

Co-Summary: A Shared Care Record for ICD Patients

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Abstract. This paper reports findings from an ongoing research project aiming to develop IT support for communication and information sharing across institutional and professional boundaries within the Danish healthcare system. The project focuses on the treatment of heart patients with implanted ICDs (implantable cardioverter-defibrillator). These are chronic patients who usually see several different healthcare providers regularly. The main findings so far are: (1) the patient's medical record(s) contain(s) very heterogeneous document types most of which are context-specific and often difficult to interpret for others than experts on the subject. Sharing these types of data across institutional and professional boundaries is not feasible. (2) Yet, it appears that a small subset of data can make sense across the different contexts and be of use to others. These data are good candidates for sharing. (3) The aim of the study is to develop new types of shared records specifically designed to meet the coordination needs across different contexts and expert domains, without imposing extra work on clinical workers (4) A prototype of a 'co-summary' is developed, and ready for pilot-implementation

Keywords. Medical record, summary, information sharing, design

Introduction

Modern healthcare systems are incredibly complex entities. They are characterized by an increasing degree of professional specialization, a more and more extensive division of labor, and a growing interdependence among relatively autonomous healthcare providers. Without adequate means of coordination and information sharing, this may lead to errors, duplication of efforts, and many other problems negatively affecting patient safety and the quality of care. [1]

In this study we are investigating work at the Cardiology Lab at Copenhagen University Hospital, which specializes in the implementation of pacemakers and ICDs (implantable cardioverter-defibrillator), and an associated heart clinic at a regional hospital. We look at the problem of information sharing in the context of care for chronic heart patients with an implanted ICD, which constantly monitors the heart rhythm and intervene when it detects a pre-specified rhythmic abnormality. The patients are treated by different clinical workers at different places: Electrophysiological specialists and lab technicians at the Cardiology Lab are responsible for monitoring the device while cardiologists at the local heart clinic are responsible for the up-titration and maintenance of their medicinal treatment.

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Sometimes, the patient's GP takes over this treatment when the patient has been up-titrated.

Each care provider produces a substantial amount of clinical data, which they store in the patient's local medical record, a collection of notes and other documents concerning a particular patient, which are essential to the clinic's treatment program, but difficult or impossible to understand for non-specialists. [2] In other words, the different care providers maintain their own specialized medical records, each of which provides only a partial picture of the patient's current condition and history of care. [3]

In this study we take a closer look at the existing medical record to first identify a suitable basis for extracting information that are relevant for interdependent clinicians across organizations and specializations, and second to present this information in a form that makes it useful – not just for the specialists who created it – but also for other clinicians with whom they only to some extent share professional knowledge and experience. The result so far is a prototype of what we, as a working title, call a “co-summary.”

1. Methods

The study is conducted in four stages.

1. We started out with doing a field study at the Cardiology Lab and the heart clinic comprising observation studies as well as interviews with key actors from four different hospitals. The aim was to understand their existing documentation practices.
2. Next, we did an in-depth study of a sample of records to understand the composition and the function of the various parts, in particular the physicians' progress notes and transfer notes, which we identified as the core part of the medical record. We observed that the, often quite voluminous, progress notes contained many “summaries” of the patient's medical history, including transfer notes and summaries of data accumulated from the ICD, and these summaries seemed to play an important role in the clinical practice. The transfer note and the summary of the ICD data can be seen as special kinds of summaries.
3. In close collaboration with two doctors from each hospital we developed a prototype of a version of a summary, meant to be used to exchange information across wards and hospitals.
4. Based on the prototype, a software company has developed a production system ready for use by clinicians. This system will be pilot-implemented in the Cardiology Lab and the local heart clinic in spring 2012 to see how it performs in “real life”. [4][5]

2. Results

Although the bulk of the clinical data generated and recorded during patient care are highly context-specific and difficult to understand for “outsiders,” we identified a relatively small subset of data that make sense to share and that can be useful outside the context in which they were initially generated. This includes medication data, extracts of technical information about the ICD unit, overview of the therapies given, and information concerning changes in the patient's general condition. These data

should be easily available in a dense format. We observed that doctors frequently write “patient summaries” as part of the progress notes to create an overview and aid memory, and that these “summaries” are also used by other specialists inside and outside the clinic. These summaries are in use already, and the clinicians are concerned about the burden of ‘paperwork’ and stress that the introduction of a shared electronic summary record must not require too much extra work on their part.

We designed a web-based ‘co-summary’ to support accumulation of summarized information about the patients’ medical condition over time. The responsibility for creating and maintaining the patient summary is shared among all clinicians involved in the treatment of the patient. The patient summary is designed to be very time efficient in use. Clinicians create or update the patient summary by filling out a simple input form. The input form contains a combination of free text fields and multi-select options through which the user inputs data about the patient’s diagnoses for specific complications or co-morbidities (e.g. diabetes and COPD), essential medical history, treatments (e.g. ablation surgery), results from medical examinations (e.g. aorta insufficiency), etc. The system then generates a short text string that gives cardiologists a brief overview of the patient’s medical status. The patient summary should be updated whenever changes occur.

By distributing the task of creating and maintaining the patient summary among all the involved clinicians and by primarily basing data input on multi-select-options instead of free text, it represents a relatively small addition to the current workload. In return, the patient summary is expected to help the clinicians quickly gain an overview of the patients’ condition in situations where they are normally pressed for time.

Based on our prototype a more robust pilot system with an improved user interface has now been developed by a software company, and we will conduct a pilot implementation of this system at the involved clinics.

3. Discussion

By offering easy access to data across organizational boundaries, and by organizing the production of a common record as a responsibility that is shared among the involved clinicians, the ‘co-summary’ represents a new approach to designing information infrastructures in healthcare. The coming pilot study will give an indication of how these concepts can contribute to the development of new, inter-organizational practices, and thereby counteract the organizational fragmentation that currently seems to hinder shared care practices, such as the ICD treatment.

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