

Healthcare IT and Patient Empowerment: The Case of Diabetes Treatment

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ABSTRACT

This short paper outlines a recently initiated research project that concerns healthcare information systems and patient empowerment. Drawing on various theoretical backgrounds, Participatory Design (PD), Computer Supported Cooperative Work (CSCW), Computer Mediated Communication (CMC), and Science Technology Studies (STS), we address the question of designing IT support for communication and coordination among the heterogeneous network of actors involved in contemporary healthcare work. The paper reports work in progress from a diabetes outpatient clinic at a large Danish hospital. The treatment of type II diabetes at the clinic is characterized by team treatment, a diabetes school, standard treatment plans, and an electronic patient record system. By studying work at the clinic as well as the patients' 'work' with their disease, we aim to come to grips with the complexity of treating type II diabetes and with the possibilities for and barriers toward enabling patients to take active part in their treatment.

Keywords

Healthcare, Patient empowerment, Diabetes

1. INTRODUCTION

The healthcare sector is a crucial component of welfare societies and, concomitantly, a complex work setting for physicians, nurses, and other healthcare professionals. This makes the development of information technology (IT) that supports healthcare work both relevant and challenging [6, 8], but it also entails a risk of focusing on the healthcare professionals' work whilst the patients are shifted into the background. The research project described below focuses on patient empowerment by means of IT support for the highly distributed and heterogeneous networks of people, organizations, and resources that constitute healthcare [3].

First, we introduce patient empowerment and the project within which this study is conducted. Then, we describe diabetes treatment at the studied outpatient clinic. Finally, we discuss the results we hope to obtain from the study.

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2. PATIENT EMPOWERMENT

Researchers and policy makers have increasingly realized that effective communication and collaboration between healthcare professionals and patients – often referred to as patient empowerment – must form the cornerstone of healthcare in the future [9, 14]. Patient empowerment is a healthcare philosophy that posits that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process [5]. According to this philosophy, cost-effective healthcare requires communication, consultation, and collaboration among healthcare professionals as well as with patients, their families, and community resources. Patient empowerment aims at transforming the relationship between patients and healthcare professionals and at educating people to prevent disease, for example by changing their lifestyle [2]. Better outcomes, lower costs, and higher patient and provider satisfaction are expected to be among the results.

A shift toward patient empowerment presents new challenges for the development of healthcare information systems [13]. Traditional initiatives focus on the computerization of patient records, providing order-entry and results-reporting functionality within the domain of individual institutions [1]. However, given the growing complexity of contemporary healthcare [7], it is essential to recognize that institution-specific systems are no longer sufficient to meet the needs of patients, healthcare providers (e.g., hospitals, clinics, and general practitioners), national healthcare systems, home-care centers, and other stakeholders. Patient empowerment requires that designers look beyond traditional concepts of electronic patient records (EPR) and realize that healthcare work is highly interactive and communicative in nature. The challenge is to build collaborative healthcare information systems (CHIS) that support the interdependent roles of patients and healthcare professionals in achieving healthcare goals [5]. The development of such systems requires resolving not only technical and linguistic problems of communicating 'across boundaries,' but also the organizational and political issues related to information sharing in heterogeneous networks of institutions and various other patient communities. Important questions to be addressed are: How can IT applications support communication between healthcare providers and patients? How can IT applications support the interactive nature of healthcare work and enable the patient to take more control over his or her own health? How can IT applications support knowledge sharing among patients and provide tools for building patient communities?

3. THE HIT PROJECT

This study is performed in the context of the Healthcare IT (HIT) project [3]. While gains in medical knowledge and technologies have improved health outcomes, the effective use of information technology holds a potential of enhancing care further through better collaboration and communication between healthcare professionals and patients. However, realizing this potential raises a host of sparsely investigated practical, conceptual, methodological, and technological issues. Through interdisciplinary research the HIT project seeks to explore the technological requirements as well as to address the potential organizational barriers and consequences of creating CHIS.

The HIT project has four main objectives:

- To evaluate the design and use of existing CHIS and examine how these systems change patterns of interaction and collaboration among patients and healthcare professionals.
- To examine and evaluate existing methods and practices for CHIS development as well as strategies for organizational implementation and continual adaptation of CHIS.
- To identify key organizational, cultural, and technical factors that facilitate or impede successful creation of CHIS.
- To develop prototypes of new, innovative CHIS applications and propose concepts, methods, and tools to support the design, implementation, and continual adaptation of such systems.

4. CASE

The HIT project consists of several subprojects concerned with different aspects of CHIS. The subproject we will outline here concerns a diabetes outpatient clinic at a large hospital in Copenhagen, Denmark.

4.1 Diabetes

Diabetes is one of eight diseases that have been pointed out by the Danish government as diseases especially worthy of attention [11]. The ambitious objective of the governmental call for attention is to stop diabetes from spreading further and to increase the life length and quality of life for diagnosed diabetics. This requires, among other things, that diabetics get better tools for living with their disease – that is, patient empowerment.

