The Patient 2.Many: About Diseases that Remain and the Different Forms of Knowledge to Live with Them

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The emancipation of patients, their organisation and their participation in medical research and health care policy has expanded tremendously. With these successful attempts at participation, however, there is one problem that has so far hardly been articulated and seems to be unrecognized in conceptions of the Patient 2.0 as an informed and active patient. This is the assumption that there is only one kind of knowledge that matters to patients, and to which they can contribute: biomedical knowledge. The paper explores different kinds of knowledge that patients need to engage with in their life with chronic disease, and articulates a particular form of knowledge – patient knowledge – as a form of practical knowledge that patients use and develop in order to relate to medical knowledge and live their daily lives with disease. The analysis of a small webcam community of Dutch patients with an incurable lung disease will show that patients need to *translate* medical knowledge in order to make it useful to their daily lives, and need to *coordinate* health care aims with other aims in life. Rather than looking for ways to *legitimate* their knowledge, patients try out strategies that may *work* in specific situations, even if temporarily. The paper argues for a better support of the development of patient knowledge and the practices for developing it, rather than singularly equipping people with medical knowledge that is often oriented towards cure rather than towards living with a disease that will not go away.

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Introduction

An emotional breast cancer patient on the news is angry about the investment activities of Pink Ribbon, the organization that tries to bring breast cancer to the attention of the public: 'Stop the pink violence! Instead support research to find out how metastases come into being and how we can prevent these from emerging. And how we can assure that people no longer *die* from breast cancer! That is what we want to know, and the money simply is not spent on this.' In the same news item, a representative of Pink Ribbon responds that the improvement of the quality of life of breast cancer patients instead of research is the aim of the organisation.[1] (News broadcast, 16 November 2010)

The angry patient in the quotation represents a paradoxical change in the attitudes of Dutch patient associations towards medical science, particularly those organizations that are dedicated to funding medical research.[2] The quoted patient argues that finding a 'cure' is of central importance and criticizes an organization for aiming to improve patients' 'quality of life'. Quality of life used to be of central importance for patient organizations, in addition to representing the interests of their members, organizing support for them, and lobbying for improved care. Modern medicine, on the contrary, is, in this quote, invested with the potential to 'cure', whereas breast cancer is a particularly good example of how modern medicine does not cure formerly fatal diseases, but turns them into chronic ones.

In these new alignments there seems to be no disagreement between the research practices of biomedicine and these patient organizations, and neither do their tasks appear complementary. Quite the contrary, patients and their organizations have become quite successful in participating in agenda setting in biomedical research and in guiding its development – even if critical studies have expressed doubts about the *effectiveness* of their participation. Rabéharisoa and Callon (2002), for instance, show that different types of patient organizations provide different types of input (see below), while a systematic review on studies in the participation of patients in guideline development shows that the actual contribution of patient representatives is judged by the participants to be quite meagre (Bovenkamp & Trappenburg, 2009).[3]

The close relationship between these often large patient organizations and medical research practices in their joint struggle for 'curing disease' has disadvantages. One of these is that the individuals with chronic disease who were formerly represented by patient organizations have

been transformed into terrifying – and sometimes even guilty – examples in the struggle to prevent others to become 'like them'. The lobbying attempts of these associations appear to be turning patients into undesirable presences by presenting their diseased condition as unacceptable, preventable or curable. They are not the target audience of the campaigns of these organizations; instead, the 'healthy' general public is (see picture 1 for an example).

Picture 1. COPD [a severe lung disease] is fatal. The text states: 'I have COPD. I used to crave cigarettes, now I gasp for air.' The image does not address COPD patients, but warns healthy individuals to quit smoking in order to avoid becoming COPD patients.

A related problem is that the public funds spent on funding (studies into) care and support for individuals with chronic diseases have decreased as compared to funds spent on research to 'find a cure'. As Moser (unpublished paper) has pointed out: millions are spent on research to develop treatments for Alzheimer's disease while

investments in initiatives and studies that aim to improve the situation of those who have to live with this disease are relatively modest. Although the chances of finding a treatment are slim, the utopian dream to eradicate Alzheimer's disease – and the fear to succumb to this condition – remain.[4] In the meantime, everyday care practices in which people live with a chronic condition are understudied.[5]

