

# Travelling Frictions: Global Disease Self-Management, Local Comparisons and Emergent Patients

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Contemporary disease self-management programs aim to renegotiate the terms on which patients participate in their own health care. Though the notion of 'patient 2.0' has mainly been used to speak to patient empowerment through IT, we therefore propose to view self-management as eliciting "the patient" in a different shape. In this paper, we explore the embedded assumptions, imagined potentials and concrete practices of the Stanford Chronic Disease Self-Management Program (CDSMP), in order to understand how this program reconfigures a particular form of global patient. To analyse this process we consider the CDSMP as a traveling technology. First, we demonstrate that its successful globalization has been enabled by tying together specific forms of theorizing, evidence-basing, and scripting in a theory-methods package. Second, we show that the globalization of the program entails various forms of localization in the national health care setting of Denmark. In this context, we examine different kinds of efforts required to maintain the 'global' identity of the program even as it is 'localized'. In particular, we show that the insertion of the program into Danish health care generates frictions. Such frictions are brought to light comparatively as Danish health care policy-makers, practitioners, consultants and chronic patients engage with and reflect upon the characteristics of the program. We argue that this analysis holds implications for 'patient 2.0', both as practical accomplishment and as a conceptual tool for social studies of medicine and health care.

*Keywords:* comparison, friction, globalization

## **Introduction: New Forms of Global Patients?**

The current global focus on patient involvement is often described as a response to the fact that health strategies have failed to recognize how people can play a positive part in building healthy lives (cf. Department of Health, 2001; Danish

National Board of Health, 2005a). Over the past decade, various self-management programs have seen the light, aiming to empower patients to perform self-care and participate in their own treatment. In the UK alone, more than 80.000 patients have participated in the so-called *Expert Patients Self-Management Course*.<sup>1</sup> Disease self-management programs would thus

seem to play a central role in the discursive construction and practical enactment of new forms of patients.

The notion of patient 2.0 is mostly used to characterize patient empowerment achieved through the use of information technology. Bos et al., for example, define patient 2.0 empowerment as 'the active participation of the citizen in his or her health and care pathway with the interactive use of Information and Communication technologies' (Bos et al., 2008: 167). It is not surprising that the terminology of patient 2.0 is affiliated with IT; after all, the notion mimics terms such as web 2.0. Even so, this usage, which specifically defines the new patient in terms of his or her interactions with information systems, is too delimited. And indeed, this special issue invites us to explore patient 2.0 as a rubric with which to sharpen analytical attention on all manners of novel patient configurations. Thus, our starting point is that in disease self-management programs, patients, too, come face to face with new roles and expectations. Such programs, too, aim to reconfigure the terms of patient participation and create new forms of empowerment. Thus, they instantiate emergent forms of patient 2.0.

Supporters of disease self-management programs argue that they bring about a win-win situation. Not only the individual patient but the health care system at large benefits when patients are trained in disease self-management. Such programs are said to empower individual patients to interact pro-actively and competently with health care systems. Their aim is to put the patient at the centre of the care process. In turn, this is thought to increase the quality of life among the chronically ill. When patients emerge as active, responsible and self-caring, resources are freed that can be spent on less resourceful patients (Lorig et al., 2001).

But if self-management programs create new forms of patients, they raise important questions in turn. Which assumptions about patients are embedded in these programs? Where do they come from? How are they expressed in practice? Such questions are crucial to address in order to understand the consequences of these programs, both for health care systems and for (new kinds of) patients.

We ask these questions with reference to the Stanford Chronic Disease Self-Management Program (CDSMP), which is concerned with the social and mental aspects of living with a chronic disease. Teaching its participants methods and techniques of problem solving in the context of living with chronic disease, this program has effectively framed itself as a global health care solution to the problems of chronic patients.

In the following, we explore several aspects of the CDSMP to learn more about the construction of a particular version of patient 2.0. First, we examine the process through which the program has managed to achieve its astounding level of success. Second, we examine how the program works to maintain its 'global' identity and coherence in the Danish national health care system. Third, we show that the insertion of the program into Danish health care generates frictions. Such frictions are brought to light *comparatively* as Danish health care policy makers, health care practitioners, consultants and chronic patients engage with and reflect upon the characteristics of the program. We end with a discussion of the implications of the analysis for an understanding of patient 2.0 as practical accomplishment and as a conceptual tool for social studies of medicine and health care.

## Methods and Empirical Materials

The paper is based on two sets of material. In order to explore how the CDSMP has been turned into a standardized health care package and enabled to travel globally, we rely on articles, reports and manuals published by Kate Lorig and her colleagues (e.g. Lorig et al., 1998; 2000; 2003) at the Stanford Patient Education Research Center. We also view as part of our data material psychologist Albert Bandura's (e.g. 1986, 1997) writings on self-efficacy theory, the assumptions of which are embedded in the CDSMP. This 'data set' is completed by other research that has critically engaged the CDSMP (e.g. Lindsay & Vrijhoef, 2009). These approaches are themselves part of the data, since they help us understand the emergence of the CDSMP as a theory-method package.

