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# Quantified Data in Cancer Rehabilitation: Way to Learn to Know Yourself Again?

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**Abstract**

Quantified data could potentially provide a great support for cancer rehabilitation. In an ethnographic study we explore the question how could quantified data support re-creating of the patient's identity in a cancer rehabilitation process. Preliminary findings point out to a potential for support to use quantified data in cancer rehabilitation when the patient makes sense of the data together with a healthcare professional. Issues connected to design implications are related to questions such as whom to involve in the design process, what to collect, and how much.

**Author Keywords**

Quantified data; cancer rehabilitation; identity; nurses; quantified self.

**ACM Classification Keywords**

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

**Introduction**

Going through cancer and cancer treatment is a life changing situation and often requires reconstructing of one's identity through learning to know oneself again because of many changes on the physical or cognitive

level[1]. Managing changes in re-creating identity might be challenging because “uncertainties, constraints, and prognoses tend to shift over time.” [2]. Collecting quantified data following the premise of Quantified self movement “self-knowledge through numbers” would seem perfectly suitable for cancer survivors. However, how can these QS inspired practices be used in cancer rehabilitation? And how would that impact those involved in the cancer rehabilitation process? Using this kind of quantified data for cancer rehabilitation has not been explored in depth yet [3]. This paper explores an existing cancer rehabilitation practice, where a tool for self-tracking for the patients is being developed. Through ethnographic study, we explore this practice and ask: how could quantified data fit in cancer rehabilitation? More specifically, we focused on the relationship between an oncological nurse and a cancer patient, and we pose a research question:

- How can the quantified data support the patient’s identity re-creation?

The insights produced from the ethnographic engagement suggest that quantified data could be used in cancer rehabilitation when both the patient and the healthcare professional collaborate on making sense of the data. Through exploration of three areas, normality, routines, and trust, we can understand how the relationship between the patient and nurse might change. This paper contributes to the workshop (and consequently also CHI community) in following ways:

- Situating the hypothetical ideas (recreating identity based on quantified data) into a

setting, where these ideas has not been deeply researched yet (cancer rehabilitation)

- Identifying questions that should be asked when designing for quantified data in cancer rehabilitation

### **Method**

This section presents framing of the study as an ethnographic study. Because the study aims to gain deep understanding of a possible change of a relationship between a nurse and a patient, various methods of data collection were deployed, such as observations, formal and informal interviews, and organizing design workshops. The empirical material was collected from September 2015 to December 2016. Two observations lasting 3 weeks were conducted, during which more than fifteen in-person consultations between the patient and the nurse were observed, as well as over 350 calls between a nurse and a patient were listened to. This paper reports on work-in-progress: the application was developed, and is going to be tested by the patients in February 2017.

### **Empirical Case**

In this section, the empirical setting will be presented: “Name of the project”, a cancer rehabilitation project that is based on work of three oncological nurses. The cancer rehabilitation process in this center builds on continual contact between the nurses and the patients, involving in-person consultations and telephone contact. The patient together with the nurse identify what the patient perceives as the most challenging health problem and then they together agree on a strategy how to handle this problem. After receiving cancer treatment in the lower abdomen, the patients

often experience problems with controlling their bowels and bladder, pain, problems with their sexual life as well as their psychosocial wellbeing. When they get in touch with the center, they are often experiencing several of these health issues simultaneously. The success of the treatment depends on the information about their daily problems that the patient provides the nurse with. As the nurses usually do not do any physical check-ups, it is mainly the patient's oral accounts that they draw from. The project nurses often experience issues with their strategy, because it is difficult for patients to recall certain types of information, for example remembering the exact number of defecations, how many medicaments they took etc. Therefore, a solution was initiated: a mobile application would be built through which the patients will self-track their health issues. The application would be connected to a smart button, Flicker, through which frequencies of up to three problems could have been counted.

## **Discussion**

In this section, three issues of the cancer rehabilitation related to identity that might be re-created by the quantified data will be explored: normality, habits, and trust.

