

Patients' lay expertise in chronic self-care: a case study in type 1 diabetes

Cristiano Storni PhD

Lecturer, Interaction Design Centre, Department of Computer Science & Information Systems, University of Limerick, Limerick, Ireland

Correspondence

Cristiano Storni, PhD
Lecturer
Interaction Design Centre
Department of Computer Science &
Information Systems
University of Limerick
Engineering Building ER1-004
Limerick, Ireland
E-mail: cristiano.storni@ul.ie

Accepted for publication

3 August 2013

Keywords: chronic disease, design, diabetes, IT, lay expertise, self-care

Abstract

Background The impact of chronic diseases in our society is growing. The idea of self-care generates understandable enthusiasm and is seen as a natural answer. It is important to develop an understanding of self-care practices that goes beyond a clinical understanding of the disease and that acknowledges everyday practicalities, and the perspective of the patient.

Objective To shed light on some of the practicalities of everyday chronic self-care, to expose to analysis the key role of lay expertise and to stress the importance of its recognition in future chronic care practices and technology.

Design Ethnomethodological investigations based on observations of a patient support group (10 months) and some shadowing sessions of everyday practices, semi-structured interviews with individuals with type 1 diabetes ($n = 14$) and professional caregivers ($n = 7$).

Analysis The qualitative data analysis was inspired by grounded theory and aimed at ordering data under emerging categories and topics.

Results The patient's knowledge and expertise is critical to grounding, integrating and complementing technical-medical/clinical knowledge in everyday chronic self-care. To deal with the intricacies and difficulties of everyday chronic self-care, individuals with type 1 diabetes develop different ways of knowing and dealing with the disease that need to be equally taken into account in the reorganization of care delivery, and in the design of the tools to support it.

Conclusion Rethinking the traditional separation between hard and soft data may be a possible first step towards rethinking the role of lay expertise in chronic care towards better supports for self-care practices and patient empowerment.

Background

The call to rethink health-care provision for citizens has become a key political, social and economic concern in our society. The increasing cost of health-care systems in administration, service delivery and technology is recognized as being unsustainable. This couples with ageing populations and an epidemic of chronic disease. In this context, a series of ideas have entered the public discourse with particular relation to chronic diseases:^{1,2} patient-centric and personalized care, patient empowerment, self-care and self-management. Some of these ideas have inspired a series of application areas where the contribution of technology is key: telemedicine, mobile and home-care, assistive technology, health 2.0 platforms, etc. The general idea is to take advantage of new information technology to efficiently redistribute health-care practices outside hospitals and clinics to citizens and their communities.^{3–5} However, the link has yet to be made between providing patients with new services and supports and their real empowerment.

Introduction

In this work, I focus on different forms of expertise that individuals with type 1 diabetes develop in constantly dealing with their disease. I discuss the role of this lay expertise in the management of chronic illness, and I argue that the development of new services and supports for the patient needs to recognize its importance and relevance. Traditionally, the organization of health delivery services or the development of medical technology has been within the parameters of the clinical setting with an expert user and a privileged and disciplining emphasis given to the biomedical knowledge and perspective. This more traditional disease-centric model is normative in nature. It assumes the scientific method (quantitative and positivist) operating an asymmetry between the expert knowledge – that needs to be supported by technology (e.g. the stetho-

scope), and lay beliefs – that need rather to be disciplined. These divisions and their assumptions risk being unreflectively reproduced in the development of services and supports for patients. In line with some recent research on patients' experiences and everyday care practices,⁶ I argue against more 'traditional' views that oppose the knowledge of medical experts to the lay expertise of patients. These views often insinuate that the first is the only one available to improve health outcomes and that the second is ill-founded and potentially harmful. I discuss instead how the two are intertwined in practice and I address a series of issues of lay expertise that does not receive adequate attention in the development of services and supports for self-management and patient empowerment.

In a market that sees self-care as the next *big thing*, studies that investigate current self-care practices and patient perspectives and that shed light on the changing *geographies of care*⁷ are needed to rebalance a mainstream trend (for instance in the design of information and communication technology and policymaking) that assumes a clinical perspective and its connotations. Indeed, one of the key intents in this work concerns the way in which, paradoxically, the call for a patient-centric health care that supports chronic self-care can ultimately lead to new ways to discipline patients within a traditional medical model that fails to fully acknowledge the patient's agency and perspective and to attend to the full range of (issues in) lay expertise. Although studies on patients exist (see next section), implications of these studies for rethinking the development of services and supports for managing chronic disease in everyday life are sporadic.⁸ In this context, I choose to look at type 1 diabetes mainly for two reasons. The first concerns the growing impact of this disease in society on a global scale.* The second concerns the particularly ubiquitous nature of this chronic condition which relates to, and influences every

*See WHO fact sheets: <http://www.who.int/mediacentre/factsheets/fs312/en/> (accessed 19 August 2013).

aspect of everyday life, thus making it a good illustration of everyday self-care practices where the perspective and expertise/experience of the patient are particularly relevant.

