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"One day it will be you who tells us doctors what to do!". Exploring the "Personal" of PHR in paediatric diabetes management

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THEMED ISSUE

“One day it will be you who tells us doctors what to do!”. Exploring the “Personal” of PHR in paediatric diabetes management

PHR in
paediatric
diabetes
management

421

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Abstract

Purpose – Personal Health Record (PHR) systems make possible to integrate data from different sources and circulate them within the illness care and management network. The new arrangements prefigure a redefinition of the relations among healthcare practitioners, patients, and caregivers. The purpose of this paper is to consider the role and the meanings attributed to information when a technical artifact enables new forms of communication within the healthcare management network.

Design/methodology/approach – The authors adopted a qualitative research design, conducting a pre-post analysis on a theoretical sample of patients and of a paediatrics department. The authors selected 12 patients (six females and six males) aged between four and 20 years old.

Findings – The patients were willing to act as “stewards of their own information” (Halamka *et al.*, 2008), but they interpreted this role in terms of restricting access to their information, rather than facilitating its dissemination. In fact, the PHR was symbolized as an instrument to support personal diabetes management but the patients want to preserve their own competence and independent management on the information regarding their “Personal” diseases.

Originality/value – This work highlights two connotation of “Personal” information. The first is the dimension of the right to the privacy of information when it is believed that it may be used to pass judgement on the patient. The second connotation of “Personal” is the assertion by patients of their competence and autonomy in interpreting the information on the basis of personal knowledge about their diabetes.

Keywords Information management, Technology adoption, E-health, Computer supported collaborative work (CSCW), Shared knowledge, Telemedicine

Paper type Research paper

1. Introduction

PHR (Personal Health Record) is an acronym which in the past ten years has joined the large family of health information technologies alongside much better known abbreviations such as EMR (Electronic Medical Record), EPR (Electronic Patient Record), EHR (Electronic Health Record), CCR (Continuity of Care Records), and others besides.

The present paper is a totally collaborative effort by two authors. If, however, for academic reason individual responsibility is to be assigned, Enrico Maria Piras wrote paragraphs 1, 5, 6; Alberto Zanutto wrote paragraphs 2, 3, 4.

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Compared with these, the novel feature of the PHR is that its intended user is the patient/layperson and not a professional caregiver or a clinician. It furnishes the former with an electronic repository of his/her data and the possibility and responsibility to manage and share the information among members of his/her care network. PHR receives increasing attention from a broad array of stakeholders (policy-makers, health-service managers, healthcare personnel) that envisage positive returns from the inclusion of patients in the production and management of their own health information – activities from which they are usually excluded. The expected benefits concern the prospect of enabling patients to become stewards of their health data (Halamka *et al.*, 2008), on the conviction that this will improve doctor-patient communication, reduce the fragmentation of healthcare systems, empower patients and informal care networks, and restrict access to sensitive information. In this regard, since the advent of the new forms of agency made possible by patient-centred technologies, some authors have begun to speak of “Patient 2.0” (Danholt *et al.*, 2013). Such expectations are founded on the belief that patients, caregivers, and healthcare personnel are interested and willing to find new forms of collaboration, and that technology can induce them to do so.

In a context characterized by the increasing delegation to patients of self-management of their health, PHRs assume an importance that transcends the technological dimension. They become tools for the redefinition of care networks, the roles and of the competences of doctors and patients, and, overall, the meaning itself of health-related information.

Patients, in fact, often have systematic forms of personal health information management. They maintain files and keep track on information concerning their health (Moen and Brennan, 2005; Østerlund *et al.*, 2005; Civan *et al.*, 2006; Piras and Zanutto, 2010). Whether the data collected by patients consist of parameter measurements not requested by doctors, self-produced logbooks, or personal observations, they are used to take decisions relative to their health; but only rarely they are shared with healthcare personnel. PHR systems make it possible to integrate data from different sources and circulate them within the care network. The new arrangements prefigured by the introduction of PHR systems offer an interesting standpoint to study the redefinition of the relations among healthcare practitioners, patients, and caregivers.

In this study we consider a specific aspect of such relations: the role and the meanings attributed to information when a technical artifact enables new forms of communication within the healthcare management network. How is it circulated and who interprets it? What happens when diverse actors have access in real time to the same information, and who has the task of interpreting it?

In order to answer these questions, we examine an experimental scheme for type-1 diabetic patients of paediatric age and their families. For this purpose, we flanked the process of the system’s design and analysed the meaning of information before and after its introduction.

In the next section, we review the studies that have addressed the topic of personal health information management. In the following sections we describe the context of the technological experiment and the methodological design of the social research. The findings will be organized into two sub-sections, presenting the framework of personal data management before and after the introduction of the PHR. Finally we discuss the processes triggered by the implementation and use of the new technical artifact which will lead us to reflect on the notion of “Personal” information.

