33rd Annual International Conference of the IEEE EMBS
Boston, Massachusetts USA, August 30 - September 3, 2011

Designing Patient-Centric Applications for Chronic Disease Management

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Abstract— **Chronic diseases such as diabetes and heart disease are the leading causes of disability and death in the developed world. Technological interventions such as mobile applications have the ability to facilitate and motivate patients in chronic disease management, but these types of interventions present considerable design challenges. The primary objective of this paper is to present the challenges arising from the design and implementation of software applications aiming to assist patients in chronic disease management. We also outline preliminary results regarding a self-management application currently under development targeting young adults suffering from type 1 diabetes.**

I. Introduction

RECENT epidemiological reports have shown that most countries are suffering, or will soon suffer from some sort of chronic disease[1]. The most alarming predictions foresee that the portion of population living with a chronic disease will be constantly rising. Until modern medicine is able to cure chronic diseases, the focus is on controlling them. In the meantime, patients generally do not reap the maximum benefits of what medicine has to offer. The average physician examines 25-30 patients per day and devotes only a few minutes to each one [2]. As a result, patients lack the support and motivation they need to continue managing their condition [3]. Intelligent systems built to cultivate positive behaviors towards chronic disease management and motivate patients on reaching their health goals are sorely needed.

With the advent of information technology in health care, there is a growing interest in developing self- management applications delivered to the patient through the World Wide Web, PDAs and smartphones. A few examples of the chronic diseases targeted are diabetes [4-7], obstructive pulmonary disease, kidney disease [8], congestive heart failure [9, 10] and neurodegenerative diseases. Common feature among the majority of these applications is the patients' ability to track/monitor personal health information (manually or via wearable sensors) which can potentially be reviewed and acted upon by participating health care providers. However, monitoring and tracking is only a subset of the features a self-management application should demonstrate. Additional features, such as motivational mechanisms and educational modules, are expected to enhance the user/patient experience and improve the application's acceptance among the patient community. Foremost, the application should be patient-centric which means it should be centered around and customizable by the patient.

In this work, we report the features and characteristics that we consider crucial to the successful operation of self-management applications and demonstrate their functionality in a diabetes management exercise. The rest of this paper is organized as follows. Section II is dedicated to presenting imperative application features. Section III, presents our preliminary work on the design of a self-management mobile application for young adults suffering from diabetes. Section IV concludes this paper and discusses future research directions.

II. Imperative Application Features

The majority of chronic disease management applications cited provide some sort of health data logging, which may be used for elementary or more sophisticated management of interventions. However, the role of a self-management application is not necessarily to suggest courses of treatment but is, primarily, to engage the patient in actively managing his/her condition. In this section, we describe the features that, in our opinion, are imperative and contribute significantly in motivating and involving the patient in self-care and thus, cultivate positive behaviors towards chronic disease management.

A. User Interface and Application Platform

Undoubtedly, the most important feature in the design of a self-management application is its user interface (UI). A poorly designed UI will discourage the user from accepting the application. There is no single recipe for the design of a successful UI. However, the general guidelines suggest that the UI must be easy-to-use, provide the least amount of information required for a task, be reliable and able to accommodate users of various ages and lifestyles [11, 12]. Furthermore, the choice of the application platform (web-based, smartphone, etc.) has to be considered based upon the application purpose, targeted user-group and environmental characteristics.

Manuscript received April 5, 2011. This work was supported by a grant from Bringing Science Home at USF Health. Bringing Science Home is supported by The Patterson Foundation (www.bringingsciencehome.com).

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B. Monitoring and Tracking

The heart of every self-management application is the data recorded regarding the patient's physical and/or psychological condition. Two different approaches dominate the literature. In one, the patient logs data of interest manually [4-7, 13], while in the other, smart, wearable sensors are utilized to automatically record the patient data [14-16]. The recorded data varies according to the targeted chronic disease, but frequently included data are age, gender, height, body weight, blood pressure; activities such as exercise and diet; and psychological effects such as mood changes.

C. Data Security and Patient Privacy

Many of the patients suffering from a chronic disease consider their condition as stigmatizing [12] and therefore, refuse to share private medical information. A self-management application, however, relies heavily on collection of private health data. Therefore, developers must ensure that patient's health information is not stored, used or shared for any reason outside the scope of the application or without the patient's consent. Research describing the data security problem and proposed solutions has been published in [17, 18].

