

A study of the fragmentation of the medical record

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‘In the early 20th century, the data in the medical record were beginning to burst the confines of the form’ (Reiser, 1991)

The medical record, the collection of notes and other documents concerning a particular patient, is a time-honored and robust institutional artifact. However, with patients with chronic ailments that typically are treated and monitored by multiple clinical workers, sometimes at different institutions, the medical record is more than ‘beginning to burst’: it is beginning to fragment.

This becomes clear from our ongoing study of the coordinative practices of clinical workers dealing with patients with ‘implantable cardioverter-defibrillators’ (ICDs), i.e., pacemakers that dub as defibrillators.

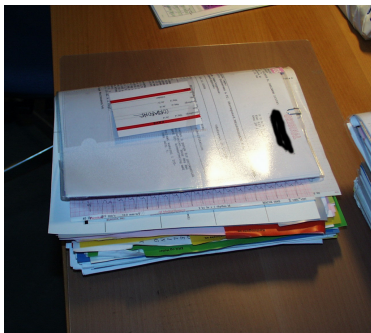
We are investigating work at the Heart Clinic of the Copenhagen University Hospital, at its outpatient clinic, and at an associate heart clinic at a regional hospital. The Heart Clinic treats patients from Eastern Denmark as well as Greenland and the Faeroe Islands. Patients with ICD implants have to be monitored on a regular basis, both in terms of ordinary cardiology and in terms of the functioning of the device. This is done by different clinical workers at different places: on one hand by the cardiologist at the heart clinic at the patient’s regional hospital and by the patients own doctor (GP), and on the other by the ‘electrical doctors’ (ICD cardiologists) at Copenhagen University Hospital and by the bio-technicians at the hospital’s out-patient clinic who download and print data from the device for specialist scrutiny. Newer ICD devices can be scanned remotely, while the patient is at home (via wireless download to a reader and subsequent transmission to the

hospital over the Internet). The data then have to be recorded, filtered, interpreted, classified, put on record, handed over, etc.

Accordingly, due to the introduction of a technology such as the modern ICD, we see the emergence of a distributed network of interdependent activities that are carried out in parallel and yet (potentially) time-critical.

The first impression of the patient folder lying there on the desk is that it is thick. Enveloped by folded transparent vinyl it holds up to about 500 sheets of paper, some loose sheets, some stapled together. The cover can barely contain the content.

Considered as a data structure, the patient folder is quite complex. Or rather, it is a motley of stuff, loosely collected in a folder. To provide some order, the first



sheet is a generic table of contents printed on a white sheet of plastic, and the content of the folder is organized into corresponding sections divided by colored separator sheets with inscribed tabs: ‘Continuations’ (grey), ‘Cardiographic tests’ (orange), ‘Paraclinical tests’ (yellow), ‘EKG and Holter’ (green), and ‘Dispatch letters’ (blue). Within each section, sheets are generally placed in inverse chronological order (with exceptions due

to haste, mistakes, etc.). The tagged separators is a recent innovation. Patient folders that were established earlier than about ten or more years ago are not organized this way, nor do they have a preprinted table of contents.

An additional technique of organization is the use of colored paper to indicate the category of information carried by the sheets. Continuations are white, administrative forms are printed on green paper, cardiographic test results are pink, references to other patients folders (in other clinics) are mauve, and so on. This coding scheme is not upheld consistently, however, as copies of test results etc., e.g., transmitted by fax or mail from other clinics, are on white paper.

When browsing the folder’s content, one is struck by the enormous heterogeneity of document types. Within the section labeled ‘Cardiological tests’ one finds, in the case of one patient, 12 different document types, altogether about 50 documents. The other sections of the folder are similarly heterogeneous. As for data types, the heterogeneity is equally remarkable: text; numerical data series; tables; prose printouts, generated by means of word processor; handwritten prose; computer printouts with handwritten annotations and comments; forms generated by means of word processor, filled in by hand; computer-generated graphs; computer-generated X-ray imagery; etc.

The ‘continuations’ consist of notes in inverse chronological order. Each entry is marked by date, sometimes by time of day, and contains a few lines describing the state, treatment plans, etc. Occasionally, notes will swell to 1-2 pages, in which case they are subdivided by headings, for instance ‘The plan is...’ or ‘Ob-

jectively: ...' in bold. Such lengthy notes recapitulate the case, for instance: '07.05.08. [9] The old medical record is now at hand.' After this follows a lengthy recapitulation of the case history as documented by records received from the hospital from which the patient was transferred.

