Designing Self-care for Everyday Life

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Abstract
Managing chronic conditions can be challenging. People in such conditions, and the people around them, have to: deal with symptoms, adapt to the resulting disability, manage emotions, and change habits to keep the condition under control. Self-care technologies have the potential to support self-care and mediate the relationship between patients (and caregivers) and the condition. However, these technologies often disregard the complexity of the settings in which they are used and fail to become integrated in everyday life. In this workshop we will discuss how to design self-care technologies that are in harmony with people's everyday life. Therefore, we invite designers, researchers and practitioners to participate in a full-day workshop in which we will reflect on each other's work, and do a design exercise with patients and caregivers.

Author Keywords
Self-care; self-management; chronic care, self-care technology, personal health management

ACM Classification Keywords
H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

Introduction

Chronic conditions, such as diabetes, pose challenges in people's everyday lives, and to society in general. To better deal with these challenges and their costs, healthcare systems around the world have started transferring care services from the clinical setting to the hands of patients and caregivers [6, 9]. Self-care technology can offer several opportunities to support the care of people outside the clinical setting.

However, most self-care technology inherits the medical perspective, which promotes a top-down organization, an objective view of health, and neglects people's actual experience with conditions [1, 11]. Outside the clinic, care is not under the control of clinicians, and competes with many different activities thus increasing its complexity.

The HCI community has investigated self-care activities to uncover the particularities and challenges that people encounter performing their own care (see [12, 4] for a review). Research-to-date has contributed greatly to understand self-care, but it focused mostly on specific care practices (e.g. medication management), performed in isolated conditions (e.g. diabetes), inside a specific context (e.g. the home). People's lives, however, are much more complex.

Outside the clinical setting, people play many different roles (e.g. teacher, mother, friend) that may conflict with being a patient [3, 7]. They have multiple motivations, as well as activities and routines they engage in. As such, care is just one aspect in their busy lives [1, 8, 10]. Moreover, people might experience more than one condition [5] or just not be at home when it is time to perform self-care activities (e.g. work, holidays) [2, 8]. This calls for a different type of self-care technologies, i.e. ones that fit with everyday life [3].

To design self-care technology for everyday life, it is important to understand how people live and care for their health. In particular, the social contexts they inhabit, the way they divide care with others, the ways they adapt to the conditions, the different resources they use, and the different perspectives they have.

In this workshop we invite designers, researchers, practitioners, patients and caregivers to discuss the challenges, opportunities, lessons learned and theoretical insights to broaden the scope of HCI research in self-care.

Goals and Expected Contributions

The goal of the workshop is to get participants to discuss the challenges of designing self-care for everyday life. We do this in two ways. One of them is through the presentation and discussion of the position papers. The other is through the engagement of participants with patients and caregivers. For this purpose, we will invite people from the Finnish Parkinson's association to be present at the workshop, and we will discuss with the participants aspects of their care and everyday life.

For the workshop we expect position papers on self-care including: reporting on recent experiments and prototypes, studies of the field, theoretical accounts and critical reflections. We are interested in contributions that discuss the issues of design, development, and use of self-care technologies for everyday life. Possible topics include, but are not limited to:

- Success (and failure) stories of self-care technology;
- Challenges of using self-care tech. in everyday life;
- Appropriation of self-care technologies;
- Solutions created by patients and caregivers;
- Collaboration and division of work in self-care;

- Enabling patient empowerment;
- Bridging clinical and non-clinical settings;
- Underlying issues of self-care tech. design or use;

Outcomes

The outcomes of the workshop will materialize in four concrete contributions. First, accepted contributions will be published as part of a technical report from one of the organizers' institutions. Second, the organizers' reflections and ideas about the workshop will be summarized as an article to be submitted to *Interactions* magazine. Third, a summary of the workshop will be sent to the national (or european) magazine of the patients' association. Fourth, if relevant interest exists, a journal special issue will be proposed.

Intended audience

We encourage submission and participation of researchers, designers, social scientists, as well as other practitioners (e.g. therapists, doctors) working with self-care and interested in broadening the scope of self-care technology design. Non-academic participants can also attend the workshop without submitting a contribution if they wish to participate in the discussions. The workshop will provide an opportunity for this diverse group to meet and coordinate common efforts.

Participants selection

We expect to accommodate between 15-20 participants in the workshop as well as 2-3 invited patients and/or caregivers.

Participants will be selected based on: a) their submitted position papers; or b) their interest and background expressed by a 500 word motivation letter (for non-academics).

Contributions will be peer-reviewed by at least two members of the program committee and selected on their quality, originality, and compliance with the workshop themes. The diversity of backgrounds of the workshop group will also influence the selection of participants.

Scheduled Activities

- 09:00 - Introduction of workshop (and organizers)
- 09:05 - Introduction of invited patients and caregivers
- 09:10 - Introduction of participants (1/2 min each)
- 09:30 - Poster presentations
- 11:00 - Break
- 11:15 - Mapping exercise of issues and challenges
- 12:00 - Lunch
- 14:00 - Introduction to the self-care of Parkinson's
- 14:15 - Work in groups with people with Parkinson's
- 14:45 - Change group
- 15:15 - Break
- 15:30 - Change group
- 16:15 - Mapping exercise of issues and challenges
- 17:00 - What to do from here
- 17:15 - Closing remarks

Organizers

Nervo Verdezoto is a Research Assistant at Aarhus University. His work combines fieldwork with user-centered and participatory design methods to further understand people's self-care practices, stakeholders' needs and how people appropriate self-care technology.

Francisco Nunes is a PhD student at Vienna University of Technology exploring how self-care technologies can be further embodied in the setting they inhabit, with a interest on Parkinson's disease.

Erik Grönvall is a Visiting Associate Professor at the IT University of Copenhagen. Erik is interested in the boundary where technology and users meet. His interests include home-based healthcare, user driven innovation, end-user control and the development of technologies for diverse and heterogeneous user groups.

Geraldine Fitzpatrick is a Professor of Technology Design and Assessment in Vienna University of Technology. She is interested on how we design technologies to fit in with everyday contexts of work, play, and daily life, with a particular interest in older people, social interaction and collaboration, and health and well-being.

Cristiano Storni is a Lecturer in University of Limerick who is researching design theory and practices, and the social shaping of technology in areas such as healthcare. He focuses mainly on self-care practices and technology in the context of chronic and less-known disease (especially type 1 Diabetes).

Morten Kyng is the Director of the Centre for Pervasive Healthcare at Aarhus University. He is interested in participatory design, computer supported cooperative work, human-computer interaction, and pervasive computing for healthcare.

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