Designing and Evaluating a Self-Management Support System for Renal Transplant Patients: the First Step

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ABSTRACT

Motivation – Thanks to the mobile measurement and tele-care technology, it becomes possible to build self-management support systems for renal transplant patients. This project aims to provide (1) a trusted and accepted self-management support systems for renal transplant patients, (2) guidelines for building a virtual coach for supporting feedback in the self-management support system for chronic disease self-management, and (3) an overview of the human factors that should be taken into account in self-management support system development processes.

Research approach – A situated Cognitive Engineering method guides the development of a requirement baseline and its design rationale of the self-management support system, including a virtual coach, for renal transplant patients. Via focus group sessions, mock-ups and rapid prototypes, (parts of) the requirements and rationale will be generated, tested and refined in relatively short iterative cycles. Furthermore, about 50 patients will use a basic version of the system to examine (1) the influence of human factors on self-management and self-management support needs, (2) the impact of a self-management support system on the behavior of chronically ill patients, and (3) the doctors' acceptance of the system.

Findings – So far the first prototype was designed and evaluated; major issues and users' values were extracted.

Keywords

Self-management support system, virtual coach, eCoach, feedback, renal transplant patient

INTRODUCTION

Chronic kidney disease (CKD) is regarded as a major public health problem (National Kidney Foundation, 2002). At the end of 2009, 14,794 people in the Netherlands were under treatment for the last stage of CKD, also called end-stage renal disease (ESRD) (ERA-EDTA Registry, 2011). The ideal treatment of ESRD is a kidney transplant (National Kidney Foundation, 2002). In 2009, 827 renal transplantations were performed in the Netherlands (ERA-EDTA Registry, 2011). However, rejection and (serious) medication side effects can occur (Crespo et al., 2001; Veenstra, Best, Hornberger, Sullivan, & Hricik, 1999). Therefore, research has started to improve patients' health and reduce cost (Abbud-Filho et al., 2007; Djamali et al., 2006; Gill, Abichandani, Khan, Kausz, & Pereira, 2002; Laupacis et al., 1996).

The proper daily management of renal transplant patients, as other chronic patients, requires them to adapt their behavior actively (Bodenheimer, Lorig et al. 2002; Lorig and Holman 2003). Self-management, the process of managing symptoms, treatment, physical and psychosocial consequences, is therefore proposed (Barlow, Wright et al. 2002). Chronic diseases self-management seems a key determinant of the healthcare effectiveness as it could increase compliance with medical standards, stimulate awareness of early physical changes, and facilitate patients' autonomy (Hagger & Orbell, 2003; Lorig & Holman, 2003).

A computer-based support system, e.g. Self-Management Support System (SMSS), helps in this context to empower the patients with control of their care process and daily activities, and therefore to increase their self-determination and autonomy (Lorig, Ritter, Laurent, & Plant, 2006). It might also reduce cost. With this in mind, the Assessment of a Disease management system with Medical devices in Renal disease (ADMIRE) project has been set up. It has the aim to design and evaluate a disease/self-management support system for renal transplant patients. This system will have a virtual coach (eCoach) to guide patients conducting daily self-management, such as measuring their medical data, and getting feedback and suggestions. By using the SMSS, it is expected that the patients will have a better understanding of their health status, be more alert when a problem occurs, and visit hospitals less frequently.

Traditionally, patients visit the hospital regularly during the first year after transplantation. During the consultation, doctors measure patients' medical data and give them feedback and suggestions. The envisioned SMSS reduces these visits. However, due to the possible complications and medication side effects, patients and doctors might have reservation towards trusting and accepting the feedback and suggestion from a SMSS. Therefore, this research focuses mainly on three aspects: 1) a trusted and accepted SMSS for renal transplant patients, (2) guidelines for building a virtual coach for supporting feedback in the SMSS, and (3) an overview of the human factors that should be taken into account in SMSS development processes.

