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User Requirement Analysis: Online Thalassemia Management System for Hospital Sultanah Aminah, Malaysia

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ABSTRACT

The care process of patients suffering from thalassemia involves continuous and complex care procedures, which produce a large volume of diverse data. This makes the management of the patient records using paper-based system cumbersome. Information technology (IT) is an essential factor in the administration of healthcare where it can improves health care quality and service. Besides that, it provides more accurate and timely information regarding patient care. Consequently, the adoption of IT tools such as Electronic Medical Records (EMR) in hospitals is a solution to reduce some barriers in the healthcare services. This solution may improve the effectiveness of chronic disease management such as thalassemia, since a lot of the patient's data will be stored and retrieved due to the frequent monitoring and treatment. In order to facilitate successful adoption of an EMR, involvement of end-users would be essentially required during the designing, implementation and usage phase. In this study, an EMR specifically design for thalassemia patient management is proposed to be implemented in Hospital Sultanah Aminah, Johor, Malaysia. The user requirement analysis (URA) of the proposed system, Online Thalassemia Management System (OTMS), is investigated and discussed in this article.

1. Introduction

Thalassemia is the most common monogenic disorder worldwide, with an estimated 365,000 affected infants born each year [1]. It is characterized by partial or no production of α or β globin chains, which form part of the structure of the haemoglobin in the red blood cells. Children with thalassemia may appear well at birth but will then develop anaemia that becomes progressively worse due to the partial or total absence of haemoglobin which if left untreated, can result in early deaths [2].

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There are different types of thalassemia, but α-thalassemia and β-thalassemia are the most important because of their potential adverse effect on health. Recent data from the Malaysian thalassemia registry showed a total of 6,624 registered patients of which majority patients are transfusion-dependent thalassemia [3]. In Malaysia, the most common thalassemia disorder is β-thalassemia which approximately 4.5% of Malaysians are carriers of β-thalassemia [4]. It is estimated that 2.1 per 1000 are affected at birth. The Ministry of Health of Malaysia estimated that between 150 and 350 babies in the country are born with thalassemia each year [5].

As with other chronic disease management, the care process is lengthy and continuous, consisting multiple different parts of procedure. Therefore, having IT tools such as an EMR to assist the process can improve the healthcare services quality. Besides providing more accurate and timely information regarding patient care [6], it has been found to improve the efficiency of hospital services especially in terms of patient data management.

However, medical records in Malaysia are still predominantly paper-based despite well documented shortcomings in terms of accuracy, completeness, availability and legibility [7]. Incomplete, illegible, or unavailable patient information may result in redundant or marginally productive visits, diagnostic and screening tests, and interventions. Preventive care and patient education may be overlooked if consultations have to focus on rebuilding clinical data.

A study shows that the reasons for the low adoption rate may be cost-, technology-, knowledge-, human-, or legal-related issues [10]. Another study shows that 'Human' context had the highest size effect of HIS adoption in Malaysian Public Hospitals [13]. This implies the importance of human skills, experience, expert, satisfaction and information quality to successful HIS adoption. Studies on how to improve EMR adoption and implementation have suggested that system developers can promote and sustain EMR adoption if they collaborate with targeted end-users in planning phases of the system [11,12].

The purpose of the study in this article is to investigate and identify the user requirement towards development of Online Thalassemia Management System (OTMS). The Paediatric Day Care Unit in Hospital Sultanah Aminah (HSA), Johor Bahru, Johor, Malaysia has being selected for the purpose of this study. In this research, series of semi-structured interviews and discussions were completed to gather and determine the user requirements.

2. Methodology

2.1 Research Approach

Based on past studies, a key factor to ensure success of EMR adoption is the active participation of end users during all phases of EMR development. A study shows that user-centered design (UCD) approach increases Hospital Information System (HIS) efficiency [13]. Analyses and a good workflow understanding help in the development of a system that fits well with current clinical practices. This approach should include active user involvement for a clear understanding of user and task requirements, iterative design and evaluation, and a multi-disciplinary approach. It helps to ensure system acceptance by its users [14] because a main barrier to EMR adoption is difficulty in finding a system that meets such needs [15].

2.2 Research Scope and Setting

Hospital Sultanah Aminah (HSA) is a government-funded multi-specialty hospital in Johor Bahru, Johor. The management of thalassemia patients in HSA is divided into paediatric and adult. The paediatric patients are under the care of the Day Care Unit by the Paediatric Department. It provides

ambulatory pediatric services, thus avoiding unnecessary overnight in-patient hospitalization. The unit provides a wide range of services for thalassemia patients, who require blood transfusion or review; hemophilia patients, who require prescription update or review; and out-patients undergoing diagnostic radiological procedures such as CT scan and MRI, who require preparation and sedation. Currently, there are 79 thalassemia patients and 8 hemophilia patients registered with the day care unit.