In order to examine the entrance of the CDSMP into Danish health care settings, we draw on whitepapers and reports concerned with the Danish adoption of the program. Most substantially, we draw on Nielsen's fieldwork, which concentrated on the enactment of the CDSMP in Danish health care (Nielsen, 2010). This fieldwork was conducted between November 2006 and July 2008, and in the fall of 2009. During these periods, Nielsen carried out participant observation at a municipal health centre in Copenhagen and with the CDSMP trained leaders program. Additionally, she participated in two Danish networks related to CDSMP: a network within Region Zealand, in which trained leaders and municipal coordinators exchange experiences, and a network, which organizes yearly national workshops and meetings for CDSMP-coordinators and trained leaders. From this substantial body of material we draw in particular on one patient's reflections on the frictions generated by the implementation of the

CDSMP in the Danish health care system. Her observations are especially evocative because of their explicitly comparative dimension and their marked contrast with official evaluations. Obviously, we do not claim that this patient represents all Danish perspectives on the matter. We choose to engage her concerns, well aware of their singularity, because of the particular clarity with which they articulate the frictional processes to which the travelling CDSMP gives rise.<sup>2</sup>

## Scripts, Packages, and Travelling Comparisons

Our approach is informed by a number of concepts developed in STS generally, and studies of science, technology and medicine in particular. We take as our starting point Annemarie Mol and Marc Berg's observation that 'medicine is not a coherent whole. It is not a unity. It is, rather, an amalgam of thoughts, a mixture of habits, an assemblage of techniques' (Mol & Berg, 1998: 3). This is why a focus on the 'ideals and ideas of medicine' is insufficient; it is necessary also to pay attention to 'practices and performances' (Mol & Berg, 1998: 3).

How to keep in view ideals and practices at once? Madeleine Akrich (1992) proposed one way forward in her work on technological scripts (see also Dodier, 1998: 53-54 on 'frames'). When creating objects, Akrich argued, innovators 'necessarily make hypotheses about the entities that make up the world into which the object is to be inserted. Designers define actors with specific tastes, competencies, motives, aspirations, political prejudices, and the rest' (Akrich, 1992: 207-208). They then inscribe these properties in their objects. For the analyst who would unpack such processes, this entails the requirement to 'go back and forth continually between the designer and the user, between the

designer's project user and the real user, between the *world inscribed in the object* and *the world described by its displacement*' (Akrich, 1992: 208-209).

In her studies of molecular biology, Joan Fujimura (e.g., 1987; 1988) offers a related view, which addresses the issue of standardization. She suggests that the packaging (cf. Akrich, 1992: 215) of theories and methods into standards makes for 'highly transportable' entities through the 'deletion of context' (Fujimura, 1988: 266). Fujimura discusses the benefit conferred on practitioners who use such packages in terms of 'doability'. Problems, she argues, 'are more or less doable depending on how difficult it is to articulate among levels to create alignment' (Fujimura, 1987: 262); for example, between specific scientific experiments, laboratories, and broader social worlds of research and application. Standardized packages that can travel between the 'levels' increases doability by decreasing articulation work (Fujimura, 1987: 277).

These analyses indicate that the ability of entities, programs, or technologies to travel is strongly related to standardization. Our case brings out this insight, which also suggests that the making of 'patient 2.0' is as much about homogenization as it is about enabling the recognition of diversity and individual choice. Yet, this is only one side of the story. For, as Akrich (1992) emphasized, tracing the actual effects of any package requires a continual movement: 'back and forth between the designer and the user'. This analytical movement makes visible that standards by themselves are not able to standardize (Jensen, 2010: 51-68), since they are dependent on a heterogeneous set of other actors. Accordingly, CDSMP cannot be understood simply in terms of homogenization, for its users also attempt to translate, challenge or undermine the program through *their* activities. Patient

2.0 is the *effect* of this interplay between standardization and translation.

Packages like the CDSMP never travel effortlessly, and the larger the distances (in terms, for example, of geography, or forms of organizing health care work or cultural understandings of health) the more effort is required to keep standards standardizing. Hence, travelling packages often gives rise to what the anthropologist Anna Tsing has described as frictions: 'Rubbing two sticks together produces heat and light; one stick alone is just a stick. As a metaphorical image, friction reminds us that heterogeneous and unequal encounters can lead to new arrangements of culture and power' (Tsing, 2005: 5). Broadly stated, frictions are generated when projects with universal aspirations encounter actors and institutions with different ideals and practices. In particular, we argue, frictions may intensify when travelling theory-methods packages *insist* on their unproblematic universality. Whereas Annemarie Mol and Marianne de Laet (2000) beautifully showed the flexibility of technologies designed with fluidity in mind, our case is about frictions arising when a deliberately inflexible technology travels.

These insights into travelling packages, standardization and friction form an indispensable backdrop to our analysis. We add to these concerns a discussion of comparative devices inspired by the anthropologist Atsuro Morita (Morita, forthcoming). In his ethnography of Thai mechanics, Morita noted that the Japanese harvesting machines they used were not only 'practical', technological devices, but also objects that evoked cultural comparison. Thus, the breakdown of a rotary cultivator was interpreted by the mechanics as resulting from the difference between Thai and Japanese environments. Morita argues that this knowledge was derived comparatively by Thai mechanics' interpretations of the 'relations embodied

in the machines they manipulate' (Morita, forthcoming). The breakdown of the cultivator, he suggests, 'produced a double vision in which the Thai and the Japanese environments were seen *at once* through their difference.'

In the following we draw on Morita's insight to analyze the CDSMP as a travelling health care package, the movements of which gives rise to travelling comparisons and frictions (Morita, 2013).

### **From Medical Compliance to Self-Management**

Diagnosis based patient education has been part of Western health care systems since the 1980s (Lorig, 1996). Traditionally, patient education has targeted specific groups such as diabetics, asthmatics or heart-patients and aimed to increase patient compliance by providing patients with knowledge of their disease, medication and symptoms (Danish National Board of Health, 2005b; 2009). In contrast with these initiatives, the CDSMP represents a new type of patient education. The novelty is in its focus on the social and mental aspects of disease rather than on compliance.

