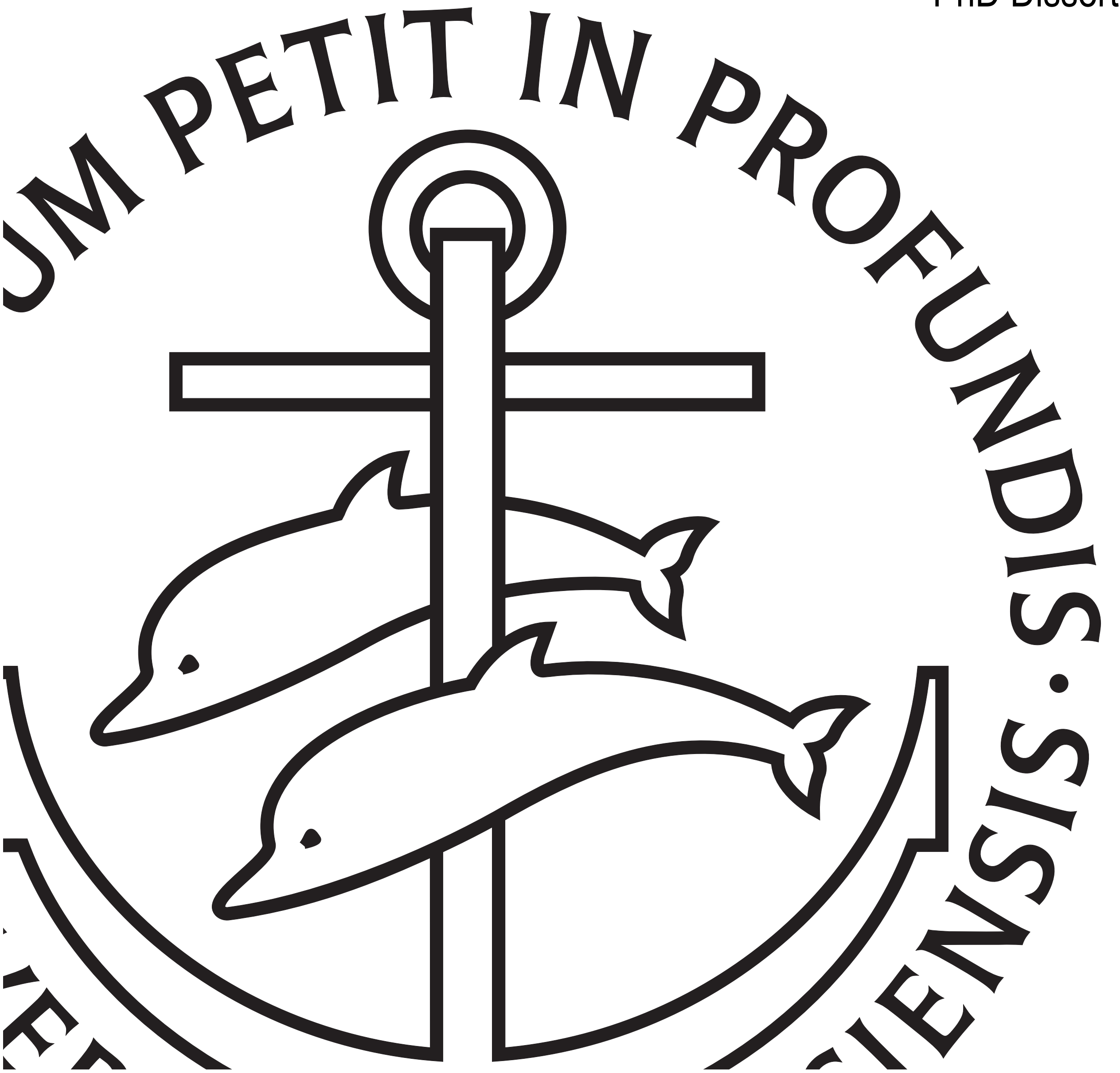
Healthcare technology in the home. Of home patients, family caregivers, and a vase of flowers

Stinne Aaløkke Ballegaard
PhD Dissertation



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PhD Dissertation

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AND MEDIA STUDIES

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Acknowledgements

As I lean back, having written the last page, I glance at the dissertation from a distance and reflect on the winding path of the PhD project: Feelings of excitement after a day of field studies, curiosity at what was said and seen, and at times frustration and a sense of being overwhelmed by the scope of the project and the immense task of analyzing and interpreting at times ambiguous information. It has been a process of exploring the farthest nooks and crannies of the research questions and efforts to comprise the answers.

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English Summary

Today's healthcare sector faces a series of challenges, as healthcare consumers expect high quality healthcare services, while at the same time there are fewer resources to support the increased burden of chronic and elderly patients. Self-care, treatment at outpatient clinics, fast track treatment programs, and home care are seen as important elements for meeting these challenges. Central to these strategies is the development of new healthcare technology that will both make different types of treatment available in the home, and support a connection between home and hospital in the form of video consultations and remote monitoring of relevant data, such as blood pressure or blood oxygen levels.

When treatment and healthcare technology are moved to patients' homes, a connection is created between two different social worlds, between hospital and home. Therefore, moving treatment into the home entails a series of negotiations to create a place for healthcare technology and self-care in the home, and in the life of the patient. In my analysis, I identify various strategies to either make healthcare technology more homelike, to make it fit the esthetics and routines of daily life, or to mimic the workflow of the hospital, and create therapeutic landscapes in the home, to support the patient in performing self-care. Some healthcare technologies are more difficult to domesticate into the context of the home than others, which has significant consequences for the work in which patients and their relative engage, to make treatment a part of the home and daily life. I explore the various kinds of work in which the home patient engage in order to live up to the ideal of self-care expected by the healthcare professionals.

Moreover, in the home, various concerns exist, and self-care is only a part of daily life. At the hospital, the person receiving treatment has the role of a patient; when treatment is performed in the home, the person becomes a home patient. This has several implications. The home patient is part of other social relationships, being also a family member, friend, and or employee. Therefore, this person may face conflicting concerns, making it difficult to perform self-care in accordance with the recommendations of healthcare professionals. Work obligations may interfere with frequent self-monitoring or participation in treatment programs with frequent consultations, which may be recommended by healthcare professionals. In the dissertation I explore the multiple and potentially conflictual concerns and considerations that home patients face.

The dissertation also demonstrates that homework extensively involves relatives. Close relatives, such as spouses, often participate very actively in treatment, both by helping to maintain new routines in daily life, for example, medication and frequent self-monitoring, and by participating in consultations and obtaining knowledge relating to the disease and its treatment. The relative thus becomes a family caregiver. Participation may be seen as a strategy for sharing responsibility. Even if the doctor carries the juridical responsibility, the home patient and the family caregivers also feel responsible for the outcome of the treatment, concurrently with the increase in self-care. Including relatives in the treatment entails obvious advantages for sharing responsibility and supporting the patient in the homework, but also carries the risk of the patient becoming both practically and symbolically dependent on the assistance. This may have consequences for social relationships within the family, which may go to the extreme of creating an imbalance in the relationship between home patient and family caregiver.

The role of healthcare technology in this context extends beyond making treatment available outside the hospital. Technology is not neutral, but transforms practice and entails both challenges and possibilities. Healthcare technology may support homework, but may also carry the risk of creating more work for the home patient and his or her relatives. Healthcare technology may be useful for supporting home patients and family caregivers in sharing responsibility, but may also risk promoting an imbalance in family relationships and impose a heavy burden on these families. Healthcare technology may include home patients in self-monitoring and self-treatment, but the new practices may conflict with recommendations of healthcare professionals, and with other aspects and concerns of daily life. Moving treatment from the hospital to the home by the means of healthcare technology may provide a great advantage to many home patients, while others will experience this development as overwhelming and chaotic. Therefore, it is important to be attentive to the transformations that occur when restructuring healthcare services: the alterations in treatment; the new redistribution of work and responsibility; the ways in which home patient and family caregiver involvement may affect social relationships; and newly arising practices and risks.

Thus, the dissertation presents an analysis of the negotiations and transformations associated with moving treatment to the homes of patients by means of healthcare technology, and discusses the implications of such transformations. The analysis is based on ethnographic studies of new healthcare technology for the home, designed for elderly people and for pregnant women with diabetes. The goal of the dissertation is to shed light on the above-described developments, and to inform discussions of what must be considered in future treatment programs that involve healthcare technology for the home.

Dansk resumé

Sundhedsteknologi i hjemmet: Om hjemmepatienter, plejepårørende og en vase med blomster

Sundhedssektoren står i dag overfor en række udfordringer, idet der fra brugernes side forventes god kvalitet i sundhedsydelserne, samtidig med at der er færre resurser til at løfte en stadig stigende arbejdsbyrde i form af behandling af flere kroniske patienter og en øget andel af ældre. Egenomsorg, ambulant behandling, accelererede patientforløb og indlæggelse i eget hjem ses som vigtige elementer til at afhjælpe dette pres. Centralt for disse strategier indgår udvikling af sundhedsteknologi, der både kan gøre forskellige typer behandling mulig i hjemmet og kan støtte forbindelsen mellem hjem og hospital i form af videokonsultationer og fjernmonitorering af relevant data som fx blodtryk eller iltprocent i blodet.

Når behandling og sundhedsteknologi flyttes ud i patientens hjem, skabes der en forbindelse mellem to forskellige sociale verdner; mellem hospital og hjem. At flytte behandling fra hospitalet til hjemmet indebærer derfor en række forhandlinger for at få skabt plads til egenomsorg og sundhedsteknologi i patientens hjem og liv. I analysen identificerer jeg forskellige strategier der på forskellig vis søger enten at hjemliggøre sundhedsteknologierne, så de passer med den æstetik og de rutiner, der gør sig gældende i hjemmet eller efterligner hospitalets arbejdsgange og etablere terapeutiske landskaber i hjemmet, der støtter patienten i at udføre egenomsorg. Nogle sundhedsteknologier er mere vanskelige at tæmme ind i hjemmets kontekst end andre, hvilket har stor betydning for det arbejde, som patienten og de pårørende har med at få behandling til at indgå som en del af hjemmet og hverdagslivet.

Skiftet fra hospital til hjem betyder også, at behandlingen kommer til at tage form af egenomsorg og at arbejdsopgaver i høj grad omfordeles til patienten og de pårørende. I afhandlingen argumenterer jeg for, at egenomsorg med fordel kan anskues som hjemmearbejde, der involverer mere end blot at huske at tage sin medicin. Hjemmearbejdet omfatter det arbejde, der er nødvendigt for at kunne leve op til forventningerne fra det sundhedsfaglige personale, hvilket er en kompleks opgave. I hjemmet eksisterer mange forskellige hensyn og bekymringer, og egenomsorgen er kun en lille del af hverdagslivet. På hospitalet indtager personen, der er i behandling for sygdom rollen som patient, men i hverdagslivet indgår denne person også i andre sociale relationer som fx familiemedlem, ven og medarbejder. Derfor kan hjemmepatienten være

konfronteret med modstridende krav og hensyn, der gør det vanskeligt at udføre egenomsorgen i overensstemmelse med forskrifterne fra det sundhedsfaglige personale. Eksempelvis kan arbejdsmæssige forpligtigelser stå i kontrast til krav om hyppige målinger og deltagelse i patientforløb med hyppig kontrol. I afhandlingen belyser jeg disse modsætningsforhold og det arbejde, som hjemmepatienten er engageret i for at skabe en balance mellem de potentielt modstridende hensyn og forpligtigelser.

Afhandlingen viser også, at hjemmearbejdet i høj grad involverer pårørende. Nære pårørende, som fx ægtefæller, deltager ofte meget aktivt i behandlingen både ved at hjælpe med at opretholde nye rutiner i hverdagen, fx omkring medicinering og hyppige målinger, og ved at deltage i konsultationer og få viden om en given sygdom og behandling. Den pårørende bliver således til plejepårørende. Deltagelsen kan ses som en strategi for at dele ansvar. Selvom lægen bærer det juridiske ansvar for udarbejdelse af behandlingsplaner, så vil hjemmepatienten og plejepårørende også føle et ansvar for udfaldet af behandlingen i takt med at de pålægges hjemmearbejde. Inddragelse i behandlingen har nogle klare fordele i forhold til at dele ansvaret og støtte hjemmepatienten i hjemmearbejdet, men indebærer også en risiko for at patienten bliver både praktisk og symbolsk afhængig af hjælpen. Dette kan have konsekvenser for de sociale relationer i familien og kan i yderste konsekvens skabe en ubalance i relationen mellem hjemmepatient og plejepårørende.

Sundhedsteknologiens rolle i denne sammenhæng er mere end blot at gøre behandling tilgængelig andre steder end på hospitalet. Teknologi er ikke neutral, men transformerer praksis og indeholder såvel muligheder som udfordringer. Sundhedsteknologi kan støtte hjemmepatienter i at udføre hjemmearbejde, men kan også indebære en risiko for at påføre dem mere arbejde. Sundhedsteknologi kan bruges til at støtte hjemmepatienter og plejepårørende i at dele ansvar, men kan også risikere at skabe en ubalance i familierelationer og påføre familierne en stor byrde. Sundhedsteknologier kan inddrage hjemmepatienter i selvmonitorering og behandling, men den nye praksis kan være i modstrid med anbefalingerne fra sundhedspersonale og kan stå i modsætningsforhold til andre aspekter og hensyn i hverdagslivet. At flytte behandling fra hospital til hjem ved hjælp af sundhedsteknologi vil være til glæde for mange hjemmepatienter, mens andre vil opleve denne udvikling som værende overvældende og uoverskuelig. Det er derfor vigtigt at være opmærksom på de transformationer, som sker i omstruktureringen: At behandlingen transformeres; at der skabes nye arbejds-arrangementer, hvor opgaver og ansvar omfordeles; at inddragelsen hjemmepatienter og plejepårørende kan påvirke sociale relationer; at der opstår ny praksis og nye risici.

Afhandlingen præsenterer således en analyse af forhandlinger og transformationer i forbindelse med at behandling flyttes ud i patientens eget hjem ved hjælp af sundhedsteknologi og diskuterer implikationerne af disse transformationer. Analysen er baseret på etnografiske studier af ny sundhedsteknologi til hjemmet, målrettet henholdsvis mod ældre og mod gravide kvinder med diabetes. Formålet med afhandlingen er at belyse ovenstående udvikling for at informere diskussionen om, hvad der bør tages højde for i tilrettelæggelsen af fremtidige behandlingstilbud, som involverer sundhedsteknologi i hjemmet.

Part I: Introducing the field

Introduction

The curiosity driving this PhD project was sparked by a visit to Jens's apartment. Jens is an elderly man who participated in the ElderTech project on assistive technologies, in which programs running on Tablet PCs were central to monitoring patient health. When asked to demonstrate how he used the computer, Jens pointed to an arrangement of flowers in the center of his living room (figure 1). Puzzled, I realized that Jens had placed the Tablet PC on a decorative doily, and further adorned it with yet another doily and a vase of flowers.

> "Jens explains that he and the technician chose to put the Tablet PC on the shelf as is was the only surface available where it was out of the way. Later, he then placed the vase on top to make it look nicer" (Ballegaard et al. 2006, 375).

Figure 1:
Jens's arrangement of the Tablet PC underneath a doily and a vase of flowers.

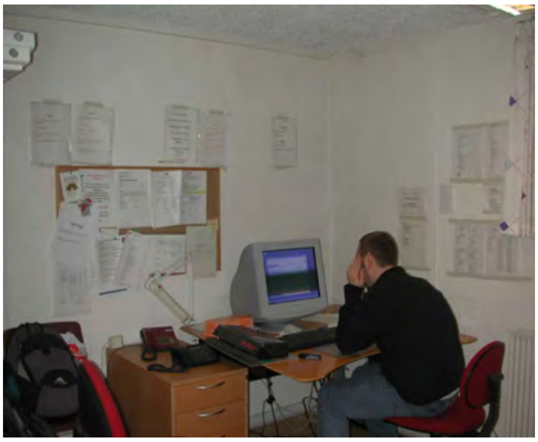

Figure 2:
Arrangement of computer, phones and papers in the office of a caregiver.

Jens's arrangement was even more notable when contrasted with the computer arrangement in the office of one of the caregivers in the same project (figure 2): The contrast between the two *social worlds* (Strauss 2010) was striking. Clearly, the arrangements corresponded to different esthetic orders, with functionality prevailing in the working arrangement of the office, in contrast to the sense of home conveyed by the flower arrangement.

