Designing for learning and knowing

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Nurses in chronic care and patients' self-monitoring data

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ACTA UNIVERSITATIS GOTHOBURGENSIS

ISBN 978-91-7963-000-3 (print)
ISBN 978-91-7963-001-0 (pdf)
ISSN 0436-1121

Doctoral thesis in Education at the Department of Education, Communication, and Learning, University of Gothenburg.

This thesis is available in full text online:
http://hdl.handle.net/2077/61820

Distribution:
Acta Universitatis Gothoburgensis, Box 222, 405 30 Göteborg,
acta@ub.gu.se

Foto: Isidora Dundjerović

Tryck:
BrandFactory AB, Kållered, 2019

Abstract

Title: Designing for learning and knowing – Nurses in chronic care and patients’ self-monitoring data
Author: Kateřina Černá
Language: English with a Swedish summary
ISBN: 978-91-7963-000-3 (print)
ISBN: 978-91-7963-001-0 (pdf)
ISSN: 0436-1121
Keywords: Nurses, chronic care, designing, learning, knowing, self-monitoring data, design ethnography, work practice

This thesis focuses on nurses’ work practice in chronic care and their learning and knowing in relation to their patients’ self-monitoring data. It is anticipated that self-monitoring data used as a support for healthcare professionals’ work will help to overcome the current challenges the healthcare system is facing. Because of the way nurses’ work builds on learning and knowing in relation to data produced by patients, they will be expected to be able to use this kind of data when delivering care to the patients. However, we need to learn about what happens when a self-monitoring tool is developed and implemented in chronic care nurses’ work practice. The aim of this thesis was, therefore, to specifically investigate the nurses’ learning and knowing when they have access to the patients’ self-monitoring data.

These issues were explored using a design ethnographic approach in a pelvic cancer rehabilitation clinic. Study I found that the nurses in chronic care intertwine the patients’ lived experience with the nurses’ medical knowledge and clinical experience to support the patients’ learning about their disease. Study II found that nurses manage the complexity of qualitative phenomena and mobile application features as a way to participate in a design process of a self-monitoring tool. Study III revealed the changes that occur in nurses’ work practice when they gain access to their patients’ self-monitoring data. Finally, the following themes across these studies were identified. First, mutual learning points to the different levels of learning that the nurses need to cope with. Second, the translation work of nurses builds on creating connections among the patients’ lived experiences, what the nurses are able to do, and the self-monitoring tools.

Acknowledgements

Writing the acknowledgment section is both exciting because it made me realize how many amazing people I got to know during the past four years, but also humbling because it made me realize how many people contributed to accomplishing the doctoral degree.

First, I would like to thank my supervisors, Jonas Ivarsson and Alexandra Weilenmann for guiding me through the wild landscape of the doctoral work. Thank you for challenging me when it was necessary and for supporting me when I needed it. I would also like to thank Hans Rystedt for guiding me through the first two years of my studies.

Much of my work has been a collaborative effort, conducted with the EfterCancern project. Working together with EfterCancern allowed me much more than just collect my empirical material - it allowed me to grow as a researcher and as a person when we tried to overcome the troubles of interdisciplinary research. Gunnar Steineck and Johan Lundin you have been great mentors, and also role models on both scientific and personal levels. Annska Sigridur Islind and Tomas Lindroth, thank you for making such a wonderful junior team. Special thanks go to the nurses - I am so grateful I could work with you and learn about your work and pelvic cancer rehabilitation. I also want to express my gratitude to the patients, who got involved in our research and made it possible for me to learn about cancer survivorship.

I would also like to acknowledge the importance of the different research environments with which I have been involved during my doctoral studies. University of Gothenburg Learning and Media Technology Studio (LETStudio), Linnaeus Center for Research and Learning, Interaction and Mediated Communication in Contemporary Society (LinCS) and DigitaL - learning in the digitalized region have always provided platforms for interesting discussions and exciting ideas going across disciplines as well as universities.

I would also like to express gratitude for the opportunity to participate in our local seminars SDS, NAIL, and MUL as they provided me with a great platform for text writing and data analysis. In this context, I would especially like to thank Åsa Mäkitalo, Mona Lundin, Louise Peterson, Annika Bergviken Rensfeldt and Anne Solli. In addition, I would like to also thank Annika Lantz Andersson for great support as a director of postgraduate studies. In addition,

Learning, communication and IT, thank you for letting me be part of the division and for interesting discussions. Especially I want to thank Beata Jungselius, Karin Ekman, Marie Utterberg, Anita Grigic Magnusson, and Ylva Hård af Segerstad.

Further, I was given the opportunity to spend two months at the University of Colorado, Boulder, and want to thank professor Gerhard Fischer for hosting me. I am very grateful for it, as my visit allowed to work with Stephen Voida at the Department of Information Science, which was a great way to understand a different field of self-monitoring data application as well as to gain deeper understanding of how research is done at a different department as well as continent.

I would also like to thank the people who provided me with invaluable feedback about my work during my doctoral studies. Many thanks go to Thomas Hillman, Miria Grisot and Frode Guribye for your support during article writing, planning, and final seminar.

Special thanks go to all the people I have met in relation to work, but who have become much more than colleagues, for their encouragement and advice throughout the process: Janna Meyer-Beining, Diane Golay, Kristina Popova, Charlotte A. Shahlaei, Masood Rangraz, Daniela Souckova, Monika Jurkovicova and Timo Jakobi. Emilia Gryska, Kristen Kao and Verena Kurz - I am very grateful we could share our academic struggles as well as all many other adventures.

Last, I would like to thank my friends, my volleyball club and my family. I would not be able to do it without you.

Gothenburg, October 2019,
Katka Černá

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Part I

Designing for learning and knowing

Chapter 1 Introduction

> *A nurse in cancer rehabilitation clinic is about to carry out one of her routine tasks: getting in touch with a patient and checking up on her state. She logs in to the interactive portal and finds the patient she wants to talk to. She checks information in the patient's electronic record about the patient's disease history, current treatment, and what they talked about in their last meeting. She also checks the available visualizations of the patient's data, which were collected through a self-monitoring application, such as various graphs representing the number of defecations and urinations per day, number of leakage occurrences, and pain levels, all from the last fourteen days. She can see that last week the number of defecations started to increase above the levels that are normal for the patient. However, over a period of five days, there were no data logged at all. The nurse knows that this is often a sign that the patient is not doing well. She then calls the patient, and first they talk about the patient's well-being. She suggests to the patient that they look at her visualizations because the nurse is concerned about the increasing number of defecations. The patient admits that she has been under a lot of stress lately, and that her colon has been acting up; and that she was hoping it would get better "tomorrow." The nurse proposes that the patient should increase the dosage of the medicine that can calm down the bowel movements.*

Chronic care is a highly knowledge-intensive environment which places high demands on nurses' work. The so often changing landscape of healthcare is made even more challenging with the continuous arrival of new technologies, which requires nurses to continuously develop as professionals and learn how to use these innovations in a meaningful way. This thesis focuses on one specific type of digital tool that has recently started to be used in chronic care: mobile applications supporting the collection of patients' self-monitoring data. It is essential that nursing education and further training at their workplaces prepare nurses in chronic care to work with these tools and the collected data, as the health of many chronic patients will depend on this. However, to do so, we first have to understand the novel situation of using self-monitoring data in nurses' work, in order to prepare future nurses for it.

Having access to patients' self-monitoring data collected through digital tools will bring challenging transformations to healthcare. Many areas will be transformed, not only on a technological level but also on organizational and social levels. The nursing profession will not be an exception, and the nurses' work practice will be changed, posing new expectations of what the nurses should be able to do and what they will need to know to support patients in chronic care. This doctoral thesis addresses these changes and the implications for the nurses' work practice. The aim of Chapter 1 is to provide the reader with reasons why this topic is significant, specifically how challenges faced by healthcare providers lead to increased use of self-monitoring data and, in turn, change the conditions for nurses' work practice. Next, the primary aim of the thesis and the research questions are presented.

There are various challenges that healthcare is going to face in the upcoming years. First, the world's population is expanding and aging (Kotzeva, 2014). Second, medical resources are not going to be sufficient, as the shortage of medical personnel and finances in the healthcare sector is expected to increase (Commission Communication to the European Parliament the Council, 2012). Even more medical personnel are going to be needed as it is assumed that more people will seek medical help since the number of chronically ill will increase, as well (Wordl Health Organization, 2014).

As a way to overcome these challenges, healthcare professionals have been continuously trying to explore new ways of how to learn more about patients' health problems. One possible means to do this, which they have now started focusing on, is to more frequently use self-monitoring data (Sveriges Kommuner och Landsting, 2005; West, Giordano, Van Kleek, & Shadbolt, 2016). Self-monitoring data is a type of patient-generated data that is collected continually by a mobile application designed for the knowledge needs of healthcare professionals. That this is the case might be the result of more general societal trends, including an increased focus on care personalization and self-care (Nunes et al., 2015), increased visibility of the topic, such as learning about oneself through one's own data (Choe, Lee, Lee, Pratt, & Kientz, 2014), and technological advances in the form of mobile applications that allow for collection of one's own data with ease (Swan, 2009).

Even though it is becoming more and more possible to gain access to self-monitoring data about a patient's life and the potential of such data has been recognized, it is still not clear exactly how this data can be used. Methods for healthcare professionals to use such data still need to be developed, as well as determining what the data mean in respect to their work practices. The implementation of digital tools creates new requirements for the learning and knowing of healthcare professionals as the possibility to access the patient's self-monitoring data is expected to change the way they accomplish their work. It is therefore essential to study the ways healthcare professionals use and learn to use self-monitoring data as their ability to effectively operate and use these new resources will have an impact on the lives of many.

Today, we can find a wide range of examples of digital tools that are developed for the collection of self-monitoring data. An area that draws heavily on the advantages of these tools is chronic disease care. Chronic diseases, such as diabetes or hypertension, have been relying on the collection of data for many years. Healthcare professionals within these areas started to draw on the possibilities offered by self-monitoring data by viewing the existing data (glucose and blood pressure levels) in the context of other relevant measures that were not accessible previously, such as physical movement or consumed food (Bengtsson, Kjellgren, Hallberg, Lundin, & Mäkitalo, 2018; Katz, Price, Holland, & Dalton, 2018). Furthermore, areas such as mental health development have used applications that support, for example, individuals with bipolar disorder to monitor changes in mood and medication intake, or changes in behavior to identify trends and consequently adjust medications (Faurholt-Jepsen et al., 2015; Spaniel et al., 2008). Other healthcare professionals who work with individuals with irritable bowel syndrome have used self-monitoring data to identify food triggers (Schroeder et al., 2017).

In contrast to previously used technologies, having access to the self-monitoring data of their patients allows the healthcare professionals to "see into patient's lives" instead of merely having access to "snapshots" (Bentley & Tollmar, 2013). The self-monitoring data can lead to more informed insights about the patient's life and disease, easier access to the data collected by the patient, more options for viewing trends, and sharing with other relevant stakeholders, as well as the possibility to easily view several collected parameters at once. Altogether, access to self-monitoring data could improve chronic disease diagnosis as well as chronic disease management.

Why is self-monitoring data different from previous data available in a healthcare context? Collecting huge amounts of data is not in itself a new thing as collecting huge amounts of data has always been a part of healthcare, for example, medical registers or food diaries. What distinguishes self-monitoring data from the other commonly used data is the possibility to continually collect large amounts of quantitative and qualitative data about only one person and from this particular person over the course of time. In contrast to other patient-generated health data, self-monitoring data is collected by the patient through a digital tool. The data collection is steered by a healthcare professional (for example by building the tool on the healthcare professionals' knowledge needs instead of that of their patients).

In other words, new digital tools make continuous patient monitoring possible by supporting the patient in recording of the data on a different temporal scale than was previously possible. Now, it is becoming possible to collect data not only during a few discrete occasions but also continually over a longer period. The difference is further amplified as the data can be collected by the patient herself (in contrast with other healthcare data collected by the healthcare professionals, such as data in an electronic patient record). Furthermore, in contrast with previous possibilities, it is now possible to measure a wide range of values in an easier way; for example, traditionally it was only possible to continually measure glucose in the blood of a person who is diabetic. Collecting additional data about qualitative aspects of life was possible only through paper forms and journaling, which are often described as cumbersome (Piras & Miele, 2017). These values can be analyzed in the context of other important data of both a qualitative and quantitative character. Finally, the self-monitoring data producing tools are now widely available, no longer accessible exclusively in laboratories in hospitals, and they are not particularly expensive devices (Bivins & Marland, 2016).

The possibility to continually collect significant amounts of self-monitoring data about one individual for a certain period is one of the reasons why self-monitoring data is considered as valuable resources in chronic care. This change will influence various types of professionals working in healthcare. However, one of those types, whose work might undergo the most significant changes, is nurses. They work close to the patients, attending to their basic needs and helping them recover not only on the physical but also psychological level (Benner & Wrubel, 1989). Their work practice goes outside the strictly medical framework, as they communicate with the patients or support them in difficult life situations (Hanlon et al., 2005). In fact, all of the nurses' tasks are based on gathering and sharing large amounts of data as a basis for supporting patients (Barken, Thygesen, & Söderhamn, 2017). The centrality of gathering and sharing information about the patient's state makes data and information management one of the most important aspects of their work (Grisot, Moltubakk Kempton, Hagen, & Aanestad, 2018). Be it an informal chat with a patient (Zuiderent-Jerak, 2015) or an official visit, transforming data and information into knowing about the patients is a driving principle of their work.

To sum up, implementation of new digital tools that support access to the self-monitoring data of patients can help solve upcoming problems in healthcare. However, at the same time, it will transform the present working conditions and pose new requirements for healthcare professionals' work practices.

Aim and research questions

Considering the way the nurses' work practices rely on learning from personal patient data, it might be their work practices that will undergo the most significant changes. Therefore, this thesis argues that having the possibility to access the self-monitoring data of the patients will change the nurses' work practices. This thesis reports the findings of a design ethnographic study conducted in a pelvic cancer rehabilitation clinic. More specifically, I focus on the nurses' work practice when a mobile application supporting patients in collecting self-monitoring data was co-designed (by developers, nurses and project members, including me) and introduced into the nurses' work practice. The aim of this thesis is to investigate specifically the nurses' learning and knowing when the nurses gain access to the patients' self-monitoring data. In order to achieve the main goal of the thesis, I posed three research questions:

- What strategies do nurses use to support patients' learning of their self-management?
- How do nurses contribute in a participatory design process of a self-monitoring application?
- How does the nurses' learning about patients' problems change when they get access to self-monitoring data?

The thesis is divided into two parts. The first part includes six chapters that describe and discuss the theoretical and methodological underpinnings of this thesis. The second part consists of three empirical studies.

In Chapter 2, the research connected to nurses' work in chronic care in the context of self-monitoring data is scrutinized. Chapter 3 outlines the theoretical lens of practices and the concepts of situated learning and categorical work are presented. Chapter 4 describes the thesis's empirical setting and my design ethnographic and analytical approach to the collected data. In Chapter 5, I present how the studies are connected to each other and provide summaries of the three empirical studies. Finally, in Chapter 6, I relate my findings to relevant research, outline limitations of this thesis, and suggest future work, as well as provide implications for practitioners (both pedagogical and design). Finally, a summary in Swedish concludes this thesis.

Chapter 2 Related research

This thesis explores nurses' learning and knowing in relation to the development and use of self-monitoring data of their patients. To be able to achieve this, it is first necessary to scrutinize already existing work and identify how the thesis will contribute to this research. Because the main interest of this thesis cuts across multiple disciplines, it is necessary to draw on multiple fields.

The first section is devoted to the traditional work of nurses in the context of chronic care. The second section focuses on the role of nurses in participatory design, the consequences of tool implementation in an existing practice, and collaborative systems mediating such work. The third section establishes the term *self-monitoring data* in the context of this thesis and discusses challenges and benefits of self-monitoring data in chronic care. In addition, the first section draws mainly on nursing literature, the second and third sections draw on human-computer interaction (HCI), computer supported collaborative work (CSCW) and science and technology studies (STSs).

Nurses' learning and knowing in chronic care

Work is not something that is simply being "done," but something that is accomplished through everyday activities (Orr, 1996). To understand the activities that make up nurses' work practices in chronic care, this chapter begins with a section on what it means to work as a nurse in a chronic care unit today. First, the nurses' work will be introduced considering the importance of knowing and learning in their work practice. Second, the challenges of chronic care will be introduced. Furthermore, these challenges are considered in the context of learning and knowing of nurses' work.

Knowing and learning in nurses work

Knowing and learning are essential elements of nurses' work, as it takes place in a knowledge-intensive environment (Benner & Wrubel, 1989). The nurses need to update their knowing continuously, and they must be able to apply this knowing in various aspects of their work. Here, I will focus on three essential aspects related to this: getting to know a patient, learning to be a nurse, and supporting the patient in learning.

First, getting to know a patient is an essential aspect of nursing care. Caring for people and their health is a complex task (Benner, 1984). On a daily basis, the nurse needs to learn about the patient and her health problems. Getting to know a patient does not only involve collecting strictly medical information and providing medical advice. According to Kelley, Docherty, and Brandon (2013), in addition to medical information, the nurses also collect a range of personal information to make the care more individualized. In an earlier study, May (1992) explored various aspects of nursing work and came to the conclusion that nurses use two approaches: one that goes for the medical knowing, and one that strives to "know(ing) the patient." Medical knowing, then, has the purpose of reducing certain elements of experienced symptoms, in order to make it possible for the nurse to handle the patients' overall experience.

As Kelley et al. (2013) argued, the nurse supports the emergence of "a deep relationship between the nurse and patient, in which the nurse engages in a continuous assessment and striving to understand and interpret the patient's needs across dimensions" (p.352). Getting to know the patient is not only about an information exchange. It also builds on the development of a relationship between the nurse and the patient, which works as a context for the nurse to understand the patient's problems.

The sources to get to know a patient range from the patient's verbal accounts to digital and paper tools, such as the patient's health records or paper forms (Kelley et al., 2013). Another study found that the nurses understanding of the patient is an essential component for the patient to participate in his or her own care (Henderson, 1997). It is important to note that in their work practice, nurses draw on different ways of knowing and combine them into richer pictures of patients and their problems (James, Andershed, Gustavsson, & Ternestedt, 2010).

Second, to be a professional nurse today requires continuous learning and development. Such learning goes beyond university training and has to be continuous throughout one's career (Lammintakanen, 2012). The nursing profession builds on various forms of knowing that the practicing nurse is expected to master. In her seminal work, Benner described this development as progress from a novice to an expert. The aspects that change are connected to the move from abstract to concrete experiences, and gradually nurses begin to view the patient's problems more as interconnected than a set of separate problems (Benner, 1984). Another seminal work on nurses' knowledge practices described four patterns of knowing in nursing: empirical knowing, aesthetic knowing, ethical knowing, and personal knowing (Carper, 1978). However, as Porter (2010) pointed out, empirical knowing has gained the most prominent position in nursing science, which she equates with the rise of evidence-based practice. However, as is also reflected in the person-centered literature, there is a strong need to take a more holistic approach to patients and their well-being.

In order to provide the patient with care according to the current best practices, the nurses need to know the latest standards, regulations, and procedures. Standards play an important role as part of the evidence-based practice (Ellingsen, Monteiro, & Munkvold, 2007). Bowker and Star defined standards as "any set of agreed-on rules for the production of (textual or material) objects" (1999, p. 13). However, even though the idea behind standards is to provide a universal solution, this is rarely the case in practice. What nurses need to know in order to do their work is not universally established, but is dependent on a given situation (Timmermans & Berg, 1997). Nes and Moen (2010) further developed Timmerman and Berg's concept of "local universality" and explored how nurses draw on different modes of knowing. The results showed how personal experience, collective expertise, and formalized knowing contributed in negotiating the emerging standards. Thus, there were various sources for the nurses to learn from in their workplace: the material environment they found themselves in, role modeling by the nurse leader, systems and artifacts, and interactions and collaborations with other professionals in the ward.

