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Self-care Translated into Practice

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Introduction: Self-care Translated into Practice

By Åsa Alftberg & Kristofer Hansson

Introduction

A major obstacle to coming to terms with the full reality of bodily life is the widespread myth that the body can be controlled. [...] The essence of the myth of control is the belief that it is possible, by means of human actions, to have the bodies we want and to prevent illness, disability, and death. Like many myths, the myth of control contains a significant element of truth; we do have some control over the conditions of our bodies, for example through the physical risks we take or avoid and our care for our health. What makes it a myth is that people continue to cling to it even where there is overwhelming evidence against it, and that most versions of it are formulated in such a way that they are invulnerable to evidence against them. (Wendell 1996:93)

Care for our bodies has become a central paradigm in Western society, placed upon individuals in order to encourage them to take responsibility for their own health. People are not only expected to lead a healthy way of life, but also to take care of themselves when they are sick. This can be seen as moral precepts, where the individual should take responsibility for what to eat and how to exercise, in brief how to lead a healthy lifestyle. But as the philosopher Susan Wendell highlights above, individual care can also be recognized as a myth. We cannot take control over our bodies in such a way that we always can prevent illness, disability, and death. The myth is part of what she calls *the disciplines of normality* (Wendell 1996:87).

The care of the self is something that according to Michel Foucault was given a meaning in classical and late antiquity (Foucault 1984/1988). It can be argued that the cultural and social consequences of the concept have increased since the nineteenth century, when care of the self to a great extent was related to the Western project of biomedicine and its striving for control over the sick and disabled body (Kleinman 1988; Nuland 1993; Wendell 1996). The care of the self has become a part of the Western medical paradigm where people are expected to take care of their bodies and their health and in this way become good citizens (Frykman 1992; Armstrong 1995). The science of medicine does not have the full responsibility to cure people; as a citizen you also have a responsibility to follow the recommendations and guidelines that biomedicine proposes. With the term *bio-power*, Foucault has described this change in relation to certain modern social institutions, such as hospitals, armies, and schools (Foucault 1975/1995, 1976/1990). With reference to Foucault, many scholars have called attention to how this bio-power also needs to be analysed as 'institutionally unbound' (Bartky 1990). It is not exclusively the institution that needs to be in focus, but a more

bottom-up perspective that analyses the individual's everyday life (Hacking 2004). In feminist analysis, Sandra Lee Bartky has argued that even if the disciplinary power is embodied and produces bodies, it is at the same time dispersed and anonymous. There are no individuals formally sanctioned to wield this power since it is 'invested in everyone and no one in particular' (Bartky 1990:80). At the same time, this statement has been pointed out as the weak link in the argument, meaning that it is unclear how people are motivated to follow self-regulating practices (Rose 1999; Steffen & Tjørnhøj-Thomsen 2004). Or put in other words, it is a question of how the socialization of this practice proceeds.

People are thus expected to take care of themselves and lead a healthy way of life. This intensified emphasis on health has also created a new medical concept, *the at-risk health status*, a social position negotiated on a societal level, accompanied by expected practices and norms (Kenen 1996). State-sponsored health education is conducted to warn the public about health risks, based on the assumption that knowledge and awareness of the danger of certain activities will result in rational avoidance of these activities. Since health is deemed a universal right and a fundamental good, measures should be taken to protect one's health. A healthy way of life must necessarily be the concern and goal of each individual (Conrad 1994; Lupton 2012).

The overall expectation placed upon individuals to take responsibility for their own life, has in cultural studies been described in terms of *neo-liberalism* and defined as an internationally prevailing ideological paradigm (Dean 1999; Smart 2003; Gilbert 2008). In this thematic section of *Culture Unbound* there are many examples of *how, if and when* these ideas affect people's everyday life. The discussions revolve around living with long-term sickness, the organization of healthcare, and questions concerning well-being. This is a special issue that analyses how cultural ideas about self-care and self-care management take practical form, looking for those social practices that are uncertain and ambiguous (Reckwitz 2002). In this introduction, we as theme-editors present the predominant themes that are discussed in more depth in the individual articles. In view of how personal strategies for living and life planning are open to continual revision and how those strategies increasingly emphasize the relationship between identity and *the biological* (Kaufman 2010), we seek to explore how this is translated into practice. Self-care and its technologies take place in everyday life, and will be examined using an ethnographic approach.

Care in Self-care

Care is a central practice in self-care, and care is something that is *done* by the individual. Many times it is a practice that starts after receiving medication, instructions and guidelines from healthcare, but it can also be much more diffuse, anonymous, and not institutionally bound. When a newly diagnosed patient seeks

information and takes part of illness-related knowledge from other sources than the doctor's office, this may create forms of caring that are not always sanctioned by the healthcare system. From this perspective, care is not defined as a category, but analysed as a concept that creates different cultural and social practices (Mol et al. 2010).

Ethnographer and philosopher Annemarie Mol shows that there are two systems at work in healthcare today: the logic of care and the logic of choice. The logic of choice turns the patient into a customer who is expected to choose the best way to take care of his- or herself. Staying healthy is then a choice, a clearly defined transaction in which something is exchanged, a product against a price. The logic of care, by contrast, is an interactive, open-ended process that may be shaped and reshaped depending on its results. This process stems from everyday experiences of the interaction between patients and healthcare professionals. Mol's study shows that on a level of everyday practice, in doing healthcare, neo-liberal ideas are not the only meaningful factor and they can be negotiated and transformed (Mol 2008).

Mol's description of care practice has parallels in the sociologist Jeremy Gilbert's discussion on how neo-liberalism emphasizes the process of commodification, which 'leads to a reduction of almost *all* human relationships to buyer-seller transactions' (Gilbert 2008:113). It has been established that this development has changed the way healthcare is organized in many Western countries, putting a larger responsibility on the patients to participate in the process of caring (Stevenson et al. 2003; Hansson 2006; Lewis 2006). To choose treatment and managing care in everyday life can be an increased responsibility, but it also concerns morality, meaning that it is the patient's apparent choice to get better. Equally, health-promoting rhetoric serves to legitimize ideologies and to create moral precepts by making statements about how individuals should conduct themselves, including when and what type of food to eat, the nature and frequency of physical activities, and even what kind of thoughts that are supposedly healthy. For example, the journalist and political activist Barbara Ehrenreich has pointed out the paradigm of *positive thinking* in today's society. As such, becoming a good citizen includes a positive attitude towards an individual responsibility for recovery from sickness, i.e. a form of self care (Ehrenreich 2009). It is a way of thinking that is in line with the commodification of wellbeing and health, into products that can be offered on a market to the responsible patient (O'Dell 2010).

Self-care can be considered as a way for the healthcare system to place the responsibility for the patient's cure on the individual and his/her family, instead of on the doctor and nurse. Self-care is from this perspective also a form of self-care management, a way for healthcare to organize itself in order to retract. Taking self-care seriously also means to become a 'good' patient from the point of view of healthcare and society. This form of socialization into the 'good' patient can be manifested through attending a rehabilitation course, as it is exemplified in one of

the following articles. Here, persons living with a chronic disease in Denmark engage in courses where they learn to exercise in the right way, choose proper food, and create good inter-personal relations. Central for this form of socialization is to be well-informed about the illness and which medical therapy to use. The medical perspective suggests that as long as the patient understands his or her disease, and how to treat it in the best manner possible, the individual will also have a good opportunity to succeed in getting better.

In this way, self-care is a perspective we can use in order to understand how we all act upon what is good health and what is not. Like good health, care is a practice that one must work to obtain. It can be to live with a kidney disease, asthma or to develop new identities in life.

Self in Self-care

At the same time as care is a central practice in self-care, there is an individual – a self – that transforms the care, through training or institutionalization, into practice. Following Foucault's interpretation this practice can be seen as a technology of the self (Foucault 1988). The historian Jerrold Seigel demonstrates in his book, *The Idea of the Self*, three components of a theory of the self that we find useful for an understanding of how these technologies are made into practice (Seigel 2005). First, a technology of the self needs self-consciousness that reflects upon our own identities, the social actions we take and the relationships with others. This is a form of self-monitoring, where we use our language and memory to be conscious about ourselves (or our selves). The second point is that the self is embodied, we have a body and many different bodily practices that form our self. This special issue provides us with many examples of how biomedicine, through training and information, gives patients new bodily practices of how to live with illness and disability. The third point is the notion that the self is a historical product of society. The sociologist Bryan S. Turner shows us this historical dimension of the self when he relates the reflective self to, as he writes, 'the eighteenth and nineteenth centuries as a consequence of the Enlightenment after Immanuel Kant's philosophical challenge to throw off traditional, that is religious, constraints on the autonomy of the individual self' (Turner 2007:29). But he also relates this to the consequences of an *expressive revolution* (Parsons 1974) in the 1960s, when the importance of choice in lifestyle and values became central in for example popular culture. A central point in Turner's argument is that the discourse of personal freedom today is challenged by accounts that are grounded in different biomedical perspectives on the body. This new biology involves, he writes, 'a language of genetic causation that is very different from celebration of the hedonistic body that characterized the post-war period' (Turner 2007:30). In this issue, this is illustrated when discussing how genetic test results can give knowledge that is irreversible and put the body in a new light. Genetic tests can

provide knowledge of future risks that put a limit on the discourse about personal freedom, since it may create an experience of determinism and helplessness.

However, at the end of the twentieth century helplessness seems to be tackled with flexibility and a constant adaption of the subject to each new role that is given (McRuer 2006). The good citizen is increasingly defined as a flexible person with the ability to adapt to every form of new knowledge that is irreversible. This follows the anthropologist Emily Martin's argument on how the society has come to reward *flexible systems* in different contexts such as economics, government organizations, psychology and so on (Martin 1994). We want to stress that managing self-care means being flexible, a form of self-consciousness where the individual changes and adapts the self to new conditions. This is a form of *inventing our selves*, to use the phrase of the sociologist Nikolas Rose (1998).

In this thematic section, we critically review the notion of a self that is linked to the good citizenship, governing him- or herself, and regarded as an individual that is socially and politically free and independent (Helén 2008). The self is in this way perceived as a person that is active and independent, according to that person's ability. However, this does not mean that the individual is relying on him- or herself. A point that we will come back to, which is also discussed in the articles, is that the self is always positioned in a social and cultural network. As Susan Wendell highlights, there is a form of ideology of what is considered as normality, concerning the self and the body (Wendell 1996).

Materiality and the Self

In the introduction of the book *Care in Practice* (Mol et al. 2010), it is emphasised that caring practices include materiality, and this is something that also is discussed in this issue when the concept of self in self-care is questioned. To understand self-care, it is central to look at the infrastructure that creates the practice of everyday life in the context of a health promoting rhetoric. According to medical ethicist Jeannette Pols, materiality may shape people's practices in two ways: by turning a healthy lifestyle into everyday routines and by increasing people's knowledge about their lifestyle and about what a healthy living is supposed to be. By using, for example, instruments designed to monitor the state of health, people are invited to turn the observation of their bodies, behaviour and conditions into a daily routine. Even the use of medical instruments and medication is converted into a routine in itself. The materiality of objects calls for making the matter into routine. People are also expected to absorb information in order to get their lifestyles right. Medical devices and medication may provide such information, or 'directives disguised as facts', and people should learn to add them to the knowledge they have already acquired and use them in practice (Pols 2010:180). Thereby, the materiality of caring practices 'bring[s] society within the self' (Turkle 2011:310).

Objects and artefacts could be considered as *practical arts* with purposes (Whyte et al. 2009). By this we mean that objects are performed at the same time as they are performing; they might, as the sociologist Bruno Latour writes: ‘authorize, allow, afford, encourage, permit, suggest, influence, block, render possible, forbid, and so on’ (Latour 2005:72). To understand how these purposes are accomplished, we need to consider the relations between people and objects. The self is held and supported by its relationship with humans and non-humans (Winance 2010). However, Annemarie Mol remarks that objects ‘do not subject themselves to what we wish them to do, but interfere with who we are’ (Mol 2008:50). Matter matters, i.e. matter is significant and produces something more than the expected, while it simultaneously changes these expectations and transforms the self. The self is an actor who is intertwined with materiality, technologies and infrastructures of care in order to be self-caring. This idea is further developed in one of the following contributions, where it is suggested that self-care is a practice that is socio-technical, material, distributed and even de-centred. Emphasized in this issue, there is no self in self-care, but an infrastructure that enables the management of self-care.

Contributing Articles

In this issue, there are six articles and one thematic review that dwell on the theme of self-care translated into practice. A central matter for all the articles is that they analyse self-care in various contexts and practices through empirical examples from Nordic countries. Moreover, it is important for this thematic section to analyse self-care from various themes and historical perspectives, which gives us the possibility to see differences and similarities in the practice of self-care.

In the first article, Annegrete Juul Nielsen and Lone Grøn present an example from Denmark, in which they discuss the knowledge production in patient led disease self-management programmes. The authors question the assumption that an informed, capable and self-managing patient represents a more democratic and patient-centric perspective and accordingly is able to challenge traditional medical authority by introducing lay ways of knowing disease. This is illustrated by the empirical example of a patient education programme directed towards the social and mental aspects of living with a chronic disease. The programme aims to encourage and motivate the participants to be their own experts, based on the experience of their living conditions as a person with a chronic disease. The participants are to inspire each other to find and test alternative ideas for how to solve common, as well as serious problems, rather than looking to science and medicine for answers to some of their challenges. The programme offers tools to take control over life with a chronic disease, but it also attempts to standardize how ‘the good life’ should be achieved. This attempt does not stand without resistance from participating patients. In fact, the authors argue that the conflict is not between lay

versus biomedical knowledge, but between different concepts of how ‘the good life’ can and should be achieved.

Patient education and learning is also the empirical starting point in the article by Susanne Ådahl, set in a Finnish context. An aspect of the illness trajectory of kidney failure, like with many other chronic illnesses, is the extraordinary amount of information patients receive and need to learn in order to live well with their kidney disease and the transplanted kidney. The patients learn to actively engage in their illness, become compliant and well-informed and additionally create social bonds to other patients suffering from kidney failure. Knowing and talking about illness, and applying this learning are forms of caring about oneself. Care is expressed in the communicative process. Being informed may empower the patient, but it is also part of care, self-care as well as care of others. It could also be described as a form of biosocial engagement, strengthening a shared identity based on failing biology through the sharing of information on this condition and provision of mutual support.

Taking responsibility for a healthy life-style additionally comprises the consideration of health hazards. How self-care management includes avoiding and preventing perceived risks is analysed by Andréa Wiszmeg, Susanne Lundin, Eva Torkelson, Niclas Hagen and Cecilia Lundberg. Here, the discussion concerns risk strategies and how they are expressed by the individual in Sweden. The authors display the ambivalence connected to the perception of risk, using the example of public attitudes towards risk- and predictive genetic testing. The notion of genetic risk is complex and difficult to understand; as a result, this notion does not provide a ground for responsible action. Biomedical information and knowledge about possible risks are translated into everyday life that is dominated by pragmatic attitudes depending on the actual situation, experiences and social relations.

What happens when the study of self-care is combined with social categorizations such as old age? The article by Åsa Alftberg and Susanne Lundin examines, from a Swedish perspective, the intersection between old age and a health promoting lifestyle. Old age is usually perceived as decay and decline, but the ageing process is regarded as something that can be delayed with self-care management and become a ‘successful ageing’. The authors show how especially the notion of activity, being active, healthy and independent, shapes the beliefs and narratives of older persons. The idea that activities are health promoting is the framework in which activities are performed, but significance and meaning are rather created from everyday practice.

Self-care and identity is a theme developed by Kristofer Hansson. His article provides a historical perspective on psychiatric care in Sweden, where a new clinical treatment emerged in the 1970s concerning the psychiatric crisis. This treatment became central for how to support the patient towards well-being and inner growth. The psychiatric crisis was presented as an opportunity for personal development, well-being and identity. The psychiatric crisis became a social classifica-

tion, which gave a new perspective on specific behaviours, while transforming these behaviours to become part of the individual's self-care project.

Could the self in self-care be deconstructed? In the article by Peter Danholt and Henriette Langstrup, the self is described, from a Danish perspective, as an actor who is intertwined with infrastructures of care in order to be self-caring. Self-care is seen as a practice that is socio-technical, material, distributed and even de-centred. Self-care is a practice of multiple actors and forces, and even though the subject is actively manoeuvring around these forces, it is done in a situated and de-centred manner. In practice, there is no self in self-care, but an infrastructure that enables the management of self-care. The authors base the theoretical discussion on chronic disease management and the use of medication in relation to chronic illness. Medication could be regarded as an infrastructure of care, meaning the connection, establishment and enactment between various actors and locations.

The issue ends with a thematic review by Anna Pichelstorfer of two key books, *The Logic of Care* by Annemarie Mol (2008) and *Care in Practice* by Annemarie Mol, Ingunn Moser and Jeannette Pols (2010). Both books deal with the question of what care is and how it is organized and practiced, emphasizing care as work or something that is done. These publications are central for this thematic section of self-care, offering new perspectives and generating the possibility to rethink current developments in healthcare as well as self-care.

In a society where individuals are required to take more and more responsibility for their own lives and their health, it is important to highlight the social and cultural processes that are involved. In this thematic section of *Culture Unbound* we emphasize the importance of *how*, *if* and *when* ideas about self-care affect people's everyday life.

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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.

Keywords: Self-care, self-management, chronic disease, health education, lay and expert knowledge, patient participation

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 unverballed 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.

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‘I Was a Model Student’: Illness Knowledge Seeking and Self-care Among Finnish Kidney Recipients

By Susanne Ådahl

Abstract

The customer based ideology currently in use in the Finnish welfare state, as elsewhere, has transformed health care. Responsibility for health, that used to be lodged within society, has become the responsibility of the individual. Self-care is part of this growing trend, where there is an inherent assumption that informed patients are more capable of making decisions about their medical regime, which in turn empowers them. Finnish kidney transplant recipients are, through various sources and forms of health information, encouraged to follow the moral imperative of engaging in certain types of health maintaining behaviour that safeguards the transplant kidney. Being informed and sharing illness related information with peers is a manner of showing gratitude towards the state; a way to, in some fashion, reciprocating the valuable gift of a kidney through caring. Taking my lead from Mol’s (2008) notion of care as a practice, as something that is done by all those involved in giving care, I ask how knowledge seeking and sharing on illness can be a form of self-caring. The aim of the article is, thus, to discuss what role illness-related information has in the process of caring for kidney failure. The data consists of in-depth interviews with 18 kidney transplant recipients narrating their illness trajectory, and additional information solicited on a number of central themes, two of which were the access to illness-related information and involvement in peer support activities.

Keywords: Transplantation, social identity, illness, health information, communication, care, reciprocation

Introduction

In the Finnish welfare state, as elsewhere, policy making has been steadily moving from preventive health care, where responsibility for health has been lodged within the health care system and the professionals working within this system, to becoming the responsibility of the individual, turning patients into ‘customers’ of the medical establishment. Discussions in Finland circle around the cost-effectiveness and efficacy of healthcare services through a process of privatisation, auditing and individualisation of service delivery (Anttonen 2002; Wrede & Henriksson 2003; Helén 2008; Ollilla & Koivusalo 2009). It is no longer an issue of medical professionals directly controlling individuals to reduce health risks, but of individuals exercising self-regulation of their bodies and of how they act, coupled with the emergence of individual obligations (Miller & Rose 1990; Castel 1991; Higgs 1998).

Issues such as patient empowerment and self-care often feature in the discussion on patients as customers, as a way of indicating that taking responsibility for one’s own health and exercising the right to choose is positive for patients. This line of reasoning has, however, been criticized and questions raised regarding the purported benefit to service receivers (see e.g. MacStravic 2000; Smith 2002; Salmon & Hall 2003; Salmon & Hall 2004). When taking into account the whole context of the lived reality of chronic illness and the varied situations in which patients and their care-givers must assume responsibility for their own health, it becomes clear that not all patients are ready or capable of assuming this responsibility. Many expect to be *cared for* and given advice by health care providers. Mol (2008) wants to draw our attention to the fact that rather than patients *purchasing* care as consumers of a service, it is an issue of care being something that is enacted through various practices by patients and all those involved in the collaborative effort of caring for the patient. The ailing body is actively attended to through a multitude of practices in numerous contexts and situations. What one finds when looking at the lived reality of illness is that the process of caring is far more intricate than a straightforward market-like relationship.

This becomes all the more significant in the case of chronically ill patients that have a long-term relationship with the health care system, for example patients suffering from kidney failure. They are in a position of dependency and as they cannot be cured their care needs to follow a sociomedical model (Comelles 1988 quoted in Masana Bofarull 2010), based on a broad definition of self-care that includes all practices – medical, logistical and social/emotional – taking place in both the clinical context and outside of it (Illich 1976). They live with bodies at risk, first through the failing state of their kidneys, and later in post-transplant life through the health complications resulting from immunosuppression use. The majority of persons who fall ill have very scant knowledge and understanding of human anatomy and on how medications, their side-effects and treatments will affect

them (Simpura 2000). Still they are expected to take responsibility for their illness and seek knowledge about it. This is expected behavior of good patients.

In this article I will focus on how patients I interviewed as part of a project aimed at studying the meanings of donated kidneys and the experiences of organ transfer¹ among kidney transplant recipients in Finland talk about and make use of the information they have been given or actively sought on their illness. The question of illness information seeking was but one theme covered during in-depth interviews.² Individuals that participated in this study were recruited through a national and local level patient organisation, and were thus what could be termed as 'active' patients in that they attended events organised by these organisations. They actively sought to educate themselves on the various aspects of their illness and to create social bonds to other patients suffering from kidney failure, to share information on illness. Some of them were peer supporters and experts-by-experience that had received official training by the national level patient organisation, the National Federation of Kidney and Liver Diseases. They trusted the expert knowledge of specialist doctors and were overall satisfied with and grateful for the care they had received. Instead of viewing kidney failure as a restricting condition and patients as passive sufferers I view them as actively engaging in their illness, seeking ways to learn to live well with kidney disease.

A striking aspect of the illness trajectory of kidney failure, like with many other chronic illnesses, is the extraordinary amount of information patients receive and need to be familiar with in order to live well with their kidney disease and the transplant kidney. My hypothesis is that receiving information to be able to make choices about one's medical treatment is an integral part of the caring that patients and medical professionals are involved in. What is central is how caring is intertwined with the communicative process. Knowing and talking about illness, and applying this learning, are forms of caring about one's failed kidneys. It is a manner of strengthening a shared identity based on failing biology through the sharing of information on this condition and the provision of mutual support – as such it is a form of biosocial engagement.

Being Informed

It is thought that the purpose of providing patients with information on their medical regime is to empower them to take charge of their illness and to make decisions about treatment options; to give them a choice (Salmon & Hall 2004). Studies on how cancer patients use information have indicated that they do value being given information on their illness, but that the communicative process was for them primarily a manner of building relationships with doctors and of building hope (Salander et al. 1996; Salander 2002). In many cases it was not used as a basis for decision-making. For them, decision-making was about coming to terms with their illness and following the recommendations of the doctor, whose

knowledge on treatment they trusted. Making a decision was not equivalent to having a choice (Salmon & Hall 2003; Salmon & Hall 2004; Wathen & Harris 2007).

Mol discusses the issue of choice extensively in her book *The Logic of Care* (2008). Her argument is that the process of informing patients is not something neutral and unidirectional, on the basis of which the patient will make a rational choice about care. Health/illness informing processes are never free from power and knowledge relationships. By using this logic, information is seen as more important than care and by focusing on choice we fail to see how care is actually practised. The ability to make choices depends on a multitude of factors such as age, gender, type of illness, class, level of education and also on the specific situations that unfold as a result of the illness; in illness bodies are unpredictable so situations can change unexpectedly (Ibid: 18). Care, to Mol, should be seen as an on-going process, built around the principle of relationality and collaboration. All those involved in the process of caring for an ill individual strive through various practices, through *doing* together, towards the best possible outcome for the patient – an improved quality of life (Ibid: 75).