2. Background and related work: health information management across boundaries

Healthcare institutions have undergone major infrastructural changes intended to generate a seamless web of information. Technology has transformed the health services by constantly changing the boundaries among competences and enormously increasing the information systems used in organizational settings (Østerlund, 2008) and the information conveyed and made available in the various healthcare networks (Zuiderent *et al.*, 2003; Mort and Smith, 2009); by redistributing tasks and responsibilities within them (Vikkelsø, 2005); and by participating in the construction of fragmented knowledge systems (Bruni *et al.*, 2007). Besides the systems devoted to healthcare professionals, there has been a proliferation of systems designed to enable the latter to communicate with patients. This has generated interest in the boundary which separates doctors/nurses and patients, organizational spaces and personal spaces, and in how information is produced, managed, and exchanged across that boundary. The abandonment of paper-based supports for digital ones enables a new relationship between patient and doctor in which face-to-face encounters become increasingly infrequent and the co-presence of a complex network of persons, technologies, practices, and care spaces becomes increasingly common (May, 2007; Langstrup, 2013). The central topic addressed by studies on the matter is technological support for chronic pathologies (Dorr *et al.*, 2007; Brennan *et al.*, 2009), spaces in which intersect the objectivizing representations of the health practitioners and the meanings that the patients attach to their experiences.

The debate on telemonitoring offers insights into the tensions and negotiations that centre on the meaning of information when it crosses the boundary of the context of production (the patient and his/her sphere) to reach the doctor. Telemonitoring tools are generally designed with rigidly distinct competences and roles in mind. The patients or caregivers are assigned the role of contributing to the production of information, and the healthcare personnel that of interpreting it. The patients are not only actively engaged in integrating the tools into their everyday routines (Piras and Zanutto, 2013), and in becoming competent users of them, but they also assume the role of “diagnostic agents” (Oudshoorn, 2008; Andersen *et al.*, 2011). The patient’s personal and contextual knowledge, relegated to the background and not considered by the monitoring technology, regains importance and is essential for interpretation of the instrumental data with additional information (Bruni *et al.*, 2007). Nevertheless, however, significant the contextual and personal information furnished by patients and caregivers may be, their contribution is rarely considered. It is the part of care articulation work that is invisible and not represented (Oudshoorn, 2008; Unruh and Pratt, 2008; Piras and Zanutto, 2010).

As noted by Moser and Law (2006) information does not travel unchanged between one place and another; rather it is altered, and so too are the contexts of production and reception. In the case of electronic logbooks what is altered is not so much the physical space as the relational one, so that the monitoring work required of the patients increases (Danholt, 2013) or space for questioning the relationship with the healthcare practitioners. Winthereik and Langstrup (2010), for example, show that future mothers who use an online maternity record interpret it as a tool with which to verify the actions of the doctors, rather than as an instrument for monitoring and information interchange among the doctors. Other studies concentrate on how self-monitoring logbooks contribute to processes of identity redefinition by supporting the

“homework” required to manage the data necessary to check the parameters strategic for the patient’s illness (Aarhus *et al.*, 2009).

The logbooks become tools used by patients to locate themselves and make themselves accountable in regard to the prescriptive rigidities of the doctors; but they are also spaces for description of one’s specific condition and of the adaptations made necessary by it (Aarhus *et al.*, 2009). They enable patients to redefine their identities, to renegotiate power relations with the doctors, and to become experts on their illness (Ballegaard *et al.*, 2008). This comes about because, as Mol writes, these management tools “do more than just passively registering the act” (Mol, 2000, p. 9). They are essential parts of the process that enables patients to become autonomous from the doctors by behaving like them, internalizing medical practices and adjusting their view on the data and measurements.

According to these studies, logbooks can help patients achieve this objective because they make the information more integrable with everyday activities. But apparently insufficiently explored are the meanings of the data, nor do these studies give adequate salience to how the meanings of the data shared with the doctors can change perception of the disease and modify control and monitoring strategies.

In this work we shall concentrate on what happens when PHR systems are introduced. In contrast with telemonitoring systems or logbooks (or online logbooks), PHRs are tools for the management and sharing of not strictly clinical information which mixes laboratory data, self-measurements, and observation of daily living – more in general, everything that the patient considers relevant to his/her state of health (Weitzman *et al.*, 2009; Markle Foundation, 2004). PHR, on the one hand, allow patients to record personal information of interest, and on the other, allow evolution of the traditional diaries and personal clinical logbooks: these are replaced by software applications so that the patient’s monitoring data can be shared online with the doctors.

In what follows we shall explore how these tools enter the doctor/family members and patient relationship, paying particular attention to the relevance of the information collected and how it is managed. What meanings does it assume for patients and doctors? What opportunities are created, and what ambiguities and conflicts may arise?

3. Research context

Type-1 diabetes is a metabolic disorder characterized by an instability of glycaemia in the blood caused by the destruction of the pancreatic cells. It causes a deficit of insulin which must be corrected by injecting synthetic insulin into the organism several times a day. Over time, the management of diabetes has changed radically from a prescriptive and rigid regime of strict diet and constant insulin therapy measured periodically, to increasingly flexible self-management models based on the patient’s self-assessment of his/her state of health several times a day with the consequent insulin correction. This model has been made possible by the increasing availability of patient-controlled technologies for diabetes self-management (glucometers, urine ketones testing kits) and for insulin self-dosage (insulin syringes, pens, pumps). In turn, this flexible model requires self-measurement of the glycaemia level, calculation of the amount of carbohydrates in food, estimation of glucose consumption in the day’s various activities, adjustment of physical activity, and systematic management of insulin doses.

Between 2010 and 2012, the paediatrics department of the main hospital of a region in north-eastern Italy and a research institute active in the field of ITC innovation in healthcare engaged in a joint project to create the “Diab-PHR”. As an integrated system for self-care and telemonitoring, Diab-PHR consists of a logbook application for patients’ smartphones (the PHR) and a dashboard for data visualization for doctors and also accessible to family members. The aim of the experimental scheme was to determine whether paper-based logbooks for patients could be replaced with an electronic instrument, and to test forms of remote monitoring by doctors.