Finally, it can be observed that the patient also needs to learn. Here, the role of the nurse is to support the patient's learning (Barber-Parker, 2002). During their interactions with patients, nurses not only provide them with current information about a particular disease but also teach the patients methods for increasing their understanding of their own problems. For example, in her study of nurse and patient interaction, Perbrandt identified three themes that the nurse and patient most often talk about during their meetings: medicines, personal topics, and explanatory content (Johnsson, Wagman, Boman, & Pennbrant, 2018). Although some of the things the nurses teach patients are prepared in advance, most of the learning that the nurse tries to support is situated and improvised. In an observational study of nurses' work, different types of pedagogical encounters were presented. There, the nurses were observed in various pedagogical moments in which they had a chance to increase the patient's understanding, depending on whether or not the nurse viewed the patient as a learning person (Friberg, Andersson, & Bengtsson, 2007).

Nurses' work in chronic care

The characterization provided above mainly represents how work is organized in ordinary acute healthcare. Such care, however, does not always fit the needs of patients suffering from chronic conditions (McCorkle et al., 2011). To overcome this gap, self-management has started being used as a standard model for how to organize chronic care. To understand nurses' work within chronic care, I will present some characteristics that are typical for this form of care. Similar to the acute care, nurses' work with chronic care also relies heavily on learning and knowing. However, their learning and knowing practices can often be further complicated by the added challenges of chronic care.

First, one of the defining aspects of self-management is collaboration in managing the patient's health problems by both the patient and the healthcare provider (Jorgensen, Young, & Solomon, 2015; Risendal et al., 2014). Chronic care is then not only about the nurse providing the patient with access to medication or advice, but also about how it requires developing a collaborative relationship between the nurse and the patient (Kralik, Koch, Price, & Howard, 2004). However, developing such a relationship is a demanding task which takes the efforts of nurses and patients alike. For example, Oudshoorn has described this as the "invisible work" required of both the patient and the nurse, something that also depends on what phase of the chronic disease the patient is in (Oudshoorn, 2008).

Second, chronic care is highly individualized, and therefore, the nurse must work to develop a unique relationship in each case based on her or his knowing of the patient. As chronic diseases develop differently for every patient, the care must be personalized and fitted to the individual's needs. However, nurses must also balance the patient's individualized needs with the nurses' own resources (Bodenheimer, Lorig, Holman, & Grumbach, 2002). When a patient is diagnosed with a chronic disease, he or she often undergoes an identity change. For example, surviving cancer and the ensuing cancer treatment become life changing experiences which often require the reconstruction of one's identity. Patients have to get to know themselves again because of substantial changes in their physical or cognitive constitution (Little, Paul, Jordens, & Sayers, 2002). Managing such a change in recreating one's identity might be challenging because "uncertainties, constraints, and prognoses tend to shift over time" (Miller, 2015, p. 2). In this process, the nurse has to provide the patient with adequate support allowing her to get to know her new self again (Grady & Gough, 2014; Hagan & Donovan, 2013; Lorig & Holman, 2003).

Third, chronic care builds on the idea that patients are expected to take an active role and become experts on their own lives (Wilson, Kendall, & Brooks, 2006). Hence, the self-management approach entails that the patients take an active role in their own care (Bodenheimer et al., 2002). This is no easy task, and it can be problematic for both the patient and for healthcare professionals (Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013). For patients to become active (and eventually independent) participants in their care, nurses first need to support them in learning how to manage their health problems. In contrast to the pedagogical encounters described above, nurses need to support the patients not only by helping them to understand what problems they have, but also in how to manage these long-lasting health problems when they leave the hospital. For example, Kralik, Seymour, Eastwood, and Koch (2007) studied patients who started living with a urine catheter and described the learning process they went through as they had to manage a new set of problems. The authors argued that it was not enough for the nurse to provide the patient with relevant information, but that the nurse needed to support this learning process of the patient.

For patients to be able to learn about their problem, they need to make a series of decisions to manage their disease on their own. However, deciding about one's own health is difficult without the support in medical and clinical expertise. For example, Mol studied diabetes patients and how they were allowed (or rather forced) to decide about their self-management (Mol, 2008). Mol problematized decisions in chronic care by showing that just because the patient is allowed to make a choice, it does not necessarily lead to better care. Furthermore, who should be making which decisions is an issue that cannot be decided in advance but has to be handled by the chronic care participants: the healthcare providers, patients, and their informal caregivers. For example, a study of self-monitoring tools supporting diabetic care showed that patients did not always use the tool in the ways intended by the clinicians or designers. In fact, the patients were, for example, able to limit the clinician in accessing their data (Piras & Miele, 2017). In addition, responsibility and its distribution may gradually change over time due to the changing character of the disease (Büyüktür & Ackerman, 2017).

Fourth, chronic care is a quite dynamic landscape which keeps on changing. As suggested in the introduction, the aging population, the number of chronically ill, the decreasing resources for healthcare—all contribute to the need of finding new ways of providing care. Some chronic diseases, such as diabetes, hypertension, or bipolar disease, have been explored for decades. As a result, we have a better understanding of what to teach to specialists who can support patients suffering from these chronic diseases (such as diabetes educators). Other problems have only recently become recognized as chronic diseases, such as cancer survivorship, and more specifically, pelvic cancer survivorship.

In addition, nurses use various tools to support the patients' learning about their own body and the health problems they experience. However, since these tools are designed to provide the nurse with relevant information and she needs to learn about the patient's problem, the tools are often specifically adapted to the nurses' needs. Hence, especially at the beginning of the treatment, the patient will need support in learning not only about herself but also about which tools to use and how to use them. New tools that should support chronic care are often explored as a way to overcome these challenges. There are various tools that are designed to support both the nurse and the patient in chronic care, such as video, devices collecting patients' data, and electronic systems supporting nurses' work (Grisot et al., 2018; Islind, Snis, et al., 2019). Although the use of digital tools points to multiple benefits, the consequences of digital tool use in chronic care are still unclear. For example, in one study, an electronic system allowed the nurses to produce knowing through video-mediated contact with the patient, overview of clinical data flow, and sharing decision-making with the patient. However, to produce knowing that would be sufficient to help the patient, the nurses often had to reason beyond the provided system (Barken et al., 2017). Another study showed that when electronic templates were used in a consultation with a chronic patient, the nurse would produce knowing in such a way that would privilege the needs of the institution rather than those of the patient

(Swinglehurst, Greenhalgh, & Roberts, 2012). In other words, using digital tools to support chronic care allows for new forms of care to emerge. However the tools may also create unanticipated consequences.

Participatory design of collaborative systems

As I have shown in the previous section, nurses' work practice in chronic care is dependent on the tools they use in supporting their own and the patient's learning and knowing about the patient's problem. Due to current developments in technology and the promises of what such technological innovations could offer, various digital tools have been introduced into nurses' work practice in chronic care. In this section, I will first introduce participatory design and the nurses' role in it. Next, I will focus on how such tools are appropriated and made to work within existing practices. Finally, I will discuss the collaborative aspects of such tools.

Participatory design

In order to ensure the collaborative aspect of designed tools, it is necessary to consider the perspective of those who will actually use them. Therefore, it is critical to understand the ways in which the tools actually mediate everyday work. In order to match the tools to the work practice, the tools' design process becomes extremely relevant. In this process, however, problems may arise, but they are also expected to be fixed. In the early years of participatory design in technology development, the users only took part in the design process without the possibility to decide about its course (Bodker, 1996). In contrast, participatory design stems from the Scandinavian tradition aimed to involve multiple stakeholders in the design process (Kensing & Blomberg, 1998). As the involved stakeholders often come from different fields and possess different expertise, a key feature of participatory design is that it builds on the mutual learning of the involved participants (Robertson, Leong, Durick, & Koreshoff, 2014). During this process, the designers have to learn about the participants' work practice, while the participants need to learn about the possible technology future development of technology. This form of mutual learning is described as a traditional feature of participatory design (Kensing & Blomberg, 1998). In other words, the participation in the process is supposed to allow the end users to imagine which technological solutions could be developed for them, so that they can make better informed decisions during the design process. The deeper involvement of the user in the design process has led to a shift in focus from user-centered to experience-centered (Sanders & Stappers, 2008). Also, during recent years, the levels of engagement in the design process have increased, and users have been more actively involved (Fischer & Herrmann, 2015).

The central questions that have to be tackled for every new design process are who should take part and how. These issues have been discussed for several decades in terms of participatory design (Sanders & Stappers, 2008). Bratteteig and Wagner (2014) pointed out that it is not only about participation as in, being present during the design process, but it is also about supporting the participants so that they are able to take an active part in the decision-making. This type of design process has started to be implemented in healthcare as well, and nurses have started becoming a part of the design process. One of the first participatory design projects, the Florence project, focused on implementation of a computer prototype as a support for nurses' work (Bjerknes & Bratteteig, 1988). More recently, Ostergaard, Karasti, and Simonsen's (2016) study focused on nurses in a design process and how their genuine participation in the design process impacted their learning and reflection about their work.

From studies focusing on tools supporting chronic care, a study reported by Ranerup and Hallberg (2015) focusing on the design of a mobile application supporting hypertension care provides us with insights about how design participants' (including nurses) intentions get inscribed into the developed tool. In this case, a certain model of care and learning became inscribed into the tool. However, the final product was not simply created by the participants' ideas, but it was also shaped by the technological affordances. The inscribed models, in turn, impacted the way the patients interacted with the tool and the way the healthcare professionals used the tool to support the patients. Another study reporting on the design process of the same hypertension tool also showed how the participants had to negotiate and agree on what features should be included in the final tool (Lundin & Mäkitalo, 2017). However, additional phenomena can be negotiated during a participatory design process. In their study that was not on chronic care but rather investigated children with disabilities in respect to participatory design, process, (Brulé & Spiel, 2019) illustrated that identities shape relationships among the design participants, in turn shaping the outcome of the design process.

The appropriation of digital tools in healthcare

Similar to other societal areas, when new technologies are implemented in healthcare, there is often no rapid or revolutionary change. Instead, the tool is gradually appropriated to the existing practice (Cuban, 2001). When it comes to the implementation of tools in healthcare, it is more about amending the existing practice than creating big changes, as new tools are almost always developed for an existing clinical practice (Vassilakopoulou, Grisot, & Aanestad, 2017). Even seemingly simple tools, such as bar code scanners of medications, can be problematic to use in the complex healthcare environment (Lee, Lee, Kwon, & Yi, 2015).

Be it a supportive talk with a patient or shift handovers in the ward, knowing is produced on a daily basis, drawing from accessible data and information. The traditional sources of data—communication with patients or medical records—have been covered extensively in current research. More recently, we have seen efforts to develop practical applications of digital tools supporting communication with the patient (for example, Grisot, Kempton, Hagen, & Aanestad, 2019; Grisot et al., 2018). Also, medical records have been studied extensively as changing from paper forms to electronic patient records has led to changes in the ways nurses produce knowing.

Even though the initial purpose of digital tools was to support existing work, they have also led to changing the ways work is possible to be done. When digital tools are integrated into work practices, they also become embedded not only in the work process but also in existing social practices. For example, Winman and Rystedt (2011) investigated nurses' shift handovers in a rehabilitation ward. These handovers were conducted verbally, but they were supported by a newly implemented electronic patient record system. During the handovers, the nurses had to reorganize the order of the information from the electronic system in order to produce an understandable outcome. By reorganizing the order of information, the nurse produced locally relevant knowing that made it comprehensible for the other nurses. At the same time, the nurse guided others in the electronic patient record system by emphasizing some and backgrounding other information, pointing to the pieces of information that were deemed most relevant. The new electronic records did not support the way the nurses were used to reading the records in handovers because the electronic system imposed a standardized form. In order to accomplish their work, the nurses now had to select and restructure the available information to render it practically useful.

However, the introduction of digital tools into an established work practice is not a simple one-way process. It is not only that the clinical practice is changed and fitted to the tools, but that the tools are appropriated to the needs of the practice (which might not necessarily be aligned with how the tools were designed). Randell (2004) studied how tools were appropriated in a healthcare institution. In an example of the early use of a hemofiltration device, she showed how the nurses viewed themselves as accountable for the machine not/functioning and how this sense of responsibility changed the way they were using the hemofiltration device. By using the device, the local understanding of accountability was changed, but it also allowed the creation of new local understandings that changed the way the devices were used. These kinds of appropriation processes are not immediate but take time. In an electronic medical record deployment study the designers observed an adaptation period during which "active reinterpretation and modification of their work practice through their engagement with the system-in-use," in other words, during the period learning how to use the new system was taking place (Park & Chen, 2012, p. 2097).

Collaboration mediating tools in healthcare

As mentioned in the section Nurses' work in chronic care, the essential characteristic of chronic care organized according to the self-management model is collaboration between the nurses and the patients. Hence, the digital tools that have been designed to support the chronic care often aim to support *collaboration* among the participants. In respect to the electronic health record, this system allows storage and information sharing, which makes the information accessible not only to those who created it. Such communication with a patient and medical records form a sort of symbiosis in nursing work: the medical record is recreated within the interaction with the patient, but at the same time, it functions as a coordinating device which provides structure to the given interaction (Berg, 1996).

According to Fitzpatrick and Ellingsen (2013), tools in healthcare aim to support information flow, sense making, decision-making, communication, negotiation, awareness, etc. As noted by Berg (1999): "the medical record […] in relation with the reading and writing activities of nurses, doctors, laboratory systems—can be seen to perform two roles in work practices. They accumulate inscriptions and coordinate activities of other entities in the work practice, and in that way afford the handling of more complex work tasks" (p. 373). In other words, the digital tool helps to distribute and coordinate tasks that the chronic care participants may not be able to fulfil on their own.

As indicated in the previous chapter, one of the big issues of chronic care is that it is complex and dynamic, which requires collaboration. But to make a tool that supports both parties in the chronic care relationship requires a deep understanding of the work and relationships that chronic care builds on. In a study of a collaborative system designed to support cardiac care, it took three iterations before the design team figured out that it was the perspectives of the different care participants (clinicians and patients, respectively) which had to be aligned through the system in order for it to support the collaboration (Andersen et al., 2018). Berg further argued that we should stop looking at the tools as "supporting" because, when they are used, they always change what the people do (and in turn know and need to know). Hence, we should be talking about mediating, since this term implies the more significant role that the tools have in the activity: "These artifacts do not 'facilitate' the ordering of tests or the keeping of the fluid balance: they alter these activities, and transform what counts as 'the fluid balance' or 'ordering tests'" (1999, p. 383).

In summary, in relation to how new tools can be appropriated into an existing clinical practice, it should be recognized that new tools do not only support the collaborative effort of the nurses and the patients, but they also create the possibility to change the way the chronic care participants collaborate.

Self-monitoring data in chronic nurses' work

In the first section of Chapter 2, I have shown how chronic care is collaborative and how the collaboration builds on the nurses' abilities to learn about the patient's problem and to support the patient's learning about themselves. In the second section of this chapter, I have shown how the nurses' participation in the design process opens the possibility to learn about the nurses' work and how the nurses' work can be changed when a tool is designed to support it. This section will situate these discussions in the context of the self-monitoring data in chronic care.

Recently, we have seen an increased interest in different forms of documenting people's actions, states, and behaviors not prompted by their healthcare providers. The documentation is now enabled by a range of digital tools (Lupton, 2016; Neff & Nafus, 2016). Many started collecting quantitative data to learn about themselves which may not be an easy task (Choe et al., 2014). For example, in a study of Finnish self-trackers, the researcher found that instead of increasing knowing about oneself, self-tracking tools oriented users to repetitive behaviors, such as keeping track of one's actions (Bergroth, 2019). They therefore argued that this created the illusion of control and self-knowledge rather than actually achieving it. Another study focused on Fitbit users. The results indicated that the users learned how to do self-care through data mediation and data sharing. In order to accomplish this, they needed to incorporate forms of ubiquitous computing and data literacy in their lives. But, that also meant that they had to incorporate the effort to be a "good citizen" into their lives (Fotopoulou & O'Riordan, 2017).

Rooksby et al. (2014) emphasized the importance of not viewing these forms of people's life documentation as something that is separate from the people's lives, but to view the data collection as something interwoven with everyday lives. Li et al. (2011) further explored the various stages in which people collect and reflect on their personal information. Their results indicated that the different kinds of questions that can be answered by the data become more important at different times. Epstein et al. (2016) then further developed this model and pointed out that it is not only different activities connected to different stages but also different goals which, in turn, impact the actual documentation practices.

Defining self-monitoring data

In this section, I will describe how self-monitoring data is defined in this thesis. I will present what the data are expected to allow us to do but also the current barriers; first, in the more general sense, but in the next step, I will situate it within chronic care. Finally, I will present examples of the self-monitoring data used by nurses.

As multiple disciplines are interested in this topic, a range of terms is being used to describe digital tools that continually collect data. For example, Lupton (2016) noted that, originally, the term *life-logging* was used. She added that, in the past, terms such as "lived informatics" and "personal informatics" have been used. Today, however, people tend to use the term *self-tracking*. Sometimes, these terms are used interchangeably (for example, in Chung, Cook, Bales, Zia, & Munson, 2015; Selke, 2016). Some authors provide us with a further typology. Lupton (2016) identified five categories: private, pushed, communal, imposed, and exploited self-tracking. More specifically, "pushed" self-tracking is what she also calls "self-monitoring," and it expresses that, in contrast to other types of self-tracking, a person starts collecting self-monitoring data when he or she is asked to do so, often in a specific context. Furthermore, Piras (2019) provided us with four labels pertaining to this kind of data collection: patient-generated health data, observations of daily living, quantified self, and personal health information management. However, as he pointed out, each of these labels symbolizes certain assumptions or a perspective. Therefore, I will first define the term *self-monitoring data* as used in this thesis to highlight the assumptions that guide the use of this term.

First, the most distinguishing characteristics of the data are that they are being collected continually. This has various implications. The patients can create a record much closer to their actual experience when they experience a documented symptom. One of the problems of the traditional methods, for example, questionnaires or the elicitation of oral accounts, is that these methods rely on patients recalling past qualitative experiences. Such tasks are demanding, and the results turn out to be very inaccurate (Bowker & Star, 1999). In the case of self-monitoring data, the patient can record the given experience either when it is happening or shortly after.

Another feature of the self-monitoring data is that it is a patient who creates the record, and not a healthcare professional, who is usually responsible for creating health records in the traditional healthcare. Self-monitoring data thereby belongs to a type of data called patient-generated health data. This type of data is defined as:

> Patient-generated health data (PGHD) are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern. (Shapiro, Johnston, Wald, & Mon, 2012, p. 2)

PGHD is then described as data that are collected about the health of a person, which can cover a range of variables and that are collected by the person herself. Especially the latter is further developed in the second part of the definition:

> PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders. (Shapiro et al., 2012, p. 2)

The definition makes an important distinction and highlights the transition of data collection from traditional settings (encounters with healthcare professionals) to the patients' homes and daily activities. Self-monitoring data as well as PGHD are not limited to the healthcare setting, but are independent of the healthcare in relation to time and space, as they can be collected whenever and wherever by the patient. The responsibility to collect the data shifts from the healthcare professionals to the patients. This also means that it is the patient who has to notice and interpret her symptoms first in order to be able to record them.

However, this definition does not fully cover the type of data that was collected in the clinic which I was studying. First, the definition does not make a distinction between paper and digital tools. Differences between paper and digital tools supporting people's work or other activities have been widely documented (Fitzpatrick & Ellingsen, 2013; Heath & Luff, 2000a; Piras & Miele, 2017; Varpio et al., 2015). In the case I was studying, I was also trying to determine the difference between the self-monitoring data and the already existing paper tool in the practice, a urinary table (for more about the table, see the chapter Summary of the studies). Second, the definition presented above views the patient as someone who *directs* the data collection and who is in full control of the data after the data collection. The self-monitoring data, in my case, could not be first reviewed and then shared with the nurse—the data became directly accessible to the nurse as they were collected. One of the reasons why this was possible is because the mobile application was designed as a tool to support the work of the nurses. Hence, the design of the mobile application was based on the nurses' clinical experience, which was translated into the structure of the tool, and not based primarily on being fitted to the disease experience of the patient (for more information about the design can be found in Chapter 5, Summary of the studies).