In the next section, I review some of the key contributions in studies of patients' everyday chronic care. I then discuss empirical material on different forms of expertise that seem key in self-management but where it is difficult to draw a clear separation between the medical and the 'non-medical'. I conclude by suggesting that rethinking the data could represent an important first step in the design of IT support for chronic disease self-management in general and diabetes in particular.

The notion of lay expertise: background

Studies of patients' everyday practices, their agency and knowledge are not new. Their origins can be traced back to early self-care movements in the 1970s. In a review of these origins, Shoor and Lorig⁹ attribute importance to the philosophy of Illich and Levin, the practical instruments of Fries, Sehnert, Vickery and Ferguson, the work of Halsted Holman, the experience of the Mayo Clinic and a series of key social movements. In the wake of these new views (as well as the influence of Foucault and his notion of biopower¹⁰), a series of new practices and literature started to question traditional authority in medical practice, critique the Parsonian notion of the 'sick role' and shed light on another side to the story. Macintyre and Oldman's¹¹ pioneering work discusses how patients with chronic illness develop their own special kind of knowledge that is rather different from that of doctors and how, from their point of view, this is *subtly superior*. Jones¹¹ first enquired about patient perceptions of drugs and prescriptions to show how patients display different degrees of literacy and may often disagree with what doctors think.¹² Morgan and Watkins confirmed these findings in their study on how patients self-manage hypertension.¹³

Critiques of the notion of compliance followed this strand. In another pioneering work,

Conrad¹⁴ showed that people adjust and adapt their regimens to suit their life situation. They may be solving a practical problem that a particular drug or procedure creates. They may choose to avoid the stigma of the condition that their medication represents. For instance, individuals with a chronic disease may be lowering the dosages to see whether their condition has improved. In effect, patients may alter their drug regimens in an effort to retain control.

This focus on the learning aspects of experiencing a disease, especially chronic, links to more recent studies discussing notions such as the informed patient,¹⁵ the expert patient¹⁶ and the lay expert¹⁷ and also discussed in relation to the idea of patient empowerment.^{18,19}

According to Prior,²⁰ the notion of lay expertise is used to refer to two distinct types of knowledge. One is the experiential knowledge developed by the patient as a by-product of coping with daily practicalities of the disease as well as, for instance, making sense of how the body reacts to medication.²¹ The other is the expert knowledge as reappropriated by non-experts and that is used to contribute,²² but also challenge²³ and dispute²⁴ the biomedical perspective. Both types of knowledge are usually discussed in opposition to the dominant paradigm of the scientific knowledge that is traditionally produced and validated according to the logic of clinical trials and confined experiments and that thus comes to acquire the character of universality. When compared with this standard, the experiential knowledge of affected people tends to be labelled as personal and idiosyncratic²⁵ and related to what is unique and specific in an individual. In this sense, the notion of lay expertise has been criticized as oxymoronic²⁰ and, although recently revamped, still tends to be associated more with the category of beliefs, or somehow understood as inferior to the clinical one.

Studies of interactions between patients and doctors in current clinical practices, consultations and rehabilitation further discuss how the dominant position of experts limits the possibilities for patient participation and empowerment^{26–28} especially in chronic care.²⁹ Common

in these more critical works is the acknowledgement that patients develop and produce a specific kind of lay and personal expertise that is vital for their self-care practices even though it may not coincide with that of health professionals. Following these lines, literature that focuses more on the impact of technology in patient participation tends to underline how the agency of patients is often limited or neglected rather than made visible and supported. For instance, Oudshoorn³⁰ uses Strauss' notion of invisible work to show that patients with cardiac diseases can become an active 'diagnostic agent' in a telemonitoring setting, but only at the price of a lot of effort, traditionally not accounted for nor specifically supported by the devised technological solution (a similar discussion can be found in Nicolini³¹). Dubben³² has argued for seeing telemonitoring as coconstructed by both medical personnel and patients. He discusses how non-use is important to understand how such technology is adopted, but also shows how it might act as a panopticon to scrutinize telemedicine in terms of surveillance and cyber control. A review of telemedicine projects by Koch³³ further displays the overemphasis on the clinical perspective and vital sign measurements with very little concern for the viewpoint of the patient or for the practical impact of such monitoring technology in their lives. Early on, Orel⁸ discussed the limits of patient technology design that does not consider instruments that could be used independently of professional assistance. He argued that field research by biomedical engineers gives the impression that manufacturers neglect above all the study of the lay environment and lay practices.

