

Emotions and Personal Health Information Management: some Implications for Design

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Abstract. This work reflects on the translation of a paper-based information system into an electronic one, taking account of the emotional dimension of material artifacts. A qualitative analysis carried out through semi-structured interviews enabled us to describe laypeople's healthcare practices, and specifically the use of "pediatric booklets", which are paper health diaries designed to provide parents with a repository of the most relevant clinical data about their children. Our analysis reveals that parents' use of the booklet does not depend only on the clinical relevance of the information contained in it. Its success rather depends on practices that reshape the booklet's original meaning. In particular, parents use booklets as containers for other clinical records, and they consider them more as objects of affection and symbols of their caring for their children than as clinical tools with instrumental value in themselves. In the discussion we consider the risks of dematerializing health information tools by underestimating the relevance of the emotional side.²

Keywords. Personal Health Record, emotions, healthcare practices, booklets, in-situ interviews, affordance

1. Introduction

The inclusion of patients in monitoring and care processes is considered one of the most urgent needs of Western healthcare systems. The active role of laypeople in this field is perceived as a step towards more democratic and participatory forms of illness management [1], as a way to cope with a general shift from treatment and cure to management and care [2], and as a strategy to reduce the growing costs of healthcare. In this regard, providing laypeople with information and communication technologies (ICTs) is regarded as the best way to deliver more efficient forms of care. This perspective is reflected by the fortune of new labels such as *computer health informatics* [3] or *personal health information management* [4] and also by the growing body of literature on Personal Health Records (PHR), these being patient-

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controlled ICTs that enable laypeople to be a part of a digital environment where information flows seamlessly among a network of caregivers [5].

This scenario presents laypeople as able and willing to manage ICTs just as healthcare providers usually do in their work practices. This, however, is more wishful thinking than an easily achievable result because the pathway that leads from paper-based systems to electronic ones is tortuous, full of pitfalls, and rarely produces the results expected. While some studies have been conducted to understand how people manage paper-based health information in their homes [6; 7], to date little attention has been paid to the emotional implications of substituting paper-based systems with electronic ones. This paper reports qualitative empirical research and reflects on the translation of a paper-based health information system into a service available via the Internet. In particular, it considers the interplay between the emotional and functional dimensions through observation of the practices used to manage health documents in the household, focusing especially on patient booklets.

2. Methods

This study is a part of a broader project of research and innovation aimed at prototyping and testing a regional PHR, this being a personally-controlled health information system designed to allow citizens to access, manage, share, and supplement clinical data. We analyzed laypeople's current practices of document management in order to support the system's technical development (here by "practice" we mean the relatively stable and socially recognized ways in which heterogeneity is ordered into a coherent set [8]). In particular, we focused on the management of "pediatric booklets" – paper records provided by the local healthcare authority to help parents keep track of the medical histories of their children – so as to explore the challenges of developing web-based versions of these documents. A first overall sample of 32 households, chosen on theoretical bases, was subjected to empirical study. Then, for the purpose of the detailed examination reported here, we selected 16 of them which were still managing a pediatric booklet. Of these, 10 out of the 16 informants interviewed were female, while seven of them had only one child, seven had two, and the last two had three children. In regard to the occupations of the interviewees, we had 5 teachers, 6 office workers, 1 professional, 3 independent professionals, and 1 PhD student. The interviews took place in the homes of the informants. This gave the researchers access to the pediatric booklets and enabled direct observation of the ways in which their management intersected with other dimensions of health information management and the activities of everyday life. The analyses was carried out by means of a grounded theory [9].

3. Results

The analysis of the interviews revealed that home health record-keeping is a very complex activity aimed at enabling laypeople to provide healthcare personnel with the information that they need. The classification of documents into distinct thematic areas is invisible work [10] required of the patient by the healthcare system in order to save time for healthcare personnel and to grant the patients themselves their doctors' full attention [7]. Here we focus on some specific practices related to the use of booklets,

and pediatric booklets in particular. A pediatric booklet is a paper file (20x15 cm.) consisting of about 70 pages. Few of these pages give information to the parents, and even fewer allow the parents to take notes on their children. The other pages are supposed to be filled out by the pediatrician or any doctor that attends to the child, so as to provide an updated clinical history of the latter until s/he turns 14. While the parents are asked to keep the booklet and bring it with them to any encounter with doctors, it is primarily a clinical tool.

The cases analyzed exhibited some shared features in how this paper-based information system was used. Firstly, the more the child grew, the fewer data were recorded in the booklet, proof that it is mostly the first phase of development that is of concern to pediatricians. Secondly, most of the parents stated that pediatricians filled out the booklet only occasionally, explaining that they preferred to use their own information systems (electronic or paper-based), and that the contingencies of the examination did not always let them work on the booklet. Thirdly, the pediatric booklet appears to have been of little or no use for the other doctors to which it was shown (e.g. in accident and emergency). Finally, none of the interviewees reported using the booklet to write information about the child's health, claiming that they were instead only its keeper, and considered it as belonging to the pediatrician.