As Morgan (2016) suggested, in healthcare, patient's data collection is common in the form of pushed self-tracking, or "when a person is asked to self-track and the self-tracking is imposed, [this] is one approach to supporting the self-management of chronic health conditions" (p. 2). In other words, when learning how to manage their chronic disease, patients are often asked to monitor their symptoms and behavior. Thus, the reason to start using a particular tool is important, as it will shape the data practice an individual will develop (Didžiokaitė, Saukko, & Greiffenhagen, 2018). Hence, there is a difference in the consequences if a person decides to document elements of their lives (self-tracking) or if they are asked to do so by a healthcare professional (self-monitoring).

Furthermore, it is also important to highlight what kind of data are possible to collect. The self-monitoring data are collected when the patient fills in a form on their mobile device. Considering the example of pelvic cancer rehabilitation, a range of symptoms and behaviors that needs to be measured are either of a qualitative character (such as pain) or they are impossible to measure automatically due to ethical or material considerations (such as defecation frequency). Instead, these lived experiences of people's lives are required to be translated from their qualitative shapes into forms supported by the digital tools. There are two situations when the lived experiences are translated: first, during the design process of the self-monitoring tool, when the design team has to translate the social practices into the features of the mobile application (Ranerup & Hallberg, 2015) and second, during the actual use of the tool when the patients have to translate their lived experience in such a way so they can answer the questions in the mobile application (Smith, 2008).

Daily self-monitoring during a longer period requires easy and continuous access. Klasnja and Pratt (2012) presented a review study on how mobile phones could meet such demands, and they suggested directions for future research that could meet the functional and design requirements "for the development of highly effective mobile-phone health interventions" (p. 184). Among other areas, self-monitoring of health-related data has been pointed out as highly promising. However, to use the application in a meaningful way, the application has to be able to produce meaningful data, and the patients need support to learn how to do that.

Finally, it is also useful to contrast these data with other terms that can be related to self-monitoring data. Big data is often described as "large, complex, linkable data" (Gu, Li, Li, & Liang, 2017), as it involves vast amounts of quantitative data collected automatically, leading to linkable data sets that cover long periods of time. In contrast, self-monitoring data are often collected manually by an individual for a limited period of time. This means that this data cannot be considered big data, but instead "small data." Both terms refer to data sets that allow for searching of trends, but the self-monitoring data do not support trend predictions in the way big data does.

Furthermore, the recording of one's (health) data can be connected to the quantified self movement (Lupton, 2016). However, as suggested above, the self-monitoring data build on a different logic. The quantified self movement represents efforts which start with a person choosing to record his or her health data. Self-monitoring builds on the existing healthcare professionals' practice, and not on the chronic disease experience of the patient. The clinical world has always been interested in the continuous monitoring of patients' well-being. Pedometers and glucose or blood pressure measuring devices represent some examples. But simple technologies such as surveys have also been used for observation and recording of patients' well-being for decades (Lee, Lawler, Panemangalore, & Street, 1987). Only recently have advances in digital tools made it possible for data collection of other measures than glucose and blood pressure, as well as collecting data that are much closer to actual experience.

Self-monitoring data in chronic care

As mentioned in the previous section, chronic care today draws heavily on various digital tools. The collection of self-monitoring data is one of the approaches that has recently become a major focus of researchers. The use of different kinds of health-related data collected by patients engaging with self-monitoring tools has been thought to offer a large potential for improving diagnosis and care planning, especially within chronic care (West et al., 2016), as well as helping individuals to promote reflection and increasing their well-being (Bentley & Tollmar, 2013). The interest in self-monitoring data concurs with visions of data-driven healthcare that can inform tailored interventions for designated individuals or groups (Goetz, 2011; Swan, 2009). However, even though chronic diseases, such as hypertension, diabetes, and bipolar disease, have been studied for an extensive period of time, the actual use of self-monitoring data as a support for chronic care remains problematic (Katz et al., 2018; Spaniel et al., 2008). Recently, researchers have been exploring additional areas where self-monitoring can be used, such as physical rehabilitation (Schwennesen, 2017), multiple sclerosis (Ayobi, Marshall, Cox, & Chen, 2017), and pelvic cancer survivorship (Islind, Lindroth, Lundin, & Steineck, 2019). Hence, the following section focuses on three important themes related to self-monitoring data in chronic care: collaboration, data representation, and data interpretation, and the challenges of these themes are discussed.

Data supported collaboration

As noted in the section about nurses' work (Nurses' work in chronic care), chronic care builds on collaboration between the nurse and the patient. The self-monitoring data collection builds on the idea that it is the patients who need to collect the data about themselves, and then review the material together with a healthcare professional. For example, individuals suffering from irritable bowel syndrome need to rely on their self-monitoring practices in order to identify which food triggers their bowel problems. However, data do not come in a ready-made form, and using data to only "inform" the consultation is not enough. The healthcare professional is required to bring in his or her medical and clinical expertise, and the patient has to contribute his or her lived experience to the consultation for the participants to be able to learn about the problem together by interpreting the data (Chung et al., 2016).

Even though one of the first studies of self-tracking pointed out that collecting ones' data to learn about one's problems is a social activity (Rooksby, Rost, Morrison, & Chalmers, 2014), many of the tools developed today are designed with a single user in mind. Nunes et al. (2015) further added that chronic care and self-monitoring happens in a social context, with caregivers as collaborators, while also pointing out that other stakeholders should be considered.

Another question is how the collaboration around self-monitoring data collection should take place: who should participate in which activity and when? While not focusing on chronic care per se, Mishra et al. (2018) studied the collaborative use of self-monitoring data in a hospital. They used the stage model provided by Li et al. (2011) and explored how patients expressed a wish to collect data also in relation to other stakeholders.

However, creating tools that can support collaboration among multiple stakeholders is not a simple task as all the different stakeholders have different needs and experiences. Zhu et al. (2017) explored how patients and clinicians shared self-monitoring data in existing clinical care practice. Their results indicated that the data sharing was hindered by the difference in clinicians' agendas and the patients' expectations on how the data would be used in the consultation. In addition, in a series of workshops with multiple stakeholders, Ballegaard et al. (2008) learned that, while clinicians (nurses and doctors) envisioned self-monitoring technologies as something to use to fix problems, the potential users of these technologies wanted technologies to help them sustain their desired lifestyle.

Data capturing and representation

The data to be collected will be impacted by how the self-monitoring tool structures this collection process. Self-monitoring tools should therefore aim to support the patients in translating their experiences into data. These translations can be challenging, especially when it comes to recording the qualitative and situated lived experiences of a chronic disease (this problem is described more in depth in Study II). One such example is pain. Adams et al. (2017) reported, from a design study on supporting pain self-management, that the exploration of design space revealed how individuals suffering of chronic pain would express variable and sometimes contradictory preferences. Furthermore, data collection does not have to only involve symptoms. For example, Ayobi et al. (2017) found that the users with multiple sclerosis strived to increase control over their disease not only by collecting data but also by intertwining self-care with various self-monitoring technologies.

Although there are perceived benefits, the continued collection of data about oneself has proved to be difficult both on an individual level as well as in clinical practice. For example, in one longitudinal clinical study a tool was designed to support both the clinicians and the individuals with bipolar disorder and it was found that the tool was eventually abandoned even though it indicated improvements of the patients status (Spaniel et al., 2008). Results from a follow-up study suggested that it was the approach to the tool embodied by the clinicians that led to its early abandonment (Španiel et al., 2015).

As self-monitoring data are a type of patient-generated data, their collection builds on the patient's active role in the data collection. But, today's tools made for healthcare are often not designed to support the active role of the patient. Storni et al. (2014) focused on diabetes patient's self-management and suggested that the current glucometers build on the traditional model of healthcare, in which the patient and the expert's perspectives are separated. This clinical perspective, where a positivist epidemiological model is supported, is thus hindering the empowerment of the patient.

The reason might be that to support patients in being active in their own care is not a simple task. Just because patients gain the possibility to collect data does not automatically lead to their active participation in their care. In a study by Oudshoorn (2008), even though cardiac patients were producing self-monitoring data by wearing specialized equipment, the patients remained rather passive. Kjærupa et al. (2018), using a similar setup, but one which would also allow the patients collect additional symptoms and metrics, reported that patients were able to take a more active role in collaboration with the chronic care nurses.

Furthermore, the way the collected data is visualized is also important. In a study focusing on mobile applications supporting diabetes self-management, Katz et al. (2018) discussed eight different ways to visualize data, ranging from journal entries to multiple types of graphs. Although the participants of this study were able to get an overview of the collected data, they were missing several features that would allow them to take further actions on this information. More specifically, they needed additional information to be able to interpret the data, as well as needing instructions on how to handle the older data.

Data interpretation

Current research has indicated that the productive use of data goes beyond the assumption that the data will provide ready-made knowing to the healthcare professionals or the patient. For example, patients with Parkinson disease were first provided with Fitbit step counters for four weeks after which they discussed their data with a neurologist during a clinical visit (Mentis et al., 2017). The access to this Fitbit data allowed for the identification of extreme values, trends, and walking strategies. By drawing on that data, the patients and the neurologist were able to gain new insights about the patient's problem, which served as a basis for further treatment. However, although the neurologist and the patient had access to the same information, it was viewed and interpreted in several different ways in the talk. The data did not become immediately self-evident, but it had to be processed and made sense of together, before it could be used for developing the treatment.

To be able to use the data, certain things have to be present. For example, clinicians might be required to become competent in more than just the medical domain (West et al., 2016). In another study by Chung et al. (2016), healthcare professionals agreed on the overall benefits of self-monitoring by the patients. Nevertheless, they rarely asked their patients to conduct any form of self-monitoring. Some of the reasons were connected to organizational issues (such as time constraints). Other reasons had to do with their own abilities and knowing, such as being able to provide suitable advice according to methods used for self-monitoring or non-familiarity with the currently available self-monitoring tools.

To learn about the patients' problem and to support the patients in managing their disease, the healthcare professionals and patients can engage in various activities. On the one hand, in chronic care, there is a need for the tools to support simpler tasks, such as searching for trends and triggers (Chung et al., 2015), or to generate and evaluate hypotheses that will help troubleshoot specific issues and guide decisions (Mamykina, Mynatt, Davidson, & Greenblatt, 2008). On the other hand, further exploration of the design space indicates that we also need to understand the role of self-monitoring data in relation to more complex issues. For example, in a follow-up study of experienced diabetes patients, self-monitoring data contributed to building narratives around the patients' identities as persons with diabetes (Mamykina, Miller, Mynatt, & Greenblatt, 2010). In another study, Kaziunas et al. (2017) focused on parents taking care of children with diabetes. They showed that what it means to care for someone gained a new dimension when the children started collecting self-monitoring data. In a similar way, Piras (2017) explored pediatric diabetes patients and their careers, where patients had the possibility to collect data through an app (in contrast to paper). Their findings indicated that this method changed what "personal" meant for this group. Interestingly enough, the provided platform in some respects reduced the collaborative elements, when switching from analog (paper) to digital form.

The above discussed literature on self-monitoring in chronic care focuses on the clinician (West et al., 2016), the clinician-patient interaction (Mentis et al., 2017), or the patient (Oudshoorn, 2008; Piras & Miele, 2017). In contrast, a couple of studies have also focused on the nurses' practices in chronic care.

Two studies reported findings from a Norwegian chronic care clinic, which treats patients with chronic diseases, such as chronic obstructive pulmonary disease, diabetes, and heart disease. Grisot et al. (2018) explored nurses' work practices in relation to the patients' self-care and identified two types of practices. Nurses had to start supporting the patients in, first, making sense of their own data, and second, in being proactive in their own care. The second study focused on the data work that allowed the nurses to personalize the care to the chronic patients through preparatory work, continuous adjustment, and assisting the patients in creating routines for producing relevant data by fine-tuning questions (Grisot et al., 2019).

To sum up this chapter, the first section indicates that chronic care builds on the nurses' ability to support patients in learning about their own problems. However, as that is further challenged by the demanding character of chronic diseases, we need to learn more about how the nurses can support patients in their own learning. The second section shows that nurses become part of the participatory design of self-monitoring tools supporting their work. As participatory design builds on the idea of mutual learning, we need to know more about what happens when the nurses become part of such a participatory design. And finally, the last section shows that nurses can use self-monitoring data as a new way to learn about their patients' problems. However, we need to know more about what happens when the nurses obtain access to this kind of data.

Chapter 3 Theoretical approach

Nurses' main task is to provide care to their patients. However, to be able to do that, they need to be able to learn how to provide the patients with the specific chronic care, learn about the patients' problems, and support patients' learning about themselves. As the development and introduction of a self-monitoring tool has impacted this setting, I chose a theoretical and conceptual framework that would help me to understand the interplay between professionals' activities in a dynamic and complex environment in relation to their professional development and a tool that embodies knowing that was translated from the professionals' activities. As my thesis work has been interdisciplinary (involving nursing studies, social science, and design-oriented fields, such as CSCW and HCI), I have drawn on a wide range of research, which is on a scale between positivism and interpretivism. This thesis follows the interpretative approach, which provides me with relevant concepts that I can use to make sense of my findings. As such, theory highlights certain features of the studied human activities, in turn reducing the complexity of the human world and, in that way, helping us to understand it.

First, I will discuss how nurses' activities are organized as practices through mutual interaction in a socio-material world in relation to knowing (Barnes, 2005; 2009, 2014; Nicolini, 2012; Schatzki, 2012). Second, I will complement this perspective with learning viewed as situated and as a feature of an individual's participation in a community of practice (Lave, 1991; Lave & Wenger, 1991). Finally, I will discuss one of the more concrete tasks that the nurses engage in, which is categorical work, and elaborate on relevant concepts (Bowker & Star, 1999).

Nurses' work as practices

Practice theory is the overarching framework that has helped me understand the activities that nurses do to provide patients with chronic care. I needed to understand these activities in the context of nurses' learning/knowing and the new tool that was developed and introduced into their practice. This theory is relevant to me as it draws attention to how people's actions are organized by their continuous interaction with each other, how the materiality of the practices further structures the social interaction, and how that impacts the implications for the notion of knowing. To be able to understand what nurses do as work practice, it is necessary to theorize these relevant features.

There is no single theory of practice (Nicolini, 2012). I have drawn on the version that had its origin in the work of Schatzki. Even in Schatzki's work, he does not use a single definition of practice, as it is a concept he has been working with for a long time and that has changed over time. He draws on multiple authors, such as Wittgenstein, Heiddeger, Giddens, and Bourdieu, and various theories, including the cultural-historical activity theory (CHAT) and the actor-network theory (ANT).

In this thesis, I have drawn on the version he presented in his text A primer on practices. In that text, Schatzki defined a practice as "an organized constellation of different people's activities" (2012, p. 13). This relatively simple statement carries in it some strong implications. The "organized" part does not refer to an external way of organizing the people participating in the practice. It refers to certain regularities in the activities of people that take place in time and space. These activities do not originate only in the individual habits of a particular person or in the sum of individuals' behavior on the group level, but in both, as these are mutually constitutive. In other words: "social coexistence is in this sense rooted in the field of practice, both established by it and establishing it" (Nicolini, 2009, p. 1394). In this way, the practice concept bridges the problem of division between the individual and the system. Further, the term constellation refers to the notion of a group of people (as practices are always social) but, at the same time, indicates a connection between the individuals in the group.

There are four main concerns that are important in understanding practices. First, the organization of practices is formed by people interacting with each other. Barnes (2005) used an example of a cavalry to illustrate how such a group is organized by the members reacting to each other within the existing practices. He viewed shared practices as activities of individual people who are constantly oriented towards each other in a given group and are adjusting their individual habits not based on some random or only material conditions but on relations to each other.

Second, practices are embodied and material—the way they are organized is determined not only by the interactions among the people in the practices, but also by the people's bodies and the physical properties of the environment. In my thesis, what people do and say is considered as the historical basis of practices, and I refer to these doings and sayings connected to each other as activities. In Schatzki's words, practice is "an open-ended, spatially-temporally dispersed nexus of doings and sayings" (2012, p. 14). By highlighting the spatial-temporal character of the activities, Schatzki points to their material character but also that they take place in time. The activities might be distributed over these two dimensions. The term nexus refers to a " field of connections and relationships." This means that, when one aspect of a relationship changes, it will affect others connected to it as well. The embodied and material aspects, together with the social functions as resources, involve people, tools, ideas but also other practices (Feldman & Worline, 2016). Practice can be then viewed as a mechanism that organizes the existing resources for social actions, hence making them accessible to the practice's participants in a certain order (Gherardi, 2009).

Third, an important aspect of practice is knowing. While Schatzki developed practice theory in a rather abstract manner, there have been various attempts to also adapt it to workplace settings. For instance, Gherardi (2014) developed Schatzki's theory and situated it in a work context by stressing the connection between knowing and practices. Even though Gherardi used both the terms knowing and knowledge, I decided to use the term knowing. Throughout this thesis, I have used the term because it fits better with my understanding of what nurses do. To be able to draw on the existing resources is not an "object" that one "has" (which is the connotation connected to the word knowledge), but it is an ongoing activity, which takes place in time and space (hence the continuous form) (Orlikowski, 2002).

What I label as knowing, according to Gherardi (2009), is "...not only an activity situated in practices, but it is also an activity distributed between humans and non-humans. Objects, tools, and artifacts embody knowledge; they anchor practices in their materiality..." (p.354). We can then understand knowing as a collective and distributed activity, which is situated in time and space. Knowing is not only part of practices, but it is also part of objects, which create fixed points in the practices. Furthermore, Gherardi (2014) conceptualized knowing as "situated accomplishment that accommodates a full range of practical resources and interactional forms according to the logic of the practice at hand" (p.13). Knowing is not something that simply takes place, but has to be interactionally accomplished according to the way the particular practice is organized.

Finally, I needed a framework that would help me understand the possible change introduced by a tool on the individual's activities. Practices are always changing. According to Schatzki, Cetina, and von Savigny (2005), it is important to view practices as ongoing and continuously unfolding through emerging, persisting, and dissolving. In Nicolini's view (2012), practices are in perpetual change. Because they are social, they are driven by activities conducted by people, and there is always a potential that they will be conducted in a different way from the previous ones. However, this potential is not endless; there is certain historicity to every practice, which directs the course of the people's activities. Thus, effort has to be spent on both changing as well as sustaining practices.

Situated learning

Every version of practice theory needs to be complemented with a learning theory (Nicolini, 2009). To understand how nurses handle the constantly evolving practices, I have related my work to the notion of situated learning. In this thesis, I view learning as always situated and as an emerging yet central feature of becoming knowledgeable in a particular domain (Lave & Wenger, 1991). This perspective means that learning needs to be understood in the social and historical context in which it emerges (Vygotsky & Cole, 1978). More specifically, I draw on Lave and Wenger's concept of situated learning. To explain this concept, I will first present my understanding of communities of practice and legitimate peripheral participation in relation to learning, as well as present Lave's unpacking of situatedness.

First, I chose this approach as it builds on the same theoretical assumptions as practice theory but explicitly talks about learning. People's actions are organized through mutual interdependence: individual participation constitutes communities of practice, which at the same time, constitute individual participation (Lave & Wenger, 1991). This is important as it shifts our focus to the actual interaction taking place instead of what is taking place only on an individual level. The idea of communities of practice originated from Lave and Wegner's work on apprenticeship, and they described it as a group of people who come together because of a common interest or concern that the group aims to solve. These people are related to each other by a set of relationships that also involve artifacts and take place in time and space (Lave & Wenger, 1991).

Second, even though this approach is explicitly interested in learning, it shifts our focus from a traditional approach to learning to the social interaction. Learning is a central feature of participating in a certain community of practice. Those who get involved with a community of practice go through a process Lave and Wenger (1991) called "legitimate peripheral participation.". This participation is on one hand peripheral, as the people start as outsiders, at the edge of a community, and by continuous mutual interaction with others gradually move towards the center of the community the more knowledgeable they become on the given problem. But at the same time, the participation is also legitimate, as it is an accepted way of becoming a member of the community.

Finally, learning is always situated, as it does not exist outside of the social context within which it takes place. In turn, learning is always learning of something, learning of a specific phenomenon by a specific group of people in a specific environment. Lave (1991) unpacked and contrasted three different views on situatedness to help us better understand it. The "cognition plus view" views a person (and his or her learning) as an individual act that is impacted by the social context. The second approach, called the "interpretive view," places situatedness into social interaction or language use. This approach shares some of the key aspects with Lave's take on situatedness, such as relational interdependency between the learning of the person and the world or that sense making is placed in "interested, intersubjectively negotiated social interaction." (p. 66). However, this approach misses that "subjects are fundamentally constituted in their relations with and activities in that world" (p. 67) which is one of the key assumptions of Lave's situated view, which is the third approach. In other words, the situatedness of learning does not only mean that individuals' learning takes place in a social context, but that they and, in turn, their learning are constituted and formed by the relationships they find themselves in, as well as constituting and forming the relationships they are in. They are not separate but mutually dependent.

