Standardising the Lay:
Logics of Change in Programs of Disease Self-management

By Annegrete Juul Nielsen & Lone Grøn

Abstract

The health political discourse on self-care is dominated by the view that the self-managing patient represents a more democratic and patient-centric perspective, as he or she is believed to renegotiate the terms on which patient participation in health care has hitherto taken place. The self-managing patient is intended as a challenge to traditional medical authority by introducing lay methods of knowing disease. Rather than a meeting between authoritative professionals and vulnerable patients, the self-managing patient seeks to open up new spaces for a meeting between experts. The present paper questions these assumptions through an ethnographic exploration of a patient-led self-management program called the Chronic Disease Self-Management Program. The program is concerned with what its developers call the social and mental aspects of living with a chronic disease and uses trained patients as role models and program leaders. Drawing inspiration from Annemarie Mol's term 'logic', we explore the rationale of 'situations of self-management' and identify what we call a 'logic of change', which involves very specific ideas on how life with a chronic condition should be dealt with and directs attention towards particular manageable aspects of life with a chronic condition. This logic of change entails, we argue, a clash not between 'medical' and 'lay' forms of knowledge but between different logics or perceptions of how transformation can be achieved: through open-ended and ongoing reflection and experimentation in social settings or through standardised trajectories of change. Returning to the literature on lay forms of knowledge and illness perspectives, we question whether programs such as the Chronic Disease Self-Management Program – despite its apparent patient-centric perspective – reproduces classical hierarchical relations between lay and expert knowledge, albeit in new forms.

Introduction

In this paper, we explore how ideas of self-care management are taking practical form in the concrete enactment of a specific disease self-management program that seeks to increase the patient's practice of self-care. Political proponents of greater patient involvement often argue that the patient – and not the professional – is the real expert on his or her condition (Danish National Board of Health 2005b; 2006; 2009).

> An observation often made by doctors, nurses and other health professionals who undertake long-term follow-up and care of people with particular chronic diseases like diabetes mellitus, arthritis or epilepsy is 'my patient understands their disease better than I do.' This knowledge and experience held by the patient has for too long been an untapped resource. It is something that could greatly benefit the quality of patients' care and ultimately their quality of life, but which has been largely ignored in the past. (Department of Health 2001: 4)

That is, by enhancing the inclusion and use of patient or lay ways of knowing disease, the health care system can support patients in becoming better self-carers as well as provide better treatment (Danish National Board of Health 2005b). As a consequence, several self-care and self-management programs have been developed over the last decade (Danish National Board of Health 2009). These programs aim to ensure that patients' knowledge of their conditions is developed to a point where they are able to take some responsibility for the conditions' management and work in partnership with their health and social care providers. The hopes associated with self-management programs are high. In the words of the British Department of Health: 'Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.'(Department of Health 2001:4). The self-managing patient is intended as a challenge to traditional medical authority by introducing lay ways of knowing disease. Rather than a meeting between authoritative professionals and vulnerable patients, the self-managing patient seeks to open up new spaces for a meeting between experts. (Danish National Board of Health 2005a). In this respect, disease self-management programs are believed to contribute to a renegotiation of the terms on which patient participation in health care has hitherto taken place.

In the following, we will question the assumption that disease self-management programs enhance the inclusion and use of patient or lay knowledge in any simple or straightforward manner. We will do so by way of an ethnographic analysis of an influential American patient self-management program, the Chronic Disease Self-Management Program (CDSMP), which is concerned with what its developers call the social and mental aspects of living with a chronic disease and which teaches participants problem-solving methods and techniques. We begin with a brief discussion of a shift within patient education, which we argue has changed

from a focus on medical compliance to emotional management. From there, we narrow our focus to describing the CDSMP's theoretical underpinnings, structure, and content and how the program works with an understanding of lay and professional knowledge as separate entities. We then present the paper's analytical framework, followed by a description of the ethnographic material on which the paper is based. The analysis considers how situations of self-management, as played out in the CDSMP, are dominated by a certain logic of change that highlights particular manageable aspects of life with a chronic condition and involves very specific ideas on how life with a chronic condition should be dealt with. In conclusion, we discuss how this specific logic of change clashes with other lay perceptions of how transformation or change can be achieved.

From Medical Compliance to Behavioural Management

Diagnosis-based patient education has been part of Western health care systems since at least the 1980s. Traditionally, patient education has targeted specific groups of patients such as diabetics, asthmatics, or heart-patients. These programs, often organised in a hospital setting, have aimed to increase medical compliance by providing patients with knowledge about their disease, medication, and symptoms (Danish National Board of Health 2005a). Diagnosis-based patient education has been taught by health professionals and often developed according to applicable medical perspectives on disease and treatment (Danish National Board of Health 2009). In the 1990s, patient education programs were criticised for not relating to problems as they are perceived by patients. The critique revolved around the focus on medical compliance not allowing and encompassing what was really the major concern of patients, namely how to manage the new life situation and its accompanying pain, disability, etc. (Lorig 1996). The critique was inspired by research within medical sociology and anthropology, where scholars like Anselm Strauss, Arthur Kleinman, Ivan Illich, and others, variously criticised medicine for patronising and silencing the patient's experience and knowledge of living with illness.