Health monitoring in the project drew my attention to the distribution of work among patients, nurses, and other healthcare professionals, where their social worlds intersected. Apart from remote weight monitoring, it was possible to view blood pressure measurements and medication intake via the computers in the offices of the nurses, social and healthcare assistants, and social and healthcare helpers[1]. However, the nurses who were supposed to utilize the new system did not develop a routine for monitoring the health of the elderly participants in the project, as they did not consider preventive efforts part of their job. The social and healthcare helpers, who assisted the elderly participants with daily personal hygiene, also declined to assume the task, as they explained that they did not have the proper training. In contrast, the blood pressure device intrigued some of the elderly participants themselves, and, despite their very different levels of ability to interpret the data, most followed the different numbers with great interest (Aaløkke et al. 2007). Thus, Jens's flower and Tablet PC arrangement, when contrasted with the practices in the nurses' offices, led me to speculate on the transformations and negotiations that occur when technology-supported healthcare services are introduced to the home. It made me wonder about the complexity of collaboration and of negotiation when establishing new work arrangements, and developing new healthcare technology that spanned two social worlds: How may healthcare technology for the home create a connection between the hospital and the home, and tie together contrasting esthetics, routines, conceptions of health and disease, and work arrangements? How may it bridge the gap between the two social worlds, and make sense in both the world of the nurses and in the homes of people like Jens?

The negotiation and establishment of collaboration between the two social worlds is highly relevant, as the Danish healthcare system currently is undergoing changes, whereby, with the aid of technology, attempts are being made to move more services into patients' homes (Ministeriet for Videnskab, Teknologi og Udvikling 2003a; Teknologirådet 2006; Digital Sundhed 2007; Danske Regioner 2010). These initiatives span two social worlds: the *professional sector* in which specialists treat and care for patients (Kleinman 1980, 53), and the *popular sector*, in which these activities and their *trajectories* are determined by the patient and other lay persons, such as the patient's family and network

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[1] The designation of occupation of the social and healthcare helper is equivelant to home help aide. A social and healthcare helper provides care and practical assistance to help clients maintain normal standard of living. Social and healhcare assistants receive more of training than social and healthcare helpers. The additional training enables social and healthcare assistants to access the need for clients' care and to plan the execution of care.

of friends, neighbors, or others in the local communities (Kleinman 1980, 50)[2]. The new initiatives blur this distinction between sectors. First, the division is crossed, as the state now promotes and regulates activities in the popular sector. Second, the distinction is transcended, as healthcare technology from the professional sector and the social world of the hospital is moved to the popular sector and the social world of the home.

Discussions of the consequences of such a shift in services, from the professional to the popular sector, point in two different directions. One line of argument emphasizes benefits to the patients. Moving healthcare into the home is seen as empowering the patient, as self-care enables the patient to avoid sequelae or late complications of chronic disease. Moreover, it is argued that patients generally recover faster in their own homes, and they avoid transportation and waiting time at the hospital. From this perspective, technology is a tool for facilitating such advantages. On the other hand, drawbacks for the patient may also be identified. The very notion of patient empowerment is questioned (Olesen 2010); it is argued that the introduction of healthcare services to the home turns patients and relatives into unpaid labor for the professional sector, although they have little influence on which treatments are offered. Furthermore, it is argued that in the context of the home, professional concerns regarding self-care may conflict with social concerns. From this perspective, the home becomes in a sense, colonized by healthcare technologies and procedures of the professional sector (Grøn et al. 2008).

With this dissertation, I wish to contribute to the discussion about shaping future developments when moving healthcare technology from the social world of the professional sector, into the popular sector and the context of the home. On the basis of my ethnographic fieldwork and study of the relevant literature, I explore, analyze, and discuss the various ways in which negotiations and transformations take place when healthcare services and technology are introduced to the home.

To introduce the field, I present a series of open research questions: How does the shift of healthcare services affect social relationships in the context of the home? What consequences does this move imply for the collaboration and distribution of work between healthcare professionals and patients, including development and negotiation of responsibilities and competences? What is the role of healthcare technology in the

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[2] Lastly, Kleinman introduces the "folk sector", which refers to the non-professional, non-bureaucratic, specialist sector (Kleinman 1980, 59). In western, countries this may be equivalent to alternative healing practices not supported by the state.

collaboration between patients and healthcare providers, and how is healthcare technology adapted by the users?

In other words, moving healthcare from the hospital to the home is not just a matter of making technology work, and being able to transmit data from the home to the hospital, or vice versa. Neither is it just a matter of developing new services and fast tracking treatment. Rather, moving healthcare services from the hospital to the home has consequences for patients, their relatives, and healthcare professionals: The role of the patient becomes that of a *home patient* (chapter 4), or even that of his or her own in-home physician; relatives may have to take on the roles of caregivers, becoming *family caregivers* (chapter 5); the home may come to resemble a clinic, and the healthcare professionals may risk focusing on documentation and collaboration between sectors, rather than on clinical work. Or, the move may increase the flexibility of treatment, and enable patients to continue working; it may help patients to avoid rehospitalization or deterioration of a chronic condition, and make it possible for the elderly to remain longer in their own homes. However, without investigations and analyses of the transformations related to this shift, it is impossible to know which scenarios are most likely to occur. This is the premise for the present discussion, and for the efforts to shape our future healthcare system.

Structure of the dissertation

I pursue the questions just raised, first, by establishing a theoretical framework within which to analyze existing literature, and secondly, through an analysis of my ethnographic investigations. Accordingly, the dissertation is divided into two parts.

The first part establishes a background for understanding what happens when patients to a large degree manage and monitor their own health and treatment in the home, with the aid of new technology: Chapter 1 provides an overview of challenges and developments in the Danish healthcare sector, which establishes the context of the PhD project. Chapter 2 presents the case studies carried out during the course of the PhD project, and which have been utilized to explore the consequences of these developments. The chapter also introduces the approaches and methods used in approaching the cases. Chapter 3 introduces symbolic interactionism as a theoretical framework for interpreting the developments within the field of study. Chapters 4 and 5 discuss the social world of the home, and the dilemmas that arise when technology from the social world of the hospital is introduced to the home. In particular, chapter 4 examines and discusses how healthcare technology is appropriated to fit into the home and everyday life of the patient, and how work and responsibility are redistributed. Chapter 5 addresses the implications of the cooperative aspects of healthcare for the social relations within the family, and collaboration with healthcare professionals. These chapters are followed by concluding remarks that discuss the complexity of the field, and transformations to keep in mind when developing healthcare technology for the home.

The second part of the dissertation pertains to the ethnographic studies, and consists of specific investigations and analyses of the case studies involved: the everyday health practices of both the elderly, and pregnant women with diabetes (papers 1, 3, and 5); a position paper elaborating on the vision for Pervasive Healthcare in the home, on which much of the work has been based (paper 2); an evaluation of a prototype used by the pregnant women with diabetes and their healthcare providers (paper 4); and a method of inquiry into health-related practices in the home (paper 6). The chapters are presented chronologically, and will be referred to throughout the first part of the dissertation.

Chapter 1: Development of new healthcare services

In many countries, the healthcare sector faces major challenges. This chapter will describe this trend as it occurs in Denmark, the strategies envisioned for solving problems, and the central players driving development. Thus, this chapter provides the context for the PhD project. Furthermore, the chapter presents the current state of healthcare technologies, and outlines two contrasting visions of the role of this technology in future developments within the healthcare sector.

Transformations in the Danish healthcare sector

This PhD project takes as its starting point the growing pressure on the Danish healthcare sector. First, the healthcare sector faces a change in the types of diseases requiring treatment (Regeringen 2002; Ministeriet for Videnskab, Teknologi og Udvikling 2003a; Teknologirådet 2006; Digital Sundhed 2007): Demographic developments predict an aging population (Danmarks Statistik 2010, 5) that will be in greater need of healthcare services, and tend to be hospitalized for longer periods of time than other age groups (ibid., 2010, 12). Furthermore, there has been an increase in chronic diseases, or what have been termed the eight "prevalent diseases" (Regeringen 2002, 32): type 2 diabetes, cancer, cardio-vestibular diseases, osteoporosis, muscular and skeletal disorders, hypersensitivity disorders, mental disorders, and Chronic Obstructive Pulmonary Disease. Chronic diseases increase the economic pressure on the healthcare sector, as treatments are lengthy and entail efforts that involve several sectors, and because chronic diseases carry the risk of sequelae and late complications. Secondly, the rise in a new type of patient, the healthcare consumer, further increases the pressure. Patients today are often well-informed about both new treatments and patient rights, and demand the best treatments by experts, in a fast, coherent program involving both private and public sectors, and services offered by both the region and municipality (Ministeriet for Videnskab, Teknologi og Udvikling 2003a). Thirdly, the cost of treatment is rising, owing to the development of new, biomedical technologies, medical equipment, and medication. Lastly, the healthcare sector has difficulties recruiting highly educated professionals (Ministeriet for Videnskab, Teknologi og Udvikling 2003a).

To meet these challenges, the state promotes self-care among patients suffering from chronic diseases, and has reorganized services in a manner that will relieve the pressure on hospital staff by moving treatment to other sectors and to the home with the aid of new healthcare technology. Before describing the envisioned healthcare services and healthcare technologies, I will first present the state's portrayal of self-care and the role of the chronic patient.

The self-caring patient

In 2002, the Danish government launched their "healthy for life" program, focusing on the prevention of the eight prevalent chronic diseases. Prevention is to be understood not only as ensuring that healthy people stay healthy, but also as preventing patients from experiencing complications of existing disorders and diseases. Prevention responsibilities and efforts are perceived as a partnership between the public health services, the private communities with which people associate, and individuals and their families (Regeringen 2002; Regeringen 2009, 16). In this lies the perspective of the active patient, who is seen as a resourceful participant in his or her own preventive efforts and self-care. According to the Danish Ministry of Health, a patient who is skilled at practicing self-care may avoid complications and rehospitalization, and experience a better quality of life. Similarly, through self-care a healthy person may avoid the chronic diseases mentioned aboπve. Thus, the self-caring patient is believed to reduce pressure on the healthcare system (Sundhedsstyrelsen 2006).

The Ministry of Health defines self-care in the following way: "to practice self-care means that the individual takes the best possible care of him- or herself" (my translation) (Sundhedsstyrelsen 2006, 5). Self-caring patients share responsibility for their health, and are included in decisions regarding their treatment by healthcare professionals. The self-caring patient should seek information, adhere to medication regimes, measure blood glucose, be attentive to symptoms, live a healthy life, collaborate with healthcare professionals, and reconcile destructive feelings related to suffering from a chronic disease. Public healthcare providers should help patients to acquire the skills and knowledge necessary to perform actual self-care (ibid., 5). Self-care is described as "…a particular perspective on prevention and health promotion covering various methods for strengthening the self-care of citizens[3] and patients, for example, through the education of patients, self-help materials, motivational conversations, and counseling" (my translation) (ibid., 5).

Patient schools play a central role in the education of the patient. In 2006, the Ministry of Health purchased a license for the American concept of patient education, the "Chronic Disease Self-management Program" (Lorig 2007), which provides the starting point for much education in patient schools today (Forchhammer 2010, 84). Beginning in the 1950s, patient education focused on specific diseases, and on providing the patient with specific skills that would help them to comply with treatment, to self-administer medication, and utilize specific technological devices. Teaching was based on lectures by healthcare professionals (ibid., 89). In the 1980s, this type of patient education changed, and was supplemented by patient schools offering standardized programs, such as the Chronic Disease Self-management Program. Now, teaching is no longer confined to dealing with specific diseases; instead, the aim is for the patients to acquire the competences needed to live with their conditions, and maintain an active, healthy life (ibid., 90). From a healthcare perspective, the earlier focus on the issue of compliance has been combined with a focus on quality of life and coping with the chronic disease (ibid., 93). The program is based on peer teaching, where the teacher him- or herself is a patient, certified in accordance with the program, and with whom groups of patients discuss their experiences. Through these discussions, facilitated and structured by the teacher, the patients share their experiences and learn from each other (ibid., 91). The decision to base the program on peer-to-peer teaching was based on the experiences of the founder, Kate Lorig, that, while patients instructed by healthcare professionals acquired more theoretical knowledge, patients instructed by fellow patients were more engaged in the self-care itself (ibid., 93).

In chapters 4 and 5, I will unfold the elaborate work of patients engaged in self-care, and discuss the implications of self-care in relation to the use of healthcare technology in the home. For now, I will address the ways in which the development of new healthcare services and technologies are pursued, and the central players in their development.

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[3] The word "citizen" in this context it is not meant to indicate that patients are forigners, but must be seen ai an attempt to address people who are not (yet) patients.

New healthcare services

Many of the proposed solutions to the problems, which the healthcare sector faces, involve restructuring healthcare services, spanning different sectors by means of new technology, and thereby affecting a range of public authorities, private organizations, and companies. The interests of the different organizations may not coincide, or may even conflict, necessitating extensive negotiations between the organizations and the interests they represent. For example, discharging patients from the hospital earlier, and treating them at home, or administering all medical treatment to patients in their homes, demands collaboration and requires negotiation regarding the distribution of economic resources between the regions governing the hospitals and the municipalities, and which are responsible for home care. Before turning to the envisioned solutions, I will briefly present the central players involved in the negotiation of outlining different strategies for reorganizing the healthcare sector, as it is important to be aware of the heterogeneity shaping the discussions and envisioned strategies.

First, there are public councils. One of the central players has been Connected Digital Health in Denmark, an organization financed by the state, the regions, and the municipalities, the main focus of which is the development of a national strategy for digitizing healthcare (Digital Sundhed 2010a). In 2010, however, the responsibilities of Digital Health in Denmark were devolved to the Regions' Health IT Organization (RSI). RSI was established in February 2010, with the aim of supporting the regions in coordinating and developing health IT (Danske Regioner 2010, 3). RSI and Connected Digital Health have focused exclusively on technology within the healthcare sector, whereas The Danish Public Welfare Technology (PWT) Foundation, supports development and testing of labor-saving technology and new, efficient ways of working along various lines of public work, including healthcare (ABT Fonden 2010a). Similarly, The Danish Board of Technology, whose concern is "to disseminate knowledge about technology, its possibilities, and its effects on people, society, and the environment" (my translation), has also participated in the discussion about healthcare technology (Teknologirådet 2010).

Secondly, cross-sector organizations contribute to the debate. For example, MedCom (the Danish Health Data-Net) is an organization financed by various public authorities, and private companies, and is focused on "developing, testing, distributing, and securing the quality of electronic communication and information in the healthcare sector, in order to support patient treatment programs" (my translation) (MedCom 2010a).

Thirdly, independent organizations seek to influence the development of new healthcare technology. The goal of the Danish Society for Clinical Telemedicine is to promote scientific knowledge and practical telemedical solutions, facilitating monitoring, diagnosis, and treatment in patients' homes (Dansk Selskab for Klinisk Telemedicin 2010).

Finally, there are various organizations representing the interests of diverse patient groups, and that promote their positions. The patient organizations engage in patient support, research, and disease prevention. Central organizations representing patients include the Danish Diabetes Association, the Danish Heart Foundation, and the Danish Cancer Society, among others[4].

All the organizations have different agendas and interests, leading to a discussion of the goals of healthcare technology development and the distribution of resources. However, two main approaches may be identified in the development of future healthcare technologies: First, efforts are aimed at making workflow more efficient, for example, via the construction of a national infrastructure supporting digital communication among the different public sectors, and with the patient. Development of fast-tracking treatment programs and telemedical solutions whereby patients are discharged earlier and monitored in their homes is part of this effort, and a focus of problems involving coordination between sectors and organizations, sometimes handled through special coordinators. Secondly, attention has been directed at strengthening the role of the active patient, by promoting and facilitating patients' own self-care (Regeringen 2002; Regeringen 2009, 15; Sundhedsstyrelsen 2006; Ministeriet for videnskab, teknologi og udvikling 2003a; Teknologirådet 2006; Digital Sundhed 2007; Danske Regioner 2010, 3).

Next, I will outline some of the projects that employ these last two above-mentioned approaches, and which have been initiated in order to explore how technology may aid the development of new healthcare services. Analyses of such initiatives will be presented in chapters 4 and 5, and focus on the transformation and implications of the distribution of work related to the introduction of healthcare services and technologies to the home.

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[4] For a complete list of patient organizations, see sundhed.dk (2010)

Supporting the clinical workflow

A variety of efforts is directed at developing new healthcare technologies to support the clinical workflow, and to enable new telemedical services, which facilitate collaboration among healthcare professionals.