Furthermore, as the complexity of society has increased, the concept of communities of practice may no longer be able to fully explain how learning takes place. As it is becoming more and more difficult and in some communities even impossible to be able to move completely to the community center, there have been efforts to reframe the concept of communities of practice. Fischer (2001, 2005, 2013) has worked extensively with these concepts and connected communities of practice to digital tools designing. He presented the design process as a meeting point of two communities of practice, which come together to work on a common problem. However, the emergent group is not a community of practice, as the people do not share the same knowing, and even though they learn from each other, it is not the same thing they are trying to become knowledgeable in. That is why Fischer proposed to view these groups as communities of interest, as learning is still taking place, but the individuals involved are not the same practitioners. This is important to know as, in this thesis, I am interested in the consequences of nurses' participation in the design process.

Categorical work

One of the activities that nurses do within their work practices is categorical work. Therefore, it was important to understand what categories are, what working with them involves, how this activity is connected to classification and standards, and how it is connected to translation. In this thesis, I view categorical work as an effort that individuals exert to create, establish and apply categories (Study III focuses specifically on this concept). This effort takes place in particular practices. Categories are simplified and fixed forms that involve knowing that had been packaged and "frozen" in these categories. Categorical work does not involve simply "applying of categories," and, in turn, producing knowing. Different stakeholders might have different needs and might aim to use categories in different ways to serve their own purposes (Toombs, 1992). Different communities of practice are connected to different sets of categories. When two different communities meet, an additional effort has to be made to make the categories work together. This perspective puts a focus on the categories that nurses employ in the patient encounters and how they highlight certain aspects of patients' bodily functions in order to explain what is happening with them or how these categories are co-created with other professionals in a design process. When one's lived experiences are aligned with the classification systems and standards, new knowledge can be produced.

The durable character of categories makes them a useful lens, especially when looking at tools, as they are often based on systems of categories, in other words, classification systems. Two authors who have expended extensive effort to understand categorical work in relation to classification are Bowker and Star (1999). In their seminal work, they argued that classification and standards are two sides of the same coin: classifications can become standardized, and standards can impose a classification. Bowker and Star defined classification as "a spatial, temporal, or spatial-temporal segmentation of the world" (p.10) and standards as "any set of agreed-on rules for the production of (textual or material) objects" (p. 13). At the same time, classification is then a way how textual or material objects are organized in a certain way, as standards are rules that have to be negotiated to be able to produce these textual or material objects. However, which knowing becomes part of which category is a political and socially steered process. It becomes especially visible during the design of tools that aim to support work practices, when the black boxes of categories have to be open and what will be involved in which category has to be negotiated (Bowker & Star, 1999).

Finally, I view categorical work as a type of translation work as it builds on the ability of the participants to translate categories from one social domain to another. Translation work takes place both in the participatory design process and during regular nurses' work practices. In this thesis, I describe translation as an activity during which heterogenous individuals or artifacts are involved in the linking of categories (Callon, 1984). The linking creates a connection that did not exist before, and to some degree, it modifies those who are connected (Latour, Sheridan, & Law, 1988).

Chapter 4 Research setting and approach

As the tool was specifically designed for the nurses I studied, a range of participatory design activities took place during the design of the self-monitoring application. This shaped my interest and, in turn, impacted the methodological choices I made. Further, as I tried to understand a relatively new phenomenon (the use of self-monitoring data in nurses' work), it was important to be able to explore the case in depth. Hence, I have framed the methodological approach in this thesis as a design ethnography. This thesis is article-based and involves one empirical case. This chapter has two sections, Research setting and Research approach.

In the Research setting section, I describe the relevant aspects of cancer rehabilitation, the EfterCancern project, and the participants in the studied clinic. In the section focused on the research approach, I introduce what design ethnography means in this thesis, how it was applied to data collection, and how the data were analyzed. Following that, ethical issues and other methodological considerations are discussed.

Research setting

In this section, I introduce pelvic cancer rehabilitation as a form of care and discuss how cancer rehabilitation can be supported by self-monitoring data. I also describe the EfterCancer project and provide descriptions of the nurses and patients.

Cancer rehabilitation

Today, chronic diseases are the main cause of death and disability worldwide, as they kill 41 million people each year (World Health Organization, 2014). Chronic diseases are often lifelong and require highly individualized treatments. Cancer survivorship is today considered a chronic disease. Major advances in cancer treatment and screening programs have led to an increasing number of adults surviving cancer (Hellbom et al., 2011). This means that the number of people requiring additional help after completion of their cancer treatment is growing. In the Nordic countries, self-management efforts to improve patients' lives after they have survived cancer is often labeled cancer rehabilitation. There is no one single definition of cancer rehabilitation (Hellbom et al., 2011). Hence, cancer rehabilitation is often labeled in various terms, such as post-cancer programs, after-cancer care, follow-up care, or symptom management of cancer survivors. The Nordic Cancer Union defines cancer rehabilitation as:

> Cancer rehabilitation aims to prevent and reduce the physical, psychological, social and existential effects of cancer and cancer treatment. Rehabilitation interventions should give patient and next of kin support and prerequisites to be able to live as good a life as possible. (Eckerdal, 2019, translated by the author)

Hence, cancer rehabilitation is a broad approach that aims to improve cancer survivors' quality of life. It goes beyond the strictly medical aspects of the treatment and combines various approaches. It involves not only the patients but also their social networks.

Self-monitoring data in cancer rehabilitation

As in other chronic diseases, even cancer care and cancer rehabilitation are expected to draw on the use of self-monitoring data to overcome upcoming challenges, such as decreasing resources and the increasing number of ill patients. However, even here, the implementation is not an easy task. A review of patient-reported data use in healthcare indicated that, although the use of this kind of data led to an improved care, it did not lead to a better quality of life or patient satisfaction (Luckett, Butow, & King, 2009). Further, self-monitoring for cancer survivors has been explored in relation to increased physical activity, which is believed to have beneficial effects on cancer survivors' health. For example, in a randomized controlled trial, colorectal cancer survivors used Fitbits to be able to engage with their physical activity data (Van Blarigan et al., 2019). Even though the results indicated that the cancer survivors' use of Fitbit was feasible, it did not lead to a significant increase in their physical activity. One of the possible impacting factors might be the role of the healthcare professional who supports the cancer survivor during the cancer rehabilitation. During a pilot feasibility study, cancer survivors were provided with pedometers to improve their health (Frensham, Zarnowiecki, Parfitt, King, & Dollman, 2014). The study reported improved physical and quality of life aspects. However, the results also indicated that a more active role of the intervention personnel was needed. In addition, as part of EfterCancern project, other researchers reported on the use of self-monitoring data use in cancer rehabilitation. For example, Lindroth et al. (2018) pointed to the change that is triggered in nurses' work practice when the self-monitoring data are introduced into the nurse-patient consultation. Here, they focused on how the nurses translated the rich patient narratives to data that the nurse could use for documentation and clinical decision-making. Islind et al. (2019) also focused on the translation work of nurses in relation to the self-monitoring data of their patients. They noted how, through the nurses' translation work, the data became mobile and were distributed. A description of the EfterCancern project follows.

EfterCancern project

The data collection was conducted within and in collaboration with the EfterCancern project. EfterCancern is an interdisciplinary project that drew on years of experience of the clinical experts involved in the field of pelvic cancer rehabilitation. The project aimed to improve the quality of life of cancer surviving patients. The project built on collaboration among clinical researchers, clinical practitioners, and researchers from the education and IT departments. These groups firmly determined the areas the project drew on: clinical research, informatics, and pedagogy. Drawing on these three areas resulted in the practical development of several digital tools, including a website, video tool, and self-monitoring application. It is difficult to place the project in one scientific category, but the publishing efforts ranged from oncological to nursing venues, but also HCI and information systems, often with a focus on learning. A professor in clinical cancer epidemiology, who has more than 30 years of experience in cancer epidemiology clinical research, led the project. Furthermore, a professor in pedagogy and a professor in informatics worked on the project during the first two years. The academic team further involved a postdoctoral researcher, who also had the function of a project manager, and two Ph.D. students (I represented pedagogy, and another student represented informatics). Finally, on the clinical side of the team, there were three oncological nurses (more information about them follows). This constellation strongly influenced the dynamics of the project, such as what kind of themes became important, which tools were developed, and other factors.

The nurses at the clinic

There have been two to three nurses working at the clinic I studied (at different moments in time, there were either two or three nurses working at the clinic). All of them have been working in oncology for many years. Their main task is to provide the patients with help and support. Furthermore, an administrator works at the clinic as well, who takes care of a variety of administrative tasks connected to the clinic's questionnaire distribution. Finally, there is also a chief physician, who helped to start the clinic and who provides the nurses with support on complex cases. At the hospital, we can find the nurses in the office of the Enheten för Bäckencancer Rehabiliteringen (Clinic for Pelvic Cancer Rehabilitation). The clinic is, however, not a regular part of the oncological department, but it is a research project for testing the clinical practice that is developed here, as well as conducting other research projects. Moreover, the nurses are in a nontraditional situation when it comes to the amount of time they have at their disposal. They can spend up to one hour per patient for a physical meeting or a supportive talk over the phone. This also allows them to adjust care to the patients' individual needs. The nurses do not follow some preset protocol that would, for example, determine how often they have to get in touch with a patient. Instead, they get in touch with the patient based on the patient's needs and based on what they have learned from their clinical practice.

The patients

Individuals who suffer from radiotherapy-induced late effects manifestations in the lower abdomen are labeled as the patients in this thesis. To label individuals suffering from a disease as patients has been continuously pointed out as problematic in the patient-centered literature, as a patient is not only a patient but also, and foremost, a person (Ekman et al., 2011). In addition, various authors in the self-monitoring literature have pointed out that it is problematic to view self-management as something that does not take place in the context of people's lives (Rooksby, Rost, Morrison & Chalmers, 2014). I chose to use the label patient for three reasons. First, I referred to the specific role they have in this context—that they are suffering from diseases, which they are treated for, and at the same time, they are in touch with the healthcare sector. Second, I deemed it relevant focus on the continuous contact with healthcare, in which self-monitoring takes place. That stands in contrast with the mundane self-monitoring approach (Didžiokaitė et al., 2018) in which people are not in touch with the healthcare providers and collect data about themselves for their own purposes, though also connected to their health. Third, the nurses commonly use the term and, because of my design ethnographic approach, I decided to use the same categories as the nurses use.

The patients who are in touch with the clinic were treated by radiation in the pelvic area. They usually had cancer of the following types: bladder, colorectal cancer diagnosis, gynecological cancer diagnosis, such as uterine, cervix, fallopian tube, ovarian, vaginal, and vulvar cancers (Hellbom, 2018). The patients come to the clinic in various ways. First, referrals can be issued; these can be either internal referrals (issued from one of the other departments at the Sahlgrenska Hospital), one's own referral, (when a patient asks the clinic to get in touch with her), or external referral. Second, the nurses can get in touch with the patients before their treatment begins. The patients are mainly women, for various reasons. First, the types of cancers they treat are often those that only women can have (cancer of uterus, etc.). In addition, because of the way this sector of Swedish healthcare is organized, some groups of patients are helped in other departments (for example prostate cancer patients).

Research approach

This section focuses on research approach deployed in this thesis. First, I explain what design ethnography means in my thesis and how I accessed the field and further engaged with it. I will then describe the collected data and the way I analyzed them. Finally, I consider relevant ethical issues and provide some methodological considerations about the trustworthiness of this thesis and my double role in the project.

Design ethnographic engagement

Engagement refers to the link between adjusting the world and striving for some kind of good (Thévenot, 2005). In other words, to engage with a certain practice also means to make changes to or impact it and, at the same time, commit to the idea of a greater good. My ethnographic engagement was therefore more than just a set of methods I used to collect data. It was more of a broad approach in relation to my ideas of social good that shaped my whole interaction with the field and the people in it. In this thesis, I have framed my engagement with the field as design ethnography. In the education field, ethnography is a common approach, and it can be described as traditional ethnography (Walford, 2009). Walford pointed out that there are different forms of ethnography, and the traditional version builds on for example following assumptions according to Hammersley and Atkinson (2007):

> In terms of data collection, ethnography usually involves researcher participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts, in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry. (p.3)

There are several traditional ethnographic studies that have focused on nurses' work or nurses' education. For example, nurses' experiences in their nursing education have been explored (Pilhammar Andersson, 1991). Further efforts have focused on how the organization of the nurses' work changes when the healthcare system is reorganized (Lindström, 2007) or how nurses learn to become part of a nursing workplace as newly graduated nurses (Bisholt, 2009). Other studies have focused on how nurses knowing changes in relation to new tools they use to provide patients with care (Wikström, 2007).

However, in my thesis, I draw on the version of ethnography that has been developed in relation to design, and which builds on Blomberg's interpretive ethnography. Studying workplaces where new technology has been implemented is an important topic in the area of education sciences (Bivall, 2015; Nilsen, 2009). Technology implementation poses new requirements for the people working in these workplaces and, in turn, requires them to learn how to accomplish their work in a new way (Heath & Luff, 2000b). Since the 1980s, technology implementation in workplaces has been studied with the use of ethnography (Blomberg & Karasti, 2013). Ethnographic understanding has been especially connected with research promoted by the CSCW community.

There has been an ongoing conversation between ethnography and design in the pursuit of trying to improve understanding of work practices in relation to (modern) technology and, in turn, to allow us to build technology that will support these practices (Hughes, Randall, & Shapiro, 1992; Luff, Hindmarsh, & Heath, 2000a). For example, Dourish (2006) tried to problematize the relationship between ethnography and design. He pointed out that, in some research related to design and technology, ethnography has been reduced to a set of techniques rather than a whole approach to the empirical material. He argued that this is problematic because the ethnographic results are viewed not as interpretations of data but as translations of user needs to design implications (among others). Furthermore, an ethnographer is not a representative of the possible users (because they should be involved in the design process, too), but one who provides another point of view, which the users themselves might not be aware of (Crabtree, Rouncefield, & Tolmie, 2012). Hence, the role of the ethnographer is not to provide the developing team with a list of features they should develop for the given practice. The role of ethnographer is to become part of the design team and contribute to development of a rich environment in which the tool can be designed. This was also a role I tried to fulfill, and hence, in my thesis, I have labelled my research approach as design ethnography.

Today, design ethnography is commonly connected with the ethnomethodological approach (Crabtree et al., 2012; Crabtree, Tolmie, & Rouncefield, 2013). Since my approach is not as analytically strict as ethnomethodology would require (I do not focus on understanding of the methods the members' use to make sense of the social order), I chose to look for a version of ethnography that would be closer to my analytical view. Hence, I searched for an approach which is interested in work practices, conducts ethnography in a technological context, and reflects on ethnography's relation to design.

According to Segeström and Holmlid (2015, p. 1), design ethnography is the appropriation of ethnography for the purpose of informing design. However, that seems more like a simplification of the relationship that ethnography and design can have. As Dourish (2006) wrote: "It might be more accurate to say, though, not that ethnography was adopted in HCI research, but rather that ethnographers were adopted in HCI research" (p.543). In a similar manner, the goal of my design ethnographic study was not to produce ready-made requirements to "simply inform" the design process. Instead, my aim as an ethnographer was to develop an ethnographic understanding of the nurses' work practice, which I could later use during the design of the self-monitoring tool. The design process would then be (in)formed not only by the developers and nurses but also someone who has a different understanding of the nurses' work practice.

One author who has extensively explored the relation between ethnography and design is Janette Blomberg. Even though Blomberg herself does not call her approach a design ethnography, I chose to do so in my thesis. The label tries to overcome the simplified view on ethnography that only informs design. Instead, I wanted to emphasize that my ethnographic engagement with the field was guided and influenced by the mutual relationship with the self-monitoring tool design process and design-oriented fields such as CSCW and HCI.

Blomberg et al. (2017) determined four key aspects of ethnography. First, an ethnographic study is conducted in a natural setting. In other words, it is an effort to learn about the world where it takes place, in contrast to laboratory studies or experiments. Thus, I collected my data at the clinic where nurses actually work with chronic care patients.

Second, an important aspect of an ethnographic study is holism. This refers to the need to view studied phenomena in their given context. It does not mean that every aspect of the practice has to be understood but that the studied phenomena are part of a certain social context. In my thesis, I chose to focus on aspects of the nurses' work practice: their strategies related to bowel and bladder management, accounts of their work in the design sessions, and their use of the self-monitoring data in their daily practice. These three activities corresponded to the research questions and were chosen for the following reasons. First, focusing on the nursing strategies allowed me to create a starting point. This study served as a way of describing some of the issues of the nursing practice that were relevant to the idea that a new tool will be accessible to the nurses later on. Second, the self-monitoring application design meetings were followed up. The design process and related data became relevant because the nurses reflected on and discussed their work practices extensively during the design sessions with the developers. And third, because this thesis's main aim is to understand the nurses' work practice in relation to the self-monitoring data of their patients, the last study focused on the actual use of the data in the supportive talks. I viewed these different understandings as connected and mutually impacting each other, and I related them to the bigger picture of the nurses' work practice in chronic care.

Third, Blomberg et al. (2017) have described ethnography as an approach that is oriented towards producing descriptive understanding. They indirectly contrasted it with design, which is oriented toward prescriptions. In other words, ethnography aims to understand and, in turn, describe how or what things are, while design aims to express how things should be done. This explanation was further expanded by Dourish (2006). According to him, ethnography does not aim to produce historical accounts of "how things were" or "simply present observations"; instead, it is interested in "relationships between observations, it is inherently interpretative" (p. 543). In other words, it is through making new connections between the particular observations that creates new understanding and goes beyond the description of particular events. Further, it is also important to view the ethnographic descriptions as situated, as created by a particular person in a particular environment. Dourish elaborated on this topic:

> Indeed, ethnography outputs are often not analytic statements purely about members' experiences, but about how members' experiences can be understood in terms of the interplay between the members and the ethnographer. ... while the goal is to reveal and explicate rather than to create, the ethnographer is far from a passive agent in the production of this organization as a research outcome. (p. 544)

What the ethnographers produce is then not some "pure" descriptions of the studied activities but an understanding that is connected to both the study participants and the researcher herself. The account of the studied practice that an ethnographer produces tells much about the studied practice as well as about the person herself. This is one of the forms of the active impact an ethnographer has on her ethnographic descriptions (more about my active role in section Methodological considerations in this chapter).

Fourth, Blomberg et al. (2017) placed an emphasis on the native point of view. This does not mean that we are trying to reproduce the participants' view of the world. But, we try to create an account that makes sense to the research community, as well as to the research participants. Thus, the categories I used to describe the nurses' work were closely related to their own practices.

Finally, an important aspect of design ethnographic studies is time. Traditional ethnographies are often described in terms of spending a long period in the field (Walford, 2009). Blomberg et al. also talked about time: "At a minimum, most would agree that ethnography requires a period of field work where the ethnographer becomes involved in the everyday activities of the people studied" (2017, p. 124).

In other words, it is important to become involved in the daily practices of the people one studies, because that will make it possible to make sense of them. In contrast to traditional ethnographic studies, I focused on a relatively small aspect of the nurses' work: the problem of frequencies (more on this problem in the Chapter 5, Summary of the studies). The problem of frequencies was identified by the nurses as one of the main problems they experience in their work; hence, we also focused on this problem during the design to develop a tool that would help them manage this problem. To understand this problem and make sense of it in the context of nurses' work practices did not require the same amount of time it would have if I had had to learn about such a phenomenon in a completely unfamiliar society (Crabtree et al., 2013). In addition, although nurses' work practice is quite complex, the setting I studied was possible to understand within a time frame that was not extensive: the nurses usually occupied one room, and there were either two or three nurses who were involved in the data collection during the entire four years. Hence, my approach in the field was a combination of intensive and compacted data collection periods (for an overview see section below Description of collected data) over a long period of time, which is described in the literature as "selective intermittent time mode" (Jeffrey & Troman, 2004, p.540).