The process of informing about illness is thus not a neutral practice, but rather a process where forms of ‘situated knowledges’ (Haraway 1991) are exchanged. The knowledge that is imparted needs to be flexible and take into account the needs and specific illness stage of the receiver of information. Biomedical knowledge is often complemented and enhanced through the use of experience-based lay knowledge and emotional support that peer support groups can offer. Practicing care through shared experiences and information is a way of building identity as a group or community. For kidney patients this identity is not contested, as diagnosis and the treatment path is more or less clear and there are official guidelines on how they should be treated. Being informed is more than just getting information; it is also about engaging in certain practices as a result of this information, of participating in *doing* one’s illness and that of others through mutual advice, listening and understanding.

Why then do patients need to get or seek out information on their illness? In Finland the right to information is clearly stated in the Law on the Position and Rights of the Patient (Finlex 1992/785); ‘the patient has a right to receive information on his or her state of health, the meaning of the treatment, the various treatment options and their effects and other matters that are of significance when taking decisions on the treatment. Information should not be given against the will of the patient.’³ It also has the pragmatic aim of helping patients understand their illness better and care for themselves. Within specialised medical care, like the transplant sector where treatments are expensive,⁴ it makes economic sense to safeguard the investment the welfare state has made in the patient. Naturally, there is simply also the desire to reduce the patient’s suffering. Being cared for does not exclude a need to be informed; it is, rather, an integral part of the care process.

Providing illness-related information is something that enables the patient to take precautions and act in a way that makes it easier to live with chronic illness; in short, of being a good patient. Some patients actively educate themselves on their illness and the therapeutic process involved. Being informed may give them a degree of control in a situation of overall uncertainty that chronic illness entails. Others again are not active knowledge seekers because they believe it is the doctor's responsibility to inform them about matters related to their illness, that they are weary of challenging his or her expertise and fear transgressing the boundaries of their patient role (Henwood et al. 2003). Some patients prefer to know less about the medical details of their condition as this causes anxiety (Leydon et al. 2000). What is central in the process of informing is that it is *done with care*, that it tends to the specificities of each individual care process (Mol 2008: 79).

Suffering from Kidney Failure

Individuals suffering from chronic kidney failure enter the realm of being diagnosed in varying ways. For many it is an issue of the illness being 'hidden', sometimes for decades in their body. The underlying causes are usually hereditary diseases, a complication resulting from having type 1 or 2 diabetes, cardiovascular diseases or an improperly treated kidney infection earlier in life. In rare cases the diagnosis of kidney failure may come dramatically as a result of poisoning (Levey et al. 2003; Munuais- ja maksaliitto 2011). Provision of health care services follows the welfare state model in Finland.⁵ In principle, this ensures that all individuals are treated equally within the health care system. For kidney patients this means that those who fulfil certain criteria will receive a transplant⁶ and all costs related to the process are covered almost entirely by the social security system. This is also linked to the fact that the current care recommendations state that the proper form of care for acute kidney failure is dialysis (the artificial cleansing of the impurities in the blood through the use of a machine), followed, in most cases, by a transplant (Käypä hoito 2011). Chronic kidney failure can be treated through changes in diet and use of medication in slowly progressing cases. The illness trajectory will usually stretch over a long period of time, depending on when the condition is diagnosed. For most patients it is thus an issue of having a long-term relationship with specialised medical care and regularly meeting with a nephrologist in a regional hospital.

Last year a total of 164 kidneys were transplanted and about 3500 patients are living with an organ transplant in Finland (Scandiatransplant 2012). Demand overrides the supply in the market for transplant organs and the prognosis is that this number will increase with the rise in diseases like diabetes type 1 and 2. At present diabetics are the largest group of patients needing kidney transplants; around 25% of all recipients (Salmela et al. 2004). Finland has relied mainly on deceased donation as the percentage of live donation is considerably lower than in

other European countries. For example, as compared to Norway and Sweden, where live donation comprises around 50% of all donations, this number is 3-5% in Finland (Salmela 2010: 2556). Recently, Finnish surgeons have been vocal about increasing live donation, which is in line with global trends (Boas 2011).

A national level patient organisation, the National Federation of Kidney and Liver Diseases⁷ actively advocates for the rights and services of kidney and liver patients. They organise public events and lectures, training courses like peer support training or rehabilitation courses at various stages of patients' kidney disease progression (pre-dialysis, dialysis, post-transplant), meetings and discussion groups (both face-to-face interaction and through web-based discussion forums),⁸ production of patient guides and policy documents (either as print material or web-based information) and a member journal that provides information on various aspects of kidney disease. Active contacts and cooperation are maintained between the patient organisation and transplant surgeons, nephrologists and policy makers in order to bring about necessary policy changes that benefit transplant patients. Throughout the history of nephrology and the development of transplant surgery in Finland medical professionals have worked to improve the position of patients. Most central actors in this field have been familiar with each other and close connections between these various actors have been established. The building of a tight knit community has been aided by the fact that all transplant surgery is carried out in one hospital, the Helsinki University Central Hospital.

Sources of Information

Kidney patients can thus easily locate options for self-education and peer-education by consulting the website of the National Federation of Kidney and Liver Diseases or doing searches on the internet. They are provided with a multitude of information throughout their illness trajectory by medical professionals in the form of guides and manuals handed out in a clinical context by medical specialists, nurses, nutritionists or social workers. On the national patient organisation's website patients can download a general guide for kidney patients, guides on physical exercise for patients suffering from kidney failure and on good criteria of care. They can order a cook book and brochures on nutritional issues, the activities of the patient organisation, prevention of kidney disease and use of salt. The general guide provides brief information in clear language on the central concerns of kidney patients; the function of the kidneys, causes of kidney disease, related illnesses, diagnostic testing related to kidney disease, different forms of dialysis, transplantation surgery, emotional issues (psychological coping), self-care (nutrition, exercise), rehabilitation, medications (effects of immunosuppressive medication and use of other medications), social security and personal stories of kidney patients. The information provides a great amount of detail on how the biological functions of the body are impacted by kidney failure. Similar issues are taken up

in rehabilitation courses organised by the patient organisation or by the Social Insurance Institution of Finland and may be the subject of lectures given in events organised by the local chapters of the national patient organisation.

Seeking information on one's illness implies that one has an active, positive attitude towards learning and a willingness to take responsibility for one's own health (see also Plough Hansen, Tjørnhøj-Thomsen & Johansen 2011). This learning takes place in various contexts, such as events organised by the patient organisation (trips, lectures, sporting and cultural activities), clinical environments and in the patient's home through broadband communication, by reading patient organisation magazines, or through personal communication with other patients. The amount and intricacy of this information is staggering. The adjustments needed to be made in the personal lives of patients, in terms of diet, physical exercise and ingestion of medications are complex and demanding. It is understandable if some patients simply cannot manage this information overload and expectations, especially in a situation of being vulnerable. The help of family members is crucial as they are a vital support in this process.

The hegemony of the knowledge of experts is still strong in Finnish society (Tupasela 2008 & 2007), although there is talk of citizens' participation and a burgeoning trend valuing experiential knowledge. The use of experts-by-experience (*kokemusasiantuntija*) has become a standard practice in patient organisations. One indication of the increased valuation of this type of knowledge in my study is the recruitment, training and use of patients as experts-by-experience by the National Federation of Kidney and Liver Diseases.⁹ They receive training to acquire particular skills in talking to other patients and advising them on how to solve medical or social problems relating to their illness.

One's social identity as a patient is strengthened through learning and sharing of experiences, by patients using each other as a therapeutic resource or by telling of their experiences to health professionals. Events where illness information is shared function as a kind of therapeutic community and moral economy of its own (cf. Guell 2011). The ultimate goal of this learning process seems to be the maintenance of a normal life where normality is defined as the need to be an active, responsible and free person in control of life (Rose 1999). The moral discourse of this social action is clear: a proper, 'good' patient should seek to live in a manner that safeguards the transplant so as to prolong its life and the life of the patient through engaging in exercise, ingesting the right nutrition, entertaining good inter-personal relations, and being compliant and well informed in terms of medical therapy use.

Patient Experiences of Being Informed

During in-depth theme interviews kidney recipients were asked whether they felt they had received sufficient information on their condition from health care pro-

professionals. The overall response was positive and most felt that information related to their illness and the treatment had always been readily available. They saw the acquiring of information as a shared responsibility; they both expected the experts to volunteer this information and realized the need to take an active role themselves.

When asked whether they had been informed about and given the opportunity to choose between different treatment options, most notably in their case the choice of dialysis, some remembered that they could choose, whereas others had a vague recollection of these situations. In most cases they were presented with options and explained how each option would affect them in their everyday life (frequency of treatment, type of equipment, types of structural changes needed to be made in the home, amount of supplies, degree of freedom afforded, place where treatment would be administered).¹⁰ They also received information on immunosuppressant medication. Here doctors simply informed the patient which medication they would be given. In this matter patients had no choice.

Trust and Continuity in Communication

It is not only an issue of imparting and receiving information, but equally important - if not more important - is the manner in which the information is communicated. Recipients desire that a trusting and caring relationship is built between them and health care professionals. Being informed is part of a broader process of creating a new and shared illness identity based on making the illness known to oneself, as part of a process of familiarisation and normalisation.

Henri's kidney failure did not come as a surprise to him as he had known since childhood that a hereditary disease would gradually destroy his kidneys. He was well prepared for his need for treatment. In 2002 he received a transplant, having spent a year in dialysis. Henri says the following about the information he received from his regular doctor;

In dialysis the good thing was that I had a doctor who had been a nephrologist all his life. He was a sixty year old gentleman and I learned to trust him. What I told him he took seriously and had it investigated. He would prescribe medications and then he would explain why these medications were given and not other ones. He was a trustworthy person. [Does it have to do with the long-term contact? I ask] Yes, and then that the more a doctor is specialised the more I trust him. I value to no end the surgeons at the surgical hospital. They were very modest and down-to-earth and ordinary, but they had an immense amount of expertise. (Henri, May 2010)

Due to the, in most cases, long-term nature of the illness trajectory in kidney failure patients will see the same specialist (nephrologist) sometimes for decades. Treatment and patient-doctor communication in specialist care is, according to the kidney patients that participated in this study, better than in general care. In addition, the personal qualities of the doctor are important. The fact that the doctor was modest and down-to-earth served to reduce the communicative distance between Henri and him, strengthening the trust between them.

Petri, a university educated man in his early 30s who has received two kidney transplants, after a long and bitter experience of problems with his kidneys and his first transplant, talks about the importance of being informed in order to be able to understand what the nephrologist was telling him about the state of his kidney failure:

I gathered a lot of information. I strove to read medical articles in both English and Finnish about all of this [kidney disease] because I wanted to be well-informed about first of all what the lab results said, because all of a sudden there came a lot of new things that I had never heard anything about. I don't like that I am told things that should be significant to me and I don't know what they are talking about. So I found out [what it was about] and I also asked the doctors what things meant. (Petri, April 2010)

He wanted to be able to engage in a dialogue with his doctor and wished for continuity of communication by requesting to always be cared for by the same doctor. In the beginning of his treatment period the hospital would send him to different doctors every time and it annoyed him, also because his diagnosis and subsequently his treatment were delayed as they could not pinpoint what was wrong with him. Being informed for him meant having a better knowledge of what was going on in his body and being able to interpret the various symptoms of kidney failure. After receiving his diagnosis he wanted to ensure he was in control of his condition and the treatment of it, to the extent that this was possible.

I said I want to go to this guy [the nephrologist], that I always want to go to this guy and they always arranged it so I could see him. At some point he said to me that go with what you feel like. Take more or less blood pressure medication. [-] A certain kind of communication level was developed, where he did not have the typical authority role of doctors, but more a kind of situation where an expert tells a person that understands. I thought it was nice that there was a dialogue that led to some kind of result [-] he would ask me something and did not just say that now we will do this. (Petri, April 2010)

Being educated and capable of understanding the medical jargon used by the medical expert was for Petri, it seems, also a matter of prestige. As a university student he was used to reading and discussing complicated texts. He wanted to apply this with his doctor to initiate a dialogue where he could feel more as an equal with the doctor. He wanted his knowledge and insight to be respected and recognised.

In 1978 Ossi received his first of two kidney transplants and at that time patients were hospitalised prior to the surgery at the nephrology ward of the Clinic of Internal Medicine at Helsinki University Hospital. He remembers the manner in which the leading nephrologist of the ward included the patient in the treatment by going through the information in the patient file with the patient:

I noticed when I was moved to [the nephrology ward] how much information can be given to a person about a serious illness. It was the habit of X [the head nephrologist]. He would take your file and come and sit next to you and [he would say] 'let's see you have that at that point [some blood value] and there is the reference value

where it should be at, and you have this and it affects you in this way'. And he would start telling me about all these things in a manner that probably is very clear to the doctors and staff, but not to the patient. He included the patient in the care and when you knew you had that blood value you knew that if I avoid eating that salty food or something like that then it would affect a certain blood value. (Ossi, April 2010)

This particular nephrologist is a legendary figure in the field of Finnish nephrology and has been active in the sector since the beginning of its development in the 1950s (Huhtamies & Relander 1997: 53). His habit of keeping patients, not only informed about the progression of the illness, but also increasing their understanding of their condition, was something he passed on to his students and the nursing staff. Increasing understanding was at this stage of the specialisation of nephrology tied to enabling patients to come to terms with their illness and to act in a manner that was beneficial to their own wellbeing. Patient involvement in treatment was in the 1970s still not very common.

Needing or Not Needing to Know

Receiving the diagnosis of kidney failure came out of the blue for Eila and it threw her into a state of shock. At first she experienced a period of denial and refusal to come to terms with the diagnosis, but gradually came to learn what her illness required her to know in order to act in a manner that was best for her and for the trajectory of her illness. After spending two and a half years in dialysis Eila received a transplant in 2006:

I really had to study what types of foodstuffs are in different foods, where there is phosphorous, where there is potassium, where is whatever I am not allowed to eat. I simply did not know what I could eat and the nutritionist tried to teach me. But I was anyways totally bewildered about what I dare put in my mouth and my family was bewildered. [-] All these types of things entered my everyday life. I was a model student. Underneath my seemingly brave and matter-of-fact manner of dealing with the situation was a dreadful fear. I always tried, that whatever I understood that they told me, I tried to realise it right away, down to the very last detail. (Eila, October 2011)

She had to fill out forms and keep a food diary, which she obediently did. The nutritionist gave her feed-back on the diary and gradually she learned to understand how and what she should eat. Her quest for knowledge was driven by fear and a need to re-assert some sense of order into a disordered reality. Knowing how to behave to best care for her illness was a comfort and enabled her to do something, to act preventively. In exclaiming that she was 'a model student' she also shows that she is aware that there is an expectation that she should be a 'good student' as this is part of being a 'good patient'.

Kaisu was confused and upset when she was told by her doctor that she suffered from a chronic kidney disease. While driving home from her doctor's appointment she thought her diagnosis meant she would die. At home she wrote him a letter and he soon called her to assure her that she would survive. He told her

about dialysis and transplantation and encouraged her to join the local patient organisation. The organisation and the patients that were active there became a vital source of information to her:

I started to attend the members' meetings and started to listen to those people [other patients], what they had and what they had been through. I knew exactly, I had seen a film there about what happens when the alarm goes and they go to retrieve the transplant kidney and the police was trying to locate the patient and all that, how it proceeds. They even showed the transplant surgery and all sorts of things. I was so full of information that it felt like I knew more than many doctors about kidney transplantation. (Kaisu, April 2011)

Filling herself with information was a coping strategy for Kaisu. It enabled her to envision the process to come and to get first-hand knowledge on this from other patients.

Heikki's kidney failure was due to a genetic disease that he inherited from his father and he knew many years in advance that at some stage he would need to receive treatment for his condition. It took many years before the disease came to the stage of dialysis and in 2003 he received his transplant, but had prior to that lived through several dramatic health related turns in his life due to a brain tumour discovered in 1996. When asked whether he feels he has received a sufficient amount of information about his illness he replies:

Yes, I have received as much as I have wanted to know, because I have not wanted too much information. [Oh, yes, why? I ask] Well, if I was told that this illness will lead to [the need for] dialysis it was sufficient enough information for me. You are probably yourself aware that the more you know the more you suffer [*tieto lisää tuskaa*]. Because of that I really have not wanted to deepen my knowledge [about the illness]. I just know that in our family this is hereditary and there is nothing one can do about it. You just have to accept it and not protest against it because there are things you can do nothing about, things that just happen. This was the type of thing you could do nothing about. (Heikki, March 2011)

The fateful nature of Heikki's condition is something he accepts because he has no other choice. From his comments it seems that it removes the burden of knowing too many details about his illness, of educating himself too much on it. He willingly places himself in the expert hands of doctors.

Sharing Information with Peers

Kaisu says that since she has been given a new life twice (two transplants) she has wanted to give something back to other patients by being actively engaged in the patient organisation and acting as a peer supporter. She stresses that she does not directly want to term it as being a manner of repaying her debt of gratitude for having received the valuable resource of a kidney. She just simply wanted to do something good;

Well, I had knowledge. [-] I had knowledge about what patients had experienced and it is better information than that which is given by a nurse or a doctor. I knew how to tell it [about the illness experience] in the right way. Telling it in the way it actually

happened. A nurse may sugar-coat some things and sometimes, I think, doctors also do this. [So it is more honest? I ask] Yes, it is much more honest. [A first-hand experience? I ask] Yes, it is like that. Regardless of who is ill and which illness it is, the one who has experienced it tells it just like it was. This is where peer support is really important. (Kaisu, April 2011)

Kaisu stresses that the peer supporter should not give any advice on medications; that one should not interfere with information that the doctor is meant to provide to the patient. She says that you engage in conversations about the basic things of life, of how the other person feels, of relationship dynamics and how intimacy is affected by chronic illness in a relationship. Sharing one's experiences and empathically communicating that one understands what the other has been through, that you care about the other, generates a sense of belonging.

What is clear in this quote is that she makes a distinction between different types of information, lay and professional knowledge. She is well aware of the value of lay knowledge and the emotional content of this information because it is based in the lived reality of illness. Lay knowledge should not replace or compete with expert knowledge – it complements it and provides a different, but vital perspective. Kaisu knows how important this type of emotionally and experientially based information is because she has herself benefitted from this type of information during her extensive illness trajectory.

Also Ossi appreciates the role of peer support in his illness. He is a peer supporter and expert-by-experience of the National Federation of Kidney and Liver Diseases, as well as an avid organiser of the local chapter of the patient organisation. An important venue of peer support is the surgical ward of the Helsinki University Hospital¹¹ where all kidney and liver transplants of the country are carried out. Following surgery most patients will spend two weeks in the ward. Before the unit was relocated to a new hospital complex patients were all in one big mixed sex room. They would eat their meals around a dining table in the middle of the room and walk together in the hallways of the hospital and the areas surrounding the hospital:

When you were in the hospital you always had a ward full of people. You got to know new people and that stopped [when you left the hospital]. That is why it is so important to get people to attend the trips [organised by the local patient organisation]. [-] At these social activities the more people talk to each other, then at some stage [they start asking] 'how is your health', and then the other person gets the opportunity to talk about it. (Ossi, April 2010)

The ward of the surgical hospital is a place where particular kinds of friendships are formed and even fictive kin relations (see also Sharp 2006). The first days following transplant surgery patients are placed in a double room and if they have gone through surgery on the same day they assume they have received their kidney from the same cadaveric donor. Some will then name the other recipient their kidney sibling and they may keep in touch with each other to compare experiences on the progress of post-transplant life. Also 'non-siblings' may keep in touch.

Another important venue of peer support, where intimate bonds of friendship may be formed, is the dialysis centre. The majority of patients who have opted to do hemodialysis will go to a dialysis centre to have their care administered three times a week for a time period of five to seven hours per dialysis session. Here they will regularly meet the same patients and nurses, who are equally important sources of information (see Gunnarson 2011).

Protected Information

A young peer supporter Matti, who is actively engaged in the youth section of the National Kidney and Liver Federation, believes it is important that young people can discuss their illness with people of their own age group. It has been difficult for the patient organisations to attract younger patients to join their activities. Matti believes the reason for this is that the activities fail to serve the interests of young people. This is why the internet is such a fruitful way of sharing experiences and information, since it is a familiar and popular socialising method:

Today it is facebook. From there [young people get their information] – that is where they share information. Facebook has been a good source of information and otherwise also, as you are all together [there]. It's very good to get information that way. During courses [organised by the National Federation of Kidney and Liver Diseases] you don't always get enough people, so then through facebook [you can get information]. So, in that sense it has been a very good invention. (Matti, October 2011)

The facebook group is closed and membership can be gained only by being recommended by a member of the group. The restrictive nature of the group is necessary as a means of protecting the identity of the users:

From the very beginning it has in a way been insiders' information [that has been shared]. We have not wanted outsiders involved because we don't want it to be known [who is active in the group] because there are regular medical things [that are discussed]. They [the matters discussed] don't belong to outsiders. When you are feeling bad and you don't know anything about this illness then you can [get information] through there [the facebook page]. The members feel that they want to share certain medical information only within the group; compare forms of care and this sort of thing. (Matti, October 2011)

The privacy and intimacy that a closed discussion forum can provide is an important aspect of inclusion for young people suffering from kidney failure. There is shame attached to illness - they would like to be healthy like other young people. Instead of centering their identity on the illness they try to manage it within their peer group, among people who understand what they are going through. Rather than relying only on the authority of medical professionals they want to create their own forms of knowledge where they can democratically share information with each other and critically discuss what they feel are problematic matters pertaining to the care they have been given.

Matti received his transplant at the age of 16 which meant that it was mainly his parents that sought out and received information on the illness. Regarding his need to get any further information he says:

I haven't needed it that much. Since I have been a peer supporter I have gotten a fair amount of experience from there and then I have asked the doctor if I have had any minor complications. [-] Maybe my parents have read more from some book and like that, but not me. [So, your parents have read up on the illness? I ask] Yes, but I haven't needed to. I guess the illness itself has educated me. (Matti, October 2011)

The idea of the illness itself as an educator is very interesting when considering the issue of knowledge as care. A bodily experience becomes personified in the figure of the illness as an educator. By giving the illness subjectivity and entering into a partnership with it Matti is enabled to care for the illness and the transplant. His bodily experience becomes his mentor and a source of self-knowledge.

Discussion and Conclusion

It is an old truth that information tends to increase awareness and that it may lead to changes in behaviour and to empowerment. This is also an assumption made in relation to information on health and illness given to patients. It is not an incorrect assumption. In some cases being given more information may make patients feel empowered, but this equation is not as straightforward as policy makers want us to believe. Being informed may empower the patient, but, above all, it leads to better caring, including both the self and others. It may be better to talk of simply care or caring, rather than using the term self-care, so as to remove the individualism from the term; because in reality it is a collective, collaborative effort. To return to Mol (2008), it is something *done* together, rather than only involving the self.

Based on what the kidney recipients in the study this article is based on said about being informed on illness, it seems that the most important aspect of receiving information and sharing it with other patients was the manner in which it was imparted; how care is expressed in the communicative process. Key notions that arose in the comments of interviewed patients were trust, endurance (continuity of communication), respect and recognition of different types of knowledge (lay and medical), integrity and inclusion. Patients clearly differentiate between professional knowledge given to them in a clinical context and knowledge based on lay experiences given by other patients. Talking about illness and treatment happens in varied contexts and leads to varied practices, all aimed at improving the patient's quality of life.

Patients talk of the importance of receiving support, of building mutual platforms of communication and exchange of information. They seldom mention the importance of choice, because in most cases they experience that they have no choice. The main priority is *receiving information in a caring manner* that is con-

ducive to trust, recognition of knowledge and mutual respect being born between doctor and patient and between patients in peer support contexts. When medical professionals engage in mutually respectful dialogue with patients the information exchange is a form of caring, because they attend to the specificities of the patient's illness experience, and the shifting contexts and situations that affect it. They listen and offer solutions, using their expertise as a resource because they want to help patients, to both *care about* and *care for* them (see also Good 1994 and Lupton 1997). Informing is a practice that contributes to the process of care.

