HeartCycle: user interaction and patient education*

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Abstract— Cardiovascular Diseases are the most prevalent and serious chronic conditions existing nowadays. They are the primary cause of death in the world and generate enormous expenditures to the health systems. Tele-monitoring and personal health systems have proven to be good options for tackling this situation; however they are still lacking many functionalities. It is necessary to find solutions that allow health professionals to follow up patients more closely and efficiently, while reducing the non-adherence of patients to the treatment regime.

HeartCycle research project (partially funded by the European Commission) has developed a personal health system for cardiovascular diseases management with the aim to address this problem. This paper describes the Patient Loop of this solution, including the different components, the adopted user interaction, and the implemented patients' education and coaching strategy.

I. INTRODUCTION

In the modern world chronic diseases constitute one of the major problems and main concern for the society. They are the main cause of hospitalizations and deaths, and their management and treatment generate enormous expenditures for the healthcare systems. The trends of the population towards increasing aging rates suggest that this problem will not improve but it will get worse in the upcoming years.

Among chronic diseases, Cardiovascular Diseases (CVDs) are considered the most prevalent and serious conditions existing nowadays. CVDs are reported by the World Health Organization (WHO) as the main cause of death in the world. In 2008, an estimated 17.3 million people died from CVDs, representing 30% of all global deceases. Moreover, it is expected that this number will increase up to 25 million of people by 2030 [1].

Current practice for CVDs includes giving patients specific medication treatment and certain recommendations on lifestyle habits. However, some aspects like daily monitoring, help with treatment routines or close follow ups are usually missing. Moreover, most of the patients only receive feedback from health professionals when they experience symptoms or visit the doctor. This produces in many cases a non-adherence to the treatment regime and, therefore, its potential clinical benefit is considerably reduced.

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Scientist, researchers and also governments have invested many efforts in trying to find out solutions that can help to manage chronic diseases in a more efficient way, mainly focused on reducing mortality and also healthcare costs. Recent studies, like the Whole System Demonstrator trial, have proven that the use of tele-monitoring systems can be a good option to improve this situation [2]. However, in order to be completely effective, this type of systems need to provide methods for motivating patients to adhere to treatment and this can be done by establishing more direct contact between carers and patients. In this sense, personal health systems that provide closed loops between health professionals and patients have become a suitable solution to achieve this goal.

HeartCycle is a research project (partially funded by the European Commission) that was born with the aim to tackle this specific situation [3]. Its goal was to provide a closed-loop solution for the management of cardiovascular diseases patients, more specifically, for patients suffering heart failure (HF) or coronary artery diseases (CAD). HeartCycle project has actually developed two different systems: Heart Failure Management, focused on helping heart failure patients to manage their health condition, and Guided Exercise, a cardiac rehabilitation system for patients who suffered a major event – such a myocardial infarction – or coronary surgery. Both systems include applications for patients and health professionals, supporting them in managing CVDs in a more efficient way.

This paper describes the patient's part of these systems (namely Patient Loop), including the different components, the user interaction solution adopted, and the patients' education and coaching strategy implemented.

II. METHODS

Although both HeartCycle systems have been developed in different platforms and using different technologies, the methodological approach followed for the design and implementation of the Patient Loop in both of them has been the same: a user centred design methodology, namely Goal Oriented Design [4], combined with an iterative software development approach and the incorporation of an education and coaching strategy.

The Goal Oriented Design methodology suggests 6 different stages (research, modelling, requirements definition, framework definition, design and support) that should be followed in an iterative way. The first phases are devoted to the identification of major problems and needs in the intended domain, as well as the definition of "personas" (that is, user archetypes that allow the designers to gather the needs, expectations and motivations of the users to whom the application is intended for) and the scenarios, describing how the users utilize the system in a certain context.

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HeartCycle project tackled the initial phase of the methodology (i.e. research) by conducting interviews with real patients. In total 26 patients were interviewed, 15 heart failure patients (5 patients in three different clinical sites - Hull, Aachen and Madrid) and 11 CAD patients (6 at the University Hospital in Aachen and 5 at the Hospital Clínico de Madrid). The interviews followed a structured protocol that included a presentation of the concept, a guided conversation on a storyboard that showed some of the potential functionalities of the concept, and a final interview, which comprised a scoring sheet. The results were analysed in specific workshops, involving experts and health professionals, where major problems and needs of HF and CAD patients were identified.

These sessions revealed one important issue that affected the further design: the needs, motivations, symptoms and medications of HF and CAD patients were different. This meant that it would be more adequate to develop two different systems, one for heart failure patients and another one for CAD ones, instead of only one as it was initially planned. Moreover, the analysis disclosed some other aspects to be considered in the later development: 1) any application to be used by patients should be very usable and easy to use and, 2) there was a clear need to add patient education and motivation strategies to the applications.

