

Designing and Implementation of Web-Based Personal Health Record for Patients with Inflammatory Bowel Disease

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ABSTRACT

Background:

Using personal health record (PHR) for the management of inflammatory bowel disease (IBD) as a chronic disease can be beneficial for the patients and provide their needs and make them more informed. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves and information from doctors, and information from their pharmacies and insurance companies. Using personal health record is one of the crucial aspects of improving personal health. In this survey, we designed and implemented a web-based PHR for patients with inflammatory bowel disease (IBD) in order to help improve the health status of the patients with IBD.

Materials and Methods:

In designing level based on observing methods and assessing documents, at first, the minimum data set was set and then required areas of designing PHR using the questionnaire method and determining content validity by IBD experts were set. The requirements were categorized based on continuous care record standards. In this survey, the process of modeling and implementing patients and physicians modules was done, too.

Results:

Basic capabilities of the system were determined in four parts. Then, the results of the survey of 17 IBD experts about 172 required data in five areas with Cronbach's alpha upper 0.7 were set. Designing and implementing were done for patients and physicians in two different modules.

Conclusion:

This system makes information coherent and enables us to access and manage the health information of the patient. We could also do remote monitoring of patients in long term cares. Also by using the results of the questionnaire survey in patients and physicians modules, we could check out changes in the quality of patients' lives and severity of the disease during the treatment.

Keywords: Personal health record, Designing, Implementation, Inflammatory bowel disease, Medical informatics

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INTRODUCTION

Currently in information era, explosion of information technology has transformed all aspects of the life and work. Undoubtedly, information is a critical source for economic and scientific improvements of each country. Medical care industry is also one of the information based world's industry. While information is so important, it should be documented, maintained, retrieved, and analyzed correctly. In health section, medical information is a key tool and has a special place

in health management plans, assessments, training, and research. Technologies such as medical health record make accurate, available, and exchangeable health information possible (1). To treat chronic diseases a continuing clinical management and permanent access to patients' information are needed, which is not possible through patients' paper history. Access to trustable data is a key factor in the management of chronic diseases such as inflammatory bowel disease (IBD). Recent published standards emphasize on information technology systems in supporting patients' care and also, optimization of clinical information management by collecting and maintaining data (2).

Availability of trusted data is a critical key factor in the management of patients who have chronic diseases such as IBD. It should also be mentioned that due to increasing improvement of science in all sections and organizations worldwide and also many problems about patients' information documentation such as losing information, lack of on time availability of patients' information and their health care history, lack of access to patients' information in different geographical areas, and considering the high volume of referrals, it is critical to replace paper based information by electronic system in health sectors.

Recently published standards in patients with IBD emphasize on the role of information technology and systems for supporting patient-based cares and optimizing clinical management by collecting information (3). The purpose of health care in chronic diseases is not just treatment, but to help patients and make them capable to remain active socially and have more independent life (4). Self-care is now moving from experts to patients and a personal health record (PHR) is a tool for facilitating and supporting self-management of chronic diseases by policy makers (5). PHR is a critical concept based on patient-centered health care, which is a property of patients and is managed by them (6). PHR is promising for improving health. A qualified PHR can facilitate the relationship between patient and physician, enables patients to observe their medical documents, and is suitable for clinical and official transactions. By using PHR, patients can involve in their care in a meaningful way (7).

Three types of categorizing PHR systems, in terms of connections to other health systems, are considered:

The first type is standalone independent model, which is a property of patients and updating is done manually by the patient. The problem of this type is that importing data is done by the patient and there is uncertainty about the accuracy of information for providers. Type two of PHR is integrated health record. It is a property of patients but updating information is done partly by patients and also insurance companies, drugstores, and providers of health cares. The other type is the limited tethered model. It is a form of integrated type, but is a property of physicians or insurance companies, although some of it enables patients to import data, limitedly (8).

Regarding the PHR content, there is low agreement about the necessary information and can differ depending on the application (5,9,10). PHR should be coded by the best ways and standards that are accepted internationally. Two types of significant standards are content care records (CDA) by Health Level Seven International (HL7) and continuous care record (CCR) by the American Association of Testing and Materials International (11).

IBD is a group of chronic diseases with uncertain cause, which has involved digestive systems of millions of people worldwide and has affected their quality of life. The cause of IBD is yet unknown. The prevalence of the disease is increasing in different geographical areas as the time passes. The prevalence of the disease is about %1 in the north of the USA and some European countries. In addition, information indicates an increase in the incidence of disease in Asia, China, Australia. The peak of this disease is between 15 and 30 year of age (12). Although the prevalence of IBD has not been investigated in an accurate way in Iran, our country is in the list of increasing rate of IBD (13).