As early as 1975, the medical sociologist Anselm Strauss argued that health personnel needed to relate to the social and psychological, rather than the medical, aspects of living with a chronic disease and introduced eight common problems that most patients with chronic conditions face. Strauss also insisted that more attention needed to be given to the ill person and his or her family at home (Strauss 1975). Juliet Corbin and Anselm Strauss took this argument further in their influential work from 1988, *Unending Work and Care: Managing Chronic Illness at Home*, where they argued that psychological and psychiatric concepts inadequately describe patients' perceptions of their conditions. Corbin and Strauss introduced the concept of trajectory as denoting not only the course of the illness but also the working relationships of those who try to control and shape it (ibid.).

In *Unending Work and Care*, Corbin and Strauss also described the different kinds of work in which patients with chronic illness engage in order to manage their conditions: Work to manage symptoms, medicine, and treatment as well as role management and emotional management (Corbin & Strauss 1988).

In a similar vein, Arthur Kleinman and other medical anthropologists criticised biomedical knowledge for patronising patients by ignoring their illness narratives (Kleinman 1988), for depriving them of power over themselves and medicalising their problems (Conrad 1992), and even for causing iatrogenic effects (Illich 2010). The inclusion of lay knowledge was intended to balance the situation, provide new information in health care, challenge medical hegemony, and make clear that modern medicine does not occupy a privileged epistemological position. In his influential work *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry* (1980), Kleinman argued for the importance of understanding the illness experience from the sufferer's position. Kleinman introduced the concept of patient and practitioner explanatory models as a means of capturing lay and professional knowledge about disease. However, these concepts were subsequently heavily critiqued for resembling the medical anamnesis or case story. Kleinman addressed this critique in *The Illness Narrative: Suffering, Healing & the Human Condition* (1988) by investigating lay understandings through a more open-ended narrative approach. He proposed health and illness 'beliefs' as concepts referring to subjective accounts and experiences of health and illness. While the work on illness experience was criticised early on for its lack of attention to how power and structure shape such experience (Young 1982), there has been an ongoing concern within the field of medical anthropology regarding how both health professional and academic practices often end up reducing the situatedness and complexity of the patient experience (Kleinman & Kleinman 1995; Mattingly 1998; Biehl, Good & Kleinman 2007).

Since the seminal work of Kleinman, Strauss, and Corbin, the idea of a separate and specific lay knowledge or expertise has been seriously criticised (Lupton 1994; Bury 2000). For instance, research within the field of science, technology, and society studies has shown the diversity of ways in which people weave scientific knowledge into their own concepts of well-being (Epstein 1996; Mol & Berg 1998; Rapp 1999; Jensen 2010). This tradition argues that lay views of illness do not necessarily conflict with medical views but may in fact echo, intertwine with, or be parallel to medical views. As Linda Hogle points out, analyses based on traditional assumptions of lay and professional expertise fail to grasp the complexities that now exist in market-based health economies, where entanglements prevail that do not follow traditional understandings of power (Hogle 2002: 277). Science, technology, and society studies have thus contributed to understandings of how dominant concepts of sickness and health are circulated, incorporated, or resisted at multiple sites.

The Chronic Disease Self-management Program

The work of Strauss, Kleinman, and others has had a significant impact on the content and composition of many patient education programs. As Mattingly, Grøn, and Meinert argue, there has been a global increase in interest in and operationalisation of what Kleinman in 1980 terms 'the untapped resources of the popular sector' (Mattingly et al. 2011). In Denmark, a wide range of patient education programs have been developed. Drawing inspiration in different ways from the insights generated by Kleinman and Strauss, these programs have integrated and allocated time to such practices as participant illness narratives and patient trajectories (Grøn et al. 2012). The Danish version of the Chronic Disease Self-Management Program (called 'Learning to Live with a Chronic Disease') is one such program, describing itself as utilising the insights generated by Corbin and Strauss in teaching patients disease self-management (Lorig 1996). As described in the British version of the CDSMP:

> Patient self-management programmes, or Expert Patients Programmes, are not simply about educating or instructing patients about their condition and then measuring success on the basis of patient compliance. They are based on developing the confidence and motivation of patients to use their *own skills and knowledge* to take effective control over life with a chronic illness. (Department of Health 2001: 5; our emphasis)

This quote illustrates how the design of the CDSMP operates with a sharp distinction between medical or professional and patient or lay knowledge. Professional knowledge is described as being concerned with the biological aspects of disease and the somatic effects of proper and timely treatment and medication. In contrast, lay knowledge is described as being about motivation, confidence, and taking control of one's own life. In short, the medical view on living with a chronic condition is described as separated from and opposed to a lay view on how these conditions influence daily life – or on how patients perceive life with a chronic condition. The CDSMP is among the most influential representatives of this type of patient education, and the program has been adopted and is practiced in 23 countries worldwide. More than 80 000 patients have participated in a so called *Expert Patients Self-Management Course* in the UK alone (www.expertpatient.co.uk).