In the department considered, patients are examined at three-monthly intervals[1]. Some days before the examination, a blood test in the hospital laboratory measures the patient’s glycated haemoglobin (HB A1c). This enables the doctors to estimate the quality of glycaemia control over the past two to three months. The clinical interview involves evaluation of the blood test results, analysis of the day-to-day measurements recorded by the patient during the previous months in his/her paper-based logbook, and adjustment of the therapy if necessary. During the interval of time between examinations, the doctors have no information about the patient’s self-management unless the family (or the patient him/herself) contacts them by telephone or e-mail. Diab-PHR offers an alternative to the paper-based logbook whereby patients can keep track of all the information relative to their diabetes (measurements, therapy, symptoms, annotations) and share it with the hospital doctors.

The electronic logbook responded to the need to monitor the actual management of the pathology due to the scant reliability of the paper logbooks. According to the clinicians, many patients compiled their logbooks irregularly and frequently relied on memory to do so, completing the missing information with invented data. This conviction was backed by a rich stock of anecdotes in the department about patients discovered compiling their logbooks in the waiting room, or about data incompatible with other measurements[2].

The experimental scheme consisted of a first phase assessing the use made of the digital logbook by the patients or their family members, and during which the data were not made accessible to the clinicians. The second phase involved implementation of the remote monitoring functionalities, so that the data in the digital logbooks could be accessed by the doctors. During this second phase, the dashboard was endowed with a system of rule-based alarms designed to alert the clinicians to the presence of certain data or combinations of them.

4. Research design and methodology

We conducted pre-post analysis on a theoretical sample identified jointly with the clinical referents in the paediatrics department. Selection was made of 12 patients (six females and six males) aged between four and 20 years old (the average age was 12). The selection criteria were the following: at least some years’ experience of managing the disease; onset of diabetes before the age of six; close compliance with the prescription to keep a paper logbook; a relatively stable clinical condition. Diabetes onset in pre-school age made it possible to analyse the progressive autonomization of the young patients in management of the disease. The age range selected furnished us with subjects belonging in every age bracket and at different stages of the educational process (nursery, elementary, lower-secondary, upper-secondary school) and with increasing life-spaces outside the home and away from direct control by the family (school, sports activities, evenings out with friends).

The first phase of the research took place before the introduction of Diab-PHR. Its purpose was to understand the practices, places, and artifacts related to the management of clinical data by doctors and patients before the technology came into use. The doctor/patient relationship was investigated with participant observation during the examinations (five sessions, one per week). Personal diabetes management was studied through semi-structured interviews with patients, their family members, and key informants (15 interviews lasting around one hour). The interviews were conducted with the persons who usually cared for the diabetes patient: the autonomous diabetics were interviewed on their own; in the case of children and teenagers one or both of their parents were also involved; for the youngest ones, only the parents were interviewed. On conclusion of the interviews, the preliminary analysis made of the field materials was presented to the doctors in the department. The discussion that followed, and which was audio-recorded and transcribed, made it possible to collect comments and observations which became an integral part of the empirical basis of this study.

Moreover, development of the prototype was followed by participation in the project meetings between doctors and developers. Collected during these actions were photographs and documentation relative to instruments for the production, management, and sharing of the information (glucose metres, paper logbooks, clinical records) that was used for the artifact analysis.

Examination of the data from the context analysis highlighted the central role in coaching and supporting patients and families performed by the local diabetes associations, leading us to include three key informants belonging to them. They were adults with type-1 diabetes and a long history of collaboration with the hospital department: the president of the local sports association of diabetic patients; a psychologist who worked with the doctors at the school camps for children and teenagers; a young organizer of the local association for families with diabetic children.

Some months after delivery of the prototypes a second round of interviews (semi-structured and lasting around half an hour) were conducted with patients and their family members, the purpose being to assess the use of the technology by patients/family and their expectations in regard to the remote monitoring system.

All the interviews were recorded and transcribed. Fieldnotes were made after observation and meetings. The material was coded using template analysis (King, 1998), a qualitative analysis technique which consists in the prior creation of labels (templates) which guide segmentation of the text. The work on the texts guides the analysis and leads to the refinement and creation of new labels. The themes that guided construction of the template originated from the five dimensions addressed by the interview outline:

- (1) division of labour in the management of information among patients, family members, and health-care personnel;
- (2) methods and tools for the collection and management of information;
- (3) intersection between information management practices and everyday life;
- (4) modes of information-sharing in the care network; and
- (5) role of personal information in the clinical encounter and in the relationship with the doctor.

5. Findings: personal health information management between paper and the PHR

The next two paragraphs will report on the two phases of the analysis describing the personal health information management before (Section 5.1) and after the introduction of Diab-PHR (Section 5.2).

5.1 *Artifacts and information between the clinic and everyday life*

The onset of diabetes obliges the patients and their family members to recast their lives in their entirety. The diagnosis requires them to begin a learning process which will persist for the rest of their lives, and in which the production, collection, management, and analysis of information is crucial.

To understand the context in which Diab-PHR was to be introduced, we observed this learning pathway by following the patients, their family members, and the instruments used to manage the disease through some significant episodes: first admission to hospital and coaching; home and periodic clinical examinations; school and spaces for independent life.