There are one Medical Officer and two nurses in-charge every day. They are the targeted end users for the proposed system in this study. The Paediatric Day Care Unit in HSA is selected because they are responsible to manage thalassemia patients and still using the paper-based medical record system.

2.3 Observation and Interview

The observation on the day care unit has been made and semi-structured interview session with the doctor and staff nurses were conducted. The interview mainly evolved around three main questions, which related to their daily routine in the day care unit, problem or difficulty that they face and their alternative to solve the problems. Their opinion and acceptance about implementing the web-based management system in the department were also being reviewed.

3. Results and Discussion

Series of semi-structured interviews and discussions were made to gather and determine the user requirements. User requirement analysis for OTMS cover the overall description of the system, specific requirements, and diagrams of the system. It states the perspective of the system, the general functions of the system, and the system expectations of the targeted end-users. Business process and requirement list were produced in this study.

3.1 Observation and Interview

The day care unit received 6-7 thalassemia patients daily. From last year's (2016) record, there are about 140-150 of thalassemia patient attendance monthly, with a total of 1700 attendance for the whole year. The unit's registered patients come from all over Johor Bahru but a few do come from other nearby districts such as Kota Tinggi and Pontian. Commonly, a thalassemia patient will come to the day care unit once-a-month. Depending on their conditions, some may have to come more frequent than others.

In this study, all of the staffs were open to the suggestion of implementing OTMS at the day care unit. From the interview, it was found that the patient's data in the department is still using paper-based which prone to the missing and incomplete data in patient's file. From the interview session, they expect that the system will reduce their workload, space and cost of managing the patient's files. As a result from the interview and observation during the requirement gathering process, the day care business processes are developed to guide the development of the proposed system. Business processes for the day care unit can be divided into two, new patient in Figure 1(a) and recurrent patient in Figure 1(b).

3.2 Requirement List

The proposed system should be available to any internet-enabled client machine in order to better assist the patient management workflow. It is intended to focus on management of patients diagnosed with Thalassemia. The system functions shall provide quick and easy access of the patients' health record. The system also shall provide a consistent and user-friendly presentation of information across the entire system and provide a user-friendly and functional platform for data entry to the database. Table 1 below lists the user requirement as gathered during the interviews, discussions and observation process.