This work aims to stress the importance of the recognition of patients' expertise in devising new forms of IT support for chronic self-care. Rather than being opposed to expert knowledge and the clinical perspective, I argue that the patient's expertise is critical to contextualizing, integrating and grounding technical-medical/clinical knowledge in everyday chronic self-care and that this needs an equal share of attention from designers and policymakers.

Methodology and data gathering

This research emphasizes the patient perspective and the practicalities of everyday chronic self-care. This concern suggests a qualitative methodology to investigate what patients really do to deal with diabetes and not necessarily what they are supposed to do from the perspective of an expert.

For this reason, an ethnomethodological approach³⁴ was used to privilege the logics, strategies and views of a limited number of subjects. The intention is to provide insights and thick descriptions of chronic self-care practices. The aim is not to generalize, but to expose to analysis some general aspects and potential issues in chronic care.

To access and investigate self-care practices and the patient perspective in diabetes, the author decided to contact a local type 1 diabetes support group (in a small city in Ireland) and ask permission to attend all their meetings. Access was kindly granted (although recording the session was not allowed), and it enabled the author to familiarize himself with the heterogeneity of patients' concerns as well as to gain further access for deepening the investigation.[†]

As expected, patients in the self-help group shared their experiences and supported one another in a peer-to-peer fashion by giving emotional support, different kinds of tips (e.g. about snacks or recipes, events and initiatives, books or articles, etc.), information, confirmation and reassurance. Group meetings were held once a month (twice for special events) for about three hours. The author personally attended the meetings for a 10-month period. Meetings were attended by a core of eight regular subjects and by a series of other participants (seven in total during the time of observation) who showed up occasionally.

As the members of the group became more familiar with the author, in-depth interviews were allowed along with a limited number of

[†]The local ethics committee approved the research design. Data gathering and processing was in line with the recommendations of the local data protection authority.

shadowing sessions (in the forms of home visits) whereby the author was invited to assist in daily routines (such as cooking, preparing for physical activities or buying food at the market).

Interviews were informal, open and loosely structured, although all included discussion of a series of general topics. Participants were interviewed extensively regarding their daily experience of dealing with the disease, their relationships with medical personnel and the pros and cons of using self-care technology. Interviewees were constantly invited to provide practical examples instead of talking in general terms.

Along with field notes about support group meetings, a total of fourteen semi-structured in-depth interviews were performed between September 2008 and June 2009.[‡] Ten of these were performed with members of the support group, while four others were performed with other individuals with type 1 diabetes recruited by word-of-mouth. A few experts (three community pharmacists, two diabetes nurses, one GP and one endocrinologist) were also interviewed about their relationship and issues with patients as well as their opinion about ongoing changes and issues in chronic care practices and technology.

The qualitative data analysis was inspired by grounded theory³⁵ and aimed at ordering data under emerging categories and topics. These spanned from data specifically concerned with certain activities (such as eating, cooking, self-medicating or doing sports), certain concerns (managing emergencies, travelling, trying new things) or interactions (either cooperative or conflicting, with medical experts, family members, co-workers or informal caregivers as well

as technologies such as glucose meters, journaling systems and so on).

For the purposes of analysis, all interviews and field notes were transcribed and processed with Nvivo. Only part of the material informs this paper. Reported names are purely fictional.

Chronic self-care in practice: everyday life and lay expertise

Dealing with a disease outside clinically controlled settings represents a very demanding task. In chronic disease especially, the traditional separation between the sick role³⁶ and the full participation of healthy individuals in society is not applicable, and the disease unavoidably gets entangled with the practicalities and the complexities of everyday life. The ubiquitous nature of a (chronic) disease is further complicated by the fact that it can be quite difficult to find a solution to a problem and stick with it because, as one participant remarked repeatedly, *it is never the same*. Therefore, control over the disease is always temporary or partial and self-caring becomes open-ended: there is always something new to learn or something unexpected to deal with. Even when an individual does the same things everyday and eats the same thing at the very same time, glucose readings may still differ. Aspects like stress, other illnesses and hormones can have a role to play and, as another participant put it: *you cannot measure those*. This aspect is even more prominent when a change of habits occurs in the life of an individual as a consequence of getting a new job, having a baby, moving into a new house, simply becoming apathetic or, as illustrated in the next extract, developing another disease or disorder:

Anne, diabetes type 1 patient: the eating disorder it's always tough to know when to inject because like I am bulimic so if you are vomiting, how many carbohydrates leave the body, how many carbohydrates stay in? If I take insulin it brings me into a low afterwards so you always have to be very careful in how much insulin you take because it affects you just like that.

[‡]Patients with diabetes were interviewed for an average of 90 minutes each. Their age ranges from 21 to 71 years, with five males and nine females. With the exception of two individuals being diagnosed <2 years before the time of the investigation, all the other participants were diagnosed more than 5 years before (one in particular was diagnosed 48 years before). Only one participant was using an insulin pump (which entails a different set of practices), while the rest of the sample was using more traditional injections.