This paper explores yet another disadvantage of the intimate involvement of patient organizations and the biomedical sciences, which is the implicit belief that only one type of knowledge is relevant to patients. This knowledge is typically defined as *information* that stems from biomedical research practices concerning treating and curing disease. Wider notions of the Patient 2.0, in particular policies on the 'expert patient' (Edgar, 2005; Greenhalgh, 2009) or the 'informed patient' (Henwood et al., 2003; Hart et al., 2004; Kivits, 2004; Lupton, 1997) in the UK, and on the Patient 2.0 in the Netherlands (RVZ, 2011; Frissen, 2011; Van der Clauw & Flim, 2011), reinforce this idea. In these policies, patients are individuals who should learn to manage their lives better with the aim of bringing increasing health care costs under control. It is expected that providing patients with (more) medical information and technologies will support them in these efforts. Self-management here means complying with doctor's orders, while assuming that there are no conflicts between medical regimes and daily life settings (Schermer, 2009), and that patients manage – and prefer to manage – their diseases alone.

Patients emerge in different ways as active participants in policy and health care initiatives (Barbot, 2006), and in the Netherlands even in official, government sponsored *professional* patient organizations. These professional organisations form one of the key negotiating partners in developing health care policy, together with health insurance companies and care providers. This allows the government to step back from directing health care developments and make health care function as a 'regulated market' (Bovenkamp & Trappenburg, 2011; Bovenkamp, Trappenburg & Grit, 2010). Knowledge, in these discourses, is either taken to be of no interest to patients (rather, their demands and preferences are) or as identical to medical knowledge.

Multiple Knowledges and Patient Knowledge

The issue I aim to explore in this paper is how patient knowledge can be articulated as a form of knowledge amidst the multiplicity of forms of knowledge within medical practices and to argue for the need to better develop and share it. In her now classic account, Annemarie Mol (2002) has demonstrated how different forms of knowledge are present within biomedicine. One could think of genetics, physiology, and anatomy to understand these different forms of knowledge or 'epistèmes' as differences in framing objects of knowledge by enacting them within the particular practices and conditions (methods, concepts, technologies, laboratories). In this paper I aim to add to this variety by outlining what the knowledge of people living with a chronic disease or handicap might entail in relation to other forms of knowledge, and to argue for its development. What is patient knowledge, how does it relate to other forms of knowledge, and how can it be made useful to people with chronic disease?

Intuitively, it is obvious that people who live with chronic disease possess knowledge needed to do this. However, this knowledge is hardly studied in academia and is not widely available to people who might benefit from it. What *is* known is that

people rarely do what their physicians tell them to do. Rather than interpreting this as patients being 'incompliant' (un-foldable), the concept of patient knowledge helps to demonstrate why it may be perfectly reasonable for patients not to follow the doctor's orders. Rather than accusing patients of non-cooperation or sabotage, my analysis might lead to more constructive ways of negotiating treatment options. The critique on incompliance is nothing new (see e.g. Strauss, 1984; Willems, 1992), but I will attempt to add to the understanding of this critique by articulating that what people with chronic disease bring to the table can be understood in terms of *knowledge.*

To explore this, I will analyse how the understandings of patients have been conceptualized in relation to the biomedical sciences, and report some findings of an ethnographic study into a small community of Dutch people with Chronic Obstructive Pulmonary Disease (COPD) who organized themselves with the use of webcams. Through these webcams they discuss matters relating to their disease and daily lives. I will show how the knowledge they use and develop can be conceptualized as a form of practical knowledge that people use to *translate* knowledge from different sources (such as medical knowledge) in order to make it useful in their daily life, and how they need to *coordinate* this knowledge with their other tasks and goals. This means that a Patient 2.0 does not only has the task of gathering 'knowledge about his or her condition', but that s/he has to deal with different and at times conflicting types of knowledge while putting in effort to make these types of knowledge useful to their daily practices. The metaphors of translation and coordination show how 'patient knowledge' is different from 'medical knowledge', although the two are not mutually exclusive.

Sameness and Difference

How can patient knowledge and medical knowledge be different but not exclusive? One way of exploring this is to trace how they *are* often taken to be mutually exclusive. This has to do with the division of labour between the social sciences and the humanities on the one hand, and medical knowledge and biology on the other.[6] Roughly speaking, the humanities represent patients as subjects who give meaning to their illness and articulate narratives about it, which has previously also been discussed under the broad category of 'knowledge of experience'. These meanings and experiences emerge when they *diverge* from medical knowledge, or they would not be patient interpretations and observations, but *patient expertise*, showing patients who have become proto-professionals in medical thinking (Pols, 2008).[7]

