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Review Paper

Electronic Healthcare Records: an essential part of Health Telematics Applications

Abstract: A healthcare record should ideally be a repository of data, describing a person's health and how it is being supported; and not, as it is now, describing a person's diseases and treatment only. The healthcare record is the basis for monitoring and decisions. Therefore it should be open and available to all authorized health professionals and to the patient. To make this easier is one of the major advantages of electronic healthcare records (EHCR). The computer-based patient record could make major contributions to improving the healthcare system. This is the motivation to initiatives, projects and routine implementations of electronic patient records. The European Union and national initiatives have put major efforts into the support of this main field of medical information processing.

1. Introduction

Modern healthcare is characterized by increasing specialization and shared care provision. This applies particularly to the management of chronic diseases with their accompanying complications (as, for example, in the case of diabetes mellitus, which is often associated with diabetic retinopathy or coronary heart diseases) and multimorbidity in the case of elderly patients. Generally, persons with chronic diseases are regularly seen by their family physician where the overall medical record is kept. For routine check-ups or, in case of complications, they are transferred to specialists (e.g., diabetologists, ophthalmologists) in ambulatory or hospital settings. Each of these settings maintains its own medical record, but communication between the healthcare providers is still insufficient.

2. Requirements for an EHCR

Even though patient records were already known in ancient times, using computers to gather, store, retrieve and interpret data has reached a new dimension [1]. This offers solutions to problems, such as:

- missing data, that are not in the medical record because examinations and tests were not performed, results from tests, examinations etc. were not recorded, misplaced or are simply not readable;
- bad quality of data, which originates from errors in typing, wrong coding, incompleteness and illegibility;
- data that are not available because the record is distributed over one or several healthcare providers;
- misinterpretation because the records originate from a different specialty or were written in a different language.

The American Institute of Medicine undertook a study [2,3] on the state-of-the-art of patient records in 1991, and stated the following requirements concerning a future electronic healthcare record (EHCR). A good EHCR has to:

- support patient care and improve its quality;
- enhance the productivity of healthcare professionals;
- reduce administrative costs concerned with healthcare delivery and financing;
- support clinical and health services research;
- accommodate future developments in healthcare technology and policy management;
- have mechanisms to ensure patient data confidentiality.

3. Early Projects and Systems in EHCR

In the early developments the medical record, the database and the medical information system were handled as one unit. The following are some typical examples:

- The Computer Stored Ambulatory Record (COSTAR), which was developed between 1968 and 1978, and is widely used in different (mostly primary care) institutions.
- The Regenstrief Medical Record

System (RMRS) which was started in 1972 and focused on computer-supported reminders for the physicians [4].
- The HELP Medical Record System whose development was started in 1975, based on the patient care process, and it provided alerts; administrative functions were added later.

Soon, it became apparent that the issue is more complex and that more factors have to be considered concerning the EHCR and, consequently, medical record systems.

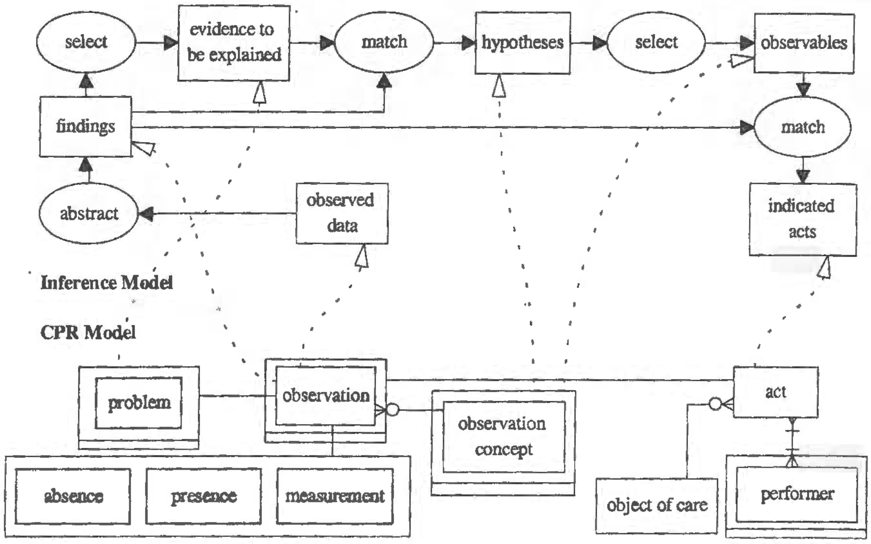

Fig.1. Conceptual model of the DIADOQ CPR and inference.

