



Modular ICT-based patient empowerment framework for self-management of diabetes: Design perspectives and validation results



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ABSTRACT

Introduction: It is estimated that more than 382 million people suffer from diabetes across the globe, most of which are between the age of 40 and 59 years. ICT can play a key role in better management of diabetes and in patient empowerment. Patient empowerment involves patients to a greater extent in their own healthcare process and disease management becomes an integrated part of their daily life. Self-management opens the possibility for patients to contribute to their own healthcare as well as to be more in control of their disease.

Objectives: The objective of our study was to explore the impact of an ICT-based patient empowerment framework in diabetes self-management.

Methods: A modular patient empowerment framework that fosters diabetes self-management was designed and implemented. The framework incorporates expert knowledge in the form of clinical guidelines, and it supports patients in the specification of personalized activities that are based on medical recommendations and personal goals, and in the collection of observations of daily living. The usability and usefulness of the proposed framework were assessed in a pilot study with the participation of 60 patients and 12 health professionals.

Results: The study revealed that a patient empowerment approach based on self-management ICT tools is useful and accepted by both the patients and the physicians. For those patients who were already disciplined in their disease management the piloted solution served as a facilitator for data logging. For the rest, it served as an incentive for better adherence to disease management principles. The ICT tools prompted many patients into becoming more physically active and into making dietary habits' adjustments. However, this impact proved to be tightly correlated with the sociocultural background of the subjects. The study also demonstrated that even in patient-centric self-management interventions the physicians still have a key role to play. However, the acceptance of such interventions by the healthcare professionals depends not only on the level of impact in their patients' disease management but also on the level of impact in their workflow.

Conclusions: It is evident that a patient empowerment approach based on self-management ICT tools is useful and accepted by patients and physicians. Further, there are clear indications that ICT frameworks such as the one presented in this paper support patients in behavioral changes and in better disease management. Finally, it was realized that self-management solutions should be built around the objective not only to educate and guide patients in disease self-management, but also to assist them in exploring the decision space and to provide insight and explanations about the impact of their own values on the decision.

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1. Introduction

According to the Diabetes Atlas of the International Diabetes Federation (IDF) some 382 million people worldwide, or 8.3% of adults, are estimated to have diabetes in 2014. If this trend continues, by 2035, some 592 million people, or one adult in 10, will have diabetes. This equates to approximately three new cases every 10 s, or almost 10 million per year [1].

Being diagnosed with diabetes often means a major shock to the person concerned. Diabetes is basically a life-long disease and like all chronic diseases it cannot be cured. Nevertheless, there are strategies for improving the patients' health status and one key aspect is self-management. Besides learning about the disease, people have to adapt their lifestyles, particularly those aspects that are related to physical activity and nutrition.

A meta-analysis and review of randomized control trials carried out by Calvin et al. [2] revealed that the use of consumer health information technologies in supporting diabetes self-management appears to have potential benefits for patients' self-management of diabetes. However, self-management is not something trivial. Type II Diabetic (T2D) patients, who typically are affected at a later stage of their lives, find it particularly difficult to change lifestyle routines that have been formulated over a long period of time. Having a chronic disease means having to cope with "something" that severely impacts one's autonomy. Patients have to learn that their behavior influences their disease status and that continuous adaptations are necessary. However, making the required adaptations may conflict with other priorities and constraints, let alone that perfect control is not possible.

As a self-management facilitator the concept of patient empowerment has emerged in recent years. Patient empowerment can be seen as a healthcare philosophy that emerges from the perception that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process [3]. Towards this direction a key point is to make patient empowerment an integral part of daily life and in particular of the healthcare process [3].

In Ref. [4] Lucas and Rojas presented a proactive health management and empowerment framework for senior citizens that supported tele-monitoring and tele-nursing functionalities for chronic patients. Its pilot study revealed that a significantly high percentage of participants had some kind of benefit from using the system. For example, almost 80% of participants learned more about their health conditions, 71% of participants had an increased awareness of their individual diet and nutrition, and 63% of participants self-reported health improvements.

In the various self-management interventions also the relationship among patients and healthcare professionals is challenged. Bjerkan et al. [6] examined the impact of an ICT based collaboration tool in individual care planning and realized that in some cases, a power transition took place in the care process, which led to patient empowerment. On the other hand, the study of Urowitz et al. [5] about the impact of a diabetes self-management portal in patients revealed a grey area in the roles that the physicians should play in the facilitation of disease management. The same study indicates that although the patient portal as such can facilitate access to useful information material, usability aspects are very crucial for keeping the users motivated in using the portal. In their study about the role of ICT in diabetes management, Spanakis et al. [7] found that although ICT-based disease management may bring profound changes in self-care and empowerment, a careful balance between information and communication is important to avoid information overload and excess. A systematic review of IT based diabetes self-management approaches is presented by El-Gayar et al. [8].

This paper presents a modular, ICT-based patient empowerment framework that fosters self-management of diabetes. The

framework was designed, implemented and piloted in the context of EMPOWER, an FP7 collaborative project supported in part by the European Commission. The framework incorporates and exploits various sources of personal health data and clinical knowledge towards supporting the patients in the management of disease related decisions and actions. Patient empowerment is fostered by personalized ICT services delivered through web and mobile applications that guide the patients in behavioral changes while ensuring adherence with evidence based treatment guidelines. This patient-centric functionality is supplemented by functionality for the physicians who remain present in the disease management cycle by guiding their patients in disease management, whilst staying informed about their progress.

2. Methods

2.1. ICT-based patient empowerment concept description

Patient empowerment interventions aim at involving patients to a greater extent in their own healthcare and disease management cycle. We approach this domain from a technological perspective, by introducing an ICT-based patient empowerment framework that facilitates self-management pathways (SMP). The SMP is a cyclical process that includes medical consultations followed by self-management goal setting, then self-management actions, then feedback collection, and finally evaluation and self-management readjustment. This framework is in line with the generic methodology for chronic disease self-management proposed and applied in practice at Stanford School of Medicine by Lorig et al. [9,8]. EMPOWER exploits various sources of personal health data and clinical knowledge in a comprehensive ICT framework that implements all these steps. This is a new concept towards the establishment of a personalized yet evidence-based patient guidance strategy.

We first apply this concept in diabetes self-management. Diabetes is usually diagnosed during a patient encounter at a physician or in a hospital. In such consultation the patient gets informed about the nature of the disease and the various rules of handling it, one of which is self-management. In this context the physician suggests to the patient the use of an ICT-based self-management framework, as a means to support lifestyle and behavioral changes that will facilitate the management of the disease. Following this, an SMP cycle emerges that is composed of the following phases (Fig. 1):

2.1.1. Specify recommendations

The entry point to the SMP cycle is a consultation where treatment goals are specified. The physician specifies recommendations on how the patient can achieve the treatment goals by self-management (e.g. "reduce weight by x kg within 3 months", "measure blood sugar before breakfast"). The recommendations are derived from a decision support tool. This blends commonly applied, evidence-based clinical guidelines, the physician's experience and the actual patient status, as indicated by various data sources. Moreover, the recommendations are issued using an ICT infrastructure in contrast to the traditional oral or written format.

2.1.2. Define/modify goals

In the next step, the patient breaks down the physician's recommendations into short-term self-management goals, stored in her/his individual PHR. These goals should be realistic and behavior specific. For example, if the patient needs to lose weight, she/he should set a goal based on her/his existing eating behavior or physical activities [8]. Otherwise, she may feel overwhelmed at the idea of all the work that is required. It is also important that patients are aware of their behavior, in particular of unhealthy habits. Only patients who are aware of their habits will make conscious choices

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