Field access and further engagement

Gaining access to the field is often considered a problematic issue (Silverman, 2005). On one hand, formally, it was not the case for me, as I came to the workplace through the project I was working in. I was introduced to the nurses during a formal two-day conference. However, even though formal access is essential (without it, it would not have been possible to conduct this research), there was more that I had to do to get access to the work practices I was interested in. As Geertz (1972) noted, one's work goes beyond formally granted access. Therefore, I placed emphasis on establishing a relationship with the nurses. In line with Blomberg's view on ethnography, an important matter for me was to make clear to them that my goal in the practice was not to evaluate their work (or say how they should work), but instead, that I was trying to describe how they work and make sense of their work practice in a way that would be meaningful for both me and the nurses.

After the introductory conference, I began to engage with the project and the clinic more often, helping out on certain tasks within the EfterCancern project. One goal was understanding the nurses' work, and therefore I started with preliminary observations several hours per week. After a month, it became clear that, in order to make sense of what I had seen so far, I needed to spend more time at the nurses' workplace. Therefore, I conducted a three-week long qualitative observation study that was documented by handwritten field notes or computer written notes. Even though video or audio would have been more suitable in certain situations, because of privacy issues and sensitive information, written notes were chosen as a way of recording the observations. Interviews with the nurses were audio recorded. During the observations, I shadowed the work of the nurses to observe how they conducted their work. The observations took place in the office where the nurses sit and work with their computers, as well as in a meeting room where they would meet with patients. Further on, short cognitive walkthroughs were conducted (Bligård & Osvalder, 2013) to complement my observational data. I stood or sat by the nurses' table and let them comment on what they do in their practice for about 20 minutes. This type of engagement helped me to become more familiar with the nurses' work routines.

The more engaged I became with the workplace, the more "visible" the field became. A field is a classic term in ethnography; however, in modern society, it becomes problematic when it should instead serve as a way of delimiting data collection, as the field has to be constructed instead of something that just exists (Falzon, 2009). First, it cannot be defined only geographically. Even though the nurses have a main office, where they work, they often go to other departments, they talk to the patients in other rooms, and they talk to patients over the phone. The way to delimit the field was to define it as the activities the nurses were doing.

Further, my ethnographic engagement was built on participation in the field. Participation in ethnographic studies can range from "fly on the wall" to a participatory observation, wherein one has to participate. My participation took three different forms throughout the project (Table 1):

Table 1.: Participation types overview

Participation type	Studied activity
Active participation	Design meetings and any other tool/practice development-oriented activities
Participant observation	Nurses' work in the office
Non-participant observation	Supportive talks

Because the aim was to gain a deep understanding of an aspect of activities taking place within a healthcare workplace, my lack of medical education and my comparatively limited medical knowledge posed a certain challenge in understanding the learning and knowing connected to nurses' work practice. On the other hand, having limited medical and nursing knowledge provided me with a certain distance, leading to the ability to ask about aspects of nurses' work that an experienced nurse might have overlooked. Furthermore, since I am not a nurse, the observation I conducted could never be fully participatory, and so I was always participating only as an observer in relation to the nurses' work. On the other hand, this position is quite common in hospitals, as it is quite usual that medical or nursing students observe their more experienced colleagues.

Description of collected data

The ethnographic fieldwork took several forms. The following presentation of data collection is organized according to the particular studies. Table 2 presents an overview of the structured data collection. However, it does not involve the dozens of more informal and less structured interactions that I engaged in with the nurses. Figure 1 puts the particular data collection in the context of the thesis's timeline.

Table 2.: Data collection overview

Data collection	Participants #	Data produced	Purpose	Timeline
Observation period I	3 nurses (I was present), 7 patients	Field notes, video and audio recordings, photographs	Understanding nurses' clinical work	October and November 2015
Design sessions oriented to nurses	3 nurses, 3 researchers (I was present), 1 communicator	Audio recordings, photographs	Understanding the consequences of nurses' participation in the design	February to April 2016
Workshop	3 nurses, 2 researchers (I was present)	Audio and video recordings	Understanding which methods the nurses use to interpret data in their work and the possible implications	June 2016
Observation period II	3 nurses (I was present), 3 patients	Field notes, video and audio recordings, photographs	Understanding nurses' clinical work	November 2016
Design sessions oriented to patients	3 nurses, 3 researchers (I was present), 3 patients	Audio and video recordings, photographs	Understanding the consequences of patients' reception of the application and the implications for nurses' work	February 2017
Observation period III	2 nurses and 5 patients, 1 researcher (I was present)	Field notes, audio and video recordings of 5 physical meetings	Understanding of the supportive talk	January to March 2018
Phone calls recording	Nurses and patients	Audio and video recordings of 21 phone calls	Understanding the ways the nurse works with the data when talking with a patient	March 2017 to June 2018

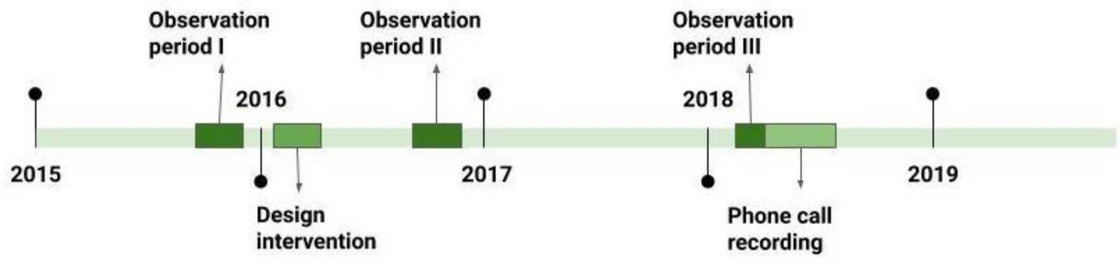


Figure 1. Data collection in the context of the thesis's timeline

Study I

First, I conducted an observation in the field where I spent three weeks shadowing the nurses. During this time, I collected field notes and photographs, and I studied the documents the nurses were using and creating. Usually, I would sit next to one of the nurses, to observe and listen to what she was doing. Especially at the beginning, I chose not to ask too many questions when they were working, as it could have disturbed their work. Furthermore, I listened to the phone calls with their patients, as it was sometimes possible to hear the other person talking over the phone. If that was not the case, I asked the nurse to briefly summarize what the talk was about. Furthermore, in the relative early stages, I conducted formal interviews with all three nurses. The interviews took place in the hospital and followed a semiformal interview guide. Finally, I also kept a journal, where I collected my own reflections about the data collection. I conducted numerous informal interviews with the nurses, and I observed several supportive talks between the nurses and the patients, as well as several informal group conversations among the nurses. Furthermore, I organized a focus group aimed at understanding how an existing tool (urination table) producing quantitative data was used and to discuss possible implications for the future self-monitoring data. The first observation ended when no new themes were identified, that is, when the social activities became too familiar, and observed activities stopped being surprising, it was time to take a step back (Kvale, 1995). After the field observation, my contact with the nurses continued over the next four years. I often came back to the clinic to collect additional material, discuss questions that I identified from the analysis, or to collect new data.

Studies II and III

Both of these studies drew on the same type of data: data collected in the form of audio recordings during the design sessions or the interactions between the nurses and the patients during supportive talks (both in traditional supportive talks and when the self-monitoring data were accessible). The difference here was that, I collected data for Study II, data for Study III were collected by me and the nurses (I collected data from the traditional supportive talks, and the nurses collected data from the talks when self-monitoring data were accessible). Considering Study III, this might seem an untraditional methodological choice within ethnography. On one hand, one could argue that the nurses could adjust the picture they were creating, as well as adjust the talks before and during the recordings. However, we could also view this as a strength, because it allowed the nurses to record the parts of the talks that were suitable for recordings, but at the same time, cover the sensitive topics that patients would possibly not want to share with others. Therefore, the nurses were able to do their jobs and provide the patients with the care they needed, but at the same time, this also allowed us to elicit needed feedback and data. This approach provided us with a perspective from the nurses, which is normally gathered only through interviews, while here it is expressed by the data they collected (Kvale, 1995).

Data analysis

Data analysis began during the first observations and continued throughout the rest of my study. Analysis is not something one does after. It is a process that begins when one enters the field and continues until one is done with the project (or, in this case, the completion of the thesis) (Hammersley & Atkinson, 1995). Study I was informed by the principles that design ethnographic studies are built on. For me, that meant that I had to read the observation notes multiple times, writing down analytical memos. I coded the ethnographic data, by describing the ethnographic material in more general terms in relation to my interest: the nurses' strategies supporting patients' learning how to manage their disease. These descriptions were further abstracted and grouped according to emerging themes. Emerging patterns were continuously compared with new data. This process was not linear, as it involved many steps in going back and forth between the various ethnographic data and analytical memos. This work process was similar to steps described by Graneheim and Lundman (2004).

For the purpose of Study II, I identified pain as a topic important for the nurses during the review of the recorded material. I read the design session transcriptions multiple times and searched for occurrences of pain, which I later explored more in depth together with the writing team.

Study III combined the field notes and transcriptions from supportive talks, and I used them to create ethnographic descriptions of the novel practice. The field notes and transcriptions were read multiple times. Another author and I conducted an open coded analysis on the transcriptions of the phone calls. In the next step, I read the transcriptions multiple times and related them to the analytical memos from the observational study. Examples from this corpus were also discussed with several research groups during the seminars.

The analysis in all the three studies has been guided by the principles of interaction analysis as defined by Jordan and Henderson (1995). Interaction analysis, as they described it, draws on traditions such as ethnography, ethnomethodology, or conversation analysis. It builds on the assumption that "knowledge and action are fundamentally social in origin, organization, and use, and are situated in particular social and material ecologies" (p. 41). In other words, knowing and human action do not originate in the individuals' habits but are produced in the social dynamics of human interaction. Activities or knowing are never abstracted—they are always situated in a given social context. The participants in the social interaction make their knowing and action accessible to other participants of the given interaction and, thus, indirectly to the analyst interested in the given interaction. On the conceptual level, the interaction analysis approach shifts the focus from an individual's habits to the interaction taking place among these individuals. Furthermore, this approach is also situated as it views knowing as taking place in a specific socio-material context. As such, this approach is compatible with practice theory and the concept of situated learning described in the previous chapter. On the practical level, I followed the steps proposed by ten Have (1990). First, the material was read and reread extensively. Together with knowledge gained during the ethnographic understanding, relevant pieces were chosen and explored in more depth. Furthermore, the chosen pieces were described in two phases. First, what was happening in the interaction was described. Second, an interpretation of this description in relation to the wider context (nurses' work) and the specific study was written.

Ethical issues

This thesis focuses on the nurses' work practice. Since it is impossible to talk about nurses' work without talking with patients and about patients' health problems and other sensitive topics, it was critical that I paid attention to the ethical aspects of my research throughout the whole research design. However, patients' personal data that could lead to identification of their identity were not collected to ensure patients' anonymity. Informed consent was gathered from the nurses whose work I studied and from patients who were involved in the data collection. The nurses and the patients were provided with information about the study in a mode that was suitable to the situation. The information explained the main purpose of the study and how the data would be collected and stored to ensure the patients' anonymity. The same was not possible for the nurses, but I chose not to directly identify them in the text.

Furthermore, it was highlighted that the patients' participation was voluntarily, and as such they could discontinue their participation in the research without any explanation. Before the patients were video or audio recorded during their interaction with the nurses, either the nurses or I informed the patient about the possibility to not to have the given consultation recorded.

When patients participated in data collection in Study I and Study III, we chose to use a two-step validation. First, the nurse contacted the patients to see if they wanted to participate in our studies. Second, when the actual data collection was about to happen, the nurse checked with the particular patients again to see if they wanted to participate so they were able to make an independent decision if they wanted to participate or not. The data were stored in accordance with General Data Protection Regulation (Viorescu, 2018). Before I entered the field, I signed a text expressing commitment to professional confidentiality. An application for the project was submitted to and accepted by the local ethics committee in order to ensure that all the methodological choices made were considered ethical. Furthermore, the ethical issues were continually discussed with the EfterCancern project group during the four years of the project to ensure that patients' personal integrity or their access to care was not negatively impacted by either the developed tools or interaction with researchers.

Methodological considerations

This section considers the trustworthiness of this thesis and discusses my role in the project.

Trustworthiness of the thesis

In contrast to quantitative studies, some authors have suggested discussing the trustworthiness of a study to evaluate the quality of its work (Creswell, 2007). That is because qualitative work does not build on the same premises as quantitative research. In quantitative work, one has to be able to evaluate if and how certain procedures were followed. In qualitative research, one needs to know if the researcher was able to make sense of the data in a meaningful way. First, credibility of this work has been ensured by continuous contact with the nurses at the clinic, which allowed for collection of additional relevant data and discussion of findings, as well as revision of the final texts with help from the nurses (especially Study I). I continuously sought to have the information validated by the informants as a way to improve the credibility of my ethnographic work.

To ensure confirmability, different methods of data collection were chosen, such as observations and informal interviews, but also audio and video recording of interactions. In turn, I was able to validate findings from my observations not only with the recorded materials, but also with a wider research community (for example, by presenting data transcriptions in closed seminars at the university). One of the aspects of trustworthiness that was challenging was possible transferability. The clinic is a research project, and therefore the nurses do not work there in a traditional way. They are often open to trying out new things and testing different strategies, and in general, they are very positive when it comes to new technologies. Also, as the clinic is a nurse-led workplace, it is not a traditional healthcare situation, making it more difficult to compare with other traditional departments (Zuiderent-Jerak, 2015). However, by providing thick descriptions of the nurses' work in this part of the thesis and the studies, I was attempting to increase the transferability of my findings.

My role in the project: ethnographer and designer

I will now comment on an important aspect of my thesis work, which was my double role in the project as a designer and an ethnographer. My role during the ethnographic work changed, depending on what data collection I was conducting. In the clinical setting, I had a more traditional ethnographic role, and I mainly observed the clinical practice. My focus during the observation was to primarily understand the nursing practice; consequently, I kept a certain distance from the nursing practice. However, during the design sessions, I took a more active role, and was continually contributing to the design process. The focus of my activities shifted, and my primary goal in those moments was to help create a tool that would actually be meaningful for the nurses. For example, I suggested ideas for features based on my observations from my data collection. An ethnographer always needs to balance the ways she is engaged in the studied situations and, at the same time, to keep a certain distance (Gill & Temple, 2014). To actively participate in the design sessions was an ethical choice for me to make. I deemed it unethical to participate in an activity where I would not contribute in the moment and where the group effort could actually benefit from my knowledge, even though it might have threatened the above described balance. In the design process, it was more important for me to create a tool well informed by knowledge about the practice, rather than to strictly follow ethnography norms. Both design and research are endeavors, where the answer is not known (Fischer, 2013). As such, there is no one correct solution to the problems, but rather trade-offs that the participants have to choose between. In a similar manner, I chose to become a more active participant in the activities connected to the design.

These two different approaches were also influenced by the two discrete roles I had during my ethnographic engagement: a Ph.D. student but also as a project member. Many times, it was challenging to separate the two roles from each other. The problems I was facing in the field were real-life problems, which had to be solved, regardless of which discipline one comes from. This was further complicated by the interdisciplinary character of my thesis work. Some decisions (such as proposing features for the mobile application) would seem unacceptable in some of the fields (traditional ethnography), they would be considered normal or even required in others (human-computer interaction).

Segelström, Raijmakers, and Holmlid (2009) recognized that there is a clash between the different roles of ethnographer and designer and considered possible frictions emerging from the combination. Mainly, they pointed out that ethnographic rigor can suffer. However, they also noted that combining these two approaches can motivate the researchers to reflect on their own methods and positions in a better way. In a way, I think having both of those roles made me blind to some aspects of the practice; however, I think that one is always "blind" in some ways. If I had not taken the role of the designer, I could have gotten a better understanding of the nurses' practice, but not in relation to design. In addition, design played an important role in the nurses' work practice, which I think I would have missed if I had not become an active part of the design process. In that way, trying to understand the nurses' work practice as a designer and not just as an ethnographer provided me with another perspective on their practice that I would have otherwise missed.

Chapter 5 Summary of the studies

This chapter provides an overview of the central results from the studies. This work builds on my ethnographic engagement with the pelvic rehabilitation clinic and has been structured around a series of separate articles. Because of this, it was not always possible to outline the full depth of the nurses' work practice in the separate studies. For this reason, this chapter has the following structure. First is an account of how the studies were written and how they relate to each other. Second, a summary of the studies is provided. This summary is divided into three sections, each corresponding to the thesis's research questions. Each section contains an ethnographic description of the research problem and how it connects to the different levels of learning in the nurses' work practice.

The progression of the studies

This thesis builds on three studies where each one aimed to answer a specific research question. To reiterate, these questions are:

- What strategies do nurses use to support patients' learning of their self-management?
- How do nurses contribute in a participatory design process of a self-monitoring application?
- How does the nurses' learning about patients' problems change when they get access to self-monitoring data?

The three posed questions imply a certain progression, and to reflect this in each of the different studies, they build on different data sets: observations of nurses' work prior to the design intervention, recordings from design sessions, and finally, observations and recordings of supportive talks using the self-monitoring tool. While the included studies have been numbered according to this order, the actual writing processes has overlapped at times (see Figures 1 and 2). I tried to understand the nurses' practice as a process (capturing the nurses' work practice before and after the data started being used) but also to view it from different perspectives (how the practice took place on a daily basis and how it was unpacked during a design process).

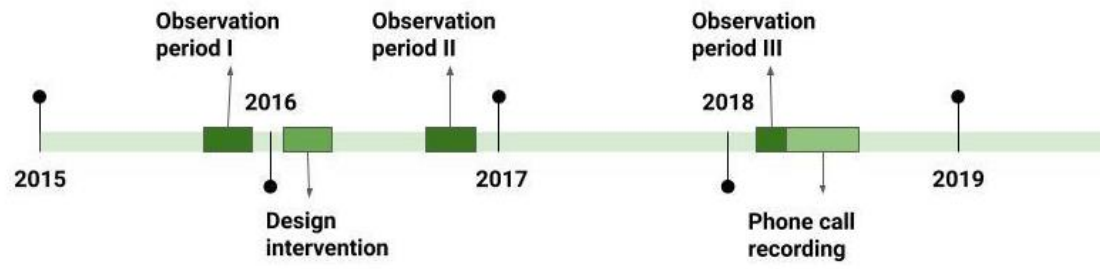


Figure 1. The data collection in relation to thesis's timeline.

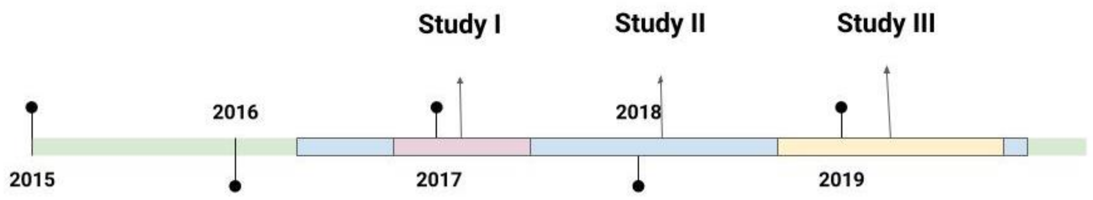


Figure 2. The studies' writing in relation to thesis' timeline.

Study I presented a description of the nurses' traditional work practice, indicating how the work was carried out without access to self-monitoring data, and it revealed the complexities that the chronic care nurses need to deal with on a daily basis. The first study's focus was impacted by the possibility to design a tool that would help overcome one of the key challenges the nurses experienced in their daily work practice. When such a tool began being developed, I followed this design process which resulted in the Study II. And, finally, as the new tool was deployed, I made observations of the actual tool in use which constituted the materials for Study III. Following is the list of the involved studies, their titles, venues (if possible to reveal), and authors.

Study I: Supporting self-management of radiation-induced bowel and bladder dysfunction in pelvic-cancer rehabilitation: an ethnographic study

Published as: Cerna, K., Ivarsson, J., Weilenmann, A., & Steineck, G. (2019). Supporting self-management of radiation-induced bowel and bladder dysfunction in pelvic-cancer rehabilitation: An ethnographic study. Journal of Clinical Nursing, 28(13–14), 2624–2634. .