The five Danish regions established in 2007, which replaced the previous division into thirteen counties, have made great efforts to develop electronic health records, as they perceive a consolidated electronic health record landscape as fundamental to supporting the clinical work at hospitals, and for making workflow more efficient (Danske Regioner 2010). This development is complemented by new initiatives on the part of the state and regions focusing on the construction of a national infrastructure and national standards, such as the Shared Medication Record and The Danish eHealth Portal. Such initiatives are regarded as essential for exchanging patient information between the primary and secondary sectors[5] (Next Puzzle 2010). According to the regions, technological developments do not stand alone in the optimizing of workflow, but must be part of an effort that includes organizational restructuring (Danske Regioner 2010).

Other initiatives focus on the development of telemedicine, which is heralded as the solution to numerous problems. According to MedCom, telemedicine allows for easy communication among healthcare professionals, for example, among hospitals, specialized hospital departments, or between primary and secondary sector in the healthcare system, thereby saving transportation of both healthcare professionals and patients, and possibly avoiding waiting time (MedCom 2010b; MedCom & Kommunernes Landsforening 2009). Telemedicine is proclaimed to be particularly relevant in the treatment of chronic diseases: Interaction between patients and healthcare providers is frequent, and it is suggested, by MedCom, for example, that the appropriate follow-up regimes and telemedical equipment may successfully replace physical meetings with telemedical communication (MedCom 2010b, 14). Furthermore, according to Connected Digital Health (Digital Sundhed), new services of remote monitoring and telemedical consultations between the home and hospital may shorten, and even avoid, hospitalization (Digital Sundhed 2010b).

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[5] In Denmark, the the primary sector refers to the parts of the public healthcare sector that functions geographically close to the citizens, such as general practitioners and home care in the municipalities. The secondary sector regards efforts and institutions at a regional level such as hospitals and specialized treatment. Often patients are reffered by the primary sector to specialized treatment in the secondary sector (Gyldendal 2011).

The telemedical solutions may involve a healthcare professional making house calls and performing treatment while in contact with a specialist elsewhere, such as a visiting nurse treating diabetic foot ulcers in the patient's home, with the remote supervision of experts (Clemensen et al. 2008). A different setup enables digital communication between the healthcare provider at the hospital, and the patient in the home, as in the monitoring of lung capacity, and consultation regarding Chronic Obstructive Pulmonary Disease, via a patient suitcase (Teknologirådet 2006, 19). This type of setup is often characterized by a specific kind of monitoring in the home, with the digital transfer of collected data to the hospital providing the basis for a video consultation (MedCom 2010b, 14).

Many telemedical solutions are parts of research projects that document the technology being tested, and the clinical outcome of the treatment. While organizations such as the Danish Telemedical Society promote the potential of telemedicine, the PWT foundation notes a lack of national standards for digital communication, and the high cost of equipment in these research projects. They argue that solving these problems is crucial, if telemedicine is to become a labor-saving technology. For these reasons, telemedicine is still regarded as experimental, since clinical and technological issues must be addressed and resolved before it can become fully functional on a national scale. Moreover, it would also be necessary to address reorganizations and transformations in the distribution of work arising frπom the use of telemedical solutions, topics to which I will return later. First, however, I will introduce a different trend in the development of healthcare technology, which focuses on the aspect of monitoring.

Supporting self-monitoring and self-treatment

Above, I have described how telemedicine is perceived as having great potential for supporting clinical workflow, and making it more efficient. A complementary approach argues that home monitoring is highly promising with regard to the future treatment of chronic diseases (MedCom 2010b, 14).

Home monitoring may take two different forms: that aimed at providing healthcare professionals with data related to the treatment of specific health conditions, or that aimed at the patient themselves, supporting them in their work of self-monitoring and self-care. Patients with diabetes already utilize healthcare technology to monitor and control their condition: they determine their blood-sugar levels with the blood glucose meter, and are able to regulate their blood glucose levels with the insulin pen. Patients in anti-coagulant treatment who suffer from various heart problems are also enrolled in self-monitoring and self-treatment programs. Utilizing a small device that measures coagulation, patients themselves take and test blood samples in their homes, and adjust their medication dosages accordingly. Self-monitoring and self-treatment are performed at home, and documented by the patient, using Excel sheets, for example. This type of self-treatment is currently supported by major hospitals, such as Aarhus University Hospital, Skejby (Skejby Sygehus 2010a).

Developing healthcare technology for patients with chronic diseases involves many – and sometimes conflicting – interests on the part of patient organizations, and the hospitals and regions offering treatment. According to the Danish Heart Foundation, 80,000 patients received anti-coagulant treatment in 2009, of which approximately 7% were enrolled in self-treatment regimes. The Foundation estimates that one third of all these patients would benefit from this form of self-treatment (Hjerteforeningen 2010). However, the treatment option is only offered by major hospitals that have the necessary expertise. Before entering into a self-treatment regime, the patients must first be referred to the hospital by their general practitioners. Here, the patients participate in an extensive training program. For example, at Aarhus University Hospital, Skejby, the program extends over a period of twenty-seven weeks, during which period the patients are taught to interpret data, and gradually to take on responsibility for adjustments to their medication: proficiency is determined by a final exam. The equipment and training program are paid for by the hospital (Skejby Sygehus 2010b). Thus, self-monitoring and self-treatment are arenas of differing interest to the Danish Heart Foundation, which advocates that the treatment be offered to more patients, the hospitals that are to train and supply the patients with the equipment, general practitioners, who may have an economic interest in monitoring the patients at the clinic, and finally, the patient him- or herself, who must be willing to participate in a training program and be able to learn the monitoring and treatment protocols.

The benefits of self-treatment, in the cases of regulating blood glucose and blood coagulation levels, are that patients are able to continuously adjust medication and lifestyle choices that affect their conditions. For example, patients with diabetes may calculate the amount of insulin needed, given their intake of carbohydrates and level of physical activity, and patients undergoing anti-coagulant treatment can adjust their medication if they have been eating broccoli or drinking red wine. According to this line of thinking, healthcare technology supports patients, and enables them to control their conditions. In other words, the use of healthcare technology is envisioned as increasing patient compliance, as it prompts patients to follow the instructions of healthcare professionals. Compliance is vital to the effectiveness of the treatment and the wellbeing of the patient (Teknologirådet 2006, 14).

The discussion above introduces an approach that seeks to benefit from the potential of healthcare technology in supporting patient self-monitoring and self-treatment. As I have demonstrated, conflicting interests complicate the effort. Furthermore, evaluations of telemedical solutions for patients with diabetes demonstrate that healthcare technology may not necessarily lead to better compliance. Larsen (2010) points out that clinical evidence demonstrates that telemedicine provides neither better nor poorer results than traditional treatment, with regard to improved patient blood glucose levels (Larsen 2010). I therefore argue that it is worth investigating the practices of healthcare professionals and patients, and to explore the complexity involved, in order to illuminate the question of why new services do not provide more cost-effective treatment, or why compliance is not necessarily improved in new telemedical programs. I will return to this in chapter 4, where I focus on the discrepancies between medical and social concerns in the home, and in chapter 5, where I investigate the notion of self-care and its interrelationship with technology. Before doing so, however, I will introduce the concept of healthcare technology, which is seen as a prerequisite to transferring healthcare services into the home.

Healthcare technologies

Up to this point, I have used the term "healthcare technology" without much introduction. However, as healthcare technology is regarded as a powerful tool for assisting the re-organization of the healthcare sector, as described above, it is important to discuss what the term may imply: What is the current state of the art, what are the underlying philosophies driving the development of new technology, and what may be considered a technology? This introduction sets the stage for future conceptualization and discussion of the role of technology as a boundary object or standardized package in the negotiated arrangements between the social worlds of the hospital and the home.

Pervasive healthcare

As indicated previously, new digital technology in the healthcare sector is not necessarily tied to the traditional, stationary PC, and new services go beyond the electronic patient record (EPR) presently being installed in hospitals. Development of new digital healthcare technology follows an international trend in *pervasive computing*, whereby information technology may be embedded in the surroundings; it may be wearable and independent of fixed points, taking, for example, the form of small sensors, and it is persistent, in the sense that devices are constantly connected to the Internet, and may be automatically collecting, calculating, and transmitting data to other units (Ministeriet for Videnskab, Teknologi og Udvikling 2003b). Furthermore, embedded, wearable, and persistent technology creates new ways of interacting with the environment, allowing users to interact with floors, tables, and other furniture (InteractiveSpaces 2010). The term *pervasive healthcare* refers to such technological developments within the healthcare sector, and is manifested as wearable biosensors, such as smart adhesive bandages with wireless sensors that collect and transmit data (e.g. cardiac rhythms) (ABT Fonden 2010b), or large screens embedded in the walls of operating theaters, through which operating surgeons may access x-rays in the EPR using voice commands (iHospitalet 2010). Pervasive healthcare envisions healthcare services as being available to the population and to healthcare providers anytime and anywhere (Centre for Pervasive Healthcare 2010).

(Un)remarkable computing

An underlying discussion of the design of pervasive computing relates to the invisibility of technology. According to Marc Weiser's vision[6] "The most profound technologies are those that disappear. They weave themselves into the fabric of everyday life until they are indistinguishable from it" (Weiser 1991, 94). This vision of technology has been the foundation for the development of pervasive computing. A design goal dominating research and development has been to make the computer invisible, both in its physical appearance, by making it smaller and consistent with the esthetic order of the place where it is to be used, and by making it invisible in use. Moreover, the vision of invisibility has given rise to a discussion of what Tolmie et al. have termed "unremarkable computing" (Tolmie et al. 2002). In this view, "the challenge for design is to […] make computational resources that can be unremarkably embedded into routines and augment action" (ibid., 404). This perspective contrasts with visions of the remarkable computer: Petersen argues that computer design, particularly for the home, may take advantage of making computing *remarkable*, advocating for interaction that is playful, and that creates new experiences and social interaction (Petersen 2004).

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[6] Later, Marc Weiser came up with the term "ubiquitous computing". Today the terms "ubiquitous" and "pervasive" computing are used almost synonymously.

Similar approaches may be identified in the design of digital healthcare technology: Small biosensors that collect and transmit heart rhythm data, which is automatically integrated into the patient's EPR, may be an example of unremarkable computing. In contrast, the design of the Nike + iPod Sport Kit (Nike 2010), while based on a small sensor collecting and transmitting data in a manner similar to that of the biosensors in the previous example, aims to transform the running experience by making the technology and the output remarkable to the user. The discussion of the underlying philosophies of pervasive healthcare, of unremarkable and remarkable computing, is important, as it promotes diverse ways of distributing agency among healthcare professionals, patients, and the technology itself. I am not advocating for either perspective, as I believe both may be appropriate in different situations. Instead, I am pointing out that technology is designed to encourage different experiences and ways of interacting with technology. This must be kept in mind, not only with regard to design, but also when analyzing and discussing the role of healthcare technology.

Digital and analog healthcare technology

I have chosen to use the term "healthcare technology", rather than "pervasive healthcare". Pervasive healthcare refers to digital technologies, which excludes analog technologies that may also play a role in self-care and clinical work.

The Danish Board of Technology (2006) suggests that pervasive healthcare should serve as a generic term covering digital technologies that integrate IT in the healthcare sector. In this respect, the term covers both telemedicine, which has been defined by the Danish Society for Clinical Telemedicine as "digitally supported services by health professionals across distances" and E-Health, which refers to services involving the Internet (Teknologirådet 2006, 16). However, analog technologies may also contribute to the working arrangements of the new services. In the framework of science, technology, and society (STS) studies, and that of symbolic interactionism, technology does not comprise only computers and other digital devices: Paper records and insulin pens may also be conceptualized as technologies. Healthcare may also move into the home through use of traditional technology. Common communication technologies in new working arrangements may be attributed different meanings, and play different roles; for example, using a telephone to transmit data when remotely monitoring cardiac rhythms may require the patient at home to interact differently with, and acquire new skills when using the telephone (Oudshoorn 2008).

This raises the question of what may be conceptualized as “healthcare technology”. Might the telephone in this case be conceptualized as healthcare technology? Is the computer in the home office included in this term, as it is sometimes used for sending messages to the general practitioner? The term “healthcare technology” is not unproblematic. In this dissertation, healthcare technology is to be understood in its broadest sense, both analog and digital. Most importantly, it is to be understood in its interrelation with organizational processes of negotiation and transformation of working arrangements, and its ability to either to push certain procedures into the home, or to be incorporated into the existing routines of everyday life.

Summing up

Healthcare technology may take numerous forms, both digital and analog, but most importantly, it may form part of different types of working arrangements, different ways of reorganizing the healthcare sector, and different types of new healthcare services. The previous chapter also noted that the envisioned potential of healthcare technology is not always fulfilled. Telemedical solutions are not always labor-saving, and do not always lead to improved compliance or quality of treatment on the part of chronic patients. This suggests that there exists a need to better understand the complexity of what occurs when healthcare technology is introduced to the home. To investigate this, I carried out ethnographic studies in connection with my participation in two projects in which new healthcare technology was developed.

I will next present the two cases, and the methods used in their investigation.

Chapter 2: Presentation of cases and methods

This PhD study was based at the Centre for Pervasive Healthcare, and the case studies were carried out in collaboration with my colleagues at the center. This chapter will introduce the reader to the approaches that I utilized to explore the cases, namely ethnography and participatory design.

Centre for Pervasive Healthcare

The University of Aarhus and the Alexandra Institute founded the Centre for Pervasive Healthcare in 2002. The purpose of the work at the Centre for Pervasive Healthcare is to design, develop, evaluate, and understand the usage of pervasive computer technologies for healthcare, in collaboration with patients, public institutions, and private companies. Interdisciplinary teams of researchers, including computer scientists, ethnographers, and engineers, are continuously engaged in various research projects and case studies (Centre for Pervasive Healthcare 2010).

Not only did affiliation with the Centre for Pervasive Healthcare provide an opportunity to study practices of healthcare technology utilization in homes and hospitals, but it also provided an exceptional opportunity to participate in and study the development of new healthcare technology for the home. This offered a unique insight into the negotiations and transformations that occur when healthcare technology is developed and introduced to the home. I primarily explored these negotiations and transformation from two perspectives: one focusing on the elderly, and assistive technologies (the ElderTech project and HomeVisits), and the other focusing on pregnant women with diabetes, and their healthcare providers (the Healthy Home project). Spanning these two areas of interest have been smaller studies, the HomeHealthTours, which are concerned with the management of health and disease in the home, regardless of age or diagnosis. These diverse perspectives provided an opportunity to collaborate with two very dissimilar groups of users with different IT skills, health conditions, and types of collaboration with healthcare providers, as well as differing housing situations and social networks. This diversity strengthens the general findings of the PhD project: apart from exploring the particularities of each group, it allowed for the identification and comparison of patterns across the two groups, to which I will return later.

The ElderTech project

The ElderTech project focused on the development of assistive technology in sheltered housing units, to promote the following: communication and collaboration among the elderly, home care personnel, and the general practitioners; medication assistance and monitoring; the elderly individual's self-care and sense of security. Seven elderly participants between the ages of 65 and 88 years had the developed system, called Roberta, installed. The technology allowed for self- and remote monitoring of their health conditions (blood pressure, weight, medication intake). Furthermore, it contained a digital version of the collaboration book, which is a tool for communication and documentation.

My participation in the project was twofold. One area of interest was the exploration of how the elderly manage and monitor their health conditions in general. A second area of interest was the evaluation of the implications of the developed system. The project lasted from 2005 to 2006, and included the development of an infrastructure, and ethnographic studies carried out prior to and during the pilot study. The partners were IBM Denmark, IBM research, and the Municipality of Aarhus, including the assisted living facility Lokal Center Fuglebakken, and Aarhus University (ISIS Katrinebjerg 2007, 50).

The Healthy Home project

The Healthy Home project explored how technology may increase collaboration between patients in their homes and the network of healthcare professionals at a hospital, and how technologies may be used to support patient self-care. Pregnant women with diabetes undergo frequent checkups at an outpatient clinic, where they are seen by up to seven specialists who monitor the pregnancy and condition of the mother, and guide the women in performing self-care. The women often spend much time commuting to and from the hospital, which is difficult to incorporate into an active life that includes working full-time. A technological solution, called the eDiary, was developed, and a month-long pilot study, in which three pregnant women with diabetes used the eDiary, was carried out.

My participation in the project involved ethnographic studies of practices and experiences of the treatment. I was also involved in the participatory design process and the development of the eDiary. Furthermore, I participated in the evaluation of the pilot study. The project lasted from 2007 to 2009, and the partners were Logica (previously WM-data), Polycom (previously KIRK telecom), Aarhus University, and ISIS Katrinebjerg. Aarhus University Hospital (Skejby Sygehus and Århus Sygehus) also participated closely in the entire project, which involved both patients and staff (ISIS Katrinebjerg 2007, 51).