The next steps were the definition of "personas" and scenarios for each of the systems to be developed, along with the different use cases that would cover all the needs previously identified. Then, the Patient Loop requirements were depicted, comprising the user's interaction requirements (i.e. device characteristics, interaction requirements, input and output methods), initial functionalities for both applications (e.g. agenda, medication, education) and nonfunctional requirements (i.e. performance, robustness, availability, reliability, security and trustworthiness, adaptability and scalability). Finally, the look and feel of the applications and the graphical user interfaces were depicted.

Finally, HeartCycle systems include an education and coaching strategy that has been based on the Heart Manual Programme (NHS Lothian), the UK's leading selfmanagement home-based cardiac rehabilitation programme for patients recovering from a heart attack [5]. The Heart Manual is a tool that helps patients to recover from this major event by providing them with educational material, addressing their misconceptions, helping and letting the setting up their own goals to tackle different risk factor, and monitoring their progress. HeartCycle has adopted a similar strategy and implemented it in the two developed systems: Heart Failure Management and Guided Exercise.

The whole process followed an iterative approach where several intermediate solutions were produced and evaluated with real patients, by means of interviews and questionnaires similar to the ones used in the initial research phase.

III. RESULTS

A. Heart Failure Management

The Heart Failure Management system implementation has been based on the commercial platform Motiva®, developed by Philips [6]. Philips Motiva® is a healthcare platform that interactively connects patients with chronic diseases (e.g. Chronic Heart Failure) with their healthcare providers using a broadband Internet connection and the TV at home.

On the Patient Loop part, the Heart Failure Management system has added new functionalities to the commercial platform: symptom questionnaires, therapy messages, and education & coaching strategy. Logically, the look and feel and graphical user interfaces of these new functionalities was determined by the environment provided by Philips Motiva®. However, there has been some innovation in the way to present each of them to the patients, aiming to improve the user interaction.

Symptom questionnaires have been designed following an absolute approach, as opposite to the relative one. This means that patients are asked each day to rate each symptom with a specific intensity value for that day (i.e. mild, moderate or severe) and not in relation with their experiences of the previous days. This approach makes possible to obtain more accurate and objective data. However, sometimes it is still difficult for patients to rate a specific symptom with these abstract values. Also, different patients may have different interpretations of the intensity level of a symptom. Thus, it was decided to present these questionnaires in the system using the so-called thermometers. Instead of just asking patients to rate symptoms based on a classic intensity scale (i.e. mild, moderate or severe), these thermometers describe different activities or situations at which each symptom can occur and help patients to better identify the correct level, minimizing the subjective rating. Presenting the information like this avoids asking several questions per symptom, minimizing the task of patients while answering the questionnaires and, thus, improving their user experience when utilising the system.



Figure 1. Example of thermometer questionnaire (answers of the question "I get out of breath")

Therapy messages have also been designed trying to find a balance between completeness and simplicity. Patients are only informed about the specific steps they have to follow, and the information that could cause them unnecessary concerns is explicitly avoided. Additionally, it has been defined a simple and similar format for communicating changes in medication and treatment. This format is used in every communication to the patients and, therefore, they can easily recognize the message and identify what they have to do.

Finally, the Heart Failure Management system incorporates a comprehensive education and coaching strategy that has been based on the Heart Manual (developed by NHS Lothian) [5]. This includes not only the relevant educational material, but also the specific approach to deliver it to patients.

The system offers each patient education and/or coaching based on the assessment of two aspects: their level of knowledge and their willingness to perform certain behaviours. Education is offered to patients with low level of knowledge on specific topics in the form of videos and texts. The gained knowledge is assessed afterwards by asking them certain questions in a quiz that evaluates if they have assimilated the specific content. If the result of this evaluation is negative, the related content is offered again to the patient later in time. The final goal of this process is that patients gain a high level of knowledge of their condition so that they can self-manage it more efficiency.

Coaching focuses on making patients adopting a self-care behaviours. It follows an approach based on Self-Regulation Theories. The system proposes the patients specific behaviours to perform in order to avoid risk factors and having a healthier lifestyle. Once patients decide to tackle a particular behaviour, the system lets them setting up their own goals and establishing an action plan. Then, it gives the patients feedback on their progress and offers support for maintenance and possible relapses [7].

B. Guided Exercise

HeartCycle Guided Exercise (GEx) system offers a complete solution for the cardiac rehabilitation of patients who suffered a major event (e.g. myocardial infarction) or coronary surgery. Patients who access the rehab programme are provided with a personalized care plan that includes a prescription of exercise sessions to be performed during 20 weeks. Guided Exercise system monitors patients while performing these exercise sessions and helps them to follow the prescribed plan. It also supports health professionals in the management and follow up of patients under recovery,

The Patient Loop of Guided Exercise system has been entirely designed and developed following the Goal Oriented Design methodology [4]. It comprises two different applications, namely the Portable Station and the Patient Station, along with a sensor and a T-shirt that the patient has to wear while doing exercise in order to be monitored.

