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Modeling a Web-based Information System for Managing Clinical Information in Hemophilia Care

Leonor Teixeira, Carlos Ferreira, Beatriz Sousa Santos and Natália Martins

Abstract— **Nowadays, Information Systems combined with the Internet, have a significant role in data storage, as in the efficiency and promptness of data transfer and can offer a large contribute in managing and manipulating the information resulting from treatment and attendance of chronic patients, as hemophiliacs [1, 2]. On the other hand, the Internet also created the opportunity of patients to insert data concerning home treatments.**

This paper briefly describes the modeling process of a Web-based information system to help the management of inherited bleeding disorders integrating, diffusing and archiving large sets of information from heterogeneous sources in scope of the hemophilia care at the Hematology Service of Coimbra Hospital Center, in Portugal.

I. INTRODUCTION

HEALTHCARE professionals are incorporating more and more in their daily work a heterogeneous set of systems to retrieve information about their patients (paper-based and computer-based information systems). This heterogeneity adds to a paradigm of data redundancy in the healthcare services in general, and hemophilia care in particular.

Hemophilia is a disease that affects about 400,000 people worldwide; however, most of these people do not have access to adequate treatment [3]. A system for patient registry is a critical tool for monitoring the identification and diagnosis of people with hemophilia and evaluating their health. As well, it serves as an essential tool for managing the disease and treatment of those patients. A registry is a database or a collection of records of people identified as having hemophilia or inherited bleeding disorders. 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 [4].

Portugal, in spite of having about 1000 patients with this disease, doesn't have a hemophilia national patient registry and most treatment centers 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*, as well as to facilitate communication between staff and patients, improve the utility and quality of clinical data and treatment information, a web-based information system under study is briefly presented in this work.

This paper is structured in four parts: (i) brief presentation of hemophilia care and information relevance in this scope; (ii) description and contextualization of the Hematology Service problem; (iii) proposal of a model; and finally, (iv) conclusions and future work.

II. BACKGROUND: HEMOPHILIA CARE AND INFORMATION

The hemophilia is an inherited bleeding disorder caused by low concentrations of specific coagulation factors [5]. With treatment products, people with this disease can live healthy lives; without treatment, hemophilia causes crippling pain, severe joint damage, disability and death [3].

The development of coagulation factor concentrates (around 30 years ago) changed the life of these diseased and made possible to treat them at home maintaining a high level of independence; thus, currently, most people with severe hemophilia are on therapy at home with infusion of the concentrate coagulation factor [6]. This circumstance also made it increasingly difficult to monitor their treatment and progress and to detect complications resulting of this treatment. Many patients go to their care center review (appointment) without their home treatment record. Even when a patient has completed a paper record, uncertainties are often expressed as 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 concentrate [4]. The advent of Internet has opened the way for the development of electronic patient records for patients with hemophilia who are on home treatment.

On the other hand, at a time when the cost of providing coagulation factor concentrates has risen significantly, it is important to the hemophilia community to establish more

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Leonor Teixeira is with the Department of Economics, Management and Industrial Engineering, Aveiro University, Aveiro, Portugal (corresponding author. phone: +351-234-370361; fax: +351-234-370215; e-mail: lteixeira@egi.ua.pt).

Carlos Ferreira is with Department of Economics, Management and Industrial Engineering, Aveiro University, Aveiro, Portugal and Operational Research Centre (CIO), Lisbon University, Lisbon, Portugal (carlosf@egi.ua.pt).

Beatriz Sousa Santos is with Department of Electronic and Telecommunication and Institute of Electronics and Telematics Engineering of Aveiro (IEETA), Aveiro University, Aveiro, Portugal (bss@det.ua.pt).

Natália Martins is with Service of Hematology, Coimbra Hospital, Coimbra, Portugal (nataliamartins@chc.min-saude.pt).

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effective mechanisms for the recording of home therapy data. Since hemophilia care is very expensive, cost-effective use of resources is extremely important. Ensuring the best 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 [4]. Consequently, improving communication between patients and hemophilia care staff and the quality and timeliness of data collection and manipulation gives the best opportunity to improve long-term clinical outcomes in cost-effective way [7].

III. CONTEXTUALIZATION OF THE PROBLEM

The *Hematology Service of Coimbra Hospital Center* requested this study in order to evaluate the feasibility and usefulness of a web-based system to collect, record, and manage hemophilia patient data, based on the above mentioned reasons. This service provides assistance to patients in three integrated Hospitals (*General Hospital*, *Bissaya Barreto Maternity Hospital* and *Pediatric Hospital*) and provides clinical and laboratorial support to other hospitals all over Portugal.