   The Chronic Disease Self-Management Program was invented at the laboratories of Dr Kate Lorig at Stanford University in the 1990s. The general CDSMP process is described as one in which participants inspire one another to find and test alternative ideas on solving both common and serious problems. Specifically, the program is organised as a series of practical workshops running for six weeks. Workshops are attended by 10 to 15 people with different chronic health problems. The workshops are led by trained leaders who must follow a tightly scripted 'Leaders' Manual'. Every minute of the course is organised using this manual, which covers content as well as interactions between workshop leaders and participants. Rigid adherence to the manual is presented as crucial in order to ensure

that each dimension of efficacy enhancement takes effect (Lorig 2003). Subjects covered include: Techniques for dealing with problems such as frustration, fatigue, pain, and isolation; appropriate exercises for maintaining and improving physical strength, flexibility, and endurance; appropriate use of medication; communicating effectively with family, friends, and health professionals; nutrition; and how to evaluate new treatments (Lorig et al. 2000).

Albert Bandura's social cognitive psychology (Bandura 1986) and his concept of self-efficacy provide the theoretical underpinnings for the changes that the CDSMP aims to bring about among its participants. Bandura promotes the importance of 'perceived self-efficacy', that is, a person's belief in his or her ability to accomplish a feat (Bandura 1997). In the CDSMP, self-efficacy is linked to individual control as expressed by the ability to determine tasks that are accomplishable and to conduct these tasks. The program operationalises the idea of self-efficacy in different ways, including weekly action plans made by participants. These plans are used to identify tasks that the planner feels confident of being able to carry out (Lorig et al. 2000).

The CDSMP has effectively framed itself as a global solution to issues of how to deal with increases in chronic conditions. By tying together particular forms of theorizing, evidence-basing and scripting the CDSMP global transportability has been enabled (Nielsen & Jensen forthcoming). However, the program has also received many criticisms including methodological and theoretical concerns (Lindsay & Vrijhoef 2009). For example, criticism has been levelled on the way in which self-efficacy theory renders the issue of control central to psychological understandings of 'thought and action'. In 'The Psychology of Control: A Textual Critique', Henderikus J. Stam (1987) argues that self-efficacy theory is capable of making the case for the special importance of establishing personal control only by separating individual agency from a host of other factors and influences. Thus, Stam suggests, self-efficacy works by 'desocializing' individuals from their social contexts, by 'deproblematizing' the relationship between structures of social relations and individual autonomy, by 'deinstitutionalizing' through lack of attention to interactions between agents and institutions, and by 'dehistoricizing' the question of social agency and control (Stam 1987: 143-8).

Analytical Approach and Empirical Materials

In her book *The Logic of Care* (2008), Annemarie Mol investigates contemporary care practices and shows that two *competing* logics are at work: A logic of care in which care is an interactive, open-ended practice and a logic of choice, in which, for instance, staying healthy is a choice made by the patient. Mol suggests that patients are not merely subjects of choice but are also subjects of many different activities. She describes her analytical approach as one in which she considers

'situations of choice' rather than focusing on whether patients can make a choice. Mol argues that this analytical approach makes it possible to show:

> ..that the ideal of choice carries a whole world with it: a specific mode of organizing action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing between good and bad; and so on. (Mol 2008: 7)

Central to Mol's analysis is her concept of logic. Mol uses the term logic to refer to particular rationales that may be unverbalised or inexplicit but that may nevertheless be inscribed into practices, habits, or technologies. In Mol's understanding, a logic is not an overarching, ubiquitous force capable of making practices coherent and defining everything within them. Logic, rather, denotes what is acceptable, desirable, and called for in a particular setting (Mol 2008: 9). Mol's use of logic resembles concepts of 'discourse' or 'modes of ordering' in denoting the way in which words, practices, and materialities at a certain time create specific, unquestioned, and culturally situated associations.

> However, I do not talk about 'discourses' or 'modes of ordering' here, but deliberately use the term 'logic'. This is because my concern is not with the ways in which socio-material orderings come into being and establish themselves, nor with the power involved in the process. Instead I am after the rationality or rather the rationale, of the practices I am studying. (Mol 2008: 8)

In analysing our ethnographic material, we use Mol's term 'logic' to inquire into the rationality ordering the specific practices and negotiations surrounding self-care management that emerge within the context of the CDSMP. Several studies have analysed and criticised the CDSMP for failing to produce its claimed effects of reduced health care utilisation among participants or for not being a catch-all expert patient program (Lindsay & Vrijhoef 2009). Previous studies have also shown how the CDSMP seeks to make commitment to and identification with 'the responsible self-managing patient' a norm that is enforced and controlled by the patients themselves (Wilson 2001; Taylor & Bury 2007). For instance, Wilson argues that although the CDSMP focuses on the rights and responsibilities of those with chronic illness, it does not simultaneously challenge professionals' assumptions toward those with chronic illnesses (Wilson 2001: 134). The patient might gain more decisional autonomy, but this is only to be used in certain situations and is accompanied by increased responsibility for illness and treatment (Wilson et al. 2007; Greenhalgh 2009). Instead of studying the specific instances of how self-care programs like the CDSMP with reference to freeing the full potential of the citizen, produce more discrete and efficient forms of social control, we turn our gaze towards the specific logic ordering action and interaction within the CDSMP. By choosing to focus on the logic ordering action and interaction within programs like the CDSMP, we wish to highlight some of the implications of the shift in knowledge base that has taken place in patient education and self-care programs.

