9

Personal Health Records

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Abstract. The paper addresses the complex interplay between patients, healthcare professionals, and technology in relation to the treatment of chronic patients. It reflects on an ongoing interdisciplinary action research project striving to design and implement IT support for communication and collaboration in the distributed heterogeneous network of chronic patients and the healthcare professionals that take care of them. An interactive personal health record (PHR) has been designed as part of the project. As such it is part of a trend to find ways to include patients in their own care process. This has been motivated by expected health benefits for the patients as well as promises to lead to reduced costs for a burdened healthcare system.

Keywords. Personal health records, patient empowerment, IT support, action research, participatory design, chronic disease management

Introduction

Modern healthcare systems are exceptionally complex entities characterized by increasing medical specialization and organizational division of labor. Without adequate means of communication, this leads to fragmentation, inefficiency and ineffectiveness of patient care. Fragmentation of care is, in particular, a risk for patients with chronic diseases, who need continual treatment from multiple specialists. Establishing good communication with, among, and about patients across professional and organizational boundaries is one of the most crucial aspect to chronic disease management (CDM). IT may have an important role to play in CDM and personal health records (PHR) may enhance coordination of care and enable patients to become active participants in their own health care. PHR are internet-based, lifelong health records that are controlled by the individual and they are meant to promote the individual's engagement in his or her healthcare as well as to make critical patient data available across healthcare delivery sites. Various versions and strategies have been applied to develop PHR (Gearson, 2007; Halamka et al. (2008); Tang and Lee, 2009; Østerlund, Kensing and Davidson, 2011).

Who would want PHRs? What purpose may they serve? How should they be integrated with other IT-systems and practices to be organizational feasible? These are still open questions that have been the focus of an ongoing interdisciplinary action research project, CITH (www.cith.dk). We strive to design and implement an interactive PHR to support communication and collaboration in the distributed heterogeneous network of chronic patients and the healthcare professionals that take care of them. So far we have designed and tested a research prototype, myRecord, focusing on heart failure patients with implantable cardioverter-defibrillators (ICD). Based on the prototype, an IT vendor implemented a scalable and secure system.

We present the research method, our understanding of current practices, the functionality of the system, and the results of the preliminary evaluations. We conclude

by discussing current challenges as to the research approach and by motivating the research questions we will work with in the next phase of the project.

1. Methods

Heart specialists, nurses, lab technicians, computer scientists, and social scientists comprise the interdisciplinary research group. We have applied an explorative, experimental, and interventionist research and system development strategy, which included some fifty patients and some of their relatives (For more details see Andersen et al, 2010). We took a user-centered ethnographic approach to understand current practices, organizational strategies, models, and IT tools. Informed by ethnographic techniques, we *explored* the daily lives of patients and their relatives, and the ways in which healthcare practitioners take care of patients from diagnosis, over referral and treatment, to periodical (virtual) monitoring and visits to outpatient clinics. We conducted interviews, observations, document and artifact analyses, and workshops, all of which are documented on notes, video, and photos. We explored the needs of the ICD patients, their relatives, and healthcare professionals thus grounding the research in concrete and vital concerns. This informed *experiments* by iterative mock-up and prototyping processes. Thus, the functionality and interface of a suite of it-services and applications were sketched to meet the needs and opportunities of patients and healthcare professionals, who tested the prototypes in increasingly realistic contexts. The prototypes allowed for *interventions* into the daily lives of patients and relatives as well as the routines of healthcare professionals. The final prototype was the foundation of a commercial implementation of a scalable and secure stand-alone system.

A clinical trial, testing the degree to which the system improves chronic disease management or these patients, is planned to take place when the technological and organizational implementation of the commercial version of the prototype is ready. Further, we will evaluate the system's economic and organizational consequences. We will study how the ideas of shared care and patient empowerment inscribed in the research prototype fare in a terrain characterized by commercial interests and efforts to consolidate systems and platforms at the national and the regional level. We will analyze the degree to which patients and healthcare professionals incorporate the system into their practices and we will continue to collect demands and wishes for further improvement of the system and the related practices. Finally, there are plans for integrating the system with other systems used in the involved clinics.