Method

I used two different approaches in exploring the Healthy Home and ElderTech projects: ethnographic fieldwork and participatory design. In the following sections I will first outline the research traditions of each, then discuss how design may benefit from a combination of these two traditions, and finally, illustrate how the two were intertwined in the various case activities during the PhD project.

Ethnography

Ethnography was a useful approach for exploring the two cases introduced above and their transformations, as this discipline relates to the study of diverse aspects of social life and cultural phenomena. This discipline involves analytical efforts of comparison and identification of patterns across studies. Moreover it involves continuous reflection and search for exceptions, in order to test the validity of the analyses of phenomena, patterns, or theories generated on the basis of empirical studies. Thus, ethnography "refer[s] to an integration of both first-hand empirical investigation and the theoretical and comparative interpretation of social organization and culture" (Hammersley & Atkinson 2007, 1).

Central to ethnography is a concern for how people perceive the world, and understanding their perspectives on practices and diverse phenomena. An important way to achieve this understanding is through extensive fieldwork, as promoted by Malinowski (1978), and becoming a part of the community one seeks to study. One much-used method in fieldwork is participant observation, where the goal is to situate oneself within the field by participating in the daily life and practices of the community, trying to understand the society from within. On the other hand, the ethnographer is simultaneously situated outside the field by his or her observation, interpreting the practices within a theoretical framework, or constructing a new theoretical framework that conceptualizes the identified patterns of practice (Eriksen 1993, 28; Schensul et al. 1999, 91). A foundation for doing ethnography is the realization that the ethnographer him- or herself is the research tool par excellence: "…knowing, for ethnographers, is first and foremost experiencing by observation, participating in conversations and daily activities of members of the community under study, and recording these observations" (Schensul et al. 1999, 72; see also Hammersley & Atkinson 2007, 17).

The use of fieldwork to gain an understanding of how people make sense of the world makes ethnography valuable in numerous settings, and for studying many issues. Traditionally, ethnography has been devoted to the study of societies and phenomena strange and exotic to the ethnographer, such as witchcraft among the Azande people (Evans-Pritchard 1937), structures in tribal kinship classifications (Lévi-Strauss 1969), or rites of passage (van Gennep 1977). Today, the attention of ethnographic studies is not only turned toward the distant and exotic, but also toward an understanding of practices in Western societies: Understanding illness and healing is not only a matter of studying the health of children in Uganda (Meinert 2008), but also concerns practices in Denmark that relate to suffering from chronic illness (Wind & Vedsted 2008), implementation of electronic patient records at hospitals (Bossen 2006), or fertility treatment (Tjørnhøj-Thomsen 2005).

Paths of the ethnographic study

Ethnographic fieldwork has been pivotal to this PhD study, and has proved useful in the effort to gain an understanding of how the participants in a study perceive new healthcare technology and the transformations of practice. The ElderTech study and the Healthy Home project offered a wide field of investigation, and the dissimilarity of the two cases provided multiple paths for pursuing categories and patterns.

In uncovering and following the multiple paths of investigation, I spent time with the elderly participants in the ElderTech study, familiarizing myself with their everyday lives, observing the installation of the assistive technology, Roberta, in their homes, and discussing how they used and experienced Roberta[7]. Furthermore, I followed healthcare professionals (a nurse, a social and healthcare assistant, and social and healthcare helper) caring for the elderly, helping them with bathing, cleaning the homes, injecting insulin, and assisting with medication administration. I also interviewed the healthcare professionals prior to and during the ElderTech pilot project. Furthermore, I visited senior citizen communities, to learn about the experiences of the seniors with various housing arrangements (Aarhus et al. 2009b) and was given guided tours of their homes, to acquire an understanding of how healthcare is perceived and practiced in the home.

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[7] See all the interview guides for the ElderTech study in appendix A

Similarly, I observed practices at the outpatient clinic where the pregnant women are treated: sitting in on consultations, observing the practices of the obstetricians, midwives, diabetes specialists, and dieticians, participating in coffee break discussions of "what just happened", and listening to discussions among colleagues on cases; this was supplemented with formal interviews[8]. I also shifted my focus to that of the pregnant women in order to understand their experiences, and followed them as they moved around at the outpatient clinic. I have been with them when they arrived at the ward where they give blood samples for testing blood glucose levels; stood in line with them to check in with the secretary at the clinic, to let the staff know that they had arrived; observed how the women take part in the record-keeping and self-monitoring when they weighed themselves, processed urine test strips[9], and measured their blood pressure; sat in the waiting room, killing time until they were called by the specialists. The women were interviewed in their homes, both for part of an exploratory study, and for part of the evaluation of a prototype in the Healthy Home project.

Thus, by pursuing various paths in my fieldwork, I investigated healthcare and technology in the home from various perspectives, exploring how people live and how they experience life in different home environments, how they practice and perceive healthcare and disease in the home and at the hospital, how they interact with existing and new technology, how healthcare professionals experience caregiving, how their work practices interact with the self-care practices of patients, and how they interact with existing and new technology. These paths made it possible to observe the encounters between people and new healthcare technology, and to explore transformations, as the users – both patients and the healthcare professionals – appropriate the technology, routines emerged, and networks were stabilized. Next, I will account for some of the concerns guiding my choice of paths of investigation.

Methods for condensed fieldwork

A main concern during the PhD project was how to carry out fieldwork in the homes. Obtaining access to the homes was not difficult, as my involvement in projects aimed at developing new healthcare technology granted an access to the homes of the elderly and the pregnant women with diabetes who were study participants. However, a main concern was the role and presence of the ethnographer in home: How does an

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[8] See all the interview guides for the Healthy Home project in appendix B

[9] The test measures glucose, ketone, protein, nitrite, and leukocyte in the urine.

ethnographer study practices in the home in such a way that the situation does not become awkward for either those living there, or for the visiting ethnographer? How can practices of disease management and healthcare technology and perceptions of these practices be explored in the home?

It takes time to establish a good rapport with participants in their homes, and to build a relationship of trust and reciprocity, which is vital to participant observation. Some of the elderly persons in the ElderTech study participated in the project for approximately six months, making it possible to establish relationships, and participate in their everyday lives: visiting them in their apartments, following them in their shared activities of eating lunch together, working out, having their Friday afternoons together, drinking coffee and singing.

Apart from the efforts to establish relationships over a longer period, I also applied a second strategy of experimenting with shorter visits to the homes of the participants. For short visits, it was essential that there be a specific purpose for the visit. This provided a basis for quickly establishing a mutual agreement between the participant and the ethnographer regarding expected behavior and the outcome of the visit. In the Healthy Home project, formal interviews provided mutual understanding of the form and purpose of the visit, namely, an oral account of experiences of living with diabetes while being pregnant. To tie together oral accounts and practices more closely, in paper 6 my co-author and I describe experiments using a method that we called the *HomeHealthTour*. The visits to participants' homes consisted of guided tours of the homes, where the participants would point out objects that they considered to be related to their management of health and disease. The HomeHealthTours method was an attempt to condense fieldwork in time and space, quickly homing in on experiences and practices regarding health and disease. Similarly, the HomeVisits consisted of visits to senior citizen communities, where the participants would show us where they lived, while explaining their reasons for moving into the senior community, and their experiences with growing old in specific housing arrangements (Aarhus & Ballegaard 2008).

The aim of condensed field studies is to prompt focused conversations on given topics, grounded in practice and in the context of the home. The rationale behind this is that, while such visits may only offer small glimpses of practices, many such visits may provide more profound, cumulative insight into broader patterns. Based on the considerations of balancing time and potential insights, I made ongoing decisions regarding different paths of investigation, varying the lengths of the visits to peoples' homes, and the context of the home.

The observations and conversations were documented differently. Informal conversations during participant observations were written down, resulting in extensive fieldwork notes, while most interviews were recorded and transcribed. Video recording was utilized when it was necessary to document the exact interrelation between objects and speech, such as the guided tours during the HomeHealthTours, and the installation of assistive technology in the homes of the elderly. This documentation provided an extensive basis for categorization and analysis of practices, and understanding health and new healthcare technology in the home. An overview of the fieldwork activities is listed in figure 3.

	Interview sessions: Elderly/patients*	Interviews: Healthcare professionals	Interviews: Other participants	Hours of observation
ElderTech project Exploratory phase	12	6		34
ElderTech project Pilot test	10	6	2 (project manager, technician)	28
Healthy Home project Exploratory phase	10	4	1 (secretary)	61
Healthy Home project Pilot test	3	4		10
HomeHealthTours	3			11
HomeVisits	6**		3 (managers)	11
In sum	Interviews: 44 Homes: 50 Persons: 74	20	6	155

Figure 3: List of field study activities

* The spouse participated in, or was present during nine of the interview sessions.

** Two of the interview sessions were group interviews with up to 12 participants

Sampling and bias

The study is based on deliberate sampling and on volunteer participation (not on randomized trials). In the ElderTech project, it was considered an advantage if the elderly participants took prescribed medication and received daily help, as this provided the elderly with an opportunity to ask for assistance in operating the new technology. In the Healthy Home project, the sampling addressed type I diabetes, variation in the use of the device for injecting insulin (pump or pen), and distance to the hospital.

Most important for the sampling was a willingness to participate, and consequently, the participants were mainly those who could manage the additional work. This led to concerns regarding bias in the studies. The dilemma is twofold, as the study concerned the development of new healthcare technology, on the one hand, while on the other hand, it was a study of practices of disease management. This potential bias was considered unproblematic with regard to the development of new healthcare, as the volunteers were considered the target group for new healthcare technology. With regard to exploring practices of disease management in the home, the potential bias was more problematic, as I wanted a broad sample, in order to learn about the numerous ways of managing healthcare and disease, and the utilization of existing healthcare technology. However, the two cases complemented each other very well, as they involved two very different groups, and provided different and contrasting insights into how healthcare and disease are managed in the home. Furthermore, the sampling within the two cases turned out to be highly dissimilar. Additionally, following healthcare professionals during consultations with pregnant women with diabetes, or visits to homes of the elderly, provided small insights into a very broad range of problems faced by persons when managing their conditions.

Ethics

All participants were informed orally and in writing[10] of the purpose of the projects. It was emphasized that participation in the projects was voluntary, that they could withdraw from the study at any time and without consequences (in the case of the elderly persons and the pregnant women) for their future treatment or care by the healthcare professionals. This was a great concern, as the participants were in a potentially vulnerable position, owing to their status (as elderly, or in need of having the condition of their baby and health monitored). Participant information has been anonymized in the analyses and presentations. Furthermore, all participants gave their informed consent, allowing us the use of photographs taken in their homes, or featuring them in other settings, such as workshops at the hospital or at the university. Workshops form part of Participatory Design activities, which I will introduce in the following section.

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[10] See appendix C for written information on the projects and for the informed consent.

Participatory Design

The tradition of participatory design refers to the involvement of users in the development of new technology, and reaches back to the 1970s in Scandinavia. One of the best known participatory design projects from that time was the UTOPIA project, involving graphics workers and their union in the development of new technology that enhanced the skills of the workers and improved the typographic quality of newspapers (Greenbaum & Kyng 1991, 12) see also Bødker et al. 1987)). Participatory design originally related to the development of systems for workplaces, as presented in the book by Greenbaum and Kyng (1991), but is increasingly being applied to new contexts, such as the design of technology for healthcare professionals or patients (Aarhus et al. 2010), the home (Petersen et al. 2009), museums (Dindler 2010), and schools (Iversen 2005).

Participatory design is grounded in a democratic vision of empowering users by having them participate in the development of technology. The vision of participatory design is to balance the power relation between system developers and users, and to have users participate fully in the process and have a voice in vital decisions (Clement & Van den Besselaar 1993, 29; Greenbaum & Kyng 1991, 1). This rests on the premise that the development of new systems is inherently political, and that conflicts of interest must be resolved during development, to avoid rejection of the end products by the users, or degrading the skills of the workers (ibid., 2). At the time, this democratic approach broke with the convention that system developers were experts, and that intended users should not be involved in the process of developing new technology. Furthermore, participatory design is based on the belief that inclusion of the users will result in better technology. The argument is that involving the end-user will result in better products, as the system design must take into consideration the complexity of context, the use situations, and work procedures. This complexity involves more than formal guidelines, as it entails unarticulated collaborative work, of which the user has greater knowledge than the system developers (Clement & Van den Besselaar 1993, 29; Greenbaum & Kyng 1991, 2, 15). From this perspective, including the users should lead to a system that supports work and enhances the skills of the user.

Moreover, the development of methods for involving users in the design activities is central to participatory design. This is an ongoing, experimental effort, which has resulted in a collection of principles, practices, and approaches to design, rather than a fixed set of methods (Dindler 2010, 21). A basis for a collaborative design involving users is that methods for establishing a common ground for collaboration and bridging the worlds of the system developer and the future user are to be applied during the process (Greenbaum & Kyng 1991, 4). Furthermore, tools and techniques for capturing the complexity of work, identifying problems, envisioning solutions, and producing prototypes are needed, and their capacity for being understood by both the system developers and users is a crucial aspect of these methods. Examples include primitive mockups in cardboard, which all participants can understand and shape (Ehn & Kyng 1991). This allows for enacting use of primitive mockups by participants in real world settings, making it possible to explore how the prototype will function and affect everyday life and work practices, and thus generate new, improved design concepts and prototypes.

New techniques and methods for involving the user continue to evolve, and discussions of democratic ideals surface sporadically, addressing the rationale and development of participatory design. Recently, Kyng (2010) outlined changes in elements of participatory design that exist in the gap between techniques and politics (Kyng 2010, 49). Research projects are now funded by establishing partnerships with private companies, transforming them from adversaries into partners; users are not only workers, but may be patients and their families, which makes it more difficult to establish frequent, ongoing collaboration with them. The setting has moved beyond the workplace, and therefore user interests must be safeguarded by researchers, rather than by trade unions. The question of intellectual property rights has become crucial to the trajectory of such projects, as ideas generated as part of the shared efforts may result in profitable products (ibid., 52). It is within this spectrum of elements that shapes participatory design projects that the ElderTech study and Healthy Home project must be understood.

Participatory design activities

Development of the assistive technology in the ElderTech project was primarily accomplished by IBM, a central project partner. Early user involvement primarily involved input from nurses, social and healthcare assistants, and social and healthcare helpers, in response to suggestions made by the system developers, and was presented in the shape of PowerPoint mockups of the user interface. Later in the process, one workshop scenario was carried out, in which nurses, assistants, and elderly participants enacted various use situations using working prototypes. The workshop scenario identified problems that demanded both technical and organizational attention, such as adjusting the sensitivity of the Tablet PC curser, which elderly users with shaking hands found difficult to control, or agreeing on who should be responsible for trivial system breakdowns, such replacing the batteries. Lastly, the users' experiences with the prototype in the pilot study provided the company, municipality, and researchers with valuable knowledge of future challenges.

The Healthy Home project was based on a process of participatory design in which a team of healthcare professionals (obstetricians, nurses, midwives, dieticians, and a secretary), representatives from companies, and a team of researchers (computer scientists, a nurse, and a ethnographer) worked together from the beginning, in a participatory design process. Later, pregnant women with diabetes also participated in workshops. Supplementing the ethnographic studies at the outpatient clinic, a series of participatory design workshops was initiated to involve the users, both healthcare professionals and pregnant women with diabetes. A Future Workshop was held, identifying problems, and generating concepts of design that envisioned future solutions. This was followed by a design workshop, in which design concepts were discussed, a waiting room workshop, to gather input regarding the design concepts from more pregnant women and their relatives, and finally, a scenario workshop, in which the design concept decided upon, the eDiary, was presented by using a mockup made of cardboard boxes and paper. Additionally, a cultural probe and a design workshop in the home during a HomeHealthTour informed the design idea of a personal health record (Aarhus et al. 2009a). Initially, the project partners had a vague idea of using technology to overcome the geographical distance between the outpatient clinic and the pregnant women going for checkups once a week or every second week, as for some of the women this demanded up to four hours of transportation. During the course of the project, these ideas were refined. Both the ethnographic field studies and the participatory design workshops indicated that moving cardiotocographic monitoring (CTG) or other parts of the treatment from the outpatient clinic to the home would jeopardize the sense of security, not only on the part of the women, but also the healthcare professionals. Instead, efforts were made to reduce the distance between the outpatient clinic and the home by supporting the women in performing self-care and improving their communication with the healthcare professionals, rather than moving the treatment site.