We do so by exploring three ethnographic pieces that form part of two larger sets of fieldwork on the CDSMP. The main data consists of interviews and observations from two CDSMP programs from two Danish Municipalities in 2006 and 2010. Between November 2006 and July 2008 and again in the fall of 2009 Juul Nielsen carried out participant observation of the CDSMP at a municipal health centre in Copenhagen as well as of the trained leaders program. Juul Nielsen also participated in two networks in relation to the CDSMP: A regional network within Region Zealand in which trained leaders and municipal coordinators exchange experiences on various issues related to the CDSMP as well as a network that organises an annual national workshop and meeting for CDSMP coordinators and trained leaders (Nielsen 2010). Lone Grøn and colleagues carried out observation of the CDSMP and interviewed with participants, trained leaders, educators, and the people in charge of the program in 2010 (Grøn et al. 2012).

The content of the analysis is thus based on a finely grained and detailed coding and analysis of the quite substantial material of the two studies, and the specific examples have been selected on account of their ability to capture the most important features observed. Specifically, we will highlight three important features of this logic: The reduction of complexity, the silencing of suffering, and the introduction of fixed trajectories of transformation.

The Reduction of Complexity

The following piece of ethnographic material is from the very first day of the CDSMP. The workshop has not started on time due to the late arrival of one of the participants who is in a wheelchair: The elevator got stuck, so she could not get to the classroom on the second floor. This delay has made the two trained leaders quite anxious since they have to make it through the entire program within the timeframe. The session starts with the trained leaders welcoming everybody and explaining the agenda of this first meeting as well as a few practical details. They explain that the first exercise is about what it is like living with a chronic disease and that everybody has to say how old they are, their specific diagnosis, and state the two primary problems they experience in relation to their condition. One of the trained leaders begins by presenting her own diagnosis and difficulties, which are summed up by the other as centring on 'anxiety' and 'problems of movement'. These words are written on the whiteboard.

> Sigvald, the oldest male participant, starts out by narrating that he is 79 years old, that he has suffered from COPD since 2004, and that his lung capacity has been measured at 37%. He seems sad when offering this information and continues: 'I shake so much that I have a hard time getting the words out, and my hands are shaking too.' One of the course guides attempts to find a word to put on the overhead: 'Could you say "motor skills"? Difficulty with motor skills?' Sigvald does not seem convinced: 'It means that I can't participate in family reunions. It's difficult for me to get out, so we've retired a bit …,' he says, glancing at his wife sitting next to him. The second course guide again asks if they should label that which has been reduced

> or is lacking as 'motor skills'. It still does not seem as if Sigvald agrees that the difficulty of reduced 'motor skills' encapsulates his predicament. The second course guide writes 'reduced motor skills' on the whiteboard.

In Sigvald's short explanation, he blends bits and pieces of medical and lay information about his diagnosis and problems. First, he names his medical diagnosis using the acronym for Chronic Obstructive Pulmonary Disease, COPD, assuming that the other participants are familiar with the disease. In order to indicate the severity of the disease, Sigvald relates the percentage of his remaining lung capacity left, namely 37 %. He follows up with a description of how this condition affects his daily life: He talks about the tremors, which impede both his ability to 'get the words out' and interfere with his hand movements. The trained leader, anxious to find a word that sums up Sigvald's situation, suggests 'motor skills'. As a way of indicating that 'motor skills' hardly sums up his situation, Sigvald elaborates on the effects of his condition and describes how it is causing increasing isolation and retirement from family life. This new piece of information paints a picture of the condition's all- encompassing effect on Sigvald's daily life – everything from breathing to movement to participating in family reunions. This information is not, however, commented on or taken in by the trained leader, who is still eager to describe Sigvald's condition using a single term. When the other trained leader again suggests reduced motor skills as a descriptive label for Sigvald's condition, Sigvald simply glances at his wife. He does not actively challenge the label, but obviously is not satisfied either.

After Sigvald, the other participants make their statements one by one, taking us through diseases as diverse as back problems (for one participant, due to a failed operation), arthritis, a brain tumour, ischia, Parkinson's disease, and pulmonary fibrosis as well as a long list of problems stemming from these conditions. Two younger women give their presentations at the end of the round.

> Dorthe tells us that she is 45, gives a Latin name for her disease, and continues: 'In case you don't know, it's chronic infection of the bowels.' She's gone through surgery and has had part of her colon removed. This has given her problems with her stomach, and she often needs to use the bathroom. This affects her psychologically because she cannot move around without constant awareness of the location of restrooms, and she suffers from exhaustion because she cannot absorb the amount of nutrients that her body demands. Dorthe also briefly relates that she has a hole in one of her valvulars and that she has had skin cancer. The diseases have made her anxious, uncertain, and depressed. The second trained leader again struggles with the precise words with which to capture the woman's story and she seems slightly annoyed by this.

> The last participant is a 21-year old woman named Karina, and she starts out by mentioning that she has problems with a herniated disc, a cyst, and whiplash. She relates very briefly and matter of factly about her disease: 'Should I talk about feelings too?' she asks the trained leaders, who do not quite know how to answer. Karina continues: 'It causes problems with headaches and concentration.' 'Thanks,' says the trained leader, looking first at her watch, then at the participants. They have all had between 40 and 80 seconds in which to tell their stories. She sums up by pointing at

the whiteboard: 'We can see that you actually share many of the same problems. Now we have to proceed to the tools for dealing with these common problems.'