Study II: Nurses' work practice in design: Managing the complexity of pain
(under review)

Authors: Cerna, K., Weilenmann, A., Ivarsson, J., Islind., A. S., Lundin, J., & Steineck, G.

Study III: Patient-generated data and the emergence of novel knowledge practices in healthcare: Designing for categorical work in chronic care
(submitted)

Authors: Cerna, K., Grisot, M., Islind., A. S., Lundin, J., Lindroth, T. & Steineck, G.

Study I: Nurses' strategies supporting patients' learning

The studied clinic builds on a central model. The idea is that, contrary to the current model in cancer rehabilitation, one has to first handle the physical symptoms to be able to proceed to manage the psychosocial problems. As the visiting patients regularly suffer from increased defecation and urination frequencies, the first step in the nurses' work is usually to decrease these frequencies. This specific problem presents one of the main issues for the nurses in their practice. The most common issue is defecation management, but other elements of care, such as management of pain, urination, and medication intake, as well as frequencies and their development over time, are relevant as well. The nurses need to know how often these events take place in the patients' lives, in order to provide them with the correct diagnosis and prescribe a suitable treatment. It has been found, however, that such information about how often something happens can be very difficult to recall, and patients are often unable to provide the nurses with information precise enough to determine this. Hence, the nurses must support the patient's learning so as to enable an assessment of the severity of the problems. The nurses have several techniques for eliciting the needed information, but the entire process of diagnosis and treatment takes a long time. At times, it might fail entirely. In this study, I focused on how the nurses solved the practical problem of detailing frequencies and some other related aspects of their work practice through which they supported patient's learning.

Study I aimed at understanding the nurses' work practice before the nurses had access to any self-monitoring data. The goal was to understand how the nurses support patients in learning how to manage their health problems. The study was directed at a specific problem: We know that there is a potential in using self-management to support patients who have received radiation in the pelvic area; however, it is not clear how exactly to deliver self-management to this particular group of patients. Recent studies have shown that a variety of different types of self-management has been used to support patients suffering from radiation-induced late effects (al-Abany et al., 2002; Dunberger et al., 2010). These different types of self-management differ in relation to time, who interacts with the patient, what form they take, and their content. In the analysis, my co-authors and I chose to adhere to the Scandinavian type of care that is provided to the patients, here labeled as cancer rehabilitation. This differs from other forms of self-management as it involves various professionals whose efforts go beyond strictly medical assistance. Furthermore, new forms of self-management have started to show potential. One example is nurse-led clinics where nurses play a key role in the self-management process. In this work, their role goes beyond providing the patient with strictly medical help, but also covers aspects such as psychosocial support or teaching the patients how to manage their chronic disease on a daily basis.

The aim of the study was to identify and describe strategies that oncological nurses use to support self-management of radiation-induced bowel and bladder issues in pelvic cancer rehabilitation patients. To answer this question, we drew on observational data of the nurses' work practice, as well as observations of 15 nurse-patient supportive talks. We conducted an ethnographic analysis of the talks, where nurses and patients discussed the patients' health problems. In the analysis, we identified three categories representing central strategies that the nurses use to support self-management of the patients. First, the nurses encourage the patients to reflect on their problems. The lived experience of the chronic disease is encompassing, and the patients often do not realize that they are experiencing a health problem that they can get help to alleviate. Second, the nurse and the patient tailor a solution together so it fits with the patient's individual needs. Every patient has distinctive needs, but at the same time, it is impossible for the nurse to come up with a unique solution every time. Therefore, together, the nurse and the patient try existing solutions known by the nurse by tailoring them to the specific situation of a particular patient. Third, the nurses keep motivating the patients to continue engaging in the self-management solutions they have devised together.

To conclude, in this study, we found that the nurses support patients' self-management through intertwining the patients' lived experience with the nurses' work practice, more specifically their medical knowing and clinical experience. In other words, the nurses went beyond simply providing the patients with information about self-management. Instead, they provided the patients with relevant categories from their clinical experience and medical knowing which they tried collaboratively to translate with the patient into the patient's lived experience. The nurses' work practice then was built on their ability to learn about the patients' problem from the patients' verbal accounts of their chronic disease experience and knowing how to co-create further solutions that the patient could manage to keep on doing by themselves.

Study II: Nurses' learning in the design of self-monitoring tool

Study II addressed the issue of nurses' participation in the design of a self-monitoring tool. The demanding and changing character of chronic care requires nurses to keep updating what they know about self-management to provide patients with adequate care. To understand what the nurses in the pelvic cancer rehabilitation clinic needed to know and learn, I will here outline some aspects of their practice. First, the pelvic cancer rehabilitation clinic is led by nurses. Nurse-led clinics are gradually being explored as a possible model for care (Faithfull, Corner, Meyer, Huddart, & Dearnaley, 2001). In these settings, the nurses not only decide and plan their own work but also have more responsibility since they provide the patients with diagnosis and further treatments, even medical ones. In addition, the studied clinic was specific in the way that it adopted and further developed a model of care proposed by the key figures of the project (Dunberger & Bergmark, 2012; Steineck et al., 2002). The proposed model was built on symptom documentation and the follow-up of the symptom progress. The nurses constantly evolved their clinical practice based on new tools but also new evidence, which was constantly gathered, discussed, and implemented into their practice. To be able to do so, the nurses were provided with several opportunities for professional development. Therefore, they participated in conferences, visited other sites that were relevant for their work practice, and engaged with scientific literature. Furthermore, they also presented their work either at the hospital or to other specialists who were interested in this kind of care. As the focus of the clinic was quite unique (radiotherapy-induced late effects manifestations in the lower abdomen treated through managing physical symptoms first and then psychosocial symptoms) the nurses often gave presentations to other healthcare specialists who were interested in pelvic cancer rehabilitation. In other words, they were used to creating accounts of their work in the healthcare context.

We found that the way the nurses supported patients in learning how to manage their chronic disease was quite a complex endeavor. This task was based on the nurses' own ability to learn about the patient's problems either from patient's verbal accounts or from measurements recorded with pen and paper. As was described in Study I, the support patients received from the nurses was dependent on what information the patients could provide. Based on this understanding and the fact that recalling detailed information about the development of their health problems over time was demanding for patients, the EfterCancern project group decided to develop a mobile application to address this problem. The aim was to build an application that could support the nurses' work practices by collecting patients' self-monitoring data. The design process of the self-monitoring application was organized according to the participatory design principles (more details on the design process in Table 3), and was thus built around the involvement of key stakeholders—in this case, nurses. Additional stakeholders who became involved were patients, a communicator, and researchers in the fields of education and informatics. The end users of the envisioned application were patients, and this often led the discussions on to topics connected to the patients' health problems. However, as the self-monitoring application was simultaneously designed to support the nurses' work, the core of the self-monitoring application had to take into account what the nurses needed to know in order to best support the patients.

The design meetings were organized as a series of meetings where the nurses, developers, researchers, and patients took part (see Table 3). Six design sessions took place at the hospital where the rehabilitation center is located, approximately once every three weeks from February to April 2016. The main themes of the design sessions were the user experience of the mobile application, the experience sampling, and the daily survey. A high-fidelity prototype was then introduced to a group of patients, and a second prototype was created based on their input. The updated prototype was then downloaded by two patients, who tested it for several weeks. The patients' experiences during the testing were then captured during another workshop and by follow-up phone calls.

Table 3.: An overview of the sessions in the design process of the self-monitoring tool

Time	**Session**	**Session aim**	**Participants**
February 2016	Session 1	Requirements solicitation	Nurse 1, Nurse 2, Researcher 1, Developer 1, Developer 2
February 2016	Session 2	Introduction of the first low-fidelity mock-up to the nurses	Nurse 1, Nurse 2, Researcher 1, Developer 1, Developer 2
March 2016	Session 3	Additional requirements solicitation	Nurse 1, Nurse 2, Developer 1, Researcher 1
April 2016	Session 4	Introduction of the high-fidelity mock-up to the nurses	Nurse 1, Nurse 2, Researcher 1, Developer 1, Developer 2
February 2017	Session 5	Presentation of a high fidelity prototype (Workshop with patients)	Nurse 1, Nurse 2, Researcher 1, Researcher 2, Researcher 3, Communicator, Patient 1, Patient 2, Patient 3
February 2017	Session 6	Discussion of the patients' experience with the app	Nurse 1, Nurse 2, Researcher 1, Researcher 2, Patient 1, Patient 2
March 2017	Phone calls	Testing of the second prototype	Nurse 2, Patient 1, Patient 2, Patient 3

Nursing work is often concerned and involved with qualitative phenomena. The design of tools that should support this work by collecting data will therefore experience a translation problem. To translate a qualitative phenomenon from its situated character into an abstract representation is a true challenge, but something that had to be addressed in the design process of the self-monitoring tool in this case. An example is the phenomenon of pain. The nurses identified pain as central to the patients' health problems and something they needed to know about. In their ordinary work practice, the nurses did not follow any formal protocols to diagnose pain, but they would improve their understanding of the situation through interactions with the patients. This meant that the methods for collecting information about pain had to be recreated during the design process. In other words, the black box of the nurses' work practice had to be opened during the design process. The focus on how pain was going to be conceptualized stemmed from the idea that it would provide an exemplary case that could deepen our understanding of the nurses' work practices.

Study II then addressed the issue of how the nurses contributed to the design process of the self-monitoring application. Departing from the principles of participatory design which builds on mutual learning (Joshi & Bratteteig, 2016), the participants got the opportunity to engage with perspectives of the different professions represented. Therefore, we tried to understand what implications the nurses' participation in the design process had for their professional learning. Empirically, the study drew on elements of design ethnography, meaning that we analyzed audio and video recordings of the design meetings among developers, nurses, and researchers.

Theoretically, we looked at activities that formed the basis of nurses' work practices. Work practices are mechanisms that organize accessible sociomaterial resources (Gherardi, 2009). Through these mechanisms, knowing that is distributed in human and non-human participants in the activities is produced. Our findings indicated that the design participants eventually overcame the problem of pain conceptualization by managing the complexity of pain representation in the self-monitoring tool. First, pain diagnosis was identified by the nurses as an important aspect of their practice. Already in the first encounter, it became evident that pain is a highly complex phenomenon. Understandably then, the nurses had troubles generating generic accounts about pain that the developers could use as clear-cut features of the self-monitoring app. During the second session, the developers introduced the first mock-up of the tool. When the discussion came to the location of pain, it turned out that the proposed representation was deemed too simple and would not match the expectations of the nurses. Hence, the developers had to increase the complexity of the representation, and during the final mock-up presentation, the developers presented a version that would better fit the needs expressed by the nurses.

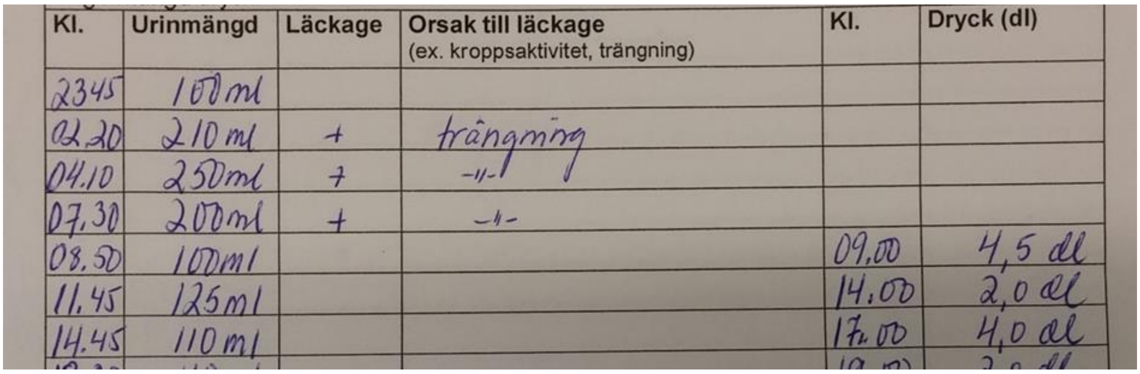
To conclude, when the nurses, developers, and researchers participated in the design process, they not only conceptualized tacit aspects of the practice to craft a tool intended to fulfil certain clinical needs, they also created a potential to change the very work practice of the nurses. As the nurses participated in the design process, their central contribution lay in the creation of accounts pertaining to their work. But, these accounts differed from how they would ordinarily have accounted for their work in relation to other healthcare professionals. The orientation to the developers and researchers opened up new perspectives and therefore offered a novel vantage point on their own practice.

Study III: Nurses' learning about patients' problems with self-monitoring data

Study III examined the issue of the actual use of self-monitoring data in nurses' chronic work practice. Nurses' work in chronic care builds on their ability to learn about the patients' health problems. In the pelvic cancer rehabilitation clinic, this is done in many ways. Although, the main source of information is by communication with the patients. The nurses communicate in two ways with the patients: during a physical meeting and over the phone. When patients decide that they want to get help from the clinic, they are invited to a physical meeting with a nurse. The organization of the talk can depend on what prior information the nurse has access to or on the expressed needs of the patient. The initial physical meeting usually starts by the nurse asking the patients for their background story, how they discovered the cancer, how their treatment went, and so forth. It should be noted that the nurses generally already have access to this type of information through the medical records, but that they choose to ask the patient for their version as well. The talk then develops differently depending on if the nurse has received a filled in questionnaire from the patient. This is a standardized questionnaire that involves some 300 questions about the patients' symptoms. The questions cover four main symptoms areas: defecation, urination, sexual life, and lymphedema. Most of the patients fill in this questionnaire in a paper form and send it back to the nurses. The nurses usually review this questionnaire before the first physical meeting. If this has been the case, the nurses usually go through the results from the questionnaire and check them with the patient, as some of the answers may turn out to be wrong. The patient could have misunderstood a question or provided an answer about a particular moment, which no longer has to be a valid answer. If this is the case, the nurses might ask the patient about their own wishes and what they need help with. If the patients are not sure where to start (as they might not even know which of their experiences are relevant in the context of the pelvic cancer rehabilitation), the nurses ask them questions about their symptoms. These questions are not standardized but are based on the previous work within the clinic (al-Abany et al., 2002). During these meetings, the nurses will already start proposing treatments, interventions, and offer advice on how to manage identified problems. The interventions can take the form of changed or new medication intake, but can also be about a change in behavior or diet. Furthermore, the nurses follow up on the development of the proposed solutions over the phone. Most of the phone calls begin with a variation of the question "How have you been?", and the talk is then developed based on what the patient identifies as important. Both the physical meetings and discussions over the phone constitute what is labeled as supportive talk in the thesis.

Another route to knowing about patients are the traditional hospital systems that are used for documenting symptoms, implemented interventions, summaries of discussions, and other relevant information. The main tool used to create this documentation is an electronic patient record. The nurses access it through desktop computers in their office. The nurses document every phone call and every meeting by filling in pre-established categories. Furthermore, the nurses also have access to other hospital documenting systems where they can find out about patients' medical history, details from surgery, and other information.

Finally, there is one more method that the nurses use to gather data about the patients' symptoms—a standardized table. This is mainly used for patients who suffer from bladder problems (there is also a table for problems with defecation). A patient receives a measuring cup and a paper form from the nurse. Whenever they have to urinate, they urinate in the cup and record the amount in the form (Figure 3). The patients are instructed to measure all of their liquid intake and urination for two days and to return the document to the nurse. It is then used for evaluating the patient's problems.



Kl.	Urinmängd	Läckage	Orsak till läckage (ex. kroppsaktivitet, trängning)	Kl.	Dryck (dl)
2345	100ml				
02.20	210 ml	+	trängning		
04.10	250ml	+	-"-		
07.30	200ml	+	-"-		
08.50	100ml			09.00	4,5 dl
11.45	125ml			14.00	2,0 dl
14.45	110 ml			17.00	4,0 dl

Figure 3. Excerpt from the urinary form.

The EfterCancern project initiated the development of a mobile application, in part as a solution to the challenges posed by this form of documentation. The design team aimed to develop a tool (here called the EfterCancern app) that would support self-monitoring of several symptoms and medications considered relevant for pelvic cancer rehabilitation. While the EfterCancern app would not be the only mobile application that the nurses recommend to the patients (they also recommend a mobile application called Tät, designed to support Kegel exercises), it is the only application that has been developed specifically for this clinical practice so far.

At the beginning of the design project, it was not planned that the team would strive to develop a mobile application. Initially, they were tasked to devise an artificial intelligence system that could provide basic support to patients and decrease the existing workload for nurses, as well facilitate patient care. However, it was found that a system such as this would have to be trained on a large data set pertaining to the nurses' work. Since no such data set existed, the focus of the design process shifted, and the developers began creating a tool that would collect the data first. This data collection was also more in line with the nurses' work—since having access to a new type of data would solve one of the key issues they had identified in their practice (i.e., the issue of frequencies).

The design process began with five meetings between the developers and the nurses. During these meetings, a first prototype was designed over a series of iterations. This prototype was then repeatedly introduced to the EfterCancern project group as well as patients, and it was further adjusted based on their feedback. During autumn 2017, a more developed prototype was tested by the first real users. In spring 2018, the application was introduced by the nurses to their patients as one of their tools. The nurses prompted the patients to provide feedback on the application, as the development of the tool was still continuing.

The present prototype, which has been in use since March 2017, is mainly focused on bowel problems (as one of the four basic areas of manifestations). It also involves several questions about pain, urination, and medication intake. There are two types of data that can be collected: a daily form and an experience sampling form (Scollon, Chu, & Diener, 2003). The daily form consists of up to six questions and should be filled out at the end of the day. In this form, the patients should evaluate their day in relation to how they experienced their symptoms. The experience sampling form should be filled out when a certain event takes place in the patient's life: defecation, urination, or pain. Furthermore, the patients can also enter which cancer rehabilitation relevant medicines they take. The patients are then able to view their own data on the phone or in an internet browser. The following images represent examples of the questions from the experience sampling section (consistency and pain intensity) and daily form (dull pain in the abdomen).

Vad hade avföringen för konsistens?

○ Typ 1: Separate hårda klumpar, som nötter

○ Typ 2: Korvformat med klumpar

○ Typ 3: Korv- eller ormformat, med sprickor på ytan

○ Typ 4: Korv- eller ormformat, jämnt och mjukt

Hur intensiv var smärtan? 0: Ingen smärta till 10: värsta tänkbara smärta

2

Antag 0 är obefintlig och 10 är den mest extrema

Idag har jag haft molande smärta i buken

○ Nej

○ Ja, lite

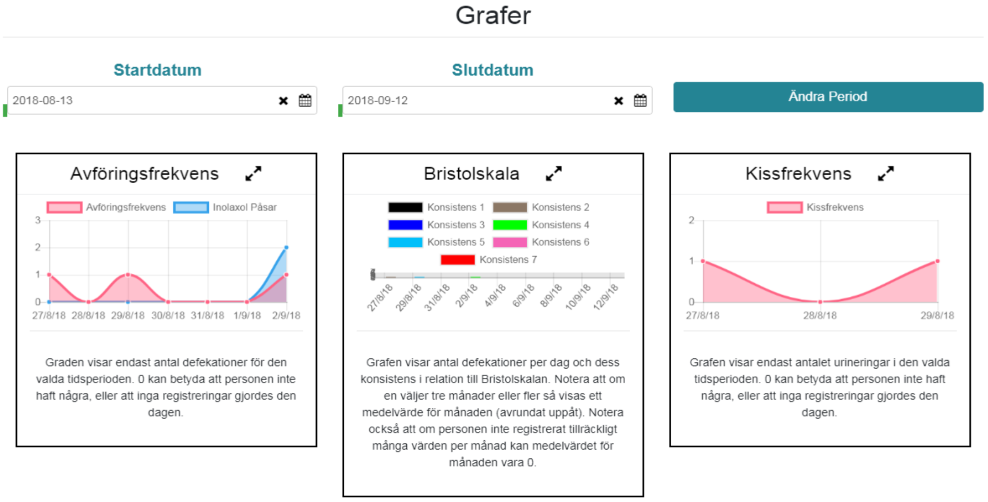
○ Måttlig

○ Ja, mycket

Figure 4. From the left: Consistency, Pain intensity, Dull pain in the abdomen.