Diabetes seems – in relation to our research project – to present an interesting and challenging object of study. Diabetes is in some aspects very clear-cut and simple and in others complicated and fuzzy. Diabetes mellitus, which is the correct medical designation, involves a heightened risk of developing serious complications in the cardiovascular system, nervous system, kidneys, legs, and eyes. Diabetics have a mortality rate considerably higher than that of the average population. Diabetes is divided into two different kinds: type I and type II.

Type I diabetes is primarily found among kids and adolescents. It is caused by a lack or cessation of the production of insulin by the pancreas. Type I diabetes is treated medically with insulin. There are approximately 15,000 to 25,000 type I diabetics in Denmark. From a general point of view type I diabetes is the less problematic of the two types of diabetes.

The chances of getting type II diabetes increase with age, and the disease was formerly known as age diabetes. It is caused by insulin resistance, meaning that the body has reduced insulin sensitivity. Type II diabetes is mostly treated through a combination of medication and lifestyle changes, such as dieting and physical exercise [12]. Type II diabetes is rather fuzzy and often occurs in combination with other symptoms and diseases such as overweight and cardiovascular diseases. Type II diabetes is quite mute and can remain unnoticed for several years without the diabetic experiencing the disease very concretely. To be a type II diabetic thus entails that you *learn* to be diabetic, and that you must continue to be so for the rest of your life [10].

It is estimated that there currently are 100,000 to 150,000 persons diagnosed with type II diabetes in Denmark and probably a similar number of undiagnosed and therefore undetected type II diabetics [12]. This corresponds to roughly 5% of the Danish population and makes type II diabetes one of the most frequent chronic diseases. When type II diabetes is allowed to develop it results in complications such as blindness, kidney malfunctions, and cardiovascular diseases. For diabetes treatment to be effective it must include the patient's active participation in both the treatment and the preventive actions against further development of the disease. Hence, patient empowerment is central to the diabetic condition in order to enable diabetics to participate actively and rationally in their treatment.

4.2 Diabetes treatment at the outpatient clinic

The outpatient clinic we are studying treats 700-900 diabetics a year and is at the forefront with respect to diabetes treatment in Denmark. The hospitals in the greater Copenhagen area have extensive and formalized cooperation programs, and here the way in which diabetes is treated at the outpatient clinic is being transferred to the other hospitals in the area. Diabetes treatment at the outpatient clinic has four distinctive characteristics:

- *Team treatment.* The work at the clinic involves close cooperation among the healthcare professionals but is organized around the nurses. On a day-to-day basis the person in charge of a patient's treatment is a nurse, whilst the physicians merely supervise the treatment and can be consulted by the nurses. This way each diabetic has a single person – the nurse – as their primary and permanent point of contact at the clinic. Team treatment is a radical departure from conventional healthcare practices, which unfold around the physician's prescriptions based on examining patients, with nurses and other staff in a merely implemental and subordinate role.
- *An educational program, known as the Diabetes School.* The purpose the Diabetes School, which consists of a weekly afternoon session for five weeks, is to give diabetics a comprehensive understanding of their disease and its optimal treatment. This enables the diabetics to take more active part in the treatment of their disease and, thereby, improves their ability to manage their disease in a way compatible with their other activities. The healthcare professionals involved in the Diabetes School is a physician, a nurse, a dietitian, a podiatrist, and an ophthalmologist, but the diabetics also learn from – and appreciate – talking with each other.
- *A standard treatment plan for type II diabetics.* Standard treatment plans are currently developed throughout the

Danish healthcare sector in an effort to rationalize the healthcare sector and improve the quality of care. With respect to type II diabetes an important objective of such a treatment plan is to define a coherent and relatively brief treatment period. Brevity is important because patients are referred to the clinic by their general practitioner, who is running a private business based on his or her patients. Thus, in convincing the general practitioners to refer patients to the clinic it must be documented that patients will return to the general practitioner after a well-defined and relatively brief period of time, normally 4-6 months.

- *A Diabetes EPR system.* During a patient's first consultation at the clinic a patient record is created and basic information about the patient and her/his symptoms is recorded. At subsequent consultations the patient record is extended with information about current status and the ongoing treatment. The EPR system reminds less experienced healthcare professionals of the information that needs to be recorded, provides the healthcare professionals with a shared – and legible – record, provides patients with a printout specifying their medication and appointments for treatment, and enables more detailed analyses of the effects of the clinic's approach to diabetes treatment.

The EPR system is relatively new, and currently it is only used within the clinic. It has, however, been decided that the other hospitals with diabetes clinics in the greater Copenhagen area will adopt the system. To provide general practitioners with access to the system a web interface is also being planned. Thus, the system is in a more or less permanent state of transition between paper and electronic records. The paper record, which formed the basis for the design of the electronic-record modules for input of patient status and treatment information, was the result of two years of discussion among diabetes professionals from the hospitals in the greater Copenhagen area and representatives of general practitioners. We find that this says a lot about the complexity inherent in the development of standards in healthcare and the work intrinsic to an at first glance mundane standard tool.