The CDSMP was developed during the 1990s by Dr. Kate Lorig, based at Stanford University, in collaboration with the California based health organization Kaiser Permanente.<sup>3</sup> In 1979, Lorig created the Arthritis Self-Management Course, which became the prototype for the CDSMP. According to Lorig and her colleagues (2003), existing types of patient education did not address the issues that really mattered to patients. For example, traditional arthritis education programs focused on disability management, while the major concern of patients was pain. Referring to the work of the medical sociologists Juliet Corbin and Anselm Strauss's (1988), Lorig and her colleagues argued that arthritis education programs should teach information about

managing disability *in the context of pain management*. Inspired by psychologist Alfred Bandura's work on self-efficacy, they further argued that patient education programs should relate to problems as *perceived by patients*.

The CDSMP can thus be characterized as a psycho-educational program designed to increase the capacity for self-management of people with chronic conditions. The aim is to improve participants' self-efficacy and their 'performance attainment' (Lorig & Holman, 2003), thereby enabling them to manage their health conditions more effectively. Concretely, the program is organized as a series of practical workshops that run for six weeks. Twelve to eighteen people with different chronic health problems participate in these workshops, which cover techniques to deal with frustration, fatigue, pain and isolation, appropriate exercises for maintaining and improving strength, flexibility, and endurance. Also, the program offers advice on the appropriate use of medications, on communicating effectively, and on how to evaluate new treatments (Lorig et al., 2000).

In these workshops, psychologist Albert Bandura's (1986; 1997) concept of self-efficacy is operationalized in different ways. In weekly plans, for example, patients are requested to identify tasks that they feel confident they are able to carry out, such as 'This week I will walk around the block once before lunch on Monday, Tuesday, and Thursday'. Self-efficacy is thus linked to *individual control* as expressed in the ability to determine tasks that are accomplishable and to actually conduct these tasks. But whence did self-efficacy arrive?

### **A Matter of Control**

Lorig's (1996) early arthritis studies were more or less a-theoretical. However, she became increasingly interested in creating an analytical foundation for understanding

observed improvements in health status. Lorig hypothesized that these improvements were related to patients' feelings of being more in control of their illness. During this period, the CDSMP came to draw increasingly on Albert Bandura's notion of self-efficacy. As Bruno Latour (1987: 22ff.) famously argued, the credibility of scientific statements depends on the gradual 'deletion of modalities,' through which what are initially controversial claims end up as unequivocal representations of facts. We therefore consider the appeal of self-efficacy for CDSMP, and look into how its 'modalities,' problems, and qualifications, were removed and evidence in its favour rendered indisputable.

At the time of Lorig's arthritis studies, Alfred Bandura, also at Stanford University, had been refining his psychological theory for years. His famous *Social Foundations of Thought and Action: A Social Cognitive Theory* from 1986 offered a wide-ranging discussion of psychological 'models of human nature and causality' (Bandura, 1986: 1-47). *Social Foundations* also defined Bandura's own contribution – the social cognitive model, which was later renamed as self-efficacy theory.

The intellectual context for the development of the concept of self-efficacy was one in which many psychologists were wary of the excess of 'environmental determinism' affiliated with radical Skinnerian behaviourism. Bandura, however, did not completely retreat from the implications of behaviourism. Rather he aimed to put cognition back into the picture. In *Social Foundations* he proposed a model in which 'human functioning is explained in terms of a model of triadic reciprocity in which behaviour, cognitive and other personal factors, and environmental events all operate as interacting determinants of each other' (Bandura, 1986: 18). Thus, he characterized 'human functioning' by

three forms of 'capability': symbolizing, forethought and vicarious.

One might wonder how the environmental determinism of behaviourism can be connected with symbolization and forethought. Bandura solved this problem by suggesting that behaviourists had failed to extend the environment *far enough*. People do act in response to their environment, he argued, but this environment includes *even their own minds*. Thus, even though: 'self-regulatory functions are fashioned from, and occasionally supported by, external influences,' he emphasized that an act 'includes among its determinants self-produced influences' (Bandura, 1986: 20).

Yet, this interactive argument faded to the background as *Social Foundations* turned to description of types of motivators and self-regulatory mechanisms located within individual agents. This inclination towards individualism was radicalized in the discussion of perceived self-efficacy. Perceived self-efficacy was defined as 'beliefs in one's capabilities to organize and execute the courses of actions required to produce given attainments' (Bandura, 1997: 3). Thus, Bandura argued that perceived self-efficacy is an especially generative capability that often allows subjects to overcome environmental obstacles. Precisely this claim was picked up by Kate Lorig and embedded in the CDSMP (1996).

Centred on individual control, self-efficacy theory is deeply infused with a common-sense Anglo-American perception of agency. Famously designated 'possessive individualism,' this perspective assumes the agency of people to be exhibited in the form of autonomous and individualized acts (MacPherson, 1962; cf. Stam 1987). In this: 'version of agency ...self-contained agents who "own" their actions, and demand to be accorded a series of rights and responsibilities' (Brown, Ashmore & MacMillan, nd: 24). As we shall see, this

is just how patients are conceived in the CDSMP.