Medical science, on the contrary, is assumed to study patient bodies and diseases as objects of medical interventions. It studies material and causal relationships and tests medical interventions to learn about their probable workings. Hence, culture and nature seem to be part of mutually exclusive domains. In such a dichotomy, patients have no knowledge about bodies, whereas the medical sciences have no space for narratives. This paper joins the critical analyses that question this divide by studying *practices* rather than accounts *or* bodies (Mol & Law, 2004; Pols & M'charek, 2008; M'charek, 2010; Mol, 2002; Pols, 2012).[8]

What does this mean for understanding patient knowledge? Vololona Rabéharisoa and Michel Callon distinguish three types of *concerned groups*, patient and family organisations that actively engage with biomedical research to change their situation and social identities (Rabéharisoa & Callon 2002; Callon & Rabéharisoa,

2003; 2008 Callon 1999; 2005). The first one consists of *auxiliary groups* (Rabéharisoa & Callon 2002). These are Epstein's (1995) 'lay experts', De Swaan's (1988) proto-professionals, and the patient associations I mentioned earlier. These groups consist of patients who are thoroughly socialized in the vocabularies and habits of medical scientists. The authors point out the limits of the influence of these auxiliary groups. They may either *delegate* research to scientists, or *participate as equals* by acquiring academic expertise. This leaves the auxiliary groups without anything authentic or substantial to contribute once the scientists start conducting their research. They do not challenge the 'paradigms' of biomedical research or add additional knowledge or insights. When the knowledge that patients bring to (medical) science does not differ from the knowledge that scientists produce, it becomes redundant for the production of this knowledge after research agendas have been set.

The second group Rabéharisoa and Callon (2002) describe is the *oppositional group*, which is not significant for their project. This type of group is not a concerned group that wants to *interfere* in scientific practices. Instead, they find different ways to help themselves or stick to uttering protests. However, when the concern is not 'influencing medical science' but a curiosity for different types of knowledge, it is a very interesting group for studying what these groups claim is useful knowledge to patients and to learn about its differences with the knowledge medical science has to offer. For instance, work has been done on diseases not recognized by medical experts (e.g. RSI in Arksey, 1994 and endometriosis in Whelan, 2007) and on diseases for which patients find medical knowledge and interventions unhelpful (as some 'mental health care survivors' claim, see e.g. Mowbray et al., 1998). These scholars describe patients as forming more or less coherent epistemic communities or communities of practice (Whelan, 2007; Akrich, 2010).

Rabéharisoa's and Callon's (2002) third group, for which the association concerned with Muscular Dystrophy they studied is the exemplar, is the *partner association*.[9] Characteristic for these groups is that they have knowledge of their own that they bring into play within the scientific practices they interfere with – or even help establish. They are the 'experts by experience', who formalize and organize collective expertise to produce a type of knowledge that is just as objective and authentic as that of medical specialists, Rabéharisosa and Callon argue.

In the partner associations there is a difference between the knowledge of the concerned groups and the knowledge of scientists; they are *complementary* knowledges (Callon & Rabéharisoa 2003: 196). But, given these differences, Callon & Rabéharisoa also argue that there is no intrinsic (2003: 169) or fundamental difference of status (2003: 197) between both kinds of knowledge. The people with chronic disease may use 'proto-instruments' for doing 'research in the wild', i.e., outside of the walls of laboratories, but this wild research is comparable to laboratory research in the sense that experiments are done, instruments are used, interventions are evaluated, while knowledge is accumulated, debate takes place, and results are written up (Callon & Rabéharisoa, 2003: 197-198).

How to understand sameness and difference here? Are there different forms of knowledge, different yet comparable as primitive methods? Do researchers in the wild ask different questions while developing knowledge that is equally valued? Or do they ask the same questions, but in different ways and spaces of production? Is experience medicalized, untouched, or both? Callon and Rabéharisoa (2002; 2003)

do not actually *show* their readers what the knowledge of the organization they study consists of and how it is produced. That there *are* differences is obvious, or concerned groups would cease to be influential in the production of knowledge. In this paper I want to learn more about the *particularity* of the knowledge present in the practices of people with chronic disease and disability, avoiding both the pitfall of harmoniously synchronizing their knowledge to scientific knowledge, and of opposing them by making patient knowledge so different that it drifts out of the realms of what one may call knowledge. Insight into this particularity may be helpful if patients are to have a more creative role than raising alarms and being the watchdog of the medical sciences.