In the two projects, participatory design was framed differently, particularly with regard to how and when users were involved in the process, and with regard to the role of the participating companies. In the terms used by Shapiro, these contrasting approaches may be characterized as “weak” and “strong” (Shapiro 2010, 71). The ElderTech project had what may be termed a weak or pragmatic perspective on user involvement: User input was regarded as offering a valuable contribution to successful design regarding what is feasible, what causes frustration, what tools would be useful, and so forth. In this instance, this perspective risks engaging elderly persons in the refinement of technology, the purpose of which they do not see, so that relationships with these users become instrumental, bordering on being exploited, in the words of Shapiro (ibid., 73). The Healthy Home project had a so-called strong approach regarding user participation. This perspective derives from an understanding of the users as social beings whose practices may only be understood in the context of interrelations with people and artifacts. To address this complexity in the design and development of future technology, researchers must not only include users in workshops, but must dedicate significant effort to the observation and analysis that inform the design space (ibid., 71).

Combining ethnography and participatory design

In this PhD project there has been a fruitful relationship between the traditions of ethnography and participatory design, as both fields informed my engagement with the project. Taking part in participatory design activities in the ElderTech and Healthy Home projects opened up a field of investigation to ethnographic studies, and proved valuable in the exploration of healthcare technology in the home. The process of identifying problems and designing the projected system provided an arena for ethnographic study of the experiences of the project participants, healthcare professionals, patients, relatives, business partners, and computer scientists. Furthermore, studying and evaluating the pilot study of the prototypes provided unique opportunities to explore how users appropriate new technology, and how routines and working arrangements are transformed, as described earlier. Thus, the participatory design processes provided a field of investigation for the ethnographic studies, making it possible to follow negotiations and transformations at first hand, observing what took place.

Furthermore, the participatory design process also benefited from my ethnographic studies of how elderly people and pregnant women with diabetes manage their conditions in their everyday lives. The complexity of the interplay of the work of healthcare professionals, and their collaboration with patients and their practices of in-home self-care would have been difficult to explore in a participatory design workshop

(Randall et al. 2007, 77), and the ethnographic studies and analyses thus helped me gain an understanding of the setting of the projected system. The ethnographic analysis identified tensions and dilemmas in the field, which open up the design space and address the roles of technology and design (Dourish 2007, 13)[11]. Thus, the ethnographic studies address broader concerns, for example, the risks and responsibilities associated with the development of new technology for supporting pregnant women with diabetes in their self-monitoring and self-treatment. In this sense, ethnographic studies provided a tool for grasping complexity, bringing sensitivity to general issues that help to open up the design space.

Throughout this study, the two traditions of ethnography and participatory design intertwined in a mix of methods and activities. Moreover, my engagement in fieldwork and participatory design activities continuously interacted with the analyses of categories and patterns, drawing on different theoretical traditions to conceptualize my observations. The ongoing process of analysis was manifested in the writing of several articles during the PhD projects. Analysis took the form of an iterative process, involving a continuous shift between theory and data, with theory constantly inspiring the development of research questions, while acquiring data inspired the use of a theoretical framework (Hammersley & Atkinson 2007, 159). This interplay of data and theory was important, as it helped to explore from different perspectives the research question of what happens when healthcare technology is introduced to the home, unfolding the complexity of negotiations and transformations. Furthermore, this interplay is an important tool, as analysis helps reveal what is at the core of the research, and further informs the ongoing investigation. This enabled me to adjust further investigations, which would perhaps benefit from my asking different research questions in a different setting (ibid., 160), for example, when moving from elderly people to women in their 20s and 30s, or moving from asking questions about managing disease, to questions about managing health. Finally, this interplay helps to test the validity of preliminary findings by returning to the field, or by exploring whether the same patterns exist in other settings. Thus, there has been an ongoing shift among research questions, fieldwork, participatory design activities, analysis, and theoretical framework (see figure 4, below).

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[11] The discussion of the role of ethnography in the design of technology stretches back to Anderson, in 1994. For a more recent contribution, see Dourish (2006) and Crabtree et al. (2009).

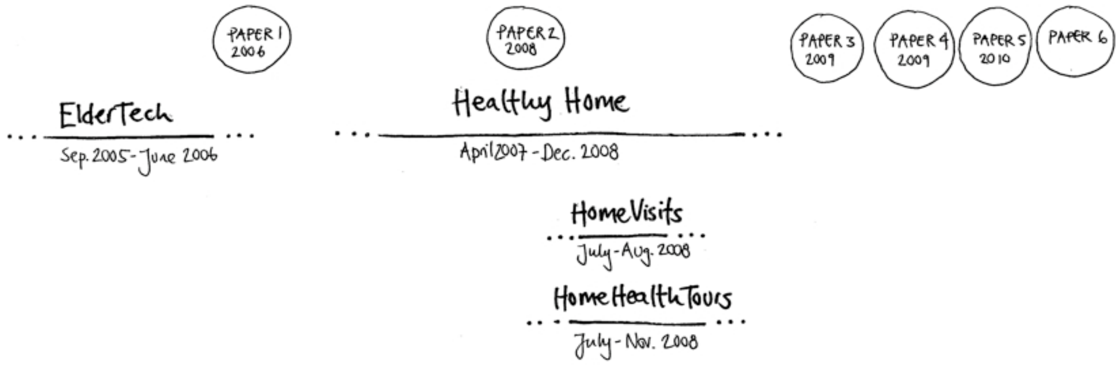

Figure 4: Overview of case studies and published papers.

Summing up

In this chapter, I have introduced the two cases – the ElderTech study and the Healthy Home project – that were central to exploring what happens when new healthcare is introduced to the home. The two cases address assistive technology for monitoring the health of the elderly, and for supporting self-monitoring and self-treatment among patients suffering from chronic conditions. The cases address challenges to the Danish healthcare sector, and the envisioned solutions that make use of healthcare technology, as described in the previous chapter. The current chapter describes the methods I used to explore these cases, by means of ethnographic studies of practices and experiences of the participants in the cases, in one instance, and, in the other, by partaking in a participatory design study in which users were engaged in the development of technology that supports self-care. I have also emphasized the interplay of fieldwork, participatory design activities, analysis, and the use of theory in the exploration of the research questions guiding the PhD project. In the following section, I introduce the theoretical approach of symbolic interaction, which has proved useful for conceptualizing and analyzing the fields of healthcare and healthcare technology in the home.

Chapter 3: Theoretical approach

To conceptualize the processes relating to the introduction of healthcare technologies, the dissertation draws on the field of Science Technologies Society (STS). Jensen et al. (2007) introduce STS as a research community in which researchers come from diverse academic traditions, ranging from anthropology and sociology, to philosophy, history, and geography. This multi-professional perspective addresses various subjects, from the study of cancer research to user involvement in the development of technology (Jensen et al. 2007, 7). Unifying this heterogeneous field of STS research, however, is a shared interest in gaining a nuanced understanding of how organizational, technological, or scientific reality is constructed through concrete, material, and symbolic activity (Jensen et al. 2007, 11). Central to STS studies is an exploration of constellations or networks of humans, machines, and other entities. In these studies of how material artifacts tie locations, humans, systems, and interests together, traditional dichotomies of macro- and micro-scale studies are dissolved (Jensen et al. 2007, 11). Thus, empirical exploration and theorizing about practices within a socio-material network are fundamental to STS.

Symbolic Interaction

Within the field of STS, I particularly draw on symbolic interactionism to conceptualize negotiations and transformations in the home. Symbolic interactionism is attentive to processes of negotiation and transformation between the various actors and the various types of work they engage in. Collaboration is an achievement that relies upon continuous work on the part of the persons working together, in order to reach mutual agreements and avoid breakdowns. Anselm Strauss is a central figure in symbolic interactionism, with his conceptualization of work, arrangements, and social worlds (Bossen & Lauritsen 2007, 139). The focus on processes and working arrangements makes symbolic interactionism a useful approach for conceptualizing what happens when healthcare technology is introduced to the home, as it enables an analysis of the working arrangements and the potential tensions between the two social worlds of the home and the hospital.

Negotiation of working arrangements

Making new technology function in a new setting such as the home is not just a matter of making it operational by plugging it in and ensuring that Windows software is up to date. Rather, w*orking arrangements* regarding the *distribution of work* must be negotiated and agreed upon: What work is to be done, to what standards, in what space, during what time period, with what resources, by whom, and with what compensation (Strauss 2010, 89). According to Strauss: "The performance of work within any organization, whether the organization is constituted formally or informally, is a coordinated collective act" (Strauss 2010, 89). Fundamental to symbolic interactionism is the acknowledgement that collaboration among the persons involved in the work is not a given, but is a matter of continuous negotiation among those involved, for example nurses, doctors, and patients. Through a process of articulation, the actors seek to align their actions to establish and maintain such arrangements, and to agree upon a course of action[12] (Bossen & Lauritsen 2007, 143; Strauss 2010, 89).

Complicating the task of reaching work arrangements are the different stances of the actors, as they are often members of different *social worlds*. Referring to Clarke (1991, 131), Strauss defines social worlds as "groups with shared commitments to certain activities, sharing resources of many kinds to achieve their goals, and building shared ideologies about how to go about their business" (Strauss 2010, 212). A social world is centered around a primary activity, which is often tied to specific sites and makes use of certain technologies. Boundaries may be fluid, and members may have both varied and multiple memberships, which are not always evident to others (Strauss 2010, 213). Memberships in different social worlds may cause conflicting interests among the actors involved, for example, in the case of nurses and doctors trying to reach a work arrangement, or conflicts regarding prevailing concerns about the social worlds of the home and of the hospital. Consequently, the persons involved will negotiate, and try to influence the arrangement, in order to persuade other people to share their particular point of view (Strauss 2010, 89). Debates take place in what Strauss has termed *arenas*. Arenas exist at all levels of interaction, from the internal discussions with one's self, to debates over national issues (Strauss 2010, 44). Debates may also relate to decisions on *trajectory management* of illness and disease, for example, how to interpret symptoms, which

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[12] The concept of 'trajectory' refers to both the course of action and to the interaction of multiple actors and contingencies (Strauss 2010, 53).

specialist to consult, and what treatment to initiate. The concept of trajectory refers to "the course of action but also embraces the interaction of multiple actors and contingencies that may be unanticipated and not entirely manageable" (Straus 2010, 53). Patients, relatives, and healthcare professionals are all engaged in trajectory management, which may conflict with, or be based on mutual agreement regarding the course of action and working arrangement.

Also central to symbolic interactionism is the proposal that there is a constant risk of breakdowns in the collaborative efforts, as contingencies may occur. The process of negotiating, sustaining, and revising work arrangements is ongoing, as contingencies and unanticipated events may interrupt work, causing disruptions in the arrangement, and breakdowns in collaboration and routine working procedures. Such disruptions require extensive *articulation work* on behalf of the actors, to get things "back on track", and modify action to accommodate unexpected contingencies (Strauss 2010, 36, 86; Star & Strauss 1999, 10). From this perspective, there can be no organizational relationships without negotiations. Consequently, the social order and the working arrangement are *negotiated orders*. The negotiated order must be worked at, and continually reconstituted (Strauss 2010, 249).

Concept of work

Strauss argues for the need to broaden the concept of work, to focus not only on formal work descriptions, but on the work involved in social interaction, such as articulation work and division of labor involved when negotiating working arrangements (Strauss 2010, 52), as described above. Work is more than paid labor in several senses: Based on empirical studies in hospitals, Strauss and his colleagues have identified multiple types of work that demand effort on behalf of either healthcare professionals or patients (Strauss et al. 1985). One example is *sentimental work*, which refers to work healthcare professionals engage in when responding to or taking into consideration a patient's reactions and emotions relating to specific procedures and examinations. This may be a matter of either getting the job done effectively, or of humane considerations (Strauss et al. 1982, 254). For example, a nurse may comfort a patient, in order for a doctor to carry out an examination more effectively, while also supporting the patient's sense of self, and not being reduced to "being a patient" (Strauss et al. 1982, 264). Other types of work conceptualized by Strauss are *patient work* and *machine work*, which are important to working arrangements when healthcare technology is introduced to the home, and to which I will return later.

Such types of work may be characterized as *invisible*. Invisible work refers to "informal work and "behind the scenes" work", and contrasts with formal task descriptions and overt work (Star & Strauss 1999, 9). The invisibility of work also addresses the issue of what counts as work, what efforts are acknowledged and appreciated (Star & Strauss 1999, 10). While invisible work is often unacknowledged, it is nevertheless often crucial to collaboration and to performing specific tasks, as it relates to the extra work needed to get the job done.

Boundary objects and standardized packages

The concept of boundary work is also important to collaboration, as it relates to concepts or objects that facilitate cooperation between social worlds: "Boundary objects are objects which are both plastic enough to adapt to local need and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites" (ibid., 393). Star and Griesemer (1989) use their concept of boundary objects to address the problem of how people from different social worlds, perhaps with conflicting interests, are able to cooperate and succeed in the performance of work (Star & Griesemer 1989, 388). Using boundary objects enables people from different social worlds to collaborate by sharing the use of certain objects or concepts, while maintaining their differences. Boundary objects may be concrete or abstract (ibid., 393), but more importantly, the concept generates an analytical focus on how people are able to collaborate, despite great differences (Bossen & Lauritsen 2007, 147).

According to Fujimura, the strength of the concept of boundary objects also constitutes an analytical disadvantage. Boundary objects are eminently suitable for providing a lens for understanding collaboration across social worlds in which actors maintain their different perspectives and agendas. This flexibility makes the boundary object an inadequate tool for examining cases where a stabilization of fact occurs (Fujimura 1992, 169; Bossen & Lauritsen 2007, 148). Therefore, Fujimura proposes the concept of *standardized packages*, which address interactions and cooperative work between social worlds, as well as the stabilization of fact (Fujimura 1992, 169). Standardized packages define a conceptual workspace, which is "less abstract, less ill-structured, less ambiguous, and less amorphous" than that described by boundary objects. "It is a gray box which combines several boundary objects […] with standardized methods […] in ways which further restrict and define each" (ibid., 169). In Fujimura's field studies, the standardized packages of an abstract theory and specific standardized technologies and work practices enabled collaboration among researchers from different disciplines engaged in cancer-related research. Moreover, as the theory was accompanied by specific, standardized technologies and procedures, work was reorganized in the different social worlds engaged in the cancer research, and their construction of problems was framed by the scope of the general theory, thereby strengthening and stabilizing the theory itself (Bossen & Lauritsen 2007, 149).

Conceptualization of healthcare technology benefits from drawing on both standardized packages that push procedures from the hospital into the home, and boundary objects that are still recognizable, but may be interpreted differently when moved from the hospital to the home. The two concepts are useful for describing different ways in which transformations take shape when new healthcare technology is introduced.

Summing up

In this chapter, I briefly introduced ideas from the field of symbolic interactionism, to conceptualize emergent themes that have their bases in analyses of the ElderTech and Healthy Home projects: The continuous negotiations of work arrangements and order, the transformations of distribution of work, and the role of healthcare technology serving as a boundary object and standardized package mediating between the two social worlds. In particular, the notion of social worlds and memberships is useful for understanding the tensions that may occur when healthcare technology is moved into the home.

Chapter 4: The social world of the home

An ongoing discussion throughout the PhD project, which crystallizes the tensions between, and contrasting characters of the social worlds of the professional and the popular sectors, addressed how to describe persons suffering from disease who is being treated at home. When admitted to a hospital for treatment, a person suffering from a disease acquires the status of a patient, which involves certain working arrangements and divisions of labor between patient and healthcare professionals. When hospital care is shifted to the home, the person becomes a home patient. This requires re-organization of working arrangements and divisions of labor. Furthermore, a home patient remains a family member, giving rise to discussions of how to define the person. Should the person be called a patient, parent, spouse, child, or perhaps resident? The dilemma arises because the person stands between two social worlds, and has memberships in both the social world of the home, and that of the hospital. Embedded in the discussion are negotiations of the balance between memberships and divisions of labor, as the person suffering from the disease, and his or her family, become responsible for much of the monitoring and treatment. Moreover, underlying the discussion of the prevailing definition are potential tensions, as the activities and concerns of the two social worlds may conflict with each other.

The tensions inherent in defining the person with a disease who is being treated at home have been central to the PhD project. The various cases and my approaches to an analysis of the tensions have resulted in persons being identified as "elderly", "pregnant women with diabetes"[13], "citizens", "participants", and "patients". In the following two chapters, however, I have chosen to use the term *home patient* to explore and highlight the ambiguous position of the person receiving or performing treatment in the home, as the person has memberships in both the social world of the home, and that of the hospital. I hope to emphasize the multiple and perhaps conflicting memberships and obligations that a home patient may experience, and draw attention to the contrasting characters of the two social worlds and thus problematize what it implies to be a patient in the home.