### **Evidence-Basing the CDSMP**

Evidence has become a key word in the medical vocabulary (Timmermans & Berg, 2003). As Eric Mykhalovskiy and Lorna Weir observe, evidence has gone well beyond the confines of medicine proper (Mykhalovskiy & Weir, 2004: 1060). Thus it is of little surprise that evidence-basing was a crucial factor in allowing the CDSMP to travel globally. For the developers this raised the thorny question of how it would be possible to evidence-base a self-management program. Bandura's (1986; 1997) work on self-efficacy offered a set of hypotheses and experiments, which in turn provided both an analytical foundation and a practical inspiration for accomplishing this feat. Bandura's experiments had centred on measuring the effects of self-efficacy. Yet, self-efficacy as such cannot be observed and thus cannot be directly measured. However, by focusing on perceived self-efficacy, it seemed possible to circumvent the problem. Thus, individuals can estimate their ability to accomplish some task (holding a snake, for example) and this estimation can be compared with their subsequent ability to actually do so.

On this basis, Lorig's experiments proceeded to determine whether changes in perceived self-efficacy were associated with changes in health status. In the mid 1990s, a randomized controlled trial was conducted to evaluate the effect of CDSMP. Approximately 1,000 people with heart disease, lung disease, stroke or arthritis participated in this three-year test. When compared to a group of patients who did not follow the program, the participants demonstrated improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress,

fatigue, disability, and limitations in social activities. They also spent fewer days in the hospital, and had fewer outpatient visits and hospitalizations. Lorig and colleagues argued that their data suggested a cost to savings ratio of approximately 1:4 (Lorig et al., 2001).

But what was the status of this evidence? In fact, self-efficacy did not shed its modalities easily. Critics of Bandura had argued early on that 'self-efficacy theory is conceptually problematic,' since 'the central concept of efficacy expectations is not unambiguously differentiated from outcome expectations' (Eastman & Marzillier, 1984: 213). Very similar criticisms were raised against the evidence base of the CDSMP. Thus, Brady (1997) argued that studies that purport to measure self-efficacy levels in relation to managing arthritis, in fact measure outcome expectations. But like Bandura's dismissive response to earlier criticisms, Lorig and Holman (1998: 155-7) argued that Brady had simply misunderstood the concept.

A number of additional methodological and analytical issues were also raised (cf. Lindsay & Vrijhoef, 2009). Taylor and Bury (2007) noted that Lorig attributed the positive effects of the self-management program to enhancement of participants' levels of self-efficacy rather than to obtained information or learning specific techniques. Several studies problematized the claim that the CDSMP leads to a reduction in the use of health care services (Gately et al., 2007; Greenhalgh et al., 2005; Lindsay et al., 2009). Finally, Greenhalgh argued that the randomized trials were based on carefully selected patients and biased towards white patients with health insurance (Greenhalgh, 2009)

As far as we are aware, none of these criticisms have had any significant influence on the subsequent development and testing of the CDSMP. Indeed, the fact that the program has generated vigorous debate

may have helped it to gain visibility and authority (Nielsen, 2010). In turn, this has vastly improved the ability of the program to travel. In the current perception of health care administrators and policy-makers, the program is indeed based on evidence (Danish National Board of Health, 2009). Evidence-basing the program allowed its developers to simultaneously present scientific credentials *and* use research articles as a platform for telling the story of the importance of CDSMP in multiple venues. As a testament to this strategy, a selected list of publication on the program's homepage in 2012 counted 70 articles and 11 books. Among them were articles and commentaries in highly esteemed medical journals like *British Medical Journal* and *The Lancet*. Thus, the efficacy of self-efficacy had been established.

### Scripting Global Health Care

We have argued that a particular translation of self-efficacy theory into the CDSMP and a subsequent effort to evidence-base the program facilitated the ability of the program to travel. Now if evidence of effect is a crucial feature of the program, it is of central import to ensure that the program remains the same when it leaves the laboratory and moves into 'natural' health care settings. To understand this effort to *maintain identity*, we draw on Madeleine Akrich's (1992) analysis of the scripts embodied by technical objects. So how has the CDSMP been scripted?

As mentioned the CDSMP was developed as a collaborative research project between Stanford University and Kaiser Permanente. In 1997, The Garfield Foundation funded a 3-year process evaluation of the dissemination process (Lorig et al., 2005). Based on the results, Lorig and her team developed a number of recommendations for global dissemination

of the CDSMP. These were later turned into an implementation manual (Stanford, 2008).

The implementation manual contains a detailed description of all aspects of the program. It describes the process of training expert patients to run the program, and outlines how each part must be conducted and how patients should be selected and managed. Rigid adherence to this detailed script is required because it ensures that the program remains evidence-based no matter where it goes. Every minute of the course is organized using a 'Leader's Manual', which covers content as well as interactions between leaders and workshop participants.

The program is built around a hierarchy of certified trained leaders. At the top are the so-called t-trainers (trainers of trainers), who are allowed to teach and certify master trainers. T-trainers are educated by leading a master trainer course while receiving supervision from another t-trainer. Such trainers can only be certified at Stanford University. In the middle of the hierarchy we find master trainers. The master trainer is allowed to train patients who lead the program. In four-day workshops, the 'master trainer aspirant' leads a trained leader workshop and reflects on the purpose of each activity. Master trainers make it possible to sustain the CDSMP locally since they are allowed to recruit and certify trained leaders. Finally, at the lowest ladder, we find these trained leaders. At trained leader workshops every activity in the program is rehearsed by participants and master trainers.

Trainers are taught at the same time how to identify patients fit to join the program and patients fit to become trained leaders of the workshops. As regards the latter, the manual admonishes trainers to 'be a little cautious' about whom they encourage. Problematic types include persons whose 'main focus in life is their chronic condition';

‘people who are super achievers despite their chronic condition’ (exemplified by ‘people who have had an amputation and run marathons’), ‘people who are judgmental’, ‘people who have “found the answer” to their disease and want to share it with the world’ and people ‘too sick to teach effectively’ (Stanford, 2008: 7-8).

