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 wide-spread 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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