5.1.1 Hospitalization and coaching: the information overload and the pact with the family. The diagnosis of diabetes and the first admission to hospital constitute a turning point in the life of a diabetic child and his/her family. At these moments, which are often emergencies, new relationships are formed among the patient, his/her parents, and the hospital department.

Hospitalization lasts a week on average, and its immediate purpose is the patient's clinical stabilization. In regard to information management, hospitalization is the time when the family members receive their first training and tasks are allocated within the care network. The parents enter the hospital department convinced that diabetes only means that their child will not be able to eat sweets. This idea is swept away by what the interviewees called a "bombardment with information":

Your state of mind is that such a huge change has taken place that you're bewildered. You can't understand what's happening to you. They explain the glycaemia curves, the insulin curves to you, and you're confused. You feel that you haven't understood anything and you'll never be able to manage the disease (Father, interview no. 1).

On the child's discharge from hospital, the parents leave the department having familiarized themselves with the material artifacts (e.g. glucometers, logbooks, insulin pens) and concepts (e.g. hypoglycaemia, hyperglycaemia, glycaemic curves, glucose rebound effect) necessary for management of the disease. They realize the magnitude of the change not only from the entry of these instruments and from the difficulty of incorporating them into their lives, but also from the broad re-symbolization of everyday objects and practices, which must now be viewed through the lens of the disease and which require new abilities of interpretation. Parents develop new way to observe their children, whose moods and mood swings, tiredness and lethargy are legible in terms of glycaemia levels on which to intervene pharmacologically or nutritionally. The parents are taught that food, by quantity and type, alters the glycaemia level, as do physical activity, stress, or influenza and menstruation. The child's physical sensations become indicators of his/her state of health to be verified with glycaemia measurement.

Education about the disease is accompanied by a precise division of tasks between the doctors and the family that, as we shall see, is of fundamental importance in explaining the scant acceptance of some Diab-PHR functionalities. The tasks of the

doctors are long-period monitoring with three-monthly examinations, management and evaluation of the disease's systemic effects. But their principal task, from the perspective of most interest here, is the education of patients and parents in regard to ordinary diabetes management. In fact, the parents must follow the child's everyday condition by measuring the glycaemia (from four to seven to eight daily measurements), calculating the caloric content of meals, adjusting insulin doses, and supervising physical activity. The hospitalization is used by the doctors to educate the family. It does not conclude until the doctors are satisfied that the family has acquired sufficient learning and can handle the most common situations, and that the division of tasks in the family is satisfactory:

[...] [during the first hospitalization] the parents are taught how to measure the glucose level, because they want both parents to be able to do the subcutaneous injections when the child is discharged, because it shouldn't be only the mother who is the "bad guy", and because it's always possible that one of the parents may be away (Mother, interview no. 7).

The training of the parents is accompanied by an invitation for them to keep track of relations between everyday events and glycaemia levels, identifying subjective connections. This invitation takes the form of two messages. The first is that every patient is unique, and that there are "as many types of diabetes [as there are diabetics] because no one has exactly the same symptoms" (informant, interview no. 1): they have different reactions to the therapy, to food, to mood, and even to the weather. The second message is that the routine of managing the disease will lead to a reversal of roles between doctors and parents: it will be the latter who explain to the former the characteristics assumed by the disease in the body of their child.

The paper logbook is located in this context of relationships. Given to the parents by the department when the child is discharged, the logbook is the main linkage between everyday management of diabetes and clinical practice. It is used to record the glycaemia measurements and the quantities of insulin, it also has a space for notes (see Plate 1). The logbook serves to anchor the parents to everyday management of the disease, so that they can keep track of glycaemia levels and report them to the doctors.

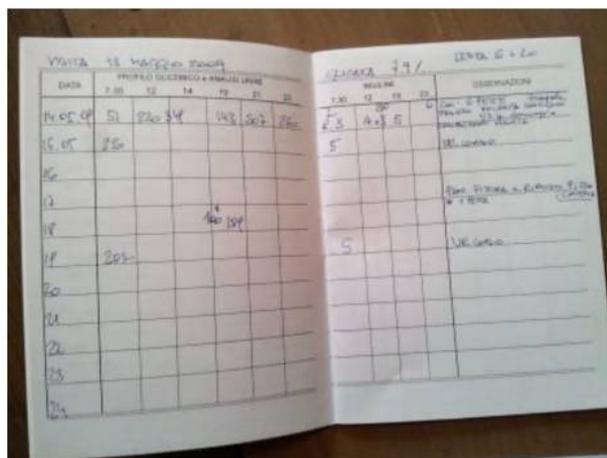


Plate 1.
Paper logbook provided
by the hospital

5.1.2 *The home and periodic examinations: the symbolization of information and domestic practices.* The return home entails a large series of changes made so that the patients and their parents can adapt to the disease and incorporate it into the family routine. This happens through a process whereby what is familiar (e.g. food, mood, tiredness) is observed through new eyes – partly constructed in the relationship with the department – which require constant comparison among previous experiences, bodily sensations, and measurements. With the return home, families begin daily practices of personal health information management which involve first adoption of the department logbook, and then its abandonment for self-produced tools better suited to tracking glycaemia levels and their relations with everyday activities:

The doctor gave us a logbook, but it was too small. So I made one myself according to what we needed. I record the amount of insulin that we give her, what she eats, physical activity, and add other notes (a cold, a cough, if she's been to a party, etcetera). Here I mark the glycaemia levels during the day. In practice, there's the week overview on the insulin doses and the week overview on the glycaemia values (the blue ones are high, i.e. 180 upwards, the red values are the low ones below 80, and the grey ones are correct) (mother, interview no. 2) (Plate 2).