Case Study: The Community of People with COPD

I will analyse one case study as a starting point for exploring patient knowledge. The case is a small community of Dutch people suffering from severe Chronic Obstructive Pulmonary Disease (COPD). COPD is a progressive lung-disease known by many as 'lung emphysema', with mine-workers, smokers, and workers in the chemical industry as the most common victims. The lungs increasingly lose their elasticity and sufferers run out of breath easily on exertion. The more severe the disease, the fewer possibilities remain for patients to move about, and some individuals hardly leave their couch at all (Habraken et al., 2008).

The patients I worked with were in a rehabilitation clinic for COPD where they stayed for a three months program, or I met them after they had just finished their three months in the clinic. Some of the patients who had returned home became friends and stayed in touch with each other using the webcams provided by the clinic.

In the clinic, patients were trained by a multidisciplinary team of professionals. They had physiotherapy classes, did sports, learned to use tools like walkers and mobility scooters, went to psychology sessions, and so on. The goal was to make people live with COPD in a better way. I conducted fieldwork and interviews over a period of six months in the rehabilitation clinic, talking to patients, carers, technicians, and managers, and attended meetings and training courses in computer use. I also followed one patient on her days in the clinic while visiting different professionals. I conducted in-depth and auto-ethnographic interviews with seven professionals and 11 patients at their homes, where I found out about the existence and the workings of the webcam community. Auto-ethnographic interviews are interviews in which the researcher asks the respondents to observe their own practices, foregrounding what they *did* next to what they thought or felt (Pols, 2010).

Patient Knowledge

The analysis gives some examples of the kind of knowledge practices the people with COPD developed to run their daily life. To frame this, I build on the work of Georges Canguilhem (1968) and Michel Foucault (1973) (see also; Struhkamp et al., 2008; Greco, 2008). Canguilhem contrasts *clinical knowledge* used by clinicians for treating patients and *laboratory knowledge* produced in the laboratory as two épistèmes (forms of knowledge) that are shaped in scientific and clinical practices, each with their own object and socio-material conditions for crafting this object. Being out of breath, for instance, is a different object in the laboratory than in the streets (Barbot & Dodier, 2002; Pols, 2011b). I will explain the theory along with the analysis of the fieldwork examples when I explore the relationships between medical

knowledge and the everyday practices of COPD patients.

Translation

For Canguilhem (1968), the laboratory stands for the medical knowledge that is scientifically produced, using methods agreed upon by – since Canguilhem: multiple[10] – medical scientific communities. Scientific practices aim to generate knowledge about the way bodies behave in particular conditions. The clinic, on the other hand, stands for knowledge developed by clinicians who treat individual patients. Their knowledge is experience-based, and is fed from various sources, such as scientific knowledge, medical tests, patients reporting trouble, and so on. It is constantly shaped and re-shaped in practice – it is tinkered with (Mol, 2008; Mol et al., 2010).[11] This also applies to patient knowledge, the patients' equivalent of clinical knowledge, but the aim and the way this knowledge is used is different. It is aimed at living daily life with disease or disability in a good way. What this 'good' entails is highly dependent on the contexts and the aims of individual patients, as I will show, as well as on their use of medical technology and scientific knowledge. What is important is that, in order to make technology and scientific knowledge useful, patients have to *translate* it. They have to make it practical. As an example, I relate the case of Mr. Hansen:

> Mr. Hansen says he was admitted to the hospital regularly and he has a supply of prednison and antibiotics in his closet, so he may start treatment quickly when it is needed. When he is admitted, he is put on a drip with corticosteroids and antibiotics immediately. He tells me that his last admission was three years ago. He says: 'The most important thing

is not to panic when I get out of breath. That helps you a long way.'

Mr. Hansen has assumed his physician's task to decide when it is appropriate to take antibiotics. In theories of self-management this may be interpreted as Mr. Hansen having obtained professional knowledge, and having become a proto-professional or expert patient, using the knowledge and know-how of professionals on the workings and use of antibiotics. And indeed, Mr. Hansen knows: 'antibiotics cure inflammations'.

From a perspective of practical knowledge, however, Mr. Hansen has different concerns. He has developed a way of knowing that is specific to the situation he is in. He needs to find out *when* he has to take his medications, and if he has to take them *now*. To explore this, his breathing is both an instrument that should be attuned for obtaining knowledge (he should not panic in order to find out what is wrong) as well as the object of knowledge (is his breathlessness caused by inflammation or something else?). Not panicking could be the intervention as well (not panicking may be the proper way to stop being out of breath). When he finds out the likely cause of his breathlessness he needs to decide if he needs medication or whether other strategies are possible.