The screen captured images (Figure 4) consist of the following questions. The first one is: "What was the stool consistency?" In this question, the patients should assess the consistency of their stool according to the established Bristol scale. The patients can choose only one option. The second question is "How intensive was your pain?" followed by a short explanation: 0 = no pain to 10 = the worst imaginable pain. This scale is a digital adaptation of a visual analog scale (VAS) that the nurses use on a regular basis. The third statement is "Today, I had dull pain in the abdomen," followed by the options No, Yes, some, 'Moderate, and Yes, a lot. The patient can select only one option.

The nurses can view the patients' data in an interactive portal (Figure 5), through an internet browser, where the data is visualized by different graphs. The images in Figure 5 illustrate the nurses' view of the patient data as it is displayed given a selected time period.



Startdatum: 2018-08-13

Slutdatum: 2018-09-12

Graden visar endast antal defekationer för den valda tidsperioden. 0 kan betyda att personen inte haft några, eller att inga registreringar gjordes den dagen.

Grafen visar antal defekationer per dag och dess konsistens i relation till Bristolskalan. Notera att om en väljer tre månader eller fler så visas ett medelvärde för månaden (avrundat uppåt). Notera också att om personen inte registrerat tillräckligt många värden per månad kan medelvärdet för månaden vara 0.

Grafen visar endast antalet urineringar i den valda tidsperioden. 0 kan betyda att personen inte haft några, eller att inga registreringar gjordes den dagen.

Figure 5. Interactive portal: nurses' view.

In the spring of 2018, the nurses started using the EfterCancern app on a more regular basis. They generally tried to introduce the application during the first physical meeting as one of their standard clinical tools. The nurses informed the patients that they should use the mobile application for 14 days, for the purpose of mapping their problems. This duration of use was a theme that came up during the design process where the nurses expressed their opinion that the EfterCancern app should not be intended to cover the entire cancer rehabilitation treatment. It should only be used for certain periods of time: to map patients' health status at the beginning of the treatment, to document their status before and after the applied intervention, and so forth. The nurses tried to be attentive to the individual needs of every patient and to let the patients choose what health problem they themselves deemed relevant to document. Some patients used the application only for the required period, but some decided to use it continuously.

Finally, it is important to mention that the EfterCancern project group did not aim to develop the app to improve the nurses' work in a quantitative way so as to make their work more efficient or faster. The EfterCancern project group aimed for a qualitative improvement of the care. This distinction is very important; the goal of the design team (involving developers, nurses, and researchers) was that the EfterCancern app should support those aspects of care that humans struggle with, such as recalling frequencies of past experiences, for the purpose of diagnosis. Thus, the intention was that the app should become a complement to the existing work practice so that the nurses could spend more of their time on the psychosocial aspects of the care.

Based on the findings of the first two studies, we then decided that it was essential to understand in what ways the actual use of the developed application could make an impact on the practice. To gain additional insights on this issue we focused the third study on the supportive talks between the nurses and the patients. Study III addressed the recent increase in the use of digital tools for PGHD by healthcare professionals. It is the healthcare professionals' knowing that needs to be translated into the technical requirements of the tool. However, it is the patients who will use the tool to collect data about their health problems on a daily basis. This situation leads to a potential change in the nurses' knowledge production practice, as well as various challenges in the novel situation. Theoretically, we used the concept of categorical work from Bowker and Star (1999) to understand how the knowledge production practices of nurses changed when they gained access to self-monitoring data (in this study described as patient-generated data). Empirically, we analyzed audio recordings of supportive talks that took place over the telephone or in person. More specifically, we contrasted the categorical work taking place before and after the design intervention in order to understand the emerging changes. Two research questions were addressed:

(1) How does the use of PGHD change the knowledge production practices of patients and nurses?

(2) How should collaborative systems be designed to support nurses' use of patient generated health data?

Empirically, this study was built on the set of data that involved observations and audio and video recordings of the supportive talks. This data included both supportive talks over the phone and physical meetings. Our findings indicated that the categorical work of the nurses changes when they get access to the patient's data. However, it also leads to new challenges that the patients and nurses have to deal with. In traditional practice, the supportive talk is built on the nurse's ability to provide the patient with a category relevant within the pelvic cancer rehabilitation. The patients, in turn, have to be able to align their prior lived experiences of their chronic disease to these categories the nurse provides to the patient during the talk. In the novel practice, the supportive talk builds on the ability of the nurse to find out how the patients have been able to align the categories from the application to their chronic disease. This also means that the patients have to do this alignment on their own, prior to the talks and without the support of the nurse.

Furthermore, several challenges appeared in the novel knowledge production practice, such as handling incomplete data sets, negotiation of reliability of the collected data, and problematic alignments of the patients' experiences with the app furnished categories. Finally, we proposed two design implications that would be important to consider when designing tools in such a way so that they make categorical work more collaborative. First, the tools should support both parties by clearly communicating both expectations and actual use. Second, the tool should support the pedagogical aspect of the chronic care.

Chapter 6 Discussion

In this thesis, I am interested in learning and knowing in chronic nurses' work practice in relation to self-monitoring tools. The following section concludes the first part of this thesis. First, the findings are summarized and then interpreted in the broader context of relevant research, more specifically in relation to the literature on chronic nurses' work, participatory design, collaborative systems, and self-monitoring data. Second, some of the limitations of this text are presented. Third, directions for further research are presented, more specifically in relation to nurses, patients, nursing educators, and designers. Further, a conclusion is provided at the end of the thesis. Finally, this thesis concludes with implications for practitioners.

Findings overview

The first study helped me understand how the nurses support patients' learning by re-interpreting of the patients' disease experience in the context of their medical and clinical knowing. The interdependence of the nurses' work and the patients' lived experience is important, as it highlights the importance of the nurses' ability to transform the patients' experience into knowing that helps her to support the patients in the management of their chronic disease.

In the second study, we saw the nurses in a new situation—in a design process—where the nurses participated not only in a co-design of a new tool supporting their work but also in the co-creation of a new way they can learn about the patients' problems. To be able to succeed with the task of co-designing the mobile applications, the nurses were required to do some activities that were outside of their regular nursing work. More specifically, to produce the categories that would later become part of the application, the nurses had to be able to provide generalized accounts of their work that were situated in the design process.

The third study illustrated how the categorical work of the nurses changed when they gained access to the self-monitoring data of the patients. The findings indicated that the way the nurse learns about the patients' problem changes, as other aspects of nurses' work become important in the supportive talk, such as finding out about the patient's ability to align with the categories presented in the app and the patient's ability to align her chronic disease experience to the categories in the application outside of the talk.

Translation work

There are three levels of translation work that are relevant to the nurses' work practice in chronic care. The first level of translation takes place when the nurse tries learning about the patient's problem through the data and when she supports the patient in learning about her problem.

Learning about the patient's problem through collecting data and making sense of them is a crucial aspect of nurses' work (Benner & Wrubel, 1989). To be able to interpret the patient's data in the chronic care, the nurse needs standards connected to the particular specialized chronic care. Bowker and Star (1999) labelled this type of work categorical work, as categories represent the standardized knowing. Islind et al. (2019) framed this effort as translation work: the nurses' task is, among others, to translate patient's data from one context to another. They take information that the patients provide them with and make sense of it, by reducing the information (taking away what is not relevant), but at the same time recontextualizing it (adding and enriching it with details). Building upon this work, we could learn more about what nurses do to enrich the patient's details.

Studies I and III contribute to this research and show how the nurse works with categories to translate her work practice into the patient's lived experience. They draw on the elements of their own work practice, with which the nurses try creating meaningful connections between the categories from their own work and the ones from the patient's experience. When the participants do not have access to the self-monitoring data, they do it together during their talk at the same time. The nurse can situate her standards in the life of the patient, and together they can decide what works for the patient and how; the nurse can tweak her standardized way of working and adjust it to the individual case of the patient. In the talk, when the participants have access to the self-monitoring data, the nurse also translates her work practice. However, she makes sense of the patient's problem in the context of the version of her standardized work practice that is represented in the application.

Another level of translation work takes place when the patient translates his or her experience when using the app. My thesis has focused on the nurses' work and does not explicitly address patient's actual use of the data in practice (that was covered by Islind et al. [2019]) . However, the way the patient understands and, in turn, uses the application is important as it impacts what will take place in the talk and as a consequence what the nurse needs to be able to do in the talk. For the patient to start using the application in a meaningful way within the given healthcare context, the nurse has to support the patient in learning how to do so. To use the application to collect self-monitoring data about her problems is not a simple task. The application highlights what the patient should look for, but then the patient has to relate and interpret her own individual experience in relation to the standardized self-monitoring questions in the application (Schroeder et al., 2017). In other words, she has to interpret her experience in terms of the clinical context and at the same time in the context of the application (Grisot et al., 2019).

Studies I and III highlight why the role of the nurse is so important: she needs to support the patients in learning how to use the application that is not limited to a simple manual input of data into the application, but how to make sense of their experience in such a way, so it is meaningful in the given context of chronic care.

Finally, translation work also takes place in the design process. Digital systems supporting work build on abstracted forms of the work (Dourish & Button, 1998). For the developers to be able to create a tool that will support the nurses' work, the nurses need to create abstracted forms of their work, so the developers can translate them into the features of the self-monitoring tool. However, these abstracted forms are not created in a vacuum but in the social context of the design process. In other words, the nurses need to formalize their work practice but in such a way so it is relevant for the developers (in contrast to, for example, other healthcare professionals). However, that is not easy as it requires the nurses to agree on the same, or in other words, the standard version of how to do their work, something they are normally not required to do in their regular practice. For example, in a study of designing new procedures by nurses, the authors showed how the nurses drew on different modes of knowing when deciding about what should be involved in the final version (Nes & Moen, 2010).

Although there are studies focusing on how nursing standards are developed, these have been about tools that support the work of the nurses, but do not involve data collected by patients. Study II contributes to the current literature and shows how nurses have to co-create a standardized version of their work so it makes sense for a tool that the patients will use to collect their self-monitoring data.

Mutual learning

The nurses studied for this thesis engaged in two types of mutual learning. The first type can be described as two forms of mutual learning: learning about the patient's problems and supporting patients in learning about their health problems. These two forms of learning in chronic care are mutually dependent on each other. For the nurse to be able to learn about the patient's problem, she tries to get to know the patient. In chronic care, the nurses' work practice builds on her ability to learn about the patient's problem in such detail that she can provide the patient with suitable care (Benner & Wrubel, 1989). But, since the patient does not know changed herself and what is normal for her (after becoming a chronic patient), the nurse and the patient need to discover what kind of problems the patient has and recreate together who the patient is. Pelvic cancer survivors experience a wide range of health problems that are difficult to manage. Most importantly, these problems are new, and the patients often do not know how to manage them—they do not know themselves, and they no longer know what is normal for them. Hence, the nurse faces a challenge: as the patients cannot provide the nurse with precise information about how their body and mind works, the nurse faces the task of trying to figure that out. By supporting the patients in learning about how their body and mind work in the context of pelvic cancer rehabilitation, she also gains more information and learns about the patients' problem.

However, the research community could learn more about how nurses can learn about the patients' health problem and, at the same time, support the patients' learning about their problem. Study I addresses this gap by providing us with insights about how the nurse tries eliciting information she needs: she develops strategies on how to support patients in their own learning.

The second type of mutual learning is connected to the nurses' participation in the design process. Even though nurses' have been involved in participatory design projects since the 1970s (Bjerknes & Bratteteig, 1988), what it means to take part in a design process and how one can prepare for it is not part of nurses' traditional training. When working, nurses learn not only during organized training but also from their colleagues (Bjørk, Tøien, &

Sørensen, 2013). In other words, nurses learn from their own community. The more they participate in the nursing activities, the more they learn to be a nurse (Lave & Wenger, 1991). However, in a design process a different situation takes place. Participatory design builds on bringing experts from different domains to work together. Hence, there is no shared community that the two groups of experts can become part of. Fischer et al. (2013) described this as more a community of interest in which the design participants gradually become knowledgeable through participation. The way participants are able to participate will then also impact what they will learn during the design process. For example, in a study of a hypertension design process, the design participants contributed by inscribing intentions into the designed tool (Ranerup & Hallberg, 2015). Another study from a design process of a hypertension self-monitoring tool highlighted how the design participants negotiated what should be involved in the final prototype of the tool (Bengtsson et al., 2018).

However, we could learn more about how nurses specifically participate in the design process of a self-monitoring tool. Study II contributes to the understanding of this problem by providing insights about how nurses can contribute to the design process when they become part of a process of a self-monitoring tool that aims to support their work.

Limitations

This thesis has various limitations. First, pelvic cancer rehabilitation involves more than problems with bowel, bladder, and pain. It is possible that learning and knowing in work practices related to self-monitoring data related to, for example, sexual problems or lymphedema would be different. However, in the current study, the nurses were struggling with the issue of frequencies connected to the previously mentioned areas, and therefore I focused on an understanding of those areas. Second, this thesis is based on a study of only one clinic. However, I spent an extensive amount of time working with the nurses there and much of what I have learned resonates with findings from areas of other types of chronic care. Third, switching between a healthcare developmental project and a descriptive study might have weakened these two positions. As discussed in the Research approach section, in the project I had roles both as a person helping to develop the nurses' work practice and as an ethnographer. Taking up both roles and switching between them during the whole project proved to be challenging, and possibly led to less exact results in terms of those two roles. However, I viewed it crucial to combine these two roles, because both of these perspectives were needed to inform my understanding of the nurses' work practice. Finally, the special character of the clinic may have made some of the findings less applicable in other contexts. The clinic is a research center, so the nurses have more time to spend with the patients than they do regular chronic care, and the care is organized based on the patients' needs rather than following formal protocols. However, even though it might not be possible to find a clinic that would fit in all these aspects, some aspects can resonate with work practices in other chronic care clinics.

Future research

The research presented in this thesis points to a number of issues that could be explored in future research. First, in Study I, I have shown how chronic care builds on the nurses' ability to support patients' learning about their own disease. Chronic care builds on collaboration and interaction between patients and nurses (Bodenheimer et al., 2002). Future studies could thus focus on the patients' role in this process and explore how the self-monitoring application contributes to the patients' learning about their own lived experience of the disease and how it impacts their identity.

Next, in Study II, I explored the nurses' participation in a design process. Participating in a design process of a self-monitoring tool supporting their work was a demanding task, as two or more communities of practice have to meet which poses new requirements for nurses' learning and knowing (Fischer, 2001, 2005). Hence, future studies could explore how nurses' participation could be supported in participatory design, so nurses can better face this demanding task.

Finally, in Study III, I focused on how the nurses' work practice changed when they gained access to the self-monitoring data of their patients. Their work could be explored further in relation to a new version of the current mobile application. We know that the needs of chronic care patients change over time, and the tools need to adapt to these changes. In addition, the possibility to analyze this kind of data by algorithms will further increase the complexity of this issue (Barken et al., 2017). Therefore, future studies could strive to understand how the nurses' work practice will change, when the tools are adapted both to the nurses' and the patients' knowledge needs.

Implications for practitioners

To conclude the first part of this thesis, I will offer a summary of what I have learned in relation to what can be useful for practitioners. This thesis is primarily intended for nurses who are interested in using self-monitoring applications to support patients in pelvic cancer rehabilitation or other forms of chronic care, nursing educators, and anyone else who is interested in chronic nurses' work practices in relation to self-monitoring tools and their design. These implications can hence inform not only nurses' formal education and training but they are also oriented toward the training taking place at nurses' workplaces, which in my thesis are connected to participatory design. Therefore, the first section provides implications to practitioners from this area in terms of what the nurses need to know to be able to work with self-monitoring data in chronic care. Because I have a strong interest in design as well, next I will also provide design implications, not in terms of how to build the self-monitoring tool for chronic care (we covered that in Study III) but rather how to organize the design process of such tools so it promotes learning.

Implications for nurses and nurses' educators

First, pelvic cancer rehabilitation includes more than assessment and management of patients' intestinal and urinary tract health issues. The nurses also support the patient in dealing with issues such as sexual health or lymphedema. However, this thesis covered those aspects of pelvic cancer rehabilitation that are of importance for quantitative documenting of manifestations of radiotherapy-induced late effects in the lower abdomen. Second, I would like to provide a brief description of self-monitoring data. This data is collected continually through a digital tool, often with a mobile application. The patient collects the data, when she interacts with a self-monitoring application or another device. The application can involve several questions that the patient answers on a daily basis.

Self-monitoring data can be used to inform one's work in the following ways:

- Provide an overview of how patients' health problem developed over time.
- Use data as concrete values that one can start talking about with patients during the supportive talks.
- Provide an insight into the patients' lives that is complementary to their own oral accounts.
- Increase patients' understanding of their own health problems as radiotherapy-induced late effects.

The following points address the situation when nurses become part of a design process of a self-monitoring tool in chronic care. Since many of the self-monitoring tools are designed in cooperation with their future users (that is, nurses and patients), it is expected that nurses will more often become part of the design process. During the design process, particular features of the self-monitoring application and questions for patients that will be involved in the application will be discussed together with the designers and developers. When deciding in a design process about features of a mobile application or questions which the patient will answer through the mobile application, the following questions should be considered:

What data do I want the patient to collect?

My findings indicate that data should be collected to provide answers regarding what is clinically relevant in contrast to what is interesting to know. Clinically relevant questions provide data that help to make a clinical decision, for example, changing a medication dose. One should also consider the purpose of the self-monitoring tool. Furthermore, at the current time, none of the data relevant for pelvic cancer rehabilitation are possible to collect automatically. In fact, all the data are collected manually, that is, patients have to use the mobile application to collect the data about their health problems. Hence, this should also be considered during the design process when making decisions about what the nurses need to learn about the patients' health problem through the self-monitoring tool.

How should the data be collected?

My findings further indicate that, as the self-monitoring data can be collected in different timescales, this impacts the type of questions one will pose to the patient. For example, when formulating questions for the patients to answer in the self-monitoring application, one has to consider that the question could be answered on a daily basis or every time patients experience a given health problem.

For how long should data be collected?

Furthermore, when formulating questions and deciding about collected data, it is important to consider the amount of data one wants the patient to collect. The data amount is related to the duration of data collection. It should be considered if one wants to learn about the patients' problem in-depth and ask the patient to report multiple measurements, then a shorter period of data collection should be used. Or, if the focus is only on one or two symptoms, the patients might be able to report them over a longer period of time.

Finally, the following aspects should be considered when the patient starts using the application that allows her to collect self-monitoring data:

Sharing with patients how to read graphs or other representations of their data

- First, one should establish if the patient has access to her own data and if she has used the access (that is, if she looked at her data).
- Second, reading out loud one's own interpretations of the graphs provides the patient with an evaluation of her own data as well as the interpretations on instruct on how to read the data.

Data interpretation

The following aspects should be considered when interpreting the data together with the patient: missing data and use appropriation.

As mentioned above, the patients collect the data through manually filling in answers in the self-monitoring application. A common reason for missing values is that the patient has forgotten to fill in her answers. However, my findings also point out that missing collected data indicates a patient's worsening health status. It is therefore important to inquire about larger amounts of missing data.

Even though the design team has designed the given self-monitoring application with certain ideas about how patients should use it, the patients might not actually use the application in that way. Since the way the patients collect data will impact the way the data should be interpreted, it is important to inquire about how the patients were reasoning when using the self-monitoring application to collect data about their health problems. For example, one of the patients answered questions about urination only in relation to urination at night. If the nurses did not know that the graph represented only night urination, it would make her draw the wrong conclusions about the patient's urination problem.

Patients' understanding of the application

My findings further indicate that patients' understanding of the self-monitoring tool will impact the way they use it. It is therefore important to make sure that the patient understands the following:

- It is only the nurses and the patient who work with the data in relation to patients' care.
- In our case, the self-monitoring application was based on the knowledge needs of the nurses, that is, what the nurses needed to know to provide the patient with care. However, not every patient might find all the aspects of the mobile application relevant to her specific case. It is important to support the patient's understanding of whose knowledge needs the tool supports.

