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Looking for Data in Diabetes Healthcare:
Patient 2.0 and the Re-engineering of Clinical Encounters[1]

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Diabetes is an interesting example of a healthcare sector where patients are responsible for producing and aggregating data about themselves, even if only for reporting details of their consultancies with specialists. This is valuable information because it orients the medical action taken on a specific patient and acts as the basis for aggregate-level investigations, and for new therapies and diagnostic procedures. The reliability, truthfulness, and accuracy of such information is therefore of crucial importance for healthcare practitioners; accordingly, being able to count on 'empowered' patients is the best way to obtain reliable, detailed, and updated data. Drawing on the results of a broader research project on diabetes services in Italy, the paper wants to address an essential feature of Patient 2.0: his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices. In doing so, we will underline the re-engineering of clinical encounters and the additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate data and information.

Keywords: diabetology, distributed and fragmented practice, doctor-patient interaction

Introduction

In the contemporary logic and rhetoric of patient empowerment, self-management and the delegation of a series of tasks and measurements traditionally associated with medical and nursing work constitute one of the most evident forms of the endeavour 'to enlist' (or involve) ordinary citizens in the management and organization of healthcare services. This alters the role of the doctor, who from someone who makes diagnoses and prescribes therapies

becomes a 'life manager' (Carricaburu & Ménoret, 2005) who intervenes in the everyday behaviour of his/her patients. But it also alters the role of the patient, who becomes, amongst other things, the convergence point of important medical information, technologies and practices, a steward of his/her own information (Halamka et al., 2008). Patients are responsible for producing and aggregating data about themselves, even only for reporting details of their consultancies with specialists. This is valuable information

because it orients the medical action taken on a specific patient and acts as the basis for aggregate-level investigations, and for new therapies and diagnostic procedures. The reliability, truthfulness, and accuracy of such information is therefore of crucial importance for healthcare practitioners; accordingly, being able to count on 'empowered' patients is the best way to obtain reliable, detailed, and updated data.

Drawing on the results of a broader research on diabetes services in Italy, the paper wants to address what we claim to be an essential feature of Patient 2.0: his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices. In doing so, we will also underline the additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate data and information, an often overlooked issue in optimistic versions of the re-engineering of clinical encounters (May, 2007).

The medical sector has not been chosen at random. Diabetes is an interesting example of a healthcare sector where patient empowerment has become prominent: self-management is seen as a key determinant of health outcomes and there is scientific evidence for its importance in regard to treatment efficacy and the quality of diabetes care (Heisler et al., 2003). Indeed, people with diabetes are required not only to shape a therapeutic plan but also to develop competences, together with a certain kind of commitment, in self-monitoring their glycaemia levels. In this regard, we shall also see that technological objects and artifacts are constitutive (Garfinkel, 1967) elements of self-monitoring and of doctor/patient encounters, so that clinical relations can be conceived as a materially heterogeneous, fragmented, and distributed practice.

The conceptual framework of our analysis consists of the diversified body of analysis that has developed at the interface between Science and Technology Studies (STS) and the contemporary sociology of medicine (Berg, 1997; Berg & Mol 1998; Mol, 2002; Timmermans & Berg, 2003), the essential features of which will be outlined in the next section.

Medicine, Technology and the Re-engineering of Clinical Relations

Opening the black box of medicine, STS have led to frame medical knowledge and practice as a process of aligning and mobilizing heterogeneous elements (data, laboratory tests, doctors, patient, healthcare structures, policy decisions). In medical practice, scientific knowledge and technologies dictate clinical criteria, diagnostic techniques, and therapeutic options, while being transformed in their turn. Not by chance, the initial study of 'medical practice as technology' (Casper & Berg, 1995) has evolved over the years into study of the 'practice of medical technology' (Timmermans & Berg, 2003), thereby further demonstrating that medicine has acquired the features of a technology in itself (Elston, 1997).

