# Learning To Know Oneself Again Through Self-monitoring Data: Dealing With Life Transitions In Chronic Care

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## Abstract

Individuals with chronic disease experience a variety of life transitions. Self-monitoring tools host a potential to support these individuals in coping with the changes these transitions bring. However, we could learn more about how these tools can support one of the ways individuals deal with life transition, which is learning about oneself again. Building on a design ethnographic study from a pelvic cancer rehabilitation, I envision challenges for self-monitoring tools design in relation to the different transitions in the individuals' with chronic disease lives.

## Author Keywords

Learning; self-monitoring data; chronic care; life transitions

## CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**; *Haptic devices*; User studies; Please use the 2012 Classifiers and see this link to embed them in the text: https://dl.acm.org/ccs/ccs_flat.cfm

## Introduction

Chronic care builds on the healthcare professional's ability to get to know the individual with the chronic disease. However, an individual with a chronic disease

have difficulties knowing who they are as they go through a variety of life transitions: from the first diagnosis to coping with the different developments of chronic disease [7]. Coping with these different transitions often lead to a need for reconstruction of one's identity because of the multiple changes on both physical or cognitive level [8]. In turn, one has to get to know oneself again or in other words re-create their identity. However, managing changes in re-creating identity when chronically ill might be challenging because "uncertainties, constraints, and prognoses tend to shift over time." [13].

Many view self-monitoring tools and the data they can produce as a possible solution to this challenge. These tools build on the assumption that we can learn about ourselves by collecting vast amounts of qualitative and quantitative data [3]. Self-monitoring data is a type of patient-produced data, often collected through a mobile application [9]. Using self-monitoring data as a support for individuals with chronic diseases is believed to support these individuals in learning about their health problems and in turn about themselves [3]. For example, individuals with diabetes were able to build their identities through the self-monitoring data, however only when they were already experts on their own disease [10].

Using self-monitoring data as a support for chronic care has proved to be challenging. We still do not fully understand how to design self-monitoring tools so they produce data that is meaningful, actionable and feasible [1] and yet the data collection is not emotionally and cognitively demanding for the individuals [5]. That is further connected to the various stakeholders who are involved in chronic care. Even though it is the individual who suffers from chronic disease, their social networks and communities are also impacted as they are involved in chronic care as well [14]. In turn, the self-monitoring tools supporting the chronic care need to allow for collaboration of the particular stakeholders whose perspectives need to be involved in the tool design as well [1]. Hence, we need to learn more about how we can support the individuals when they are going through these transitions of forming identity and how we can support it with the self-monitoring data and other related social technologies.

This text tries to attend the problem of how one's learning about their identity can be supported by social technologies. I draw on a design ethnographic work in pelvic cancer rehabilitation clinic that I conducted as the main empirical work during my PhD studies. A mobile application was built to support the work of the nurses at a pelvic cancer rehabilitation clinic. The research team, which I have been part of, built together with the nurses a mobile application to support nurses' work. The application has now been in use for almost two years, and strongly impacted the work of nurses and in turn also the patients' wellbeing (reported for example in [2,4]. However, these results also indicate that to be able to use the data to support patients in learning about their problem, we need to pay closer attention to the consequences of the self-monitoring tool use in relation to the cancer survivor's transitions they go through. In this text, I identify challenging issues that a future study will address.

## Method and setting
My research draws on a design ethnography study that lasted for four years. This study aims to gain a deep understanding of how cancer survivorship can be

supported by self-monitoring data. More specifically, I focused on oncological nurses and how they use a new self-monitoring tool to learn more about the cancer survivors' health problems as well as how they support the survivors' learning about themselves without and with the self-monitoring data. Various methods of data collection were deployed, such as observations of the nurses' work practice at the clinic, clinical documents collection, photographs, formal and informal interviews with nurses, survivors and the mobile application developers, and organizing design-oriented workshops.

The data collection has been conducted in a pelvic cancer rehabilitation clinic, where three oncological nurses work. The cancer rehabilitation process in this clinic builds on continual contact between the nurses and the survivors, involving in-person consultations and telephone contact. The survivor together with the nurse identify what the survivor perceives as the most challenging health problem and then they together agree on a strategy how to handle this problem. As the nurses usually do not do any physical check-ups, it is mainly the survivor's verbal accounts that they draw from. The oncological nurses often experience issues with their strategy, because it is difficult for survivors to recall certain types of information, for example remembering the exact number of defecations, how many medications they took, etc. Therefore, a solution was initiated: a mobile application was built which the survivors can use to collect self-monitoring data related to their health issues. This data can in turn inform the nurses' work.

### Life transitions in cancer rehabilitation
Transition from cancer treatment to cancer rehabilitation might seem to be less demanding than actually starting cancer treatment itself. However, for many it is not the case. Once the cancer survivors are proclaimed cancer-free, it does not mean they do not suffer from any health problems. Radiation-induced health problems can appear weeks but also years after the cancer treatment is over, requiring the survivors to adjust continuously to these changes. As any individual suffering from chronic disease, every person experiences the consequences of radiation in a very individual way. The problems can range from controlling their bowels and bladder, pain, problems with their sexual life and their psychosocial and existential wellbeing. When the survivors get in touch with the clinic, they are often experiencing several of these health issues simultaneously. The nurses handle the issues one at a time. It is common that once they help the survivor to overcome one health problem, another problem becomes visible.

To cope with the various transitions in the chronic care, the survivors need to learn how that manage their old and new health problems. The success of the cancer rehabilitation depends on the information about their daily problems that the survivor provides the nurse with. Therefore, the nurses use a range of tools to understand in which chronic disease phase the survivor is. Mainly they draw on a 300-questions survey that the survivor fills in before the first visit, survivor's verbal accounts of their chronic disease and the self-monitoring application. The application provides the survivor with a series of questionnaire that they can fill in, either on a daily basis or through experience sampling. The nurses ask the survivors to use the application for two weeks. Meanwhile many of them do so, some kept on using their application for several weeks or months, regardless if the clinic nurses was in

touch with them or not. If the nurse is still in touch with the patients, she reviews the data together with the survivor during a phone consultation.

## Future work

In the following section, I identify possible challenges that emerge when we try designing self-monitoring tools for individuals with chronic disease. These individuals strive to learn about themselves again as a way to handle transitions connected to their chronic disease but that can be further complicated by the following challenges.

First, chronic care does not happen outside of people's lives - on the contrary, the self-management of chronic disease is intertwined with the individual's life [6]. Hence, the survivors have to juggle learning about their own disease and their new identity, as well as taking care of family, work, travelling but also break-ups, job loss or other life disruptions [12]. By becoming survivors, they can become involved in new communities but also leave behind some of their existing networks [11]. The question is:

- How can self-monitoring data support the individuals in participating in this complex social environment?

Second, nurses often talk with survivors about what is normal because for them aspects of life that we take for granted (regular defecation frequency, controlling your bladder), are often disrupted by the cancer treatment and survivors often have to learn again how their own mind and body works. However, that is difficult, because their health problems are so complex. The self-monitoring data could provide a support for

the survivor's learning process to better understand how their body and their mind "normally" work. But what might be normal at one point can potentially change further on, as the chronic disease develops, the individual starts suffering from other chronic diseases or starts suffering from other problems related to aging.

- How can the self-monitoring data support the individuals in establishing their possibly ever so changing "normal"?

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