As was the case with Sigvald, Dorthe's situation proves difficult to condense into just a couple of words. Like many other participants, Dorthe suffers from several different and quite severe diseases – both physical and psychological in nature. In her short narrative, Dorthe paints a picture of a daily life characterised by bowels problems, anxiety, physical exhaustion, uncertainty, multiple diagnoses, depression, and reduced mobility. The complexity of Dorthe's situation and suffering is, however, addressed by the trained leaders as a question of finding the one or two words that can 'encapsulate' her experience. As with Sigvald, no words of compassion or sympathy are uttered in response to Dorthe's story. By the time the round moves on to the last participant, Karina, she has picked up on the course format for how to present one's condition. Karina describes very matter of factly that she suffers from three severe diagnoses. Despite this hardly being a situation experienced by most 21- year- olds and thus presumably a far from easy situation to be in, Karina willingly reduces her situation to something that can be written on the whiteboard, namely headaches and problems with concentration.

As the stories of Sigvald and Dorthe illustrate, participants do not turn up at the course perceiving or thinking of their conditions and how they affect their daily lives in ways that can be easily summed up with two descriptive labels. Rather, they perceive their problems as quite complex and related to the individual situations they face. However, the introductory round not only introduces participants to each other but also to the logic of the program. The 12 individual and complex illness narratives are transformed or standardised into a few words written on a whiteboard. Some of the words (often pain, social isolation, anxiety, reduced mobility) have been ticked off several times, signalling that more than one participant has mentioned this as one of his or her major problems. Rather than dwelling on the participants' own perceptions of their problems, the program starts out by standardising the participants' illness narratives to the course format. Complicated or complex phenomena are transformed into simple ones. This serves several purposes. First, it is to make clear to the participants that what they might previously have thought of as an individual complex life condition is, in fact, common and shared by the other course participants. Second, the reduction of complexity aims to make the problems faced by the participants seem more manageable. As the trained leader states: 'Now we have to proceed to the tools for dealing with these problems.'

The reduction of complex phenomena into simpler, more manageable ones transcends the entire enactment of the CDSMP. One of the most striking and recurrent features for many of the participants is the constant concern with maintaining time and format throughout the six workshops. The uneasiness of the trained leaders caused by the late arrival of one of the participants is but a small example of the pervasiveness of time and format within the program. While the

tight time management no doubt serves the purpose of keeping the workshop within a timeframe manageable for people living with chronic conditions, the tight time schedule and rigid adherence to manuscript also acquires other functions and is ascribed different meanings in the enactment of the program. It could be argued that one of the reasons for reducing, for example, complex illness narratives to single words is merely a 'practical' matter of not letting the introductory round go on for hours. However, over the course of the workshops, it becomes clear that the tight time schedule also supports a specific *logic of change* that organises action and requires that situations and problems be presented in a short and manageable way. as illustrated in the introductory round. It is not only a concern with time management but more broadly with a specific approach to transformation or a logic of change that the participants are to learn, take up, and embody for the duration of the program. Next, we will focus on another important feature of this logic of change: The silencing of suffering.

The Silencing of Suffering

In the following piece of ethnographic material, we are several weeks into the program, and some of the participants have acquired the specific logic of change, which orders interaction within the program. During a problem-solving exercise, a participant, Birte, is talking about her problems arranging a trip that she wants to take but that she finds overwhelming. The other participants and the trained leaders are brainstorming possible solutions to Birte's problem.

> Birte says: 'Yes, I guess I should figure out what to bring.' 'You could write it down,' the trained leader suggests. Birte still seems overwhelmed, almost resigned: 'I'm used to being able to plan, but with what I have now, I can't do anything. I could've been an administrator!' Another female participant suggests that Birte should get her volunteer health visitor to help her do the planning. 'I can only sit on my ass!' Birte responds, as if she did not hear her, and the other participants seem frustrated by Birte's insistence on her suffering: 'But we're all in the same boat, Birte. You have to tell yourself that you need to look at the positive side of things. It's just small steps. You want everything, but it's small steps,' the female participant says. The trained leader then suggests that Birte should look at the three-wheeled bicycle that she has talked about before, but Birte says that there is a problem with the weather. The trained leader now seems irritated too and remarks that, in that case, the bike will be ready for spring! 'So you can start looking forward to that,' the other female participant suggests. But Birte continues: 'Then there's the damned walker … can I get in to town with that one? I have a handicap. It doesn't look good. I feel embarrassed.' Birte looks very unhappy by now.

By insisting that no easy solutions can be found and that the situation is painful, Birte is not complying with the logic of change, which organises interaction in the program, and she is told so indirectly by the other participants and the trained leader. The logic of change underlying the program insists that Birte handle her problems by acting on them, for example by focusing on manageable parts or elements of the problem. Insisting that the problem is painful, in the way Birte does,

is deemed to be incorrect behavior. The logic of change is thus also characterised by the silencing of suffering, as problems are only dealt with as things that can and must be acted upon. The silencing of suffering also occurs in precisely that form, that is, through silence. In one situation, a mother mentions that she has had a hard time and has actually never really gotten over the fact that her son died when he was nine years old. Presented with this type of profound suffering, instances of unsettlingly long silence appear. Finding a manageable element that can be acted upon in order for the participant to feel proactive and in control of things does apparently seem inappropriate to both the trained leaders and other participants. However, as the logic of change organising interaction in the program does not offer strategies for this kind of profound suffering, silence ends up being the only response. We now turn to the final feature that we see as characteristic of the logic of change guiding the CDSMP, namely fixed trajectories of transformation.