The distinction between medical expertise and lay knowledge loses its salience here, although one could say that Hansen engages in practical ways of knowing that came from the expertise of his physicians. When articulated as a proposition ('antibiotics cure inflammations'), this knowledge is abstract. For Mr. Hansen, however, it has become *embodied* knowledge that has been transformed into a lived practical knowledge that may tell him whether he needs antibiotics *in this situation*.[12] This is a translation from clinical concerns with

antibiotics (what is in it, what does it do, and for which symptoms) towards practical ones (do I need to take these pills now, is this the proper situation for doing so?). Mr. Hansen cannot use routines, skills, or rules of thumb, but has to explore open questions every time breathlessness strikes (what is going on, what can I do).

Note that it makes sense to speak of different bodies here. The laboratory body present here is about the inflammation of lung tissue that produces breathlessness. The solution for this body is to feed it medications that cure the inflammation. Mr. Hansen's body at home is a body that may panic when out of breath, making it unable to diagnose itself while anticipating the worst scenario. Here, the remedy is to become calm. Also at home, Mr. Hansen has to find out what caused his breathlessness in this particular situation, as there may be different reasons for being out of breath. There is also a body that is shared by Hansen and his clinician, which is a body that is generally in doubt about the need to see the doctor or not. A 'bag of pills' at home is the preferred option over having patients like Mr. Hansen see his GP when in trouble, guided by the idea that Hansen is able to treat himself more promptly on his own initiative.

Palen and Aalökke (2006) describe patients who need to take different types of medication regularly. They show that these patients are not particularly concerned with the exact nature and working of every pill they take anymore. They translate 'pills for high blood pressure and cholesterol' into a task of *remembering* to take 'the blue pills thrice a day with the meals, and the white ones two times, but not with the meals, yet with milk'. They try to do this without turning their home into an open medicine cabinet by leaving visible cues for all visitors to see. They creatively invent material cues: they put the medications with the breakfast items, store the pills in different places and sequences in order to remember to take them. Hence, they translate medical remedies and technologies into practical and workable strategies within their daily socio-material practices. One may analyze this as the creation of material memories, distributed cognition or the workings of the extended mind (Bowker, 2006; Hutchins 1995; Clarke & Chalmers, 1998), here, to make the environment take part in memory work.

Coordination

The practical knowledge of patients is aimed at living everyday life with disease or disability in a good way, where what is 'good' needs to be established locally. In their daily practices, taking care of their disease is only one of the concerns these patients have. They need to combine care for their condition with other matters of importance. Apart from being ill, people are also parents, employees, partners, and so on. Even though the laboratory, the clinic and everyday life may not be in opposition to each other, they are not the same either (Strauss, 1984; Willems, 1992). They need to be *coordinated*.

> 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 my domestic work. Because, you see, I always love my house being 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 when the next day arrives, when I feel well again, I should not try to do everything at once, but keep dividing the work into small chunks. And with the kids too, I have to make it clear to

them: this is what mum can do. And yes: because mummy is short of breath now, mummy cannot, cannot do things.

It is not Mrs. Yildrim's body that is the object of doctoring. It is her love for 'tidy and clean', and for the tireless kids who want to play continuously. She needs to find ways to coordinate these matters and has to develop knowledge, skills and talent for improvisation in concrete situations. The household as well as the upbringing of the children had to be re-arranged. A clear distinction between professional and lay, or medical and non-medical concerns does not do justice to the complicated mixture of relevant variables that need to be coordinated and reorganized here. Lungs, children, love and norms of cleanliness all play a part.

Patients reported yet other problems to deal with, such as relinquishing work, difficulties and guilt feelings of involving one's spouse, the sudden depression that emerged from having to face a life very different from the one imagined before, and so on. The patients had to coordinate these matters by developing practical knowledge about them, often without professional advice to help them do so.[13] They need to coordinate different matters of concern, to set priorities and weigh different goals against one another in order to formulate an acceptable course of action. And this is not always what the doctor would think is best, or rather, this constitutes a situation in which a creative clinician may support imagining solutions. The love for a tidy and clean household may be just too strong.

Legitimation

Another difference between the 'épistèmes' of scientific and clinical (professional) knowledge is the way in which knowledge is legitimized. The knowledge of Evidence Based Medicine, for instance, provides statistical evidence to show the probable workings of particular treatments for specific groups of patients. Clinical knowledge derives its authority and reliability from the experience of the clinician that is built on a great number of observations on the way patients react to treatment and advice, as well as on the ongoing process of observing, intervening and evaluating *this* particular case. Does the patient improve? If not, what else could be done? Clinical knowledge is about tinkering and adjusting treatment and care for individuals, not about finding general evidence.