Abandonment of the department logbook and the creation of a personal one highlights the incongruity between the instructions given by the doctors and the tools furnished by the department. Whilst the doctors stress the importance of paying attention to numerous aspects of everyday life, the logbook only allows the recording of strictly clinical data (glycaemia and insulin). Creation of a personal logbook confirms the family's decision to take in charge the disease and integrate it into everyday routine. Whereas the department logbook is designed to facilitate consultation during the clinical encounter and to make the family's management of the disease accountable, the purpose of the self-produced logbook is to meet the family's need for information, to establish relations between events and the state of the disease, and make decisions on the therapy or the management of everyday commitments. Hence the logbook

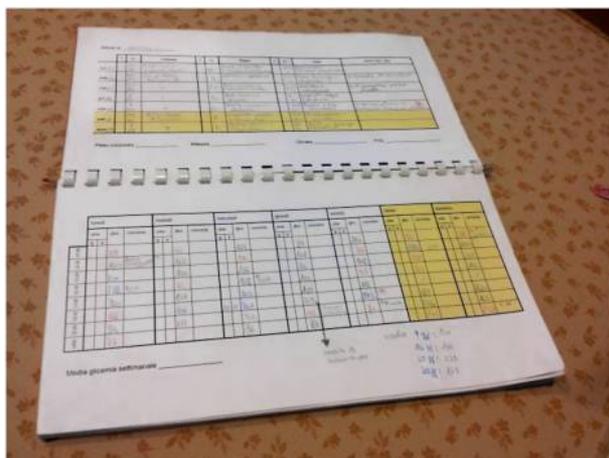


Plate 2.
Family-designed
paper logbook

becomes a resource for the retrospective reconstruction of the clinical history and at the same time a basis for decision making:

Practically every day I leaf back through the logbook to understand what to do. It lets us see how we managed the glycaemia on the day when we ate the same thing that we're going to eat today, so that we can adopt the best strategy (father, interview no. 1).

The switch to a self-produced logbook signals that the information has been collected and organized more for the family than for the doctors, who will be required to make the extra effort of understanding the logic adopted by each individual family. Every self-produced logbook differs from the others in terms of the information that it contains, modes of visualization (vertical or horizontal, colours to indicate hyperglycaemia and hypoglycaemia), and the presence of free text and annotations. The logbook kept by the family is not intended for the periodic clinical examinations, although it is also used in those contexts. The wealth of information that it contains and the memories that it calls to mind during the clinical encounter make it an instrument furnishing much more information than can be managed during the 15 minutes allotted by the hospital to examinations.

The methods and instruments for the management of diabetes information confirm the progressive emergence of the perception that the family's knowledge is superior to that of the doctors with respect to everyday management of the disease – as stated by the doctors during the first hospitalization. On this hinges a redistribution of roles between the department and the family. In light of interpretations of the data collected and its own experience, the family decides whether and how to respond to the instructions given by the doctors:

We record everything. The doctors know the theory but not the practice. So you have to adjust what they say to your particular case. The instructions they give are not always the right ones for you. You may have to alter something. It may happen that they tell you something: for instance, give her a cracker in the case of hypoglycaemia. But the cracker acts after two hours. So at that moment what you need is a sachet of sugar, which has an immediate effect. A fruit juice, for example, may contain more sugar than is required, while a sachet of sugar is enough (father, interview no. 1).

The implicit redefinition of the pact between the doctors and the family is approved by the former, who acquire the role of long-period managers, leaving everyday matters to the family. In regard to information management, this entails that the doctors concentrate on the long-period glycaemia indicators (glycated haemoglobin, High Glucose Blood Index, Low Glucose Blood Index) and on counselling, while the information relative to measurements and data annotations collected day by day is interpreted and managed by the family.

5.1.3 The school and everyday life-spaces: autonomy and controlled management. The progressive autonomization of children in their diabetes management follows a pattern closely linked with the acquisition of broader independence from the parents corresponding to entry into the education system or change of school, attendance at all-day school and use of the cafeteria, the start of regular sports activities, and the beginning of more intense relationships with peers outside school. On following these events, one observes a progressive responsabilization that leads from total dependence to the performance of routine operations (measurements, insulin injections) under strict supervision, to autonomy in therapeutic management (insulin dosing), and finally to the end of parents day-to-day monitoring and a full independency.

The autonomization process can be described metaphorically as a series of “leaps” preceded by preparatory “run-ups”. These leaps forward consist in acts of emancipation necessary to respond to the new life-situations that mark the maturation of children. They are preceded by more or less prolonged preparatory periods during which the parents act as educators who stimulate the child’s learning with constant work on the information contained in the logbook:

In the evening, when we do the logbook, we see if we have done everything right, or if we should have used more or fewer insulin units. This work, which we do together, has helped her manage on her own. For instance, the school cafeteria once changed the menu at the last moment, pizza instead of pasta, and she knew how to adjust the dose by adding half a unit of insulin (mother, interview no. 8).