D. User Motivation and Psychological Support

Multiple studies have revealed that patients suffering from chronic diseases fail to control and adequately manage their condition [19], a finding that is vastly attributed to the lack of motivation due to lifestyle behaviors and/or the psychological trauma resulting from living with a chronic disease [3, 20]. This lack of motivation is particularly intense in patients who live alone and cannot rely on friends or family to keep track of their condition (e.g. elderly people or young adults moving away from their childhood home, etc.) [21, 22]. As with most new technology, patients are excited to use new applications; however, soon the enthusiasm is transformed into additional burden. Personalization of the application [13], motivational theories [23, 24] and embedded social interactions are just few of the mechanisms that may retain user motivation and therefore, cultivate positive behaviors towards the management of chronic disease.

E. Evidence-Based Decision Support

In addition to cultivating positive behaviors, the ultimate objective of a self-management application is to provide recommendations which presumably will improve health outcomes. These recommendations delivered in the form of suggested interventions, reminders, etc. emanate from current clinical knowledge and practice guidelines. However, not all knowledge is weighted equally. Evidence-based medicine provides a methodological and systematic way of assessing all available evidence/knowledge [25, 26] to derive information critical to prognosis, diagnosis, therapy and other health issues [27]. As an evidence-based medicine group, we urge the utilization of knowledge derived by systematic reviews to support the design of most features included in a health application. Unfortunately, the majority of self-management applications, with few exceptions [9], lack such consideration.

The most widely accepted sources of systematic reviews are those of Cochrane Collaboration [28] and Campbell Collaboration [29]. However, information collected from these sources is hard to digest, even for practitioners [25]. Therefore, when used, it should be delivered in a lay language the average user would be able to comprehend.

F. Learning Behaviors

The utilization of a self-management application presents an opportunity to educate patients on different elements of their chronic disease [14-16] as well as assist them in identifying and changing behavior patterns which are harmful or helpful to their condition. In this concept, education is not necessarily aiming at training patients to manage their disease (an effort which has been shown unsuccessful [30]), but to help them understand the disease's manifestations. For example, some diabetic patients may be unaware of the relationship between the glucose levels and eyesight. Therefore, through the application, the patient may learn the effects of abnormal sugar levels on the human body and ways to control them. Furthermore, analysis and visual presentation of aggregate personal health data may prove to be helpful in discovering previously unknown trends of harmful behaviors in the patient's lifestyle (e.g. skipping breakfast and exercise, etc.).

G. Communication

Finally, a self-management application should be able to demonstrate capabilities of communication with data repositories; as long as precautions for data security and patient privacy are maintained. Ideally, the application should interface with a health provider's Electronic Medical Records (EMR) system [31], or alternatively with a dedicated health server, to exchange health information. Subsequently, health information can be reviewed by authorized health care professionals (e.g. treating physicians) in order to generate treatment recommendations delivered through the application.

III. Prototype -Diabetes Management In Young Adults

Diabetes management is particularly intense for young adults transitioning to adulthood, facing distractions resulting from constant lifestyle changes and endless challenges (moving away from home, beginning a new job, starting new relationships, enrolling in college, etc.) [21, 22]. We are currently developing a diabetes management application targeting young adults. In this section, we present preliminary work on the design of this application with emphasis on the features discussed in Section 2. An overview of the system architecture of the application is illustrated in Figure 1. The system, at the high-level, is composed of the patient interface, decision system, and

communication modules. Each module is detailed in the subsequent sections.

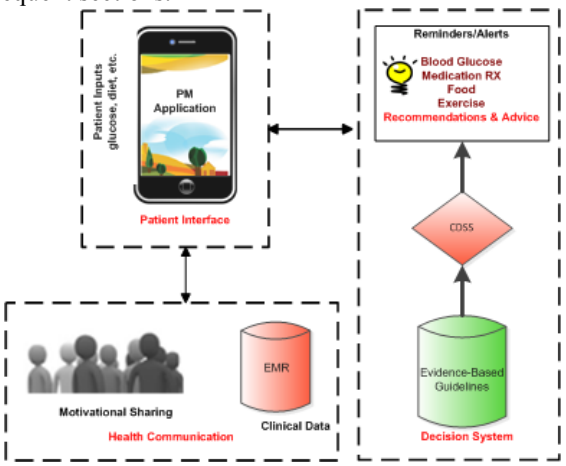
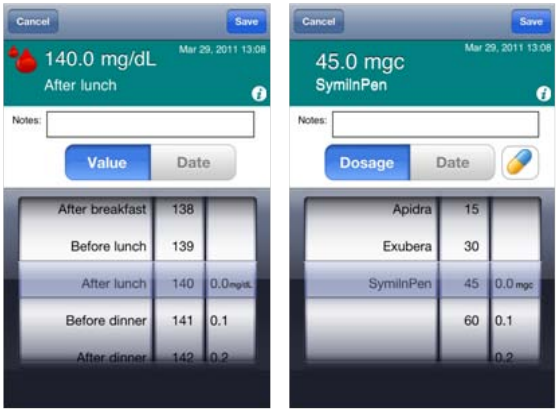


Fig. 1. High-level system architecture.