The Portable Station is a software application that runs on a PDA and has been designed to guide patients through their exercise sessions. Combined with the sensor and the T-shirt, it monitors certain vital signs and gives patients continuous feedback and recommendations that help them to follow the prescribed exercise at any time. The Patient Station is an application that includes certain functionalities to support patients before and after the exercise sessions, such as messages (to receive information from the doctor or the system regarding the care plan and progress), calendar (to visualize pending and executed exercise sessions), personalization (to set up the dates and time for doing exercises), results (to visualize the progress) and learning (including a complete educational material on their disease, risk factors, advice to exercise, quizzes, etc.). Through a complete closed loop, professionals are able to control the progress of the patients and provide them with feedback whenever it is needed.



Figure 2. Patient Station screenshot

The user interaction and user interfaces of both the Patient Station and the Portable Station have been designed and developed considering several important aspects such as simplicity, usability, easiness to use, usefulness and attractiveness. Even though they are running on different devices, both of them have the same look and feel and common elements. The Patient Station includes five different sections (i.e. home, messages, calendar, exercise and learning) each one with a distinctive colour and icon that is replicated in every screen. This facilitates the navigation and the interaction with the system itself. Moreover, the application includes an avatar, "Hearty", introduced to give tips, advice and present results to the patients in a friendly way.

The Portable Station application is intended to be used by patients during the exercise sessions, therefore it includes certain innovative elements in the way to show the information while patients are exercising. The information during the exercise session is presented visually on a screen in a very simple way: one bar with the goal heart rate and another bar with the current heart rate values. Additionally, the background of the screen has a specific colour that, combined with a blinking code, indicates the patient the action he has to do. In this way, a green background means that he has to continue exercising with the same intensity level, blinking green indicates to speed up, yellow to slow down, and red to stop immediately. As the PDA is intended to be worn in the upper side of the arm, this design of the user interface and interaction facilitates patients to follow the instructions of the Portable Station very easily without continuously looking at the screen.



Figure 3. Portable Station screenshot

Guided Exercise system also includes an education and motivation strategy that aims to increase the knowledge of patients, to motivate them to follow the prescribed exercise program, and to convince them to continue following healthy habits once the rehabilitation program finalises. As it was done in Heart Failure Management system, the strategy has been based on the one developed in the Heart Manual (created by NHS Lothian) [5]. The Patient Station includes a section dedicated to the educational material that includes information on the health condition of patients, risk factors, importance of exercise, how to tackle different aspects of the recovery, etc. This information is given in form of text and pictures and is accessible to the patients at any time.

However, in order to be more effective, the system includes a specific strategy to deliver the educational content. During the rehabilitation programme, patients are continuously receiving messages with recommendations to check specific contents. These recommendations are completely personalized and based on: 1) the responses of the patients to misconceptions questionnaires that are prompted at certain stages of the rehab process; 2) the phase of the rehab program where the patients are; 3) patients performance and compliance with their exercise plan. Moreover, at the very final stages of the program, patients can select certain topics of their interest and the system will build the suggestions based on these preferences.

IV. CONCLUSIONS

The implementation of HeartCycle Patient Loop components of both systems has followed an iterative approach where three different versions of these applications have been implemented before achieving the final one.

Each iteration, including the final one, has been evaluated with real patients conducting direct interviews that included questionnaires with Likert scales and semantic differentials [10]. These evaluations were focused on the assessment of several aspects such as: the defined concepts, the education and coaching strategies, and the user interfaces of the applications. Moreover, different usability tests have been performed on the different mock-ups and prototypes developed in the progress of the project. Intermediate tests have been very useful to identify possible improvements that have been applied in subsequent versions of the system. The final one was also evaluated before deploying it in real settings, showing very good outcomes on aspects like usability, satisfaction and acceptance of the proposed solution by the patient.

The two final HeartCycle systems, Heart Failure Management and Guided Exercise, have been deployed to be tested in two randomized clinical trials, involving 120 and 60 patients respectively. Each study is being conducted in three different sites in three European countries: Germany, United Kingdom and Spain. From the Patient Loop perspective, the study intends to validate aspects like effectiveness and usability of systems, acceptance, and efficiency of the proposed education and coaching strategies. This is being done by analysing both qualitative data (obtained from questionnaires done to the patients) and quantitative data (obtained from the system data logs). The initial feedback obtained so far combined with the outcomes of previous evaluations performed before the deployments in real settings anticipate excellent results in the parameters assessed.

The studies are currently running and are expected to finalise by the end of August 2013.

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