen's life and of his life with him. There is a temporal dimension in what is strange; it becomes common after some time, when one has seen it often enough.

A third strategy was to turn differences from bad presences into good presences. This is the strategy of turning a once pejorative label into an honorary one. Difference is turned into something positive in the same way as one would value the exceptional endeavours of sportspeople or artists. Here is Mrs Clarke again, whom we left a few pages ago with her scooter parked in the shed, never to be taken out again:

And then my grandson came a few days later. He took his football out of the shed. 'Granny, you have a motorbike! Shall we go racing?' And I said: 'Don't even think about it!' 'O, come on, let me do it! Can you come and pick me up at school on the motorbike?' Well, the kid drew me over the line. I go everywhere, now. 'My granny has a motorbike, my granny can race!' He is so small, he does not see it as deterioration, he likes everything. Same with the stair lift: 'My granny has an elevator in her house! And she has her own parking space, *nobody* is allowed to park there, because it has *her* sign on it!' He feels he has a super-gran. Well, that makes it easier for you as well.

To be different may also be a good thing if it allows one to be a super-granny and a scooter to be a racing bike. In this example, not only the audience and the objects, but also the words changed meaning. Objects that once carried a stigma became tokens of pride. Of course this is a provocative strategy, as it plays with positive and negative appreciations and stereotypes. But this status of the exceptional body is a wonderful opposite to invisibility to perform valuable and exceptional differences.

Embodied subject positions

In the previous sections, I analysed different bodies and social subject positions. First, I discussed the *distributed body* which walked and was breathing at a specific time and place, but not in another, depending on the presence of specific aids, technologies and helpful others. This was a body that was disruptive for social relations when it became incomprehensible to uninformed others. This incomprehensibility turned out to be a consequence of the visual absence of the disease, rather than of a stigmatizing presence. Helpful social positions will not be helpful when matters of disease are erased.

Helpful positions were found when a *shared body* was enacted; a body which was part of a *community* that shared embodied experiences. This allowed for a

consideration of new norms and routines that were helpful for bodies having difficulty breathing or driving mobility scooters. 'Having COPD' became a set of norms in a collective of bodies, meaning that they could not walk far, and had to find new ways of dealing with this, such as driving mobility scooters or taking breaks. Another helpful position was when the body was lived as something that could be *educated* and trained. Instead of natural or singular reactions to getting out of breath, a variety of other reactions were suggested and practiced. The patients became assistants as well as pupils and could creatively help shaping solutions because their body was a *source of knowledge*. This offered a creative potential of dealing with breathlessness, where consultations of others with COPD was pivotal.

A final position highlighted was a set of *transportable* bodies. COPD ways of living were transported to outside the COPD community because they were made visible in numbers or in time. Another transportable body was the *exceptional* body, which was valued for its rare possibilities. The body as a source of knowledge about COPD may also be seen as an exceptional body. With these transportable bodies, patients positioned themselves as developers of norms. As a team, fellow patients helped design helpful presences and transported these to different places to make them acceptable to others. Going out on a scooter can be scary if done alone; it is much easier to act tough when in a group.

Much more than the modern positions of the (lonely) autonomous expert patients, my analysis points to the potentials of continually *sharing* experiences, making collectives and creating bonds of individuals helping each other, rather than managing oneself. These experiences do not only transform fellow patients into excellent shoulders to cry on, but also turn them into confidence boosters and assistants. Amongst each other, patients could be in the position of *helping others*, a much more powerful and desirable position than being the one needing help. This knowledge resembles the knowledge that may be developed in self-help groups rather than the biomedical knowledge of the expert patient.

Closing remarks: developing practices of patient knowledge

Rather than trying to be a good citizen without a body, living the body as a source of knowledge provides opportunities to be good citizens without trying to erase chronic diseases or handicaps. Fostering what I will call practices of 'patient knowledge' and finding ways to make this knowledge available to others contains a political promise for 'embodied empowerment' that is as yet underexplored. There is no systematic collection and development of patient knowledge or the practices in which it is made, used and transferred. As a type of knowledge that is aimed at finding ways to live with disease in daily life, there is an enormous potential for improving ways of living with chronic disease by sharing knowledge, or jointly producing it when needed. Developing patient knowledge also provides potentially interesting positions for participation in the wider community. People with chronic diseases or handicaps can be experts who may also be employed as professionals in the health care system.

This has, for example, been achieved among patients in long term mental health care in several countries. Patients have organized themselves to develop what they call 'knowledge of experience', which is a form of the daily life knowledge described above. Some of these patients have paid jobs in mental health care institutions to support patients and educate staff. This movement started out of discontent with

modern psychiatric knowledge, which was experienced as not very helpful in living daily lives with chronic psychiatric problems (see Boevink 2006a, b; Mead, Hilton, and Curtis 2001; Mowbray, Moxley, and Collins 1998; Dixon, Hackman, and Lehman 1997). This practice may provide interesting models for other people with disabilities or chronic disease 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). What potentials do others use for making differences present, and what kinds of presences are addressed elsewhere? Which ones are good and why? There is no singular 'language of nature' to speak the final word about disease and disabilities, yet there are multitudes of practices. It's high time to develop useful vocabularies that articulate them.