Besides the programmed leaps, prepared with the assistance of the family, there are those induced by the introduction of new technical devices. Diabetes management practices are closely bound up with technical artifacts. A change in the latter can produce interruptions in the way that information is produced and shared in the care network, increasing the patient’s independence from the family. This applies in particular to all those patients who have changed from insulin dosage with pens to insulin pumps, which are attached to the body and gradually release insulin through a cannula and allow the injection of extra doses if necessary:

He’s been able to manage the insulin pump right from the first day. At the beginning [the patient was 10 years old] I also helped, but now he’s excluded me. He only calls me when he hasn’t got time to fill the pump or re-set the system (mother, interview no. 6).

The last step towards independent management is autonomy in compilation of the logbook or, to be more precise, the conclusion of control by the parents. This action is particularly closely supervised by the parents, and it is the last task that they continue to perform even after they have transferred pharmacological management of the disease. Compiling the logbook is described as a practice in which the patient participates with the parents. The constant presence of the latter appears to be the factor that allows the practice to be reproduced over time.

With self-management, compilation of the logbook becomes more sporadic. The transition to greater independence reduces its perceived usefulness. When the logbook loses its connotation as an instrument for information sharing and accountability to the family and the doctors, and becomes a mere reminder, the young patients describe its compilation as less useful, and as significantly less important than the ability to process information and make the necessary adjustments to daily routine:

Before every meal you have to do a finger stick and according to the glycaemia do one unit more or one unit less of insulin. Then, as soon as I wake up, I do a finger stick, if it’s under 100, I don’t do the insulin injection. If it’s above 150 I do an injection, and if it’s above 200, I do two. I drink a cappuccino and eat two slices of bread with jam. I go to school. Mid-morning I do a finger stick, and if I’m okay I eat some biscuits or drink a coffee. I go home, I do the stick. Depending on what’s for lunch I do a unit less of insulin. Same thing for my afternoon snack. I do the stick and I eat some fruit. The same thing for supper (patient, interview no. 2).

5.2 The PHR in the hybrid network and prefiguration of the telemonitoring system

Diab-PHR was introduced in this consolidated texture of relationships. Some months after its entry into use, the experimenters were interviewed to understand the use of the instrument and its role in mediating information in the care network. We shall now

concentrate on information management, evidencing the role of the PHR in facilitating the greater autonomy of certain patients, and in the perception of the telemonitoring system as intrusive and as a breach of the original care pact.

5.2.1 Diab-PHR as an instrument for self-management. The introduction of Diab-PHR was accompanied by redefinition of information management responsibilities within the family network. The transfer of responsibility from parents to children took place with consignment of the logbook application. On that occasion, the parents told the developers of the system that it would be the children who used the device (the only exceptions being two children of pre-school age). They justified the choice on the grounds that they had scant familiarity with new technologies, and that the children needed to become autonomous and more aware.

The interviews carried out some months after consignment of the device evidenced, on the one hand, satisfaction with the instrument among the young patients, and on the other, delegation by the parents to the children of the task of managing the logbook.

The satisfaction of the patients was mainly due to their perception of exercising greater control over their diabetes because of the immediacy of identifying trends and values on which to concentrate attention, thanks to the visualization of the data time series. Moreover, the application furnished the experienced eyes of the patients with information necessary to estimate the glycated haemoglobin trend. This is the main indicator used by the doctors during the clinical encounter to evaluate control of the disease. It therefore furnishes further information for self-evaluation and anticipation with respect to the interview with the doctors.

Use of the application allowed radical change to be made to the modes and timing of data management, which became an individual-interstitial activity and lost the characteristics of cooperative-planned work that it had previously possessed. Data entry no longer had a definite space-time frame (“In the evening, when we do the logbook, [...]”) (mother, interview no. 2) characterized by a family ritual. Instead, it was part of the flow of everyday activities (“I may enter the data from the evening before in the morning on the bus, and the morning data in the afternoon”) (daughter, interview no. 2).

The handover of responsibility stimulated by introduction of the electronic logbook was even more marked by the simultaneous reduction of the role of the parents in analysis of the data:

She’s entirely independent. We have complete trust in her. She’s able to manage it on her own. After a while we were reassured because we saw that she was ready. She knows that it depends only on her. At this age, it’s right that they should acquire awareness (mother, interview no. 8).

We’re relaxed about it. If she tells us that everything is all right, okay. Every day we ask her how it’s going. First the diary set my mind at rest, then she’s shown great maturity (mother, interview no. 5).

Also testifying to this change was the lack of use of a webpage set up to visualize the data. This tool had been designed to give parents constant access to the information without having to use their children’s application, and by means of a technology with which they were familiar (web browser). However, apart from some test accesses by a handful of parents at the beginning of the experimental scheme, the tool had been entirely ignored.

5.2.2 Telemonitoring as a breach of the therapeutic pact. The project for development of the system envisaged that the technical test of the logbook would be followed by

a second phase in which the experimental telemonitoring scheme would enable the doctors to read the logbook data through a dashboard and be alerted by a rule-based system. Prefiguration of the consequences of this innovation was a central topic of the second interviews.

The doctors and developers considered this functionality to be a merely technical channel of communication with the family. Patients and parents, however, considered this tool an unwanted factor in redefinition of their roles. Two areas of potential tension emerged in regard to the division of the diabetes management tasks between the department and the family established during the first hospitalization and confirmed during the three-monthly examinations.

