A Self-Management System for Chronically Ill Patients

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ABSTRACT

This article describes the User Centered Design Process for providing chronically ill patients tools to better self-manage their conditions. Stroke, congestive heart failure and chronic pain are complex conditions in which regulated physical activity can provide real improvement of symptoms and health conditions. In particular the work is focused on how the authors gathered the guidelines from the patients, how they translated them into interface design and how did the patients react to the paper prototypes. Paper prototyping is a quick, inexpensive and easily modifiable way to create intermediate artifacts that can be iteratively modified by early evaluation with intended users.

Keywords: Chronic illnesses, Human-Computer Interaction, Human Factors

INTRODUCTION

This article describes the collaboration between a group of chronically ill patient volunteers, Health and Social Care researchers, Human-Computer Interaction designers and computer scientists in an Information and Communication Technologies Healthcare project, aimed at creating technologies and services supporting the Self-Management of chronic illnesses. The intended users were involved by collective activities for better understanding of their daily life, expectations, and their willingness to include a new technology in their routines. Trying to interpret the users’ needs, the project team conducted an early prototype phase, involving several iterations and intermediate artifacts, ending with a cooperative evaluation made by the chronically ill patients. The conceptual models emerged in this phase are described by showing the digital static screenshots as artifacts standing in the design process between the paper and the interactive prototypes.

The Self-Management of a chronic condition implies a shifting of responsibility from the Healthcare professional to the patient, who is actively involved in facing the different aspects of his illness and in engaging in behaviors that improve his health conditions (Torsi et al., 2010). This paper is focused on a process of Participatory Design (Blythe et al., 2002) between Health and Social Care researchers, chronically ill patients and designers of Human-Computer Interaction (HCI) and it is in particularly based on stroke, heart failure, diabetes and chronic pain conditions. These conditions have potential for improvement when regular and supervised exercise is undertaken. The project adopts the Participatory Design methodology under several perspectives. First, HCI researchers worked in collaboration with Health scientists (Health and Social Care researchers, physiotherapists,
nurses, psychologists) in each phase of the user-centered design process with an exchange of theories, paradigms, and methods during the user studies, and a joint effort during the concept development, in the paper prototyping and early evaluation phases. Participatory Design has also taken place with patients, caregivers (Schofield et al., 1998) and health professionals of the three conditions, with Focus Groups about their practices and routines, and Future Workshops (Jungk & Mullert, 1987). Future Workshops are a particular kind of Focus Group in which the participants, in our case the chronically ill patients, were involved in creative games allowing design solutions for supporting the Self-Management of their condition to emerge. Also, oblique methods to elicit design concepts were applied in the contexts of specific interviews e.g. Technology Biographies (Blythe et al., 2002), Cultural Probes (Gaver et al., 1999; Gaver et al., 2004). Technology Biographies are interviews that focus upon media they used in the past, media that are currently part of their daily life, and the media they wish to have but that still don’t exist. The biographies were created with the patients of post-stroke hemiplegia and chronic pain in order to better understand which kind of technologies they were prepared to accept into their routines. Cultural Probes are packages of mixed materials that we gave to chronically ill patients to understand them better. In our packets there was a Media Diary, in which they were asked to mark the time they used the different media, some games allowing them to reveal their life story, their networks of parenthood and friends, and their wishes, in order to give us a full picture of themselves, their networks of parenthood and friends, and their wishes, in order to give us a full picture of themselves, and allow the designers and the stakeholders to design more specifically for them. The ongoing results were regularly shared among the Health scientists, the HCI practitioners, the computer scientists and the stakeholders, and following discussion, concluded with commonly agreed guidelines were applied to the later prototypes. The HCI specialists based on Activity Theory framed the design of the Self-Management system as a problem of supporting Higher Psychological Processes of self-managing a chronic condition. Activity Theory comes from the tradition of Soviet Psychology, stating that human cognition is not an isolated and abstract activity that takes place in the inner of the individual. Instead it is based on the manipulation of physical and cognitive artifacts, that can be provided by the cultural context, and that are a lever on which to base reasoning (see e.g. Dourish, 2004).

In a previous publication (Torsi et al., 2010), some theories that explain different strategies by which a chronically ill patient can self-manage his condition are gathered and fully described. Such as, the Self-Efficacy, the Transtheoretical Model, Acceptance and Commitment Therapy, and Activity Pacing. Self-efficacy is based on self-reflective introspection and self-beliefs in order to regulate actions and change behavior while restructuring motivation and building anticipatory scenarios to pursue. Goal setting is a device for creating the context for Behavior Change and it is based on formulating specific, measurable, activity-related, realistic and time-specified goals. The Transtheoretical Model is a predictive tool for modeling Behavior Change. People come through different stages when modifying their habits. There are sequential phases of change in which individuals alter their perception of themselves and of the environment towards the objective of change behavior. Acceptance and Commitment Therapy is a Cognitive Behavioral Therapy (CBT) to manage the occurring of painful symptoms in a chronic condition. It is based on the tenets that bad feelings are part of the individual and that therefore it is counterproductive to try to reject them. Activity Pacing is a cognitive behavioral strategy in order to cope with chronic pain while planning everyday activities while balancing between activity and pain and making a little less when pain is absent and a little more when it occurs, thus preventing discontinuous patterns of activity (Torsi, 2010). Our hypothesis is that those theories of Self-Management can be considered as cognitive artifacts in order to face chronic illness and to live with them. Their intention is to support activities e.g. self-driven rehabilitation, Behavior Change, the
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