A. Interface

Considering the age group of our target user population, we chose the Apple iPhone as the first application platform. The iPhone is an internet and multimedia-enabled smartphone. We followed the UI guidelines described to deliver a user friendly interface, displaying the necessary information in a single screen. Screenshots of prototype glucose and medication-logging screens are depicted in Figure 2. There are five main components illustrated in each screenshot. The data detail component, appearing in the upper part of the screenshot, is used to summarize the information entered. Next, the *Notes* textbox is used to record a user custom note regarding the particular data entry (e.g. big meal, intensive exercise, etc.). The actual values/dosages and date are input via a carousel. The command buttons are used to switch the carousel modes between values/dosage and dates).



(a) (b)

Fig. 2. Application screenshots for (a) glucose logging, (b) medication logging.

B. Monitoring and Tracking

At this early stage of implementation we decided to record data that most frequently appear in a diabetic's vocabulary, such as: weight, height, glucose measurements, medication, activities, diet, mood changes and physician appointments. However, the application allows for tracking of custom information that the individual patient wishes to track such as stress, sleep, smoking, alcohol consumption etc.

In the glucose-logging screen, Figure 2a, the patient records glucose levels, time and date, the activity that characterizes the measurement (e.g. after exercising, after eating breakfast, etc.) and personal notes. Time and date are set automatically, however the user may change these values. Precautions have been set for entering a future date. In addition, activities are preselected depending on the time of the day the measurement is recorded. Similarly, in the medication-logging screen, the patient records medication consumption, date, time, and personal notes. A custom defined list of medications the patient receives is used to populate the medication "carousel".

C. Data Security and Patient Privacy

Patient data are stored locally using a SQLite relational database management system. Therefore, data security is at the patient's discretion and relies on the passcode lock mechanism provided by the iOS operating system. Additional access restrictions methods may be imposed at the application level at the expense of ease of use.

D. Evidence-Based Decision System and Motivational Support

Primarily, we utilize the latest available evidence on diabetes care to generate alerts and reminders for each individual patient. By reviewing relevant literature and the guidelines from the American Diabetes Association we generate decision rules that aim at maintaining the patient's physical and mental health such as physician appointments, values outside normal limits, etc. In addition, we use the latest available evidence to support new application modules. For example, we implement a social network embedded into the application to operate as motivational mechanism. This is due to systematic reviews that reported a moderate effect of social interactions to health outcomes for patients with diabetes [32].

E. Learning Behaviors

There are two modes of learning supported in our application. First, we utilize evidence from the literature to describe to the patient the effects of his/hers lifestyle changes to his/her health outcomes. For example, we can show to the patient the effect of reducing his/her physical mass by 10% on his/hers risk of developing diabetes related complications [12]. The second mode of learning originates from the patient's recorded aggregate health data. Specifically, we provide graphical impressions of the observed data for a period of time defined by the user. A simple observation of the resultant graph, will assist the patients identify potentially harmful behavior patterns.

F. Communication

Our ultimate goal is to interface our application with the EMR of our institution. We are designing and implementing our application to enable information exchange with the

EMR system. We envision our application to present the capability of recording critical health information, such as frequent drops in glucose levels, into the patient's EMR and alert the treating physician that an intervention may be necessary.

IV. Conclusion

We have presented preliminary work on the development of a patient-centric diabetes management application for young adults. The paper emphasizes seven features crucial to the successful operation of such applications. Even though we are presenting results for a prototype system, we feel that our efforts serve as the platform for multiple research directions with significant potential.

There is a tremendous amount of work to be completed in the near future, especially with regards to research synthesis of all available evidence regarding management of diabetes. Based on our findings we will generate the material and knowledge necessary to support the mechanisms utilized in the diabetes application. In addition, there is a significant amount of work on the design of the UI as well as the communication language used in the application. We have access to a focus group of young adults who are willing to help us understand and implement an appealing and functional UI appropriate for the particular population.

Another future research direction is the development of tools which will enable physicians to monitor, with least effort, the progress of each patient. This task involves significant challenges since physicians are already overwhelmed with their workload and are reluctant to add further responsibilities. Finally, we envision our application as a part of a randomized controlled trial to study the effects of each of the mechanisms presented in diabetes management and health outcomes, at large. Based on the results of our study, we will direct our efforts to a variety of chronic diseases.

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