Web-Enabled System Design for Managing Clinical Information

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INTRODUCTION

Healthcare is characterized by a highly complex environment where the process of patient care requires an unusual amount of communication between different healthcare professionals (HCPs). For a better patient care, the various HCPs have to cooperate, a processed often called shared care (Garde & Knaup, 2006; Schabetsberger, Ammenwerth, Andreatta, Gratl, Haux, & Lechleitner, 2006). Nowadays, there is an increasing incorporation of a heterogeneous set of Information Systems (ISs)—paper-based and computer-based—on the daily work of HCPs, in order to retrieve information about patients (Coiera, 2003; Van-Bemmel & Musen, 1997). The complexity of the patient care process combined with the heterogeneity of the information resources leads to a paradigm of data redundancy in the healthcare services in general, and hemophilia care in particular.

Hemophilia is a chronic disease that affects about 400,000 people worldwide; however, most of these people do not have access to adequate treatment (Evatt, 2005). A system for patient registry is a critical tool for monitoring, identification, and diagnosis of these patients; furthermore, it serves as an essential tool for managing their treatment. A registry is a database or a collection of records of people identified as having hemophilia or inherited bleeding disorders (Evatt, 2005). The purpose of a registry is to define the population demographics and collect observational data on specific hemophilia health concerns such as the prevalence of viral infections, factor inhibitors, implementation of prophylaxis for children or different product usage (Baker et al., 2004).

Portugal, in spite of having about 1,000 patients with hemophilia, doesn't have a hemophilia national patient registry, and most hemophilia treatment centers (HTCs) don't have a specific system to store and manage information concerning this pathology.

In order to help the management of this information at the *Hematology Service of Coimbra Hospital Center* (HS_CHC), as well as to facilitate communication between HCPs and patients, and improve the utility and quality of clinical data and treatment information, a Web-based IS under study is briefly presented in this work. To guide this study, namely along its design process, we followed an approach that combines a *grounded theory* approach with evolutionary design based on constant development, evaluation, and refinement of the generic domain model.

BACKGROUND: HEMOPHILIA CARE, INFORMATION AND TECHNOLOGIES

Hemophilia is an inherited bleeding disorder caused by low concentrations of specific coagulation factors (Bolton-Maggs & John-Pasi, 2003). With proper treatment, people with this disease can live healthy lives; otherwise, hemophilia causes crippling pain, severe joint damage, disability, and death (Baker et al., 2004).

Around 30 years ago, the development of coagulation-factor concentrates changed the life of these patients and allowed to treat them at home maintaining a high level of independence; thus, currently, most people with severe hemophilia are on therapy at home with infu-

sion of the coagulation-factor concentrate. While some studies demonstrated significant quality of life benefits associated with home therapy using coagulation-factor concentrates (Teitel et al., 2004), this increased the difficulty to monitor their treatment and progress as well as to detect complications. For instance, many patients arrive at their care center without their home treatment record. Even when they have completed a paper record, uncertainties are often expressed as to the validity of the data, because it is possible that much of the data is entered retrospectively immediately prior to the clinic visit. Thus, there is an urgent need for the collection of meaningful outcome data for hemophilia, and in turn this means being able to obtain accurate records of home administration of coagulation-factor concentrates (Baker et al., 2004).

Web-based IS have the potential to support the ongoing care needs of patients as well as the collaborative management of with a chronic disease, like hemophilia. According to Baker et al. (2004) and Walker et al. (2004), one of the most relevant applications of electronic recording through the Web is the identification of early episodes of bleeding in the home setting, which otherwise would not have become apparent until the time of the patient's next clinic visit. A Web-based IS is also particularly helpful in identifying inappropriate use of coagulation-factor concentrates during home therapy.

Since hemophilia care is very expensive, cost-effective use of resources is extremely important; however, ensuring better data quality requires a continuous improvement process that includes the adoption of new information technologies, timely data entry, and rigorous audit and definition of data fields (Baker et al., 2004; Haux, 2006). Improving communication between patients and hemophilia center HCPs and the quality and timeliness of data collection and manipulation gives a better opportunity to improve long-term clinical outcomes in a cost-effective way (Collins et al., 2003). Moreover, improved communication pathways with HTCs can help minimizing the sense of isolation that patients with this disease may experience.

WEB-BASED INFORMATION SYSTEM TO SUPPORT HEMOPHILIA CARE

Motivation and Problem Context

The HS_CHC (one HTC in Portugal) requested the present study in order to evaluate the feasibility and usefulness of a Web-based IS to collect, record, and manage hemophilia patient data, based on the previous mentioned reasons. This HTC provides assistance to patients in three integrated Hospitals (*Central Hospital*, *Bissaya Barreto Maternity Hospital* and *Pediatric Hospital*) and provides clinical and laboratorial support to other hospitals all over Portugal.

Nowadays, the Portuguese Health Service uses several different computer-based ISs, in order to support the information flow and communication between different HCPs. The computer-based ISs used in HS_CHC are, basically: (i) *Integrated Hospital Information Systems* (IHIS)—which allow to visualize, manage and archive the administrative information while creating a clinical process; (ii) *Medical Support Information System* (MIS)—which allows to visualize, manage, and archive the clinical information during the medical appointment; (iii) *Nursing Support Information System* (NIS)—which allows to visualize, manage and archive nursing information during treatments; (iv) *ClinidataXXI*—to archive clinical analysis results and laboratorial information providing online service at the three aforementioned hospitals.

These computer-based ISs represent generic solutions, since they were developed to support general requirements of hospitals and cannot respond to the specific needs of hemophilia care. However, hemophilia center HCPs generate a lot of information when they observe their patients. Part of this information is in electronic format and is stored in computer-based ISs, but another part (i.e., home treatment records) is on paper format and is stored in paper files.

At present, patients record the result of hemophilia home therapy in paper diaries and send them to the HTCs by post, or bring them when they attend routine review appointments. This system has a number of weaknesses, as often paper records are incomplete or not returned. Furthermore, the period between individual infusions of treatments and receipt data may be long, which is undesirable, since that data is very important for clinical decisions about treatments. In this pathology, the information result of home therapy is more

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