4. Data, Knowledge and Communication

One of the main tasks of an EHCR is to exchange data between different healthcare professionals and institutions to allow the person involved - patient or professional - to take into account previous periods of treatment and its results. On the other hand, knowledge in medicine doubles about every five years. Necessarily, knowledge in certain areas has to be available for the healthcare professional or the patient in a computerized way. This, on the other hand, requires systems that can handle large amounts of data coming from different sources and modalities. A common approach to data management is therefore necessary.

Several projects aimed at defining the need and use of data, CHIC: in primary care and quality assurance, ORCA: in cardiovascular diseases, EUROCARDS: for administrative and emergency purposes, DIABCARE: in quality assurance, and DIADOQ.

The DIADOQ[1] project aims at assuring the quality of care for diabetic patients by means of task-specific decision support for clinically relevant problems in diagnosing, therapy planning, and monitoring of diabetes. To achieve the constant availability of the knowledge bases and guidelines, a CPR system for Diabetes outpatient clinics has been developed, supporting both routine work and knowledge-based decision support.

The conceptual model of the CPR (Fig. 1) is based on the "Clinical View of the Common Basic Specification" [5]. A controlled vocabulary is maintained in a frame-based conceptual system. The vocabulary enables the structured recording of nearly all patient data, including history taking and physical examination. It is an extension of the EURODIABETA dataset [6] and currently comprises more than 2,000 concepts.

The frame representation of the concepts forms the basis for the automatic generation of screen forms for user input and for data representation at runtime. Each medical item of the CPR system keeps a reference to its corresponding concept. Laboratory concepts, for example, provide references to normal ranges. These can depend on the patient's age, gender, etc. They may be measured for different specimens (e.g., urine, blood) in different units (e.g., mmol/l, g/dl).

The CPR system adopts a problem-oriented medical record [7] as a natural model of the CPR for managing a chronic disease. Patient problems, organized in a problem list, provide a concise medical summary of the patient and serve as justifications of performed medical acts. Thus, the CPR system does not only record the medical data of a patient, but additionally keeps a record of justifications and acts leading to this data. The possibility to represent the process of healthcare delivery in the medical record lays the foundation for the identification of steps where knowledge-based decision support could beneficially be applied [8].

In Fig. 2 different functions supported by knowledge bases available in [9] are indicated. This support employs methods ranging from simple

[1] DIADOQ - Optimized Care Through Knowledge-based Quality Assurance: Diabetes Mellitus. The organizations involved are: Institute for Diabetes Research, Düsseldorf; GSF - MEDIS Institute for Medical Informatics, Neuherberg; Institute for Diabetes, Karlsburg; University Hospital of Erlangen-Nürnberg, Nürnberg; IMIB - Institute for Medical Informatics and Biometry, Dresden; Department of Diabetes, München-Bogenhausen; Boehringer Mannheim GmbH, Mannheim; Institute for Mathematics, Ludwig Maximilians University, München. DIADOQ is part of the German MEDWIS (Medical Knowledge-bases) research program.

textbook representations up to inferences by causal-probabilistic networks (CPN) [10] and artificial neural networks (ANN).

For example, the managing of the problem list is supported by an electronic medical textbook of relevant problems in the field of Diabetes. For each problem typical signs, symptoms, test results and relevant diagnostic medical actions are listed. These profiles have been elaborated by the DIADOQ Diabetes experts supported by a tool based on the controlled vocabulary and the underlying ontology of the knowledge base. Coupling the knowledge base to the data of a specific patient [7], possible explanations of patient problems and medical acts for further investigations are automatically proposed by the system.

Dedicated knowledge modules support the user during the performance of difficult medical acts. One such an example is a neural network for the diagnosis of secondary failure of OAD (Oral Antidiabetic Drugs) therapy.