Now, paper records in the original paper-record format are routinely produced as printouts from the Diabetes EPR system. An updated paper record is given to the patients after each consultation at the clinic. This paper record is partly for the patients' personal use as it contains information about the current status of their diabetes, their medication and other ongoing treatments, and their appointments at the clinic. The patients are, however, also seen as an effective means of transporting pertinent information between the healthcare professionals at the clinic and those outside of it, primarily general practitioners, podiatrists, and ophthalmologists. As much of this information is highly specialized and not understood in detail by the patients, they transport the information by bringing the paper record to all their consultations with healthcare professionals.

The patient's general practitioner, podiatrist, and ophthalmologist may make handwritten entries in the paper record. These handwritten entries will become available to the healthcare professionals at the clinic if and when patients remember to bring their paper record to the next consultation and the healthcare professional remembers to consult it. Selected entries will be typed into the EPR system and thus become part of the permanent record. In addition to the paper record the patients have a booklet

for recording their blood-sugar measurements. Patients and healthcare professionals discuss these measurements during consultations, but the blood-sugar measurements are not entered into the EPR system.

The EPR system serves as a vehicle for recording and mediating diabetes information among all the involved actors for purposes of mutual awareness, status evaluation, treatment revision, appointment reminding, and other activities related to the treatment of type II diabetes. The EPR and the paper record thus support the coordination of the treatment [4]. A prerequisite for serving this function is that the EPR system, including its printouts, spans the paper-electronic boundary.

4.3 Research questions

The above description of work at the outpatient clinic leads to our research questions:

- How are patients empowered through their treatment at the outpatient clinic? What does empowerment entail in practical terms? What does it take to produce empowerment?
- How are the records produced by the EPR system circulated among, grappled with, and used by the different healthcare professionals at the clinic, the patient, the general practitioner, and other actors involved in the treatment?
- How can the EPR system be redesigned to further improve the communication between healthcare providers and patients in order to enable patients to gain even more control over their health?

4.4 Methodology

The approach adopted in the overall HIT project is analytic in seeking to understand the complexities of contemporary healthcare work and the challenges involved in creating CHIS, and constructive in striving to develop prototypes of innovative applications as well as concepts, methods, and tools to support the design and deployment of CHIS.

Given the communicative and interactive nature of healthcare work and the social nature of the design and implementation processes we aim to improve, it is necessary to adopt a multidisciplinary approach in which computer science is supplemented by a number of IT research disciplines that address technical as well as social, organizational and cultural issues. In our case these disciplines include PD, CSCW, CMC, and STS.

Concretely we will conduct field studies at the outpatient clinic, including observations of work and consultations, qualitative interviews with healthcare professionals and patients, and thinking-aloud sessions of the use of the Diabetes EPR system. We will attend the Diabetes School (the educational program for the diabetics) and, to the extent possible, follow the paper-based record as the patient carries it from one healthcare professional to the next. Later, we plan to make design workshops where various stakeholders are brought together to envision new tools for and elements of diabetes treatment.

5. DISCUSSION

A concept central to the way work is organized at the outpatient clinic is 'shared care' meaning that the responsibility for the treatment of the diabetic is distributed between the healthcare

professionals and the patient. Being a diabetic is about becoming well-regulated, and this requires knowledge about the parameters that affect the disease and the early symptoms of being ill-regulated. The essence of being well-regulated is to counterbalance the body's reduced insulin sensitivity with a conduct that entails a reduced need for insulin. As for other chronic conditions the treatment is restricted to disease management. For type II diabetes this management is complicated by the near absence of immediate effects of failures to stay well-regulated. Thus, for many patients the disease materializes through the various procedures, tools, and technologies involved in the treatment. These procedures, tools, and technologies help remind the diabetic of her condition and sharpen her sensitivity to her disease. The disease, which is otherwise silent, gets a voice.

From an ontological, STS-inspired point of view we can say that to the diabetic type II diabetes is not a condition residing inside the body – in terms of the reduced ability of the cells to absorb insulin – but primarily a condition materialized through a range of activities and practices such as participation in the diabetes school, a diet program, and the paper record that must be brought to consultations and, in general, reminds diabetics of the parameters important to their condition. These activities and practices make the condition manifest and concrete. Following the diabetes school at the outpatient clinic is intended to support patients in adjusting their lifestyle, but this is a lengthy and intricate process. Whereas the diabetes school is five afternoon sessions, the adjustments should be enduring. Therefore, from our point of view as IT designers it is a central consideration to develop tools that support the day-to-day work of being a diabetic. This, however, raises a host of complicated questions about issues such as 'the healthy body' and individual autonomy versus compliance with best practices. What does it mean to empower patients and who are the stakeholders in this empowerment? How can empowering IT tools be made usable to the large group of elderly diabetics with little or no IT experience?

With the study of the outpatient clinic we aim to come to grips with the complexity of treating type II diabetes and the work involved in enabling patients to partake actively in their treatment. This includes understanding how the EPR system supports the work, the treatment, and the production of empowered patients. Based on these findings we hope to be able to outline how IT tools can support diabetics and in what ways.

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