
Informing the Design of Personal Informatics Technologies for Unpredictable Chronic Conditions

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Abstract

Personal informatics technologies, such as consumer fitness tracking devices, have an enormous potential to transform the self-management of chronic conditions. However, it is unclear how people living with relapsing and progressive illnesses experience personal informatics tools in everyday life: what values and challenges are associated with their use? This research informs the design of future health tracking technologies through an ethnographic design study of the use and experience of personal informatics tools in multiple sclerosis (MS) self-management. Initial findings suggest that future health tracking technologies should acknowledge people's emotional wellbeing and foster flexible and mindful self-tracking, rather than focusing only on tracking primary disease indicators and optimising health behaviours.

Author Keywords

Personal informatics; self-tracking; self-monitoring; chronic conditions; multiple sclerosis.

ACM Classification Keywords

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

Context and Motivation

Emerging personal informatics technologies have great potential to support people in understanding and living with chronic conditions. They aim to "*help people collect personally relevant information for the purpose of self-reflection and gaining self-knowledge*" [4] and include consumer health technologies, such as wearable fitness tracking devices and food journaling apps. However, the design of consumer health technologies tends to focus on optimising human behaviour, such as increasing physical performances. It is unclear whether they can support people's lived self-care practices and the unpredictability of relapsing (e.g. migraine, epilepsy, MS) and progressive (e.g. Alzheimer's disease, Parkinson's disease, MS) chronic illnesses.

My research focuses on informing the design of future health tracking technologies through an ethnographic design study of self-tracking in MS self-management. MS is neurodegenerative causing relapses and a wide range of symptoms affecting people's vision, cognition, and movement. Individuals living with MS often choose to monitor their health and wellbeing themselves outside of the clinical setting. Health tracking applications for MS tend to be medically-grounded focusing on predefined and structured documentation of symptoms and relapses in order to inform the clinical assessment of the progression of the disease. People's personal data collection preferences and individual understanding of their overall physical and psychological health and wellbeing often fall short.

Personal informatics technologies offer the means to better support the practical and emotional needs of people with MS. They offer not only physical and physiological real world data that could inform clinical

decision making, but could also empower individuals to better understand their bodily changes and adjust to the unpredictability of MS beyond the clinical context: for example, wearable fitness tracking devices provide data (e.g. steps and heart rate) that are associated with primary disease indicators and symptom triggers, and typically offer educational and social scaffolding to pursue a healthy lifestyle. However, it is unclear whether personal informatics technologies can help people living with MS to self-manage their conditions: there is little knowledge about how people with MS use and experience personal informatics tools, and how the design of future health tracking technologies could better support existing values and overcome current limitations and potential unintended effects.

Background and Related Work

Within personal informatics research there are psychological, phenomenological, and humanistic streams [1] which have yielded models of self-tracking by focusing on knowledge workers who are generally young, technologically savvy, and healthy. Less attention has been paid to individuals with chronic conditions and how they use and experience personal informatics tools in self-managing their health.

Most health-related research in HCI has focused on the understanding of self-management practices and the use of self-care technologies in common conditions, such as diabetes, hypertension, and asthma [5]. Studies on self-management highlight the lived experience and open-ended nature of self-care practices. In contrast to personal informatics systems, self-care technologies are specifically designed for people with chronic conditions and typically support individuals in monitoring and managing primary disease

indicators with or without the involvement of caregivers and clinicians.

Studies within health informatics have explored in which ways wearable physical activity tracking devices could be leveraged in order to measure gait patterns and assess the progression of MS. Research has, furthermore, investigated the clinical assessment of disability in MS patients with the help of Microsoft Kinect. But there is more to managing MS than measuring disease progression. Medically and neurologically informed studies suggest that MS requires a high level of self-management and indicate that a healthy lifestyle might alleviate several MS symptoms and foster an increased quality of life.

Research Question, Goals, and Methods

I am investigating the following research questions: how do people diagnosed with MS use and experience personal informatics tools in MS self-management, and what are the design implications of this understanding for future health tracking technologies?

To answer the stated research questions, this thesis adopts an ethnographic design research orientation by combining ethnographic methods and technology probes. In doing so, this study pursues the following research goals (RG):

RG 1: review personal informatics research in order to position the work in the literature and adopt personal informatics as a lens for the study of self-tracking tools in chronic illness self-management;

RG 2: (1) conduct an interview study on how people living with MS use personal informatics tools in MS self-management to reveal values and limitations of existing technologies, and derive design implications for future tools; (2) analyse the design of paper bullet journals on the social media site Instagram in order to inform derived design implications and learn how to design a technology probe (e.g. how to overcome limitations of existing digital self-tracking tools through flexible self-tracking);

RG 3: develop and investigate a technology probe in the wild in order to elicit situated data, examine self-tracking and reflective thinking practices in MS self-management over time, and to evaluate previous findings and design assumptions;

RG 4: create a research and design framework that builds on the developed understanding of self-tracking practices (RG 1-3) in order to (1) mediate the values and limitations of current personal informatics tools and the deployed technology probe, and (2) present related design strategies and tensions for future health tracking technologies.

Status, Findings, and Next Steps

I have completed the literature review [1], interview study [2], and analysis of paper bullet journal photos on Instagram [3]. Findings illustrate how people with MS regained a sense of control over MS by intertwining individual self-care practices (e.g. pursuing a healthy lifestyle) with different self-tracking tools (e.g. fitness tracking devices and paper notebooks), and self-tracking practices (e.g. fitness tracking and symptom

tracking) and styles (e.g. documentary and diagnostic). They abandoned self-tracking tools especially when experiencing negative emotional wellbeing (e.g. when overly focusing on monitoring symptoms). These practices highlight the importance of supporting flexible and mindful self-tracking. The analysis of paper bullet journals builds on these findings and presents two directions for flexible and mindful self-tracking: *digitally extending analogue self-tracking* and *supporting digital self-tracking as a mindful design practice* as opposed to focusing only on passive automation and predefined presentation of personal data. Next, I intend to iteratively design and evaluate a technology probe that supports flexible and mindful self-tracking with people with MS (RG 3) and, finally, develop a research and design framework (RG 4).

Current and Expected Contributions

This research aims to make the following contributions to self-care technologies [5] and personal informatics [1,4]: the first contribution is a grounded theory literature review on self-tracking in personal informatics. It addresses unarticulated methodological differences by characterising three streams of research and presents personal informatics as a sensitive lens to understand self-tracking in chronic illness management; the second contribution is the development of a technology probe that can be used by other researchers to explore situated self-tracking practices; the third contribution is a qualitative account of the use and experience of personal informatics tools in MS self-management. Based on this understanding, my research aims to contribute a framework for future research endeavours drawing attention to the roles of personal preferences and emotional wellbeing in self-tracking relapsing and progressive chronic conditions.

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