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[13] Regrettably, these women are called "pregnant, diabetic women" in paper 2, as the definition focuses on the women's health conditions. The paper therefore holds a paradox, as the main argument in the paper is that developing technology should include a broader perspective on the everyday lives of the women, as their lives revolve around more than disease management.

In the following section I will address the work in which home patients engage, in order to domesticate, utilize, and interpret healthcare technology. Furthermore, I will discuss the implications of the new distribution of work, where home patients are given more work and responsibility in their interaction with healthcare technology, and the role of healthcare technology as a boundary object, bridging the two social worlds. I base these discussions on cases from existing literature and on my analysis in paper 1, which explores how the elderly manage their medication, and paper 5, which analyzes the boundary work in which home patients engage, in their efforts to domesticate healthcare technology.

Sense of home and therapeutic landscapes: negotiating the order of the home

Treatment of home patients in the home may challenge the order of the home. When home patients are cared for at home, or if home patients self-monitor or self-treat in the home, it becomes a "place of healing", conceptualized as a *therapeutic landscape* by Donovan and Williams (Donovan & Williams 2007, 202). The therapeutic landscape implies a transformation of the physical and esthetic order of the home to facilitate care, as healthcare technologies bring new odors, sounds, esthetics, and activities to the home. As I will discuss later, the transformation of the home into a therapeutic landscape has several advantages, as healthcare technologies assist the home patient and family caregivers in performing care and treatment, and help to prevent accidents (ibid., 207). However, the therapeutic landscape contrasts starkly with the order of the home. For example, Wang and Barnard (2008) note the conflicting esthetic orders of healthcare technology and that of the home. In their study, both ventilator-dependent children and their parents found the equipment to be the foreign and intimidating (Wang & Barnard 2008, 504). Healthcare technology within a therapeutic landscape may challenge the home patients' *sense of home*. This is described by Wentzel (2004) as a sense of feeling at home, which relates to how persons inhabit and feel at home in a dwelling, such as a house or apartment. It may be a specific scent that conveys a sense of home; it may be a feeling of relaxation, of privacy, or of control (Wentzel 2004). A sense of home is apparent in pictures from the HomeVisits to senior housing communities (figures 5 and 6)[14].

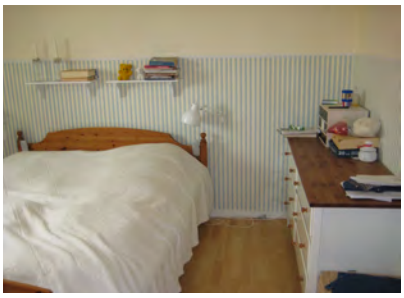

Figure 5: Bedroom.

Figure 6: Living room.

When healthcare technologies are introduced, the home patient has to bring order to the physical space of the home (Douglas 1991), and balance the two contrasting orders. One way of establishing order is to domesticate healthcare technology. With reference to technology, *domestication* refers to "the processes through which technology becomes part of human cultures", and how technology is integrated into everyday life, and into a world of symbols and meanings (Lie & Sørensen 1996, 1). In my reading, domestication is a concept that encompasses all strategies for taming technology so it behaves in accordance with routines of everyday life and the esthetic order of the home. One strategy for domesticating healthcare technology may be that of *home-making*. Home-making refers to the tactics involved in making yourself at home, and the concept is directed toward the things and actions making it a home. The concept draws on the work by Wentzel (2004), who have studied practices children engage in to make themselves at home[15]. Persons may also utilize the tactics of home-making when hospitalized, for example, by placing personal artifacts, gifts, or flowers on the windowsill or on any other horizontal surface, or by hanging photographs or drawings on the wall, thereby creating clutter (Swan et al. 2008) and personal space, enabling the person to feel at home while away from home. Home-making may also include tactics involved in making healthcare

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[14] Wentzel uses "homeliness" to describe an individual feeling, and therefore these pictures are merely examples. However, studies of homes in non-Western societies demonstrate that the meaning of home differs. In his analysis of Kabyl houses, Bourdieu demonstrates that these homes are organized in accordance with dichotomies of high/low, light/dark, and male/female, which reflect the way the world is organized, in the perspective of the Kabyl people (Bourdieu 1996). In her analysis of houses in Tibet, Hørsted explores how reciprocal relationships are embedded in the structure of the house, as construction of the house is dependent on a mutual effort of the entire village (Hørsted 2005).

[15] In Danish, Wentzel (2004) has turned the noun "hjem" (home) into a verb and constructed the concept of "hjemliggørelse" (home-making). In this, way the home as a location disappears, thus, home-making is a tactic and practice, not a place (Hansen et al. 2010, 2, drawing on Wentzel 2004).

technologies more homelike and consistent with a sense of home, such as Jens's flower arrangement, described in the introduction. Home patients engage in very different domestication and home-making tactics in response to a given healthcare technology being introduced to their homes.

Domesticating healthcare technology

One instance of home-making is provided by Wellard and Street (1999). In a study of home-based dialysis, they demonstrate how one family placed their dialysis machine in the living room, a public area of the home, but engaged in diverse home-making strategies to increase the sense of home despite of the alien character of the machine: First, the family created a mobile arrangement, enabling them to alter the status of the machine, pushing it aside and giving it a marginal position when not in use. Secondly, when not in use, the machine is hidden within a wooden cabinet, made especially for this purpose, making it "inconspicuous" and fitting the esthetic order of the home. Thirdly, when it is in use, the home patient inhabits the arrangement of the machine, making it almost a control center, with the telephone within reach and at the center of social activities during treatment (see figures 7 and 8 for similar strategies). In contrast, two other families established a fixed clinic in the home, which is neatly arranged in a style similar in its ordering to that found at the ward where they received training in utilizing the machine. Thus, their strategy is not a matter of creating a sense of home. On the contrary, it mimics the order of the hospital, constructing a therapeutic landscape dedicated to managing a condition. The dialysis machine is placed in private rooms, in a sense making the therapeutic landscape invisible to guests (Wellard & Street 1999, 133).

In the work in which home patients engage to domesticate healthcare technology, they address both the physical perspective of a house and the culturally negotiated order of the home, as they deal with orders of sense of home, therapeutic landscapes, public and private. Deciding on a location for the dialysis machine is challenging, as it does not have a natural place in the home. Home patients must decide how to make it fit the order of the home, or mimic the order of the hospital. They must decide whether the dialysis machine should visible or invisible to guests, and how to attain such an effect, by either placing it in closed, private rooms, or by camouflaging it when it is placed in public rooms.

Figure 7: Example of how a Danish home patient has domesticated a dialysis machine by placing it in the center of the living room (http://www.dkterp.dk/hjemmedialyse.htm), in a strategy similar to that of the first family described in Wellard and Street's study.[16]

Figure 8: The home patient moves the machine to a corner of the living room when it is not in use. The home patient explains that it takes half an hour to an hour to prepare for home dialysis, getting the equipment ready and placing all necessary items within reach (ibid.).

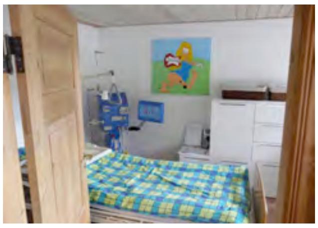

Figure 9: The same home patient later set up the dialysis machine in a dedicated room, in an attempt to perform dialysis while sleeping (ibid.). This strategy resembles that of the other two families reported on by Wellard and Street.

As healthcare technology is tangible, home-making strategies or strategies of domestication often draw on the physical structure of a house, as the textures, surfaces, and shapes of walls and entrances affords specific usages (Norman 2002): Doors may be open or closed, creating boundaries between public and private areas; large devices may kept in private areas of the home, out of sight of visitors; smaller objects may be concealed and hidden in cabinets (this is described further in paper 5). Thus, public and private spaces are used to make healthcare technology visible and invisible. Just as the physicality of the house has affordances, so does healthcare technology, making it easier to domesticate pills than a dialysis machine or motorized vehicle (figure 10).

Figure 10: Jens's motorized vehicle is placed in the bedroom, out of sight of visitors and, out of the way in his two-room apartment.

Figure 11: Jens's kitchen counter, where pillboxes on the right are left visible, to prompt him to take his medication.

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[16] These three photographs were taken by a home patient in 2007 and 2010. Informed consent has been obtained, allowing them to be displayed here. All other photographs in the dissertation were taken by fellow researchers or me, and used with the consent of the home patients.

It is important to note that some home patients use the equipment's physical properties to purposely stage therapeutic landscapes. In paper 1, my co-author and I explore how the home patients create distributed systems for managing medication intake, where medication is placed strategically and visibly throughout the home. Jens, the home patient introduced previously, takes advantage of the physical affordances of the kitchen counter, where medication is placed next to the morning coffee, to prompt him to remember the specific medication to be taken at that particular time of the day (figure 11). As it is small, the medication could easily have been hidden in a drawer. However, Jens finds that turning the kitchen counter into a small-scale therapeutic landscape helps him to better manage healthcare and disease.

Thus, for some home patients, strategies for balancing the order of the home may involve attempts to create therapeutic landscapes that may mimic the order of the hospital, or may take the form of home-made methods for managing medication. Home-making strategies, aimed at domesticating technology in accordance with the order of the home, may also be employed to preserve a sense of home. However, it is important to note that despite their intentions and deployment of diverse strategies, not all home patients are successful in their attempts to balance the contrasting orders of home and hospital. Some home patients may struggle unsuccessfully to promote a sense of home, as the healthcare technology proves too difficult to domesticate, while other home patients may fail to create a therapeutic landscape that enables them to manage their condition. In the following section, I will address the potential implications of the efforts to domesticate healthcare technology.

The enabling and constraining character of healthcare technology

Domestication of healthcare technology is not only a matter of making machines fit the esthetic order of the home. Domestication also related to being able to integrate healthcare technology into, or segment it from the routines of everyday life. My co-author and I further explore this in paper 5, where a matrix enables an analytical positioning of strategies of visibility or invisibility, and integration or segmentation. The examples presented in the paper draw on more or less deliberate strategies on behalf of the home patients. Here, I will further elaborate the discussion of the ambivalence related to integrating healthcare technology into the everyday lives of home patients, who have little choice regarding when to use their machines.

According to a study by Lehoux et al. (2004), home patients who are dependent on oxygen therapy by means of home ventilators often have ambiguous feelings about healthcare technology: On the one hand, the ventilators enable the home patients to live at home; on the other hand, they are experienced as constraining, difficult to domesticate and integrate into the everyday lives and routines of the home patients. Based on their studies of the use of ventilators at home, Lehoux et al. argue that, although counterintuitive, healthcare technology that generates autonomy also constrains the behavior and the range of actions on part of the user (Lehoux et al. 2004, 622): "[…] giving specialized medical equipment to chronic patients often embodies a very limited and constraining response to the mobility, economic and social needs resulting from the illness, while providing them with a highly valued opportunity: living at home" (ibid., 623). Lehoux et al. argue that technology is always both enabling and constraining, also in the matter of the perceived autonomy of the user. The participants in the study rely on their ventilators, and are spatially connected to the technology. While they are able to leave their homes by connecting themselves to portable cylinders, they feel uncomfortable doing so. Home patients are uneasy in public spaces, being very conscious of the visibility of not only the tube, but of the portable cylinder (ibid., 637). Moreover, the ventilator is noisy, making "a regular shlick… shlick sound that is loud enough to be heard by people within a 2-metre range" (ibid., 631). The home patients in the interviews focus on their physical limitations, such as being unable to climb stairs, or ride a bicycle. Others explain that they had to give up working full time, as they quickly lose their breath, and have to adjust their pace when feeling unwell. Furthermore, they are concerned that other people become highly anxious when witnessing situations of ventilator malfunctions or incidents of acute respiratory problems. They are very conscious of how others perceive them, and may even disconnect themselves from the ventilator[17] for short periods of time, to avoid having to answer questions from people unfamiliar with their condition (ibid., 637). The use of the ventilator thus creates an ambivalent feeling: "It's keeping me alive, but I'm not living" (ibid., 636). The very technology that enables them to breathe, move around and stay at home, rather than being confined to an iron lung, is at the same time perceived as a hindrance to their autonomy and their previous way of life.

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[17] The home patients in this study are in oxygen therapy, and require only partial assistance to breathe. They are advised to be connected 12-15 hours a day (Lehoux et al. 2004).

Domestication of ventilators is difficult, as their physical appearance is very much that of technology from the social world of the professional sector, and is associated with disease, which the home patients in the study find stigmatizing. Thus, the ventilators are difficult to integrate into the lives of the users, and in many ways the users work to adjust their everyday lives to make their routines fit the order of the ventilator, rather than adjusting and domesticating the healthcare technology to fit into everyday life.

From the above examples of domestication of dialysis machines, pills, motorized vehicles, and ventilators, it is evident that some healthcare technologies are easier to domesticate than others, both with regard to their physical appearance, and with regard to the routines of everyday life. In the following section, I focus on a different aspect of how healthcare technologies become part of the social world of the home, namely by means of the work in which home patients engage, when utilizing healthcare technology in diverse and unexpected ways.

Distribution of work

Moving healthcare technology and services from the social world of the hospital into that of the home is based on the premise that this will enable home patients to participate more actively in the monitoring of health and treatment, and in a way that has the same quality and efficacy as similar treatment at the hospital, outpatient clinic, or general practitioner. This raises several questions related to how working arrangements are negotiated, what work is entailed, how it is distributed, and how home patients appropriate healthcare technology. Furthermore, it raises questions of how healthcare technology may serve as a boundary object between the two social worlds. The following discussions draw on analyses developed in paper 3, which explores how pregnant women with diabetes interrelate with healthcare technologies at home and at the outpatient clinic. I will also include cases from the literature on various healthcare technologies, such as ventilators and dialysis machines, to explore perspectives that may differ from the use of smaller devices, such as blood sugar meters.

Making healthcare technology work

Moving healthcare technology to the social world of the home also means that *machine work* (Strauss et al. 1985, 44) becomes the responsibility of the home patients and their family caregivers, rather than of healthcare professionals at a hospital. They must *tend to the machines*, insuring that they are monitored, repaired, or replaced (Strauss et al. 1985, 44). Moreover, home patients also become involved in the *medical use of machines*; that is, how machines are utilized for diagnosis, therapy, or maintenance of life. Consequently, home patients engage in connecting and disconnecting themselves to and from machines, monitoring and interpreting data from the machines, scheduling the use of the machines; they must learn to operate medical equipment with clinical safety and accuracy (ibid., 45). The work involved in getting healthcare technology to function is significant, especially when it comes to life-support technologies, for example, where home patients are dependent on ventilators, as explored in the following section.

Locker and Kaufert (1988) examine the impact of healthcare technology on the trajectories of people with post-polio respiratory disabilities (Locker & Kaufert 1988, 23). Home patients who are entirely dependent on mechanical respiratory support have relied on different technologies that involve various distributions of work among home patients and healthcare professionals. Previously, the person would be confined to an iron lung, a cylindrical tank that rendered the patient immobile and passive, both in breathing and in operating the machine. At the time that Locker and Kaufert wrote their article, a newer technology had become available in the form of mobile pressure ventilators, which blow air into the lungs via an oral tube or a tracheostomy. This healthcare technology also renders the home patient passive in breathing, but highly active in working with the machine (ibid., 25). Locker and Kaufert note the vast amount of machine work related to utilizing the ventilator, for both home patients and their helpers:

> "[They] had to learn how to manage the equipment and its needs. They had to learn how to connect and disconnect the machine, alter the volume of air it produces, recharge the batteries, milk the hose, maintain the cascade, suction the patient, use an Ambu-bag in case of machine failure, and learn to recognize when the machine was about to fail" (ibid., 33-34).

Lehoux et al. (2004), who have studied the use of oxygen therapy, describe similar machine work (Lehoux et al. 2004, 617). This healthcare technology has obviously improved since 1988, the time of the Locker and Kaufert study. According to Lehoux et al., it is now considered a simple device to operate, in comparison to the other technologies on their study: Tubes are easy to connect to either the fixed concentrator or the portable cylinders, and the maintenance of the equipment is limited to cleaning and changing filters, scheduling the refilling of the portable cylinders, and keeping emergency cylinders, in case of power failure. Nurses or therapists teach home patients how to set the flow rate, and to calculate how long a portable cylinder will last (ibid., 629)[18].

Thus, technological developments in oxygen therapy have transferred the machine work from the healthcare professional to the home patient. Tending to the ventilator and making it work have become easier over time, and thus more suitable for home patients to use in the homes. Yet, how the ventilator is utilized depends on the ability of the home patient to learn to use the technology, as well as the skills and knowledge of the home patient (ibid., 623). While this type of machine tending is most likely invisible to healthcare professionals, the work is crucial, as failure may be life-threatening, if the home patient miscalculates the duration of the portable cylinder, or fails to keep the ventilator functioning. With the re-distribution of work also follows a redistribution of responsibility, which may have severe consequences, if the oxygen therapy is not administered properly.