In peer support contexts patients give out information about their own lives with chronic illness with the aim of helping others facing the same predicament. It is about understanding the other, communicating empathy, listening, giving emotional support and practical advice, and of creating shared practices. It is also information that is located in the lifeworld of the patient – this is a place that other patients recognise and can connect to. It strengthens a sense of mutuality, a shared identity, and belonging to a community that also includes doctors that care well for patients. The high value of this information is based on the fact that it is situated, that is, linked to specific contexts and situations. Context here refers both to when the other, one's peer, experienced it, and the context of the communicative event itself. Contexts for sharing peer based information varies; it can be in the surgical ward, during rehabilitation courses, discussion clubs or during leisure activities such as trips organised by the patient organisation, at home through conversations taking place over the telephone or on the internet. For some young patients anonymity and privacy is important, something that protects them, enabling them to talk more freely about difficult experiences. It allows them to maintain a social presence in the community of young kidney patients without needing to disclose their identity or attend any collective social gatherings (see Hardey 2002).

The use of peer information and sharing of knowledge is for most recipients a form of reciprocation, a way of thanking for the valuable transplant received. What is striking about this form of giving back is that it is directed to other patients (see also Sharp 2006; Shaw 2010). As such it reflects a moral economy that highlights solidarity and altruistic motives directed inward, towards one's own community. Since they have received a kidney¹² (nearly) for free they are engaged as volunteers, without receiving monetary compensation, in the patient organisation peer support activities. It is not directed explicitly to the health care system or welfare state that has enabled them to get a transplant, or to the kin of the deceased donor who have given their consent to the donation.

One must, however also recognise that reciprocation is a feature of the whole system of health care. Although it is a legal obligation to provide patients with information about their illness the practice is also part of an on-going circulation of practices, of giving and receiving care within the chain of care. Kidney recipients heed the doctor's recommendations because they know it is good for them

and they trust the expert knowledge of the doctor. They expect the state, represented as the doctor, to care for them. They also want to show they are good patients. In this sense they are showing gratitude to the welfare state for having received the valuable resource of a transplant and having been given an extension of life. The doctor regularly provides information to the patient so he or she can follow the care regime in the best possible way in order to feel better. Reciprocating by sharing information, experiences and practices among peers contributes to the process of care.

The production of information and knowledge by transplant recipients is still an under-used resource in Finland. Little is written about this resource and, although the patient organisation actively markets peer support services to patients, few use this opportunity. Another factor that contributes to the scant use of lay knowledge is the overall lack of visibility that organ transplantation has as a phenomenon in Finnish society. For example, when new legislation was passed on organ donation in August 2010 there was hardly any public debate on the issue prior to the legislative change. The patient organisation organises public events on the International Organ Transplantation Day, which is one of the few occasions when the general public are exposed to the issue, as well as stories occasionally featured in popular magazines and daily papers. Recognition of the caring potential of information and experience sharing within the transplant community, and particularly in relation to the value of lay knowledge and experiences, would thus be important in light of constant cut-backs made in the health care sector. As consultation times will be shortened to save money doctors will have less time to advise and discuss with patients – less time to provide care through the practice of informing. In this context, patient-to-patient sharing of knowledge and experience will become an increasingly valued resource.

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Notes

- ¹ This is a term used by anthropologist Lesley Sharp (2006), meaning the larger socio-medical process which includes organ donation, procurement and transplantation.
- ² The research that this article is based on is the first of its kind in Finland and is a three year project, 'Solidarity and the Body as Gift – Ethnographic explorations into the social and cultural context of organ transfer in Finland', funded by the Academy of Finland (project number 1131907). The project looks at how donation can be understood as a social and cultural practice through the giving and receiving of transplant kidneys, and specifically investigating the various stages and social relationships that were created as a result of the diagnosis of kidney failure as understood by kidney transplant recipients. A multi-sited ethnographic research approach was used where participant observation was conducted of various events organised by the National Federation of Kidney and Liver Diseases and a regional partner organisation (lectures, rehabilitation courses, sporting events, theme days, discussions of a kidney club, recreational trips for members, and other social gatherings), studying documents produced by the patient organisation and illness stories produced by patients, as well as conducting 18 in-depth interviews with kidney recipients, most of whom were recruited through these two organisations.
- ³ Translated from Finnish by the author.
- ⁴ In 2007 home-based dialysis cost 40 000 euro a year, whereas clinic based care cost nearly twice as much (Inomaa 2007: 27). A transplant operation, though costly, pays itself back in three years.
- ⁵ Following Jokinen and Saaristo (2000) I understand the Welfare State as an actor that aims to provide its citizens with a reasonable livelihood and conditions of life based on equality. Its central tasks are to organize child care and other forms of care services; activities related to provision of housing; health promoting activities; production of educational activities; prevention of unemployment; provision of general infrastructure and income redistribution; and provision of services mainly through income received through taxation.
- ⁶ Central criteria that have to be fulfilled in order for a patient to be put on the organ waiting list is age, progression of the kidney disease (are they in dialysis), that the patient does not suffer from cardiovascular disease, cancer, infections, and excess weight (Saha et al. 2010). In Finland all patients must be in dialysis in order to be placed on the waiting list for a kidney transplant. The usual (minimum) time needed in dialysis before being put on the organ waiting list is 6 months. Waiting time for transplant is on average 2 years, but can range from 1-10 years.
- ⁷ The funding of the organisation is provided by the state and RAY - the Finnish Slot Machine which basically means that citizens themselves provide the funding by playing on slot machines (Munuais- ja maksaliitto 2010).
- ⁸ Internet access is good and computer literacy fairly high in the general population in Finland so many patients would be able to avail of these resources. Of those individuals interviewed for my study the majority had internet access and used it. There are also closed patient forums where mainly young patients discuss their illness and issues related to everyday life.
- ⁹ This category of experts is also used by various other organisations in the health and social services sector. They are defined as individuals who have a personal experience of a certain health or social problem, have received special training and are used in the strategy, evaluation and rehabilitation work of municipalities and other institutions (Kokemusasiatuntija 2011).
- ¹⁰ Patients can choose between peritoneal dialysis (either continuous or ambulatory), that uses the abdominal lining to filter out bodily impurities, or hemodialysis where the patient's blood is circulated through a machine that contains a filter membrane (Alahuhta et al. 2008). Perito-

- neal dialysis is usually done by the patient at home and hemodialysis can either be done independently by the patient at home or then at a dialysis centre.
- ¹¹ The surgical ward moved to a large new hospital complex in the autumn of 2011, but all the kidney recipients that participated in this study had gone through surgery in the old hospital.
- ¹² They pay for the surgery and the time spent in the hospital, but these fees are highly subsidised as part of the welfare state funded social security system.

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Difficult Questions and Ambivalent Answers on Genetic Testing

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Abstract

A qualitative pilot study on the attitudes of some citizens in southern Sweden toward predictive genetic testing – and a quantitative nation wide opinion poll targeting the same issues, was initiated by the Cultural Scientific Research Team of BAGADILICO. The latter is an international biomedical research environment on neurological disease at Lund University. The data of the two studies crystallized through analysis into themes around which the informants' personal negotiations of opinions and emotions in relation to the topic centred: *Concept of Risk, Relations and Moral Multi-layers, Worry, Agency and Autonomy, Authority, and Rationality versus Emotion*. The studies indicate that even groups of people that beforehand are non-engaged in the issue, harbour complex and ambivalent emotions and opinions toward questions like this. A certain kind of situation bound pragmatism that with difficulty could be shown by quantitative methods alone emerges. This confirms our belief that methodological consideration of combining quantitative and qualitative methods is crucial for gaining a more complex representation of attitudes, as well as for problematizing the idea of a unified public open to inquiry.

Keywords: Genetic testing, risk, public attitude, responsibility, complexity, ambivalence

Introduction

Ulrich Beck (1992) declares that the proliferation of risks is the hallmark of our current situation. Whereas dangers in the pre-industrial society ‘assaulted the nose or the eyes and were thus perceptible to the senses, the risks of civilization today typically escape perception’ (Beck 1992: 21). The expansion of these unseen and abstract hazards constitutes a shift wherein a new cultural and social formation can be seen: the risk society (Beck 1992; Mythen 2007). In relation to the proliferation of risks, this late modern configuration has partly removed the collectivist risk management of the traditional welfare state, favouring a form of prudentialism where the individual is responsible for managing risks (O’Malley 1996: 197).

In today’s biosociety, the responsible individual is seen as someone who takes rational steps to avoid and insure against risk. This is done in order to become independent, and to avoid becoming a burden for others. Hence, a rational self-interest and risk management is articulated as an everyday practice of the self (O’Malley 1996: 200). In addition, in today’s biosociety, and parallel to the cultural, social and political development; scientific development within genetics and genomics has produced an increased knowledge about human genetics. This scientific development has created new possibilities for diagnostic prediction by means of using genetic tests. Subsequently, genetics and genomics is placed within a general discourse of disease prevention, illustrated by the advent of such sub-disciplines as public health genomics and community genetics (cf. Khoury et al. 2000).

Previous research have shown that methods such as the use of genome analysis and genetic testing will alter the individuals’ self-understanding as much as it changes the health system and how society treats disability and illness (cf. Novas & Rose 2000; Lemke 2004). As preventive medicine intersects with genetic research and technology (Arnoldi 2009: 100), it makes the responsibility for one’s genes and the risks they might encompass a personal and individual obligation. Genetics and genomics seem to give rise to reactions that contradict the rational and prudent responses about responsibility that are proclaimed within today’s biosociety. Our point of departure in this article is that scientific understanding and evaluations of risk seem to be incompatible with those representations that are invoked by lay-men in their everyday life. Genetics is deeply connected to human emotions and moral beliefs. We draw on our own previous research as well as on broad multidisciplinary discussions (Wexler 1996; Lundin & Åkesson 2002; Ferreira & Boholm 2005; Franklin 2006; Liljefors, Lundin & Wiszmeg in press). We are interested in what happens when genetic risk assessment enters the realm of everyday life and matters of the body. How do people perceive risk, and which strategies will the individual be in need of? We use the concept of risk perception

in Beck's sense, that is to describe why people define and sense risk and threats in different ways (Beck 1992).

The article aims to explore how people relate to and talk about situations that arise in relation to genetics and genomics. This is done on the basis of two studies conducted by the authors: the qualitative survey *Knowledge of Disease* (2010), and the nationwide opinion poll *Public Research – Genetic Diseases* (2011). The authors belong to the cultural, social, and natural sciences, which means that we also lean on previous qualitative and quantitative studies (Lundin 2002; Lundin & Idvall 2003; Torkelson 2007 et al.; Lundberg et al. 2008; Hagen 2011).

It is our ambition to present how the presumed individualized responsibility of avoiding and preventing perceived risks is expressed on an individual level. We look at how this gradual shift in the discourse creates multiple layers of attitude and opinion in the individual (Bauman 1993; Frank 1995). Our studies point to instances of ambivalence in people's accounts regarding experimental biomedical research and predictive genetic testing, when discussed on a general level. We want to emphasize the methodological and political importance of paying attention to such ambivalence. This also means that we call for a more thorough consideration of the methods used for gathering data for ethical discussion and drawing up guidelines in modern biomedical research. Hence, in our discussion we wish to problematize the idea of a general public (cf. Ideland & Lundin 1997; Gottweis 2008; Hansson et al., 2011; Plows 2011). The idea of a one-dimensional public united by opinion is highly problematic. The ignorance of the existence of ambivalence may, in fact, help legitimize this false and simplified picture.

We will begin with a section that accounts for the methods that were employed in order to obtain our empirical material. The subsequent five sections will present and elaborate on this empirical material. In the last section, we address the question of a unified public in conjunction with genetics and genomics within the late-modern risk society.

Methods

Our discussion relies partly on a qualitative empirical study of the attitudes of a number of citizens in southern Sweden with regard to risk- and predictive genetic testing. This survey, *LUF 232 – Knowledge of Disease* (2010), was conducted by means of an open-ended questionnaire, distributed among 122 previously volunteering respondents of the Folklife Archive at Lund University, who receive questionnaires on different themes 3-4 times a year.¹ Our article also relies on the subsequent quantitative nationwide opinion poll *Public Research – Genetic Diseases* (2011) that explores the same theme as the survey, and aims at capturing ethical and moral dilemmas on these issues to a greater extent than quantitative surveys traditionally do. (For methodological details, See appendix, p.16) We chose this methodological design in order to make the opinion poll as nuanced as

possible. Both studies were initiated by the Cultural Scientific Research Team, which is part of the interdisciplinary research project BAGADILICO,² researching possible therapies for Huntington's and Parkinson's disease.

We discuss the results and the material of the open-ended questionnaire and the opinion poll, both from a qualitative perspective and in relation to the data generated by the quantitative methods applied in both studies (Calculations of frequencies of themes in answers to the open-ended questionnaire *LUF 232 – Knowledge of Disease* were also made, as well as a measurement of the level of agreement on a scale of 1 to 5 with regard to two different statements). We point to instances of ambivalence in people's accounts regarding experimental biomedical research and predictive genetic testing. Reasons for these ambivalences and the empirical, methodological, and political importance of paying attention to ambivalence, and the possible consequences if we do not, are also addressed. We will present a selection of statements produced by the open-ended questionnaire that hint at ambivalence on issues that arise from the interaction of concrete context and abstract reflection, when the individual tries to make sense of the posed questions in the inquiry. We have found five themes around which the respondents' negotiations centre: *the Concept of Risk, Relations and Moral Multi-layers, Worry, Agency and Autonomy, Authority and Rationality versus Emotion*.

The Concept of Risk

In the nationwide opinion poll, *Public Research – Genetic Diseases* (2011), we posed the question whether one would like to find out what diseases one runs the risk of being afflicted by, such as Alzheimer's disease or cancer. A majority of 60 percent answered that they would not. There were no significant differences between women and men. If the disease in question would be incurable, as many as 70 percent would not like to find out, although more men than women were positive to finding out. When searching answers to these questions in qualitative data, as in the survey *Knowledge of Disease* (2010), another picture comes forth, showing how genetic tests raise questions about the *meaning* of being at risk. A young man put it like this:

If you have, let's say, a 20 percent elevated risk of getting prostate cancer, what would you do with that information? And can you trust it? [...] On the other hand: if there are tests that offer precise results, and if it is possible to discover elevated risks of treatable disease, and if they are discovered in an early stage, there might be a point in having a test and then acting on the basis of that. It's just not possible to give an unequivocal answer to a question like this.

The term *genetic susceptibility* denotes an elevated risk of certain diseases due to various genetic variations. In many cases the genetic tests that detect these genetic variations are applicable in testing for diseases where we have a complex interaction between several genes, and between these genes and the environment.

Most of our common diseases, such as diabetes and cardio-vascular diseases have this complex interaction. Due to this complexity the actual prediction on the basis of a genetic test is difficult to make. This situation can be compared to so-called monogenetic diseases (where the disease is caused by a single mutated gene), like Huntington's disease, where the genetic status decides whether you will fall ill or not. The genetic test for Huntington's disease only gives you information on *absolute* risk, in comparison to most of the genetic susceptibility tests that in many cases only provide information on relative risks.

It is often extremely hard for individuals to make sense of statistical risk on a personal level (Sachs 1998) and test results showing a genetic predisposition that indicates a heightened risk of a disease (Lock & Nguyen 2010). This means that the individual risk-ratio given by the susceptibility test has to be related to the general risk within the population and the incidence of disease in the individual's family. The existence of these different kinds of tests raises a great many questions about what a risk really is, and what significance and meaning this worrying concept is (or should be) given in your life.

The problem with the concept of risk in relation to test results and in relation to something as culturally elusive as genes (cf. Åkesson 1999) is that, as with the case of knowledge, it is irreversible. It is indeed impossible to go back to not knowing of your estimated risk once it has been stated. So in some sense, it is the knowledge of the risk that brings the risk into existence for the individual. The risk originates from the knowledge. But what is a risk, and what does knowing about it really mean? How can you assess how or whether a percentage point of elevated risk is going to affect your life? Previous studies show that undefined knowledge, such as that of risk, possesses great power to affect and influence people's emotions (Lundin 2002).

As mentioned in the introduction, the proliferation of invisible hazards and dangers are an important feature within the late-modern society. The elusive and invisible character of our genes makes it difficult for individuals to understand the meaning of the risk estimates (Hagen 2011). As the quotation above exemplifies, by indicating that risk has been confused with discoveries of actual disease, it can also be problematic for a layperson to discern the difference between an 'elevated risk' and an early stage of a disease. The increased use of these kinds of tests also raises the question of where to draw the line between an observed deviation, that is, a *diagnosis*, and a prediction of progression, a *prognosis* (cf. Konrad 2005).

As Beck argues (1992), the notions of modern risks are often detached from the sensations of human experience, making them all the more difficult to fathom and even calculate. Estimating the impact of the risk, even if not knowing the actual numbers, of something quite tangible such as being hit by a car when crossing a busy road gives you agency to choose not to cross the road, because you can physically and emotionally relate to what could happen if you do. Test results stating elevated risks of certain diseases do not provide that kind of agency

based on direct lived experience. In order to make sense of such risks in this same concrete manner, there is need for previous reference. This could, for example, be to have had a close relative suffering from a genetically hereditary disease. However, not even this experience grants clear alternatives of action.

Relations and Moral Multi-layers

Our opinion poll showed that a slight majority was negative towards finding out about what diseases they were at risk of passing down to future generations. Between men and women no difference was detectable, but the youngest respondents (age 15-29) were the most positive. When asked to state how much they would *worry* about being afflicted with or passing down a genetic disease, the majority stated a mean value of 3.5 on a scale from 1 to 5, where 1 symbolized the least worry and 5 the most. Here, a significant difference between men and women were detectable in that women would experience the highest level of worry to a greater extent than men.

Relational and societal contexts can help us better understand this seemingly general negative attitude. As discussed by other scholars (cf. Sachs 1998; Åkesson 1999; Lock & Nguyen 2010, etc.), effects on kith and kin can deeply affect how we reason regarding what actions are preferred and what precautions should or should not be taken to prevent disease or passing on affected genes. An elderly woman reflecting on and discussing these issues with herself illustrates this:

I don't know if I, when I was young, would have wanted to know whether I would be afflicted with a genetic disease. I guess I wouldn't have had children in that case. My grandchildren's grandmother on their mother's side was afflicted with a serious genetic disease, but no one knew, and she died after my grandchildren were born. They can't donate blood, but in other respects I don't believe they think about falling ill. It would have been very sad for me if these children did not exist. They grew up so close to me.

The close relationship to her grandchildren is the main reason this woman finds it hard to believe that she herself would have made the decision to take a predictive genetic test, had she had the chance when she was younger. She expresses worry that her standards of that time may then have influenced her to make the seemingly emotionally difficult decision not to have children, which would have resulted in not having these dearly loved grandchildren. This exemplifies how layers of time perspectives, experiences and different relations present in the moral negotiations within a person can create a kind of pragmatic moral that is mouldable to the situation at hand. What affects your personal and intimate sphere of relations and yourself might not always, or maybe even not very often, coincide with your moral and ethical standards formed in, for and adapted to a contemporary general level. As one of our recent studies point out, people's reflections are based on a personal and situation bound morality, which does not necessarily coincide with what they generally consider to be ethically justifiable (Lundin & Idvall 2003).

In addition, the woman above indirectly reasons about how age and its cultural implications in relation to starting a family is highly relevant when debating with herself about wanting or not wanting to know of coming diseases. If her awareness of a genetic disease had hindered her from having children when younger, she would not have wanted to know. The love for her existing children and grandchildren can make the thought of not having them unpleasant and even unimaginable. The woman's response illustrates the contradictory thoughts that genetics raises, in this case paradoxical attitudes towards parenthood.

The correlation³ we found between age and a high assent in will among our respondents to *LUF 2323 – Knowledge of Disease*, to know what diseases they are at risk of being affected by, irrespective of whether they are curable or not (one of the statements to which the respondents graded their concurrence), adds more complexity to this issue. The correlation indicates that within the context of our open-ended questionnaire; the older you are the more willing you are to obtain knowledge about possible diseases, regardless of whether they are curable or not.⁴ This is interesting to consider in relation to the quotation above. The account given from this one single woman gives us an insight into the complexities of trying to consider possible outcomes in hindsight, and the different layers of reason undoubtedly added by time and experience. This is a piece of information that, with difficulty, could be gained from quantitative data only.

Another interesting finding is a correlation⁵ in the will to know what future diseases you (our respondents) are at risk of being affected by, irrespective of whether they are curable or not, and on how important our respondents rated receiving information on new medical research findings in general, implying that the will to know about your own health coincided with a will to know about medical findings in general. The correlation between the two statements in our survey is worth noting in relation to their possible correlation with the European Union report *Europeans and Biotechnology in 2010: Winds of Change?* (Gaskell et al. 2010). This report states that the more information available, the greater the will to know and the thirst for more information. A question worth asking in relation to this, as previously addressed in *The Concept of Risk*, is to what extent this thirst for information arises from the irreversibility of knowledge that people have gained? Could this situation rather be an unavoidable effect of the increased knowledge proliferation in this field, than an attitude by choice?

Worry, Agency and Autonomy

Two thirds of our respondents of *LUF 232 – Knowledge of Disease* shared the view that the most important factor was the possibility of taking measures in relation to the information received. One third of them also stated that they would like to obtain information about diseases they might be at risk of, even if no cure or palliation is available at the moment. Two thirds did not. The opinion poll

Public Research – Genetic Diseases also showed that, nationwide, more than two thirds of the respondents do not want to know about incurable disease.

Two middle-aged men in the survey *Knowledge of Disease* (2010) illustrate the importance of being able to act upon the information given to you:

This [genetic research] opens for possibilities of circumventing some built-in threats to our health, or lessening their effects. This is of course positive in many cases, but can also mean groundless worry and anxiety about being afflicted with inherited diseases and premature death, in many people. Thus, the knowledge in itself can form a larger threat than the possible disease itself.

If there is something that can be cured or at least be relieved, then that's a different story. However, if I just know that it might break out but not when, and I can't take any measures to prevent it, then I think it's a bit useless.

From their accounts you can also understand how they perceive it as meaningless to get information that does not give you any options or alternatives of action. This attitude is interesting in relation to that, nationwide (*Public Research – Genetic Diseases* 2011), men in larger proportion than women would like to find out about incurable disease. The opinions expressed in the accounts provided by the men above can be described as a strategy of handling the fact that they themselves are objects *and* subjects of science. Although, choosing to live with uncertainty as to whether one is going to be affected by a disease without a cure, is not an apparent choice for all. Certainty in the form of a test result can, despite the high degree of complexity involved, provide meaning for individual subjective experiences, even if the test result proves to be positive (Konrad 2005; Hagen 2011).

The prudentialism of the neoliberal citizenship expects the men from our study quoted above to act as subjects upon information, considering their health and bodies as objects (O'Malley 1996; Rose 1996). Furthermore, as the first man puts it, there is reason to worry that the knowledge these new techniques facilitate might cause anxiety. To understand the concern this man expresses, Beck's concept of *the latent becoming manifest* when risk is highlighted (1992) might be of help when trying to understand the possible implications of the subject/object positions of the individual. The threat has become manifest and calls for action, but if no measures (either in form of choices or actions) can be taken in relation to this newfound risk, the manifestation does not automatically provide the individual with agency.

Some people risk feeling left with a sense of helplessness and not being able to fulfil one's responsibility (cf. Rose 2007). Others yet feel empowered by having gained information to help guide their decisions for life adjustments – even if those do not encompass a cure. This is obviously highly dependent on one's general life situation and former individual and collective experiences, such as social position, gender, and age.

Authority

Not all respondents seemed to agree that their own autonomous agency in itself was the most valuable factor in these issues, nor that the presence of choice in itself safeguarded positive outcome of personal agency.

The opinion poll confirmed this latter view by informing us that the majority of the Swedish population, on a scale from 1 – not adjusting at all – to 5 – fully adjust – would *totally* (5) adjust their lifestyle to doctor's orders if it would have impact on their risk of developing some genetic diseases.