It can be stated in particular that research has divided between two trajectories, which, though interrelated, have different nuances:
a) the role of diverse tools (software, guidelines, protocols) in the 'rationalization' of medical work (Berg, 1997; Timmermans & Berg, 2004). Focusing on the use and alternation of instruments makes it possible to show how they embody different configurations of what 'medical practice' is, what 'science' is, and what constitutes 'rational' medical knowledge. The most general process is the one whereby medical practice and instruments reciprocally construct each

other: the development of instruments is inextricably bound up with the emergence of (and competition from) new forms of medical rationality, just as a new instrument establishes the boundaries between what is 'rational' and medical practice itself. To summarize, protocols, clinical guidelines and decision-support technologies are the means by which medical knowledge and its exercise are rationalized (Berg et al., 2000; Moreira, 2005).

b) the processes of relational materialism and heterogeneous engineering (Law, 1987, 1994) that embody medical practice. In evident continuity with an actor-network theory approach (Callon, 1986; Latour, 2005), technologies, drugs, organizational devices, and infrastructures are all seen as elements embedded in a heterogeneous network of relations with other instruments, practices, groups of actors, and types of professional expertise. From this perspective, the body and subjectivity can be seen as the effects of a network of heterogeneous materials (skin, bones, enzymes, cells, clothes, machines, and so on) – an ordering process catalogued as a 'person' (Law, 1994: 33). The different branches of medicine, in fact, each with its techniques of inquiry and consolidated knowledge, contribute to constructing different medical representations of the body (Berg & Mol, 1998; Mol, 2002; Berg & Akrich, 2004). In other words, if a body 'holds together', this depends not on some type of coherence internal to the body (which precedes the knowledge produced about that body), but on the fact that the different coordination strategies adopted have been able to re-assemble and align a multiplicity of versions of reality (Mol & Law, 2002: 10).

But how do these processes re-engineer clinical relations? Various researches have sought to highlight the main shifts occurring, focusing for example on the introduction of electronic patient records, telemedicine services and, more in general, the plethora of new medical technologies and the ways in which they act in healthcare systems and practices (Lock, Young & Cambrosio, 2000; Brown & Webster, 2004; Hyysalo, 2010). Carl May, in particular, argues that doctor-patient relationship is no longer a dyadic and 'private' encounter, but a 'corporate' one. In fact, contemporary medical technologies, together with technocratic management interventions, re-engineers clinical encounters, 'as systems and practices become increasingly oriented around the collection, collation and distribution of evidence and information about individual clinical histories and epidemiology' (May, 2007: 35). Moreover, the doctor-patient encounter takes place in a much more complex and dispersed organizational network, where 'the doctor' is just one of the many organizational interfaces patients encounter. Because of protocols and clinical guidelines, doctors themselves inhabit an increasingly governed terrain, so that also the assumption of the doctor-centred clinical autonomy is partially displaced (May, 2007).

An exhaustive survey of this ramified corpus of studies would fall outside the scope of this article. Before describing our research, however, there is a study that should be briefly recalled, both because it introduces the case examined in what follows, and because of its analytical standpoint, which resembles the one that we adopt.

In an outstanding article on the 'body-we-do', Mol and Law consider the case of hypoglycaemia and glycaemic control:

> So how is hypoglycaemia done? A first important mode is, indeed, by knowing it. Knowing is a practice: it only

becomes possible to talk about 'a blood sugar level below 3.5 mmol/l' if someone's skin is pricked, a blood sample is taken, and its sugar level is measured. This used to happen in the laboratory. A technician would puncture a vein, collect some blood in a small tube, insert it in a machine and read the outcome. This still happens, but it has been joined by another measurement practice. Since the necessary machinery has been miniaturized, people with diabetes can now carry it round with them and measure their own blood sugar levels. They prick a finger-tip and squeeze a drop of blood onto a measurement stick. The stick is put into a slot in the machine and within a few seconds a number is displayed. (...) Pricking the finger may hurt, the number may take some while to appear – and so on. (...) But measuring your blood sugar level is also difficult in a management meeting (...) or if you are shopping in town with your friends; or if you are teaching a class of children. Nevertheless, it is possible to measure one's blood sugar level in a clean kitchen or in the bathroom – that is, in a location in which circumstances are as well tamed as in a laboratory. In this way hypoglycaemia may be enacted as a blood sugar level below 3.5 mmol/l. (Mol & Law, 2004: 45)