Healthcare technologies and trajectory work

Moving healthcare technologies into the home also implies a redistribution of the work involved in interpreting data and adjusting treatment accordingly, from being the responsibility of the healthcare professionals to that of the home patients.

While the work in which home patients engage may appear to involve identical work, the experiences and strategies for managing the trajectory of the conditions may differ dramatically (e.g. see the analysis by Storni (2010) on appropriations of the blood glucose meter and blood pressure monitor). In paper 3, my co-author and I explore the contrasting work and trajectories of two pregnant women with diabetes, Maja and Ida[19]. Maja's machine work, involving the operation of a blood glucose meter, and injecting insulin the on basis of interpretation of the data generated by the blood glucose meter, gives her a feeling of controlling the trajectory of her pregnancy and diabetes. With the assistance of this healthcare technology, she feels able to keep her blood glucose level stable and low, as advised by the diabetes specialist and obstetrician at the outpatient clinic. She is able to do her *homework*. Grøn et al. (2008) have used the concept of homework to refer to the healthcare-related work that healthcare professionals expect the patients and their families to carry out at home (Grøn et al. 2008, 72). Doing your

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[18] For more on home oxygen therapy treatment in Denmark, see Hvenegaard et al. 2009.

[19] The pseudonym Ida has been utilized twice in the papers. In paper 1, Ida is an elderly woman, whereas Ida in paper 3 is a pregnant woman with diabetes.

homework in this case, is to produce a record of stable, low blood glucose measures. To do this, home patients must not only calculate insulin intake, but will engage in other types of work, such as adjusting and creating everyday routines regarding when and what to eat, establish reminders to measure blood glucose, or make arrangements with their husbands to be aware of symptoms for hyperglucemia. Ida engages in similar work to that of Maja of measuring blood glucose levels and injecting insulin. However, she does not experience this as a resource for managing the trajectory of her condition; rather, despite her desire to live up to expectations, and despite her efforts, she does not manage to keep her blood glucose figures stable. She has suffered from diabetes since childhood, and is therefore experienced in managing her condition. However, her efforts are complicated by severe nausea during her pregnancy, and she suffers from depression, which influences the trajectory of her condition. Getting out of bed and even eating are at times insurmountable tasks for Ida. According to Grøn et al. (2008), performing self-care and adhering to treatment and clinical guidelines may conflict with the home patient's way of life and social relationships. Resolving these conflicts, and paying equal attention to both clinical and social concerns, involves significant work on part of the home patient, and the efforts may ultimately prove fruitless (ibid., 72). Ida tries to resolve conflicting concerns and expectations of these two social worlds, but finds herself unable to balance incompatible concerns and perform her homework. She is extremely frustrated, and fears the consequences of her inability to manage her condition, as high levels of blood glucose affect the unborn child. Consequently, she tries to reject the work and responsibility distributed to her, by suggesting hospitalization. Thus, Ida creates an opportunity for direct negotiation of the working arrangement in which daily treatment is in hands of the home patient, and monitored by checkups by specialists at the outpatient clinic. Owing to practical and social circumstances in the social world of the home, Maja and Ida has very different experiences of managing the trajectories of their condition through their work of using and interpreting healthcare technologies, despite their common efforts to live up to the expectations defined by the social world of the hospital. From the perspective of the social world of the hospital, the outcome of Maja's and Ida's efforts may be interpreted in terms of compliance and non-compliance. This perspective risks being oblivious to the actual work performed in the home, and to the non-medical reasons for non-compliance. The concept of compliance becomes further nuanced when exploring another way of performing homework, which may also be interpreted as non-compliance.

As mentioned earlier, the working arrangement in which home patients monitor and perform adjustments in home treatment is based on the premise that this will happen in congruence with the practices recommended by healthcare professionals; that expert users will comply with the treatment program. However, as Danholt (2008) describes the practices of the 67-year-old Bernd, suffering from diabetes, a paradox occurs: Bernd has had type 2 diabetes for 23 years, and is head of the local diabetes association. Thus, Bernd is highly knowledgeable about diabetes but he is also somewhat irregular in the eyes of his healthcare providers, who proclaim that his blood glucose figures are not optimal, and that he does not live in accordance with what he knows (ibid., 114). Danholt describes the arrangement in Bernd's apartment, which he uses to attend to his diabetes: In a box on a shelf near his favorite chair are items such as medication, two insulin pens, his blood glucose measuring device, the strips for the device, the lancing device and needles for taking blood samples, and so forth. This arrangement enables Bernd to attend to his diabetes and perform his self-monitoring and self-care in accordance with the guidelines of healthcare professionals (ibid., 115). Ideally, Bernd should also bring his insulin and devices for measuring the blood glucose whenever he leaves home. This would enable him to adjust his insulin intake at meals in accordance with a calculation of the relation between the measured blood glucose level, the carbohydrates in the food, and expected physical activity. However, Bernd leaves his box at home, ignoring his diabetes, and must repair his blood glucose levels upon returning to his apartment. Consequently, his blood glucose levels oscillate considerably, which is not recommended by healthcare professionals (ibid., 116). Rather, a tightly regulated, low blood glucose level is preferable, as this decreases the risks of complications later on, such as blindness, and damage to the kidneys or liver.

Danholt argues that Bernd chooses to leave the box with his equipment for managing his diabetes at home for two reasons: First, the arrangement is difficult to dismantle, and undoing the assemblage entails the risk of Bernd being unable to perform his self-monitoring and self-care anywhere (ibid., 120). Secondly, it is precisely because Bernd is an expert that he is confident that he can repair his condition later. He has experience and knowledge, which enable him to regulate his insulin intake "in a causal-mechanical way", and therefore dares to use the insulin to repair his blood glucose level in ways that others, who are inexperienced in the use of insulin, would not (ibid., 122). Storni has made a similar argument regarding the use of blood glucose meters by expert users:

> Now its use goes beyond the simple measuring to calculate how many units [of insulin] to inject; its appropriation takes the form of a deeper entanglement with the intricacies of real life where doctors are no longer in the picture. From being an instrument of compliance, the glucose meter has become a means of self-management and self-determination where the levels of glucose can be tweaked and adjusted to gain increasing control over the disease." (Storni 2010, 551)

According to Danholt, this behavior is not due to the lack of knowledge or inability to manage the disease correctly; instead, the behavior is a result of the actions of a home patient who is highly skilled, competent, and confident in managing the condition (Danholt 2008, 122).

Arrangements in which the work of self-monitoring and self-treatment are assigned to the home patient may result in surprising trajectory management, as home patients engage in machine work and the interpretation of data generated by the healthcare technologies in ways that contrast with those of the professional sector. Home patients may use their agency in accordance with their own perspective on trajectory work, and engage in work that contrasts with recommended behavior. This kind of usage questions the assumption that notions of compliance and self-care may be transferred directly to the social world of the home: Not because home patients are ignorant or unwilling, but because they use their knowledge to construct healthcare practices that balance concerns between home and hospital. The question becomes, how may healthcare technology be designed to support home patients in pursuing a balance that is sensitive to both the performance of homework, and to routines and concerns of everyday life. This is a central matter to which I will return shortly, in the discussion of healthcare technologies as boundary objects and standardized packages.

Distribution of diagnostic work

While the discussion in the previous sections focused on how home patients engage with machine and trajectory work related to self-monitoring and self-treatment, I will now turn to cases where healthcare professionals are in charge of remotely monitoring heart patients in their homes. The purpose is to explore the work entailed in such monitoring, and how work is distributed in such a setup.

In the Netherlands, a program has been developed to lessen the work-load of specialized cardiologists, allowing the general practitioner to diagnose heart problems on the basis of home monitoring of home patients with heart conditions. The home patient makes electrocardiograph (ECG) recordings at home, using a portable recorder, and transmits the data to a call center staffed by nurses and a few cardiologists, who forward it to a general practitioner (Oudshoorn 2008, 274). A study of this setup has shown that the work of the home patient involves more than just strapping on the ECG recorder and transmitting the recordings. The home patient must not only learn to operate the ECG recorder and perform the invisible work of adjusting the recorder, but more importantly, the home patient must also learn to determine *when* to record. This decision is not trivial, as the recording should capture irregularities of the heart rhythm that occur infrequently and unexpectedly. Thus, recording the ECG requires the home patient to undertake what Oudshoorn has termed *diagnostic work*, paying close attention to their heart rhythms and assessing the nature and seriousness of the condition (ibid., 276). The diagnostic work and the work involved in making the recording is further complicated by the fact that the home patients often experience fatigue and anxiety when they experience heart rhythm irregularities. The home patient may be overwhelmed by this diagnostic work, which may result in the non-use of the healthcare technology, where recordings are not being made (ibid., 278).

In this case, the working arrangement involves distributing the diagnostic work to the home patient, which is invisible to healthcare professionals, but is nevertheless difficult to perform. A potential non-use would similarly be invisible to the general practitioner who is to receive the data. Most likely, the lack of data would prompt the general practitioner to inquire about the missing data, but substantial effort and training on part of the home patient would still be involved, for him or her to be able to perform the invisible, diagnostic work, and make the recordings.

Healthcare technologies as boundary objects and standardized packages

The above exploration addressed the role of healthcare technology as an attempt to bridge two social worlds. The exploration identified contrasting and conflicting concerns of the two social worlds, and described negotiations and transformations of esthetic orders and working arrangements that occur when healthcare technology is introduced to the context of the home. In these transformations, healthcare technology may be conceptualized as boundary objects and standardized packages tying together the two worlds. These two concepts relate to a discussion of how to shape future healthcare technologies to be deployed in the home, as the two approaches imply different transformations, and different risks or dilemmas. Standardized packages may push specific procedures into the home, while boundary objects may be adapted to fit the routines of everyday life.

Standardized packages are often difficult to domesticate, as they have fixed, standard procedures built in, and a physical appearance that is difficult to adjust. The dialysis machine may be seen as an example of such a standardized package. The sheer size of the machine, and its contrasting esthetic order may prove difficult to domesticate by making it either less visible or more homelike, in accordance with the esthetic order of the home. The standardized package may transform the home into a therapeutic landscape and a place of healing that resembles the esthetic order of a hospital. Moreover, the standardized package has procedures and timetables that move with the healthcare technology, from the social world of the hospital into the home. Following strict procedures and fixed schedules tied to these standardized packages may interfere with the routines of everyday life. According to Strauss (2010) "routines are standardized patterns of action" (Strauss 2010, 194), which are linked in complex sequences and combinations, involving persons both within the organization and collectives external to the organization (ibid., 196, 198). Therefore, changing existing routines involves not only the persons performing the standardized pattern of action abandoning or altering their sequence of actions, but also that a consequent renegotiation of working arrangement with persons outside the organization must occur. Wellard and Street (1999) describe how the social lives of home patients alters dramatically. Home-based dialysis is time-consuming, and confines not only the home patient to the home; the families in their study all experience feelings of social isolation and being bound to the home because of the treatment. Maintaining social routines, such as being the member of a club, is difficult. In one case, a married couple scheduled dialysis on specific days, in order for the husband, who was receiving treatment, to continue his club activities. Unfortunately, the wife's club activities coincides exactly with the days on which dialysis is scheduled, making it impossible for her to attend (Wellard & Street 1999, 134). Thus, new routines in the home, related to scheduling dialysis, interlock with the routines of other people and organizational arrangements, and therefore have far-reaching consequences, which may not be immediately apparent.

While the *standardized package* may be perceived as an intrusion that conflicts with routines and the esthetic order of the home, there are also advantages to such healthcare technology. The therapeutic landscape created by the dialysis machine evoking the clinical setting may help home patients to carry out treatment in accordance with hospital procedures. It is important to keep in mind that home patients often have an interest in performing treatment correctly, and that for some, performing dialysis in the home may be preferable to spending time at an outpatient clinic. In paper 5, my co-author and I analyze how home patients deploy diverse strategies for integrating and segmenting disease and healthcare technologies in their everyday lives. One of these strategies is based on an approach in which healthcare technologyis highly visible, taking the shape of a therapeutic landscape, and treatment of the condition plays a pivotal role in everyday life. This type of strategy is not only identified in cases of standardized packages such as large dialysis machines, which are hard to domesticate, but also in cases with relatively small devices for managing diabetes, which presumably demand less work to domesticate. This emphasizes how some home patients prefer to have healthcare technologies take the form of therapeutic landscapes, and that it is not necessarily something that only occurs when it is inflicted upon home patients by means of standardized packages. In other words, standardized packages may be interpreted as both invasive and as supportive. However, with the above exploration of different approaches to healthcare technology, I argue that it is the situation, and the desired strategy of the individual home patient, in which the duality must be understood.

Healthcare technology may also take the form of a *boundary object* that is recognizable in the social worlds of both the hospital and the home, but is flexible enough to be adapted to both. Healthcare technologies such as pills and devices for managing diabetes may be seen as boundary objects, as they are more easily domesticated physically, in accordance with esthetic order of the home, by using a box, purse, or egg cup, for example. Systems for managing medication may be quite elaborate, as demonstrated in paper 1, and necessitate ongoing efforts of domestication and adjustment, for example, when medication is altered. Small boundary objects may also be mobile, and thus interfere less with the routines and everyday lives of home patients, when compared to the fixed dialysis machine. Thus, boundary objects seem preferable, as they entail less domestication work on part of the home patients when introduced to the home. However, the very flexibility of the boundary objects, which enables home patients to interpret and use the technology in different ways, may also be seen as a disadvantage. First, boundary objects do not provide home patient with procedures, and users must establish systems themselves for managing medication, for example. Pills may be taken at specific times of the day, or not at all, depending on the system created by the home patient. Secondly, the ways in which the boundary object is utilized may contrast with the behavior intended by healthcare professionals. Boundary objects do not enforce or transfer the ideal of compliance, which exists in the social world of the hospital, to the social world of the home. Paper 1 illustrates the divergence in perspectives between the social world of the professional and popular sectors, regarding medication management. Healthcare professionals are interested in establishing whether home patients took x mg of a Latin-named drug at 07.30 hours, whereas home patients describe their medication intake in accordance with their daily routines, and used lay terms for the medication, for example, that "medication for the blood" was taken after breakfast. Moreover, the flexibility of a boundary object may be overly taxed, whereby envisioned compliance is lost or transformed, as Bernd's case illustrates, where he deliberately segments his diabetes homework from his social life outside the home, and subsequently repairs his blood glucose levels.

The introduction of healthcare technology to the social world of the home requires the home patient to assume new tasks and homework, which are alien to this social world. The new working arrangements may conflict with home concerns, and may impose a divergence of visions and approaches to compliance with treatment regimes. These dilemmas raise the question of how a successful transition may be defined, and what the design requirements of new healthcare technology should be. Is it possible for healthcare technology to be flexible enough to enable home patients to choose strategies of visibility/invisibility of healthcare technology, and of integration/segmentation of disease management, while simultaneously supporting home patients in their homework, to ensure that treatment is performed in accordance with procedures of the professional sector? In other words, is it possible to develop healthcare technology that combines the benefits of boundary objects and standardized packages in very flexible solutions? Or does the dilemma need to be approached in terms of diversity in healthcare services, so that home patients who do not succeed in domesticating healthcare technology or performing their homework will not be faced with frustrations similar to Ida's?

Summing up

This chapter has addressed the role of healthcare technology as a bridge between the social worlds of the hospital and of the home. This chapter has described the ambiguity and tensions created by the introduction of healthcare technology to the home. First, the chapter explored how the person living at home with a disease, or home patient, has to balance contrasting esthetic orders of home and therapeutic landscapes. Secondly, the chapter investigated various types of working arrangements and divisions of labor between patients and healthcare providers, and described the emergence of new working arrangements in which homework and responsibility are distributed to the home patient. Thus, diagnostic work, which was previously the responsibility of healthcare professionals, may become part of the homework that home patients are expected to perform. This chapter has demonstrated that these new working arrangements make home patients more responsible for their own health and treatment. While much of this work is invisible to others, it is nevertheless important for future discussions of the distribution and negotiation of responsibility between home patients and healthcare professionals. I argue that the contrasting concerns of the two social worlds may create new practices and understandings of treatment, which differ from those recommended by healthcare professionals. Thirdly, the chapter discussed the potential of healthcare technology in the forms of boundary objects and standardized packages, arguing that a duality exist within both approaches, which poses a challenge for the design of future healthcare technology. The capacity of a standardized package to push procedures into the home has the advantage of promoting practices in keeping with recommended practices for treating disease, and the disadvantage of being potentially insensitive to the concerns in the home. The flexibility of boundary objects has the advantage of easy integration into the everyday life of the home patient, but is also a drawback, as this may result in practices that pose risks for managing the disease condition.