There might be several reasons for this, and the examples of certain statements seem to ascribe value to something other than personal agency and control. To some, the authority of a clinician or trust in research findings seemed to be more of a guarantee that what would happen to them was the best possible, which was also indicated by the recurring theme '*adjusting my lifestyle*' in response to the question of what to do with presumed information about genetic disease. Two women in our qualitative survey express this trust in doctors and medical findings. One of them focuses on the prescription and order itself, saying that 'I'd adjust my life to what was prescribed as the best for me'. The other woman to a higher extent assumes the desired individual responsibility of today for her health, although she makes it clear at the same time that she would also trust the information she finds to be able to help her:

Then I'd try to gain all possible knowledge, to be able to prevent and ease the symptoms of the disease.

This trust in authority and in doctors' direct orders or information from elsewhere, could indicate a desire to be free from a responsibility that threatens to be overpowering. This trust can open up for, and originate from, an urge to be morally freed from potential consequences that might be impossible for the individual to grasp. As for the quotation from the first woman, her reaction could be interpreted as an act of resistance to the increasing demands on the individual to assume this responsibility and to prevent potential risks. But it is worth noting that trust in authorities in the field does not necessarily mean letting go of your agency. Choices in accordance with advice from authorities are just another way of facilitating your personal agency and taking advantage of the knowledge already gained by others.

Rationality versus Emotion

As discussed above, many respondents find it difficult to answer whether they would have had children if they had known that they could pass on genetic disease. In a similar way, it is difficult to answer whether they would want to know what diseases they might be afflicted with while they are healthy.

There are no guarantees that, with a positive test result in your hand, you would still be happy that you took the test, when rationally arguing the pros and

cons with yourself. An elderly woman in our qualitative survey reflects on how there is no going back from knowing:

Yes, I would like to know what diseases I risk being afflicted with or passing on. [...] Even if there is no cure now, there might be one in the future. I would always like to know. (Why, this is written while I'm healthy. How I would react when sick, no one knows.)

On the other hand, one might need to view the human as a versatile creature, with resources to try out new ways of constructing meaning about what life brings. The knowledge attained, and the reasons for attaining it, are mouldable entities. Ways will be found to fit knowledge into our personal world of social, cultural and emotional landscapes. Explanations as to why a test was or was not taken or what the result of a test meant for us can be constructed and re-constructed over and over, and narration in itself changes the story and the feeling of initial experience (see e.g. Butler, 2001 on narration *per se*; Frank, 1995; Sachs, 1998).

The following statement of a woman in the qualitative study shows a very sober way of reflecting over the complexities of reason contra emotional response:

Having thought about it some more, I feel that it might be good to know, and to get used to the thought of future diseases. I think I'd like to know. [...] My reason tells me all this, but I'm more uncertain of my emotions. It takes a lot of courage to receive knowledge about a possible future severe disease, and it takes great strength to be able to handle that knowledge.

This woman is obviously worried about how she might react if she took a predictive gene test and the result was positive. Even if it is not mentioned in this case, it seems to be connected with an irreversibility of knowledge. As previously discussed, the information you gain will unavoidably influence and be integrated with your actions, and it will create and make visible what we call 'ambivalence' in qualitative accounts on genetic research. In our experience drawn from the work with the opinion poll *Public Research – Genetic Diseases*, the process of negotiations between the self and society resulting in ambivalences toward genetic testing, cannot be visualized solely with quantitative methods.

To Make Solid What's Liquid: The Question of a Unified Public

The background of our investigation is the cultural and political formation of the risk society, wherein the individual citizen is positioned as an active and prudent subject (Beck 1992; O' Malley 1996). Due to the development within genetics and genomics, bodily risks can be detected on the level of the DNA-molecule. The individual is supposed to manage these risks through actions that are both rational and preventive. As noted by Åkesson (1999), the expansion of genetics and genomics relocates threats and dangers to the inside of our bodies. Moreover, these threats and dangers diverge from traditional forms of cultural

representations as these genetic threats and dangers are represented through abstract forms of statistical calculations (Åkesson 1999: 121). The notion of genetic risk is difficult to understand, and cannot easily form the basis for rational and responsible action on behalf of those who go through genetic testing. The genetic risks can thus be said to create experiences of abstract uncertainty.

One aim of this article has been to capture and discuss people's attitudes to biomedicine, genetic diseases and genetic research. The empirical material shows that the responses of many participants within our studies can be characterized in terms of ambivalence towards the issues that arise in relation to genetics and genomics. The ambivalence visible in our studies can be interpreted as an example of the form of abstract uncertainty described above.

Moreover, the answers given by the participants in the studies are also complex in relation to different layers of time perspectives, experiences and different social relations upon which the answers are situated within. The attitudes that come forward in our investigations are of a pragmatic kind, very much dependent upon the actual situation within which the genetic test is taken – a circumstance that quantitative research on its own with greater difficulty can capture. Previous research, conducted on Huntington's Disease, has shown that the results of predictive genetic testing for the disease is often correlated with so called transition points (Tibben 2007). These transition points can be events such as entering a long-term relationship or deciding to have children, and it is at these points that individuals become fully aware of the result of the genetic test (Tibben 2007: 166).

The views and attitudes of individuals – the so called public – can thus be understood as both complex, heterogenic and dynamic towards genetics, genomics, and biomedicine. Previous studies suggest that there is no unified public whose attitudes and opinions can be captured (e.g. Plows 2011). It is particularly difficult, as discussed, to get a picture of how people view biomedical and genetic research (Åkesson 1999; Gottweis 2008; Ideland & Holmberg 2010; Hagen 2011). However, with the need for legitimization of research follows a wish to gain these citizens' participation and approval. There is reason to believe that these endeavours are at risk of failing, if they are based upon a notion that such thing as a unified public exists. If anything, the idea of a unified public excludes the diversity of the many, often contradictory approaches that appear when people reflect upon issues such as biomedicine and genetic research. Furthermore, the idea of the unified public excludes the voices of specific stakeholders and 'opinionated' persons.

Along the lines of Gottweis (2008) and Plows (2011), and with our empirical material as support, we would argue that there is no unified public and therefore no cohesive public opinion that can be addressed on the issue of genetic preventions. Attempts to create formal participatory arrangements where the public is viewed as united could lead to disarming self-appointed interest groups

who view themselves as stakeholders, by replacing their voices in the debate with those of a non-engaged and disinterested public (Hansson et al. 2011). Furthermore, as our two studies indicate, we would argue that even the most seemingly non-engaged individual or group of people harbour complex feelings and opinions on this topic. Our material shows how allowing complexities from people's individual experiences and relational negotiations to be visible can 'liquefy' the seeming solidity of quantitative accounts.

We suggest that one important response to meet this heterogenic public is the development of methodological tools that better capture the complex attitudes among people (Lundin & Idvall 2003). This is especially important as genetics and genomics become entwined with visions of responsibility and prudence that presuppose both a rational and unified public in order to achieve a large-scale prevention of disease within society. By taking into account the complexity and ambivalence, the dialogue between researchers, patients, relatives and all the people viewed as the general unified public will be facilitated. Without dialogue and without accurate methods of research, the erroneous picture of a general unified public open to inquiry will remain, which in turn can result in negative consequences for research as well as for individuals. If room for ambivalence were allowed in the material used for drawing conclusions on how advanced technical genetic biomedicine is perceived and also accepted or unaccepted in people's everyday lives, there is a better chance of arriving at the core issues and main reasons for the manifest ambivalences that life sciences give rise to. We want to point out the importance of taking into account uncomfortable answers and deeply felt opinions, thereby starting the necessary process of dialogue.

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Notes

- ¹ The majority of the respondents in *LUF 232 – Knowledge of Disease* are elderly people. The high age of the respondents affect the outcome of the study in the sense that the collective and individual experiences of gene technology, culturally and socially, are limited to the latter parts of their lives.
- ² BAGADILICO (Basal Ganglia Disorders Linnaeus Consortium) is an international research environment at Lund University, working on developing and improving treatments for the neurologically caused Parkinson's and Huntington's diseases, and also for improving the quality of life for patients and their families. BAGADILICO consists of an estimated 120 researchers (March 2011) from the three disciplines Medicine, Engineering and Humanities, and is affiliated with the Department of Experimental Medical Science and the Faculty of

Medicine. The humanistic research within BAGADILICO is carried out by the Cultural Scientific Research Team (CSRT).

3 r=.20, p<.05.

4 No correlation was found between gender and the degree of “will to know” regarding the quantifiable statements of X X – X X X. We did find that the gender aspect considering motives of caring about passing on or not passing on genes might need further investigation, since we interpreted the qualitative material supplied by the women within the study as being more ambivalent regarding this.

5 r=.54, p<.05.

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Appendix: The Survey

Method

Due to the space it would occupy in this article, we choose not to reproduce the exact phrasing of the questions in the qualitative open-ended questionnaire *LUF 232- Knowledge of Disease*, nor of the quantitative nationwide opinion poll *Public Research – Genetic Disease*. The full questionnaire is available through the Folklife Archive in Lund; search for *LUF232—Kunskap om sjukdom (Knowledge of Disease)*. The main results of the nationwide opinion poll *Public Research – Genetic Disease* will be addressed later in the article under the thematic results in relation to the qualitative main findings of the open-ended questionnaire *LUF 232- Knowledge of Disease*.

The qualitative study was conducted first and the quantitative study second, in order to triangulate sources. We aimed at finding the most nuanced questions possible for the nationwide opinion poll, in order to contribute to methodological development in targeting the public.

The Qualitative Study: LUF 232- Knowledge of Disease received forty-three answers (at the time of the analysis), producing a response rate of 35 percent. In addition to being qualitatively evaluated, thirty-nine of these answers were also quantitatively analysed for the frequencies of themes mentioned in responses. This method does not make the results quantifiable or generalizable by quantitative research standards, but gives us an overview of the proliferation of opinions expressed within the group of respondents. We chose this combination of methods due to interest in methodology and because we wanted an explorative view on the data we produced. We are aware of the high variation in response rates among the different questions in the questionnaire, and we are interested in this methodological issue. Earlier questionnaires on biomedical and genetic research distributed via the Folklife Archive have shown the same tendency for low response rates. We can speculate that this internal tendency might derive from the complexity of the themes of these questionnaires in particular, causing the respondents to refrain from answering. Furthermore, the open-ended questionnaire format is a method with many special features; the surface impression is that of a survey, but the questions are usually embedded in some text intended to guide the respondent's thoughts to certain problems or themes. In addition, the respondents of open-ended questionnaires are free to compose their answers as it suits them, as they were in this case. This often generates a letter-writing style of text, enabling respondents to answer one question at length and to skip another. Answering an open-ended questionnaire in full length usually requires both time and effort (For more information on the open-ended questionnaire as a method, see e.g. Hagström 2009: *Frågelistan som källa och metod*. Lund: Studentlitteratur AB.).

The qualitative evaluation of the accounts given in of *LUF 232 – Knowledge of Disease* examined the diverse ways of handling and negotiating the ethical dilemmas that occur between the consequences for the individual's life in relation to the idea of general guidelines for "the greater good", and the dilemmas manifested in the negotiations between what is identified by the subjects themselves as emotional reactions versus rational reasoning. We investigated how the respondents handled this by shifting between diverse and sometimes seemingly contradictory arguments. We looked into how these strategies in turn create multiple layers of opinions – ambivalences. Through this process, the material crystallized into themes, which are the ones presented and elaborated on in this article. The material was processed both by Wiszmeg and Lundin, and the themes developed through a dialectical process where the material at hand and Wiszmeg's and Lundin's preliminary understandings in the field were constitutive of the result.

In addition to the qualitative questions in *LUF 232 – Knowledge of Disease*, our respondents were to grade their assent to two different statements, with fixed alternatives. The statements were: *I would like to know what diseases I am at risk of being affected by, irrespective of whether they are curable or not*, and *It is important to me to receive information on new medical research findings in general*. The degrees of assent (the same alternatives applied to both statements) ranged from 1 *Do not agree at all* to 4 *Fully agree*. A fifth alternative outside the scale was also given: 5 *I do not care*.

The majority of the respondents of *LUF 232 – Knowledge of Disease* are elderly women, and the average age is just over 70 years. The sample of qualitative data from our study is chosen for

its relevance to the aim of discussing ambivalence in accounts, thus problematizing the idea of a unified public. The material has been translated from Swedish to English.

The Quantitative Study: Public Research – Genetic Diseases is a nationally representative study. Its design was based upon our previous results from *LUF 232 – Knowledge of Disease. Public Research – Genetic Diseases* included 1000 Swedish respondents interviewed by telephone, and were conducted by Swedish branch SIFO of TNS, a market research company, in May 2011. The respondents were asked to answer 10 questions with on beforehand stated alternatives. The interviewers of SIFO were supplied with the minimum of background information they needed to be able to conduct the interviews. The respondents had to answer the questions on the spot.

Results

The results of *LUF 232 – Knowledge of Disease* show that more than half of our respondents would like to know what diseases they are at risk of being affected by (11 out of 21 respondents would like to know what diseases they are at risk of being affected by, 10 out of 21 did not). A slightly larger majority, 70 percent of the responding respondents, would like to know what diseases they are at risk of passing on (7 out of 10 respondents would like to know what diseases they are at risk of passing on, 3 out of 10 would not). 33 percent of our respondents would like to know, even if there were no cure or effective palliation (4 out of 12 respondents would like to know even if there is no effective cure or palliation, 8 out of 12 would not). No responses were generated by the question whether they would like to know if there was a *risk* of being affected by disease, and only two responses were received on whether they would like to know if there was a *certainty* of being affected – and those two responses were positive. When respondents were asked what they would do with information about what diseases they are at risk of being affected by or passing on, statements that they would worry and that they would adjust their lifestyle according to the doctor’s orders were the most common (Table 1).

Themes	Number of times stated
worry	8
adjust my lifestyle	7
do all the things I have wanted to	2
let it inhibit life	2
avoid passing it on	2
plan my life	2
“clean up” after myself	1
consider information to relatives	1
let it affect my career	1
trust in my faith	1

Table 1. Different themes concerning what the respondents would do with information about what diseases they are at risk of being affected by or risk passing on (more than one alternative per informant is possible).

In response to both quantifiable statements in *LUF 232 – Knowledge of Disease*, most of our respondents chose the highest degree of assent: *I fully agree*. We received a total of 31 responses to the first statement which were: *I would like to know what diseases I am at risk of being affected by, irrespective of whether they are curable or not*. Seven respondents chose the lowest degree of assent, four respondents chose the second lowest degree of assent, another four respondents chose the second highest degree of assent and twelve respondents chose the highest. Moreover, four respondents stated that they did not care. To the statement *It is important to me to receive information on new medical research findings in general*, we received 32 responses. Two chose

the lowest degree of assent, four chose second lowest degree of assent, seven chose the second highest degree of assent and eleven the highest. In addition, seven stated that they did not care.

As have been stated in note 1, the main results of the nation wide opinion poll *Public Research – Genetic Diseases*, is being addressed under the thematic results in the article in relation to the qualitative results of *LUF 232 – Knowledge on Disease*.

‘Successful Ageing’ in Practice: Reflections on Health, Activity and Normality in Old Age in Sweden

By Åsa Alftberg & Susanne Lundin

Abstract

This article aims to contribute to the critical examination of the notions of health and activity, and to discuss how these cultural and social constructs have impact on elderly people’s lives. An ethnographic perspective gives fruitful inputs to explore how old people deal with the image of old age as one of decay and decline, while they simultaneously relate to the normative idea of so-called successful ageing. The focus is thus on how elderly people create meaning, and how they manage and make use of the contradictory cultural beliefs that are both understood as normality: old age as a passive period of life involving decline and disease, and activity as an individual responsibility in order to stay healthy. The study sample is created with two different methods, qualitative interviews and two different questionnaires, and the majority of the respondents are 65+ years old. The article demonstrates the intersection between old age and a health-promoting active lifestyle. The notion of activity includes moral values, which shape the beliefs and narratives of being old. This forms part of the concept of self-care management, which in old age is also called successful ageing. The idea that activities are health promoting is the framework in which activities are performed, but significance and meaning are rather created from practice.

Keywords: Self-care, health, activity, normality, ageing, practice, lifestyle, old age, health-promoting

Introduction

'Exercise becomes more important in old age' is the headline of an article in the Swedish lifestyle magazine *Hälsa* (*Health*). The article stresses the importance of good nourishing food and physical exercise in old age, in view of the fact that 'ageing means vulnerability and frailty'. It finally makes the point that 'successful ageing is connected to high protein intake and regular exercise' (Hälsa 2011). 'Successful ageing' is a notion and ideal also used within gerontology, meaning wellbeing, health and an overall active engagement with life (Torres 1999). A similar term is 'active ageing', linked to wellbeing, independence and health, which derives from established gerontological theories (Venn & Arber 2011). Both concepts aim to empower older people to be active and independent, and to avoid the expected negative consequences of ageing, such as dependency and poor health. To be successful in old age is understood as to be healthy and active, while what could be called unsuccessful ageing is associated with frailty, illness, loneliness and dependency on others (Gilleard & Higgs 2000; Hepworth 2000; Cruikshank 2003; Blaakilde 2007; Jönson & Larsson 2009).

The association of activity with health implies a perspective of power and normality that permeates late modernity. Thus, becoming old is more than a biological process. It also means that people are sorted into special social categories. Old people are 'the others' of modern society, who represent what the rest of the population does not want to be, but hopes all the same to become; namely old, with infirmities as well as a shrinking future. Categorisations of this kind are cultural constructs, and as such, they often say more about the values of the time we live in than about the actual conditions of age groups. Old people are not alone, of course, in being ascribed a type of alien status in society. Nevertheless, the very category of 'old' highlights and refers to various forms of disciplining and systems of control – it constitutes altogether a specific focal point that makes plain the state of tension between body, health and ageing on the one hand, and ideas about normality on the other (Foucault 1994). Activity could therefore be looked upon as a means to be normal and to lead a normal life. Good health requires an active, disciplined body; the individual is expected to strive towards being strong, fit and healthy (Lock & Scheper-Hughes 1996:62; Lundin 2008).¹

There is a broad scholarly discussion on the paradigm of activity (Giddens 1991; Conrad 1994; Lupton 1995). However, in the field of elderly research this paradigm is seldom critically scrutinized. Nevertheless, some important studies address the notion of activity as a cultural and social construction. They include, for example, Susan Venn's and Sara Arber's (2011) discussion of how elderly people's views on and approaches to 'active ageing' are intricately linked to the bodily changes that arise from the ageing process. Moreover, Sandra Torres and Gunhild Hammarström (2006) contribute to the discussion by showing that the ageing process can either be regarded as biologically determined and natural, or as

something that can be influenced and postponed by lifestyle. They demonstrate that old people may perceive the process of growing old either as a limitation that must be accepted, or as something that one should counteract (cf. Werntoft 2006).

Our overall aim is to contribute to the critical examination of the notion of activity and to discuss how this cultural and social construct has impact on elderly people's lives. As a development of the discussions that suggest that people relate to either one or the other concept, we assume that these approaches and concepts *interact* with each other. We are, thus, interested in how notions relate to practice, that is, the doing of ideas (Shove 2003). We argue for the necessity to examine the activity norm and its promoting of health from an ethnographic perspective that shows how it is rooted and manifested in individuals. We believe that field observations and in-depth interviews give fruitful inputs to explore how elderly people deal with the image of old age as one of decay and decline while they simultaneously relate to the normative idea of so-called successful ageing. The focus of the article is thus on how elderly people create meaning, manage and make use of what appears as contradictory cultural beliefs that are both understood as normality: old age as a passive period of life concerning decline and disease, and activity as an individual responsibility in order to stay healthy.²

In this article we lean towards critical cultural science. We are inspired by analyses, such as Lock's and Scheper-Hughes' (1996), which point out that power structures are connected to conceptions of the body (cf. Gillearn & Higgs 2000; Venn & Arber 2011). They argue that the perception of how this body of ours should be used occurs against the light of a moral mobilization in which people, as Nikolas Rose emphasises (1999), are expected to be responsible and take care of themselves. We have also found Stephen Katz (2000) useful, who argues that the concept of activity and productivity are incorporated as key elements into older people's lives and in their stories of everyday life. Katz points out that even though older persons freely participate in various activities, they are aware of the correlation between activity and a larger ethical regime of self-disciplining in later life.

Methods

Our empirical data is collected in Sweden. The study sample is created with two different methods: qualitative interviews and two different questionnaires. Even though the methods differ, the same question themes and types of questions, concerning experiences of ageing and health in relation to everyday life, were used in the questionnaire *Ageing and Health*, LUF 227, and in the interviews. The aim of the questionnaire *Biomedicine and Prioritizations in Health Care*, LUF 214, was to cast light upon views of advanced medical treatments, i.e. measures that are expensive and that bring to the fore questions about who in society should be given precedence. Using various processes of creating data can provide different per-

spectives and understandings (cf. Lundin & Idvall 2003). The interviews give access to deeper knowledge concerning each individual, whereas the questionnaires increase diversity using a larger number of participants. Yet, both methods employ a micro-perspective to create an understanding of comprehensive cultural processes (cf. Kaijser and Öhlander 1999). Additional material that is used include official government recommendations and reports like *Prioritisations in Health Care* (SOU 2001:1), as well as press coverage and other media reports.³

Interviews

The interview study is part of a research program concerning elderly people and geriatric care, conducted by the Vårdal Institute.⁴ Interviewees were contacted during their participation in an intervention study⁵ connected to the overall research program. Those who were regarded as reluctant or as having difficulties to participate in the intervention were not asked to participate in the interviews. Our study focuses on people's perceptions and experiences of ageing, health and activity. However, one has to consider that the intervention project may have facilitated the interviews by increasing the participants' reflections on the topic. We perceive this not as a negative element in the investigation, but rather as a way to open for an awareness and thoughtful response.⁶

The participants, six women and four men, were living in condominiums or rented flats in an attractive city district of Gothenburg, a large town in the west of Sweden. They were between 80 and 90 years old, and were not dependent on assistance in everyday life. The interviews were carried out in the respondents' homes, where they had lived most of their adult lives or moved to after retirement. All the women, except one, were widows, while only one of the men was widowed. The others were still married, and their spouses sometimes participated spontaneously in parts of the conversation. We used an interview guide, thematically structured, as a point of departure for discussions of experiences and perceptions of ageing and health, and descriptions of everyday activities. The interviews lasted between forty-five minutes and three hours, and were recorded digitally. Afterward they were transcribed verbatim.⁷

Questionnaire

The questionnaire is constructed as a thematic open-ended questionnaire, where a group of respondents are asked to write down their answers: thoughts, opinions, memories and experiences of a certain subject (cf. Hagström and Marander Eklund 2005). The questionnaire is distributed to an existing pool of respondents bound to the Folk Life Archives at Lund University. These people fill out and respond to questionnaires sent to them on a regular basis (approximately twice a year).⁸ The questions follow specific themes and the respondents decide which questions they want to answer. These permanent respondents have initially replied to an advertisement from the Folk Life Archives or they have heard about it in

other ways, for example through a friend. The only requirement is that you enjoy writing. Regarding the questionnaire *Ageing and Health* (LUF 227), 62 answers were received from respondents aged from 42 to 93, even though the majority of the respondents (75 per cent) are 65 years and older. The majority is living in the countryside or in smaller cities, primarily in the south of Sweden. Some receive assistance from community care or get help from relatives or neighbours to cope with certain daily chores. Furthermore, the answers from *Biomedicine and Prioritizations in Health Care* (LUF 214) were predominantly received from older people. Of a total of 61 respondents, 90 per cent were between 45 and 89 years old.

It is important to discuss and reflect upon the questions of the questionnaire (and of course upon the questions asked in the interviews). What does the researcher want to know? How can the questions be formulated in order to encourage the respondents to bring forth their own views and not what they think the researcher or the archives want to hear? Perhaps the questionnaire gives the opportunity to interpret the questions more freely, while the interview is more of a well-defined situation, accepted and initiated of both parties (cf. Kvale 1996). Nevertheless, both methods are ultimately about communication, which requires some level of mutual understanding (cf. Lundin & Idvall 2003:191).

To Deserve Health

The most common justification of activity is that it is healthy, in all ages (Cruikshank 2003:159pp). The activity device in old age is put into words by a woman, aged 73, in the questionnaire LUF 227: 'don't stop doing things because you're growing old, because you'll only grow old if you stop doing things'. And the notion of growing old implies illness, isolation and dependence on others.