The first element was the perception of having lost control over the data, which were regarded as integral and private parts of a person's identity. In doctor-patient and patient-family relations, clinical information is not neutral; rather, it is emotionally connoted as a judgement that transcends the clinical dimension and concerns the personal sphere. With the onset of diabetes, its "correct" management – as testified by the glycaemia levels and by the glycated haemoglobin value – is perceived as a factor used to evaluate the individual and his/her abilities, personal and parental, just as usually happens with educational performance:

There's always this sentence that I will never forget: either you're good or you're not good! There's a good patient, and there's a bad one. So that being good means having good glycates. How can you say that a person is good on the basis of his or her glycates? (informant, interview no. 1).

Compliance with the diabetes management model proposed by the department, and as testified by the data, became a motive for pride, frustration, or shame according to the case and the life-period. In this context, one understands the efforts made by patients to impress the doctors with faked or even entirely invented logbooks, or ones which patients claimed that they had lost. Some interviewees regarded a logbook constantly accessible to the doctors as an intrusion into their private space and, in any case, as a signal of scant trust in them and therefore as stigmatizing:

I believe that for some parents it can serve [...] to keep check on negligent ones [...]. We always call when we have doubts. The doctor knows us, and she knows what we're like. We always write everything in the diary (mother, interview no. 2).

The second cause of tension concerning the division of tasks between doctor and family/patient was the automatic interpretation of the data by a rule-based system which alerted the doctors according to parameters determined by a set of guidelines. In this case, the families and patients were sceptical about the applicability of general rules to their specific cases. For example, one rule established that an alarm would be triggered if glycaemia measurements exceeded 300 for two consecutive days. However, in the experience of the parents and patients, this sequence of values was not worrying if the cause was known. In the case of a highly emotional patient, for example, an event that caused excitement could easily produce such values:

When they had the surprise party for the teacher's birthday, her glycaemia went up to 396. If she has high values (like 396) and I understand the reason, I don't have problems. For her birthday, I expect two days of high values, because that's the way she is (mother, interview no. 3).

For the interviewees, the sequence of values that set off the alarm did not in itself constitute a complete set of data on which to take action. They believed that

responsibility for the most appropriate interpretation should remain with the family or the patient, since they alone had all the information necessary to decide whether medical intervention was necessary. Even when glycaemia readings reached alarm levels, the respondents did not feel the need for a medical consultation if they could understand the cause and had strategies with which to reduce the values to an acceptable level:

I believe that the alarms may be for those that don't know what to do. If she has 200 (glycaemia) for three or four days and we know that it depends on the period, then it's corrected, and I see that we can manage everything well (mother, interview no. 8).

Moreover, in some cases, reliance on a rule-based system to interpret the data was perceived as potentially harmful. Indeed, some parents thought that a banal (for the patient) set of events might induce the doctor to change a functioning therapy:

It only takes a cold, the period, or anything else and she immediately goes up to 200. If this information reached the doctor, she would change the therapy, but it wouldn't be necessary because there's a reason for it (mother, interview no. 8).

6. Discussion and conclusion: about the "Personal" of PHR

The research studied the process and effects of the introduction of a PHR for the management of type-1 diabetes in children and designed to provide the patients and their parents with a self-care tool and telemonitoring functionalities between them and the hospital department. We analysed information management practices and the meanings attached to them within the care network before the system's introduction. We then observed the sense-giving processes enacted to incorporate the new artifact into everyday routine and life-spaces.

The management of diabetes and handling the relative information are segmented practices distributed in a network. Such practices take shape as two processes of task allocation within the network. The first process is the macro-division of tasks between the department and the family. It begins during the first hospitalization and is confirmed with the periodic clinical examinations. This process is very rapid, and it sharply distinguishes the everyday management activities which pertain to the family (e.g. glycaemia measurements, calculating insulin correction doses, physical activity) from the long-period monitoring, which is the responsibility of the department (e.g. analysis of the glycated haemoglobin values, periodic controls on the disease's collateral effects). This distinction assigns different tasks of information collection, management and interpretation between the department and the family. The second process is the progressive delegation of responsibilities for information production and management from family members to the children. This process is slow, and it proceeds in leaps generated by external events.

The analysis has shown how introduction of the PHR has accompanied these processes. On the one hand, it confirmed the existence of a domain of competence autonomous from the doctors. On the other, it was an opportunity to increase the "Personal" dimension in diabetes management by the young patients with respect to their family members. This challenges certain scenarios envisaged by medical informatics, and according to which the PHR is mainly a tool for information-sharing within the healthcare network, suggesting that it can also be used to establish or reaffirm the desire for greater autonomy in management of one's own health without reliance on clinicians.

In the case considered, even before the introduction of the new technology, the patients were already more than diagnostic agents (see Oudshoorn, 2008; Andersen *et al.*, 2011). They considered themselves to be substantially autonomous operators able to manage the information and to take decisions. In this context, Diab-PHR was perceived by the patients and families as an ambivalent application generating tensions within the network of relations with the clinicians. On the one hand, it confirmed, by supporting, the work of personal management of the data necessary to control the disease. On the other, it denied the autonomy of the patient/family in such management by giving the doctors space to intervene in everyday routine, and was thus perceived as breaching the therapeutic pact.

