

“It’s like a guardian angel watching over you!”. Conflicting representations of patient-centered infrastructures by doctors and patients

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Abstract. Coordinating health professionals and patients through digital infrastructures can be more difficult than foreseen during the design phase. This work reflects on one specific hindrance that might occur: the onset of conflicting representations about the infrastructure and its purposes. The analysis focuses on the testing of a Personal Health Record for youth asthma management, a tool intended both to empower the caregivers and to provide professionals with real-time access to their patients’ data. As the testing progressed, doctors and patients developed distinct and somewhat conflicting representations of the application. The analysis of these representations of the infrastructure reveals the underlying differing reciprocal expectations in the management of the disease.

Introduction

The greater frequency of chronic illness is increasingly leading to forms of delegation of medical activities to patients, family members, and caregivers. Patient-centered infrastructures such as Personal Health Records (PHRs) are considered to have the potential to allow new patterns of patient-doctor relationships by providing the former with tools to manage their condition more autonomously, and by requiring intervention of the latter only in specific cases

(Halamka et al. 2008). In the public discourse these activities are usually depicted positively, with the stress on how they augment the free resources of the healthcare system and enable patients to become less dependent on it. Despite this optimistic scenario, however, coordination among healthcare infrastructures that connect professionals and laypeople proves to be more complex than envisaged by the designers. This is particularly true in cases where technologies simultaneously support selfcare practices and remote monitoring, as often happens with PHRs. Analysis of the practices of personal health information management by patients, in fact, reveals that the collection and management of health data is only partially determined by relations with the doctors. Empirical studies show that patients' self-learning about their condition involves the collection of information deemed 'excessive' by the doctors (Piras and Zanutto 2010), and that its purpose is to take decisions in first person without consulting doctors (Civan et al. 2006)..

Context and methodology.

This work reflects on the implications of a project to design and test a PHR aimed at empowering people with youth asthma and allow remote monitoring by doctors. The PHR enables parents to keep track of information on their children's disease (e.g. medications, symptoms, observations) and doctors to visualize it through a web-based dashboard intended to replace the existing paper-based logbooks. The system was tested in everyday life for one year on a small sample of patients (seven families) and the pediatric department of an Italian region.

We followed a qualitative research design, conducting two rounds of semi-structured interviews with the families involved (first round: context analysis; second round: evaluation of use of the technology). The purpose of the interviews was to elicit forms of personal health information management and how they change in the transition from the paper-based to the digital system. Interviews were complemented by observations of the clinical encounters and interviews with the head of the department and the three doctors involved in the trial.

The conflicting representations of the infrastructure

The analyses revealed that, as the testing progressed, doctors and patients developed distinct and somewhat conflicting representations of the telemonitoring application. We identified four conflicting representations.

1 “guardian angel” vs. monitoring education efficacy. Asthma is a chronic condition that requires patients/caregivers to respond rapidly in the case of an acute attack. The education received by parents enables them to be efficient in preventing deterioration of their child's condition on the majority of occasions,

and they become more and more capable as experience accumulates. At times, however, parents are unable to tell whether the condition requires a pharmaceutical treatment (bronchodilator) or whether it will go away without intervention. In this case, parents are reluctant to call doctors, because they are afraid of seeming too apprehensive, and they generally wait until the condition worsens. Parents believe that complying with record-keeping may trigger prompt action by doctors/nurses so that they receive help when decision are difficult to make.

On the other hand, doctors do not see the dashboard as a real-time intervention tool. They rely on the education provided to parents and perceive the application as a tool useful for retrospectively monitoring the correct application of the notions taught to parents by analyzing how they have responded (drug administration) to the stimuli (symptoms).

2 being monitored vs. patient empowerment. The second element of potential disruption regards the intended beneficiary of the information. The parents involved in the trial were quite satisfied with the paper logbook which they had previously used. They used the digital application on the assumption that it would significantly modify their relation with the doctors and the hospital, perceived as guardian angels constantly monitoring their children's condition. When asked why they were complying with use of the PHR, they answered that it provided doctors with all the information they needed.

Doctors and nurses did not deny that this was one aim of the infrastructure. They believed, however, that this was secondary. In their view, the technology was a part of the existing relation characterized by an empowerment paradigm in which compiling the logbook would primarily make parents more knowledgeable about their child's condition and able to take autonomous decisions.

3 single case analysis vs. long term trends. Parents did not show particular problems in management of the condition. Nevertheless, even in the better controlled cases, there were some episodes (asthma attacks) that were difficult to decipher. Parents believed that the digital logbook, which allows the input of more information than the paper-based one, could provide doctors with enough data to gain better understanding of these specific events in the health history of the child, thus enabling them to make recommendations to the caregivers.

Doctors did not see how the technology could help in this respect because of the high number of variables involved in a single attack. On the other hand, however, they thought that the constant use of the digital logbook and the standardized data could help them to acquire reliable time series information and to detect patterns helpful for tracking the evolution of the patient's condition.

Discussion and conclusions.

The management of children with asthma is “work” (as parents call it) that requires the cooperation of medical personnel and the family. When the condition is deemed “stable and controllable” by doctors, the most common way to address it is to delegate the vast majority of the requisite tasks to parents. The medical personnel perform the role of educators and define their tasks as the provision of knowledge and skills required for autonomous management by parents of day-to-day needs, restricting their intervention to emergency cases.

The implementation of a new patient-centered infrastructure engenders a conflict which is made visible on analyzing its different representations by doctors and parents. The former consider it a tool to be framed in the existing paradigm of “patient empowerment”. From this perspective, the digital logbook is primarily considered a tool with which to monitor parents’ ability to manage their child’s condition and become more knowledgeable about it, and to help them detect long term patterns and the course of the disease. Put roughly, the main benefit that doctors see in the new technology is that it enables them to evaluate the patient (and the parent’s management) at distance and decide the best schedule for the periodic examinations.

The parents’ representation of the infrastructure, however, is quite different. In their view it serves the purpose of reducing the gap between the daily life of the child and the hospital through constant monitoring and the possible provision of timely advice in case of need.

These conflicting representations of the infrastructure reveal the underlying differing expectations in the management of chronic disease by doctors and parents and the role of new technology. For the parents, the implementation of the new technology is the occasion to question the existing division of labor with the hospital. Implicitly they ask for a redistribution of the care burden established in the pre-digital era, attributing the medical personnel with some responsibility in the management of the everyday lives of their children. The doctors, on the other hand, do not seem willing to re-discuss the overall frame of their relationship with patients, and they perceive the technology as a way to stress it even more.

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