We thus see how it is possible to frame hypoglycaemia as a materially heterogeneous practice that involves bodies, texts, machines, organizational devices, and other socio-material processes in its performance. This idea will serve as the background to almost all the research examples that we present below, together with the idea that medical knowledge (and practice) is distributed, fragmented and shared between (Bruni et al., 2007):

- the patient, who brings knowledge about his/her body and sensations to the consultancy;
- the doctor, who translates the patient's subjective knowledge into elements of 'scientific' knowledge through its conversion into medical terminology and a narration of the patient's state of health;
- the medical community, within which the various participants learn the systematic use of medical vocabulary and application of a professional vision (Goodwin, 1994);
- the organizational rules and medical protocols, which based on segmentation of the therapy and intervention processes into a sequence of micro-actions;
- the technologies and the objects that participate in the activity and constitute its setting.

In light of the idea of medicine as a materially fragmented and distributed practice, we shall show the ecology of actors, relations, artifacts, knowledges and situated practices involved in diabetes check-up encounters, focusing in particular on the additional work required to doctors and nurses in order to 'check-up' not only the patient, but also the data s/he brings with her/him.

Methodology and Research Context

The research was conducted in 2009 at four diabetology services located in various parts of Italy (north and islands). Access to the field has been facilitated by personal relations of one of the two authors with a few diabetologists, together with a previous professional collaboration he had with the Italian Association of Diabetologists. Although present in clinical encounters, the diabetologists agreed not to reveal the identity of the researcher to patients and

to 'secure' ethical aspects by making all the data anonymous.

At each centre the observation lasted for an entire working week, following doctors and nurses involved in patients' clinical examinations and taking the form of a 'focused ethnography' (Knoblauch, 2005): short-term field visits; data/analysis intensity; audio recording; focus on selected activities; continuous coding; and sequential analysis of notes and transcripts.

The observation covered a total of 141 clinical examinations among check-ups in doctors' surgeries and in the diabetology department. Free and semi-structured interviews were conducted with 22 of the 30 subjects (doctors and/or nurses) encountered at the diabetology centres. Then examined was the use of diagnostic instruments (such as the glucometer to check glycaemia levels), together with the common documents (such as clinical reports and laboratory test results) patients carry with them.

It should be borne in mind that diabetes mellitus is a complex chronic disease: the toxicity caused by the high level of glucose in the blood affects various organs and parts of the body (heart, limbs, eyes, nervous system), for which reason it is not always possible to identify a major lesion to a specific organ. This requires the systemic and synergic management of the patient, with the involvement of different medical specialities and diagnostic-therapeutic technologies.

In this process, a diabetes patient is required not only to shape a therapeutic plan, but also to pay attention to habits and lifestyle and develop competences in self-monitoring glycaemia levels. The glucometer and the glycaemia logbook are the main instruments involved in patient disease self-management[2].

In the sections that follow, we shall look closely at the use of both these tools and the practical meanings that they assume in managing a patient's disease, analysing two particular activities that take place during a check-up: inspecting the paperwork, and verifying the relations among patient, tools, and his/her lifestyle.

Check-up Patient 2.0: Re-engineering Clinical Encounters

The periodic check-ups conducted on people with diabetes consist largely in the collection (by the doctors and/or nurses) of the data brought by the patient. The objective for the diabetology team is to update the patient's clinical record with new data and to compare these with the previous ones.

It may therefore seem that the task of doctors and nurses is merely to gather/compare data so to have an updated dataset from which to draw information on the patient and his/her specific case. Management of the clinical encounter, however, is much more complex than this, because it also involves a series of activities performed to gain a picture which is broader than that performed by data and medical technologies.

Inspecting the Paperwork, Reassembling the Network

An activity often performed by nurses (as in other situations of complex diseases/therapies) consists in ensuring that the patients' paperwork is 'in order'. In the waiting room, the nurses check the 'completeness' (as they used to say) of the patients: that is, whether they have brought their medical reports, test results, and any other documentation that may furnish information necessary for the evaluation and adjustment of the glycaemic control. In fact, medical reports, test results, data, and information may be missing for various

reasons. The most common are that patients are more or less cooperative, and therefore take (or do not take) the tests and check-ups in time for the next diabetological examination; or that patients, even if cooperative, have been prevented by circumstances to have the required tests taken (e.g., when specialist examinations prior the date of the appointment with the diabetologist).