This extract resonated with those studies (Mol,⁸ above all) that discuss how good (self-) care, and (self-) management does not see the *medical* as separated (if not opposed) to the *non-medical*: good care is instead hybrid. Resonating with Mol³⁷ this shows that disease, illness, technology, treatment and the practicalities of everyday life come together as a package, and we should study and deal with them in that way. Indeed, this is what many patients do. Due to the ubiquitous, open-ended and chronic nature of the disease, affected individuals (as well as some of their caregivers) unavoidably develop a form of expertise that is not necessarily opposed to a medical one (nor better, nor worse) but that derives from the need to integrate, appropriate, contextualize and compromise the medical and universal aspects of the disease with the complexity of everyday, mundane and personal activities. This expertise can be simply visceral (endogenous, primarily mediated by the body) or reappropriated (exogenic, primarily mediated by language and the patient's capability to understand biomedicine) and takes various forms such as planning skills to adjust self-medication to certain (foreseen or not) activities, learning how to interpret bodily signals or how to artfully integrate and appropriate new medical technology in everyday life.

Self-managing insulin intake

Self-managing insulin intake is a good illustration of the hybrid nature of knowledge and expertise developed in chronic self-care practices. To adapt insulin intake to daily activities, people with type 1 diabetes develop what we might call 'plans' that are the results of the accumulation of experience through personal adjustments and experiments (outside the medical gaze).

Seamus, one of the participants with a high level of expertise, describes these plans as conjectures regarding insulin injections and expected physical activities or food intakes. Every time he makes a plan (taking a walk, eating out, or playing football on a Sunday

afternoon) he needs to know his glucose level and to readjust his insulin intake to make it fit the planned activity. So for instance, if he plans to go out for a walk after lunch, he will need his glucose level a bit higher and so he will inject fewer units before his lunch. How few is a personal matter that has been learned through trial and error. Drawing on his eighteen years of experience, Seamus also discusses how he adjusts the insulin intake when his expectations about glucose level (based on his plans) are not met (e.g. glucose readings are higher) and need further readjustments.

Seamus, diabetes type 1 patient: 'Considering my age, weight and height I need to inject 1 unit to re-adjust a glucose level of 180, 2 units for 210-220, 3 units for 250 and so on...if I am sick however I need 2 units more regardless of my glucose readouts. If I am away my concern is to avoid hypos, so I am more careful with insulin. When it comes to sport my rule is that if my glucose is at 180/190 then I need sugar, if it is higher I need both sugar and 1 or 2 units of insulin...in fact, at least for me, if I do sport with high sugar then my level – paradoxically – does not go down. If you do not know your level, it is always better to have sugar: I prefer to risk hyperglycemia than a hypo...so I try to follow a plan, but I have to adjust every time I see I am over 180. But this works for me...adjustments and plans are highly personal.'

When asked about how he developed this knowledge or who supported it, he answered: *Nobody teaches you that, you have to find it yourself*. In recalling that period he mentioned the feeling of *being suddenly catapulted* into a new life. However, he then showed how the development of new expertise often had a social nature:

Seamus, diabetes type 1 patient: '...getting to know other people with the same condition... that helped a lot: seeing that some indulge in a social dinner without worrying too much, or in sport activities...that gave me confidence to try things'.

Observations in the support group confirm the social nature of the development of lay expertise. For instance, how to deal with 'the munchies' was considered an important topic

of discussion. It was interesting to see how almost all individuals in the group have their own way to deal with it, and so the conversation in the group often turns into a lively exchange of tips and recipes, often supported by the display of their journals. A peculiar one comes from Adam, a 70-year-old man with type 1 diabetes who, for instance, eats green bananas when he gets hungry outside meal-times: *while it contains a good nutritional value, a green banana has very little sugar*, he said.

Understanding one's own body

Unfortunately, changes in life or diet are not always under control, and becoming an expert in coping with the disease is often painful and nasty. The following extract comes from the above-mentioned participant who developed an eating disorder and clearly illustrates this issue:

Anne, diabetes type 1 patient: let's say if I had a *bad morning* I would probably not eat a lunch in order to prevent more vomiting, so in the afternoon then I can wait until my *body calms down* again, test then and whatever it is, react *then*, take *then* insulin which of course my doctor doesn't approve because she wants me to take insulin right with my food, I said no I'm constantly going low then which forces me to eat again and then I am back...you see?

This passage highlights not only the difficulties of dealing with such a problem and the lack of technical support to deal with it; it also reaffirms the problem of separating the *medical* and the *non-medical* in devising such supports. The unfortunate participant knows 'the theory', and she is rather knowledgeable about glucose levels, how insulin acts and its relation to carbohydrates. However, this knowledge becomes inseparable from her understanding of a *bad morning*, a *calmed body*, and *then*. Moreover, the extract shows how following a medical prescription based on universal assumptions (e.g. people do eat at lunchtime) is too simplistic and fails to adapt to the complexity and uncertainties of life. Although limited in her capability to control what is going on with her own body, she has at least learned

to wait and to let her body calm down even if she knows this will not be approved of by her doctor.

