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Supporting appropriation of self-monitoring tools in clinical settings: the case of pain in cancer rehabilitation

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Abstract. Self-monitoring tools, which support clinicians' work through collection of patient generated data, have been used increasingly in chronic care. Their appropriation by the patients is crucial but at the same time can be problematic, as unexpected use of tools used as a support for clinical decisions might lead to wrong decisions. In this poster, we present preliminary findings from an ethnographic study from a pelvic cancer rehabilitation clinic. We present an empirical example of a patient who appropriated a self-monitoring application to register her pain in an unexpected way. Our findings aim to understand better how to support appropriation of self-monitoring tool in a clinical setting.

Introduction

Recently, self-monitoring tools have been increasingly used in healthcare because of their potential to support and improve collaborative work that chronic care builds on (Fitzpatrick & Ellingsen, 2013). Self-monitoring tools facilitate continuous data collection by patients through engagement with a digital tool, often in a form of mobile applications. These tools can support healthcare professionals' decision-making and in turn improve patients' health (Mentis et al., 2017). Successful and meaningful use of these tools depends on how well they will be appropriated by the patients and the health care professionals (Dourish,

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2003). We define appropriation as using a tool by the user in unexpected ways, that is, in ways that the designing team did not anticipate when they were designing the tool (Stevens et al., 2018). In clinical settings, self-monitoring tools are built in such way so that they support work of the healthcare professionals, but it is the patients who use the specific mobile application for data input (Grisot et al., 2018). Both of these stakeholders can appropriate the tools in different ways, as appropriation is socially situated (Stevens et al., 2018). Different ways of tools appropriation can lead to situations, which are problematic in the context of chronic care. For example, when the patients start using the tools in unexpected ways, it might stop being possible for the clinicians to interpret the data in a meaningful way (Piras & Miele, 2017). Therefore, we need to understand more how the self-monitoring tools are used in unexpected ways by the patients in clinical settings. Contributing to overcome this gap, this poster presents preliminary findings from an ethnographic study from a pelvic cancer rehabilitation clinic. We hope that our findings will help us understand better how to support appropriation of self-monitoring tool in a clinical setting.

Appropriation in cancer rehabilitation

This text reports preliminary findings from an ethnographic study, which we conducted in a pelvic cancer rehabilitation clinic. The clinic aims at helping patients, who received pelvic cancer treatment, and who now suffer from late effects of the cancer treatment, which dramatically decrease their quality of life. The oncological nurses working at the clinic get in touch with the patient and try providing them with help. To be able to provide the patients with suitable treatment, the nurses need to gain access to a specific information, such as development of pain over time, which is difficult for the patients to recall. That is why a self-monitoring tool - a mobile application - was built to support the nurses' work and their clinical needs and in turn the well-being of the patients. The nurses can access the data through an interactive portal. This text is part of a broader ongoing ethnographic study, which started in 2015. The ethnographic study involves understanding of the nursing work practices through observations and interviews, as well as recorded phone calls, during which the nurses talk to patients who had been using the mobile application.

The following example is from one of the recorded talks and we interpret it in the wider context of the nurses' work practices. The patient used the application for two weeks. The nurse made a phone call after that time to ask the patient several questions about the patient's experience with the application. When the nurse asked the patient how she had experienced registering her pain in the application, the patient answered:

“Em that was easy. Because I could not precise where pain is where pain sits completely I thought then I put [the point] in the middle of the abdomen. Like that I have at least a starting point so to speak the pain was in the whole abdomen So to say when it started.”

(Phone talk, Audio recording, November 2017)

In this example, we can see that the patient tried registering information about her pain. The first thing she had to do in the application is to show where their pain is located on her body, by placing a point on the image of a body (Figure 1, Image of a body in the application).



Figure 1 Image of a body in the application

However, the patient had difficulties doing this. It was not possible for her to show that her pain was in the whole abdomen area, because the application allows only placing a pin, which points to a very limited area on the picture. However, that did not stop her from using the application. Instead, she placed the pin in the middle of the abdomen, “to have a starting point”. The nurse inquired about this by summarizing the patient’s problem, and then they moved to another question.

This example shows how patient can appropriate the tool in unexpected ways: for the patient to mark a pain at one spot means that she was having pain in her whole abdomen. However, this is not an information that is accessible to the nurse when she reviews the data. The data in the system would indicate that the patient had pain in the middle of the abdomen; in contrast to where she actually experienced her pain: in the whole abdomen. As different location of pain indicates different causes, the nurse would have troubles interpreting the data in a meaningful way. In the given interaction it did not become a problem, because the talk was mainly focused on design of the tool and not on diagnosing the patient. However, if the data would be actually used by the nurse to diagnose the patient, the patient’s appropriation of the tool would become a challenge. If she would keep on continuously registering that she has pain in the middle of the stomach, the way the nurse would read the data would be also that this is where she has her pain, which could in turn lead to a wrong diagnosis.

Concluding remarks

In this poster, we focused on the problem of patients' appropriation of self-monitoring tools in the clinical context of pelvic cancer rehabilitation. In our empirical example, we illustrated that a patient can use a self-monitoring tool in a way that is meaningful to her, but not necessarily meaningful for the nurse and in the wider context of the pelvic cancer rehabilitation. Even though patient's appropriation of clinical tools might be problematic, in its consequences it should not be viewed as a problem but more as an opportunity. The question becomes how to handle this situation in design? First, the application could prompt the patient to register not only her symptoms but also the way she registers them, however that would add more questions that the patient has to handle and that are not valid for all the patients (as only some patients appropriate the tool in unexpected ways). Second, the design of the application could have been more pedagogically informed: the application could prompt the patient to communicate the way she uses the application to the nurse; or the system could prompt the nurse to ask the patient about the ways she collected specific data sets. In this text, we view appropriation in a very limited way, and mainly lift the issue of appropriation as a possible challenge in the clinical setting. In our future work, we would like to conduct an in-depth analysis of the phone call talks, where the nurse talks to the patient about her data, and study appropriation more in depth, to be able to understand the consequences of it in the clinical setting.

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