Such an explorative, experimental, and interventionist research and system development approach we consider necessary to be able to answer the following research questions: How may PHR be designed and implemented in ways that allow patients to take an active part in their own care process? How will healthcare professionals make use of patient generated data in their work? How may this be done in order to lead to increased health benefits for the patients as well as reduced costs for a burdened healthcare system?

Care for ICD patients involves multiple participants, but the main work takes place at a Heart Center (HC), patients' homes, and local hospitals. ICD patients connected to HC, have the implantation and the ICD follow-ups conducted at HC though some of these patients live far away. ICD follow-ups takes place every three months and consists of monitoring the ICD and taking action according to the patient's changing situation, when the ICD does not work right, or when it has to be reprogrammed. An

increasing number of ICD patients have a telemonitoring set up at home that is able to read and send the status of the ICD to HC. The local hospital's responsibility is to stabilize the patient by checking and adjusting the medical treatment. This takes place during ambulatory visits also every three months.

2. Results

We consider a grounded understanding of current practices, IT tools, organizational strategies and models, as well as the research prototype and its evaluation to be results.

2.1. Understanding current practices

The user-centered ethnographic approach helped us understand how patients and healthcare professionals were hindered in taking efficient and appropriate actions due to insufficient and fragmented information. Healthcare professionals spend a large proportion of the time allocated to the ICD follow-up and the medical check-up to collect the information needed. Further, for the ICD follow-up, the current telemonitoring solution only supports the interpretation of the ICD-data, and only in unproblematic situations. The information that patients contribute when they are physically present is missing, and a lot of time is spent on collecting such information from various paper based and electronic systems (see Andersen et al., 2010). We learned that time is spent more efficiently and with better results for both parties when patients have prepared themselves for the consultation.

A survey of patient acceptance of remote ICD follow-up with 474 patients (81,2% replied) showed for instance that 95% of the patients were very content or content with remote follow-up compared to in-clinic follow-up, and that 44% would like more detailed information concerning ICD-leads, battery status and ICD-therapies. 45% would like to consult a cardiologist after transmission (Petersen et al, 2012).

2.2. The prototype: myRecord

The survey and the user-centered ethnographic approach in combination with design workshops and interviews informed the experimental and iterative design of prototypes involving healthcare professionals and patients.

myRecord is a PHR the overall purpose of which is to support collaboration in the heterogeneous network of healthcare professionals and patients in order to keep the patient in a stable condition and to intervene in due time before a potentially critical situation gets out of hand. In its current state it is a web-based stand-alone system that supplements the current telemonitoring set-up. The prototype helps ICD patients and healthcare professionals in managing the disease. The various functions include an overview of *past and future appointments* at HC as well as at the local hospital, patients' registration of symptoms that physicians need to know about and free text notes taken to prepare for appointments, a *diary*, a *medicine list*, an overview of the *network* of patients and health professionals that a patient has agreed to share (part of) his or her health information with, *questions and answers* between consultations, and a *document folder* for health related documents like lab test, discharge letters, and x-rays. Further, there are access to *patient information and guidelines*. Finally, it supports the building of a network among ICD patients for sharing ideas, concerns, and experiences.