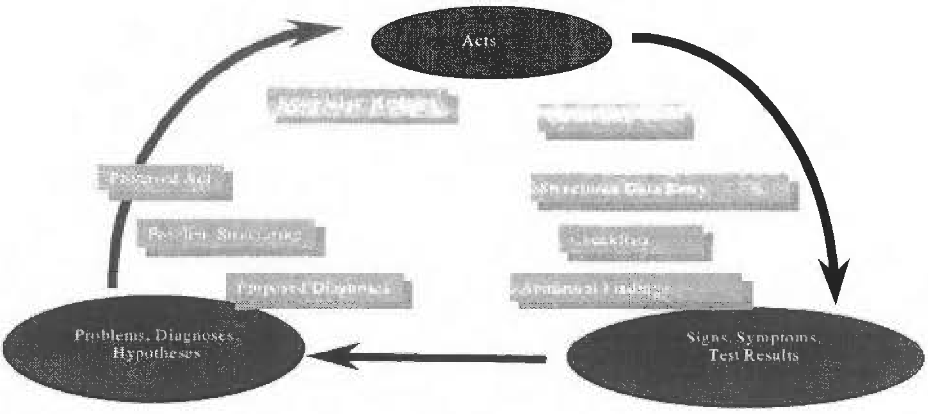

Fig. 2: Knowledge based support functions in DIADOQ.

The foreground form in Fig. 3 shows the result of the interaction with the CPR indicating the inclusion and exclusion criteria of the knowledge base, the used patient data from the medical record and the resulting decision certainties displayed in a bar chart.

In the background form of Fig. 3 a patient's problem list and to-do list of medical actions are displayed in the main window of the CPR system. All interactions with knowledge modules are treated like any other medical act in the system.

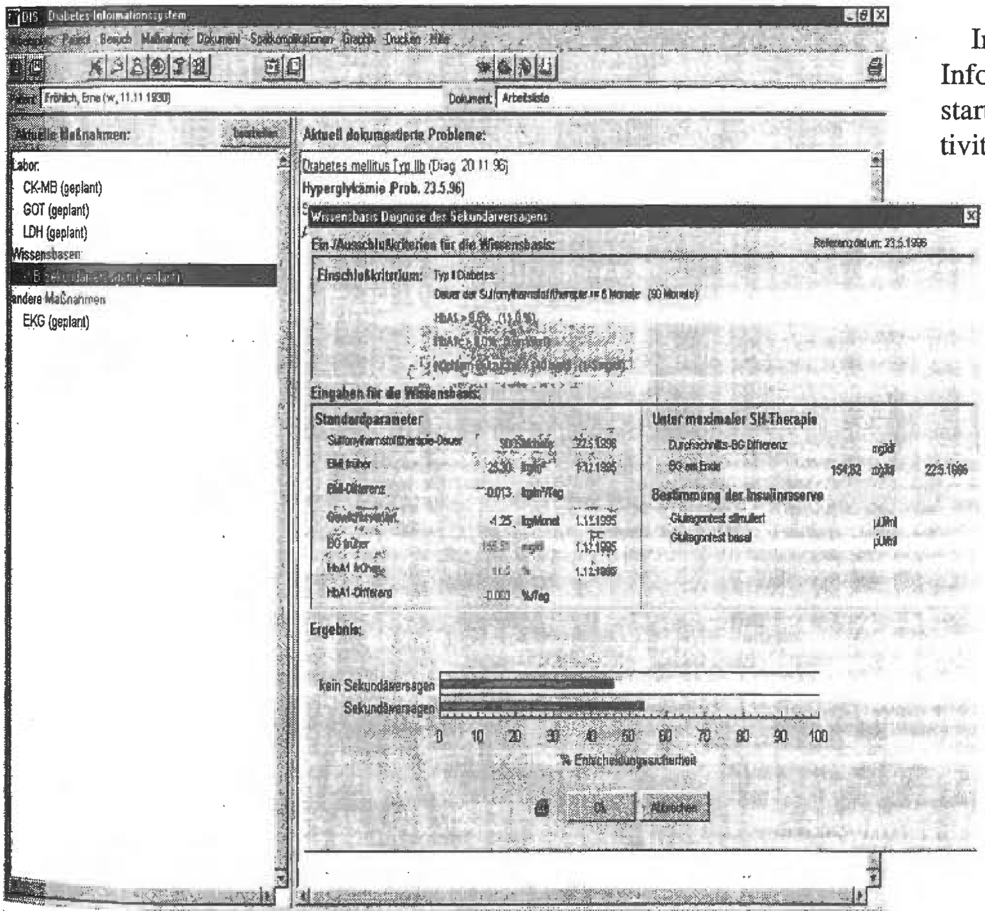

Fig. 3: Decision support in the DIADOQ CPR system.