Other reasons are due to the action of specialist. It often happens, in fact, that the diabetologist interviews a patient (and, if need be, the person accompanying him/her) to understand what has happened during examinations by other specialists. In short, the diabetologist scrutinize the information that s/he receives from the patient, how it has been produced, who has participated in its production (practitioners, relatives, diagnostic instruments), what other points of view and knowledge have been added or lost in the process.

Inspecting the paperwork is therefore not the mere collection of information to update the patient's clinical record. Its purpose is to reconstruct the dynamics in which particular recommendations, prescriptions, suggestions, and so on, have been made. Provided as an example is a case where a specialist (cardiologist) requests suspension of one of the therapies prescribed by the diabetologist. The reason for the request is not immediately clear to the diabetologist, who therefore asks for further information:

> Doctor: Sorry, but I haven't quite understood what happened during the examination, why... you see, it's written here that I should stop the therapy.
> [The doctor reads out the cardiologist's recommendations]
> Patient: I don't know.
> [The doctor turns to the patient's daughter, who has accompanied him]
> D: Were you there during the examination?

Patient's daughter: No, my mother went, but she told me that it was a young doctor, not the chief consultant we usually go to.
D: Wasn't Doctor [name] there? Who was it?
[the examination report has been stamped with the name of the chief consultant, but the initials are indecipherable].
Daughter: I don't remember if my mother told me, but I can ring her if you want.
D: No no, it's not important...[turns to the patient]...but can you remember what he said?
P: He told me that I'm really not right, he looked at the analyses, first they did an electrocardiogram and then...
[his daughter shows the electrocardiogram trace]
D: But do you remember why he told you that you weren't all right? It's not that he's written very much, and I'm beginning to think that the person who examined you didn't look very carefully, because for me you're not so bad, though not extremely well, which is normal in cases like yours, let's say... anyway, I don't see the reason for stopping this therapy... unless he asked for some clinical tests to be done and temporary suspension of the therapy... do you remember if he said something like that?
P: Well, he said that I should come back so that the chief consultant can see me.
D: When?
P: In a month.
D: Did he give you any other tests to do?
P: Yes...the twenty-four hour test.
D: It's not written here...he forgot to write it. So I think he wants to do a check...All right, so I'll suspend this [drug], but be sure to call me if you feel that something's wrong.

It is not rare for specialists to omit information from clinical reports (due to carelessness or for some other reason), thus delegating to patients the task of bringing such information to other clinical contexts. Whence derives the importance of another figure, that of the 'companion', who can help reconstruct what happened during the specialist examination. Not coincidentally, in the above example, one of the first questions that the diabetologist asks the patient's daughter is whether she was present at the last specialist examination and the fact that there had been a change of companion emerges as a potential cause of the loss of important information (to the point that the patient's daughter offers to telephone her mother, who had been present during the specialist examination).

Therefore, the different 'papers' that the patient brings to an appointment are not always (by their nature) exhaustive, but require additional work by the diabetologist: reconstruction of the situation in which the data have been produced and interpretation of the logic behind them. Far from a purely rational model of approaching problems, doctors and nurses are accustomed to weighing up data, distinguishing between 'old' and 'new', between data produced by 'us' (the diabetology team) and by 'others' (general practitioners or specialists who have examined the patient), as well as between the recommendations of an experienced doctor and those of a novice. Here we see emerging the bricolage work doctors and nurses are accustomed to in order to keep up clinical data coherently[3] and 'sort things out' (Bowker and Star, 1999), as well as the situated logic they seem referring to in order to plan future actions.