The idea seems to be that being healthy and in good health is not something people simply are, but something they must strive for, and deserve. Good health is described as a loan, which can be retained with the right genes and a correct lifestyle. An 83-year-old man writes, as a reaction to an on-going media debate on prioritizations in health care, in the daily newspaper *Sydsvenska Dagbladet's* letters to the editor, that:

All people have to prepare for old age by keeping themselves healthy as long as possible. I do gymnastics for 15 minutes a day and take an hour-long walk every evening [---]. I feel super and have never been ill, apart from a few injuries on the job. Society has to invest much more in fitness activities; it saves money in the long run. Geriatric care is miserable, people are kept locked up as if they were criminals. (Sydsvenska Dagbladet 23/04/2003)⁹

Similarly, one of the interviewed men, aged 85, argues that staying healthy is something everyone should think about:

You don't think about your health as long as you enjoy good health. But when it begins to falter, you will understand what it means to be healthy. How foolish of people not to think about looking after themselves in order to stay healthy. It's possible I

didn't consider that myself when I was younger. But my wife and I have done plenty of sports and been outdoors and we used to go skiing in the winter. That has made us stay healthy.

Later on during the interview, the man accounts for his chronic diseases; he has a stomach disease and rheumatism. Recently, because of an eye disorder, he has undergone surgery. Clearly, there is more to good health than being free of illness and diseases. Most of the respondents claim to be in good health, even those with relatively serious illnesses and disabilities. This suggests that good health involves more than being healthy; good health implies well-being on many different levels. As long as the consequences of ill-health are possible to adapt to, and everyday life can continue without changing too much, there seems to be no reason to consider yourself as ill or unhealthy. Everyday habits and routines are important for the experience of health. Poor health, on the other hand, is described as not being able to work and perform daily chores; i.e. not being able to be active.

Many respondents claim to be in good health in relation to their age; that is to say *despite* their old age. Since ageing and old age are associated with poor health, the concepts of ageing and health are intrinsically interwoven and cannot be explained separately. Health and ageing are intimately linked together (cf. Alftberg 2010). The belief is that health deteriorates the older you get. The expression 'age is beginning to show' signifies that at a certain age, one should not be surprised of bodily decline and disability. It is difficult to describe ageing without using health as a reference; people talk about their ageing in terms of how they feel with reference to illness and ailments. Similarly, health can be described in age metaphors: 'on a bad day, I feel like a hundred years'. To be active is a sign of health and, if it concerns an elderly person, a person young for his or her age. A male respondent of LUF 227, aged 72, illustrates this:

To my wife's dismay, I still climb on a ladder and wash the house, remove moss from the roof, fell trees or clear the brushwood from the common grove across the street. Is that a sign of health or sheer stupidity? One fine day I may lie on the ground, bruised and broken, after falling off the ladder.

It seems that old age is considered a risk, regardless of health status. Climbing a ladder becomes unsafe, even for a healthy individual, because of the age of that person. Old age stands out as a period of increased risk of injuries, and that is something to be prepared and take responsibility for. Possibly, the wife mentioned in the quotation is taking that responsibility, trying to make her husband stay off the ladder. As shown by Arber and Ginn (1995), the traditional female care for the family lingers on, in our case articulated as male health being a female responsibility. This was illustrated in the interviews with the men that were married; often the wives spontaneously participated and developed the accounts of their husbands' health conditions (Alftberg 2008).¹⁰

Another example of the notion of activity as a means of promoting health can be found in relation to people's views on health care, and the question of what

should be prioritized in health care. Indeed, people's views on health care tell us about their values and what they deem to be 'normal'. As our study on *Biomedicine and Prioritizations in Health Care* (LUF 214) shows, people's way of life is important when reflecting on who should receive cost-intensive care (Lundin 2008). In our questionnaire, just over 40 per cent of those responding stated that older people should give younger people precedence in life-threatening illnesses, while 58 per cent demand that regardless of age, people should take responsibility for their health in order to be considered for expensive treatments.¹¹ Thus, for example, a 73-year-old man thinks that 'a heavy smoker who does not intend to stop smoking should not receive treatment for lung cancer', and a 63-year-old woman says that 'if you don't want to contribute to your well-being and try to hold off lifestyle-related illnesses, then you shouldn't be surprised that resources and prioritisations have to be taken into consideration'. Another person who answered the questionnaire, the wife of a man who is on the waiting list for a new organ, says:

It disturbs us when he is terribly ill and we know there are people who precede the waiting list – people having mistreated their bodies all their lives, while my husband was born with this disease, which he has been struggling with all his life.

The results of our questionnaires correspond to those of researcher Elisabet Werntoft (2006). Her studies indicate that age is an important factor in prioritisations in Swedish medical care. At the same time, she emphasizes that 80 per cent of the old people who were consulted in her studies thought that factors like pain or way of life, for example, were more pressing to take into account than age. As Rose (1999) points out, the concept of health is permeated by a moral imperative stating that health is something one must work to obtain. It has to be earned!

The Making of an Active Life

An active lifestyle emerges as important and is motivated for reasons of health and postponing the ageing process. The empirical data exhibit different forms and descriptions of activity. The respondents give detailed accounts of associations and club activities, exercise, gardening, solving crosswords or simply being able to carry out everyday household chores without help. A common activity is walking, alone or together with a spouse or friends. When walking, a certain kind of stick is often used for support, the so-called Nordic walking poles. The stick has long been a symbol of old age, attached with notions of decreased mobility and inactivity (Odén 1994:9). Nordic walking poles associate instead to exercise and movement, in line with the activity norm. In contrast to ordinary sticks or canes, Nordic walking poles provide a more youthful and sporty appearance. The poles are associated with physical fitness rather than impaired ability, and we argue that they create a different representation of old age, corresponding to the notion of activity (cf. Alftberg 2011).

Taking a walk is perceived as a healthy and sound activity. Still, it can be difficult to motivate yourself to do it. One of the interviewed women, aged 90, describes what usually happens when she is thinking of walking:

If I plan to take a walk, I might think: 'Should I be taking a walk now? Nah, I'll do that tomorrow instead. No, get yourself going now!' I wander around the house and discuss with myself: 'Go outside and take a walk! Nah...' Perhaps I start to do some housework: 'No, don't do that, you can do that when you come home! All right, all right!' Finally I get so tired of myself nagging: 'All right, I'll take a walk then!'

The woman explains that even when she is not in the mood for walking, she knows she needs the exercise in order to feel bright and cheery. In this way she is able to perform other activities she is more interested in. It appears that performing health-promoting activities is a responsibility that cannot be ignored even at lack of interest or dislike.

A finished working life is expected to change into an active retirement life (cf. Nilsson 2011). The respondents stress that they are living a normal life, which includes physical, mental and social activities. The only exception seems to be that more time is required; an interviewed 80-year-old woman describes herself as being 'not as nimble and quick as before'. But even though activities take more time, it is not considered a problem. The point is that you at least *try* to do them. It appears to be important to attempt to be active and independent, according to your own ability. But this also requires the right attitude or approach (cf. Torres & Hammarström 2006). This can be illustrated by quoting another of the interviewed women, aged 87, who talks of a friend of hers:

She's almost ninety years old, but she's alert and in her right senses. It's lovely, she's such a positive person too – because there are so many people who just grumble and complain. Darned, I get so tired of it. It won't help feeling sorry for yourself; one has to get out and about. Of course, some days I find it difficult, but you can't stay inside all day.

She goes on telling how she activates herself on days when the weather is too bad for being outdoors. Since she lives a few floors up in a block of flats, she uses the stairwell for exercise. By going down to the front door, and then up again, and doing this every two hours, she will get the exercise she feels she needs. Another female friend of hers has impaired vision, but the interviewed woman means that her friend could at any rate activate herself with audio books or by listening to music. The ideal of a health-promoting, active lifestyle remains even with poor health. The attitude is essential. As mentioned in the quote above, feeling sorry for oneself is not an acceptable behaviour. An 86-year-old woman in LUF 227 also articulates this, when she describes how to age well:

I believe that mental training is as important as physical exercise. Reading, discussing, solving the cross-words and above all, spending time with your friends and not isolating yourself, as well as not feeling sorry for yourself that things are not the way they used to be.

What happens when an older person does not have the strength or desire to be active? Several of the respondents describe themselves as lazy when they have given up a regular activity. One of the interviewed men, aged 80, explains that he will not go out walking as much as he used to because he has become a little lazy. A woman in the questionnaire LUF 227 comments that, as a result of her indolence her interest in doing sports has diminished. The fact that she is 81 years old and describes herself as overweight appears not to be significant to her. She could have used other explanations, but chooses to describe herself as idle.

Nevertheless, according to the respondents, the emphasis on activity may actually be overdone and result in impairing people's health. An interviewed woman, aged 87, explains that a friend of hers shows an unhealthy behaviour:

She's a bit restless, I think. [---] She wants to help and she'll be there to help each and everyone all the time. I think this is not good for her. It becomes stressful in the end, when she's expected to be here, and needs to be there, and ... She has a very nice cottage, then suddenly she plans to have a dinner party and cook all this food – I asked if she expected a crowd of people coming. The whole thing is somewhat restless.

Self-care could be described as keeping a balance between rest and activity. Too much activity causes too much stress and stress causes illness. Too much activity implies restlessness, where restlessness could be seen as one end of a scale where the opposite end is inactivity. The middle of the scale is the normal, healthy point of activity. It therefore seems to be a difference between being active and being restless. Restlessness is an exaggeration of the amount of activity one does, and a sign that the responsibility of maintaining one's health is not taken seriously. Both inactivity and restlessness can be regarded as the antithesis of prevailing ideals, and therefore may possibly cause illness and disease (cf. Sontag 1990). The normative notion of activity creates meaning when activities are actually done, and the performance also shapes what is regarded as normal and what is regarded as deviant (cf. Shove 2003).

Good and Bad Activities

Normality in relation to the amount of activity discussed above also includes normality concerning the *nature* of activity, what kind of activities you perform. All activities should primarily be beneficial to your health. This idea leads to frequent responses concerning physical utilities, possible psychological values and certainly social benefits; the ultimate activity may be described as something that combines busyness with pleasure. Activity must not be entirely amusing, but it has to be health-promoting and wholesome. Accordingly, it would be appropriate to speak about good activities and bad activities, ranking 'good' in the same category as 'normal' and 'bad' as 'deviating'. Being active, as we have discussed above,

is connected to moral virtues such as responsibility and normality (cf. Katz 2000). People can be active in the right way as well as in the wrong way.

A female respondent in the questionnaire LUF 227, aged 70, puts a gender difference in relation to the proper manner of an active lifestyle:

I believe men age quicker than women, due to the fact that men are less active than women. Of course, there are active men, but many of them just sit in front of the television or lie on the sofa.

Several of the participants, primarily females, express the opinion that men appear to be less active than women. The experience is that older men are not to be found in social contexts as clubs and associations as much as women, even considering the difference in the average length of their life. A common view is that women are expected to have a stronger social network than men; consequently, the significance and meaning of activity might differ between the sexes, and gender will affect the perception of 'normal' activity (cf. de Beauvoir 1977).

In the quotation above, watching TV or lying on the sofa are perceived as bad activities or not actual activities at all. We want to show how these occupations are culturally and morally loaded, giving an example from an interviewed 80-year-old woman:

I find it wonderful to have a television in my bedroom. My son joked about the danger that I will stay in bed all day. I prefer to watch TV in bed, I think it's wonderful. If I'm tired I turn it on and see if there is anything good, and I can relax and rest while watching. [...] I enjoy quiz shows. Not that I know the answers that much, but you could always learn something.

Lying in bed all day is described as a hazard, at least by the woman's son. The activity norm becomes more challenged when lying down compared to sitting up. In Western historiography, there is a perception of correlation between upright posture and moral virtues. Classical accounts of human evolution are illustrated with pictures of stooping apes gradually turning into humans standing straight with their head high and body erect. Man's eventual achievement of upright posture is the foundation of culture and civilization, of moral height (Ingold 2004). Lying down could consequently be regarded as the opposite of being in possession of moral virtues. Perhaps the posture of the body becomes more significant in old age because of the image of old age as decay and decline, and therefore a higher risk of confinement in bed. An upright posture is also considered as a characteristic of a health-promoting active lifestyle.

It is not only the horizontal position that is a danger. With its associations to inactivity and passivity, the television is a moral hazard as well. Nevertheless, the woman quoted above claims to prefer quiz shows since they give her the opportunity to learn something. No matter how much she enjoys lying in bed and watching TV, the pleasure and fun must be legitimized in terms of health. The quiz shows offer mental exercise, and she can learn from it. Activities that are performed for their own sake and represent their own goals, with the main empha-

sis on the emotional, aesthetic and sensual, are not regarded as healthy enough and disguised in rational, instrumental explanations (Ronström 1998).

Are Activities Leisure or Work?

Not all activities have the same status and some pursuits are not even considered to be activities, like watching TV as mentioned in the example above. But perhaps there is a question of ability and capacity that needs to be noticed. Depending on health and ability, watching television or going shopping may be described as important activities that account for the whole day. It is important to try to lead an active life, adapted to the current situation that may involve impending illness, disabilities and ailments. Venn and Arber discuss similar attitudes concerning day-time sleep and old age. They state that attitudes and practices of ‘active ageing’ are intricately linked to the bodily changes that arise from the ageing process. The desire to be active later in life leads to primarily different attitudes to day-time sleep. Those who accepted daytime sleep did so in recognition of decreasing energy in old age, and acknowledge that napping is beneficial in helping themselves maintain active lives. Those who resisted daytime sleep did so because time spent napping was regarded as being both unproductive and as a negative marker of the ageing process (Venn & Arber 2011). We argue that this means that old age actually transforms what an activity is considered to be. One example is an 81-year-old woman who puts in writing her week schedule in the questionnaire LUF 227:

Monday	- National Pensioners’ Organization
Tuesday	- Comfort-group
Wednesday	- Day off
Thursday	- John’s brother comes to visit
Friday	- Supermarket
Saturday	- Nothing!
Sunday	- Church

The chores of everyday life, such as shopping in the supermarket on Fridays, are defined as important activities that require scheduling. One occupation per day can be enough to feel busy and useful. In addition, the schedule describes Wednesday as ‘day off’, and Saturday is labelled ‘nothing’. The notion of activity looks like a form of work to be done, which explains the desire for a day off. In retirement, wage work is replaced by another kind of work called activities. Hence, there can be time off from ‘leisure time’ in retirement, if retirement is defined in terms of activities.

A schedule maps out time for work and time for leisure. The notions of time and work are related. They are both fundamental Western metaphors that we use and live by, according to George Lakoff and Mark Johnson. Both concepts are perceived as resources; something that can be measured, used and saved. The connection between time and work has consequences for the comprehension of non-work, or leisure. Leisure becomes part of the same metaphorical thinking, and is understood as something to use, spend, save, waste or lose (Lakoff & Johnson 2003). Activities in old age can be said to take on the form of work, health work, in order to age successfully; to be healthy and active, to fulfil oneself and not become a burden on society (cf. Ronström 1998).

As was mentioned in the introduction, Venn and Arber (2011) suggest that the notion of activity is incorporated into the lives of older people. Even when freely participating in a wide range of new and continuing activities, older persons are aware of the correlation between activity and the imposing overall structure concerning self-disciplining in later life (cf. Katz 2000). We would like to add that the notion of activity results in the transformation of meanings of occupations and activities in old age. Solving the crosswords changes from an easy-going and pleasant occupation to a health promoting activity, just as everyday chores and pursuits develop into scheduled labour.

Successful Ageing in Practice

This article has examined how elderly people manage and make use of two contradictory cultural beliefs that are both understood as normality: old age as a period of life characterized by disease, and activity as an individual responsibility in order to counter a declining ageing process. As pointed out by Katz (2000), activity is a conceptual and ethical keyword that shapes our understanding of later life. Activity must be considered part of a larger disciplinary discourse in the management of everyday life and as ‘the hallmark of responsible living’ (p. 144). The lifestyle magazine *Health*, introduced in the start of this article, is one among many culturally and morally loaded voices that stress the importance of ‘successful ageing’. They function, in the words of Rose (1999:74), as a kind of technology for making people responsible.

However, as our empirical data shows, the importance of attempting to be active sometimes appears to be more important than the activity itself. This means that the proper attitude or state of mind is as central as the actual performance of health promoting activities in order to postpone ageing (cf. Lock & Scheper-Hughes 1996).¹² Our material shows that activity can be understood in terms of good or bad activities, and some pursuits are not considered to be activities at all. The concept of activity includes moral values, which form the beliefs and narratives of being old (Katz 2000). Although, depending on health status, watching TV or phoning a friend can be experienced as healthy and useful activities.

It appears that activity does not only mean physical exercise, but mental and social exercises as well (cf. Gunnarsson 2009). Activity also has a connection to independence; by including everyday chores as activity, people demonstrate the will and capacity to cope on their own. Our ethnographical data shows that individuals assume that leading an active life demands efforts, and that good health should be deserved. Nevertheless, they agree that such activities should not be exaggerated. In order for activities to be healthy, they need to be carried out in a balanced manner – neither too much nor too little. Furthermore, it is important to emphasize that as one gets older, the meaning attached to activities is transformed. Easy-going occupations, in substance done for amusement and enjoyment, are not considered to be sufficiently healthy. They are therefore described and defined as useful and salutary. Likewise, everyday chores and recreational activities change into health work, becoming part of the practice of successful ageing.

We have demonstrated the intersection between old age and a health-promoting active lifestyle. This forms part of the concept of self-care management, which in old age is also called successful ageing. The idea that activities are health promoting is the framework in which activities are performed, but significance and meaning are rather created from practice. When making activities a regular part of everyday life, normative routines are created. As we have showed, carrying out activities produces normality just as much as the normative notion of activity generates the performance of activity. We argue, in accordance with Elizabeth Shove (2003), that dominant beliefs and rhetoric in regard to a particular phenomenon set the scene for specific actions, but it is practice that gives power to these ideas and concepts. Meanings are created primarily through practice and action (Shove 2003:191).

The process of ageing is full of contradictions and paradoxes (Jönsson & Lundin 2007). People want long lives, but do not want to get older, or rather: they want to grow old in a very special way. Through strategies such as conscious food choices, and physical and mental training, many are seeking a life in which characters of old age are kept away. It is about ageing in the ‘right’ way. Or, in Margaret Lock’s and Nancy Scheper-Hughes’s (1996) terms, to become politically correct bodies. That is, bodies reflecting both a biological age as well as society’s normative expectation of personal responsibility. Describing health from a perspective of power helps reveal how health in modern society increasingly signifies normality. Health stands out as a guardian of norms and values, as well as a point of reference. The idea of health and activity create a framework for how ageing is defined and looked upon. Ageing is interpreted by these concepts, and affects the experiences of growing old as well as the organization of everyday life.

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Notes

- ¹ There are a number of discussions that define these processes in terms of 'ageism', an analytic concept to describe discrimination based on people's age (Butler 1975). We have chosen not to employ the concept of ageism.
- ² This contradiction is apparent. At a deeper level, these beliefs have the same starting point; the expected decline in old age stresses the importance of health promoting activities even more. The anticipated decay thus acts as a reinforcement of the notion of activity.
- ³ In the last few years, there has been repeated coverage in Swedish media about the rights of old people. In articles as well as letters to the editor there have been discussions of neglect or mismanagement of in-home services and homes designed for the elderly, or protests that sick old people do not have access to care.
- ⁴ Vårdalinstitutet, the Swedish Institute for Health Sciences, is a national environment for research and development in the field of health care and social service in close cooperation with the universities and the health care principals. This article, as well as Alftberg's dissertation project, is part of the Vårdal Institute's research program concerning elderly people and geriatric care. (<http://www.vardalinstitutet.net>)

- ⁵ The intervention project is a health-promoting and preventive intervention aimed at preventing functional disability and restriction of activity.
- ⁶ Before starting the interview field work, the project underwent an ethical review by the Regional Ethical Review Board of Gothenburg University, Sweden.
- ⁷ Files and transcripts are currently kept by Åsa Alftberg and will later be kept at the Folk Life Archives at Lund University.
- ⁸ The questionnaires for this study, *Biomedicin och prioriteringar i vården* [*Biomedicine and Prioritizations in Health Care*] LUF 214, and *Åldrande och hälsa* [*Ageing and Health*] LUF 227, were designed by Åsa Alftberg, Susanne Lundin and Charlotte Hagström at the Folk Life Archives at Lund University. (<http://www.lu.se/folkklivsarkivet>)
- ⁹ All quotations are translated by the authors.
- ¹⁰ For a discussion on gender and ageing, see e.g. Arber and Ginn 1995, Arber, Davidson and Ginn 2003, Calasanti and King 2005.
- ¹¹ The questionnaire responses have been processed with SPSS.
- ¹² The Swedish Welfare State has a long tradition of cultivating an ideal of conscientiousness, which relates to the modern society's increased emphasis on the individual's own responsibility (Hirdman 1992; Ambjörnsson 1993).

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Crisis and Caring for Inner Selves: Psychiatric Crisis as a Social Classification in Sweden in the 1970s

By Kristofer Hansson

Abstract

This article aims to contribute to the understanding concerning the introduction of crisis psychotherapy in the 1970s in psychiatric clinics in Sweden. The article discusses how this psychotherapy became central in the work of the clinics in supporting patients to well-being and inner growth. The ambition was that patients in an acute crisis-situation would be offered care immediately, aiming at a short and intensive contact with the professionals to avoid hospitalization and long-term sick leave. These ideas were by no means new; in the 1960s, a Western debate had emerged in which the hospitalization in psychiatric clinics had received criticism. In Sweden, the psychiatrist Johan Cullberg was a key actor during the 1970s in the introduction of the psychiatric crisis perspectives. Here, his publication 'The psychic trauma' from 1971 is analysed. The publication inspired psychiatric clinics to introduce crisis psychotherapy in three different pilot projects. The projects were presented in articles in the *Swedish Medical Journal*. These articles have also been analysed here. Self-care is highlighted through this material as a concept to be analysed. The question is discussed as to how the concept of the psychiatric crisis initiated and institutionalized a new form of social classification in which the patients were to take more responsibility for their own inner growth.

Keywords: Psychiatric crisis, crisis psychotherapy, inner growth, self, self-care, social classification, classificatory looping

Introduction

We all are likely to run into psychiatric crises – the person who never does, is rather to be pitied. It is also a situation where we all should have the right to receive help – help to listen to our own capabilities of finding a solution, not to run away from the sometimes painful self-defining that the situation often contains (Cullberg 1971:3, my translation).

In the publication ‘The Psychic Trauma: About Crisis Theory and Crisis Psychotherapy’ from 1971, the Swedish psychiatrist Johan Cullberg presented the concept of the psychiatric crisis. In this text, the crisis is presented as something essential for the human being and something we must *not run away from*. The psychiatric crisis should instead be seen as an important part of how humans define their inner self, almost necessary for the individual in order to develop a strong and complete self. In this article, the psychiatric crisis will be used as a starting point for discussing how crisis psychotherapy in the 1970s manifested a specific psychological being that was expected to take responsibility for his or her own inner self, a form of self-care. Focus is on how this form of self-care is institutionalized; how patients in crisis are categorized in an outpatient care unit in Sweden.