The second dimension of the CDSMP script is licensing. Although the CDSMP is meant for public use and benefit, the program is also for-profit. Thus, Stanford copyrighted its training program for leaders of the CDSMP. Before an organization can offer the CDSMP it must therefore purchase a license. The license establishes the legal obligations of the implementing organizations and protects Stanford’s intellectual property. It also enables Stanford to keep track of the network of all licensed organizations.<sup>4</sup>

In combination, these requirements and procedures instantiate the CDSMP script. The script packages together training of (patient) leaders inside a structure that facilitates a particular selection of patients via a licensing agreement that ensures that Stanford is able to control its global use. Each of these requirements is bound up with the need for the program to remain evidence-based, thereby enabling it to travel. Thus, self-efficacy, evidence-basing and scripting are all tightly interconnected. Together, they have turned the CDSMP into a globally travelling health care package. We now turn to consider how it travelled to Denmark.

### **The CDSMP Travels to Denmark**

Danish health care is a so-called Beveridge-type system, which means that it is based on general taxation and covers all inhabitants. Most services are offered by public providers at the regional or local level. Access to a wide range of health

services is basically free of charge (Olejaz et al., 2012). Currently, a range of self-care and disease education programs form part of Danish national health services. They are offered by municipal and regional health care institutions and by patient associations (Danish National Board of Health, 2005c; Grøn et al., 2012). Among these, the CDSMP is presently the most widespread. In 2012, 71 out of 98 Danish municipalities offered this program. How was this astonishing coverage brought about?

In November 2005, the Danish National Board of Health sent out a press release, which stated that the board recommended the adoption of CDSMP as part of the national health system. It described the CDSMP as ‘a cheap and effective tool to secure the many hundred thousand Danish citizens living with a chronic condition a better life’ (Danish National Board of Health, 2005d).

Prior to this announcement, the board, in partnership with the Danish Arthritis Association and the counties of Copenhagen and Ribe, had conducted a pilot test with thirty-two arthritis patients. The purpose had been to determine whether the CDSMP was culturally acceptable in the Danish context, and to examine the appropriateness of the organizational set-up within the Danish health care system. In conjunction with the pilot test, managing doctors, nurses and occupational therapists participated in a number of workshops, where a representative from the Stanford Patient Education Research Center demonstrated the program. Also during this period, the official program course book was translated into Danish, and seven people were educated as master instructors at Stanford (Danish National Board of Health, 2005b).

The excitement with which the CDSMP was greeted was not unique. Indeed, at the start of the new millennium, self-care, self-monitoring, holistic patient trajectories

and patient education were much debated in Danish health care policy. The general context of these debates was the pressing question of how to strengthen national health care with a view to future challenges, especially the increasing number of chronically ill (Danish National Board of Health, 2004; 2005a; 2006). In 2003, the National Board of Health initiated the Public Disease Project, the goal of which was to develop an idea catalogue of disease prevention that would enable the integration of health promoting efforts and treatments. The CDSMP was selected as a test case and became one of the initiatives targeting patients suffering from muscular and skeletal diseases.

The idea catalogue lists a number of reasons for choosing to test the CDSMP (Danish National Board of Health, 2004). First, the CDSMP aligned with the above-mentioned political interests. Second, the use of experienced patients as workshop leaders and role models was emphasized as an asset. Third, this meant that the CDSMP was cheap: Apart from the cost of training patients to lead the program, and the purchase of the course itself, it required few resources. Finally, the program was described as effective, since it had been evidence-based. It was thus found to be implementable within the existing organizational structure of Danish health care.

Highlighting the effectiveness of the CDSMP, the catalogue pointed to the fact that the program was also used in many other countries. Indeed, the pilot group had visited both Norwegian and English health centres to gain first-hand knowledge of their experiences. The catalogue refers to the British experiences in very positive terms: the results included increased patient involvement, documented effects of better self-care, more physically active patients and less contact with the National

Health Service. Summarizing, the catalogue presented the CDSMP as a catch-all program, which would be effective across different chronic conditions and patient populations (Danish National Board of Health, 2004: 12-13). Shortly after the catalogue was published, the Danish National Board of Health purchased a CDSMP license from Stanford.

### **Global Standards Meet 'Cultural Diversity'**

The CDSMP has travelled to countries as diverse as Denmark, Saudi Arabia, Japan, Australia and South Africa. As noted, the program is both sold and bought on assumption of its universality. Even so, the contexts in which the program will be put to use are not universal, but specific, often national. This relation between universality and specificity creates the potential for frictions. Frictions arise as the assumptions embedded in the program's script rub up against the expectations of its new users; it is a 'reminder of the importance of interaction in defining movement, cultural form, and agency' (Tsing, 2005: 6). From the point of view of CDSMP's developers, the aim is to maintain the global coherence of the program even as it travels. This is probably why the CDSMP are at pains to address issues of cultural appropriateness (Stanford, 2008). From the point of view of its users, however, the program has to somehow fit into a complex set of already existing health practices.

The CDSMP implementation manual takes a great deal of care to describe special considerations for working with the program in different cultural settings - as it is said: 'even your own.' The concept of cultural humility is used to designate an approach to cultural issues, characterized by avoiding stereotypes since: 'One size seldom fits all' (Stanford, 2008: 24). Even so the manual also insists that its program activities are:

designed to be as near as possible culturally neutral. This means that they are usually acceptable in any cultural setting as long as the leaders and participants are from the same culture (and sometimes socioeconomic status) and the workshops are offered in a site and at a time that is culturally acceptable for the population being served (Stanford, 2008: 23).