In this study, at first, we tried to investigate the critical concepts in PHR for patients with IBD and then the design of an easy web-based system based on the standards for patients and physicians was done.

MATERIALS AND METHODS

At first, for extraction of information requirements and main features of a PHR, total medical records of patients with IBD in a period of one year in Shahid Faghihi Hospital and 17 free medical records available in MYPHR (the website of The American

Table 1: Information quality of data dimensions (14)

Quality of Data Dimensions	Definitions	Requirements
Accessibility	Easy information extracting and rapid retrieval	Using web and easy access just by connecting to the internet
Amount of data should be appropriate	Extracting data volume based on requirement	Program designing with facilities like data filtering
Believability	How much the data is accurate and valid	Designing as two different and safe modules
Concise Representation	Extracting data shortly	Using multiple forms and reporting
Easy using	Extracting and using data easily	Using the standards
Security	Accessing data safely	Information confidentiality and privacy policy

Health Information Management Association), were assessed.

In extracting system's requirement, one of the key factors is qualified data, which has been considered according to table 1.

Using the whole information gained in the previous levels and also by comparing PHRs on the web and patients' records and also by consulting with specialists of gastrointestinal diseases, basic qualifications of the design of PHR for IBD patients were determined and a draft of inquiries for the minimum data set was prepared.

This questionnaire contains demographic, diagnostic, follow-up, history and General and specific disease information. The validity of the questionnaire was determined by six gastroenterologists by the content validity index of 99%.

Reliability of the questionnaire was confirmed by the whole gastroenterologists working in Shiraz University of Medical Sciences (12 adult gastroenterologists and 5 pediatric gastroenterologists) by Cronbach's Alpha testing with alpha more than 0.7.

At the next step, based on standards of continuous health record and content standard, the requirements were categorized and modeling the patient and physician modules was done using The Unified Modeling Language (UML). Finally, the implementation was done by PHypertext Preprocessor (PHP). The architecture was designed as modules and menus, which enable system to add new components or substitute other components. The architecture was designed as three layers and at the second layer that is the commercial layer, some of the services were put and users by using Http protocol could run and access the program. For creating interoperability standards forms were designed by XML programming language.

Considering the web presence of the program, testing and debugging of executable section of the software of PHR for patients with IBD were done by programmer team and research group and trouble shooting was done and after several times debugging, the accuracy of factional capabilities of PHR for patients with IBD was confirmed by these groups.

RESULT

There are different types of PHRs, beginning with independent systems, up to systems that can be connected to PHR. Capabilities of PHRs are usually different based on their applications and their types (15).

In this study, after initial assessments, basic requirements and qualifications of web-based PHR in five basic concepts were determined (table 2).

During the assessment done for determining the minimum data set required for patients with IBD in the patients' records, 172 data types of the patients in five aspects of personal information, social and familial history, clinical symptoms, diagnostic and treatment information, and total information about IBD were determined, which each group consisted of subgroups and its related data.

Basic qualifications of patient's and physician's portal were determined and categorized based on standards of CCR & CCD. Patient's portal was designed (figure1). At first, the patient logs in the system and after making an account, receives the password and user accounts. Then, he/she completes areas about demographic information and patient's biography, shares his or her information with physician, and in every visit, they could observe previous information and could change them.

In physician's module (figure2) working with the system is done as follows:

Table 2: Requirements and primitive capabilities of PHR

Row	Title	Explanations
1	System's security foundations	Saving privacy with putting up anti-section policy in the main page of the system Security of confidentiality of information and accessing of physician with permission of patient • Standards by using two standards: CCR* & CCD*
2	Information type	<ul style="list-style-type: none"> • Forms • Personal and contact information • Allergic information, glucose level, blood pressure, blood group, weight and height, vaccination • Drugs information • Familial and social history information • Diagnostic and treatment information
3	System facilities for user	<ul style="list-style-type: none"> • Sharing information • Importing and extracting information • Editing and deleting information • Accessing to information • Attaching the information • Relationship with other systems
4	System's services	<ul style="list-style-type: none"> • Sending patient's and physician's message • Assessing patient's quality of life by questionnaire of quality of life of patients with IBD • Determining intensity of disease by UCAI* & CDAI* questionnaires • Reporting