The diabetology team is particularly interested in understanding the nature of anomalies among values – as when there is a mismatch between the glycate values[4] and the glycaemic pattern recorded by the patient. In the following example, the patient is relatively young (under 40 years old) and was diagnosed as diabetic only a few years ago. The nurse notices the mismatch and alerts the diabetologist:

> Nurse: Doctor, there's something here that doesn't match.
> Doctor: What?
> N: See, the glycaemic pattern in the logbook is good, but the glycate doesn't correspond to the average.
> D: Did you do the test with his glucometer [i.e. whether comparison has been made between the patient's and the clinic's glucometer to verify whether the values coincide].
> N: Yes, we did that... and it was in order.
> D: How long have you had diabetes?
> P: I was diagnosed with it three years ago.
> D: How are the test results?
> Nurse: Good.
> [the nurse hands the test results, the logbook and other sheets of paper to the doctor]
> D: Yes, not bad...how have you been feeling lately?
> P: Not bad, I'd say good, at times I get a bit tired.
> D: What's your job?
> [the doctor begins to enter the data into an electronic clinical record]
> P: I work at the Post Office.
> D: Are you always indoors? Do you do any sport, or at least go for walks...do you take exercise?
> P: Yes, at the office...well, yes, I sometimes exercise, but I don't do any sports.
> D: Have you been to the dietician lately?
> P: No, but I've kept to the diet prescribed some time ago.
> D: Right...where's the ferritin? You need to keep check on it...do you eat lots of legumes and red meat?

[the diabetologist enters the patient's electronic record and looks at his family anamnesis]

P: Yes, I like them a lot and the dietician told that they're good for you...I also eat vegetables, like tomatoes and stuff with vitamins.

D: I'm beginning to understand...listen, the problem is your iron intake, go back to the dietician after these tests and get him to look carefully at the diet you're following.

[the diabetologist stops entering data into the computer, and then write a request for a series of laboratory tests on the clinical report]

D: You need to do some blood tests... have there been cases of iron deficiency or excess in your family?

P: My father has had problems, but I don't know exactly...

D: Can you find out?

P: Yes, my mother will know for sure.

D: Well if you could find out, so next time we'll add it to your profile...in the meantime we'll do this iron test and check out your liver. For now we'll leave it like this...I can see from the logbook that things are going well...even if the glycate is no use today, the rest of the values are fine. Carry on like this, then let us have the information from the laboratory and your mother as soon as possible.

The nurse directs the doctor's attention to the discrepancy between the glycate level and the glycaemic pattern, stressing that the body's response does not match the values recorded. The first doubt raised by the doctor concerns the patient's glucometer, but the nurse has already compared glucometers and can confirm that the instrument used by the patient is reliable. Moreover, there seems to be no doubt concerning the truthfulness of the logbook and/or the patient's capacities: he shows himself to be competent and cooperative, and his logbook is accordingly judged to be reliable. The diabetologist then follows up on an intuition. He notices that the value showing the concentration of iron in the patient's blood (the ferritin) is missing from the laboratory test results. He then obtains further information from the patient about his iron intake and looks for additional data in the family anamnesis (present in the electronic patient record). Still lacking reliable data for a diagnosis, he asks the patient to take some tests; have his diet reassessed by the dietician; and consult a nonclinical source (his mother) to ascertain any family problems with iron intake.

In both these situation, the purpose of inspecting the paperwork is to collate fragmented data and items of knowledge: the clinical reports and laboratory test results; the information accumulated about the patient; the knowledge of the patient himself; that of his family members; that of other specialists; as well as that of the diabetologist and the nurses. From a material point of view, this collation work requires the doctor to move among artifacts of different kinds and technical complexity (the electronic clinical record; the glucometer; laboratory test results; the patient's logbook), distributing his action among the different elements at his disposal (as when he removes his gaze from the computer screen to write a request for laboratory tests on the patient's clinical report). Moreover, note that these same artifacts are in the hands of patients: it is them who use the glucometer, who write the logbook and who brings into medical encounters tests results and specialists' recommendations.

In this process, we can see how checkup encounters are constructed through a network of heterogeneous actors, elements and bodies of knowledge, where the patient becomes the main point of convergence of clinical information, tools and practices.

Clinical encounters therefore also interweaves with verification of the relation among patient and instruments.

Verifying the Relationship among Patients and Instruments

The main technology available to patients to attain and maintain a good state of health is the glucometer, a device that measures the concentration of glucose in the blood. However precise, the glucometer may be subject to anomalies and malfunctions, for which reason (as also seen in the previous episode) one of the first things that doctors and nurses do when they notice discrepancies in a patient's data is to compare the glucometer used by the patient with that of the clinic (in order to ensure that it is working properly).