The manual gives examples of the smooth adoption of the CDSMP in very diverse settings. As an example it offers the case of First Nations People in Canada:

We have been surprised at how well some of the exercises worked with tribal people who I'd have thought would be reluctant. When we held a focus group with rural First Nations People in Canada, they wanted longer sessions so that they would have time to sit around and talk before the program started. They quickly reminded us that their diet was mostly wild animals and berries. They wanted few other changes. When we did the same thing with urban Indians in the United States, they changed the symptom cycle to a Native symbol and added a short prayer. With Native American communities, either prayer or silent reflection is added to the beginning of most classes and more emphasis is placed on low fat low salt foods (Stanford, 2008: 24).

Strikingly, the 'necessary changes' among rural First Nations communities are very minor and strictly 'cosmetic.' In the Danish context, too, cultural diversity issues were raised and resolved with reference to cosmetic adjustments.

## **Circular Comparisons and Cosmetic Adjustments**

As noted, the CDSMP was tested to determine whether the program was acceptable in the Danish context. The National Board of Health hired a private consulting company, Rambøll Management, to conduct the evaluation. The evaluation report provides an entry point for analyzing the traveling frictions and local comparisons of the CDSMP.

To determine whether the program was appropriate, Rambøll defined a number of indicators. They related to such themes as relevance, the quality of course materials and cultural transferability. The overall conclusion was that the program was indeed transferable and that patients with chronic conditions would benefit from it. However, despite the recommendation to disseminate the program in Denmark, the evaluation also indicated certain problems:

On the two first days of the workshop the master instructors experienced some resistance against the program, which was perceived as too rigid, blunt, inflexible and impersonal. According to Kate Lorig, this is common, as the program breaks with ordinary teaching principles and requires adaptation. It is Kate Lorig's experience that resistance disappears as the participants experience on their own body that the process works for them and as they see that it works for other participants. This also happened during the third day of the demonstration project's trained leader workshop (Danish National Board of Health, 2005b: 14).

In fact, the report mentions several problems and challenges. Participants questioned different aspects of the program including its length, particular activities and

effects. However, each line of criticism is rebutted in the way illustrated by the quote. The recurring answer is that the program rests on many years of experience and has been thoroughly tested. Each criticism has been encountered before and is already taken into account. Readers are assured that the effectiveness of the program means that eventually 'resistance disappears.' This is a striking example of what we might term *circular comparison*. What is at issue is the question of cultural difference. When something resembling such difference is encountered, however, it is rejected because the program is already known to be globally effective. Since the program is solidly based on experience and evidence, there can be no truly important cultural issues. Therefore, there are no such issues. While differences are thus by no means overlooked – since they are explicitly discussed – they are analysed in such a way that they cannot help but be subsumed under the program's taken for granted universality.

An interesting example is afforded by the question of cultural applicability. Eight out of thirteen participants from the pilot demonstration in Ribe County in Western Denmark responded that they regarded some aspects of the program to be problematic. In comparison, none of the participants from Copenhagen had any similar reservations. The evaluation report interpreted these differences in the following way:

It is thus possible that attitudes towards the program's applicability come from a generally skeptical attitude among the provincial participants towards applying American concepts in a Danish setting rather than a concrete skeptical attitude toward this program. However, to determine whether this is the case goes beyond this report (Rambøll, 2005: 23).

On the one hand, the report thus argued for the importance of ensuring cultural applicability. On the other hand, concrete questions or reservations were dismissed, or explained away, with reference to peculiar cultural tendencies, such as a 'generally sceptical attitude' said to characterize 'provincial participants' in contrast to the supposedly more internationally oriented Copenhageners. Eventually the report reached the conclusion that the only relevant 'cultural adaptation' was the removal of an activity where participants had to assign 'A durable power of attorney'. This requirement was found by Danish participants in general to be 'too American'.

In conclusion, the report reiterates the necessity of appropriateness:

As regards the transferability of the concept to a Danish setting, the four partners [performing the pilot test of the program] agree that it is doable as long as the translation of the program, adjusts the concept to Danish circumstances and culture, while at the same time being loyal to the [program's] method. It has been necessary to "peel off" the American approach, but the opinion is that the concept as such is generalizable (Rambøll, 2005: 41).

The report does not elaborate what is meant by the 'American approach' but assumes the ability of Danish readers to recognize it. More importantly, however, the quote suggests that, whatever the American aspects of the program might be, they are located at an outer layer that can be peeled off. What will be left after such peeling has taken place is the core of the program: precisely that which is not American but universal. The National Board of Health accepted these arguments and concluded that the program could be implemented with only minor adjustments.

## Eliciting Comparative Frictions

As far as Rambøll and the National Board of Health were concerned, Kate Lorig's perspective on the CDSMP was thus vindicated. In this interpretation, the Danish health care system and its patients may have a few distinct traits, but this does not subtract from the universality of the CDSMP. Rambøll's circular comparisons evoked no real frictions.

Yet some Danish patients engaged in different comparisons. In these comparisons, the qualities of the CDSMP approach were elicited, not as global and universal (with an American coating), but as distinctly *un-Danish*. In contrast with Rambøll's interpretation, these comparisons did bring to light frictions. In this section, we focus on a set of comparisons made by one critical patient participant. Of course, we do not think that this patient is representative of the views of Danish patients at large. We choose to engage in detail with this comparative statement because it offers a particularly vivid depiction of the frictions to which the CDSMP gave rise as it entered Danish health care. This is important, not least, because these frictions are so perspicuously absent from official documentation like the Rambøll report.