Tinkering is also part of the struggle of patients trying to deal with disease in their daily life practices. Their knowledge practices are about *improving* their situation, rather than proving that certain facts are true or effects probable (Mol, 2006; Moser, 2010). They need feasible individual strategies rather than probabilities for populations.

> Mr. Torenstra: With working it is even more difficult. When I was present at a meeting on a building site, I sometimes just stood there to watch things. And these things did not interest me in the least, if I may say so, but I needed air so badly that I would just stand somewhere to look at something with great interest. To not show your colleagues that you were out of breath. So I often came in when they were finishing their third or fourth cup of coffee. And well, at a certain point, this does not work anymore. [his face drops and the mood shifts to sadness]
> I: Then you had to relinquish work. Jeez.
> R: Yes, that is quite a blow, really. That … erm, yes … Because you think you have lots of friends, but if you are out of a job, very little remain, really [laughs].

Torenstra's strategy of using breaks for studying his environment to mask his breathlessness worked for some time, but when the situation changed, it failed. Gazing at things is not a strategy that needed proof of its probable working, but can be tried out and used temporarily. Evidence-based remedies are backed up by research, but may not work in individual cases. 'Practicing patients' have to tinker with new strategies when the old ones become obsolete. A good (legitimate) strategy here is a strategy that *works* in the setting of a particular situation, and patients find out if it does by trial and error. What 'works' may be considered in different ways, for instance by weighing short term goals with long term goals, or health gains with other concerns. There rarely is only one strategy available. Alternatives need to be considered and may also be acquired by practice.

> 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 provides more stability. Then move the upper body down, bend through the knees, use support from a wall if possible. Two women grumble that support is not often readily available. 'You can also ask someone 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.' It is pretty clear to me that they do not consider asking for help as a valid option.

What used to be a very simple task has become a difficult thing. There are different ways to deal with these difficulties, each bringing new complications. To get something from the floor may demand agility, but one could also ask for a helping hand, which implies a very different way to deal with the situation. These are among the different technical and social abilities one has to learn in order to deal with the situation, and may demand help from different resources and the training of different skills: to learn how to bend down in a better way, or to ask somebody for help. If one has trouble conquering stairs, one may take them in tranches, invite people to one's own stair-less house, take extra medication, or stop seeing stair owners. This is something patients have to figure out in each new context they are in –taking temperaments and norms into account.

Organizing Knowledge Practices: Caring Communities versus Managing Individuals

Knowledge to deal with disease may be used and developed by individuals. However, sharing experiences in a group of experts with the same type of bodies makes the development of knowledge much easier. Some of the COPD patients in my study formed a community through their webcams after leaving the rehabilitation clinic. They provided each other with support, providing advice and getting some in return. At times, they talked 'just to have a chat' or cheered up a friend who had a bad day. In this way, they provided each other with distraction, but also with knowledge.

> Mrs. Jaspersen: 'She [the webcam friend] told me some crazy things. She said that when she gets out of breath, she puts two chairs beside her own, one to the left, one to the right, and then she puts her arms on the back of the chairs.' Mrs. Jaspersen looks at me slyly, as if daring me to challenge her. Having convinced herself that I am interested, she adds: 'You know what? I tried it and it really helps me too!' Mrs. Jaspersen points out how she has pre-set the

chairs inconspicuously around her dining table so that she can quickly take up this position by only moving one chair. Dragging furniture around is not easy when you are out of breath! The arrangement has to be subtle; there is no other option when one wants the house to look spic and span at all times.

The example demonstrates how advice was exchanged and strategies refined. These kinds of practical solutions of easing breathlessness were typical for these patients. They could not be found on the internet, but demanded active 'clinical trials' by the patients. However, their findings did not travel outside this specific circle of friends and hence remained unknown to other people with COPD – and their professional caregivers

Patients also helped each other assessing what might be the matter in particular situations, foregrounding the activity of knowing rather than the exchange and development of techniques. They did this in various ways. For instance, they knew their friends well, and could see if something was wrong with them by looking at changes in their familiar appearance on the webcam. They noticed something was wrong even if the person did not report trouble verbally. They also used their bodies as diagnostic instruments for each other, by sensing if there might be reasons for being breathless other than inflammation of the lungs, such as low air pressure, pollution or panic. They used each other's bodies and experience to assess if they were dealing with a change in the weather, or whether it was time to go and see the doctor or take medication. Together they tried to figure out what was wrong and what strategy would fit this particular diagnosis.