In his book, *Inventing our Selves* the sociologist Nikolas Rose argues that there has been a transformation in the Western society; the individual is increasingly regarded as a psychological being with an inner mental process of growth. This has changed ‘our conceptions of what persons are and how we should understand and act toward them, and our notions of what each of us is in ourselves, and how we can become what we want to be’ (Rose 1998:11). Rose links this change to the growth of psychology in Europe and North America in the twentieth century and to how the psychological knowledge has come to have a central role for how individuals are *caring for their inner selves*. Emphasized by the philosopher Michel Foucault, the care of the self is an old idea from the classical and late antiquity concerning how the subject relates to his or her own actions (Foucault 1990). This idea was accentuated when psychology made the self into a psychological knowledge. From this theoretical perspective, the psychological knowledge highlighted by Rose’s Foucauldian perspective can be regarded as a form of self-caring project that is placed upon individuals, making them responsible for their own inner growth. As we will see in this article, conceptualizing the self with psychological knowledge in this way provides a new perspective for what the human being can be and for what she or he can strive. In this article, this theoretical argument will be analysed from a Swedish perspective using the psychiatric crisis as a case of how crisis psychotherapy in the 1970s initiated and institutionalized a new form of psychological knowledge in which patients were to take increasing responsibility for their own inner growth. More specifically, the subject of the analysis is the *crisis psychotherapy* that was introduced in the psychiatric treatment in clinics during the 1970s. In this article, the crisis psychotherapy is utilized as a case for discussing how care of the self has become part of the Swedish psy-

chiatry, and how cultural ideas about self-care received practical form in a specific psychiatric treatment.

The crisis psychotherapy was a treatment, which in Sweden presented an alternative to more traditional psychiatric treatments in the 1970s. The ambition was that patients in an acute crisis-situation would be offered care immediately, with the aim of a short and intensive contact with the professionals to avoid hospitalization and long-term sick leave. These ideas were by no means new; in the 1960s, a Western debate had emerged in which the hospitalization in psychiatric clinics had received criticism (Goffman 1961; Szasz 1961; Scheff 1966; Foucault 1967). It was not just an attempt to find a new psychiatry, but also a process of finding other ways to perceive the patient who consulted the clinic for treatment (cf. Micalé & Porter 1994). In Sweden, the psychiatrist Johan Cullberg was a key actor in the 1970s in the introduction of the psychiatric crises perspectives.¹ Particularly, the previously mentioned publication from 1971, 'The Psychic Trauma', became central for many of the psychiatric clinics that introduced the crisis-treatment (Cullberg 1971).² A main point in Cullbergs publication was how the psychiatric crisis was presented as having a developmental potential for the individual; meaning that the crisis could be something beneficial and normal to go through. This alternative psychiatric treatment can be considered as a means for the clinic to give the patient more responsibility for his or her own potentials to grow as a human being. In this article, this matter is analysed as a change in the attitude of the psychiatric clinics, which implied avoiding hospitalization of the patients and instead focusing upon the patient's possibilities to handle the psychiatric crisis on their own under the care of a psychiatric treatment.

Method

In the psychiatric disciplines – the clinics, as well as the psychiatric researchers – paying attention to the patient's acute crisis situation was a perspective creating a new classification of when a patient had a crisis and what care that patient needed. In the early 1970s, the theories of the psychiatric crisis were gradually applied in psychiatric treatment in Sweden. Consequently, the classification of what a crisis is also started to interact with certain kinds of behaviour among the patients. This is what the philosopher Ian Hacking defines as *classificatory looping*; meaning that *social classifications*, in this case the psychiatric crisis, interact with the behaviour that has been classified (Hacking 1999). Social classifications can be studied methodologically through what Hacking names a *style of reasoning*. In which way is social classification associated with an ontological discussion concerning the different kinds of behaviour that should be incorporated in the specific classification that is identified as the psychiatric crisis (Hacking 2004)? Through the theories about the psychiatric crisis, psychiatry gained a territorial extension that provided the professionals new principles, or logical sentences, for their style

of reasoning concerning some specific human behaviour. In examining those sentences closer, it is possible to study the social classifications that are associated with the psychiatric crisis supporting the objectivity of the theoretic framework behind the concept (of the psychiatric crisis). Hacking points this out when he writes, 'The truth of a sentence (of a kind introduced by a style of reasoning) is what we find out by reasoning using that style. Styles become standards of objectivity because they get at the truth' (Hacking 1992:13). In this article, the style of reasoning in Cullberg's publication is studied. The style of reasoning is also examined in articles of other psychiatrists on how crisis psychotherapy initiated a new form of psychological knowledge implying that the patients should take more responsibility for their own inner growth.

For my analysis, two different empirical categories have been used to study the style of reasoning concerning the psychiatric crisis. The first category consists of Cullberg's short publication 'The Psychic Trauma' from 1971 (Cullberg 1971). This publication was the first longer and more comprehensive introduction to crisis theory and crisis psychotherapy in Sweden.³ The publication is of importance since it introduced the psychiatric crisis perspective, but also started to inspire other psychiatrists to introduce crisis psychotherapy in psychiatric clinics. Cullberg's main reasons are presented in the article and are analysed with Hacking's theoretical perspective arguing that the style of reasoning can unfold those social classifications that give the arguments their truth (Hacking 1992). Focus is on those sections in the publication where Cullberg claims that patients ought to be more responsible for their own inner growth. These arguments are analysed in relation to the criticism of the psychiatry in the mid 1960s and 1970s (see *Psychiatric Crises and Selves*).

The second category comprises the articles of other psychiatrists, in which they present and analyse their introduction of the new crisis psychotherapy in clinics. Through a search in *Swedish Medical Journal*, I have found three articles from the 1970s that present these clinical introductions. The articles are 'Crisis Intervention in an Outpatient Care Unit – Alternative Psychiatric Care' (Stenstedt 1973, my translation), 'Crisis Therapy – An Alternative' (Boëthius et al. 1977, my translation) and 'Two Years of Experiences of Crisis Therapy' (Ardelius et al. 1978, my translation). As the titles proclaim, these articles represented trial projects at different clinics in Sweden, where crisis psychotherapy had been introduced, used and evaluated. The question for the three different trial projects was whether crisis psychotherapy could be used in clinics and if it had any benefits for the patients. The first article – 'Crisis Intervention in an Outpatient Care Unit' – is probably the first documented example of interventions applying crisis psychotherapy in Sweden. The pilot project started as early as December 1971 at the Psychiatric Clinic, Karolinska Hospital in Stockholm. Thus, this was the same year that Cullberg's publication 'The Psychic Trauma' was published. The reason why everything started the same year is that the psychiatrist Karin Stenstedt, the writer of

the article, was a colleague of Cullberg's and well versed in his reasoning. By analysing the article, it is possible to give a perspective on how the arguments in the publication were transformed to the clinic. For this reason, my analysis is focused on the first article from 1973. The two other articles are mentioned to illustrate the fact that the arguments of Stenstedt and Cullberg were used in other clinics. Stenstedt's reasons are analysed with regard to Hacking's classificatory looping. The introduction of the concept of the psychiatric crisis in clinics started a form of interaction with the kinds of behaviour that had been classified (Hacking 1999). First, this interaction is presented as a new classification that is introduced in clinics (see *A New Classification*); thereafter, the new classification is analysed as a form of self-care (see *Individualized Care*).

Psychiatric Crises and Selves

From the mid-1960s, an increasing amount of actors articulated a criticism of the kind of psychiatry that was practiced internationally as well as in Sweden. Among many things, it was a critique of an individual approach to how to care for people's mental health problems. This was seen as a structural problem. A central point was also the critique of those norms in society that concerned what was considered as normal development and adaptation to society. The criticism was directed towards a prevailing belief that people would adjust to what was considered normal, and that this would bring about a more harmonious society; if people behaved 'normally', the society would also function more normally (Ohlsson 2008; Jönsson forthcoming).

Cullberg's publications from this period originated from the criticism of regarding people as a form of individual normality. Instead, Cullberg came to join those who preferred to regard people as part of the community. A principal matter in this critique, and this was pointed out very clearly in Cullberg's publication, was that the individual had the right to occasionally feel bad and receive appropriate treatment for this malaise (Cullberg 1971). Considering the publication more closely, we can see how Cullberg integrated this theoretical view of the self and at the same time presented his perspectives in a medical mode, more appropriate for the psychiatric disciplines. For example, we find that traditional medical case histories were presented, representing typical traumatic situations that may lead to crisis. The typical traumatic situations that are presented by Cullberg comprise object loss, loss of autonomy, reproductive problems, problems with relationships, social shame, changes in the societal structure and external disasters. In the publication, Cullberg also describes a model to understand the course of the crisis, as well as symptomatology and treatment. In this way, the psychiatric crisis was a concept with inherent opportunities to see each patient as a psychological individual who was entitled to self-defining and psychological help.

In the principles of crisis psychotherapy, Cullberg points out that the therapist had the role of a catalyst for the healing process. He writes, 'He should give the patient an opportunity, under as decent conditions as possible, to go through the crisis so that he achieves a new direction and preferably with experiences that increase his self-knowledge' (Cullberg 1971:31, my translation). The patient had the responsibility to not repress the crisis, but instead promote a healing process that would give him possibilities to go through the crisis. The professionals had the role of supporting this process of the patient's quest to feel better. Accordingly, not only the healing process was important, but the crisis was also a way to conceptualize the self.

Cullberg reveal that this provided the professional a new role in the healing process in which the responsibility should not be the doctor's or the therapist's, but the patient's. Hence, he saw two immediate consequences for the professionals. The first point was 'The therapist's task is *not* to give back what the patient has lost or to take away the painful reality'; the second point was 'The therapist's task is not *primarily* to cure or remove the 'symptoms', because these are part of the process and the reality' (Cullberg 1971:31, my translation). Of course, if the patient had too much pain or self-destructive manifestations he or she should be given some form of alleviating treatment. Nevertheless, the fact of the matter was that the patient should take responsibility for the painful reality involved in the crisis.

This can be seen as the first step to find new perspectives on patients that had a psychiatric crisis. Moreover, the primary step was taken for a classificatory looping in which theories about psychiatric crises could be used by psychiatric clinics to identify the kind of behaviour that had been classified in theory (Hacking 1999, cf. Blumer 1971). In this classificatory looping, the patient's psychiatric crisis was something that he or she should be encouraged to understand as a self-caring project. It was in enduring the painful reality that the patient had the possibility to invent himself (Rose 1998). For this reason, Cullberg's point of views can be seen as a rationalized programme for the patient.

A New Classification

In December 1971, a pilot project started at the Psychiatric Clinic, Karolinska Hospital in Stockholm, offering crisis psychotherapy. The project was later presented in the article 'Crisis intervention in an outpatient care unit' in *Swedish Medical Journal* (Stenstedt 1973, my translation, see also Falk & Stenstedt 1973). The background for the project was that the clinic was to be rebuilt and the beds reduced from 77 to 31. At the same time, the responsibility for the patients should not be affected. An outpatient care unit consisting of nine professionals was assembled, with two psychiatrists, one psychologist, one social worker, two psychiatric nurses, one occupational therapist and one part-time physiotherapist. Assis-

tant manager was Karin Stenstedt. The aim for the unit was to receive patients in emergent crisis situations and provide them with swift and individualized care. It was vital to offer various kinds of activities and be flexible to the patients' needs. This might involve individual conversations, movement treatment, occupational therapy and so on. Consequently, the ideas of the psychiatric disciplines were implemented in actual practice by professionals with set guidelines for how the crisis treatment should be managed (Rose 1998). The theories about the psychiatric crisis were transformed into guidelines and practical counselling with patients.

Although there were no medical diagnoses for crises, the crisis treatment affected how to classify the patient. In the article, Stenstedt highlights the matter '[...] at the beginning of the work of the outpatient care unit, the concept of crisis was not very consistently defined among the professionals in the unit' (Stenstedt 1973:4157, my translation). The professionals used the definition of the psychiatric crisis that Cullberg had described; but at the same time, it was a definition that needed to be more consistently applied in the outpatient care unit. As Stenstedt points out in the article, the definition of the psychiatric crisis became more solid the longer the professionals in the outpatient care unit worked together. Returning to Hacking, this can be seen as a classificatory looping in which the psychiatric crisis gave rise to new classifications; this provided new cases, which created more knowledge about the cases, generating more experts, which created a need for more research and so on (Hacking 1999). The psychiatric crisis should be seen as a concept that constantly was changing while it was in the loop.

However, the classification was also confirmed while it was in the loop, giving the professionals possibilities to distinguish between patients that had a psychiatric crisis and those who had not. Thirty-nine percent of the patients who came to the clinic were classified as having a psychiatric crisis. The remaining were classified according to three, at that time, traditional diagnoses: psychosis, neurosis and borderline.⁴ Those who received the psychiatric crisis classification had been affected by an event that was said to trigger crisis. The description of these triggers was largely taken from Cullberg's publication 'The Psychic Trauma'. In Stenstedt's article this is pointed out:

The most common cause for crisis is undoubtedly more or less acute relationship problems; about a third of the cases concern infidelity. In frequency after relationship problems are problems at work. [...] Next are those who have consulted us because of object loss, particularly due to the death of a close relative. Then there are those who consulted us in relation to reproductive problems (Stenstedt 1973:4157-4158, my translation).

The triggers can be regarded to be so common that we can expect many cases that could confirm the classification of the psychiatric crises. However, there were other projects in the 1970s that confirmed these classifications. One example is reported in the article 'Crisis Therapy – An Alternative', using Cullberg's psychiatric crisis criteria from 1971 (Boëthius et al. 1977, my translation).⁵ In 1978,

‘Two years of experiences of crisis therapy’ was published (Ardelius et al. 1978, my translation). In the later article, there was not only a confirmation of the classifications presented in the articles from 1973 and 1977, but also a statement from the authors that this treatment was something society should offer patients suffering from a psychiatric crisis:

In recent years, the acute crisis reaction that people may develop has received ever more attention. A crisis reaction means that a previously healthy and functioning human being is affected by a substantial setback in life; the loss of a relative or any other matter that places new demands on the individual. [...] In these cases, society must be willing to provide crisis treatment (Ardelius et al. 1978:4147, my translation).

Social classifications, here in the form of the psychiatric crisis, interacted not only with the kinds of behaviour that had been classified, in this case the acute crisis reactions, but also became something that could be used in an argumentation that society should invest resources in this treatment. Psychiatric crisis, crisis reactions and crisis psychotherapy were parts of a classificatory looping in the 1970s; which confirmed the importance and established the need to work with this psychiatric perspective in society (cf. Hacking 1999). Cullberg’s psychiatric crisis criteria were vital points in this looping, but it was in clinical practice that the classified behaviour started to interact and create a classificatory looping. It was in the psychiatric clinic that a transformation from psychiatric crisis theory to care practice took place (cf. Mol et al. 2010). When these theories were introduced, the professionals attained new perspectives on what a patient was and which responsibilities the patient had for his or her own well-being.

Individualized Care

Likewise, the introduction of the psychiatric crisis in clinics had an impact on, what may be termed as *the care practice*, in which the introduction of the psychiatric crisis created other forms of cultural and social practices in the clinic (cf. Mol et al. 2010). Regarding Stenstedt’s article, some of these practices can be analysed in relation to the criticism of psychiatry in the 1960s and 1970s. Primarily, there was a concrete aim for the outpatient care unit at the Psychiatric Clinic, Karolinska Hospital: the intention of not hospitalizing the patients. This idea must be understood regarding the context of the general criticism of psychiatry in the 1960s and 1970s (Ohlsson 2008). In the article, this criticism can be discerned:

The aim was therefore to try to organize a small outpatient care unit, which without waiting time, would be receiving patients in emergency crisis situations and for a limited time giving them an intensive problem-focused contact. An exceedingly important point was the possibility of individualized care. This should be adapted in a flexible way to the specific needs of each individual. Firstly, the intention was to be able to offer various forms of activities; secondly, and above all, to provide patients with an opportunity to work through their current problems in group discussions or private conversations (Stenstedt 1973:4154, my translation).

Returning to Rose's arguments, the psychiatric disciplines, here in the form of a new small outpatient care unit, were generated to meet the requirements that the patients at this time were considered to have (Rose 1998). The aim of the care was to be flexible in view of the individual's needs, with no waiting time and designing a problem-focused contact with the patients.⁶ This specific psychiatric discipline was created in contrast to the old psychiatry care; consequently, it defined what the discipline should not be. Simultaneously, this redefinition of psychiatric care also influenced the idea of what a patient is and should be. The patient appeared as an actor that was expected to be interested in individualized care, having specific needs of this care. Thus, the objectives with the outpatient care unit were to transform the mental health services for some of the patients who needed treatment.

The outpatient care unit organized a new type of treatment; the focus was said to be on adjusting the care for the patients' needs. In this reorganization, the patients were increasingly regarded as isolated individuals, separated from a unifying patient category. This is a cultural process that arose during the 1970s and that has been widely analysed within individualization theories (Giddens 1991; Lasch 1991; Beck & Beck-Gernsheim 2001). In these theories, the character of the individual is pointed out as increasingly negotiable and less governed by traditions and norms. A person's character tends to be more of 'for the time being' and less consistent. Based on such cultural process, I want to argue that Cullberg's psychiatric crisis criteria provided a possibility for the psychiatric clinics to meet this new group of patients, and at the same time create this patient within the social classification of the psychiatric crisis (cf. Hacking 1999). A central point for this line of reasoning is that the patient should now feel that he or she was in a process of psychosocial development, that every stage in life contains experiences and challenges for the human development.⁷ In the practical work in the outpatient care unit, as described in the three articles, focus was on helping the patient to understand and explore his or her own feelings. In Stenstedt's article, this is pointed out very clearly: 'The patient must be allowed and encouraged to express those feelings of sadness, shame, hostility, anxiety etc, that are associated with the crisis situation and are often perceived as forbidden' (Stenstedt 1973:4155, my translation). The patients ought to take their feelings seriously and be encouraged to talk about how they feel.

The Swedish researcher Claes Ekenstam, historian of ideas and sciences, has stressed that in the 1950s and 1960s a representation of people as *feeling human beings* became more common. This was not a new idea but it attained a strong position in disciplines such as psychology, sociology and biology. It was a representation that emerged in a polemic against the understanding of humans as being rational and calculating, an idea that can be found in the description of man as mechanical, economic or stoic (Ekenstam 2007). Reasoning concerning the feeling human being is vital in the understanding of how the psychiatric crisis, not

only became part of the perspectives of the psychiatric clinics in meeting the individualized patient, but was also significant in the presentation of a treatment that could interact with the behaviour that had been classified through the psychiatric crisis (cf. Hacking 1999). It became essential for the care that the patient was encouraged to take his or her emotions seriously; through her feelings, the patient could take responsibility for her own potentials as a human being. This was highlighted in Stenstedt's article: "An important aspect on crises, that needs to be emphasized, is that these are not necessarily entirely negative life experiences, but contain positive aspects and provide opportunities for development. The crisis holds, as Lydia Rapoport (1967) puts it, significant 'growth-promoting potentials' (Stenstedt 1973:4155, my translation). An important part of this reasoning was the change in the responsibility of the psychiatric clinic for the patient; the psychiatric crisis became something for which the patient had responsibility for as well.

The psychiatric crisis became a social classification that affected how the professionals should take care of the patients and what responsibility the patient had for his or her well-being. I would like to draw attention to the shift towards encouraging the patient to take responsibility for the 'recovery' and for the opportunities of development embedded in the psychiatric crisis. The psychiatric crisis interacted, not only with the behaviour that had been classified, but it also evoked a new moral for which responsibilities the patient had for his or her own well-being.

Discussion

As pointed out in this article, theories about the psychiatric crisis and crisis psychotherapy in the 1970s created opportunities in the psychiatric clinics to respond to the patient as *the feeling human being* (cf. Ekenstam 2007). A significant conception during this period was the representation of the human being as a feeling person; another prominent idea concerned individualisation. In the following quotation, we can sense how the professionals in the outpatient care unit felt that their ideas were well suited for the times:

When we started, we did it entirely according to the conviction, based on our experiences on the weekly ward, that an activity like this should be able to fill great practical needs. Like many others, we had been inspired by Johan Cullberg's publication 'The Psychic Trauma' (1971) and had begun to be interested in psychological crises and crisis therapy (Stenstedt 1973:4154-4155, my translation).

The impression is that it was conviction that made them start using the psychiatric crisis as a possibility to regard the patient in new perspectives (cf. Foucault 2003). This conviction has many similarities to Hacking's explanation of how social classifications can change our consciousness and let us enter new worlds (Hacking 1992). Using theories about the psychiatric crisis is one example of how professionals attained new perspectives in the 1970s and regarded the patients from

the ward in a slightly new way. At the same time, it is important to point out that this feeling of conviction is related to the self-fulfilling potential in the psychiatric crisis theory. There must be a classificatory looping when the social classifications interact with the behaviour that has been classified (Hacking 1999). This perspective could be confirmed by interaction with the patient, and with other professionals. Further, if we go back to the quotation, Stenstedt stresses that ‘many others’ had been inspired by Cullberg’s publication.

Partly, it was an expected change in the psychiatric clinics. Patients were not to be hospitalized, but were instead provided with a psychiatric treatment that could give individuals possibilities to handle the psychiatric crisis largely on their own. The crisis psychotherapy was now to be a support for the patient on his or her way to well-being and inner growth; this is an argumentation that has been highlighted in previous studies (Frykman 1994; Rose 1998; Ekenstam 2006). Through this change, the internal and mental self-control of the patients emerged, replacing the external control. On the basis of this reasoning, my claim is that the psychiatric crisis can be seen as a form of a self-caring project for the individual. Not only do social classifications interact with the behaviour that has been classified, but they also interacted with a moral category of what a patient was and should be.

Finally, if we once again return to Hacking, he discusses how social classifications can change our experience of which moral category we belong to (Hacking 1999). I would argue that the psychiatric crisis had this effect in the 1970s when new conceptual meanings changed how a crisis situation could be experienced, altering the responsibilities of the individual in this situation. Thus, self-care should be understood as a central part in the classificatory looping of this specific social classification consisting of the psychiatric crisis. When the psychiatric crisis as a social classification interacts with the patient’s behaviour, this is when self-care also can be activated and be institutionalized as a practice in the care unit (cf. Mol et al. 2010). Therefore, self-care must be analysed in relation to those social classifications that are a part of a historical and cultural context.

In order to understand this change, it is important to relate the transformation in the psychiatric clinics to a more general change in the historical and cultural context. Using these different cultural expressions, the article shows how self-realization and individual development became embedded as a cultural ideal. It can provide us with perspectives on how self-care came to be used in practice in the beginning of the 1970s and influenced both healthcare and the everyday lives of people.

Conclusion

In this article, I have studied how the psychiatric crisis became a social classification in the 1970s, not only providing new perspectives on some specific kinds of behaviour, but also transforming this behaviour to be part of a self-caring project.

I have traced this historical development to international psychologists and psychoanalysts; it was introduced in Sweden through the psychiatrist Cullberg, in the publication 'The Psychic Trauma' from 1971 (Cullberg 1971). In the 1970s, these theories about the psychiatric crisis and crisis psychotherapy were tested in different pilot projects at psychiatric clinics. In the article, the pilot projects are understood as answers to the need of encountering patients with individualized requests, which enhanced the need for a treatment that took the feelings of the patients seriously. The patient's care for him or herself became more important than external control. This provided opportunities for the crisis psychotherapy to be regarded as a self-caring project.

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Notes

- ¹ The concept of the psychiatric crisis developed theoretically in the 1940s and onwards; many psychologists and psychoanalysts from America came to use the word. See for example the psychiatrist Eric Lindemann (Lindemann 1944), the psychoanalyst Elliot Jaques (Jaques 1965) and the psychoanalyst Erik Homburger Erikson (Erikson 1993).
- ² In 1975, Johan Cullberg published the book *Crisis and Development* (1980), which became a very popular textbook in Sweden. However, the shorter publication from 1971, which was used in the alternative psychiatric treatment, is studied in this article.
- ³ In the 1970s and the beginning of the 1980s, more crisis-titles were published in Sweden by both Swedish authors and translated authors. See for example: Ekselius et al. 1976; Fried 1978; Folksams sociala råd och TCO:s socialpolitiska råd 1979; Ewing 1980.
- ⁴ The classification was divided into the following categories: psychosis 7 percent, neurosis 45 percent, borderline 5 percent, "crisis" 39 percent and others 4 percent (Stenstedt 1973:4157).
- ⁵ Moreover, a similar point was the focus on preventing long-term hospitalization and that the patients should go back to work as soon as possible.