Here is what the patient told us:

Whoever has conducted it [the evaluation of CDSMP] has made a strong selection of patients. And that's what you have to be careful about because that is what is selling the program. I am quite critical about precisely that issue. Because you lose everyone else. You put this group of patients on a pedestal and say they are great, it's just the others that can't be bothered. I am being too crude but it [the CDSMP] requires so many resources. It definitely has in my case,

with this condition, and it is no joke. It really has taken a lot of effort.

This statement, we suggest, offers a sophisticated comparison between the embedded assumptions of the CDSMP and the Danish health care system. First, the patient accuses the evaluation of a selection bias. In this, she unknowingly repeats academic criticisms of the CDSMP (Greenhalgh, 2009). She then notes that the claim to 'catch all' patients is a matter of salesmanship. Her experience is that the program is not for everyone as it 'requires so many resources'. According to this participant, the program includes only 'elite' patients. At the same time, it individualizes blame for those unable to join by suggesting that they simply cannot be bothered. Doing so, the program risks 'losing everyone else', that is, losing the majority of weak patients. Pointing to the strongly individualized version of patient-doctor relationships enacted by the CDSMP, the description articulates friction between the program's universal claims and the realities of at least some Danish patients.

In addition, the statement embeds a comparison of the different institutional contexts of American and Danish health care.<sup>5</sup> It defines the CDSMP as a zone of friction where different concepts of health care encounter one another. The individualized mode of interaction that undergirds the CDSMP exemplifies such a difference. Specifically, the participant's assumptions about the role of the health care system as a 'care taker' of sick citizens are challenged by the CDSMP. To reiterate, our point is not to judge the accuracy of the patient's view. Rather, the aim is comparative. Clearly, for this patient, the CDSMP 'produced a double vision' in which Danish and American health care environments 'were seen *at once* through their difference' (Morita, forthcoming).

Though the patient personally finds the CDSMP rewarding, her comment circles around the expectation that the health care system should be for everyone regardless of individual capacity. She complains that a program focused on self-management and efficacy is prone to lead to unequal health outcomes, privileging those who have sufficient resources to fulfil its obligations. In that sense, she articulates one of the central pillars of the welfare state: that the individual is never entirely free but always to some extent shaped by 'environmental factors'. If certain patients cannot be 'bothered' to join the program, this can be presumed to relate to their social position (cf. Danish National Board of Health, 2009: 87ff). Her critical remarks also make clear that the health care landscapes inhabited by patients (new or old) are moral ones. Pointing to the difference between welfare health care as it 'ought to be' and as it 'is becoming' with the introduction of the CDSMP, the comment points to the existence of social and institutional differences that are not merely cosmetic and that cannot be resolved by minor adjustments. These are differences in the relationship patients have to themselves, to the health care system, and even to society at large.

Unpacking this single quote has allowed us to glimpse a whole set of presuppositions, embedded in the CDSMP, about the relationship between patients and health care systems. An entire 'institutional analysis', which makes clear that the assumptions of the CDSMP are by no means universal, is thus wrapped up in this comparison. Reversely, the assumptions of the participant herself are *also* brought to light as a consequence of the distinctions she draws between her expectations of Danish health care and what the CDSMP delivers. In this sense, too, we are witness to comparison as a 'double vision', one that inevitably also has its own blind spots.

### Traveling Frictions: Holding Together the Global and the Local

Those who make a practice of comparing human actions are never so much at a loss as to put them together in the same light; for they commonly contradict each other so strangely that it seems impossible that they have come from the same shop (de Montaigne, cited in Ezrahi, 1990: 15).

By now the CDSMP is a tightly scripted program that comprises a number of interrelated components. As a theory-methods package, it has succeeded in turning chronic disease management into a 'do-able problem' (Fujimura, 1987) on a worldwide scale. It is sold as a universal solution and it has global success.

We have shown that CDSMP's ability to "go global" was achieved by some very specific means. It involved transforming the program from an un-theorized, 'experiential' entity, into a theorized, evidence-based one. It involved constructing a detailed script which interrelated every part of the program in a standardized whole. Finally, this standardized solution was premised on the configuration of a new form of patient, who is individually self-possessed, 'self-efficacious' and capable of taking charge of his or her own health destiny. Yet to our Danish patient interlocutor, and to other critics of the program (such as those briefly mentioned, only to be dismissed, in the Rambøll report) this universal patient seemed to carry traces of its American context of development. The CDSMP, in other words, is at once global – since it has spread all over the world – and local – since its assumptions are by no means universally held. While packaging the CDSMP into a tightly interrelated whole has facilitated its dissemination, various components of the program were also contested as it travelled. Thus, we have highlighted some

of the ongoing efforts, and the continuous vigilance, required to maintain the program's global identity.

Outside of Stanford, a host of actors with different interests in, and interpretations of, the CDSMP became entangled with it. In particular, we emphasized how the program gave rise to a series of comparisons in the Danish context. Rambøll and the National Board of Health evoked a number of circular comparisons that downplayed issues of institutional or cultural difference. Looking closely at the critical and evocative remarks made by one patient participant, we elicited a different set of comparisons, which addressed the CDSMP from the point of view of its assumptions about the relations between patients and the health care system at large. Viewing the CDSMP as a technology, we were thus enabled to trace some of its travelling frictions. This analysis suggests that the program not only embodies a script; it attempts to transport an entire standardized context. It is precisely the discrepancy between this context and the Danish one that is articulated by the patient's comparisons.