*Continuity of Care Record
*Continuity of Care Document
*Crohn's disease activity index
*ulcerative colitis activity index

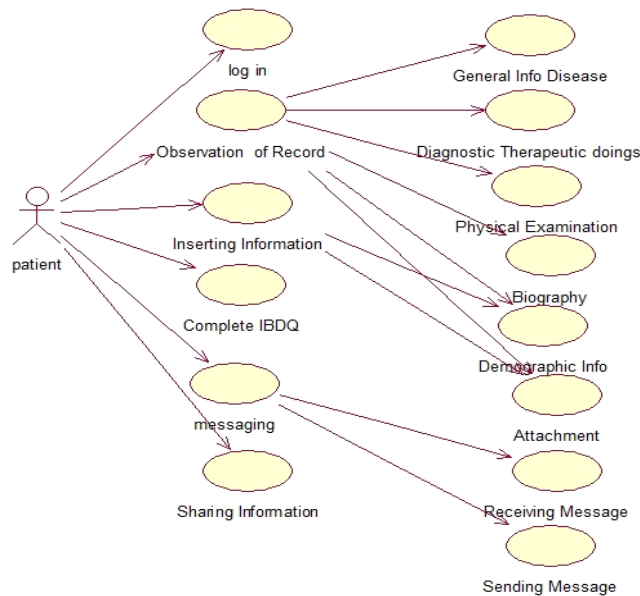


Fig.1: Use-case Diagram for patient

Physician logs in the system, makes an account and receives user ID and a password. Then he/she observes the patients' list and could search the specific patient's name in the list and observes his or her record. In addition, the physician could complete the information about physical examination, diagnosis, treatment operations, and general information about the disease. In every visit, the physician could observe

pervious information and change them, if needed. Also, the physician could add notes and observe other physicians' notes.

System architecture was done in the form of three main layers, which has the advantage that it can easily be integrated with other systems and so, separate hardware could be considered for different layers easily.

Data storage is done based on the database table.