Acknowledgements

I want to thank the patients and professionals for their support for this research, and Dick Willems, Amade M'Charek and Ingunn Moser for comments on earlier drafts. I also thank Annemarie Mol for a long history of thinking about matters of disease and illness, Sabine Ootes and Evelien Tonkens for our work together on citizenship, the VSBfonds and the EU (EFORTT) for funding my research.

Notes

1. Using the concept of 'subject position' provides pointers to analyse how the subject is embodied within particular practices. This would not be possible with a concept of, say, 'social role'. Furthermore, the concept makes space for empirically establishing the character of the *agency* of the subject in a particular situation. It *situates* this agency by linking it to particular arrangements and practices. Unlike a concept of the 'patient perspective' (see also Velprey 2008), it makes space for observing non-verbal activities, or ways in which particular positions are enacted or 'done', without those enacting it being explicitly aware of it (Mol 1998; Pols 2005).
2. See: Involve, as part of NICE in the UK; in France INSERM does the same thing; and in the Netherlands there is a participation programme by the major research funding agency, Zonmw, see <http://www.zonmw.nl/nl/onderwerpen/alle-programma-s/patientenparticipatie-in-onderzoek-kwaliteit-en-beleid/>
3. In this paper I want to foreground bodies and illness, hence, I will boldly speak of 'patients'.
4. <http://www.rivm.nl/bibliotheek/digitaaldepot/FactsheetCOPD.pdf>
5. Fellow patients rarely show up in texts about emancipation of patients; patients are supposed to be part of society and deal with 'normal' people rather than their fellows in fate. This has unintended discriminatory effects and makes the importance of fellow patients for social integration invisible. See Pols 2008.
6. See for the move towards daily life and the connection of this knowledge to clinical knowledge: Struhkamp, Mol, and Swierstra 2009; Osborne 1992; Mol and Pols 1996; Mol and Law 2004; Winance 2001, 2007; Moser 2005; Pols 2010a).

References

- Barbot, J. 2006. How to build an 'active' patient. *Social Science and Medicine* 3: 538–51.
- Barbot, J., and N. Dodier. 2002. Multiplicity in scientific medicine: The experience of HIV-positive patients. *Science, Technology and Human Values* 27: 404–40.
- Barnes, C., G. Mercer, and T. Shakespeare. 1999. *Exploring disability*. Cambridge: Polity Press.
- Boevink, W., ed. 2006a. *Stories of recovery. Working together towards experiential knowledge in mental health care*. Utrecht, The Netherlands: Trimbos-instituut.

- Boevink, W. 2006b. From being a disorder to dealing with life. *Schizophrenia Bulletin* 1, no. 2: 17–19.
- Davis, L.J., ed. 1997. *The disability studies reader*. New York: Routledge.
- Department of Health. 2001. *The expert patient: A new approach to chronic disease management for the 21st century*. London: Department of Health.
- Dixon, L., A. Hackman, and A. Lehman. 1997. Consumers as staff in assertive community treatment program. *Administration and Policy in Mental Health* 25: 199–208.
- Edgar, A. 2005. The expert patient. Illness as practice. *Medicine, Health Care and Philosophy* 8: 165–71.
- Elias, N. 1976. *Über den Prozess der Zivilisation. Soziogenetische und psychogenetische Untersuchungen*. Baden-Baden, Germany: Suhrkamp Taschenbuch Verlag.
- Epstein, S. 2008. Patient groups and health movements. In *The handbook of science and technology studies*, eds. E.J. Hackett, O. Amsterdamska, M. Lynch, and J. Wajcman, 499–539. Cambridge, MA: MIT Press.
- Goffman, E. 1968. *Stigma*. Harmondsworth, UK: Pelican.
- Greenhalgh, T. 2009. Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal* 338: b.49.
- Habraken, J.M., J. Pols, P.J.E. Bindels, and D.L. Willems. 2008. The silence of patients with end-stage COPD: A qualitative study. *British Journal of General Practice* 58: 844–9.
- Hendriks, R. 1998. Egg timers, human values and the care of autistic youths. *Science, Technology and Human Values* 23, no. 4: 399–424.
- Hughes, B. 2009. Wounded/monstrous/object: A critique of the disabled body in the sociological imaginary. *Disability and Society* 24, no. 4: 399–410.
- Hughes, B., and K. Paterson. 1997. The social model of disability and the disappearing body. Towards a sociology of impairment. *Disability and Society* 12, no. 3: 325–40.
- Law, J. 2002. *Aircraft stories. De-centering the object in techno-science*. Durham, NC: Duke University Press.
- Mead, S., D. Hilton, and L. Curtis. 2001. Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal* 25, no. 2: 134–41.
- Mol, A. 1998. Missing links, making links. The performance of some atheroscleroses. In *Differences in medicine*, eds. M. Berg and A. Mol. Durham, 144–65. London: Duke University Press.
- Mol, A. 2002. *The body multiple. An ontology of medical practice*. Durham, NC: Duke University Press.
- Mol, A. 2008. *The logic of care*. London: Routledge.
- Mol, A., and J. Law. 2004. Embodied action, enacted bodies. The example hypoglycaemia. *Body and Society* 10: 43–62.
- Mol, A., and J. Pols. 1996. Ziekte leven: Bouwstenen voor een medische sociologie zonder disease/illness-onderscheid [Living disease: Building blocks for a medical sociology without the illness/disease distinction]. *Kennis en methode. Tijdschrift voor wetenschapsfilosofie en wetenschapsonderzoek* 20, no. 4: 347–61.
- Moser, I. 2000. Against normalisation: Subverting norms of ability and disability. *Science as Culture* 9: 201–40.
- Moser, I. 2005. On becoming disabled and articulating alternatives: The multiple modes of ordering disability and their interferences. *Cultural Studies* 19: 667–700.
- Moser, I. 2006. Disability and the promise of technology: Technology, subjectivity and embodiment within an order of the normal. *Information, Communication and Society* 9, no. 3: 373–95.
- Moser, I. 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, no. 2: 81–96.
- Moser, I., and J. Law. 1999. Good passages, bad passages. In *Actor network theory and after*, ed. J. Law and J. Hassard, 196–217. Oxford: Blackwell Publishers.
- Mowbray, C.T., D. Moxley, and M.E. Collins. 1998. Consumers as mental health providers: First person accounts of benefits and limitations. *Journal of Behavioral Health Services and Research* 25: 397–411.
- Oliver, M. 1996. *Understanding disability: From theory to practice*. Basingstoke, UK: Macmillan.