Design implications

Not all ethnographies need to produce design implications (Dourish, 2006). However, I would like to use my focus on learning and share what I have learned, not necessarily in relation to the final product (the self-monitoring tool) but rather in relation to the actual process of the design. My findings indicate that, when professionals participate in the design of a tool that aims to support their practice, their professional development can be shaped in mutual engagement with their contribution to the design process. Design workshops should therefore be organized not just with the idea of developing a tool that will support the existing work practice, but in such a way that also aims to support learning of the participants about their possible new practice. My findings indicate that, when the nurses talk about their work during the design process, it motivates them to engage in activities that are usually not involved in their traditional work practices. They will reflect on their own work (why do they do certain tasks in a specific way), but also share their clinical experience with their colleagues. Even though the nurses often discuss cases with each other, they rarely get insights into how their colleagues actually go about their work, which is something that becomes possible during design sessions. The participants' contributions can be supported in the following ways:

- Promote sharing reflections on their own work and create a space where participants feel comfortable sharing with their colleagues and other relevant stakeholders.
- Explicitly focus on design meetings as a possible space where one can reflect on one's work and get access to the work practices of others.
- Explicitly present learning as one of the possible (and intended) outcomes of the design process.

Summary in Swedish

Inledning

Kronisk vård är en mycket kunskapsintensiv miljö som ställer höga krav på sjuksköterskor. Hälso- och sjukvården är en miljö som ofta förändras, och det ständiga införandet av ny teknik innebär ytterligare utmaningar för sjuksköterskor som hela tiden måste utvecklas professionellt och lära sig att använda den nya tekniken på ett meningsfullt sätt.

Denna avhandling fokuserar på en specifik typ av digitala hjälpmedel som nyligen har börjat användas inom kronisk vård: mobilapplikationer för insamling av patienters självmonitoreringsdata. Eftersom kroniska patienters hälsa är beroende av dessa insamlade data är det viktigt att sjuksköterskor inom kronisk vård utbildas och fortbildas på arbetsplatserna så att de kan arbeta med dessa hjälpmedel och data. En förutsättning för att förbereda framtidens sjuksköterskor på den nya situationen med självmonitoreringsdata i sjukvårdsarbetet är dock att vi först förstår den.

Hälso- och sjukvården kommer att ställas inför olika utmaningar under de närmaste åren, till exempel en växande och åldrande befolkning (Kotzeva, 2014), brist på medicinsk personal och finanser (meddelande från kommissionen till rådet och Europaparlamentet, 2012) och ett stigande antal kroniskt sjuka (World Health Organization, 2014). En möjlig lösning på dessa utmaningar kan vara att hälso- och sjukvårdspersonal använder självmonitoreringsdata i större utsträckning (Sveriges Kommuner och Landsting, 2005; West, Giordano, Van Kleek, & Shadbolt, 2016). Självmonitoreringsdata är en typ av patientgenererade data som samlas in kontinuerligt av en mobilapplikation utformad för hälso- och sjukvårdspersonalens kunskapsbehov. Dessa data möjliggör kontinuerlig patientövervakning genom att patienten kan registrera data på en annan tidsskala än tidigare. Till skillnad från tidigare tekniker kan hälso- och sjukvårdspersonal med hjälp av självmonitoreringsdata ”se in i patienternas liv” i stället för att bara få ”ögonblicksbilder” (Bentley & Tollmar, 2013).

Trots att det allt oftare går att få tillgång till sådana data om en patients liv och potentialen med dessa data är känd är det fortfarande inte klart exakt hur de kan användas. Ett område som drar stor fördel av dessa hjälpmedel är den kroniska sjukvården. Hälso- och sjukvårdspersonal inom kronisk vård utnyttjar de nya möjligheterna med självmonitoreringsdata genom att betrakta befintliga data i ett sammanhang av andra relevanta åtgärder som tidigare inte varit tillgängliga (Katz et al. 2018), genom att identifiera tendenser (Faurholt-Jepsen et al. 2015) och möjliga triggers (Schroeder et al., 2017).

Tillgången till patienters självmonitoreringsdata innebär alltså en rad fördelar, men förändrar också de nuvarande arbetsförhållandena och ställer nya krav på hälso- och sjukvårdspersonalens arbetspraktiker. Sjuksköterskor är en av de yrkesgrupper inom hälso- och sjukvård vars arbete kan komma att förändras mest. Sjuksköterskornas arbetsuppgifter bygger på att samla in och dela stora mängder data för att hjälpa patienter (Barken, Thygesen, & Söderhamn, 2017). Betydelsen av insamling och delning av information om patienters tillstånd gör data- och informationshantering till en av de viktigaste aspekterna i deras arbete (Grisot, Moltubakk Kempton, Hagen, & Aanestad, 2018). Att omvandla data och information till kunskap om patienterna är en drivande princip i deras arbete.

Syfte och forskningsfrågor

Med tanke på att sjuksköterskornas arbetspraktiker bygger på lärande från personliga patientdata kan det mycket väl bli deras arbetspraktiker som kommer att genomgå de största förändringarna. I denna avhandling argumenterar jag därför att sjuksköterskornas arbetspraktiker kommer att förändras i och med sjuksköterskornas tillgång till patienters självmonitoreringsdata. Denna avhandling rapporterar resultat från en designetnografisk studie på en bäckenbottencancer rehabiliteringsklinik. Mer specifikt fokuserar jag på sjuksköterskornas lärande och kunskap vid samutveckling (mellan utvecklare, sjuksköterskor, projektmedlemmar och mig själv) av en mobilapplikation för patienters insamling av självmonitoreringsdata och vid dess införande i sjuksköterskornas arbetspraktiker. För att kunna besvara den huvudsakliga frågan ställer jag tre forskningsfrågor som var och en besvaras av en specifik studie. Studie I fokuserar på de strategier sjuksköterskor använder för att stödja patienter att lära sig självmonitorera sin kroniska sjukdomsupplevelse. I Studie II undersöks hur sjuksköterskor bidrar till en deltagande designprocess vid utveckling av en självmonitoreringsapplikation. Studie III utreder slutligen hur sjuksköterskors lärande om patienters problem förändras när de får tillgång till självmonitoreringsdata om sina patienter. Avhandlingen är indelad i två delar. Del I består av sex kapitel där denna avhandlings teoretiska och metodologiska fundament beskrivs och diskuteras. Del II består av tre empiriska studier.

Relaterad forskning

I detta avsnitt granskas relaterad forskning. Först och främst är kunskap och lärande elementära delar av en sjuksköterskas arbete (Benner & Wrubel, 1989). Inom kronisk vård försvåras dock arbetet av de kroniska sjukdomarnas beskaffenhet. Att vårda patienter innebär inte endast att samla in strikt medicinsk information och att ge medicinsk rådgivning (May, 1992). Att lära känna en patient är istället baserat på sjuksköterskans förmåga att individanpassa vården till den specifika patienten och att skapa en djup relation till patienten (Kelley, Docherty, & Brandon, 2013). För att arbeta som professionell sjuksköterska i dag krävs även fortlöpande lärande och utveckling under hela arbetslivet (Lammintakanen & Kivinen, 2012). Slutligen kan man även se att patienterna behöver lära sig, och här består sjuksköterskans roll i att stödja patienternas lärande (Barber-Parker, 2002). Inom kronisk vård kompliceras sjuksköterskors lärande och kunskap ytterligare av den kroniska vårdens utmaningar. Först och främst baseras kronisk vård på samarbete mellan sjuksköterskor och patienter (Bodenheimer et al. 2002). För det andra behöver sjuksköterskan ge patienten en mycket individualiserad vård baserad på en unik relation som i varje enskilt fall är beroende av sjuksköterskans förmåga att lära känna patienten (Grady & Gough, 2014). För det tredje bygger kronisk vård på tanken att patienterna intar en aktiv roll och blir experter på sina egna liv (Wilson, Kendall, & Brooks, 2006). Nya hjälpmedel används i ökande grad som ett stöd inom kronisk vård, men på grund av komplexiteten i denna typ av vård kan hjälpmedlen även skapa oväntade konsekvenser (Grisot et al., 2018; Islind, Snis, et al., 2019).

I förhållande till hur nya hjälpmedel kan implementeras i befintliga kliniska praktiker bör man för det andra känna till att nya hjälpmedel inte bara stöder sjuksköterskornas och patienternas sammanlagda ansträngningar utan att de även skapar möjligheter till förändrade samarbetssätt mellan den kroniska vårdens deltagare. Som en följd av dagens tekniska framsteg och förhoppningarna om vad sådana tekniska innovationer kan erbjuda har olika digitala hjälpmedel införts i sjuksköterskors arbetspraktiker inom kronisk vård. För att säkerställa samarbete i användningen av de framtagna hjälpmedlen var det nödvändigt att beakta perspektiven hos dem som faktiskt kommer att använda dem. Eftersom inbjudna deltagare ofta kommer från olika discipliner med olika sakkunskap är ömsesidigt lärande hos alla inblandade deltagare en viktig aspekt i den deltagande designen. Utvecklarna behöver förstå deltagarnas arbetspraktiker, och deltagarna å sin sida behöver lära sig om möjliga tekniska framsteg (Robertson et al. 2014; Kensing och Blomberg 1998).

Även om syftet med de digitala hjälpmedlen var att underlätta det befintliga arbetet ledde de även till förändringar i hur arbetet kunde utföras. När digitala hjälpmedel integreras i arbetspraktiker blir de inte bara en del av arbetsprocessen utan även av befintliga sociala praktiker (Winman och Rystedt 2011). Att introducera digitala hjälpmedel i etablerade arbetspraktiker är dock ingen enkel eller enkelriktad process. Det är inte bara de kliniska praktikerna som förändras och anpassas efter hjälpmedlen, utan även hjälpmedlen anpassas efter praktikernas behov (vilket inte nödvändigtvis överensstämmer med hur hjälpmedlen designades) (Randell 2004).

I och med att en grundläggande aspekt inom kronisk vård är samarbete mellan sjuksköterskor och patienter syftar de digitala hjälpmedlen inom kronisk vård ofta till att främja samarbete mellan deltagarna. Enligt Fitzpatrick och Ellingsen (2013) syftar hjälpmedlen inom hälso- och sjukvård till att stödja informationsflöden, meningsskapande, kommunikation, förhandling, medvetenhet osv. Men eftersom syftet med hjälpmedlen för självmonitorering ofta är att samla in data om patienters kvalitativa erfarenheter är det fortfarande svårt att hämta in och framställa sådana data, både på individuell nivå (Adams et al. 2017) och i kliniska praktiker (Spaniel et al. 2015).

Sammanfattningsvis bygger kronisk vård på sjuksköterskans förmåga att hjälpa patienterna att lära sig om de egna problemen. Eftersom detta arbete försvåras ytterligare av de krävande förutsättningarna vid kroniska sjukdomar måste vi lära oss mer om hur sjuksköterskorna kan stödja patienterna i deras egna lärande. Sjuksköterskor är vidare i dag ofta en del av den deltagande designen av hjälpmedel för självmonitorering som stödjer deras arbete. Eftersom deltagande design bygger på tanken om ömsesidigt lärande behöver vi veta mer om vad som händer när sjuksköterskor ingår i den deltagande designen. Slutligen kan sjuksköterskor använda självmonitoreringsdata som en ny metod för att lära sig om sina patienters problem. Vi behöver dock veta mer om vad som händer när sjuksköterskor får tillgång till den här typen av data.

Teoretisk utgångspunkt

Praktikteori är den övergripande utgångspunkten för denna avhandling. Sjuksköterskornas aktiviteter betraktas alltså som praktiker som organiseras genom ett ömsesidigt samspel i en socio-materialistisk värld i relation till kunskap (Schatzki 2012; Barnes 2005; Nicolini 2012; 2009; Gherardi 2014). Denna teori är relevant för mig eftersom den uppmärksammar hur människors agerande organiseras av deras kontinuerliga samspel med varandra, hur praktikernas väsentlighet vidare formar det sociala samspelet och hur detta ger konsekvenser för kunskap. I denna avhandling använder jag Schatzkis version av praktikteori. I linje med hans infallsvinkel betraktar jag praktiker som ”en organiserad konstellation av olika människors aktiviteter” (Schatzki, 2012, s. 13). Det betyder att människors aktiviteter äger rum enligt viss regelbundenhet i tid och rum, något som inte beror enbart på de enskilda vanorna hos en viss person eller hos summan av de enskildas beteende på gruppnivå, utan på en kombination av båda eftersom de är ömsesidigt konstituerande (Nicolini, 2009). Praktikernas organisering formas av människor som interagerar med varandra (Barnes 2005). Praktikerna är förkroppsligade och materiella – sättet de är organiserade på är inte endast beroende av samspelet mellan människorna i praktikerna, men också av människornas kroppar och av miljöns fysiska egenskaper (Schatzki 2012). Kunskap är också en viktig aspekt av praktiker. Det är en aktivitet som är situerad i praktikerna, som fördelas mellan människor och icke-människor och som förankrar praktikerna i deras väsentlighet (Gherardi 2014). Eftersom praktiker är sociala är de också alltid föränderliga, och förändringarna styrs av praktikernas historicitet (Nicolini 2012).

Jag kompletterar detta perspektiv med min uppfattning av lärande som en alltid situerad och framväxande men ändå central egenskap i processen av att tillägna sig kunskap på ett visst område (Lave & Wenger, 1991). Det här perspektivet betyder att lärandet måste förstås i den sociala och historiska kontext där det uppstår (Vygotsky, 1978). Människors agerande organiseras genom ömsesidigt beroende: enskilt deltagande utgör praktisering i grupp som på samma gång utgör individuellt deltagande (Lave & Wenger, 1991). Med andra ord betyder lärandets situering inte bara att en persons lärande äger rum i ett socialt sammanhang, utan att en person, och i förlängningen dennes lärande, utgörs och formas av de relationer som personen befinner sig i, på samma sätt som de utgör och formar de relationer de befinner sig i. De är inte separata utan ömsesidigt beroende.

En av sjuksköterskornas mer konkreta arbetsuppgifter är kategorisering (Bowker & Star, 1999). I min avhandling ser jag kategoriseringsarbete som något som människor utövar för att skapa, etablera och tillämpa kategorier. Världen delas in i olika kategorier genom en klassificeringsprocess som äger rum i förhållande till standarder som är överenskomna regler för framställningar av objekt. Vidare betraktar jag kategoriseringsarbete som en form av översättningsarbete eftersom det bygger på deltagarnas förmåga att översätta kategorier från en social domän till en annan. Jag beskriver översättning som en aktivitet där heterogena individer eller artefakter ingår i en sammankoppling av kategorier (Callon, 1984).

Forskningsmetod och bakgrund

Denna avhandling rapporterar från en klinik som fokuserar på rehabilitering av bäckenbottencancerpatienter. Cancerrehabilitering är en form av vård som ges till canceröverlevande och som syftar till att förebygga och minska de fysiska, psykologiska, sociala och existentiella följderna av cancer och cancerbehandling (Eckerdal 2019). Som vid andra kroniska sjukdomar bör självmonitoreringsdata kunna användas under cancerrehabiliteringen. Även här är dock implementeringen en svår uppgift (Luckett et al. 2009; Frensham et al. 2014).

Datainsamlingen gjordes på en klinik under ledning av tre onkologisjuksköterskor som ger primärt stöd och behandling till patienter som har fått cytostatika och/eller strålbehandling mot nedre delen av buken. Många patienter som står under cancerbehandling överlever sjukdomen men får livslånga konsekvenser av behandlingen. Ett vanligt problem är att de ofta lider av svåra störningar i tarm och urinblåsa, vilket ofta är förenat med smärta i nedre delen av buken och relaterade områden. För att lindra patienternas symtom behöver sjuksköterskorna få tillgång till viss typ av information, t.ex. tarmtömningsfrekvens. Eftersom patienter har svårt att komma ihåg sådan här information i efterhand togs en mobilapplikation fram för datainsamling om patientens symtom och beteende, dvs. självmonitoreringsdata. Kliniken är med i det tvärvetenskapliga projektet EfterCancern som syftar till att förbättra canceröverlevandes liv.

Metodologisk utgångspunkt i min avhandling är designetnografi – en metod som bygger på Blombergs tolkande etnografi. Jag valde den här utgångspunkten för att den betonar betydelsen av insamling av data i en naturlig miljö, den betraktar de studerade metoderna ur ett holistiskt perspektiv, den framställer beskrivande förståelse av de studerade praktikerna och den understryker betydelsen av deltagarna infallsvinkel (Blomberg et al. 2017). Avhandlingen tar stöd i ett etnografiskt datainsamling som startade hösten 2015 och som omfattar ett brett spektrum av data (ljud- och videoinspelningar, registreringar från kvalitativa och kvantitativa observationer, fältanteckningar, intervjuer osv.). Data analyserades antingen med etnografisk analys enligt steg som liknar dem som beskrivs av Graneheim och Lundman (2004), eller med interaktion analys (Jordan och Henderson 1995). Gällande mitt arbetes etiska aspekter vidtogs omfattande åtgärder för att undvika negativ påverkan på patienterna och sjuksköterskorna. Informerade samtycken inhämtades från både patienter och sjuksköterskor. En etisk ansökan beviljades för projektet av en lokal etisk kommitté. Utöver detta diskuterades de etiska frågorna frekvent i forskningsgruppen EfterCancern.

Denna avhandling bygger på tre studier. Studie I redogör för observationer av sjuksköterskors arbetspraktiker och stödsamtal med patienter. Den syftar till att förstå hur sjuksköterskor stöder patienterna i deras lärande om hur de kan hantera sina kroniska sjukdomar. Resultaten indikerar att sjuksköterskorna stöder patienterna genom att fläta samman patientens upplevda erfarenheter med sin medicinska kunskap och kliniska erfarenhet. Studie II fokuserar på sjuksköterskornas bidrag i designprocessen av en mobilapplikation för självmonitorering. I denna studie analyserade vi ljudinspelningar av designmöten där utvecklare, forskare och sjuksköterskor diskuterar applikationens egenskaper. Resultaten tyder på att sjuksköterskorna bidrar till designprocessen genom att hantera komplexitet i designsammanhanget när de får ingå i den deltagande designen vid framtagandet av applikationen. Studie III fokuserar slutligen på ljudinspelningar av stödsamtal mellan patienter och sjuksköterskor. Fynden indikerar att sjuksköterskorna fick en ny metod för att lära sig om patientens problem. När sjuksköterskorna fick tillgång till patienternas självmonitoreringsdata förändrades deras kategoriseringsarbete. Mer specifikt sammanfaller patienternas upplevda erfarenheter av den kroniska sjukdomen med kategorierna inom kronisk vård och med sättet som sjuksköterskorna använder de kliniska kategorierna under samtalet.

Avslutande kommentarer

Denna avhandling undersöker sjuksköterskors lärande och kunskap inom kronisk vård när hjälpmedel för insamling av självmonitoreringsdata utvecklas och senare införs i deras arbetspraktiker. Resultaten indikerar att sjuksköterskor inom kronisk vård deltar i olika former av ömsesidigt lärande som de måste hantera. Sjuksköterskorna deltar vidare på flera nivåer av ett översättningsarbete som bygger på deras förmåga att skapa kopplingar mellan patienternas upplevda erfarenheter, vad sjuksköterskorna har möjlighet att göra och hjälpmedlen för självmonitorering. Frågeställningar för framtida forskning skulle bland annat kunna vara patienternas och hjälpmedlens roll i patienternas lärande om den egna sjukdomsupplevelsen, hur sjuksköterskornas deltagande kan främjas i deltagande design samt framtida förändringar i sjuksköterskornas arbete när mobilapplikationen vidareutvecklas för att passa patienternas enskilda behov eller omfattar innovationer såsom artificiell intelligens.

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Part II

Empirical studies

Study I

Cerna, K., Ivarsson, J., Weilenmann, A., & Steineck, G. (2019). Supporting self-management of radiation-induced bowel and bladder dysfunction in pelvic-cancer rehabilitation: An ethnographic study. *Journal of Clinical Nursing*, *28*(13-14), 2624–2634.

Study II

Cerna, K., Weilenmann, A., Ivarsson, J., Islind., A. S., Lundin, J., & Steineck, G. (*under review*). Nurses' work practice in design: Managing the complexity of pain.

Study III

Cerna, K., Grisot, M., Islind., A. S., Lundin, J., Lindroth, T. & Steineck, G. (*submitted*). Patient-generated data and the emergence of novel knowledge practices in healthcare: Designing for categorical work in chronic care.