In the development of lay expertise, learning to interpret bodily sensations is indeed an important step (also shown by Wilson¹⁸). Many of the participants recalled this aspect during interviews, and it was also a topic for discussion in the support groups. An example comes from a participant who was trained in Germany, before moving to Ireland.

Martha, diabetes type 1 patient: Like when I was diagnosed they were all talking about hypos... and I said: 'put me into a hypo' I want to feel what it feels like before I leave the hospital. [...]

Although it may not necessarily be idiosyncratic, as argued by Davison *et al.*,²⁵ this knowledge is nevertheless subject to constant revision. This reaffirms the (already noted) open-ended nature of chronic care practices.

Ellen, diabetes type 1 patient: Also, sometimes it's difficult because sometimes you can get the symptoms of a hypo and your bloods would be fine, why is that happening now, so you're, sometimes you feel your blood sugar is racing down very fast you feel the hypo very late so you're very low already.

Fed by this lack of certainty, medical and experiential/lay entities are brought into relationship with each other to generate experience where expert knowledge is related to other ways of knowing the disease. The key use of the glucose meter in almost all of the examples discussed so far reaffirms this point. Indeed, the glucose meter turns out to be a key tool for everyone to make sense of certain sensations as they each learn to correlate certain feelings with high and low glucose readings. And so, while on the one hand the glucose meter imposes a medical perspective through the logic of monitoring and the emphasis on quantified values, on the other hand this logic is reappropriated and brought into relationship with various experiential and mundane aspects (making sense of a symptom, adjusting insulin to match a plan, readjusting insulin to correct a value after an activity, and so on).

Appropriating technology, producing personal data

In a previous work, I have discussed multiple ways in which individuals with a chronic disease appropriate self-monitoring technologies.³⁸ This appropriation is indeed multiple as it goes from the development of frantic overchecking in self-monitoring practices, to more productive ways to engage with the technology and make it fit one's own life. In this sense, affected individuals also (have to) become experts in artfully enmeshing the technology (a glucose meter or a diabetes journal in these cases) in a variety of different practices (from cooking to driving, from travelling to planning and adjusting insulin) and with heterogeneous material (from food scales to a *calmed body*, from a calculator to a bag to carry insulin while driving). The expertise of the patient also extends to the mundane aspects of managing the equipment and appropriating actual technology in use. This sort of articulation and an often-invisible work³⁶ is another key aspect in self-care practices, with important design implications. Indeed how to store insulin, to conserve it in unusual circumstances (abroad, or in a hotel with no fridge) or to carry it around were recurrent topics of discussion in the support groups, along with discussions about how to use the glucose meter and to journal personal data.

This last aspect turned out to be discussed in particular by participants who often complained about how frustrating they found their consultations with medical experts. To their eyes, the experts seem concerned only with a series of values that the patient is required to monitor. For the patient, many important aspects remain out of the picture and everything is reduced to what the doctors want them to journal. Indeed, while affected people might find it useful to journal different things (e.g. what they have eaten, for how long they ran, how they feel), this 'non-numerical' information often tends to be disregarded or overlooked by doctors who want their patient to just keep track of their numbers. When asked

about their journaling practices and what sort of extra information is written down, some of the patients (three, in fact) confessed that they simply hide their 'extra information' to their doctors – as illustrated in the following extract:

Gabriela: I type those [extra information] out for my doctor because if I handed that to her she would be like, what is this?? So she has a format where I just put in the numbers, I just put in the readings and the units. That's all! She doesn't want to know anything else. [...] She's not really doing her job properly; she doesn't look at what I eat. [...] Some doctors would make judgments on one reading.

Investigating this aspect, I discovered that some participants keep two separate logs in journaling their values, one for the doctors where they put what the doctor wants, and one for themselves with what matters from their perspective. Current design of glucose meters or journaling does not seem to give full voice to users' concerns and – more or less explicitly – reproduces a more traditional form of biomedical reductionism. Gabriela continues her explanation by bringing in her glucose meter and showing how a similar issue characterizes the design of her equipment as well.

'I got this new meter [...] (it) is supposed to do most of this for me but you see it has a log book, [...] you can enter your meals but you have to enter them as [...] amount of carbs, you can't say what it was just say 35 grams of carbs and then fibre, fat and protein. It's just very restrictive, it gives you, it's like multiple choices so you can't actually free write'.

