



Design of a Web-enabled System for Managing Clinical Information in Hemophilia Care

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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. On the other hand, the Internet also provides the opportunity of patients to insert data concerning home treatments.

This work briefly describes the **design 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 the scope of the hemophilia care at the **Hematology Service of Coimbra Hospital Centre**, in Portugal.

1. Background: Hemophilia and Information Management

1. **hemophilia** is a **chronic disease** that affects **about 400,000 people worldwide**, however, most of these people do not have access to adequate treatment.

- In Portugal, there are about **1000 hemophilic patients**;
- Portugal doesn't have a system for a **national registry of hemophilic patients**;
- In Portugal most hemophilia treatment centers (HTCs) don't have a specific system to store and manage information concerning this pathology.

2. **Hemophilia care is very expensive** and cost-effective use recourse is extremely important.

3. Improving communication between patients and professionals of HTCs 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.

The **new Information and Communication Technology** has an important role in this field and can offer a large contribute for managing clinical information in hemophilia care.

2. Case Study: Motivation and Problem Contextualization

This study was requested in order to evaluate the feasibility and usefulness of a Web-based IS to assist in the hemophilia patient care at a Hemophilia Treatment Centre located in Portugal - **Hematology Service of Coimbra Hospital Centre**.

- Provides assistance to patients in three integrated hospitals (General Hospital, Bissaya Barreto Maternity and Pediatric Hospital).
- Provides clinical and laboratorial support to other hospitals all over Portugal.

Kind of Information Systems (ISs) used:

Computer-based ISs

1. Integrated Hospital Information Systems - IHIS
2. Medical Support Information System - MIS
3. Nursing Support Information System - NIS
4. ClinidataXXI system

Paper-based ISs

1. Home treatment record
- ⊗ **Weaknesses:** paper records are incomplete or not returned.

⊗ **Represent a generic solution** => can't respond to the specifics needs of hemophilia care.

⊗ **solution: an integrated IS for this specific pathology**

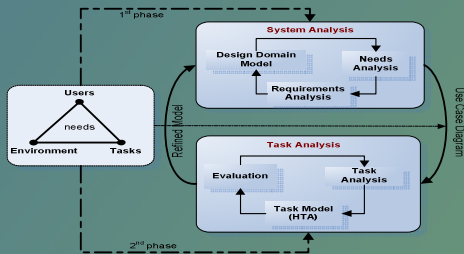
3. Solution: Web-based Information System

Goal of the Web-based IS - to support the management of inherited bleeding disorders, which involves the integration, distribution and archive of large sets of information coming from heterogeneous sources.

Process of system design

In our **process of system design** we took into consideration:

- the **environment** of which the Web-based IS is one component;
- the **people** who are supposed to use the system;
- the nature of the **tasks** they have to perform.



1st phase - System Analysis

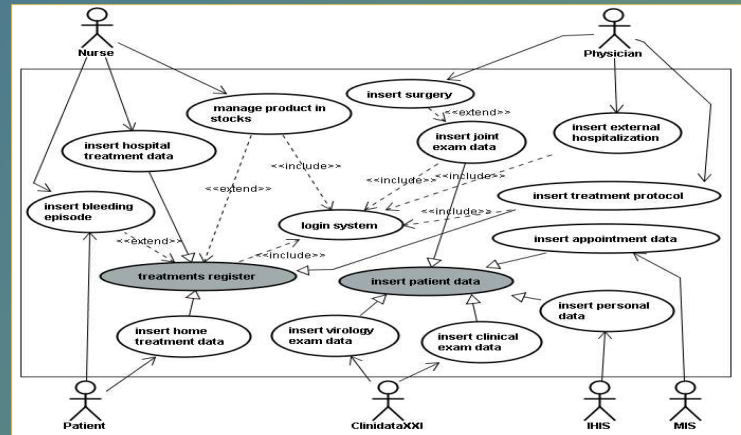
- **understanding the characteristics of this specific practice** (direct observation, documentation analysis and unstructured interviews);
- **developing a domain model** (using systems analysis methods formalized through the *Unified Modeling Language*).

2nd phase - Task Analysis

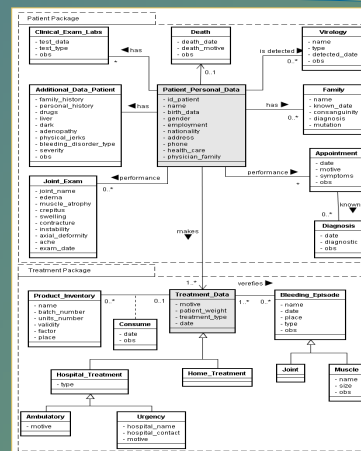
- Validate and improve the functionalities and domain model of the application.

4. Results

Use-case diagram: actors and main functionalities related with the insertion task.



Generic Domain Model



→ the **patients' personal data** is important object to record the data obtained from the medical program routines (appointments) and medical diagnosis;

→ Patients' data are stored with a **unique identification**;

→ Each patient can undergo **many treatments**;

→ **treatments** consist of infusion of blood products which are in **stock**;

→ When a blood product is consumed in the sequence of a treatment, the system should register this occurrence and automatically **update the stock**.

5. Conclusions

→ 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;

→ This work describes the process of modeling a Web-based IS for managing clinical information in hemophilia care. Using a web-based information system:

1. Patients can have direct access to the system, allowing them to view their clinical history;
2. Patients can introduce treatment data in the system through the Web;
3. The process of management and stock control of the products used in treatments can also be improved.

6. Future work

- Developing and implementing this technologic solution in **Hematology Service of Coimbra Hospital Centre**;
- Extend this study to other Hemophilia Treatment Centre in Portugal.

In order to

- ⊕ Contribute to the system of **hemophilia national patient registry**

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