The Portuguese Health Service, in order to support the information flow and communication between different healthcare professionals, uses several different computer-based and paper-based Information Systems (IS): The computer-based IS are, basically:

1) IHIS (Integrated Hospital Information Systems) - which allows to visualize, manage and archive the administrative information while opening a clinical process;
2) MIS (Medical Support Information System) - which allows to visualize, manage and archive the clinical information during the medical appointment;
3) NIS (Nursing Support Information System) - which allows to visualize, manage and archive nursing information during treatments;
4) ClinidataXXI - to archive clinical analysis results and laboratorial information providing on-line service at the three above mentioned hospitals.

These computer-based IS represent generic solutions, since they were developed to support general requirements of hospitals and healthcare centers and can't respond to the specific needs of hemophilia care. However, medical professionals of hemophilia care generate a lot of information when they see their patients; part of this information is in electronic format and is stored in computer-based ISs; but another part (home treatment records) is on paper format and is stored in paper file.

At present, patients record the result of hemophilia home therapy in paper diaries and send them to the hemophilia treatment center 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. Moreover, the period between individual infusions of treatments and receipt data may be long, which is undesirable, since that data is very important for clinical decision about treatments. In this pathology, the information is more than a resource, as further clinical decisions about patients' treatment depend on it.

The fact that the information concerning hemophilia patients is spread throughout different ISs is an obstacle for quality of data, fast retrieval of information and, consequently, healthcare quality. The need of an integrated information system for this specific pathology is obvious, and new technology has an important role in this field. These were the reasons that motivated the present work.

IV. OUR PROPOSAL

As mentioned, the goal of this proposal is to develop an information system to help the management of inherited bleeding disorders, which integrates, distributes and archives large sets of information from heterogeneous sources in the scope of hemophilia care at *Hematology Service of Coimbra Hospital Center*. The followed methodology involved until now two stages: requirement analysis and modeling. Requirement analysis is an important part of the software engineering process, where the needs or requirements of the system are identified [8, 9]. Having identified these requirements appropriated modeling techniques should be used. An object-oriented environment of design was selected, since it will allow incorporate new components based, for instance, in decision support methods or technique for formulating complex queries on the stored data. We have chosen the Unified Modeling Language (UML) since it is a object-oriented design technique representing a standard language for specifying, visualizing, constructing, and documenting the artifacts of systems [10, 11].

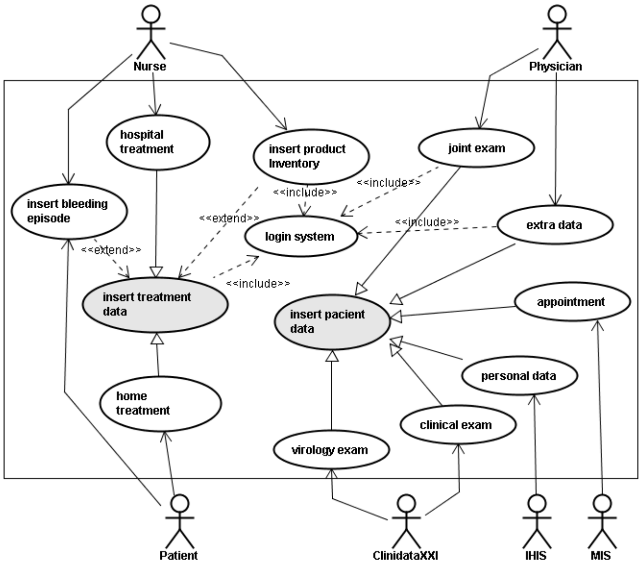


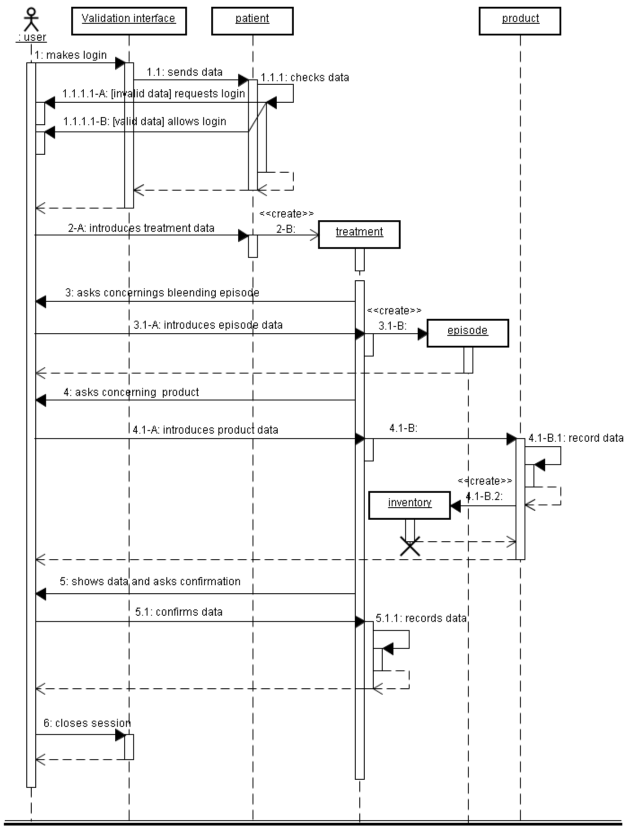
Fig. 1 –Use case diagram including insertion tasks.