Together with the glucometer, comes the glycaemia logbook where patients have to take note of their glycemic values. If the logbook is not regularly and properly compiled, the work done by the glucometer becomes useless.

Although very different from a technical point of view, the two artifacts are essential to each other and so is their correct 'maintenance'. In most of the cases, patients are perfectly aware of this, but nevertheless they sometimes try to delegate to one of these two artifacts the demonstration of the impossibility of carrying on self-monitoring:

> Doctor: Why have you stopped record-ing the glycaemia?
> Patient: The machine doesn't work, it's not my fault.
> D: Why doesn't it work? Let me have a look at it...have you got it with you?
> P: Certainly, here it is [takes the glucom-eter out of her bag]... here it is, see? I turn it on and it flashes like this.
> [the doctor looks at the glucometer's display panel]

D: Listen Mr [surname], how long have you been using this model?
P: Since when you gave it to me!
D: When was that?
P: Just over a year ago.
D: And this has never happened before? [the doctor points to a symbol in the lower-right part of the glucometer dis-play] You see this symbol here...?
P: Yes...
D: The symbol is saying that the strips that you're using have expired...that's why the glucometer is flashing, because it knows that the strips are no good, so it won't let you do the tests unless you use new strips... You've done too few tests in the past months...and you can see it...if I count how many results you've written here [pointing at the glycaemia logbook] and then if I count how many strips are left, I can immediately see that you've actually done at most half of the tests written down. Let's be clear about this: you have diabetes, I know how to keep it under control, but if you're not serious about checking it, I can't do anything. Giving me fake data doesn't help me to help you, using the glucometer like this doesn't help either of us... these strips expired a month ago, you've got one month of strips left over... more than thirty tests which haven't been done.... and you have the good fortune of not using insulin and having to do only a few tests... but if you carry on like this, there's the risk of insulin dependency and four tests a day... is that what you want?
[The patient is silent]
D: I'll let you have some more strips, but you must use them as I've told you. I'll also get the nurse to explain clearly what the [glucometer's] symbols mean, so that the next time you won't be stopped by a trivial notification like this...

The glucometer automatically verifies expiry of the strips, so that one month before the expiry date, a message appears on the display panel to warn the user that the strips are about to expire. After that date, an error message appears, and it is no longer possible to perform tests. The doctor is somehow sure that in one year this occasion must have happened before and that the patient should be able to understand that there is something wrong with the glucometer, but it is in the logbook that he finds the confirmation of his suspicions (checking the number of strips together with the number of tests written). It is clearly one of those well known situations in which the 'thing' to be repaired is the user rather than the machine or, better, the relationship between the user and the machine (Orr, 1996; Suchman et al., 1999). In fact, when the diabetologist realizes that the problem is not a malfunctioning of the device but the patient's reluctance to its use, he shifts the discourse from the disease to individual responsibility (for instance, by telling the patient that incorrect glycaemia measurements may make the disease worse). In these cases, the disease becomes a property ('*you have diabetes...*'), whose state and progress partially depend on individual behaviour. In this sense, the doctor is not simply telling the patient how to use (correctly) the glucometer, but begin morally lecturing him, stressing the central role he, the patient, plays in the treatment of his condition ('*I know how to keep it under control, but if you're not serious about checking it, I can't do anything. Giving me fake data doesn't help me to help you, using the glucometer like this doesn't help either of us*').

This kind of moralizing comes into play every time doctors and/or nurses envisage the risk of examining 'fake data'. Sometimes patients refer to the (supposed) malfunctioning of the glucometer, but at other times they try to stack the logbook, in order to avoid reproaches for their conduct (and inaccurate production of data), as in the following example:

Nurse: Mr [surname], already here?
Patient: Why? Isn't it my day?
N: Well, we saw you just a while ago, what's happened?
P: My glycaemia. isn't right...I told my GP...
N: ...and he sent you here. I see...can you show me what you've brought?
P: What do you want...it's nothing more than a month and a half ago.
N: Okay, but can I see the logbook?
P: Whatever you want, here it is!
[The patient takes the logbook out of his shoulder bag and hands it to the nurse. The nurse looks at it]
N: I can't understand much from your logbook...You don't seem to have written it up properly.
[The nurse notes the presence of suspiciously 'round' numbers in the logbook, and a linear trend in the glycaemia levels, as well as invariably the same colour of ink and apparently 'continuous' writing. All of this suggests that the glycaemia logbook has not been used properly, and that it has probably been compiled a posteriori, before going to the doctor. The nurse shakes the diary as if to say that the data are fake, and turns to the patient]
P: What's all this about the logbook, it's me you should worry about!
Nurse: That's what we're doing, and as best as we can, but we can't help you if you don't help us. [...] It's you who has to carry out the treatment...we can help you with it, but you must get on with it.
P: Yes, all right, we'll see what the doctor says.
N: In the meantime I'll tell you what you need to do...you've got to keep close

check on your glycaemia, measure the values correctly and transcribe them, so that you can adjust the dose and follow the diet better...

A peculiar professional vision (paying attention the colour of the ink, the type of hand-writing, the invariably 'round' glycaemia values) permits the nurse to understand that the patient has not kept the logbook appropriately. Treating it as a form to be compiled prior to the examination and thus avoid reproach, here the patient uses the logbook as a legitimizing tool. In a quite paradoxical way, it is like if he recognizes the relevance of the logbook and, at the same time, dismisses it with his conduct. In this way, even more paradoxically, the main tool ought to be a reference point for detailed information translates in an additional source of unreliable data and interferences. This is due to the fact that the logbook is the main linkage between everyday self-management and medical practice and patients (in order to be 'accountable') need to show the doctor they act responsibly. Thus, filling out the notebook, not just living healthy, becomes a primary concern for people with diabetes[5].

As in the previous example, the nurse takes further action to repair the relationship between the patient and its logbook, mainly adopting the same kind of moralizing practice we have seen deployed by the doctor before. Interestingly, she uses more or less the same words as him[6] ('*we can't help you if you don't help us. [...] It's you who has to carry out the treatment... we can help you with it, but you must get on with it*'), signalling the typicality of patient's behaviour, as well as of clinicians' response.

We can see here the glucometer and the logbook as expressions of both the process of delegating (Latour, 1992) bits and pieces of activities to non-human actors and the stretching out (Nicolini, 2007) of medical

practices in space and time. What is peculiar here, by the way, is that, once in the hands of the patient, the glucometer and the logbook become occasions for a further delegation and stretching out. That is, the delegation to the glucometer of the impossibility of carrying on self-monitoring and the stretching out of the logbook in terms of a legitimizing instrument of individual accountability.

Moreover, however much doctors and nurses remind patients that they must make correct use of technologies and medicines, blunting the effects of habit or the so-called 'hunger effect' requires further work, as emphasised by a diabetologist specialized in the dietary education of patients:

> For the insulin therapy to be effective, it's necessary to organize an educational programme based not only on CHO counting[7] but also on the development of specific algorithms for adjustment of the insulin dose so as to off-set possible hyper or hypo-glycaemic episodes. This science (so to speak) sometimes suffers from patients' habits, especially when they assess the glycaemic index in relation to portions. If they are in the habit of using household measures, rather than more accurate ones like scales...with the ingredients measured uncooked...there's certainly no lack of personal interpretations of the glycaemic load. In fact, there are cases of people who, even though they've taken the course (...) keep on getting the quantities very wrong...a spoonful, a handful, or a glassful are always much more than the normal. I don't know if they do it on purpose or because they're hungry, but sometimes the portions are almost double. Habit leads them astray in the calculation.

This comment shows that correct management of the therapy mobilizes not only the glucometer but also other scientific instruments (such as an algorithm for counting carbohydrates), which are in their turn associated with further 'domestic' instruments (scales, for instance). This interplay of associations produces a delicate balance between self-monitoring and glycaemic control: patient's habits in counting are not always associated with the precision required by correct exercise of the scientific practice related to carbohydrates schemas and prescriptions, so that they may jeopardize (upstream) the accuracy of the calculations made (downstream). And also weaken the alignment of self-care instruments that support the Patient 2.0 and contribute to the re-engineering of clinical encounters.