Fixed Trajectories of Transformation

In the last field note excerpt, we are at the end of a session and are about to go through the participants' individual action plans. As described earlier, an action plan is a concrete tool for change, specifying a concrete action to be done in the following week. A scale from 0 (completely unconfident) to 10 (completely confident) is used to indicate how realistic the plan is. In this ethnographic piece, we move from talk of suffering to the tools applied to it, to the kinds of actions that are intended to remedy suffering. A participant, Vagn, is going through his action plan for the following week:

> Vagn: 'I'll walk 15 minutes a day.' He does not seem overly enthusiastic or engaged in the exercise. He leans back in the chair and continues. 'I guess I'm at 7 or 8 because of pain and the weather, which could have an impact on whether I will get out.' One of the trained leaders looks at him worriedly: 'Do you think it is realistic then, doing it 7 times a week?' 'If the weather is like last week – sunny!' he replies with a crooked smile. 'Maybe you should lower your goal to four times a week to make room for a couple of days with bad weather?' the trained leader asks. 'But then I'll always only get out the last four days of the week,' Vagn replies – and the trained leader seems to give up. Nobody says anything for a few seconds. Then Emmy starts out in a low voice: 'I'm not sure … I attend a COPD program three times a week and then this on Wednesdays.' The trained leader asks: 'Could your action be to continue doing that?' Emmy pauses, we all know that a proper action has to be something new, but then she nods. 'Or do you have other action plans?' the trained leader asks quickly. Emmy: 'Sometimes I do yoga exercises on pillows at home. But it's difficult getting it done. I don't always have the energy'. The trained leader suggests: 'Could it be a small exercise?' Emmy: 'It could maybe be once a week, and then it would be a 6 instead of twice a week, which would get a 5.' The trained leader nods: 'Good luck to you!'.

Vagn and Emmy both understand the concept of the action plan, but they differ in the way they engage with it. Vagn challenges the trained leaders' attempt to make him downsize his ambitions in order to reach the desired goal, by offering a dif-

ferent perspective on how to initiate change and transformation: by making an ambitious plan in order to reach a goal that is a bit lower - or at least to avoid setting standards too low. While you could argue that this shows that Vagn actually knows something about himself and how he achieves change, this is not in line with the CDSMP, where the desired goal of 'self efficacy' is believed to come about via a very specific 'mechanism': The making and keeping of a simple and realistic plan of action. What is at stake here is not the content or volume of an action but the learning of a specific trajectory of transformation. As was the case with the participants' illness narratives, CDSMP's action plan format standardises the participants' individual understandings of how lifestyle change is achieved. Although some participants like Vagn may bring other perspectives of change and transformation to the fore, the weekly sessions of planning and relating last week's action plan show participants that self efficacy can only be strengthened by following a fixed trajectory of transformation: To first plan and then successfully carry out an action, no matter the content or the size of the action. In practice, this often entails participants being asked to scale down their ambitions in order to gain 'realism', which also means that the actions planned will be reduced from going for a walk every day to, for instance, cleaning up in the kitchen drawer or writing a Christmas card. Or, in cases like Emma's, participants are asked to engage new routines or actions when they already seem to be in over their heads. The need to comply with program format overrules individual perceptions or needs. Continuing a given action is not within the transformative trajectory that participants have to learn. It is stated clearly in the program concept that the action plan has to be about a new activity, not just something that you are already doing. Although she initially tries to adjust the format to Emma's specific situation, the trained leader realises her mistake and asks for any new action that Emma can identify as the content of a new action plan.

As we have argued, the logic of change that organises action and interaction in the CDSMP emphasises manageable problems. Some participants find this strategy rewarding in terms of creating more confidence, joy, satisfaction, self-worth, etc. It might even be the only possible kind of action, pragmatically speaking. However, as we will discuss more in depth in the following paragraph, the emphasis on manageable problems and actions does seem to come at a price in terms of the kinds of problems, actions, and selves that are blinded out. This includes problems and sufferings that do not go away and to which there are no singular or straightforward solutions, actions that demand careful judgment in order to determine the highest good in complex situations of conflicting concerns, and the kinds of selves who are crafted through situated and ongoing reflection and experimentation in social contexts. In the final part of this paper, we will discuss competing logics of change to the one dominating the CDSMP and will return to the sociological and anthropological writings on lay knowledge and patient perspectives in order to discuss these findings.

Competing Logics of Change in Self-care and Self-management

In the present paper, we have explored the notion of the self-managing patient, denoting a more democratic and patient-centric perspective, which challenges medical authority by introducing lay ways of knowing disease. Through an empirical analysis of the enactment of a specific self-management program, the CDSMP, and the identification of a specific logic of how patients perform self-care through fixed trajectories of change, we have challenged that this is the case in any straightforward or simple manner. As the empirical analysis has illustrated, the program's aim of developing patients' confidence in and motivation to use their own skills and knowledge to take effective control over life with a chronic illness is challenged in the enactment of the CDSMP by other elements of the program's design. The demands of rigid adherence to the program's tight time schedule, the use of action plans as the prime tool of (self-)transformation, and the trained leaders' use of a manuscript leaves little room for individual and situated illness experiences and practices. Thus, despite intentions of addressing problems as they are perceived and experienced by patients, the CDSMP leaves little room for the complexity and suffering expressed by some of the participants. Rather, a very specific logic of change organises action and interaction and teaches the participants to distinguish between good and bad responses to a given problem or challenge that they experience. The logic of change ordering the enactment of the CDSMP is first of all characterised by equating self-care with action. The correct response to a problem or challenge is always to *act*, never to 'wait and see', accept complexity, or try to ignore the pain of the issue at hand. The logic of change ordering the enactment of the CDSMP is also characterised by directing attention towards the more manageable aspects of life with a chronic condition and by standardising the trajectories of how changes are decided and achieved. The operationalization of social cognitive theory in weekly action plans as the prime tool for bringing about change produces a new standardised knowledge of what life with a chronic condition entails and how one should live with such conditions.

