

Medication as Infrastructure: Decentring Self-care

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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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