Discussing the need to provide their doctors with numbers, one of the participants made the interesting distinction between those regular readings that a diabetic takes because their doctor asks them to (which he labelled as fetishes) and those readings that instead fit daily practices and that, for instance, support adjusting the insulin intake. In this sense, most of the current technological support affords this fetishization of biomedical data and acts as a normative barrier to personalization and the development of a patient's perspective and expertise.

As discussed, supports for self-care fail to address how the medical perspective and the lay expertise are inseparable and intertwined in practice and seem to simply and uncritically reproduce normative and reductionist logics that essentialize different types of knowledge: the scientific one and its lay counterpart. Differently from more traditional clinically controlled settings, where much work is done to separate the medical from the non-medical (not to mention the countable from the non-countable) with the key contribution of technology, self-care practices in chronic disease are hybrid and the produced knowledge is relative – not in the relativistic sense of the term, but because it is produced by bringing universal biomedical understandings into relationship with the everyday experience of the disease.[§]

Discussion: supporting the integration of lay expertise in chronic care

...Accurate knowledge must derive from affected communities. [...] Knowledge from affected groups is not merely another voice in a relativistic world. Instead knowledge is a counter-hegemonic force introduced by those who are usually excluded from science. Hartsock³⁹

In the empirical section, I discussed various forms of lay expertise that people with type 1 diabetes develop in dealing with the practicalities and intricacies of the disease: adjusting insulin intakes, understanding one own body, appropriating technology and producing lay data. Although neither clinical nor produced in controlled experiments, this expertise is key to dealing with the disease while at the same time maintaining an active social role (being a mother, an employer, a husband, and so on). In this sense, chronic care is not just a matter of attending medical prescriptions; it is populated by a variety of different elements, view-

points and voices: sometimes they align with one another, at other times they do not.

Rethinking data

The discussed case shows how elements that were traditionally purged from medical care practices in hospital and clinics – such as the perspective of affected individuals, the uniqueness of individual circumstances, or the complexity and uncertainties of clinically uncontrolled settings – are becoming key elements to the improvement of health outcomes and dealing with the emerging problems of our health-care systems. Indeed, as we attend to the patient's experience of the disease, the illness loses its exclusively medical character and becomes difficult to reduce, reify and fix into one trajectory, one language or one perspective, let alone an authoritative one.

Chronic care is a context where things that worked yesterday might not work today; things that work in the hospital might not work in a domestic environment; and things that work for the patient might not work for the doctor, and *vice versa*. In such a context, reducing the disease to a biomedical 'object' frustrates the experience of living with it and makes it difficult to support the patient's voice, perspective and expertise. This is because once a certain perspective (e.g. the clinical one) is assumed, then lots of other things get fixed: a language, a set of priorities and options, the specific circumstance for making a decision, what counts as relevant, what choices to make and how, when and in what terms to talk about an issue and so on. Authoritative knowledge (which acquires its character from the scientific and objective nature of its disciplined constituents assuming a spurious separation between the disease and the rest of life) simply acts as a barrier to the participation of the different voices (that of the patient *in primis*) that characterize chronic care.

Chronic care in clinically uncontrolled settings is uncertain, much is unknown, unpredictable and out of control. A normative and authoritarian attitude precludes looking at the

[§]In facing these challenges, we developed a design approach (Storni, 2013b⁴²) and a journaling platform enabling the personalization of self-monitoring practices in type 1 diabetes (Storni, 2013a⁴¹).

disease in different and multiple ways, and by doing so, it kills social learning and dialogues between different parties.[¶]

We have seen that patients need to constantly compromise between heterogeneous aspects of their life. They and their caregivers often need to act as investigators, experimenters and reflective practitioners with their own body and therapy, and in doing so, they develop a language, a capacity of diagnosis and various forms of expertise. To do this, they need to integrate and bring into a relationship different elements such as, for instance, certain physiological values to certain sensations, or plans, or uncertain circumstances. And sometimes the results might differ from the medical prescription: in everyday chronic care, numbers are important but not always and everywhere, and more importantly, not in isolation.

Thinking otherwise may result in leaving patients alone as they wonder about how to take control over their lives. Technology and policies can be of great help here, but developers and policymakers might need to rethink some of their assumptions. One first possible move towards improved chronic self-care supports for patient empowerment (that also suggested the development of a platform for the personalization of self-monitoring practices in diabetes that I discussed elsewhere^{41,42}) is to overturn yet another traditional opposition: that between hard and soft data (e.g. physiological values and patient accounts) that is core to this issue. Discussing this opposition, Berg⁴³ wrote:

These are not two wholly different types of data; rather, the difference is a gradual one. In fact, the argument that formal tools cannot deal with 'soft' data is nothing more than a tautology, since what we call 'hard' data are simply those data whose production has been disciplined. This disciplining is a highly heterogeneous affair; 'hard data' are robust only because so much

work has been put into stabilizing them. There is no intrinsic softness or hardness to data: what is measurable (and by what and who) is the outcome of the negotiation process involved in the construction and implementation of new diagnostic procedures ... (pg. 101)