Conclusions

Focusing on check-up encounters in diabetology, in this article we have sought to show an essential feature of Patient 2.0 That is, his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices.

'We can't help you, if you don't help us', doctors and nurses used to say in many occasions, in order to recall patients' attention on the importance of their collaboration for the assessment of the therapy. Note that this is something that goes beyond the issue of patients compliance: the expectation is not simply that the patient will responsibly follow doctor's indications, but that s/he will actively engage in the production of core reliable data. From this point of view, trying to transform patients in 'stewards of their own information' (Halamka et al., 2008), Patient 2.0 is supposed to be a diagnostic agent in him/herself.

This may imply the use of medical instruments such as the glucometer and artifacts such as the glycaemia logbook, the relationship with other clinicians and/or the support of family members[8]. All these elements materialize around two main activities characterizing clinical encounters in diabetology: inspecting the paperwork and verifying the relations between patients and instruments. Here, it takes place an evaluation of the reliability and the accuracy of the data brought by the patient, together with a delicate work aimed at linking fragmented and contextual items of knowledge together and, eventually, moralizing the conduct of the patient. This is so, because data are performative (Bowker, 1994; Mort and Smith, 2009): they account for the situation of the patient and compel doctors to take further action. Not only, in the case of Patient 2.0 they also account for patients' behaviour (in private), their willingness to collaborate and their skills regarding the use of medical technologies (as seen in particular in occasion of the verification of the relation among patients and instruments).

In other words, in the case of Patient 2.0 data 'overflows': they are not merely about the patient's clinical condition but they become significant also in terms of patient's capability, responsibility, virtues and habits[9]. We see here how the 'interactivity' which characterizes Patient 2.0 leads to a paradox: patient empowerment also implies empowerment of the doctors and other healthcare practitioners, who besides making diagnoses and prescribing therapies, must now decipher (and make clearly accountable) the process of production and use of the data patients bring to clinical examinations. In this sense, Patient 2.0 is not necessary an enhanced patient, but the effect of the constant, invisible work (Corbin & Strauss, 1994) made by doctors and nurses in order to keep coherently together bits and pieces of information.

Finally, the constant reference to technological objects and artifacts of various kinds is constitutive of both Patient 2.0 and the re-engineering of check-up encounters. From this point of view, it is peculiar how sometimes clinical encounters focus on the way these (mainly, the glucometer and the glycaemia logbook) are 'administered' by patients. This means also that Patient 2.0 is supposed to be able to develop medical and technical expertise, so to 'help' instruments to work correctly.

Consequently, in the case of Patient 2.0 clinical encounters are *de facto* re-engineered:

- the production of reliable data is highly dependent on the patient;
- medical tools and technologies are in the hands of the patient;
- doctors and patients are equally caught in the web of production, management and administration of data and technologies.

Patient 2.0 inspires further investigation regarding the shifting of accountability for the production and management of clinical data, together with deepening the understanding of the hidden and additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate the overflowing of data and information.

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Notes

1 This article is the result of a collaborative effort by the two authors. If, however, for academic reasons, individual responsibility must be assigned, Attila Bruni wrote section 1 and the Conclusions; Carlo Rizzi wrote the Introduction and section 2.

Section 3 was written jointly by the two authors.

2 The former is a diagnostic tool measuring the concentration of glucose in the blood; the latter is a form of medical report compiled by the patient.

3 We are grateful to an anonymous reviewer for this nice suggestion.

4 Glycated haemoglobin is an indicator of the average level of glycaemia in the previous 2-3 months. This average reveals whether and to what extent the patient has maintained good metabolic compensation. This value is part of the 'glycaemic target' which the patient must achieve and keep below a certain threshold.

5 Again, here we thank an anonymous reviewer for having highlighted this.

6 These episodes were recorded in two different centres.

7 CHO counting is a practice taught to patients involving calculation of carbohydrate intake.

8 As nicely noted by an anonymous reviewer, referring to a different medical context, Levinson (2010) has underlined how techniques of documentation can translate a macro discourse into a local practice.

9 For the last time, we thank an anonymous reviewer for having suggested this.

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