> Mr. van Leeuwen: The contact with my fellow patients is really nice. There's always a night when you wake up short of breath, things are not working out, and then you think: Is this me, is it my illness, or what? If you can talk to another patient, and he or she feels just as bad, then you think: Well, I'm not the only one suffering today. Then it turns out that there is a storm depression coming or weather like that. That has the same effect on you as going up a mountain: less air pressure. If your breathing is bad and there's less oxygen in the air, you notice it right away, definitely. And then you see: Well, it's not just me.

With their practice, patients showed that self-management, as a way in which well-informed individuals manage their own life with the help of up-to-date medical knowledge and technologies, is not a model that fits the situation of the COPD patients. It is no fun to have a chronic and progressive disease. It helps if one can talk to knowledgeable others – experts – for advice when in doubt. The relationships in which one is not only a patient asking for help, but also a person caring for others, is motivating and rewarding, and is different from the a-symmetry of a professional caring relation. It is much easier to consult a friend when one is not sure if there *really* is something wrong. And it is also different from having to figure out things for oneself. The exchange and development of practical knowledge is facilitated by participating in a community of *patient experts*.[14]

Problems with Organizing Practices of Patient Knowledge

The Patient 2.0 as an active patient with unlimited access to *any* kind of knowledge and groups of people to share experiences with on the internet does not exclude the development of practical

patient knowledge. The internet allows for extensive networks and freedom to connect to and build communities that may be useful and rewarding to participate in. These communities do, however, develop different types of knowledge as well. The way of 'collecting data' through websites such as 'patientslikeme.com', or the collection of narratives on sites like www.patientervaringsverhalen.nl (patient experience stories) is very different from the articulation of active practices of knowing the COPD patients had organized, a form of knowledge development and exchange that is also common in smaller patient organizations. My suggestion is to articulate this latter form of knowledge or epistème of practical patient knowledge in order to make it available for others and stimulate its development. One way to do this would be to make it easier for patients to get organized, with the internet and webcams as possible tools to do this.

However, my research into webcams in a home-care setting also demonstrated that it is difficult for people to find ways to get organized. Patients experience webcam contacts as intimate contacts; they are not prepared to call 'just anyone in the phonebook'. Good relationships and friendship turn out to be a prerequisite for individuals to connect with each other through webcams. Sharing the same disease is not sufficient to connect to someone else, face to face or though webcams.

> Mrs. Quest: I'm seldom in touch with the others [COPD patients, by webcam]. I don't have time, I don't really feel like doing it. What would you get? You'd both go: 'Oh, I suffer this or that, I've got pains in my arms and legs.' And then I'd think: I don't want to know, and they don't have to know this about me. Sounds crazy, maybe, but I don't want to burden other people with my ailments. These people

> [others in the project] have COPD too. And if they said: 'Oh, I'm so out of breath and I need my inhaler!' Well, same here, but why tell everybody about it? Who needs to know? That's what I think, at least. Maybe others think it is wonderful to discuss that together. But as for me, so far, I don't need to know about other people's sufferings.

For communities assisted by ICT (or not) to emerge, creative strategies were needed to bring people together. This organization of communication needs more effort, interest and research, but it may prove to be a good strategy. People may exchange and develop practical knowledge and find this more rewarding than merely asking and receiving care from professionals or attempting to 'manage' their condition by themselves. This also fits the recent policy concerns about how to care for an aging population with a decreasing number of carers. It may be a worthy task for patient organizations to take on.

Sharing Knowledge

The small community of Dutch COPD patients constitutes only one case study. More analyses of different patient groups, using different technologies, is needed to draw both more general and more specific conclusions on what epistème can be called patient knowledge – and how many epistèmes there are. Some conclusions are already clear though. The COPD patients showed that medical knowledge from laboratories and clinics are part of their repertoire, but that people with chronic disease have to translate these knowledges and coordinate these with the different goals they have in life. Patients are not looking for a legitimation in the form of statistical evidence to test their home-made solutions. Instead, they need strategies and techniques

that *work* in their particular situation, here and now. These strategies may be of a (well-researched) medical nature or come in the guise of a suggestion to push around chairs.