To understand their health situation, patients need certain skills and knowledge. A number of education programs have been conducted for chronic disease self-management (Clement, 1995; Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Besides getting training from nurses and doctors, an educational coach of the SMSS is proposed to provide knowledge and guide patients. With this educational coach, patients would be able to access needed knowledge at any time and get support if needed. In addition, the health feedback need to be designed carefully so that they can understand easily and therefore accept the system more.

Another issue of acceptance of the self-management support system is trust. Due to the possible complications and side effects after transplant, doctors and patients alike may not be willing to totally rely on a self-management support system. They may prefer a more traditional health care process (i.e. face to face). Therefore, more work is needed to understand design factors underlying users' trust on the system.

RELATED WORK

Before describing this research, some related work is introduced briefly below.

eHealth

eHealth deploys information technology in the medical domain, and could help in self-management (Alpay et al., 2010; Alpay, van der Boog, & Dumaij, 2011; Blanson Henkemans, 2009). Various eHealth services have already been developed for self-management of chronic conditions, and have been demonstrated to be useful (Kroeze, Werkman, & Brug, 2006; Rogers, Essa, & Fisk, 2007). In this project, eHealth provides the tele-monitoring and tele-communication between patients and doctors, which is one of the essential techniques of this SMSS.

Persuasive Technology

Persuasive technology, which aims to change users' attitudes and behaviours (Fogg, 2003), can offer benefits to the healthcare. This technology could for example deal with large amount of data and have multiple modalities. It can, as a result, provide recommendations based on accurate and significant numbers, and present in the most suitable modality. It seems that persuasive technology can be used in this research to provide patients with more insight of their health status, and hence enhance their trust in the system.

CURRENT RESEARCH

Currently the research focuses on understanding and increasing patients' acceptance of the system. It is conducted through a situated Cognitive Engineering (sCE) approach, and already a patient acceptance questionnaire has been designed.

Situated Cognitive Engineering

Situated Cognitive Engineering is an iterative process where a requirement baseline is continuously refined by reviews and prototype evaluations (Neerincx et al., 2008; Neerincx & Lindenberg, 2007). The sCE approach has already been used successfully in some healthcare projects, such as integrating computer assistants in eHealth services for personalized support (Blanson Henkemans, 2009; de Haan, Blanson Henkemans, Neerincx, & van der Mast, 2005) and designing a multi-modal memory restructuring system for post-traumatic stress disorder patients (Brinkman, Vermetten, van den Steen, & Neerincx, 2011).

There are three phases in the development of a self-management support system (Figure 1). In the first phase (*Domain Analysis*), the work domain of conducting self-management for renal transplant patients are analyzed, including the operational demands, the human factors knowledge, and the technology. The second phase (*Requirement Engineering*) is to specify the core functions, claims about the functionality and use cases, and these result in system requirements. These requirements are tested and refined in the third phase by reviews and experiments *(Justification & Refinement).* This approach will be used iteratively in different stages of the research for different parts of the SMSS. Here the sCE approach in first year of the research is presented.

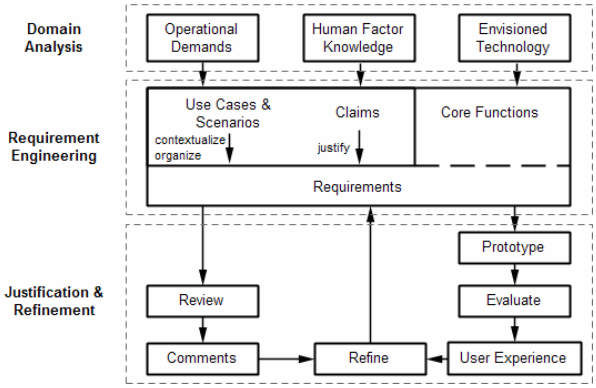

Figure 1. Situated Cognitive Engineering process.

Domain Analysis

During the domain analysis, existing knowledge and current healthcare situation of renal transplant patients was explored. A nephrologist and a hospital researcher were consulted several times to obtain the necessary information. Focus groups with experienced patients and self-management experts were held. The general

idea of the self-management and a self-management support system for renal transplant patients were presented and discussed.