- ⁶ Another vital matter for the outpatient care unit was to reduce medication of psychotropic drugs. With this form of crisis treatment, the attempt from the outpatient care unit was to get away from medicalization and instead try to find other forms of care for those patients who needed psychiatric help. Psychotropic drugs were in the article defined as the less desirable option for treatment, and were considered to make the patient passive and regressive in the course of his or her illness (Stenstedt 1973).
- ⁷ Here, I use Erik Homburger Erikson's terminology (Erikson 1993). The terminology was introduced in Sweden by Cullberg (1980).

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Medication as Infrastructure: Decentring Self-care

By Peter Danholt & Henriette Langstrup

Abstract

Drawing on science and technology studies (STS), and specifically the concept of infrastructure as conceptualised by Bowker and Star (2000; Star 1999), this paper argues and empirically demonstrates that self-care may be considered a practice that is thoroughly sociotechnical, material, distributed and de-centred. Comparing the practices related to medication in the treatment of asthma, type 2 diabetes and haemophilia, we show that in practice there is no ‘self’ in self-care. More specifically, the ‘self’ in self-care is an actor who is highly dependent on, and intertwined with infrastructures of care, in order to be self-caring. Infrastructures of care are the more or less embedded ‘tracks’ along which care may ‘run’, shaping and being shaped by actors and settings along the way. Obtaining prescriptions, going to the pharmacy, bringing medication home and administering it as parts of daily life are commonplace activities embedded in the fabric of life, especially for those living with a chronic condition. However, this *procurement* and emplacement of medication involves the establishment and ongoing enactment of infrastructures of care, that is, the connections between various actors and locations that establish caring spaces and caring selves.

Locations and actors are included as allies in treating chronic conditions outside the clinical setting, but these infrastructures may also be ambiguous, with respect to their effects; they may simultaneously contribute to the condition’s management *and* neglect. Particularly precarious is management at the fringes of healthcare infrastructure, where allies, routines and general predictability are scarce. We conclude by arguing that these insights may induce a greater sensitivity to existing infrastructures and practices, when seeking to introduce new infrastructures of care, such as those promoted under the headings of ‘telemedicine’ and ‘healthcare IT’.

Keywords: Self-care, infrastructure of care, medication, chronic conditions, exnovation

Introduction

John knows where his asthma inhaler is – in his house there is one in the bathroom medicine cabinet, and when he bikes, he carries one in the pocket of his cycling jacket. When he travels, an inhaler is always among his toiletries. He has had asthma for a number of years, and though he rarely has an attack, he can vividly describe the terror of having one without having an inhaler at hand. So the inhalers are there, prescribed by his primary-care physician, whom he rarely sees, but who wires a repeat prescription to the pharmacy when John needs a new inhaler. John takes care of himself.

The brief excerpt above is a trivial and mundane example of self-care, of taking care of oneself. But what does ‘self-care’ mean? When further scrutinised, the narrative reveals that it involves at least three elements: John, asthma, and medication, their relations and how they play out. Moreover, this is not simply about three elements, but rather three *actors*, each of which is endowed with different capabilities and agencies. First, there is a person, John, who moves about and attends to his condition, mostly in a rather subtle and almost invisible manner. Yet asthma is ever-present, owing to its potential for sudden emergence, John must be prepared for this. This preparation entails quite a lot of work: he has to remember his medication, leave it in accessible places, renew his prescription for the medication, evaluate his condition when in situations that might lead to an asthma attack, and so on. This leads us to the condition, asthma, certainly also an actor, a disease capable of acting on John and affecting him and his body in a substantial and potentially life-threatening manner, if it were not for the third actor, the inhaler, which, owing to its agency and functionality, is capable of aiding John’s restoration in case of an asthma attack.

This demonstrates that living with a chronic condition like asthma, or, as we will discuss later in this paper, type 2 diabetes or haemophilia, might fruitfully be regarded a practice in which a range of actors are at work, and the role of the person in this field of forces is one where a range of concrete actions and arrangements must be employed in order to manage the condition.¹ Drawing on the field of science, technology and society studies (STS), and specifically the concept of ‘infrastructure’ as conceptualised by Bowker and Star (2000; Star 1999), we argue and empirically demonstrate that self-care should be considered a practice that is thoroughly sociotechnical, material, distributed and de-centred. To state this in a somewhat self-contradicting manner, in *practice*, there is no ‘self’ in self-care, since the ‘self’ is an actor who is thoroughly dependent on, and are ineluctably interconnected with other actors and entities in infrastructures, to *become* a self-caring subject. In terms of actor-network theory, we could say that the ideal self-caring subject is an *outcome* and a *product* of the successful association with multiple others (Latour 1987). The point is, despite the fact that we may intuitively understand that we depend on the care of others – persons or artefacts – especially with regard to illness, the discursive articulation of self-care overshadows and downplays the individual’s dependence on a collective. Our analytical conception

of infrastructure allows us to engage with self-care as a sociotechnical, material, distributed and de-centred phenomenon consisting of an association of multiple actors, including medication, knowledge, healthcare professionals, and also cupboards, shelves, boxes, pens, paper, refrigerators, pockets, bags, phones and so forth. Thus, infrastructures of care are the more or less embedded ‘tracks’ on which care may ‘run’, shaping and being shaped by actors and settings along the way. The concept serves to identify the way in which healthcare is materially inscribed and spatially distributed: healthcare in a chronic condition is a shared activity, even when it is *self-care* (Willems 1995; Mol 2008). This way of perceiving self-care is not entirely at odds with what we consider as the common and frequently articulated version of self-care, but supplements it in important ways. For instance, the WHO defines ‘self-care’ as follows:

Self Care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals (WHO 1998).

Similarly, the Department of Health in the UK states:

Self care by definition is led, owned and done by the people themselves. It is the activities that enable people to deal with the impact of a long term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them - work, socializing, family...Self care support can [also] be individualised and specific to a person's needs and circumstances, based on an understanding of the person's beliefs, capability, knowledge base, acceptance of their condition, attitude, confidence and determination. (Department of Health 2007)

The emphasis is on human action and collaboration between human beings, and moreover, self-care is closely related to knowledge and information, and human virtues such as beliefs, attitudes, knowledge, confidence and determination. This perspective implies that self-care is primarily a matter of being a knowledgeable, rational, autonomous individual, much in accordance with the idea of Man that emerged during the Enlightenment (Shapin & Schaffer 1985; Latour 1993). We do not argue that these aspects and virtues are unimportant. They are not – far from it. Instead, we wish to demonstrate and argue that these qualities are intimately related to concrete, technical, material and situated circumstances. We believe that this perspective provides a more adequate understanding of self-care, whereby we become able to understand the ‘good’ reasons for ‘bad’ self-care, to paraphrase Harold Garfinkel (1967/1991).

Not only does self-care perceived as a sociotechnical, material, distributed and decentred practice, provide a more robust understanding of the practice of managing a condition, it also challenges deterministic understandings of the patient as *either* a rational, autonomous being in control of his or her condition, *or* as a per-

son disciplined by a regime of power (see also Willems 2000). We acknowledge that the current intense focus on self-care may be interpreted as a neoliberal approach with a strong interest in the wellbeing of the individual that shies away from the overarching and custodial role of the classical welfare society. The challenge for neoliberal governance is to govern through non-governance, that is, through the construction and mobilisation of the subject as a free agent, whereby the subjects assume increased responsibility for their lives (Dean 1999). We also acknowledge that the huge market for self-care products and services may be viewed as a consequence of and in accordance with neoliberal ethos. This said, the focus of this paper sees, on the one hand, self-care as a practice involving multiple actors and forces, where the subject is active in attending to these forces, but in a highly situated and de-centred manner, bound up in relations with multiple others. On the other hand, self-care is also a practice where ‘the ideal practice’ designated by the medical regime or the neoliberal policymaker is only seldom realised: actions and actors appear to escape and resist the ideals of self-care, yet in a skilled and in a different sense, self-caring, manner.

The medication involved in chronic conditions may be seen as an infrastructure whereby care is distributed, shared, enacted and resisted. Obtaining prescriptions, going to the pharmacy, taking medication home and self-administering it as part of daily life comprise an extremely commonplace set of activities embedded in the fabric of life for those living with a chronic condition. However, this *procurement* and *emplacement* of medication involves the establishment and ongoing enactment of infrastructures of care, that is, a connection among various actors and locations, enabling caring spaces and caring selves.

The thesis of this paper is that underpinning the management of chronic conditions are various infrastructures that constitute intricate parts of treatment and healthcare practices. It is important that they are described, analysed and acknowledged. Medication is part of such an infrastructure, and in the empirical section of the paper we present and analyse medication practices for haemophilia, type 2 diabetes and asthma, as care infrastructures.

This paper is organised as follows: In the next section we present the theoretical background of the study. We then present the background and methodology of the empirical study we conducted. Then, we present and analyse empirical data regarding the procuring and emplacement of medication in the treatment of asthma, haemophilia and type 2 diabetes, and present the varying ways in which infrastructures of care may be enacted. Finally, we discuss the implications of our study with regard to understanding and supporting self-care in chronic conditions.

Infrastructures, (In)Visibility and Multiplicity

Sociologists of science and technology Susan Leigh Star and Geoffrey Bowker have studied the practices of making and maintaining information infrastructures.

They hold that the study of technological infrastructures is important, since infrastructures are intrinsic parts of daily life (Bowker & Star 2000; Star 1999). Technical infrastructures are an inextricable part of the reality that shapes and facilitates human actions and perceptions. Star and Bowker note that infrastructures are often considered merely technical, neutral constructs upon which other entities and activities run. However, this perception renders them somewhat trivial, insignificant and invisible. Therefore, Star and Bowker, as well as other STS researchers, argue that we need to attend to how infrastructures are built, rebuilt and merged with other infrastructures; how they have fringes and require continuous maintenance. Thereby we may acknowledge the omnipresence of infrastructures and the invisible work involved in building and maintaining them, and their many consequences for our existence. Infrastructures and technologies are political, in the sense that they create differences among actors, and they allow certain actions to happen, while impeding others. French sociologist and philosopher Bruno Latour has also argued that the technical is intrinsic to the social (Latour 1987; 1999). When technical infrastructures such as healthcare information systems (Bowker & Star 2000) or transportation systems (Latour 2002; Peters 2006) are ‘unpacked’, it becomes evident that these infrastructures are indeed contingent, social and historical constructs. They have a point of origin, and have undergone transformations over time owing to numerous contingent processes and negotiations. They are heterogeneous, since no single overarching logic or principle has formed them, and they are constructed and function as they do thanks to a heterogeneous conglomeration of political, technical, social, economic, historical, practical and other reasons.

Attending to technological systems as infrastructures, and employing the strategy of infrastructural inversion (Bowker 1994) – that is, ‘opening up’ and following the construction and maintenance of infrastructures – is important. Following the ecological perspective, as developed by Gregory Bateson (1973), Star and Ruhleder (1993) also caution us against thinking about infrastructures in a strictly representational manner, as objective things. They state that: ‘infrastructure is fundamentally and always a *relation*, never a thing’ (1993: 253), and argue that an infrastructure, for example railway tracks, cannot and should not be analytically bracketed from other elements that co-constitute them, such as timetables, railway stations, trains, engines, wheels, standards, passengers and so on. Without these elements, the railway tracks would have no relevance, they would lose their quality as ‘railway tracks’, and simply be iron girders. So, infrastructures are networks. They are intertwined with multiple other actors and elements, in order to become properly functioning infrastructures. Ironically, the process of association and alignment of all these elements is what results in the perception of infrastructures as merely ‘technical things’. We tend to lose sight of the complexity inherent to properly functioning and pervasive structures and things, not *despite* these qualities, but *because* of them. Only when they break down do infrastructures emerge

and become visible (Heidegger 1927; Latour 1999). Infrastructures are also relational in another sense. In our encounters with them, they tend to move in and out of our existence, depending on how we are situated. For instance, for most people, a staircase or a door constitutes an infrastructure that *affords* their mobility and enables them to move around.² However, for the physically impaired person in a wheelchair, a staircase or a door is a significant obstacle that impedes their movement (Star 1999; Law & Moser 1999). The relational aspect of infrastructures constitutes an important analytical understanding in this study, since it implies that infrastructures must be considered emergent, situated entities that become potent and real in specific occasions. They are never simply there or not there, but partially and potentially existing and emergent. Moreover, identifying when, how and for whom certain infrastructures afford or impair action – such as care – provides valuable insights into the study of infrastructures of care, for instance.

The concept of infrastructure enables us to foreground the ‘backstage’ aspects of the relations that distribute ‘care’ across space and actors. In contrast to technical infrastructures, such as those that underpin trains and computer systems, infrastructures of care are rarely acknowledged as also being technical constructs that involve standards, artefacts and spaces and that also require extensive work to establish and maintain.³ This understanding enables us to see the crowdedness or emptiness of the spaces between the clinic and the home, and consider the fringes of care infrastructures, where care is inhibited or ends for someone or something.

Another concept that has contributed to our study of self-care is *exnovation*. In her study of uncertainty and risk in neonatal care, the Dutch STS scholar Jessica Mesman employs the concept of *exnovation* to foreground the many invisible care and safety activities:

Exnovation refers to the attempt to foreground what is already present – though hidden – in specific practices, to render explicit what is implicit in them. Where innovation can be defined as ‘to make something new’, exnovation pays attention to what is already in place and challenges the dominant trend to discard existing practices... A focus on exnovation allows us to bring to light implicit matters of actual practice and to develop a fresh perspective on the ingenuity of the professionals and the specific structure of their practices. (Mesman 2008: 5)

In the concept of exnovation we find the acknowledgement of the idea that existing practices are not necessarily transparent and immediately and completely exposed to our view. Exnovation explicates the idea that reality ineluctably depends on our practices of seeing and interacting with it. Reality is contested, and by definition, controversial (Latour 1999). The concern with improvement in healthcare – whether in the professional practices of neonatal care, or in the self-care practices of those with chronic conditions – is premised on assumptions of deficiency and lack. Mesman’s work enables us to appreciate care as embedded and already present in existing practices. Consequently, introducing novel technologies to existing infrastructures of care is likely to interfere with, and potentially jeopard-

ise the ecology of care.⁴ While this caveat may be read as a dismissal of all attempts to innovate, we suggest instead that we should be sensitive of existing infrastructures, and potentially mobilise and recombine them in subtle and novel ways.

Finally, when studying the infrastructure of healthcare, there is the question of power (Leder 1998). One widespread conception is the asymmetrical one, where the medical regime of the healthcare system is considered more powerful than the private life and home of the patient. In this view, the home is territorialised by the medical regime, the former being the weaker party. But when looking more closely at the ways in which people and patients practically handle the recommendations, prescriptions and regimes, we see numerous ‘acts of resistance’ against this supposedly all-powerful medical regime. Put slightly differently, people are seldom docile, disciplined subjects in every instance of their lives, since the interstices of daily life are filled with multiple concerns, forces and desires that shape and form our actions. Consequently, the explanations behind these ‘acts of resistance’ are extremely difficult to describe in complete detail. Also, we consider it simplistic to consider such acts as acts of an autonomous, rational subject who exercises his or her ability to choose. Instead, we see these acts as *outcomes* of heterogeneous assemblages of multiple actors and forces. Ideal medical treatment is *translated* by the practices of exercising treatment, whether in a specific clinical situation or in the homes of the patients, due to the arrangement of matters. We concur with the understanding proposed by technology studies, wherein a given technology is always in the hands of its future users (Akrich 1992). It may be that a specific technology or treatment plan prescribes certain behaviour, but it is nonetheless *de-scribed* and accommodated to the practices of the patients, in and by the way in which they make use of the treatment. This symmetrical understanding of the power relation between healthcare systems and patients is methodological, and when studying infrastructures for healthcare and self-care provides us, as researchers, with the opportunity to look for the reciprocal transformations of healthcare organisations and patients’ homes and lives.

These various concepts constitute an analytical resource. They encourage us as researchers to recognise more differences among artefacts and practices, and potentially become more sensitive to the specific characteristics of those practices.

Mapping and Comparing Infrastructures

The study on which we base our empirical analysis employed a qualitative, ethnographic approach, and involved three different chronic conditions: type 2 diabetes, asthma and haemophilia. The three conditions were selected as much for their many differences as for their similarities. What they have in common is that they are chronic conditions, and that treatment rests on extensive involvement of the patients through home-treatment and various degrees of self-monitoring, but when

it comes to their demographic characteristics, the medication involved, their symptoms, and their consequences, they are decisively different. Our study samples for each condition were based on five to eight persons, who were interviewed and encouraged to show us and tell us about their daily practices surrounding their conditions. These observations were made both in the participants' homes and during clinic visits. The study's central hypothesis is that the mundane, daily practices of those with chronic conditions constitute more or less visible and ingrained infrastructures, which are of great importance with regard to managing a chronic condition. In other words, our study addresses the arrangements that make chronic conditions manageable (Gomart & Hennion 1999).

In our analyses of interviews and observations, we employed Adele Clarke's Situational Analysis approach, which suggests a 'mapping approach' for analysing relational phenomena (Clarke 2005). Our interest was to identify the infrastructures of three chronic conditions, and compare the issues at stake when maintaining and developing these infrastructures. The first analytical step entailed going through our material, and identifying in detail all entities and actors involved in the management of chronic conditions. An important feature of this analytical approach is that it does not presume any ontological distinctions regarding what might count as an actor in a particular situation. Such constructivist approaches, compels the researcher to identify and map actors on the basis of their importance to the situation. In this light, an actor might be a person, an institution, a technology or a discourse. Rather than presuming which actors are central (patients, doctors, hospitals etc), we ask which entities *act* in the management of the chronic conditions, and are parts of the infrastructure. As suggested by both Star (1999) and Mesman (2008), this enables us to discover naturalised and invisible actors that are parts of infrastructures. Secondly, we mapped the relations between these actors, in order to make the infrastructure arrangements visible, and to identify and compare what emerged as the most important actors, clusters of actors or junctions between actors in the infrastructure. As mentioned previously, from a medical perspective the three conditions that we compare are highly different, but in our analysis we used similarity and difference as analytical tools, rather than ontological attributes (Scheffer & Niewöhner 2010). By framing the conditions as alike, on the one hand – all being constituted through particular infrastructures – and, on the other hand, juxtaposing the actors and relationships found in connection with each condition, we sought to find 'alternative objects of comparison' (Langstrup & Winthereik 2010), to enable us to understand the subtle practices and ambivalences of chronic condition management.

Medication as Infrastructure in Chronic Condition Management Practices

This paper focuses on medication practices as infrastructure. This means that the practices should not be regarded as elements *in* the infrastructures of managing asthma, diabetes 2 or haemophilia, but rather as simultaneously *being* both the infrastructure and its elements. Our claim is that each of these practices takes part in shaping and maintaining infrastructures, and that they provide analytically comparative lenses that enable us to see interesting differences between the particular arrangements for each condition. Through their more or less inconspicuous actions, these social, material and discursive actors distribute chronic care far beyond the clinical setting. While we do suggest that medication, control, the body and the home are central to all three conditions, still each of these aspects entails different things for the actors involved, and functions as both a resource and a challenge for the overall infrastructure, in each of the three diseases. These actors are not the same everywhere. Their behaviour varies greatly across, and even within each infrastructure.

Medication is a ubiquitous part of chronic condition management. But looking at medication as an actor, not as a passive entity located in various places, or as something to be addressed in terms of compliance or adherence, we recognise that medication constitutes an important infrastructure of chronic condition management, in specific, ambiguous and indispensable ways.

Medication: Delegating Tasks and Responsibilities to the Home

Medication is a central material actor in chronic condition management. That medication is important in the treatment of chronic conditions may be a trivial observation, yet medication is often seen as a discrete entity whose entire capacity lies in its molecular composition. Seeing it as an actor and as providing an infrastructure of care shows that as a more or less embedded element; medicine is what links most of the actors involved in chronic condition management. The material objects that supply inhalable steroids, insulin, and factor concentrates, the most important pharmaceuticals that these patients are prescribed, are central in allowing treatment to be performed away from the physical site of the medical clinic (Prout 1996; Willems 2000). The medication for these diseases is designed and parcelled in ways that make it possible to administer by those without technical expertise. For instance, the inhaler allows the asthmatic patient to self-administer a specific, dosed amount of inhalable steroid by turning a ring on the base of the inhaler (Ibid.). In different ways, the designs of the insulin pen used by some people with type 2 diabetes, and of the factor concentrate kit used by haemophiliacs, also delegate tasks and responsibilities to patients (Akrich 1992). These tools encapsulate an envisioned relation between the person with the disease and a medi-

cal regime (Prout 1996). However, the prescribed, envisioned behaviour requires a network of other things and arrangement in order to be enacted in practice. In our study we found the activities related to *procuring* medicine – how medication reaches the intended user – and the emplacement of medicine – how it is situated in the home and in the daily routines of the people taking it – to be too important and precarious, and sometimes ambiguous accomplishments.

Procurement and ‘Holding Work’

The logistics of prescriptions, pharmacies, and telephone calls for renewed prescriptions are some of the arrangements that enable procurement. Logistics allow medication to travel, and thus relate the various settings involved in treatment, most importantly, the clinic and the home. For our participants with asthma, the procuring of medication only required a telephone call to their general practitioners’ offices, and a visit to the pharmacy, once the disease was diagnosed and a strategy for treatment established: ‘Well, I have always [...] just called my general practitioner and told the secretary that I need a new blue inhaler, and then I got it’, to quote Alice, a young woman with asthma. For type 2 diabetes, medication is often more closely monitored by the medical professionals involved in its treatment, and it involves more visits to the clinic for changes and adjustments, before a visit to the pharmacy is possible. For haemophilia patients, the situation is much more complicated. Looking at the complicated practices of procuring clotting factor for haemophilia, it becomes evident that the logistics involved in asthma and diabetes management depend on the generic and naturalised standards of prescriptions, private pharmacies, public reimbursement and individual co-payment. These standards do not apply to haemophilia treatment, and other arrangements must be aligned to make clotting factor travel beyond the walls of the clinic. The factor concentrates that haemophiliacs self-administer to prevent or treat bleeding are extremely costly and fragile (their shelf life is short, and some brands must be kept cool). Moreover, this treatment has a history of not only helping, but also harming the patients taking it. In the 1980s and 1990s a great number of haemophilia patients were infected with HIV and hepatitis through their factor concentrates. For these reasons, haemophilia treatment has a separate infrastructure arrangement connecting the patient more intimately to a clinic – via the medication – than is the case with either asthma or diabetes. Haemophilia patients telephone the special haemophilia clinic (there are two such specialist clinics in Denmark) to renew prescriptions; a nurse, who will phone the hospital pharmacy to issue it to the patient, takes the call. Finally, the medication is picked up at the hospital by the patient, brought to a hospital closer to the patient, to be picked up there, or brought directly to the patient’s home (by taxi). Owing to the previously mentioned special characteristics of the medication, the stock of factor is closely monitored by the prescribing authorities: batches and shelf life are noted by nurses at

the clinic, and in case of surplus factor allocated to, but not used by a patient, the nurses may retrieve the already distributed medication from one patient, and redistribute it to another, as evident in this field note:

The telephone rings, and Anna, the nurse, answers. It is the patient she left a message with earlier. It is apparent from their conversation that they know each other. Anne says, that she has 'today's offer' for the patient. She has some surplus medication, which she thought he might be able to relieve her of. If not, they will have to destroy 80,000 kroner [app. 10,000 euro, ed.] worth of factor concentrate: 'But it won't be necessary if you can use it'. She asks if he can come by and pick it up. In the next moment, while he is still on the phone, she opens his file and they start talking about his treatment and some problems he has experienced lately.

As this field excerpt indicates, the various arrangements involved in procuring clotting factor not only shed light on the various practicalities involved in getting medication, they also identify the actors and the efforts involved in their infrastructures. In asthma treatment, the call to the GP's secretary – a person who is quite possibly unacquainted with the patient's medical and personal issues – is often the only communicative relation to the clinic for long periods of time. As indicated above, the phone call involved in the case of haemophilia differs from this greatly, as the call is answered by a specialised nurse, who in all but very few cases knows the person calling quite well, and has been involved in his or her treatment over time. In the field note, the nurse is the one contacting the patient to offer him surplus medication, but the call also becomes an occasion for talking about the status of treatment. At other times, we observed similar conversations when patients called for prescriptions and were asked how they were doing, and were reminded that it was time for a check-up. It is evident that in haemophilia treatment, the medication is of great interest to the hospital clinic, since it is a much more valuable and scarce resource for which they are accountable than in the two other cases. In the other cases, once the prescription leaves the clinic, medication is the responsibility of other actors in the infrastructure, and mainly that of the patient. Thus, the activities involved in procuring medication variously affords or impedes the continuation of relations among the actors involved in the managing of a condition. In haemophilia, these activities affords what Cocksedge and May (2005) term 'holding work', that is, the medical professional's invisible, and to some extent quite extensive efforts to keep the patient connected to the clinic, and thus, to his or her treatment over time.