This argument has clear implications for the reorganization of the delivery of health services and the support of chronic self-care (for implication about the design of technology see Storni, 2013a,b). It suggests acknowledging the need of new spaces that can account for the different voices and new tools that give visible form and expression to what is relevant from the perspective of the affected individuals. In their politics (*per* Winner⁴⁴), normative and reductionist perspectives – and the tools and policies that take those for granted – fix what counts as information, assume what should be attended to, privilege and discriminate, include and exclude. When things are known, the risks clearly calculated and the settings under control (as in the traditional acute disease-centric model and in institutionalized settings), disciplining and silencing in the name of hard data and objective science might be the best option. When things are much more complicated and open-ended and the settings are uncontrolled, however, the paternalistic strategy falls short and prevents dialogues and the generation of new knowledge about chronic care *in the wild*. As argued by Jasanoff⁴⁵, the danger of authoritative approaches is that we may end up working with 'conceptual models that seek to separate science from values, and that emphasize prediction and control at the expense of reflection and social learning'.

Conclusion

In this paper, I have discussed patient lay expertise in chronic care as key to addressing the growing impact of chronic disease in our society. Through the analysis of an ethnomethodological study of everyday self-care practices in diabetes type 1, I have described some forms of lay expertise that turned out to be key to self-care and that have the potential to rethink the way we

[¶]In this sense, even the recent emphasis on genomics and genetics in the rise of the so-called personalized medicine – which seem to carry the hubris of objective science – carries the same stamp and risk to generating the same issue. On this, see Kera and Storni⁴⁰.

think of chronic care and open new spaces for the development of new supports for real patient empowerment. Rather than unreflectively reproduce a biomedical perspective and its normative underpinning, design that supports the patient should be hybrid and equally support the different voices in play, even if this may mean bringing to the surface their inherent conflicts and differences (as in the case of conflicting journaling practices). Rethinking the traditional separation between hard and soft data (and so also rethinking the tools for their production and validation) is a possible first step towards new supports for better chronic self-care and, perhaps, an opportunity to know the diseases more fully/holistically. Indeed as Suchman⁴⁶ claimed: Technological change can [...] be an occasion for either the expansion of existing forms of authoritative knowledge, or for their transformation. At the core [...] is the question not only of how information flows, but of who defines what constitutes 'information' in the first place.

Acknowledgements

The author wishes to acknowledge funding support from the Irish HEA PRTL Cycle 4.

FutureComm (<http://futurecomm.tssg.org>) programme'.

References

- Bauer J, Ringel M. *Telemedicine and the Reinvention of Healthcare*. New York: McGraw-Hill, 1999.
- Wootton R. The development of telemedicine. In: Rigby M, Roberts R, Thick M (eds) *Taking Health Telematics into the 21st Century*. Abington: Radcliffe Medical Press, 2000: 17–26.
- Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA: The Journal of the American Medical Association*, 2002; **288**: 2469–2475.
- Wagner E, Groves T. Care for chronic diseases. *British Medical Journal*, 2002; **325**: 913–914.
- Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 2002; **48**: 177–187.
- Mol A. *The Logic of Care, Health and the Problem of Patient Choice*. New York: Routledge, 2008.
- Williams A. Changing geographies of care: employing the concept of therapeutic landscape as a framework in examining home space. *Social Science and Medicine*, 2002; **55**: 141–154.
- Orel T. Designing self-diagnostic devices. In: Buchanan R, Margolis V (eds) *Discovering Design*. Chicago, IL: Chicago University Press, 1995: 77–104.
- Schoor S, Lorig K. Self-care and the doctor-patient relationship. *Medical Care*, 2002; **40**: 11–40.
- Foucault M. *The Birth of the Clinic*. London: Tavistock, 1973.
- Macintyre S, Oldman D. Coping with migraine. In: Davis A, Horobin G (eds) *Medical Encounters: The Experience of Illness and Treatment*. London: Croom Helm, 1977: 61–72.
- Britten N. Patients' ideas about medicine: a qualitative study in a general practice population. *The British Journal of General Practice*, 1994; **44**: 465–468.
- Morgan M, Watkins CJ. Managing Hypertension: beliefs and the responses to medication among cultural groups. *Sociology of Health & Illness*, 1988; **10**: 561–578.
- Conrad P. The meaning of medications: another look at compliance. *Social Science & Medicine*, 1985; **20**: 29–37.
- Henwood F, Wyatt S, Hart A, Smith J. 'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health & Illness*, 2003; **25**: 589–607.
- Greenhalgh P. Patient and public involvement in chronic illness: beyond the expert patient. *British Medical Journal*, 2009; **338**: 629–631.
- Epstein S. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values*, 1995; **20**: 408–437.
- Wilson PM, Kendall S, Brooks F. The Expert Patients Programme: a paradox of patient empowerment and medical dominance. *Health & Social Care in the Community*, 2007; **15**: 426–438.
- Fox NJ, Ward KJ, O'Rourke AJ. The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science and Medicine*, 2005; **60**: 1299–1309.
- Prior L. Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health & Illness*, 2003; **25**: 41–57.
- Monaghan L. Challenging medicine? Body building, drugs and risk. *Sociology of Health & Illness*, 1999; **21**: 707–734.

