Designing Self-care Technologies for Everyday Life: A Practice Approach

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Abstract

The number of self-care technologies in HCI is growing; too often though, these are medically-oriented, failing to integrate in everyday life. In this study I focus on the self-care of Parkinson's using a practice lens. Understanding everyday practices will enable me to derive design considerations for creating technology that integrates well in everyday life, which may benefit other chronic conditions as well.

Author Keywords

Self-care technologies; everyday practices; Parkinson's disease; chronic care.

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ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Research Situation

I am just beginning the third year of my doctoral work at the Vienna PhD School of Informatics. I have completed the required courses, and passed both comprehensive and qualifying exams. I have conducted a literature review, performed fieldwork and plan to submit by the end of 2015. In the doctoral consortium, I hope to receive critical feedback on the work I have accomplished and on the planned upcoming studies, so that I can better shape my thesis.

Context and Motivation

Chronic conditions are medical conditions that have no cure or definitive treatment. Care is focused on creating a good quality of life for as long as possible [10]. Chronic conditions create a number of challenges for patients and carers, including: dealing with symptoms, facing disabilities, understanding and coping with complex medication schemes, and obtaining useful medical advice [14]. The condition may also have an emotional impact, and force radical lifestyle changes. These characteristics require patients and carers to self-care, or to manage the condition by themselves. Self-care in this proposal refers to the activities that people living with a chronic condition undertake to manage the condition outside of professional care as part of their everyday life. This is complementary to, but different from, the clinical care undertaken by healthcare professionals. It includes activities such as observing changes in the body, acting on symptoms, managing treatment, and dealing with the different consequences of living with a chronic condition [4].

In this work I focus on Parkinson's disease (PD). PD is a neurodegenerative condition with a great impact in everyday life. People need to manage medication, perform exercise, adapt their lifestyle to their "new" bodies, and manage their emotions through losses of ability. Accompanying self-care is also the certainty of fluctuations (of condition state), and progression. Such challenging self-care makes PD a good example to study how patients and carers adopt and adjust self-care practices to build the life they want to live. Studying these practices will enable me to derive considerations for technology to adapt to this situated, improvised, and changing care.

Background and Related Work

Self-care technology has the potential to improve the lives of people living with chronic conditions. Previous work has shown, for example, how self-care technology can be used to support learning about the condition [9], monitor disease symptoms and signs [12], and explore and adapt treatment [1]. However, despite significant investments to date, self-care technologies still have a relatively low uptake [6]. In analysing the literature, it is common to find possible reasons for this non-acceptance: symptom-oriented technologies, over-reliant on sensor readings that disregard the experience of living with the condition [12]; one-size-fits-all approaches that ignore the situatedness of self-care practices [13]; and the challenge of interpreting and making sense of sensor data in isolation from lived experience [3]. These challenges show the difficulties of designing technologies to fit everyday life. Recognising the challenge of designing for self-care, compared with the clinical setting [7], this thesis follows a different approach, aligned with the practice paradigm [8].

Social practice theory is used as a lens [8,11], which makes practices the central focus of this study. Practices, in this context are "routinized way[s] in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood" [11][p. 250]. Applying social practice to self-care recognises that self-management practices are not static, but rather dependent on spatial and temporal contexts, entailing materialities, bodies, aspirations and values, that are constantly rebuilt and improvised. This lens provides a tool to understand self-care activities, considering the complete environment in which they happen, and therefore embracing that self-care is only one dimension of people living with a chronic condition [2].

Thesis, Goals and Methods

The main research question orienting this work is: *How can we design self-care technologies for patients with Parkinson's that fit everyday practices?* This research question operationalizes into four goals (RG). I describe each, documenting its methods and status (completed ☑, in progress ◌, planned ☐).

☑ *RG1: Explore the design space of self-care technologies*. The idea was to understand the main issues in self-care, considering the different points of view (e.g. patients, clinicians), and the different research areas involved (e.g. medicine, sociology, computing), which I did with a literature review.

☑ *RG2: Understand the everyday practices involved in the self-care of Parkinson's*. I used interviews, observations, and ideation workshops, to achieve this objective. The in-depth interviews were held with patients and carers and focused on learning to deal with the disease, treatment and everyday life. The observations were conducted in an outpatient neurology clinic, to observe the interactions with clinicians. The ideation workshops were held with patients and carers, and were conducted after using technology probes (based on the findings of previous fieldwork). The different conversations were recorded, transcribed, and analysed with grounded theory [5].

◌ *RG3: Derive considerations for designing self-care technologies that integrate better in everyday self-care practices.* Drawing on the work conducted so far I am deriving considerations to be used when designing self-care technologies that account for the self-care practices of patients with Parkinson’s and their carers.

☐ *RG4: Use design considerations in creating self-care technology*. I plan to develop a self-care technology based on the opportunities identified in the fieldwork and design considerations of this work. The prototype should be deployed for some months and be used by patients or carers. The evaluation would be based on interviews, at different stages, to understand the effect of using the technology in the everyday practices. Results would also enable one to iterate the design considerations developed in the thesis.

Dissertation Status

I have completed RG1 and RG2. RG1 included a literature review of studies indexed by HCI Bib[1], containing terms related with self-care technologies. The review enabled me to map existing technologies, uncover common design challenges, and draw opportunities for technology. A paper with the findings was submitted to TOCHI and is undergoing revisions.

RG2 included multiple in-depth interviews, with 9 patients and 8 carers, as well as 12 observation sessions at the hospital (with different patients). This enabled me to understand everyday practices and uncover some of the issues in self-care. These findings contributed to a paper, submitted to the International Journal of Medical Informatics, on how patients and carers collaborate in self-care and how system design should adapt to this situation. Another part of the findings inspired technology probes that were given to three groups of patients and carers to use for a week. Following this, ideation workshops were conducted. A reflection on the conducted fieldwork generated a conference publication submitted to CHI ’15 on the opportunities of self-care technology for Parkinson’s.

RG3 is the current focus of my work. After concluding a first version of the design considerations, I am planning to further iterate and inform them. This can be done with a study that evaluates the deployment of a technology that integrates the principles of this thesis (RG4), but there may be other ways of informing and iterating the design considerations. I would like to discuss the different alternatives to validate the outcomes and making the thesis stronger.

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[1] http://hcibib.org is a search engine of HCI publications.

I have not started to write the thesis document yet. I have a rough outline and the manuscripts submitted for publication that will be adapted to chapters.

Expected Contributions

This work has two expected contributions. First, it will provide a greater understanding of the everyday self-care practices of people living with Parkinson's, presenting ways in which technology can help. Second, it will provide advice for designing technologies that better integrate in everyday life. Being so, it should be useful to researchers working with Parkinson's, or with self-care technologies more generally.

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