### *Normality*

Nurses often talk with the patients about what is normal as aspects of life that we take for granted (regular defecation frequency, controlling your bladder), are often disrupted by the cancer treatment and patients have to often learn again how their own body works. However, that is difficult, because their health problems are so complex. For example, loose feces are a common problem for the patients. There are

medicines that can decrease the looseness, but no universal rules on how often and how much of it to take exists. The nurses have their strategies how to teach the patients' to manage loose feces, but it builds on remembering how certain dosages work. But that can be influenced by many other factors, such as food, patient's mood etc., hence managing this type of health problems becomes a complex task. Not being able to recall this kind of information makes it more difficult for the patients to learn how their body works as well as recognize their own improvement (which is an important aspect of wellbeing). Here the quantified data could provide a support for the patient's process of re-learning, when the patient would collect data about themselves and the nurse could help them develop better understanding of how does their body "normally" work.

### *Routines*

Some of the routines that the patients develop support their wellbeing (going for a walk every day), but some might be harmful. For example, many patients have problem with controlling their bladder. Many of them develop a routine, when they always urinate before leaving home "just to be sure" even though they do not really feel the need. However, urinating without actually having sufficient amount of urine in the bladder "teaches" the bladder to send signals that it needs to be emptied even though it does not have to. This can lead to highly sensitive bladder that "sends signals" all the time, making the patient feel urgency to urinate constantly. Here the quantified data could serve for the nurse to detect harmful routines, but it would also provide the patient with material to consciously develop new routines that works. On the collected data, the nurse could illustrate possible harmful effects of certain

routines, and through reflecting with the patient around the data together they could also build new routines.

#### *Trust*

Because of consequences of the cancer treatment, patients often state that they do not recognize themselves and that they cannot rely on their body. For example, they cannot fully control their bladder anymore. In other words, they often do not feel that they can trust their own body. Nurses often lift up the patient progress, but they can provide them only with oral accounts. For example one of the ways of treating urine leakage is pelvic training - it takes up to three months of everyday training before any results can be recognized. As the progress often happens on a very small scale and can be visible only after a longer period, the quantified data could provide support for the patients in trusting their body again.

#### **Conclusion and implications**

Finally, in this section we will sum up the issue of quantified data in cancer rehabilitation as a support to patient's identity re-construction. As our findings suggest, the patient makes sense of the data in relation to their life, and the nurse makes sense of the data in relation to the medical standards and her experience. These results resonate with suggestions from similar research [4]. Together, they can co-create the most suitable cancer rehabilitation for the patient, where the data are not just "only numbers" anymore, but are a lived aspect of the rehabilitation[5]. Considering design, several questions need to be considered:

#### *Who to involve?*

In this paper, we provided an example of only one relationship, in the text represented by the nurse and patient. However, in the real life, many more people are part of the cancer rehabilitation process: family members, psychologists, social workers, and many more. However, should all of them be involved in the design as well? And to what extent and how, considering practical conditions of designing such tool?

#### *What to collect?*

Cancer rehabilitation requires a very individualistic approach. What to collect should be decided by the patients together with the nurses. However, that would mean that the nurse or the patient would need to know how to collect various types of data. Who from them should have this kind of knowledge? Or should a data specialist be involved?

#### *How much?*

On one hand, the nurse needs often very precise information from the patients to be able to provide them with a diagnosis as precise as possible. On the other hand, that might mean that the patient needs to collect a lot of information about their life. Together they can balance out what needs to be measured, without the patient feeling too overwhelmed by the data collection, but at the same time still providing enough information for the nurse.

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## Two data relationships

### *Nurse and a patient in cancer rehabilitation*

I am interested in how the relationship will change between a nurse and a patient on the personal and practical level, during cancer rehabilitation process. I am interested in questions such as: How to decide on what kind of data to collect? How can the nurse use the quantified data to support the patient who is going through cancer rehabilitation? What do the patient and nurse need to be able to know/learn in order to be able to use the data?

### *Patient and healthcare*

The second type of relationship I am interested in is what kind of relationship would be produced when a patient comes with their own data into healthcare? For example in Sweden, the patients (or potential patients) are motivated to collect all their data in one single place (a system developed by the state). What kind of relationship would be produced when the patient would start using such system?

## Biography

My name is Katerina Cerna and I am a PhD student at University of Gothenburg at the *Department of Education, Communication and Learning*. My project focuses on change of the nursing practice in relation to a new type of quantified data. More specifically, I aim to explore how the nurses will develop as professionals when they gain access to data collected through self-tracking and smart devices. My project draws from a workplace study of a cancer rehabilitation center, where the project nurses gain access to the new type of quantified data of their patients. The study focuses on three areas of the nursing practice: participation in design sessions, where self-tracking application was being developed; workshops focused on development of methods how to use the new quantified data in their practice, and the actual usage of the new data in their practice.