- 22 Rabeharisoa V, Callon M. The involvement of patients' associations in research. *International Social Science Journal*, 2002; **54**: 57–63.
- 23 Barbot J. How to build an “active” patient? The work of AIDS associations in France. *Social Science and Medicine*, 2006; **62**: 538–551.
- 24 Arksey H, Sloper P. Disputed diagnosis: the cases of RSI and childhood cancer. *Social Science and Medicine*, 1999; **49**: 483–497.
- 25 Davison C, Davey-Smith G, Frankel S. Lay epidemiology and the prevention paradox. *Sociology of Health & Illness*, 1991; **13**: 1–19.
- 26 Barry C, Bradley A, Colin P, Britten N, Stevenson F, Barber N. Patient unvoiced agenda in general practice consultations: qualitative study. *British Medical Journal*, 2000; **320**: 1246–1250.
- 27 Cahill J. Patient participation: a concept analysis. *Journal of Advanced Nursing*, 1996; **24**: 561–571.
- 28 Opie A. ‘Nobody asked me for my view’: users’ empowerment by multidisciplinary health teams. *Qualitative Health Research*, 1998; **8**: 188–206.
- 29 Anderson RM, Funnell MM. Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator*, 2000; **26**: 597–604.
- 30 Oudshoorn N. Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology. *Sociology of Health & Illness*, 2008; **30**: 272–288.
- 31 Nicolini D. The work to make telemedicine work: a social and articulative view. *Social Science and Medicine*, 2006; **62**: 2754–2767.
- 32 Dubbeld L. Telemonitoring of cardiac patients: user-centred research adds input for surveillance theories. In: Lyon D (ed.) *Theorizing Surveillance: The Panopticon and Beyond*. Collumpton: Willan Publishing, 2006: 182–205.
- 33 Koch S. Home Tele-health: current traits and future trends. *International Journal of Medical Informatics*, 2006; **75**: 565–576.
- 34 Garfinkel H. *Studies in Ethnomethodology*. Oxford: Blackwell Publishing, 1967.
- 35 Glaser BG, Strauss A. *The Discovery of Grounded Theory*. New York: Aldine Publishing Company, 1967.
- 36 Parsons T. *The Social System*. Glencoe, IL: Free Press, 1951.
- 37 Mol A. Proving or improving: on health care research as form of self-reflection. *Qualitative Health Research*, 2006; **16**: 405–414.
- 38 Storni C. Multiple forms of appropriation in self-monitoring technology: reflections on the role of evaluation in future self-care. *International Journal of Human–Computer Interaction*, 2010; **26**: 537–561.
- 39 Hartsock N. *The Feminist Standpoint Revisited and Other Essays*. Boulder, CO: Westview Press, 1998.
- 40 Kera D, Storni C. Interfaces for Nutrigenomics and Nutrigenetics: connecting participatory design with citizen science projects. In: *Extended Abstracts of the Third International Workshop on Smart Healthcare Applications*, 2010, p. 14.
- 41 Storni C. Design for future uses: pluralism, fetishism, and ignorance. Proceedings of NORDES Design Research Conference, Marmo/Copenhagen, 2013a: 50–60. Available at: www.nordes.org/nordes2013/pictures/Nordes2013Proceedings.pdf, accessed 20 August 2013.
- 42 Storni C. Design Challenges for Ubiquitous and Personal Computing in Chronic care and patient empowerment: a case study re-thinking diabetes self-monitoring. Proceedings of NORDES Design Research Conference, Journal of Ubiquitous and Personal Computing, 2013b; published online 14 August 2013. Available at: <http://link.springer.com/article/10.1007%2Fs00779-013-0707-6>, accessed 20 August 2013.
- 43 Berg M. *Rationalizing Medical Work: Decision-Support Techniques and Medical Practices*. Cambridge: MIT Press, 1997.
- 44 Winner L. Do artifacts have politics? In: MacKenzie D, Wajcman J (eds) *The Social Shaping of Technology*. Philadelphia, PA: Open University Press, 1985: 28–43.
- 45 Jasanoff S. Technology of humility. *Minerva*, 2003; **41**: 223–244.
- 46 Suchman L. Practice based design of information systems: notes from the hyperdeveloped world. *The Information Society*, 2002; **18**: 139–144.