

Peer-Facilitated Collaborative Disease Management using Mobile Telephony

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Abstract— Collaborative Disease Management (CDM) refers to interventions that improve outcomes of disease that have been developed on the basis of social learning and self-regulation theories. This research investigates the existing work in peer support, one form of CDM, and proposes an extension to the peer support remote model to incorporate interactive technologies such as mobile phones. We discuss the research problems relating to the design of a mobile health application called Mobile DSMS, a prototype developed based a framework developed as part of the PhD research. We identify existing user-centered approaches in the field of mobile health, describe how these methods were applied to the design and development of a prototype known as Mobile DSMS and we explain how the outcomes of an forthcoming field study are expected to advance the area of CDM and HCI using mobile devices.

Keywords—collaborative disease management, human-computer interaction, remote peer-support

I. BACKGROUND

Collaborative Disease Management (CDM) refers to interventions that improve outcomes of disease that have been developed on the basis of social learning and self-regulation theories [1]. Through the use of CDM, patients mitigate the complications associated with the disease by learning from others in their community and practicing better self-management behaviours. This reduces both the individual and national costs of managing the disease e.g. medication, clinic visits, surgeries etc. CDM lessens the burden that is placed on the limited health care resources of a nation. Instead of every citizen competing for the same fixed set of limited resources, CDM leverages the power of the individual experiences that come from living with a disease. Therefore one of the equally important aspects of CDM is that it has the power to be self-sustainable since it utilizes the human resources of the same people that live with the disease.

Peer Support is one form of CDM. It is based on the idea that patients, although they have problems, do have some resources that can be leveraged to help other patients [2]. It is fueled by the fact that peers have a common interest and therefore peer support takes place between people who are in equal positions – the principle of reciprocity. Peers are people in similar life situations. Therefore both people with the illness and their families can benefit from support.

Research has shown that models that build on peer support have proven to be both successful and cost effective as they

combine the traditional peer support, that is, encouragement from someone else with a similar condition, along with a more structured education programme and assistance [3]. Peer support provides informational support, emotional support and mutual reciprocity which leads to an increased confidence, increased understanding of self-care and a perceived feeling of community. This translates to better lifestyle practices, prevention of further complications and an overall improved quality of life. Presently there exist several models of peer support falling into two main categories: face-to-face self-management programs and remote self-management programs. In the remote model we have telephone-based support and web and email-based programs. The research described in this paper intends to extend the remote model to include mobile devices such as mobile phones and physiological meters for home use.

II. RESEARCH PROBLEM

Most of the existing peer support systems [4, 5, 6] are web based and not everyone has access to computers or a reliable internet connection, especially in developing countries where diseases such as diabetes, heart disease and asthma are more prevalent. Furthermore, research [7] has also shown that these systems not as effective and useable in enabling patients to make informed decisions relating to their disease. Therefore, there is a need to offer a more easily accessible and usable channel for people to engage in effective peer support remotely.

III. METHODOLOGICAL APPROACH

At the start of the research a literature review was carried out to identify existing technology enabled CDM systems and existing mobile health systems and a framework was developed to demonstrate how CDM using mobile technologies allow users with similar disease management interests to virtually gather and share experiences, ask questions and provide support and problem-solve remotely through the use of mobile devices [8]. The term problem-solve in this context refers to the person's ability to identify patterns in their disease management routine and how this information can be used to influence health outcomes. A prototype was then designed based on this framework called Mobile DSMS – a mobile application to facilitate remote peer support for patients living with chronic diseases such as diabetes and hypertension. This prototype is intended to validate the framework as well as investigate issues relating to the design and development of a

CDM system using mobile telephony. A focus group was then conducted to obtain preliminary feedback on the design of the application. Since this system is novel in the design and delivery, a user-centered approach [9, 10] was employed and prototyping was used to gain some preliminary research outcomes as to the perceived usefulness of the system's concept and its design. The next stage is the refinement of the mobile application design based on the outcomes of the focus group and a 3-month field testing where the user interacts with the system in their personal environments.

A. The Framework

Mobile Health is a rapidly growing area of research. It can be defined as the use of mobile technologies for the provision of health care services. The use of mobile phones, in particular, for the delivery of health care is becoming more widespread especially in developing countries where access to health care resources is limited but mobile phone usage is high. Existing mobile health projects have focused on communication structures that connect the patient to his/her health care provider. ICT in this context is intended to make the delivery or exchange of information between these entities more efficient. The research presented in this paper, however, focuses on engaging the communication between patient and patient, built on the social networking culture of the power of communities. In the proceeding scenario, we present a use case scenario for CDM using mobile technologies, and then we discuss the different components of the supporting framework.

Meet Rajesh the farmer. Rajesh has been living with hypertension for the last 10 years. He has recently started noticing that his vision is becoming impaired on occasion. Rajesh suspects it may be related to a change in his diet but he does not have any written record of his past blood pressure readings to confirm this. He lives in a rural village and is not scheduled to visit the clinic for another three months. He knows that one of his neighbours, Carlos, also lives with hypertension but he is not sure when next he will be meeting him. Rajesh wants to take action soon before his condition starts to worsen. This is where CDM using mobile technologies can make a difference. The framework is broken up into five components: the CDM Mobile User, The Support Context, Data Management and Sharing, Socio-Economic Aspects: Facilitators & Inhibitors and Security & Privacy [8]. This PhD concentrates on human-computer interaction research questions stemming from the framework.

B. Focus Group

In January 2012, the researchers at the University of the West Indies conducted a mixture of questionnaire, individual interview and focus group, to examine the preliminary perceptions of the Mobile DSMS application. Twenty-Four patients and caregivers visiting their medical practitioner were asked to participate in the study. Out of the 24 people surveyed, 21 volunteered their responses. The volunteers were given a questionnaire to obtain demographical information. The participants were then presented with a screenshot prototype. The researcher explained each screenshot and asked the participants to think aloud on what they saw in the screenshots and their initial perceptions. The main objective of this study

was to investigate the participants' interest in using the Mobile DSMS application and to obtain suggestions for improving the application. Some of the results of this study are published in [11].

C. The Next Stage

Currently, the outcomes of this study are being used to refine the prototype and another focus group will be held to discuss the proposed changes to the system design. In June/July 2012 a field trial will be conducted so that users can access the system in their local settings and further design changes are expected based on usage in uncontrolled environments.

IV. RESEARCH & SCIENTIFIC CONTRIBUTION

This research is expected to contribute to the area of peer-facilitated CDM and human computer-interaction, in particular, the user-centered design of peer-facilitated mobile healthcare applications. Some of the research questions to be answered include:

- What affordances of a mobile device promote remote CDM?
- How can health data be visualized effectively on a mobile device as to facilitate more informed decision making?
- What are the design limitations of mobile devices in the area of CDM and how can these limitations be mitigated?

V. DISCUSSIONS AND FUTURE WORK

At the consortium, we wish to present the results of the methodology that has been conducted to date and to discuss (1) the user-centered techniques applied in designing this mobile health care application and (2) proposed data visualizations techniques for CDM data using mobile telephony.

Future work involves investigation into the design of interfaces of other type of mobile devices including physiological meters, tablets and body sensors and the clinical effectiveness of use of mobile telephony in the delivery of CDM.

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