Despite this discontinuous and fragmented use, all the parents kept the pediatric booklet constantly to hand and took it with them for any contact with health facilities, and whenever they travelled with their children (e.g. holidays). This seeming paradox is explained by the fact that, invariably, the book was used by parents as the place in which to keep all other health records. During the interviews we observed pediatric booklets filled with discharge letters, prescriptions, vaccination certificates, and any other diagnostic reports produced by medical facilities, with the exception of voluminous documentation such as radiological images. It was not rare to find booklets containing printed web pages to show to the doctor, leaflets picked up in a pharmacy, business cards of doctors, and, more in general, any other sort of paper document relating to the child's health.

Another finding was that when the children turned 14, the booklet was not shown to the general practitioner to be evaluated. Rather, it was kept at home in the same spaces where the parents retained cherished objects concerning their children (toys, first communion favours, school reports) in order to preserve them and eventually give them to their sons and daughters when they left home. For the early years, the booklet was usually regarded as precious because the parents and pediatrician both paid close attention to the healthy development of the children. In these years, therefore, parents accumulated a number of health records concerning both routine contacts (e.g. vaccinations) as well as sporadic and exceptional ones (e.g. emergency room, hospitalization) with health care facilities. At this stage of the child's life, parents took the booklet with them to encounters with doctors, so that it became the easiest place to store documents arising from the meeting. After a few such interactions, the book became almost "naturally" the depository of health documentation.

Overall, the paper-based booklet was a tool with limited clinical utility in the strict sense but of great importance in terms of the reassurance that it gave to parents. For the latter, the book represented the history of the child's development punctuated by 'minor incidents'. Because of the way in which the booklet was structured, in fact, it was not suited to accompanying a child with a complex pathological condition; and in fact, when such a condition occurred, the booklet was abandoned and specific files or folders were used.

4. Discussion and Implication for System Design

The analysis of the practices described above suggests that use of the pediatric booklet by the parents turn it into a new artifact: a *booklet-container-symbol* used not only for practical purposes but also to testify to parents' own care-giving role. Initially, it is used by pediatricians to monitor various parameters associated with growth. Thereafter, the material affordances [11] of the booklet are exploited by the parents to appropriate it. The appropriation – the process of adaptation and adoption of the artifact [12] – depends on the materiality of the other objects with which it is put in connection by the users, such as clinical documents produced by healthcare facilities. In other words, the widespread use of the booklet can be interpreted as concerned both with the intrinsic characteristics of the object (e.g. forms to be filled out) and its possession of the same materiality as the other objects, so that it constitutes an “ecology of use” with them.

The practices centred on the booklet also suggest that its widespread use also deals with its re-symbolization, so that it becomes not only a clinical tool but also the symbol of the parents' care and attention for their children. This process culminates with the final loss of all relevance as a medical instrument (when children turn 14) and its new collocation alongside other objects of affection, a clear sign that it now has a purely emotional and symbolic value.

The study of the practices related to this object raise substantial concerns about its possible translation into a digital information system. Although the information contained in its pages could be easily engineered, this would not guarantee a systematic use “substitutive” of the one observed. Achieving this result would require providing the users with a “system” (physical and functional) able to act as a frame of reference for all health information in regard to the child. The electronic system should maintain the features of a “booklet-container” of other records and of a “booklet-affective symbol”, in the absence of which it would risk becoming an impoverished artifact.

These two dimensions remind us of two distinct challenges for the design of electronic systems for health care. The first requires a response in terms of digitization, access and standardization of health information, bearing in mind the importance of their integration. Although this is a primary objective at the current stage of development of information systems, it is far from being reached.

Even more complex is the second challenge: that of responding to the loss of the emotional dimensions due to the practices of using physical objects and replacing them with electronic systems.

Responding simultaneously to both these challenges does not seem straightforward, therefore. Health document management combines both retrieval of clinical records and their cataloguing in the booklet, but also the latter's use as a container of service information (e.g. a specialist's visiting card); a request to be made to the doctor (e.g. a note on a new therapy); documents useful for obtaining health services (e.g. prescriptions, health insurance cards). The emotions that parents associate with the paper-based booklet derive precisely from these continuous forms of use, which should, albeit in different forms, be “jointly” reproducible in an electronic device.

Currently, the design of healthcare information systems concentrates largely on the development of interoperable tools that afford easy access to information, for example with the support of multi-platform systems. This choice, however, is based on the idea that people give priority to “information.” Our analysis instead suggests that the affective value of the pediatric booklet as a “material object” resides in its ability to convey meanings and feelings generated by the large number of social practices in

which the tool is used. For this reason, the design of systems like this one should incorporate these “emotional experiences of use.” This would seem to explain, for instance, why some objects with scant interoperability but which are “technologically dedicated” seem better suited to emphasising the affective dimension that surrounds the use of any device. These “dedicated” objects safeguard a certain “materiality” of the original use. Study of the paper booklet confirms its limited clinical relevance but, at the same time, its importance in affectively reassuring parents as a comprehensive device “dedicated” to the health practices performed for their children.

Also its engineered version must therefore be able, on the one hand, to safeguard the functionalities that make it a support for storytelling about the healthcare experience in which the children’s medical reports, analyses, and growth curves are collected, and on the other, to accompany digital and otherwise [13] memories relative to other aspects of childhood and preadolescence such as school, sport and hobbies.

The research confirms that the paper-based booklet is, in this sense, a valuable tool in the construction of the parents’ identity as attentive to their children. This aspect should be set as the basis of the designers’ work.

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