2.3. Evaluation

The prototype has been evaluated first in patients' home during preparation for medical check-up and ICD follow-up mediated by telemonitoring. Further, it has been evaluated at the local hospital during face-to-face consultations and at HC when the lab technician and the physician go through the transmitted ICD readings and take the appropriate actions. We did not find it relevant at this stage to perform any formal evaluation. Instead, we collected reactions from patients and healthcare professionals as they used the system in realistic situations and during interviews afterwards. Some patients hesitated to use the prototype since they felt fine, and they did not want to focus too much on the disease. However, they would have liked something like this around the time when the ICD was implanted and shortly after, and if their situation got worse. Quit naturally patients, lab technicians, and physicians look forward to an integration of myRecord with other relevant systems. E.g. in the current prototype patients have to type in the medication they take, but in Denmark such information will soon be available from a national database. The healthcare professionals would like integration with e.g. their EHR in order to be able to produce a quick overview based on data from physicians' notes, medication, lab test, and myRecord. Further, integration with national databases would make reporting required data more efficient.

Most patients felt that the system helped them being better prepared for the ICD follow-ups and the medical check-ups, and that this resulted in better answers from the healthcare professionals. Also they appreciated the more detailed response they received on the remote ICD reading instead of the short standard reply or even no reply in case the lab technician evaluated that every thing looks normal. Even though it took time to deliver the more detailed response, lab technicians expected that they would save time because fewer patients would call and ask about medication and the status of the ICD's battery. Patients and healthcare professionals appreciated the ability for patients to contribute with information necessary for the interpretation of the remote reading of the status of the ICD. Earlier healthcare professionals had to search in various paper and electronic systems, and some times they had to call patients for information about medication and their wellbeing. "It allows me to focus much faster on what I can do something about" one physician said. Observing another physician we noted that patients, who asked questions through the system helped him structure the face-to-face consultation and his notes in the medical record. Further, the physicians liked the idea of being able to assign tasks for the patients to perform until the next consultation. At the same time however, they expressed concerns that the system would lead some patients to focus too much on their disease.

3. Discussion

For the next phase the dominant research questions will be: Which elements of myRecord survive, get stronger, are changed, are forgotten during the technical and organizational implementation and use, and which new elements emerge? We address these questions since we have experienced in the past, and it is also documented in the literature, that even the best-laid plans have to be altered when the rubber hits the ground. Designers and users change their opinions as they learn more. Another set of questions are related to the degree to which patients will use myRecord in their daily practices, and the degree to which healthcare professionals will look for patient

generated data while they perform their jobs. Further, we will pursue a clinical trial and analyze the system's economic and organizational consequences. Finally, we will study the ways in which myRecord will, or will not become part of the technological infrastructure that is part of the basis for the distributed heterogeneous network of chronic patients and the healthcare professionals that take care of them.

We are aware of some of the current and prospective challenges as to the applied research approach and the design and implementation strategy. First, boot strapping is always difficult, and it is to be expected that it will take some time before the system holds enough data to be relevant for both patients and healthcare professionals. During the prototyping phase we were able to ensure that patients entered data and that the healthcare professionals consulted myRecord. However, this will neither be possible nor desirable as more patients and healthcare professionals are introduced to the system.

Second, we are confident that an explorative, experimental, and interventionist research and system development strategy is necessary to further innovative it-systems and related practices. However, we are not sure we found the right way to combine research and systems design. Based upon our experiences Andersen et al (2011) discuss new ways to combine the two endeavors and they propose to introduce new design interventions early in the process to foster an improved understanding of problems and opportunities as well as a way to test design ideas. They found that intervening before "fully" understanding the situation also raised new issues to be researched.

Third, it is still to be proven that our strategy to increase the health benefits of patients without increasing the burden of the healthcare professionals will actually work. We choose to extend patients' communication with healthcare professionals but restricting them to tick physician-motivated categories, and allowing not too much free text, and by setting limits as to how many questions patients are able to raise before face-to-face or remote consultation. We choose to intervene by offering new ways for communication and collaboration in the distributed heterogeneous network of chronic patients and the healthcare professionals that take care of them, based on our understanding of their needs, concerns, preferences, and opportunities. The degree to which it will work is still an empirical question that has to be tested in real life situations. The answer to this will help us understand whether or not we chose an appropriate research approach and design and implementation strategy.

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