- Pols, J. 2005. Enacting appreciations: Beyond the patient perspective. *Health Care Analysis* 13, no. 3: 203–21.
- Pols, J. 2006. Washing the citizen: Washing, cleanliness and citizenship in mental health care. *Culture, Medicine and Psychiatry* 30, no. 1: 77–104.
- Pols, J. 2008. Which empirical research, whose ethics? Articulating ideals in long-term mental health care. In *Empirical ethics in psychiatry*, eds. G. Widdershoven, T. Hope, L. Vd. Scheer, and J. McMillan, 51–68. Oxford: Oxford University Press.
- Pols, J. 2009. Burgerschap in relaties. Over zichtbaarheid, onzichtbaarheid en het belang van lotgenoten [Citizenship in relations. About visibility, invisibility and the importance of fellow patients]. *Maandblad Geestelijke volksgezondheid* 64, no. 9: 760–74.
- Pols, J. 2010a. Telecare: What patients care for. In *Care in practice*, eds. A. Mol, I. Moser, and J. Pols, 171–93. Bielefeld, Germany: Transcript Verlag.
- Pols, J. 2010b. Wonderful webcams. About active gazes and invisible technologies. *Science Technology and Human Values*. DOI: 10.1177/0162243910366134.
- Shakespeare, T. 2006. *Disability rights and wrongs*. London: Routledge.
- Sherlock, J. 1996. Dance and the culture of the body. Where is the Grotesque? *Women's Studies International Forum* 19, no. 5: 525–33.
- Sörensen, E. 2009. *The materiality of learning. Technology and knowledge in educational practice*. Cambridge: Cambridge University Press.
- Struhkamp, R., A. Mol, and T. Swierstra. 2009. Dealing with in/dependence: Doctoring in physical rehabilitation practice. *Science, Technology and Human Values* 34: 55–76.
- Taylor, S., B. Shoultz, and P. Walker, eds. 2003. *Disability studies: Information and resources*. http://thechp.syr.edu/disability_studies_2003_current.html#Introduction
- Thomson, R.G. 1997. Feminist theory, the body and the disabled figure. In *The disability studies reader*, ed. J.L. Davis, 279–92. London: Routledge.
- Trappenburg, M. 2008. *Genoeg is genoeg. Over gezondheidszorg en democratie* [Enough is enough. About health care and democracy]. Amsterdam: AUP.
- Velpy, L. 2008. The patient's view: Issues of theory and practice. *Culture, Medicine and Psychiatry* 32: 238–58.
- Winance, M. 2001. *Thèse et Prothèse. Le processus d'habilitation comme fabrication de la personne*. Paris: ENSMP, CSI.
- Winance, M. 2007. Being normally different? Changes to normalisation processes: From alignment to work on the norm. *Disability and Society* 22, no. 6: 625–38.
- WHO. 1980. *International classification of impairments, disabilities and handicaps*. Geneva: WHO.
- Zola, I.K. 1991. Bringing our bodies and ourselves back in: Reflections on a past, present and future 'medical sociology'. *Journal of Health and Social Behavior* 32: 1–16.