Emplacement and Making the Home an 'Enabling Place' in Treatment

The concept of emplacement in relation to medication refers to the activities involved in incorporating medication into the daily physical and social life of the person with the condition, and others who live with him or her (Aarhus & Ballegaard 2010; Hodgetts et al. 2011). In our study, we found that all medical devices

and equipment are often kept in specific places. For instance, one person, Bernd, an elderly man who had had diabetes for 20 years, keeps all this medication and equipment in a box on the bookshelf just behind his place at the dinner table. Whenever he sits at the table to eat, read or rest, he simply reaches for the box. This placement and arrangement help him to manage his condition. Their location may be described as an *enabling place*, the specific arrangements of which provide him with certain capacities or abilities related to managing his condition (Duff 2011). This is a quite simple arrangement, which is also recommended by healthcare professionals when they instruct people on self-care, but it accomplishes the important work of keeping things together, and helping to establish a routine that acts as a reminder and therefore helps Bernd to attend to and manage his condition. Part of what the arrangement does is connecting itself to existing and stable arrangements: the place at the table, the regularity of breakfast, dinner time and so on. Similarly, John, who has asthma, keeps his asthma inhaler in the bathroom, next to his toothbrush. This way, he not only remembers to take his preventive medication in the morning (and sometime in the evening), when he routinely brushes his teeth, but by brushing his teeth *after*, instead of before inhaling the steroid, he also prevents oral fungal infection, a side effect that causes some people with asthma to cease taking their preventive medication.

Janus keeps his clotting factor in the living room cupboard, close to the dinner table, where he usually takes his preventive medication every second morning. The factor that Karl uses needs to be kept cool, so he keeps it in the refrigerator, next to the juice and ketchup. Thus, these places are more than mere locations – they are allies that help weave medication into the fabric of everyday life in the home, as both material objects and as activities. Ironically, establishing the infrastructure through these emplacements in the home may also impede other actions, such as taking medication when away from home. For instance, Bernd, with type 2 diabetes and his box on the shelf, brings neither his insulin nor his blood sugar measurement device with him when he visits the centre for the elderly, just across the street from where he lives. He visits the centre several days a week for four to five hours, and he often has his lunch there; ideally he should bring his insulin and his blood sugar measurement device with him. The main reason he does not bring these things along is that he easily forgets things, and is afraid that he might lose them. Thus, we see how the emplacement both enables him to manage his condition locally in his home, and has also become a manifest structure that he is reluctant to dismantle and jeopardise. His neglect of his condition when going out is partly premised on, and related to a concern for an infrastructure that enables him to manage and attend to his condition in his home. An obvious suggestion would be that Bernd should simply have several sets of devices and insulin pens. He already has several that he could bring with him, and although this is obviously better for his condition, it would still create more work for him, in terms of administering and displacing the additional set of medication. This example is illustrative,

since it tells us about the intricacies and contrasting aspects of managing chronic conditions, and how managing chronic conditions include material arrangements, and treating them involves spatially and temporally situated practices. This facilitates a shift from thinking in terms of people being more or less capable of managing their conditions, to understanding chronic condition management as involving instances or events that are inextricably intertwined with material arrangements and infrastructures. This helps us to shift our focus from human subjects as autonomous and detached beings, to a focus on practices in which human beings are entangled with materiality, technologies and multiple others.

Tinkering with Medication

Bernd's story, although probably quite widespread in relation to managing diabetes, is also highly specific to the condition, itself a relational point. Bernd's behaviour is tied up with the extent to which it is important to him to inject his insulin as he should, and the point is that no immediate danger is posed, if and when Bernd does not take his insulin in strict accordance with his treatment plan. What happens is that his blood sugar level increases, which has no or few consequences for him at the moment; however, in the long run, poorly regulated blood sugar increases the risk of diabetes-related complications, such as reduced eyesight, decreased sensitivity in the extremities, kidney disease and cardiac arrest, among other things. In contrast, for people with haemophilia and asthma, both preventive medication and emergency medication play significant roles. It is crucial that they have their emergency medication at hand, if and when they are injured or have an asthma attack. Therefore, they engage in activities that ensure that they can access their medication immediately. This means bringing the medication with them, and storing it in specific places. People with haemophilia and asthma are preoccupied with anticipating and planning their actions and activities: bringing factor in the boot of the car when attending a bachelor party, which might involve a bit of romping about; having the asthma inhaler in a purse, when going to a party where people might smoke. This anticipatory work involves the placing of medication in pockets, purses, cars and other transportable sites, and may be further understood as work done at the fringes of the infrastructure. It is in these anticipated places, where routines and allies are potentially scarce, that an infrastructure sometimes collapses. Going on a road trip with friends from a rock band not only means not being able to avoid cigarette smoke, but also jeopardises the routine of brushing teeth and taking preventive asthma medication. Still, it might be a worthwhile trade-off. On the other hand, for people with haemophilia, being situated outside the infrastructure rendering medication unavailable in case of an injury may have fatal consequences. Therefore, when venturing out, proximity and the existence of safe passage back to the care infrastructure are always considerations of a person with haemophilia. For instance, travelling abroad always involves locating the

nearest hospital with expertise in treating haemophilia, and carrying a patient ID card informing about the condition and the specific brand of medication used, should the person be brought to a hospital in an unconscious state. The placing of medication in physical locations and daily routines also introduces ambiguities when managing 'the passages' to situations and places in which people's lives also unfold, but which are less structured and predictable, and may be valued for that very reason (Law & Moser 1999).

But even at home, the placing of medication in relation to everyday life can involve complexities, ambiguities and the negotiation of trade-offs. The expansion and stability of a permanent infrastructure involves alliances with other actors already in place in the context of the home, such as daily routines, boxes and toothbrushes. These allies may also be human actors, such as partners and parents. It is acknowledged throughout the literature discussing chronic conditions that relatives play a significant role in managing life with a chronic condition (Corbin & Strauss 1988; Charmaz 1993; Scambler & Scambler 2010). With regard to medication, relatives are often included as part of the infrastructure, in terms of their reminding and assisting to take medication. But this alliance also contributes to the potential fragility inherent in the infrastructure. For instance, Karl disgusts injecting himself with his clotting factor. Previously, he only had to be medicated when he was injured, and then he would go to the hospital and have the factor administered by a nurse. Now, he also requires preventive treatment, and this means having injections every day, therefore, the nurses taught Karl's wife to administer the injections. The regimen prescribes that Karl should have his injections in the morning, as he will then have the highest level of factor in his blood during the day, when the risk of bleeds is highest. However, Karl's wife has to get up early for work, and Karl prefers to start his day a bit later. Therefore, they have developed an alternative routine where they administer the injections in the evening, when they have more time. This is not medically optimal, because Karl will have the highest level of factor while he is asleep, and lower levels while he is awake and active, but the trade-off is weighed against concerns for other things, such as his wife's job and the value of a calm morning. In chronic condition management, there are many such examples of 'tinkering' with the medication, and mobilising other actors in medication practices, thereby making the infrastructure durable, but at the same time necessarily disregarding some of the prescribed actions inscribed in the medication and treatment regime (Mol et al. 2010). If, as Willems (1995, 2000) has suggested, compliance may be understood as the establishment of *flexible networks*, this 'tinkering' may be seen not as non-compliance, but instead as located experiments with the elasticity of the network: 'How far can I stretch this particular relationship, before it breaks?'

Considering medication in terms of procurement and emplacement has shown us how the infrastructure underlying chronic condition management involves the ongoing execution of local socio-material practices. Medication, as objects and as

activities, is embedded in daily life with a chronic condition, and locations and actors are included as allies in treating chronic conditions outside the clinical setting. We have also seen how these infrastructures may be ambiguous with respect to their consequences; they may simultaneously contribute to both management *and* neglect of the condition. Particularly precarious is the management at the fringes of the infrastructure, where allies, routines and general predictability are scarce. Though the location of this fringe varies among the three conditions (the other side of the street, the party, travelling abroad), some of the strategies are shared: avoidance or anticipation of activities and places, emplacement of medication in mobile locations (pockets, bags, cars), or simply throwing caution to the winds, leaving medication and treatment routines behind, either to keep what is already in place secure, or to do something more fun. Furthermore, these examples contribute to the production rather than the reduction of complexity, with regard to what medication is. Medication is not a universal tool for treating disease. The role it comes to play is relative, and dependent on other elements and actors in the network surrounding the chronic condition. The implication of these conceptions is that, as part of an infrastructure, medication has an ambiguous quality, being somewhat trivial and somewhat invisible, and then suddenly, in specific situations, it may emerge as a decisive factor that interferes with, or intervenes significantly in other practices and actions. This dynamism of eruptive, emergent factors that are sometimes potential and invisible, and at other times actual and decisive, challenges the common notion of a landscape that includes certain stable and singular elements that may be discovered and described. Our analysis creates the opportunity to think otherwise, regarding such ontological assumptions. In keeping with notable contributions to the field of STS, we suggest an ontology of partially-existing and multiple objects (Latour 2000; Jensen 2010). In such an ontology, a landscape and its elements can never be pinned down, fully described and territorialised, but are continuously in-the-making, and the quality and status of its various elements is fluctuating and relative to other elements.

Discussion and Conclusion

In this paper we have implemented the concept of ‘infrastructure of care’ as an analytical lens that enables us to see the complex topology created by interconnected spaces and actors involved in the management of chronic conditions. We come to understand medication as more than pharmaceutical objects or substances that effortlessly end up in people’s cupboards, pockets and bodies. Our analysis reveals several interesting points regarding medication as part of an infrastructure of care, and the self-care that it affords. The relational aspect of the role of medication is evident. In some situations, medication seems to function as an *infrastructure* and in others, as *infrastructuring*. Thus, it is *both* a structure on which other care activities ‘run’ *and* the ongoing ‘doing’ or enactment of care (Mol

2002; 2008; Mol et al. 2010) that participates in the formation of infrastructures. The procurement practices provide a good example of the first aspect. Here, medication has the role of initiating and facilitating communication and interaction between the patient and the healthcare system. Medication becomes a crucial actor for the way in which the patient and healthcare system distribute responsibilities and shared care tasks. A simple telephone call may afford holding work that not only reminds patients of appointments, but more importantly, builds personal and affective relationships between patients and medical professionals (Cocksedge & May 2005). When nurses and patients share an interest in the medication as a life-saving remedy as well as a scarce and costly resource, as is the case with haemophilia, this provides occasions for care that transgress any clear delineation of professional care versus self-care.

The emplacement practices provide an example of how medication shapes and forms infrastructures in the home, and for the individual patient. Medication initiates the building, structuring and maintenance of arrangements that support the patient in performing self-care by adhering to the treatment plan, while at some points, as we have seen, it may also contribute to neglect of the condition. However, this should also be regarded as a form of healthcare performed at the fringes of the infrastructure: caring for the optimal treatment results may be traded-off against caring for the stability of a durable medication routine, or caring for those who share the burden of your illness with you. This, we find, emphasises the point that medication practices are translational, where neither the patient nor the medication, nor yet the healthcare system may be said to have determinist power over the other. Medication as both *infrastructure* and *infrastructuring* brings attention to the fact that medication both produces and carries a workload for the patient. The various established infrastructures in which artefacts and activities become connected and mutually intertwined minimise certain types of work, such as remembering, collecting and gathering medication and may also carry the larger part of the workload of care in a manner that prevents other types of care, or renders them difficult to execute. Properly working self-administration of medication for acute events, and a smoothly running prescription practice in asthma treatment may circumvent the necessity for professional monitoring and clinical discussions of treatment. When we compare the three conditions, it seems the more standardised and embedded the role of medication in the treatment, the less communication and interaction is required. Consequently, care tasks that people themselves perform more easily go unnoticed and unacknowledged as self-care activities. This is a point with some relevance to the recent focus on healthcare IT as technical fixes of the challenges of chronic conditions, and as the primary means of promoting self-care (e.g. Danish Regions 2011). In keeping with the arguments of infrastructural inversion (Bowker 1994; Bowker & Star 2000) and exnovation (Mesman 2008), our analysis foregrounds the background elements of self-care, and not least, the thoroughly materially-inscribed and spatially-distributed nature

of chronic care that already exists in the way patients and professionals address chronic conditions. Focusing exclusively on the promises of telemedicine and IT-supported monitoring systems risks neglecting the complex ecology of healthcare that already facilitates self-care, and already connects the clinic and the home. Designers and policy-makers often operate with the metaphor of a gap that needs to be bridged by information technology. However, wherever we look, when studying practices of chronic care, there may be no IT infrastructures, but the terrain between the home and the clinic is certainly not empty, as we have shown. Thinking more inclusively in terms of infrastructures of healthcare makes it possible to describe and acknowledge the often challenging and ambiguous ways in which people with chronic conditions already engage in taking care of themselves, which are facilitated by, but which may also diverge from the objectives promoted by the healthcare system.

We suggest moving away from the idea of a lack of (technological) infrastructure to an idea of an ecology of infrastructures and practices that must be considered when seeking to promote new ways of facilitating healthcare. This may induce a greater sensitivity to existing infrastructures and practices, and to the subtle and often invisible work of weaving together entities and actors in what may come to be properly functioning practices (Suchmann 1995; 2002). Introducing an IT infrastructure for self-care into the specific context of chronic conditions is to inevitably intervene in an area that has already installed orders, structures and practices – it is always *already infrastructured*, and self-care is always already at work.

As Annemarie Mol argues, in *The Logic of Care* (Mol 2008) actors – human as well as non-human – *do* things, and no actor needs to act alone: ‘in the logic of care the action moves around. One moment you care and the next you are taken care of. Care tasks are shared in varying ways [...] You do not have to do everything by yourself. You cannot: even doctors with diseases need professional care’ (Ibid: 80).

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Notes

- ¹ We employ the term 'chronic condition' instead of 'chronic illness' or 'chronic disease' as a deliberate analytical strategy. We wish to avoid the categorical dichotomy (introduced in medical sociology by Talcott Parsons) between the 'objective' *disease* designated by medical science and the patient's 'subjectively' experienced *illness*. By the general term 'condition', we wish to facilitate an analysis of the chronic condition as an emergent, heterogeneous phenomenon that comes into being through the association and intermingling of 'objective' and 'subjective' aspects and entities. The problem with the classical distinction is that it forecloses an analysis intended to pragmatically follow how conditions come into being. This analytical strategy is inspired by actor network theory (Latour 1987, 1993) and cyborg theory (Haraway 1991, 1997). Following this argument, we are aware that we risk creating the general impression that chronic conditions are all the same. We are well aware that this is not so. Chronic conditions are by no means general. Not only do they differ from one another, but the same condition is *interpellated* and *translated* in multiple ways, depending on a range of highly individual and situational aspects: the age of the person with the condition, the length of time since diagnosis, the severity of the condition, the person's capabilities and skills, social, educational, economical and other aspects, the medication, the health care system, and so on. This understanding is central to the argument of the paper. Our emphasis on medication as one aspect among many that affect how a condition develops is concordant with this understanding.
- ² The concept of *affordance* was coined by James Gibson (1966). Gibson argues that: 'an affordance is neither an objective property nor a subjective property; or it is both if you like. An affordance cuts across the dichotomy of subjective-objective and helps us to understand its inadequacy. It is equally a fact of the environment and a fact of behaviour. It is both physical and psychical, yet neither. An affordance points both ways, to the environment and to the observer.' (p. 129). The concept emphasises the co-constitutive interplay and process of becoming, of subject and object, insisting on their relative and non-determinist relation. Though Gibson's work is rarely adequately acknowledged, the ecological perspective has, as already mentioned, greatly influenced the work of Star and Bowker (e.g. Star & Ruhleder, 1993; Star, 1999 and Bowker & Star, 2000).

- ³ The concept of work is as central to Bowker and Star's understanding of what makes an infrastructure function, as it is to the chronic illness literature's understanding of what makes health care function, in the literature on chronic illness. In this latter literature, the concept of work has been used to emphasise the activities that patients and relatives engage in, within and outside medical institutions (Strauss et al. 1985; Corbin & Strauss, 1985). In our paper we aim at combining these insights by foregrounding the work involved in establishing and maintaining infrastructures of healthcare.
- ⁴ Thinking in terms of ecology of care emphasises the interdependence of the multiple environmental, human and technical entities that make up healthcare.

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Thematic review by Anna Pichelstorfer

Questions about how people should be cared for and what good care should entail are increasingly discussed. New strategies, such as self-care, are introduced to cope with socioeconomic challenges that follow from an ageing population and its implications for the health care system. Although caring is not a 'new' phenomenon, social sciences have not shown much interest in this topic so far. Recently, two books have been published that deal with the question of what care is and how it is organized and practiced: Annemarie Mol's monograph *The Logic of Care* and *Care in Practice* a book edited by Annemarie Mol, Ingunn Moser and Jeannette Pols. Both books provide a new perspective on care and help to rethink current developments in health care. While Mol's (2008) analysis is based on a single case, on the treatment and life with diabetes, Mol, Moser and Pols (2010) assemble 13 empirical studies from different areas. They engage with farming, health care and care for elderly or people with disabilities. Each of them provides a substantial description of a very specific and local situation, thus setting certain aspects or versions of care practices in the foreground. As will be shown, this is one of the great strengths of the work presented here.

Referring to previous research that has shown the public importance of care and referring to literature that studies the carer/cared relationship and medical ethics, both books stress that within these understandings and frameworks the specificities of care are lost. In contrast the authors want to strengthen care practices and actors involved in them by articulating what care is. Their main aim

is not only to contribute to a scientific debate but also to bring care to the public sphere and help to improve it in its own terms. With this normative approach to research, they want to prevent care from being submitted to control and simplified schemes of welfare politics that do not fit its logic or live up to the complexity of care practices.

This understanding is also reflected in their research design. One of the common features of all contributions is that they only provide a rather vague definition of care. They do this on purpose, as they conceptualize care, not as a fixed category, but as a term to be explored. In order to understand the "rationale" or the "logic of care", Mol studies how care is being done in everyday practices. Similarly, the authors of *Care in Practice* do not restrict care to a certain domain or site but understand it as a doing, as a mode or style. Therefore, they promote an ethnographic approach to learn about the nature of care practices and argue that we have to immerse ourselves in those practices to research them. The researchers spent time in nursing homes or clinics (A. Mol, I. Moser, T. Moreira) and participated in care practices on farms (J. Law, V. Singleton). They used auto-ethnographic experience (J. Taylor, H. Harbers) or described in great detail the usage of technologies that are intrinsically part of care practices (D. Lopez/B. Callen/F. Tirado/M. Domènech, J. Pols, B. Winthereik/H. Lanstrup, D. Willems), or situations in which the quality of care should be assessed or improved (e.g. B. Kraeftner/J. Kroell/ I. Warner). Mobilizing these ethnographic stories helps to make the reader understand the logics in each

situation, which are often ambivalent and provide reflections on what good care should entail. Only by leaving the term care vague, can it be attended in its complexity and specificity.

Both books show that care is best understood as shared work, involving not only professionals but also patients, their families and other human beings as well as bodies, technologies and all sorts of material elements. Hence, care is conceptualized as a set of materially heterogeneous practices that are always local and specific. An ethnographic research approach leads to new perspectives on technology, patients' rights and responsibilities, as well as quality improvement within health care. This will be exemplified in the following paragraphs.

One of the main insights the book has to offer is a reconfiguration of the relationship between technology and care. Technology is not considered as cold or as something that necessarily is opposed to a warm, kind and generous care, but is seen as an element of care itself. In line with STS (Science & Technology Studies) literature, many of the contributions in the book show that technologies are fluid, they have diverse and sometimes unexpected effects and change expectations and aims of care. Thus, one cannot think of technologies as an instrument that can be introduced to achieve a specific effect. One must be aware that technologies are similar to people's habits or hopes and expectations constantly adjusted in care practices in order to achieve 'good' care.

A second point I want to emphasize is that the focus on practices results in a critical engagement with the conception of patients as customers or citizens having certain rights and responsibilities to care for themselves and choose the 'right' treatment. Both books show impressively how the ideal of the patients choosing for themselves can lead to poor care. This does not imply that the authors would oppose the idea of an active patient. On the contrary, by studying practices, they manage to articulate an alternative to the much discussed hierar-

chical dichotomy between an active carer and a passive person being cared for. When they analyse care as shared work between different human and non-human actors, it becomes visible that "care activities move between doctors, nurses, machines, drugs, needles and so on, while patients have to do a lot as well" (Mol 2008: 32). In care practices, patients and technologies are actively involved in care activities.

Furthermore, the contributions show that there may be different versions of what might be 'good' within one caring practice. They illustrate that good care does not equal patient autonomy or efficiency. Good care is always a collective achievement and involves "persistent tinkering in a world full of complex ambivalence and shifting tensions" (Mol/Moser/Pols 2010: 14) to keep together all the multiple versions, values and objects of care. In articulating a different understanding of the neoliberal idea that individuals should take responsibility for their own health, the authors offer valuable contributions to the study of health care, technologies and to ethics of care.

Since practice – besides care – comes up as a central concept, they speak to the work of practice theorists as well. Both books exemplify that only by looking at practices, do ambiguities within care become visible and can be investigated. Furthermore, it is emphasized that within care, action is more important than actors and those who are involved in practices may shift. In doing so, the authors provide a different understanding of actors, similar to that in practice theory, which conceptualizes actors as carriers of practice (see e.g. Shove et al. 2012). Practice theory corresponds to the way they approach their research objects and to their conceptualization of body and mind, things and humans, structure and agency and the attempt to overcome these dichotomies. The authors emphasize the importance of the non-verbal in caring practices and the active involvement of bodies. They attend to uncertainties in practices, de-

center humans and do not contrast care and technology, but describe care practices as consisting of various elements that are continuously (re-)arranged. In that way, they show how change can be conceptualized in practice theory. Change cannot be achieved by controlling certain elements such as bodies or technologies but must be seen as an element of practices themselves. What follows from this perspective is that improving (health) care can only be accomplished in practice and not controlled or introduced in general forms or principles from the outside.

But the approach deployed in both books could also have benefited from engaging with recent work in social theory focusing on practices (e.g. Schatzki et al. 2001; Reckwitz 2002). By emphasizing the tinkering of care practices, its uncertainty and ambiguities, the perspective of how care practices are stabilized or transferred between different settings cannot be attended to. Looking at other approaches in practice theory might have provided an input on how to study both routines and change in care practices. Furthermore, while being engaged with practices, the authors do not attend so carefully to the term 'practice' as they do to 'care'. This might have provided the reader with a clearer account of the use of the term practice, which is applied in very different ways throughout the articles and not reflected upon.

As all the empirical studies explore quite well, care comes in many versions. We learn for instance that killing is not necessarily opposed to care, that each person in a collective is simultaneously subject and object of care, that the prob-

lems care deals with are not located in a person's body but in a collective. This is one of the great strengths of both books: the contributors try to test and develop theoretical concepts through empirical research and find new aspects within care. What has not been spelled out so far are analytical concepts developed from their collective effort to unravel care practices; that is, to bring together all the different versions of caring, to compare and contrast them and see what can be learned from them. Nevertheless, the high quality of all essays and the careful approach to research and writing make a wonderful contribution to current discussions about how to organize and practice good care. Both books illustrate beautifully that certain ideas to increase the efficiency in the health care system must be reconsidered. Ethical principles (e.g. patient autonomy) or the introduction of technological devices to promote self-care do not just delegate tasks from professionals to patients, but change problems, solutions and meanings; thus change care practices themselves and may lead to decreasing quality in health care.

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