As seen in the analysis, this logic of change occasionally clashes with other logics or perceptions of how transformation can be achieved: Some participants insist on leaving room for the suffering, which is part of their life. Other participants insist on change being brought about by other means, like setting too lofty a goal in order to achieve something slightly less ambitious. The opposing logics of change introduced by the participants can be characterised as ad hoc, messy, and situated (Grøn 2005). Rather than universal claims of how lifestyle changes must be enacted, some participants seem to insist on the existence of uncontrollable aspects of life. This entails that the clash comes to revolve around different 'logics of change' rather than between lay versus biomedical perspectives. The clash no longer is between a lay versus a biomedical understanding of disease and its proper treatment. With patient education and self-care programs like the CDSMP hav-

ing shifted their knowledge from medical compliance to emotional and role management, the clash comes to revolve around how the individual patient can perform care of the self and obtain desired lifestyle changes. The clash between the lay and the professional, we argue, is now between different perceptions of how change or transformation comes about: Through open-ended ongoing reflection and experimentation in social settings, allowing for situatedness and complexity of the illness experience, or through standardised trajectories of transformation.

Standardising the Lay

In this paper, we have shown how the logic of change ordering the enactment of the CDSMP leaves little room for individual illness experiences and practices. Returning to the literature on lay forms of knowledge and illness perspectives, it can therefore be questioned whether programs like the Chronic Disease Self-Management Program reproduce classic hierarchical relations between lay and expert forms of knowledge (albeit in new forms) rather than further a patient-centred approach. Keeping the work of Strauss and Kleinman with which we began this paper in mind, the expertise practiced in the CDSMP is not so much the patient's but that of social cognitive psychology. More time and effort are used to learn and rehearse making changes and performing problem solving, as it is prescribed by the program's logic of change, than on the participants' sharing of their own experiences, knowledge, and perspectives on life with a chronic condition. The expertise practiced in the CDSMP is not so much embodied by the participating patient as by the program manual, the time schedule, the weekly action plans, etc. The critiques that the fields of medical sociology and medical anthropology levelled against biomedicine in 1970s and 1980s specifically addressed the biomedical reduction of the complexities of patients' lived experience. Both Strauss and Kleinman developed analytical strategies that sought to make it possible to incorporate the patient's perspective into both academic and health professional understandings and strategies. However, the way in which these insights are operationalised in the CDSMP seems quite far from the original intentions described earlier in this paper. In this light, it seems fair to question whether the use of social cognitive psychology in the CDSMP is taking on the role that biomedicine was criticised for playing in patient education programs in the past – since the logic of change ordering the CDSMP also works by reducing and standardising the lay illness experience.

by The Danish Ministry of Health and Prevention and the Region of Southern Denmark.

Annegrete Juul Nielsen is an assistant professor at the Department of Public Health at the University of Copenhagen. Her research broadly investigates how health care technologies are enacted in relations between health policy, clinical practice and patient lives. Particularly, Annegrete Juul is interested in global relations and infrastructures between health systems, produced in relation to transfer and global dissemination of health care technologies. E-mail: anjn@sund.ku.dk

Lone Grøn is an anthropologist, Ph.D., and senior researcher at KORA, Danish Institute for Local and Regional Government Research. Lone Grøn has done extensive research in patient perspectives on chronic conditions, health education and self-care. In particular, Lone Grøn has worked with the significance of clinical and everyday contexts for behavioral change. E-mail: lg@dsi.dk

References

Bandura, Albert (1986): *Social Foundations of Thought and Action*, New Jersey: Prentice Hall.
Bandura, Albert (1997): *Self-Efficacy: The Exercise of Control*, New York: W.H. Freeman.
Berg, Marc & Annemarie Mol (1998): *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, Durham, NC & London: Duke University Press.
Biehl, Joao, Byron Good & Arthur Kleinman (2007): *Subjectivity: Ethnographic Investigations*, Berkeley, Los Angeles and London: University of California Press.
Bury, Michael (2000): *Health and Illness in a Changing Society*, Second Edition, London: Routledge.
Conrad, Peter (1992): 'Medicalisation and Social Control', *Annual Review of Sociology*, 18, 209-232.
Corbin, Juliet M. & Anselm L. Strauss (1988): *Unending Work and Care: Managing Chronic Illness at Home,* San Francisco: Jossey-Bass.
Danish National Board of Health (2005a): *The Patient Education Program: Living a Healthy Life with Chronic Disease*, Report on Pilot Test, Copenhagen: Danish National Board of Health.
—— (2005b): *Chronic Disease: Patient, Health Care System and Society*, Copenhagen: Danish National Board of Health.
—— (2006): *Patients with Chronic Diseases: Self-Monitoring, Self-Treatment and Patient Education*, Copenhagen: Danish National Board of Health.
—— (2009): *Patient Education: A Health Technology Assessment*, Copenhagen: Danish National Board of Health.
Department of Health (2001): *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*, London: Department of Health.
Epstein, Steven (1996): *Impure Science: AIDS, Activism and the Politics of Knowledge*, Berkeley, Los Angeles and London: University of California Press.
Greenhalgh, Trisha (2009): 'Chronic Illness: Beyond the Expert Patient', *British Medical Journal*, 338, 629-631.
Grøn, Lone (2005): *Winds of Change, Bodies of Persistence. Health Promotion and Lifestyle Change in Institutional and Everyday Contexts,* PhD dissertation, Aarhus: Department of Anthropology and Ethnography, University of Aarhus.