The aim of the first stage is to identify the characteristics of information, the needs of the users, the key tasks they will perform with the system and the system functionality. In this stage, analysis of electronic sources of computer-based ISs and of material sources of the paper-based ISs were performed; direct and indirect observation were used during clinical practice as well as interviews with physicians.

After this stage the actors and functionalities of the systems and main classes of information, were identified.

Due to the fact that use case modeling is generally regarded as an excellent technique for capturing the functional requirements of a system [12], the use case diagram of UML was used to describe the external elements (actors) and functionality (use cases). The identified actors are the physician, nurse, patient (human users), and IHIS, MIS, ClinidataXXI (other systems). Figure 1 shows which actors interact with each use case for the main functionality, as well as the key processes involved in information introduction.

Sequence diagrams of UML are interaction diagrams that specifies how functionalities are carried out (what messages are sent and when). In Figure 2 this diagram was used to describe how objects (actor and classes) collaborate to execute the ‘insert treatment’ functionality.



Note: user can be a patient or a nurse

Fig. 2 –Sequence diagram including ‘insert treatment’ functionality.

In order to represent the static structure, showing object classes, attributes as well as relationships between those object classes, a class diagram of UML was used, Figure 3.

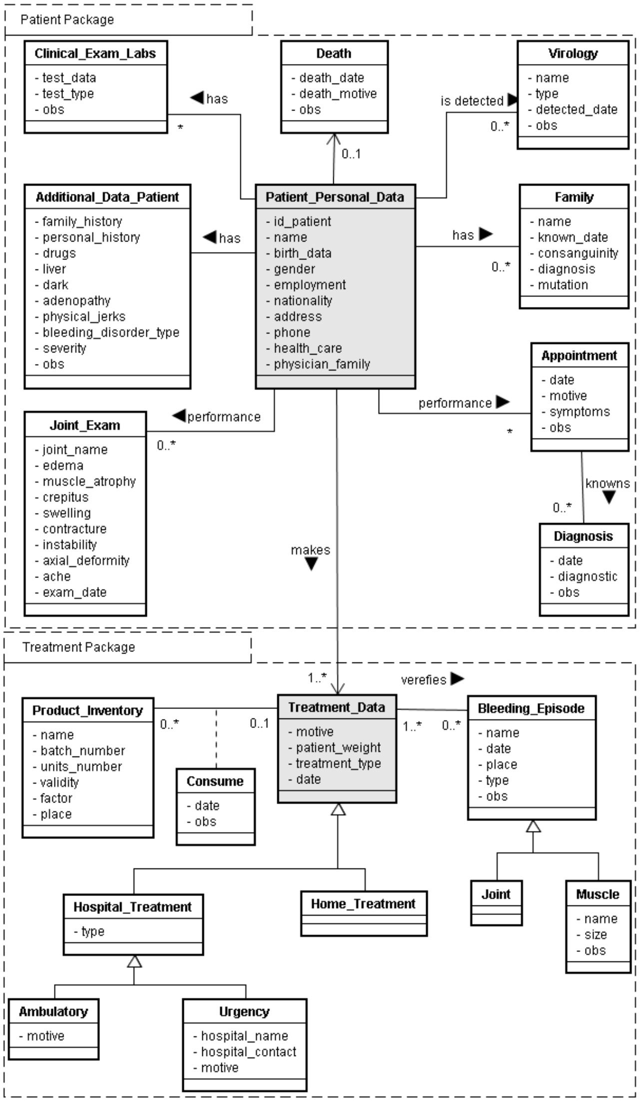


Fig. 3 - Class diagram of generic conceptual model.

Besides the patient personal data, it’s also important to record the data obtained from the medical program routines (appointment) and medical diagnosis. The patients’ data are stored with a unique identification; each patient has a virology history, as well as, a history concerning clinical analysis. Part of this information is stored in IHIS (personal data) and in ClinidataXXI (results of clinical analysis and virology exams). In order to eliminate data redundancy the proposed system will be integrated with the existing ISs, namely, IHIS, MIS and ClinidataXXI.

Also regarding the patient, it’s necessary to store additional data obtained during the first medical appointment, such as family tree and family history, joint condition, treatment history, etc.