5. Standardization, Interoperability and Security

In 1989 the EU-AIM (Advanced Informatics in Medicine) Programme started to support standardization activities through CEN TC251. In the course of time the following interoperability requirements were found to be the most important:

- Definition and content *of data;* this may be described by the words terminology and coding;
- Structure and architecture of data.

[2] DIABCARD – Improving Communication in Health Care based on chip card technology: example Diabetes. Partners involved: GSF-Research centre Munich-Neuherberg (co-ordinator), Diabcare France, Paris, Diabcare office, Munich, , DIABEM foundation, Barcelona, IBM Germany, Infineon Technologies Munich, Roche Diagnostics, Mannheim, University of Linz, University of Magdeburg, University of Munich, University of Perugia, University of Vienna, Zentralinstitut für die kassenärztliche Versorgung Köln, funded by the EU in the TAP Health Care initiative HC.

The Telematics Application Program (TAP) in Health Care [11] aimed at supporting this issue by various projects concerned with this matter.

An example following the European and G7 approach is DIABCARD[2] which deals with disease management in diabetes care. For people with a chronic disease, their many records, held at different locations, often pose a problem. In distributed healthcare systems the records are rarely communicated between physicians.

DIABCARD addresses the patient record and the communication aspect using chip card technology developing the DIABCARD Chip Card based Medical Information System (CCMIS).

The DIABCARD Data Set (DCDS) has been developed mostly on the basis of existing data sets, and clinical scenarios describing patient management in Diabetes care. The current version is 2.2. There will be a subset or minimal data set used in each DIABCARD implementation site. Beside the site specific data this will be the:

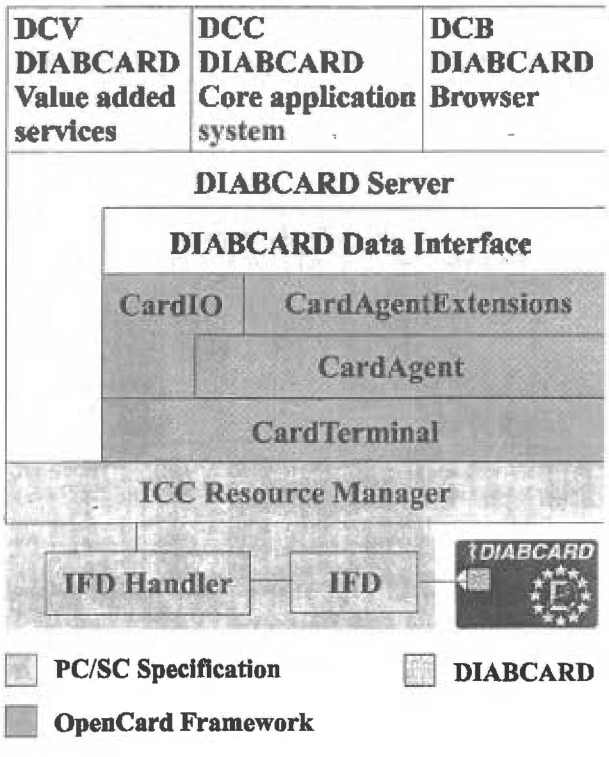

Fig. 4. The DIABCARD Architecture

- European/G7 administrative data set for interoperability between G7 card projects
- European/G7 emergency data set for interoperability between G7 card projects
- Diabetes passport as a basic monitoring tool for all DIABCARD sites
- Basic Information Sheet (BIS) for DIABCARE quality improvement.

The DCDS is interoperable with Cardlink [11] using its emergency data set. Data items needed for the pilot tests were added. Existing and emerging standards, for example for data storage ASN.1-structure (ISO 8824, 8825, etc.), have, as far as possible, been integrated.

Experiences in projects mentioned above and further analysis and OO-design led to the DIABCARD chip card based medical information system (CCMIS). Its main principles are
- modularity;
- adaptability;
- interoperability;
- user-centred design;
- security.

This resulted in an architecture (Fig.4) and first implementations.

On the top level of the DIABCARD architecture we find the applications consisting of
- the DIABCARD Browser, which allows the user to view the card's content without any special programming effort;
- the DIABCARD Value Added Services which will make possible the integration of third party software, e.g. for quality assurance or statistical data analysis; and
- the DIABCARD Core System – a medical record system for diabetes management.

