
Improving the Self-care of Parkinson's Through Ubiquitous Computing

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Abstract

Self-care has already been studied from the perspective of the patient. However, few studies focus on tools to learn about the disease in complete autonomy. We argue that these technologies can be crucial to allow patients to learn about their disease and adjust treatment, therefore, we propose to study them for people with Parkinson.

Author Keywords

Self-care, Parkinson's Disease, Pervasive Healthcare.

ACM Classification Keywords

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

Introduction

Parkinson Disease (PD) is a progressive degenerative disorder that affects the nervous system. The disease is characterized by a number of motor symptoms, such as: tremor, slowness of movement, rigidity and postural and gait impairment (see [1][2]), and non-motor symptoms, like depression, pain and sleep disturbances. As a result, people with Parkinson (PwP) are likely to experience a reduction in autonomy as part of living with the disease (see [3]).

Fortunately, medication exists and has a very strong effect (Levodopa). At times, even well trained

specialists will have troubles in identifying the symptoms, because they are very attenuated. At other times however, PwP will lose control of their bodies, their thoughts, and their feelings. A phenomena that is likely to increase as the disease progresses.

To better manage the disease, PwP visit regularly their neurologist or general practitioner. During the appointments, the practitioners may use movement tests, interviewing and other methods to assess the status of the disease. Based on this assessment, the doctor is likely to recommend treatment adjustments for the next six months, when another appointment will take place.

In the next months, the patient will manage the disease by himself. Just like many other chronic diseases, the PwP must learn about the disease, and experiment with the body to know what works, and what does not.

This thesis aims to understand the role ubiquitous computing can have in this process. There are two basic large research questions: RQ1) How do people with Parkinson self-care? And RQ2: How can ubiquitous technologies improve the self-care of people with Parkinson?

Previous Work on Technologies for Self-care

Previous work on technologies for self-care exists, especially for people with diabetes. Here we categorizes literature in three groups: 1) Learning enhancing; 2) Explore and tinker; 3) Online support communities; and 4) Collaborative interpretation and action.

Learning enhancing technologies are a group of artifacts that support reflection and discussion during the learning process. Such artifacts can bring more

information into disease education classes [4], or virtual spaces [5], that enables members to discuss and learn from each other examples.

Explore and tinker relates with technologies for experimenting with treatment to achieve the control of the disease. Their role is to provide either more information, or to display information in a new way, that can help patients detecting patterns [6], or closely monitor changes in their treatment [7].

Online support communities are technology-enabled support networks that provide members with social accountability, motivation and emotional support [8][9]. Using these tools, members inform others of their actions and commit to plans, together. They are then able to celebrate their achievements with others and to keep motivated in pursuing their plan. By observing the success of others, one is likely to follow their example and to engage in a friendly competition.

Collaborative interpretation and action are tools that enable patients to collaborate in the diagnosis and adjustment of treatment for their diseases. While self-manage by themselves could be very difficult (see [10][11], by collaborating with their clinicians, patients contribute to better treatment decisions. They also become more knowledgeable of their condition and active in its management.

Some studies already focused on using technology to self-care. However, literature seems to lack solutions to explore and tinker. This is probably due to the fact that managing the disease by oneself can be quite complex. However, as the pressure to move care to the home increases, it is fundamental to consider this type of tool for self-care. This thesis may rely on this type of tool to

help people with Parkinson better understanding what interacts with their bodies and hinders their treatment.

Research Approach

The methodology of this thesis is not yet completely defined, but three stages are likely to exist. These are: a literature review on self-care, a qualitative study on how PwP self-care, and the evaluation of design interventions for improving their self-care.

The literature review should analyze different communities that relate to self-care, including: medicine, sociology of health and illness, medical sociology, pervasive healthcare, and ubiquitous computing. By analyzing the different perspectives, it will be easier to understand the complex area of self-care, including research problems, discussions and trends.

Parallel to the first study, a qualitative study of self-care for Parkinson disease will be conducted. This shall focus on understanding the activities of the day-by-day management, the main issues, and the people involved in the care. This will draw on interviews with people with Parkinson, caregivers, and doctors, as well as, the observation of medical appointments. The analysis will follow the Constructivist Grounded Theory method [12].

Drawing on the first and the second study, design interventions will be empirically evaluated to understand the effect that ubiquitous technologies can have in the management of the disease.

Current Status

The literature review studied has been started and is likely to give way to a publication on technologies for self-care. The qualitative study has also started. Seven interviews were conducted with people with parkinson

and are being analyzed at the moment. As the analysis advances, other interviews, and a number of observation sessions, will contribute to the emerging theory.

Based on the results from the interviews, a design intervention is being planned at the moment. This consists of a prototype that enables logging symptoms, for individual learning or discussing with the clinician. Symptoms are enriched with pictures or videos, and are further complemented by contextual information such as, last meals, last exercise activities, weather conditions, and others. By using the information, the system is able to suggest observation patterns for self-care. This means that the system can learn from the information supplied and infer events, to observe carefully, as they may be related with an accentuation of symptoms.

Objectives for Attending the Ubicomp DS

The attendance of the UbiComp doctoral school will provide the opportunity to better discuss this work with peers and to observe how other students frame their questions, reflect on their methodology, and express their contributions. By the time of the doctoral school, this work will be more advanced and at the right point to receive feedback that can be implemented in the thesis. Finally, the participation in the doctoral school might enable the author to contact with experts in the field that might help making a better contribution to the UbiComp community.

Biography of the Author

Francisco Nunes is a PhD student at the HCI group of Vienna University of Technology, working under the supervision of Prof. Geraldine Fitzpatrick. His PhD program started in October 2012 and should be

finished by October 2015. Before joining Vienna University of Technology, Francisco worked for four years at Fraunhofer AICOS institute, where he was involved in designing and evaluating technology for

older adults. He also received a Master in Informatics and Computer Engineering from Universidade do Porto in Portugal.

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