As already noted, we do not claim that this comparison provides us with a basis for making general claims about the reception of the CDSMP among Danish patients. Indeed, even if the vividness of the comparison and its exemplary status in contrast with official views is granted, the scope of the analysis that we have offered might yet be queried. After all, the patient herself qualifies her interpretation as 'too crude'. The crudeness to which she refers is in the claim that the CDSMP unequivocally distinguishes between good patients, who are put on a pedestal, and bad patients defined by their laziness. The analytical crudeness that we might replicate in relying on this depiction is one that sees the CDSMP as wholly individualized in contrast with a wholly social Danish system. Insofar as we had traced in ethnographic detail the new

sociotechnical networks into which patients are spun, this black and white picture would quickly blur (see Nielsen & Grøn, 2012).

However, rather than taking this route, by now so routine in STS, we have aimed to engage these on-going transformations of health care systems and patients from the point of view of the comparative 'double vision' to which the CDSMP gave rise. While this has enabled us to trace some connections in the emergent networks of global healthcare, the central issues on which we have focused are different. In particular, our analysis raises comparative questions concerning why and how culture, society and institutions matter for health care initiatives – and, not least, for patients. So what does the trials and tribulations of the CDSMP teach us about patient 2.0?

### **Patient 2.0 as Fiction and Practice**

As noted in the introduction, patient 2.0 is often defined in terms of the use of information technology for health purposes. The increasing availability of health information means that patients may gain a more active role in managing their diseases. This is said to reconfigure the role of patients, and empower them vis-à-vis doctors. As we have seen, a similar ideal of patient empowerment inspires the CDSMP and other self-management programs. Indeed, new forms of patients may be created by much more varied transformations of and in health care than those directly relating to the use of information technology. At the same time, our analysis allows us to pose certain critical and reflexive questions concerning the notion of patient 2.0. Thus, we note that arguments for patient empowerment via information technology and via self-management are premised on similar dreams of universality. 'The universal bridge to a global dream beckons to us' in both cases (Tsing, 2005: 85).

One way to understand patient 2.0 is to consider the term as describing a new form of patient that is emerging globally. This approach accepts that initiatives like the CDSMP produces qualitatively different kinds of patients. This is a claim that Kate Lorig and her colleagues would support: it is one they are already making (Stanford 2008). Yet it is quite insufficient from the point of view of social studies of health care and medicine, which must look closer at the frictions 'between aspiration and practical achievement' (Tsing, 2005: 85, see also Mol and Berg, 1998). For such studies, we need to focus not only on ideals and aspirations of health care but also on 'messy and surprising' practices (Tsing, 2005: 3). We are obliged to consider in much more detail whether, how, and how generally, new forms of patients are produced – and with what consequences. Only by doing so can we know whether self-management allow us to glimpse new and truly global forms of patients or, rather, bring us face to face with the emergence of groups of 'expert' patients that, while certainly new, are very specific (Nielsen, 2010).

Thus, we need to pay careful attention to the way in which the notion of patient 2.0 thrives on a rhetoric of generalization and universality. After all, there is nothing universal about the multifarious ways in which patienthood is enacted in different countries, cultures, or institutional settings. For the same reason, there is little reason to think that *any* concept, no matter how encompassing, can encompass all these diverse ways of doing health care. Thus, we conclude that adopting patient 2.0 as a guiding conceptual vision for social studies of health care and medicine is risky. In particular, it risks replicating on analytical territory the same kind of global dream that is embedded in the CDSMP. Reflexively, therefore, we are best served by viewing patient 2.0 as an analytical fiction. But of

course, if treated with care, fictions can be both powerful and generative.

Finally, then, our case also testifies to the emergent reality gained by the CDSMP's travelling package of theory, methods and practices. Indeed, it is particularly noteworthy that the program continues to generate universalizing health care futures (Jensen, 2010: 31-51) and travelling frictions alongside one another. The CDSMP emerges as a global health care platform not because chronic disease is really everywhere the same but because the program aims to recreate the same context everywhere and thus to turn chronic disease into the same global problem. The process through which this happens is also the process whereby a particular form of patient 2.0 may gradually become more universalized. Such processes deserve careful analytical, and critical, attention. Here we have argued that a focus on travelling health care programs, their frictions and comparisons, and the new forms of patients to which they give rise, can help focus our attention.

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- 3 Kaiser Permanente is an integrated health-care system that serves over 8 million members in the United States.
- 4 See <http://patienteducation.stanford.edu/licensing/>.
- 5 What is the "American context" of health care? We do not claim to know this in much detail. We do know that American health care delivery and financing is privatized to a degree unimaginable in Denmark. We also know that the question of public, not to mention national, health insurance, is politically fraught. But our task is not to compare and evaluate the "real" differences between Danish and American health care systems. It is, rather, to explicate how differences come to be experienced and articulated comparatively, when the CDSMP, perceived by some Danish patients to be distinctly American, becomes part of the Danish system.

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## Notes

- 1 See [www.expertpatient.co.uk](http://www.expertpatient.co.uk).
- 2 This analytical strategy is similar to Michel Callon and Vololona Rabeharisoa's article "Gino's Lesson on Humanity: Genetics, Mutual Entanglement and the Sociologist's Role", where the authors grapple with the single case of Gino, a muscular dystrophy patient who refuses to understand the "lessons of genetics" (Callon and Rabeharisoa, 2004). Callon and Rabeharisoa offer this specific case as singular but *exemplary* (cf. Jensen, 2011); that is, as allowing them to address much broader issues of agency and subjectivity in medicine.