The idea that patients manage their disease on their own proves to be erroneous and undesirable. People do not become alone when they become ill; they have family, friends, fellow patients, employers and others to deal with and to learn from. The COPD patients in my case study were often scared and insecure, and enjoyed to get advice and support – and provided it in return. They (we!) are socially and materially embedded individuals, not individual managers of individual lives. The technologies provided to us may support and expand on this sociality by organizing patients (e.g. through the use of webcams) or restrict this sociality by imagining care as a matter of individuals receiving cure and managing their lives.

Because of the need for a particular type of practical knowledge to support a life with disease, it is important that this knowledge does not get stuck locally, but can be practiced and shared with others. This would be a worthy task for patient associations. Rather than focusing only on biomedical research to find a cure, they may stimulate the systematisation, development, and sharing of patient knowledge needed to live with chronic disease as well as the organization of practices to do this. Scientists other than biomedical researchers might be engaged in this work: ethnographers and other social scientists, maybe nurses and physiotherapists, patients who are researchers, clinicians who understand what it means to live with disease, or mixtures of these.

Patient organizations could also engage in their classic task of organizing people with chronic disease, to provide breeding grounds for patient knowledge. There is a task for health care practices here as well. The organization of care for people with chronic diseases in groups would mean a shift from the understanding of disease as a concern for individual bodies only. This would provide people with chronic disease with places to meet and would facilitate the formation of supportive networks. Technologies like webcams and the internet can be mobilized to support caring communities and shape the Patient 2.0 as someone to share and develop practical knowledge with. This requires – at least for part of the time – letting go of the dream of cure and its paradoxical appeal to demand attention and money for something that cannot be done away with. Chronic disease is here to stay –people will have to appreciate the limits one faces when one has a chronic disease, but they can also be encouraged to creatively explore the *possibilities* that emerge for living with chronic disease in a good way. Developing and sharing knowledge and learning to relate different forms of knowledge might be just the thing for Patients 2.Many.

Acknowledgements

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Endnotes

1   See http://nos.nl/artikel/314030-pink-ribbon-gaf-18-procent-aan-onderzoek.html

2   The big funding organisations are, for instance, for cancer, cardiovascular disease, and recently: COPD and Asthma. Other large patient organisations (e.g. for diabetes) are engaged in developing 'standards of care', engaging, so to speak, in doctors' tasks.

3   See also the special issue of STHV on these matters edited by: Kontopodis, Niewöhner & Beck 2011.

4   The sociology of expectations shows how the sciences expand not by referring to matters of fact, but by cultivating hope (see Brown 2003; Brown & Michael 2003; Borup et al. 2006).

5   But see recent studies in care for examples how this may be done: Mol et al. 2010; Mol 2008; Mol & Law 2004; López & Domenech 2009; Winance 2006; Moser 2010; 2011.

6   There are of course 'disciplinary tresspassers', such as Foucault 1973; Jonsen & Toulmin 1988, Toulmin 1976; Shaikh et al. 2008; Schmidt et al. 2007; Potofsky et al. 2011, but there is no research tradition into clinical knowledge that is part of the medical curriculum. Clinical knowledge is transferred through 'bedside teaching', classes and case histories, but it is not a discipline in (medical) research in itself.

7   For an extensive review of the vast literature on patient experiences and the relation to knowledge, see Pols 2012b.

8   Foucault has eloquently criticized this division in the 'Birth of the Clinic' (1973), see also Osborne 1992 and Pols 2012, ch 2.

9   Michel Callon described another variety between the auxiliary and the partner association in 1999: associations that do not change scientific work, but enrich results with the richness of local and concrete situations.

10   As I mentioned, Mol (2002) and others showed how laboratory knowledge may be understood as multiple.

11   Tinkering comes from the French term 'bricolage', coined by from Lévi-Strauss 1966, but see also: Prior 2003; Barbot & Dodier 2002; Hester 2005; Mol et al. 2010.

12   Elsewhere I called this form of knowing 'know-now', to signal the situated and semiotic nature of this active way of getting to know things (Pols 2012b). It differs from 'skills', because it is never completely automatic.

13 Habraken et al. (2008) show that many Dutch COPD patients do not get help with these kinds of daily life questions. They see the pneumonolgist once a year, and when they are lucky, a COPD nurse every four months. It depends on the GP whether he or she will be of assistance here, because the patients usually do not ask for help. GP's may feel they have little to offer, looking at medical solutions that are lacking, rather than coaching patients in daily life problems.

14 As a contrast to *expert patients*, patients who have medical expertise, *patient experts* possess knowledge on the practical concerns of living with disease.

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