Requirement Engineering

With the knowledge obtained in domain analysis, scenarios and use cases were developed. They help to understand patients' and care-givers' opinions of conducting self-management with a self-management support system in clinic. The main activities in the use cases and scenarios are patient measuring themselves, reacting on feedback from the SMSS, and communicating with their care-givers. Claims behind each scenario were derived from human factor theories. Corresponding storyboards and video prototypes were created to give users a better understanding and extract their opinions. From the scenarios and claims, the first design requirements were established.

Justification and Refinement

There are two ways to test and refine the requirements: review by experts and experimental test with users. So far a prototype has been developed and the experiment with it has been conducted (Wang et al., 2012).

A website www.mijnnierinzicht.nl (MNI) (Bonstato b.v., 2011) is part of the SMSS in the ADMIRE project. After patients measure their medical data, they can input the data into MNI, which should then provide feedback and suggestions. To make the self-management support system safe, easy to use, and trusted, MNI was evaluated by expert reviews, refined based on their comments, and then tested.

Six human-computer interaction experts have done the expert review. They were asked to say anything that they liked or disliked in MNI, and how much they liked or disliked. A few issues were pointed out, including high interaction load, poor navigation, and lack of compatibility.

Based on the expert review, the requirements, and existing design principles, several design suggestions can be made. To investigate patients' acceptance, three different main design idea were established: simplicity, empathy and empowerment. Paper prototypes were developed and evaluated in an experiment.

Twelve non-patients participated in the experiment. The prototypes were shown to them in six different sequences to eliminate the learning effect. They were asked to complete some predefined tasks and think aloud. After that, they filled out questionnaires about their preference.

Acceptance Questionnaire Design

To investigate patients' acceptance of a SMSS, a questionnaire was designed based on the Technology Acceptance Model and its extensions (Davis, 1989; Davis, Bagozzi, & Warshaw, 1989; Venkatesh, Morris, Gordon, & Davis, 2003). Constructions were obtained from the literature to study their relation with patients' acceptance. To increase the reliability of the questionnaire, each construct was operationalized by a set of questionnaire items taken from the literature. These items were adapted for a SMSS.

To examine the content validity, a panel of nineteen experts with related backgrounds were asked to indicate for each item whether it is 'essential', 'useful, but not essential', or 'not necessary' to measure the underline construct. From their indication, four to eight items were selected for each construct based on the Content Validity Ratio (Lawshe, 1975).

Considering the patient population (elderly, Dutch), the next step was a workshop with two patients, one professional Dutch writer, and six researchers to rewrite the questions. Each item was discussed, until consensus was reached.

SUMMARY OF PRELIMINARY RESULTS

From the sCE approach, several issues of the SMSS were uncovered, such as trusting the systems' feedback and having different perceptions of responsibilities. The possible values of the patients (e.g., safety and health) and the care-givers (e.g., saving effort, controlling responsibilities) behind these issue were extracted.

The experiment suggests that users might have more trust in the empowerment feedback, and that the feedback could influence their ability of reporting their previous day's health status.

A patients' acceptance questionnaire was created, especially for evaluation of SMSS in renal transplant domain.

RESEARCH PLAN

In this year (2012), a field study of around 50 renal transplant patients using the SMSS for one year will start. In this study, the prototype will be tested, and the acceptance questionnaire will be distributed. Furthermore, a second iteration of sCE will start to collect additional information besides the field study. Interviews and focus group will be conducted, to identify users' values and refine requirement baseline.

In 2013, the responses of patients acceptance questionnaire will be collected. Both its validity and patients' acceptance will be analyzed. Furthermore, a health/treatment model which could predict patients' health status will be built. Implementing such a model in a SMSS might help in improving the users' acceptance of the SMSS by giving patient a better understand of their own health status and potential future trajectories.

In 2014 and after, an eCoach model will be built as part of the SMSS. This model will include, besides the health/treatment model, an educational model. After these models are established, they will be evaluated on the effectiveness together with other result will lead into a best practice recommendation.

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