Grøn, Lone, Martin S.Buch, Mikka Nielsen, Eline Boisen & Laura E.B. Rahbæk (2012): *Egenomsorg og patientuddannelser i grænsefladen mellem medicin og humaniora*, DSI rapport. København: Dansk Sundhedsinstitut [Self-Care and Patient Education in the Borderland between Medicine and the Humanities, DSI Report, Copenhagen: Danish Institute of Health Care Services Research].

Hogle, Linda F. (2002): 'Claims and Disclaimers: Whose Expertise Counts?', *Medical Anthropology*, 21:3-4, 275-306.

Illich, Ivan (2010): *Limits to Medicine. Medical Nemesis: The Expropriation of Health*, Harmondsworth: Penguin Books.

Jensen, Casper Bruun (2010): *Ontologies for Developing Things: Making Health Care Futures through Technology*, Rotterdam: Sense Publishers.

Kleinman, Arthur (1980): *Patients and Healers in the Context of Culture. Explorations in the Borderland between Anthropology, Medicine and Psychiatry*, Berkeley, Los Angeles and London: University of California Press.

—— (1988): *The Illness Narrative: Suffering, Healing & the Human Condition*, New York: Basic Books.

Kleinman, Arthur & Joan Kleinman (1995): 'Suffering and Its Professional Transformation: Toward an Ethnography of Interpersonal Experience', Arthur Kleinman (ed.), *Writing at the Margin. Discourse Between Anthropology and Medicine*, Berkeley, Los Angeles and London: University of California Press.

Lindsay, Sally & Hubertus J.M.Vrijhoef (2009): 'Introduction – A Sociological Focus on "Expert Patients"', *Health Sociology Review*, 18:2, 139-144.

Lorig, Kate (1996): 'Chronic Disease Self-Management: A Model for Tertiary Prevention', *American Behavioral Scientist*, 39, 676.

Lorig, Kate & Halsted Holman (2003): 'Self-Management Education: History, Definition, Outcomes, and Mechanisms', *Annals of Behavioral Medicine*, 26:1, 1–7.

Lorig, Kate, Holman Halsted, David Sobel, Diana Laurent, Virginia Gonzáles & Marian Minor (2000): *Living a Healthy Life with Chronic Conditions: Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema & Others*, Colorado: Bull Publishing Company.

Lupton, Deborah (1994): *Medicine as Culture: Illness, Disease and the Body in Western Societies*, London: Sage.

Mattingly, Cheryl (1998): *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*, Cambridge: Cambridge University Press.

Mattingly, Cheryl, Lone Grøn & Lotte Meinert (2011): 'Chronic Homework in Emerging Borderzones of Health Care', *Culture, Medicine and Psychiatry*, 35:3, 347-375.

Mol, Annemarie (2008): *The Logic of Care: Health and the Problem of Patient Choice*, London and New York: Routledge.

Nielsen, Annegrete Juul (2010): *Traveling Technologies and Transformations in Health Care*, PhD thesis, Copenhagen: Copenhagen Business School Press.

Nielsen, Annegrete Juul & Casper Bruun Jensen (forthcoming): 'Travelling Frictions: Global Disease Self-Management in Local Versions', *Science Studies*.

Rapp, Rayna (1999): *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, London: Routledge.

Stam, Henderikus J. (1987): 'The Psychology of Control: A Textual Critique', Henderikus J. Stam, Timothy B. Rogers, & Kenneth J. Gergen (eds): *The Analysis of Psychological Theory: Metapsychological Perspectives*, Washington: Hemisphere.

Strauss, Anselm (1975): *Chronic Illness and the Quality of Life*, Saint Louis: The C. V. Mosby Company.

Taylor, David & Michael Bury (2007): 'Chronic Illness, Expert Patients and Care Transition', *Sociology of Health and Illness*, 29, 27-45.

Wilson, Patricia, Sally Kendall & Fiona Brooks (2007): 'The Expert Patient Programme: A Paradox of Patient Empowerment and Medical Dominance', *Health and Social Care in the Community*, 15:5, 426-438.

Wilson, Patricia (2001): 'A Policy Analysis of the Expert Patient in the United Kingdom: Self-Care as an Expression of Pastoral Power?', *Health and Social Care in the Community,* 9:3, 134-142.

Young, Allan (1982): 'The Anthropologies of Illness and Sickness', *Annual Review of Anthropology,* 11, 257-285.