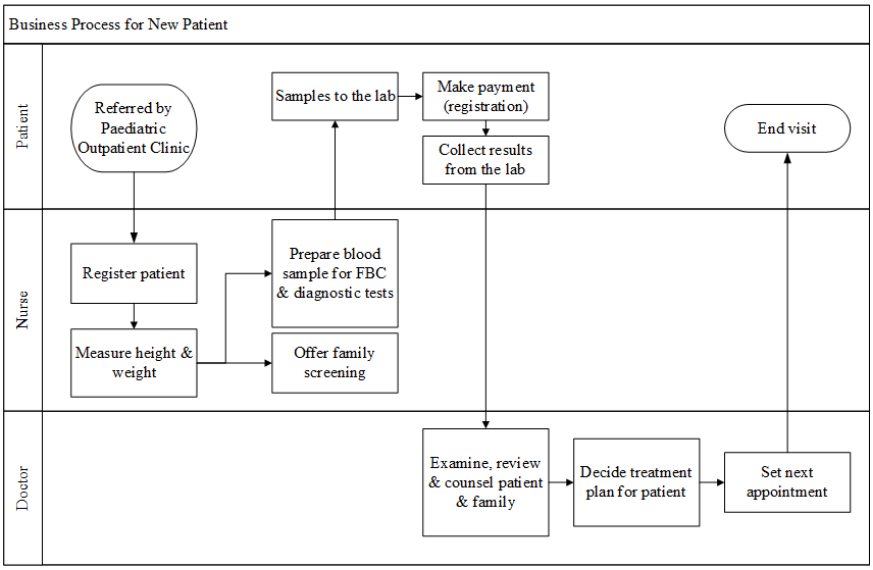

Fig. 1(a). Business Process for New Patient

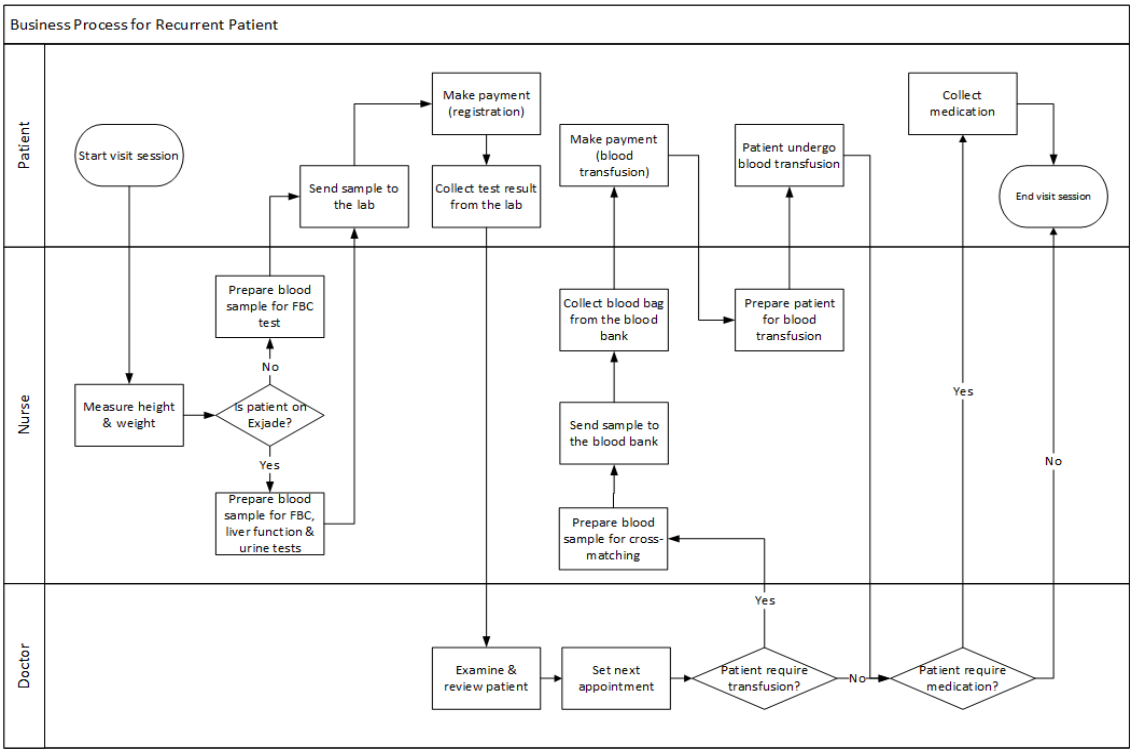

Fig. 1(b). Business Process for Recurrent Patient

Table 1
Requirement list and the descriptions

Requirement	Description
General	The system identify and maintain patient record
	The system supports both a total paperless function and a hybrid function, where the contents of the electronic record can be printed for inclusion in the paper chart
	The system date and time stamps all entries
Demographics	The system has the capability to create, review, update and delete patient demographic information as well as other non-clinical Information from the patient record
Medical History	The system supports capture of patient medical and surgical history
	The system documents patient drug allergies
Current Health Data	The system has the capability to create, review, and amend information about the patient's condition and result obtained from laboratory, radiology tests and/or procedures
	The system has the capability of printing referral letters
Visit - Consultation Notes	The system record and capable of printing consultation notes
	The system has the capability to automatically update other sections of the record with data entered in the consultation note (e.g. test results, appointment date)
	The system has the capability of printing consultations notes
Results	The system accepts results data through direct data entry
	The system displays results in a customizable, intuitive, and flexible format
	When displaying results, the system, at a minimum, displays the patient name, date and time of order, date and time results were last updated
	Quick access to results
Template Forms and Letters	The system has the capability to print any laboratory/radiology test order form template for manual transmission
Reminder & Alerts	The system includes an appointment reminder capability
	The system uses visual cues to highlight missed appointments and abnormal results
Medications	The system stores prescription information
Confidentiality and Security	The system controls access to the system
	The system incorporates audit trails of each access to specific data
Technical	The system incorporates a consistent user interface for data entry independent of the platform
	The system will be accessible and available to all authorized users
Ergonomic Presentation	The system places emphasis on user friendliness and functionality
	The system incorporates a consistent presentation of information across the entire system
	The system provides consistent formatting to aid users in finding information

4. Conclusion

In conclusion, this article presents the user requirements needed to develop an EMR, specifically for thalassemia patient management in HSA. In order to ensure the effectiveness and acceptance of the system, UCD approach, in which observation and series of interview session has been carried out to identify the end-user requirement. The business process and the requirement list will play a significant role in the next development stage of the proposed system. The list can also be a reference to any effort to develop a similar system in the future.

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