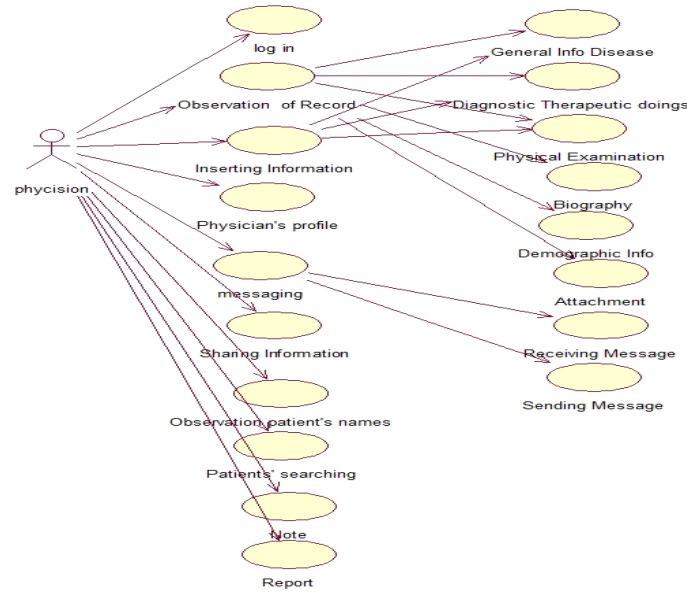


Fig.2: Use-case Diagram for physician

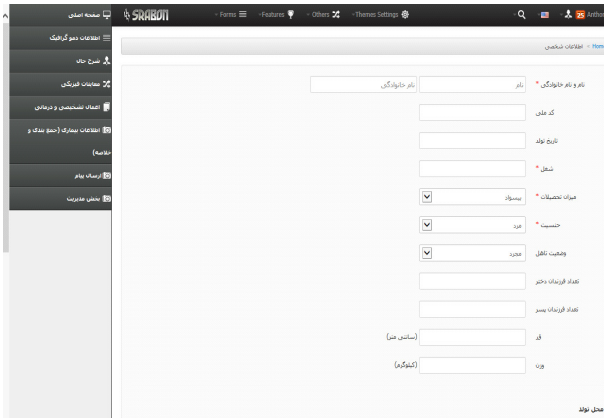


Fig.3: Main page

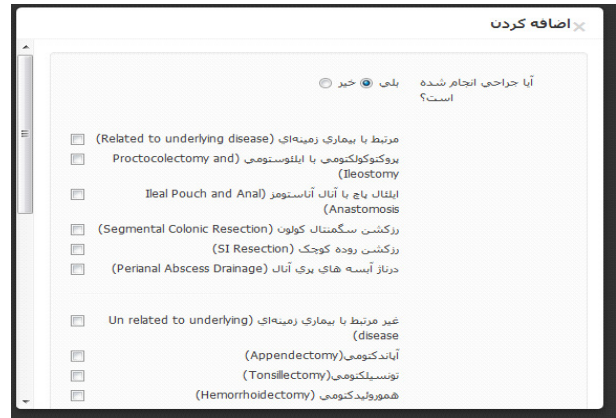


Fig.4: Insert operation

Additionally, this database supports transparent database encryption, which can be used to improve data security.

System coding was done by PHP programming language and in visual studio programming environment (figures 3, 4)

DISCUSSION

There is a low agreement on which information is critical in a PHR and this can be different according to the record's application.

In this study, after initial assessment, requirements and primitive qualifications of a web-based PHR

was determined in four concepts, which are security foundation of the system, information type, systems facilities for user, and system's services. In the study of Almen and colleagues in 2013, to study the required functions for design of a web-based PHR, three basic categories, which were health information, user's actions, and connections, were determined (16). In this study, other significant functions were identified and classified in four categories and their details were expressed.

And considering the fact that this record is about patients with IBD, both public information of patients, which are usual in PHRs, and special data about this disease, should be considered.

In assessing the minimum data set for patients with IBD in patients' records, 172 data types were determined in five aspects. Each group consisted of subgroups and related data. This grouping causes more suitable organized information in the system.

In a study in 2012 by Bardhan in England, the data items of birth date, date of disease diagnosis, sex, disease intensity, history of smoking, current and before treatment, familial history, surgery, main diagnosis, and date and cause of death were considered (17). The whole information mentioned, except date and cause of death, are considered in this study. In addition, other data types were identified and confirmed by physicians.

In this study, a total list of the required minimum data set in a PHR for patients with IBD was created in five sections. Although there are several PHR systems, there are yet obstacles for their acceptance. Basic obstacles are: fees, acceptable standards, technical issues, privacy and data security (18,19).

Using standards creates cooperation capabilities and enables the system to exchange information using some mechanisms. In several studies that have been done in order to design and implement systems about health, these two standards CCR and CCD were used (7).

In this study, PHR for patients with IBD was designed integrally, considering its application.

This system was designed in two modules. In each module the fact that which data should be completed by physicians and which data should be completed by patients have been determined.

In several studies about designing and implementation of PHR, because of advantages of integrated record, this architecture has been used (20-22).

Based on the health providers' idea, security and privacy are always the main concerns in an electronic health information system (20). In 2012, in a study by senior and colleagues available PHRs were assessed in terms of privacy and security. In this study, security, and privacy of a PHR system, considering ISO 13606 standard, was assessed. Security in terms of availability, confidentiality, honesty, and answering was defined.

In this study, privacy policy was put up on the main page of the program and is available and in terms of management of data access, it is just available for health care providers with patients' permission. The system design is different from other PHR systems

in terms of inherence and application. This system is particularly for patients with IBD and was designed and implemented the data related to this disease. In addition, a questionnaire related to this disease has been put up in the system, for assessing the changes of patient's quality of life and changes in disease intensity in the treatment period.

PHR is used in order to provide information for patients by accessing health information. Using PHR leads to extensive achievements, including patients' empowerment for active participation in self care (22,25-27).

CONCLUSIONS

Non-integrated clinical data of patients do not create suitable medical history. PHR is able to collect patients' health information, focusing on Patient-centered care.

In this study, by designing and implementing PHR for patients with IBD we helped to consolidate IBD patients' information. Also, PHR enables users to access and manage patients' health information and do the remote observation of patients in long term care.

Considering the fact that patients with IBD have many problems in their daily life such as social, familial, and work problems and these difficulties have made their life less and less qualified, by using results from assessing questionnaire in patient's module, the quality of life of patients could be assessed in the treatment period. By using questionnaire in physician's module, physicians could also assess changes in illness severity during the treatment period.

As the cause of this disease is unknown up to now, physicians could evaluate data by assessing reliable data in patient health records. By using message interaction system, patients and physicians can interact with each other in any time and place and physicians could decide based on total information in the records.

CONFLICT OF INTEREST

The authors declare no conflict of interests related to this work.

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