Concepts developed in the DIADOQ and the ByMedCard system were used to implement the DCDS in the DIABCARD Core System (Fig. 4) [12], the electronic patient record for all 8 sites. First evaluation of the system has been performed leading to an optimised user and functional adaptation.

Security features have been implemented on a first level [13] on the basis of principles and methods developed in the ISHTAR and TRUSTHEALTH projects.

The following characterises the Core System:
- patient visit orientiation
- documents
- extensive and interoperable data set as controlled vocabulary;
- communication by chip cards;
- authentication by health professional cards.

The design tried to stay as close as possible to the doctor's daily routine workflow. The electronic patient record is handled analogue to a paper based medical record system using the document paradigm. The documents are attached to patients' visits; and stored with date and time of creation, respectively modification, its performer and status (time stamp). Predefined documents, implementing the full DIABCARD data set, are provided as 'pre-assembled system'. The DIABCARD document generator supports the flexible creation of documents by the user which is prerequisite for acceptance by the user.

6. Second Generation European Projects and Systems

The following projects had a major influence on the approach towards the ECHR and the development of Medical Record Systems:

- DIOGENE (an integrated hospital information system) with a special telephone-oriented user interface developed and used successfully in its initial phase. It started with a very centralized system and has moved to a distributed one in the last years [14].
- PEN&PAD clinical workstation [15] for healthcare professionals which concentrated on structured data entry and retrieval and which was a basis for the GALEN project. It is running in different environments and is also integrated into a physician's office system.
- ORCA, which is an open record for direct patient care [16] and which is part of the I4C TAP project. It offers a generic structure for record sharing and record keeping tailored to specific needs, e.g., cardiology.
- EUROCARDS defined the European administrative and emergency data sets for health cards and their visualization.
- DIABCARD which has built an EPR for patients [17] with diabetes based on several standards including EUROCARDS, and EURODIABETA [6]. Communication is performed via an intelligent chip card (a smart card). For the architecture a layered approach was chosen to achieve interoperability on all levels.
- DIADOQ has developed a problem and document oriented EPR supporting knowledge-based decision support, clinical guidelines, and quality assurance [8]. It is a basis for the DIABCARD CCMIS (Chip Card-based Medical Information System)

At the same time the EHCR-SupA [11] was started which works on:

- dissemination of results of European Third Framework projects,
- giving expert advice and training to user groups, and
- a maintenance mechanism to collect feedback of experience.

7. Assessment of the EHCR

Assessment as part of the evaluation process should be an integral part of system development. For EHCR the assessment should be built around the patient record functionality. Categories, which should be covered in any case are:

- Access in terms of availability, convenience, reliability, and ease of use;
- Data quality described as legibility, accuracy, completeness and meaning;
- Data security which includes integrity and privacy;
- Flexibility, adaptability and extensibility to users' needs;
- Effectiveness and efficiency;
- Usefulness and usability;
- Integration into legacy systems and other applications.

However, more complex functions, such as data acquisition, retrieval and workflow management should be considered.

8. Conclusion

The EHCR is a broad research field, and is patient and user oriented. It has to take into account very different user groups and institutions. EHCRs are mostly designed for use in clinical routine, that does not meet the requirements of modern healthcare. Computer power and networking enables the wide application and dissemination of EHCRs. On top of that clinical cases could be used for education and epidemiological research. As standardization of the medical record and interoperability of the medical record systems and parts succeed, the quality of healthcare provision and its use will improve.

Analysis of the routine work has to be the starting point to define the scope of the required knowledge-based support. Only when persons involved in the delivery of care are supported in their daily routine, acceptance of information systems in general and knowledge bases in particular is achievable.

The DIADOQ CPR supports the explicit representation of the medical acts, facts and main inferences underlying the process of healthcare delivery. A controlled vocabulary is maintained by a frame-based concept system. This representation is the foundation for a consistent and comparable recording of patient data and for the flexible adaptation of screen forms to clinical contexts. The explicit and structured representation of the process of healthcare delivery enables the tight integration of knowledge-based decision support in the CPR system.

The DIABCARD approach to communication between different partners in healthcare, using chip card technology, has to be integrated into current CPR systems. It will also show its functionality as a portable medical record system, complementary to emerging internet solutions.

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