This evidences a paradoxical superseding of Mol's statement concerning the relation between autonomy and competence in the management of the disease. If "autonomy *vis-à-vis* a doctor is possible for those who manage to become like a doctor" (Mol, 2000, p. 19), then only the patients are able to be truly autonomous, for only they can act "like but better than a doctor". The demand by the doctors to intervene in everyday routine through a rule-based system was considered useless or harmful because it was founded on decontextualized data. This was therefore a reversal of perspective whereby the refusal to consider the doctor a "life manager" (Carricaburu and Ménoret, 2004) was justified by the perceived superiority of the patient's experiential knowledge of the context and of the specific form taken by his/her diabetes, so that s/he could interpret it better than the doctor (Storni, 2010).

The words of the patients and their family members echoed the considerations of Berg and Goorman (1999) concerning the need for further work to disentangle information from its context of production ("the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in, the more work is required to disentangle the information from the context of its production", Berg and Goorman, 1999, p. 52). The patients and their families did not regard this work as necessary.

The second process of autonomization – of the young patients with respect to their parents – signals another element which disrupted the PHR's introduction by accelerating the handover of responsibility for management of the disease. This was certainly due to the parents' evaluation that the patient had reached sufficient maturity, and to their desire to stop performing an activity which many of them called "a second job". Nevertheless, it is interesting to consider the "how" of this occurrence by destructuring the spaces and time of information management and making them variable and contingent. The paper logbook was supervised by the parents, often being kept in a shared space (e.g. a drawer in the kitchen). It was the central object of a family ritual (often daily) which involved the co-presence of the patient and one or both parents, entry of the data, the highlighting of anomalous values with different colours, evaluation of the glycaemia trend, and the decision on possible insulin corrections. The system introduced thus changed the chronic care infrastructure (Langstrup, 2013) of the disease's management by disconnecting the elements of the practice. It eventually led to the end of close supervision by the parents. The possibility for the patient to compile the logbook at any time or place disconnected the moment of data entry from that of its visualization. It does not seem coincidental that the parents were little interested in viewing the dashboard if they could not immediately discuss their interpretations with the children. To use the categories proposed by Nelly Oudshoorn (2009), Diab-PHR was unable to create a "digital proximity" that replaced the "physical proximity" characteristic of the use of the paper logbooks, instead becoming a technology that contributed to shaping an autonomous patient (Lehoux *et al.*, 2004).

The question of whether an autonomous patient or a patient who enjoys family support is preferable is left for evaluation elsewhere (see Grimes *et al.*, 2009).

Building on these analysis, we would like to conclude reflecting on the meaning of the “P” in PHR. What exactly does “Personal” mean? The literature suggests two meanings. The first is that “Personal” is a synonym for “lay”, as opposed to “professional”, “medical”, “nursing”, or some other adjective suggesting that the user possesses a specific form of recognized expertise. In this sense, “Personal” signals that the technology – although it has features in common with those used by the professionals – contains non-validated information, personal observations, or at any rate data which do not originate from clinical sources. The second meaning signals that the tool is managed by laypeople. Some authors specify this dimension by means of another label – Personally Controlled Health Record (Weitzman *et al.*, 2009) – which stresses more control over the record than its content.

This work has highlighted other connotations of “Personal”. The first is the dimension of the right to the privacy of information when it is believed that it may be used to pass judgement on the patient. In the case of the telemonitoring scheme, the constant accessibility of information was perceived, not as the transmission of a parameter’s values, but as continuous judgement on the patient’s compliance with the doctor’s instructions and the patient’s “goodness”. The reactions provoked by the prospect of telemonitoring signal that the patients would accept the judgemental activity of the doctors if it were restricted to the space-time frame of the clinical encounter, but they rejected continuous and pervasive scrutiny. The second connotation of “Personal” is the assertion by patients of their competence and autonomy in interpreting the information on the basis of personal knowledge about their diabetes.

The case presented invites reflection on some of the expectations aroused by the introduction of PHRs. These have been hailed by many as instruments able to reduce the fragmentation of healthcare systems by entrusting the patients with the task of collecting, managing, and sharing the information in their care networks. These scenarios are based on the conviction that the patients are in the best position to perform this work and that they are willing to do so because it will give them access to the best expert at any particular moment. The analysis of the introduction of Diab-PHR has furnished only partial confirmation of these scenarios. Patients symbolized it as an instrument to support personal diabetes management and as confirmation that they had their own sphere of competence and independent management of the information and the disease. The possibility that, at any moment, the doctors could access the data was perceived by the patients as an intrusion into the personal sphere – as a sign that the medical personnel did not trust their capacity for self-management. The patients were willing to act as “stewards of their own information” (Halamka *et al.*, 2008), but they interpreted this role in terms of managing access to their information and allowing the doctors to view it only upon request.

This outcome raises a number of issues concerning the introduction of systems for the self-management and remote monitoring of chronic diseases. The case analysed demonstrates the difficulty of inserting a new system into a consolidated ecology of relations between doctors and families, with effects that are perceived as potentially disruptive by some actors. For the patients in particular, the clinical data on their state of health was a feature of their self-representation. This confirms that personal health information management is an emotionally connoted activity (Piras and Zanutto,

2011), and data inspection by healthcare practitioners is regarded by patients as a judgement on them as persons rather than on their clinical conditions.

In this regard, it would be interesting to conduct further research on these topics with patients who have adopted similar systems from the first onset of the disease onwards.

Notes

1. Once a year, the patient attends the day hospital for examination by specialists (nephrologist, oculist, neurologist) on problems correlated with diabetes.
2. One of the clinical aims of the experimentation described here was to gather more and more reliable data. Although this is an important topic, its discussion would fall outside the scope of this paper.

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