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Experiences and Insights from the Development of a Mobile Self Management System for Cystic Fibrosis Sufferers in Tasmania.

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Abstract

Among approaches aimed at addressing chronic illness are a number advocating the improvement of patient self-management and self-efficacy skills as a means of improving health outcomes. While comparison between these approaches is difficult, most report benefits. It is clear however that considerable uncertainty remains over the best methods for supporting patient self-management.

For sufferers of Cystic Fibrosis (CF) a major challenge in this regard is how to effectively support a transition from a model of care that is heavily reliant on specialists and parental control to one supporting self-guided management, particularly amongst adolescents and young adults.

This paper explores these issues in the context of experiences and insights emerging from the development of a mobile self-management system for cystic fibrosis patients' across Tasmania. Based on case study research within the CF community, initial insights highlight how patients involved with the mobile self-management system have readily accepted it and actively incorporated it into their daily routine.

Keywords:

self management, self efficacy, computer communication networks, mobile phone

Introduction

This paper presents experiences and insights from a project exploring how mobile technologies can be used to support the development of self-management and self-efficacy amongst cystic fibrosis (CF) sufferers across Tasmania. While supporting self-management and self-efficacy amongst the chronically ill has been shown to have benefit, the role that information and communication technologies (ICTs) can play remains under-researched. There are currently few systems that allow patients to remotely monitor and self-manage their health conditions in a non-obtrusive and cost effective manner. More significantly, many of the systems that do exist, fail to acknowledge the conceptual and practical difficulties of avoiding simply replacing dependency on health professionals for dependency on technology.

Information systems (IS) clearly have a role to play in enabling home based medical systems. Indeed, some research points to positive outcomes for patients with chronic illness in self–managing their conditions with ICTs. It is acknowledged that computer based support systems can be valuable tools to assist with the management, education and ongoing care of a patient's chronic illnesses. In particular, wireless mobile technologies are well suited to support the remote self-management and self-monitoring of a chronic health condition with patient cohorts that are geographically dispersed or where cross-infection is a clinical risk. Other considerations include fees and costs associated with any telemedicine system. Internet based systems rely heavily on connectivity, access speeds, suitable ICTs in the home . There is also a need to consider the nature of the information to be made available to the health care team and the patients. If mentors supporting patients are better informed their ability to monitor and assess patient's progress with goals and action plans can be more improved . The remainder of the paper explores these issues.

Aims / objectives

The overall aim of this research project is to determine the impact of a mobile system on CF patient's ability to self manage and monitor their condition. The project also aims to examine the effectiveness of communication between patient's and health professionals through this mobile system.

The objectives of this research are;

1. To explore how effective the use of mobile technology is in supporting self-management and self-efficacy amongst CF patients.
2. To determine if the use of mobile technology improves information access and communication with specialised health care providers.
3. To capture any perceived or realised benefits gained by patient's from using the mobile system.

Methods

This research adopted a case study methodology and recruited participants from within the Tasmanian CF community. All potential participants received a letter outlining the study and asking for volunteers. Respondents willing to participate then attended their regular CF clinic for consent, baseline measurements and randomization. Recruitment was undertaken within the following selection criteria.

Information systems development

The mobile self-management system was developed to enable participants to closely monitor their own disease through an electronic patient diary and respond to changes based on self-efficacy skills learned through a mentoring process at the beginning of the trial. The intention is to conduct comparisons between participants in the intervention arms and those who have received usual care. There will also be comparison made between the two intervention arms, i.e. outcomes in those with the IT tool versus those without. This will allow determination of whether mentoring alone is sufficient to enhance self-efficacy or whether additional tools such as IT provision value add to the process, or even whether the IT tool itself is what most effectively facilitates self-efficacy and self-management.

This project develops a model of integrated care that promotes patient self-management and self-efficacy supported by an information system. It is anticipated that this will promote the participant's active involvement in their own management, health care decisions and improve quality of life for adolescents and adults with CF. The anticipation is that in the long-term, this will result in better and sustainable outcomes.

System development

The design of the mobile system was broken down into three core components.

1. The development of a suitable mobile phone application that captures and renders clinical information from patients.
2. The development of a mobile phone server application to capture and send clinical information to each patient involved with the mobile phone trial.
3. The development of a database with a web-based interface to store all phone data, action plans and progress notes.

Every day CF patients are asked to run a customise CF application on their mobile phones that poses a set of questions forming a daily symptom diary. Some questions were randomly generated to improve data quality. On average it takes a patient four minutes to complete the diary. A data packet is then sent to a messaging server for capture and passed on to a database for consolidation and interpretation. Mentors and researchers are able to access a real time feeds of the information as it is sent via an online interface. This means that mentors and patients can be located remotely from the data service but still interact with the system in real time. CF patients also have the facility to gain a summary of key data elements to provide indicative progress with their condition and to use for reflection and response as part of their development of self-management and self-efficacy skills. Mentors are able to review their patients remotely and are able to contact patients directly to review or revise action plans and goals.

Experiences and insights to date

To date a number of experiences and insights have been generated by this on-going project:

- The time required to capture daily symptom information is relatively short and the mobile system supports the rendering of progress information in real time.
- The messaging of clinical information via SMS is very cost effective and sustainable.
- The interface used in the mobile phone application is highly intuitive and has incurred only limited time and training cost with this patient cohort.
- The use of mobile phones does not inhibit the scope of the patient's daily activities and is successfully integrated into their other use of the phone.
- Patients enjoy the flexibility of being able to complete or review data as and when it is convenient for them.
- Early indications are that self-management will be improved in both active arms of the trial. It remains too early to make specific remarks about the impact of the mobile system per se.

Conclusion

This paper has presented some of the initial experiences and insights gained whilst developing and implementing technology for a project exploring how mobile technologies can be used to support the development of self-management and self-efficacy amongst cystic fibrosis (CF) sufferers across Tasmania. The project is ongoing and so the final results are pending.

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