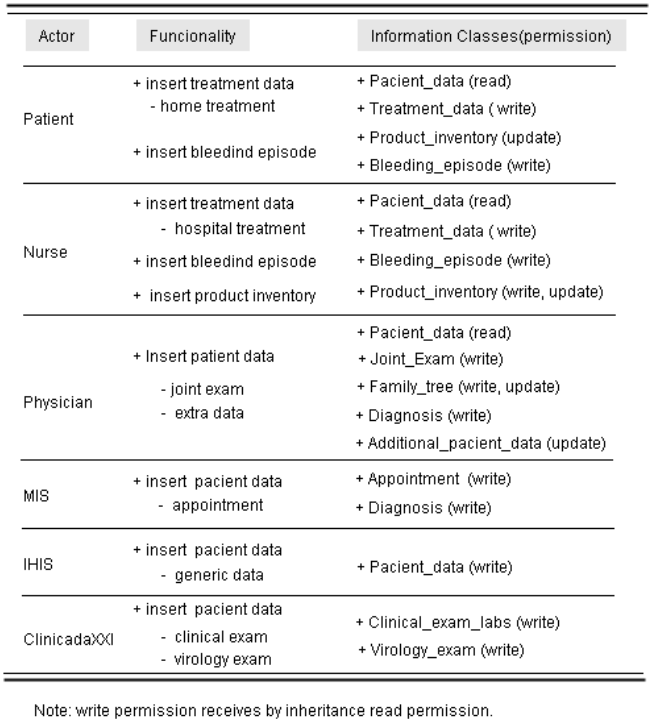
Each patient has many treatments. The treatments can be “on demand” or prophylactic. “On demand” treatments have associated bleeding episodes (in a joint or in a muscle). On the other hand, treatments can be made at home or at a hospital treatment center.

Usually, treatments consist of infusion of a blood product (coagulation factor concentrates) which are in stock; thus, functionality concerned with management of the blood products inventory should also be integrated.

When a blood product arrives at treatment center, a nurse inserts its data into the system (name of product, data of reception, batch number, number of units per batch, validity). A blood product can be in different places, as it can be given to patients for home treatment or to a distant treatment center. When a blood product is consumed in the sequence of a treatment, the system ought to register this occurrence and automatically recount a number in stock.

The model shown in Figure 2 was organized in two large information groups: patient package and treatment package. The information classes included in both groups can be visualized (read), inserted (write) and updated (update) by different actors through different functionality.

TABLE I
RELATIONSHIP BETWEEN FUNCIONALITIES AND INFORMATION CLASSES.



Actor	Funcionality	Information Classes(permission)
Patient	+ insert treatment data - home treatment + insert bleedind episode	+ Pacient_data (read) + Treatment_data (write) + Product_inventory (update) + Bleeding_episode (write)
Nurse	+ insert treatment data - hospital treatment + insert bleedind episode + insert product inventory	+ Pacient_data (read) + Treatment_data (write) + Bleeding_episode (write) + Product_inventory (write, update)
Physician	+ Insert patient data - joint exam - extra data	+ Pacient_data (read) + Joint_Exam (write) + Family_tree (write, update) + Diagnosis (write) + Additional_pacient_data (update)
MIS	+ insert pacient data - appointment	+ Appointment (write) + Diagnosis (write)
IHIS	+ insert pacient data - generic data	+ Pacient_data (write)
ClinicadaXXI	+ insert pacient data - clinical exam - virology exam	+ Clinical_exam_labs (write) + Virology_exam (write)

Note: write permission receives by inheritance read permission.

Table 1 shows this relationship between the functionality presented in the use case diagram, the information classes presented in the class diagram and corresponding permission.

V. CONCLUSION

Information Systems together with the Internet offer presently significant opportunities to healthcare professionals and patients to improve their communication and joint management of chronic diseases. On one hand, they offer healthcare professionals analytical tools to transform data into information and mine relevant information through data queries. On the other hand, using a web-based information system, patients can have direct access to the system, allowing them to view their clinical history, as well as introduce treatment data. The management and stock control of the products used in treatments can also be improved.

In this paper we describe the process of modeling a Web-based information system for managing clinical information in hemophilia care to support patients assisted at the Hematology Service of Coimbra Hospital Center. The first phase was to identify the information gaps in the service. Then, we proceeded to the requirement analysis with business process assessment, direct and indirect observation techniques and interviews with healthcare professionals. Six actors were identified: patient, physician, nurse, and three already existing Information Systems (MIS, IHIS and ClinidataXXI). Based on the identified actors and needs, a generic conceptual model was developed using Unified Modeling Language.

This model is now under test, before we can proceed into other phases of system development, which will include the design and test of a conceptual model for the user interface and a prototype.

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