The idea of subjecting this enormous heterogeneity of relationships, categories, and document and data-types, to one monolithic data-base scheme seems bizarre.

The patient folder is the key artifact in an institutionalized coordinative practice. It retains the character of the stack of notes, compiled as an *aide memoire* by a solitary doctor. But it is an coordinative artifact by means of which clinical actors keep each other up to date with respect to the state and treatment of a particular patient; with respect to each other's observations, plans, and occasional uncertainties, and with respect to the informational basis for clinical assessments and decisions.

The patient folder is hefty. It documents the trajectory of chronically ill patients as represented in doctors' notes, lab reports, test results, clinical imagery, and so on, and it thus gains size and weight over time. Because of the number and sheer size of patient folders, the hospital's archive of patient folders is dispersed over multiple locations. Thus, when patients are due for checkup or have an appointment for a consultancy, their folders have to be retrieved. This task is carried out by the laboratory's clerical assistant who spends about three hours daily retrieving the folders for the patients scheduled for the same day, by locating them in one of the archives and hauling them back to the laboratory on a cart. Back at the laboratory, folders are placed on the desks or shelves assigned to laboratory workers or doctors' assigned to take care of the respective patients. In addition, folders are temporarily placed on shelves in case the patient did not turn up or is expected to come in for checkup within the next week. Finally, for a variety of reasons folders also find temporary station on doctors' desks in the various sections of the Heart Clinic, outside of the laboratory. Thus, because of the nomadism of patient folders, it may require considerable effort and time to locate and fetch a particular folder.

At the Heart Clinic, the clinical record concerning a particular patient is not confined to the content of the patient folder. In fact, the clinical record is distributed over an assortment of paper-based and electronic archives and databases (Fitzpatrick, 2004). In this context, the most important 'satellite record' is what is called the 'green folders'. It is a large set of suspension folders, housed in about 40 cabinet drawers in the hallway. Each folder contains information about a particular patient's ICD unit, its configuration, and printouts from the data accumulated by the unit. The 'green folders' are maintained by the bio-technicians at the outpatient clinic and are only occasionally accessed by doctors. To ensure some coordination, a summary of the 'read-out' (number of events, etc.) is manually entered into the 'continuations' in the patient folder.

The time-honored patient-centered medical record has worked very well for centuries and has proved very flexible in its contemporary incarnation as an institutional coordinative artifact. However, our study indicates that it is now coming apart. First, the sheer size and heterogeneity of the patient folder makes it difficult for a busy clinician, in the context of a brief routine consultation, to obtain an overview of the patient's history.

Second, its robustness as a dynamic shared record of the state of the patient was predicated on its being localized: a center of documentation and coordination of a specialized local clinical practice. Thus, when it comes to supporting documentation and coordination across a network of specialists, the medical record in its current incarnation comes up short. At best, satellite records are emerging, at the cost of painstaking and error-prone manual synchronization and replication work. At worst, communication and coordination among interdependent clinical workers breaks down. The issue is not simply one of overcoming geographical distance by means of IT, nor is it one of establishing common clinical documentation standards across multiple institutions. Raw ICD data are not understandable to GPs, and as it is now, even ordinary cardiology specialists will not be able to interpret the data confidently. In the words of 'a veteran of emergency rooms, post-operative wards, and intensive-care units':

'The remarkable advances of ultramodem biotechnology have brought with them complexities of such magnitude that medicine sometimes seems in danger of being overwhelmed by forces of increasing intricacy and incomprehension. In certain situations, only the small number of superspecialists who deal in a particular aspect of diagnosis or therapy are equipped to interpret a finding or observation.' (Nuland, 2002).

Integrating novel clinical technologies in medical practice undoubtedly requires that new coordinative practices are also developed: practices of interpreting, translating, categorizing data for the benefit of other clinical practitioners.

In collaboration with 'electrical doctors' at Copenhagen University Hospital and cardiologists at the associate regional heart clinic, we are currently engaged in their (tentative) development of such practices. More specifically, in an attempt to address both of the abovementioned issues, we are developing an experimental coordinative artifact, a digital form, that supports distributed cardiologists in producing, collaboratively and ongoingly, a shared 'summary' of the state of the patient and his or her device.

References

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