Chapter 5: Collaboration in the social world of the home

In the previous chapter, I explored how new working arrangements involve various types of work on part of the home patient to domesticate the technology in the context of the social world of the home, just as diagnostic work and homework become concerns of the home patient. In this chapter, I will first address the work of family caregivers, and discuss the implications for social relations in the home, and further elaborate on a discussion of how responsibility is distributed in new working arrangements. In these discussions, I draw on paper 3, which addresses how the husbands of pregnant women with diabetes are involved in self-care. Second, I focus on the work of healthcare professionals, to explore further implications of new working arrangements. In particular, I draw on literature on the professional monitoring of heart patients, and the evaluation of the eDiary prototype in paper 4, regarding how new healthcare technology may involve different kinds of work for the healthcare professionals in their interaction with home patients and their relatives.

Family Caregivers

Self-care is not only an individual effort, but also a highly collaborative one. Kleinman (1980) describes how a network of family, friends, and neighbors take part in disease trajectory management (Kleinman 1980, 50). Based on ethnographic studies in Denmark, Meinert and Paarup state that healthcare professionals often expect the family of a person suffering from disease to participate in treatment and rehabilitation, supporting the home patient (Meinert & Paarup 2007, 157). Therefore, when a person becomes chronically ill, it may have far-reaching implications for the organization of family social life, altering the routines of the everyday lives of the home patient and his or her relatives, and giving rise to new routines and new worries (Locker & Kaufert 1988, 32)[20]. Not only is the home patient expected to perform homework as described previously, but working arrangements also include relatives, when working out who must perform

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[20] That the disease of a home patient also affects the family is emphasized by a recent Danish study, which shows that the partners of women with breast cancer have a 40 % greater risk of developing depression that requires treatment. The findings are based on data on 1,162,596 men, collected over a period of 13 years (Kræftens Bekæmpelse 2010).

which tasks involved in treatment and care. Depending on the severity of the condition, relatives may perform the practical machine work of healthcare technology, provide personal assistance, such as helping with hygiene, getting dressed, or changing dressings, but will also perform sentimental work, reassuring and comforting the home patient; they may often escort the home patient to the hospital, attend meetings with healthcare professionals, and even serve as anchor person, managing communication among various healthcare professionals, as persons with chronic conditions are often treated for several conditions simultaneously. Thus, the relative of a home patient suffering from an illness has not only the role of relative, whether a spouse, parent, or child, but also assumes the role of caregiver, becoming a *family caregiver*. As does the term home patient, this term of underscores the ambiguity and potential conflicts of concerns, which the distribution of caregiving work may introduce.

Distribution of work to family caregivers may be experienced as disruptive to the social world of the home and the social relations within the context of the home. Wang and Barnard describe how parents of ventilator-dependent children experience conflicts and tensions between being a parent and a caregiver: “Reading a story and then to have your child choke and you have to suddenly step into medical mould … is often like, your brain takes ten or fifteen minutes to get into gear[21]” (Wang & Barnard 2008, 504). In the new working arrangement, the family caregiver may experience tensions between concerns arising from assisting with the healthcare related homework, and the concerns associated with being a parent, for example. Grøn et al. (2008) report on a Canadian ethnographic field study of the complexity and conflictual character of the rehabilitation of a teenage girl (Grøn et al. 2008, 84). The girl, Latoya, suffers from sickle cell anemia, and is wheelchair-bound, following a stroke. With the aid of her father, Mason, she participates in a home rehabilitation program to exercise and increase the flexibility of her leg muscles (ibid., 85). However, it is clear to the physiotherapists that Latoya and Mason do not adhere to the program, as her body “is shaped like a chair” (my translation) (ibid., 88). While Mason and the physiotherapist seem to agree on the goals of the program, conflicting agendas exist. A series of social issues dominate the concerns of the father, rather than adherence to the clinical program. Latoya lives with Mason, who has been awarded sole custody, as her mother has been declared unfit. Mason has a new wife, who resents the time he spends on his daughter. Additionally, his mother is

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[21] Verbatim quotation.

very ill, and needs his help. Furthermore, Mason feels uncomfortable performing the exercises with his daughter, as this involves firmly gripping her on the upper thighs. As he has a previous record of violent behavior, he fears that, were this to cause bruises, it might result in a charge of child abuse, and deprive him custody. Moreover, Latoya has expressed the feeling that she does not wish to live. Therefore, Mason's priorities are to give her hope, and all the love and affection he can, rather than force her to perform exercises against her will, exercises that are painful, and of which she cannot see the purpose. Rehabilitation becomes a secondary concern, resulting in a conflictual relationship with the physiotherapist, who is frustrated by the lack of compliance on the part of the father (ibid., 88).

This working arrangement creates tension on the part of the family caregiver, who is faced with conflicting concerns of being a parent and of performing homework. This example relates back to the previous discussion of homework, compliance, and conflicting concerns between social worlds, as discussed in chapter 4, and illustrates that the complex sociality related to homework is vital for work related to the trajectory of a disease, and that social concerns may often overrule medical issues, even if the condition is serious (ibid., 89). This example further identifies implications regarding social relations in the context of the home, as the inclusion of a family caregiver in performing homework may create a degree of dependency between the family caregiver and the home patient. Locker and Kaufert (1988) elaborate on this in their study of ventilator-dependent home patients, introduced in the previous chapter, where the authors explore how oxygen treatment creates a practical dependency. Home patients who are unable to breathe on their own are in need of constant respiratory support. If the ventilator malfunctions, as many of them have experienced, they are dependent on the help of other people to perform machine work, in order to survive. Therefore, many of them feel uncomfortable being alone, and prefer constant company, either that of family caregivers or trained helpers. Closely related to the practical dependency is also a symbolic dependency on the family caregiver, where the home patient experiences a loss of independence, loss of self-esteem, and feelings of vulnerability (Locker & Kaufert 1988, 34). Such a dependence may alter the relationships that exist in a family. Douglas (1991) describes the order of the social world of the home as being based on reciprocity. Inspired by Mauss (1990), she describes everyday life in the home as a *gift community*, in which family members engage in reciprocal relationships with delayed and disguised exchanges of gifts (Douglas 1991, 302). In this sense, an exchange of gifts may take the form of favors done by the family caregiver, such as helping with homework, machine work, or simply by being present. Central to a reciprocal relationship is the symbolic exchange of gifts over time: It is through the exchange of gifts that the relationship is confirmed and reconfirmed. However, being unable to return a gift puts the recipient in debt to the giver (Mauss 1990). Such asymmetrical relationships hold potential conflicts or tensions, as the family caregiver may either feel superior, or that the generosity is being exploited, and the home patient who receives assistance may feel in endless debt, or inferior[22].

Thus, the new working arrangement not only implies tensions regarding the concerns of conflicting social worlds, but may also have implications for the reciprocity of social relations in the home. Furthermore, moving healthcare services into the home, and involving family caregivers also has implications for how responsibility for treatment is experienced and distributed.

Distribution of responsibility

Often, family caregivers and their participation in homework are invisible to healthcare professionals, and may be omitted from formal descriptions in new working arrangements, when treatment is moved to the home. In the home-based dialysis treatment program described in chapter 4, the family caregivers were hardly addressed by healthcare professionals, with regard to changes in treatment, despite the fact that they were highly involved in the homework (Wellard and Street, 1999, 135). This has implications not only for the ability of the family caregiver to assist and perform homework, but also has implications for the central strategy for sharing responsibility in the family.

The husbands of pregnant women with diabetes, described in paper 3, were eager to participate in consultations at the outpatient clinic, as they saw this as way of sharing responsibility. In their opinion, joint efforts would enable them to think of more questions, and to discuss and remember what the doctor said, rather putting the burden solely on the wife. A visit to the outpatient clinic generally consists of two or three consultations with different specialists, making it difficult for one person to remember all the information. Consequently, unaccompanied women must perform the work of

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[22] Boas has described potlatch festivals among native tribes in North America, in which the exchange of increasingly valuable gifts leads to an asymmetrically dominant relationship between rival tribes (Eriksen 1997, 204 referring to Boas 1897).

bringing information back and forth, and may subsequently give brief accounts of the consultations to the husbands. This makes it difficult for the husbands to participate and support the women in performing the homework, for example, by reminding them to eat, inject insulin, or being particularly attentive to early symptoms of hyperglycemia. Being present during consultations was a central strategy for sharing the responsibility of understanding the complexity of the women's conditions, and sharing responsibility for the subsequent homework. Implicitly, this strategy also relates to a shared responsibility for the health of the unborn child, and must also be seen in terms of a dilemma of blame and guilt: For, what happens if the child has birth defects that may be due to poor regulation of diabetes? In paper 3, it is mentioned that Ida has an eight-year-old son who is handicapped, owing to lack of oxygen during birth. The boy weighed more than expected, and was delivered by means of an emergency cesarean section. To her, this raised questions of who was responsible, who was to blame: herself, for not better controlling her blood glucose levels, and for not being able to deliver vaginally, or the midwife, for misjudging the weight of the unborn child, and not intervening earlier? Furthermore, such situations may also allot blame to the home patient and family caregiver: Why did she not perform her homework correctly? Or, could the husband have better supported the pregnant woman's homework?

Strategies for sharing responsibility for treatment are therefore not trivial, as they also relate to sharing the responsibility for the outcome of the treatment. Distribution of work and responsibility is an issue often discussed in terms of jurisdictional responsibility, particularly if new healthcare services span sectors in the healthcare system. In a project involving home treatment of heart patients, Dinesen et al. (2007a; 2007b) have described discussions of distribution of responsibility among the cardiologist at the hospital ward, the general practitioner, and the district nurse visiting the heart patient in his or her own home. Discussions resulted in a clear legal distribution of responsibility for treatment, wherein the cardiologist at the ward was responsible for treatment both during hospitalization at the cardiology ward and during home treatment, until discharge (Dinesen et al. 2007a, 4). However, the same study demonstrated that, although the cardiologist may have the juridical responsibility for the treatment, family caregivers also feel responsible for the home patient, and experience anxiety during home treatment (Dinesen et al. 2008): "All the spouses/partners of patients admitted to home hospitalization tended to be concerned about their loved one and felt a heavy responsibility for him or her" (ibid., 244). According to Dinesen et al., being at home with the home patient caused anxiety on the part of the family caregivers, as they were afraid of not knowing how to act, and whether they were actually able to act, should emergencies arise. Anxiety also stemmed from uncertainty related to the ability to interpret symptoms and changes in the condition (Dinesen et al. 2008, 244).

Thus, working out new arrangements and distribution of work also entails negotiations of the distribution of responsibility. It is important to consider that responsibility may be experienced differently in the social worlds of the home and the hospital. While the hospital may have more or less clear-cut jurisdictional agreements on who is responsible for treatment, this type of jurisdictional responsibility is not comprehensive. In the social world of the home, responsibility is closely tied to the performance of homework, and includes family caregivers who may be more or less directly involved in the actual caregiving. This kind of responsibility refers more to a feeling, and a sense of moral obligation to yourself and family members. For lack of a better term, this may be called "reciprocal responsibility", harking back to the reciprocal relationship tying together the family, as described previously.

Strauss et al. (1985) note that the shared participation in treatment and sense of responsibility on the part of patients and hospital staff may lead to conflicts. Monitoring for symptoms is the foundation for assessing and managing risk and provides the basis for initiating adjustment in treatment. Monitoring is performed by both patients and staff but is often invisible to others. Thus, staff members may notice symptoms of which the patient is unaware, just as the symptoms noted by the patient may not be expressed to staff members. This may lead to conflict, as the patient and staff may observe contradictory symptoms, and initiate contradicting changes in the treatment (Strauss et al. 1985, 94). According to Strauss et al., this a particularly important issue when patients engage in self-assessment and monitoring at home (ibid., 97). In the following section, I focus on healthcare professionals, and explore the work-related implications of the new division of labor and responsibility.

Work of healthcare professionals

The new working arrangements entail transformations in the work carried out by healthcare professionals, both with regard to new procedures, and to interacting with home patients. Based on a comparative study of nursing practices at a call-center and in a clinic, Oudshoorn (2009) argues that healthcare services are not merely replicated when moved from a clinic to a telemedical service at a call-center, but that the transformation involves new practices that create a different kind of care, changing the character of the work and healthcare service, as well as perspectives on health conditions (Oudshoorn, 2009, 390, 402).

Fundamental to the change in practice is an alteration in the interaction with the patient: Nurses at a cardiology clinic rely on *physical proximity*, where they "physically touch and care for patient bodies" (ibid., 393), and in connection with this, attempt to create a *narrative proximity*. Narrative proximity refers to the practices by which healthcare professionals get to know the patient, by hearing and trying to understand the patient's story (Oudshoorn 2009, 393, referring to Malone 2003, 2318). However, in telemedical treatment, physical and narrative proximity are replaced by communication mediated by information and communication technology, and data from biosensors; what Oudshoorn calls *digital proximity* (ibid., 397). Digital proximity requires that the telenurses[23] develop new communication skills, in particular when using an ordinary phone (versus a video conversation): they must learn to persistently ask the home patient to describe symptoms that nurses have traditionally been able to see for themselves; they must learn to listen to the home patient, to the breathing, and to what is said implicitly; and to be able to assess the severity of the situation by listening to the anxiety of the people in the background (ibid., 399). Moreover, digital proximity at the call-center is based on a strict protocol for interacting with the home patient. The call-center monitors automatically transmit data on blood pressure and weight, which home patients measure on a daily basis. Alterations trigger an alarm at the call-center, and the telenurse must call the home patient. A protocol on the computer then guides the telenurse through a specific line of questioning, to determine the urgency of the problem (Oudshoorn 2009, 398).

According to Oudshoorn, the new arrangement causes transformations in which the focus shifts from establishing narrative proximity through open conversation, to acting on data generated by devices in the home, and pursuing an inquiry into the condition by means of protocol-driven communication. Furthermore, the role of the nurse changes from that of a counselor for the patient and relatives, to improve self-care on an *optional basis*, to acting as an assessor of data, where self-care, in the form of measuring blood pressure and weight, becomes an *obligation*. From this perspective, transformations occur not only in the work of the telenurse, but also in the work of home patients, and imply a

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[23] The word "telenurses" is Oudshoorn's term for nurses employed at the call-center, who interact with home patients through telephone conversations.

change in perspective on the condition being treated. Oudshoorn argues that the character of the condition treated alters from a focus on *illness*[24], which includes the experiences of the patient, to that of a *disease*, which focuses exclusively on the condition from a biomedical point of view (Oudshoorn 2009, 403).

Healthcare services based on digital proximity have been criticized as fragmenting home patients into decontextualized representations in the form of images, graphs, and other types of data, where these representations, rather than the whole patient and how the patient experiences the disease and its development, comprise the information on which a diagnosis is based (Mort et al. 2003, 284). However, it is widely acknowledged within STS that persons have multiple memberships in social worlds, as the very notion of "home patient" implies, and that humans are what Mol (2002) would describe as *multiple*, in the sense that they are practiced differently in diverse contexts. From this perspective, fragmentation is not a negative phenomenon to be avoided, but is instead a fundamental condition of being human. Oudshoorn's analysis does not attempt to judge the two working arrangements. Rather, her goal is to demonstrate that work and healthcare services are not replicated in telemedical solutions, but that transformations occur, which alter the services and the character of the work carried out by healthcare professionals, and the way in which patient condition is perceived. In a related study of home monitoring of ECGs performed by home patients, described in chapter 4, Oudshoorn (2008) identifies other types of work that are redistributed in new working arrangements. While the purpose of home monitoring of heart conditions was to relieve cardiologists, this does not mean that work disappears. Instead, work is redistributed to others in the working arrangement: to home patients, who become diagnostic agents; to telenurses, who must engage in *inclusion work*, persuading patients who are unsure of their ability to master technological devices to participate actively in remote ECG monitoring (Oudshoorn 2008, 280); to teledoctors, who make preliminary analyses of the data and perform sentimental work, reassuring anxious home patients who are worried about the severity of their condition (ibid., 281); to the general practitioner, who has jurisdictional responsibility for analyzing the data. While much of this work is, to a large extent, invisible to others, and entirely overlooked in formal work descriptions, it nevertheless plays an important role in new working arrangements.

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[24] For a discussion of the distinction between "illness" and "disease", see Hahn 1984.

From this perspective, different working arrangements result in work being transformed and distributed in diverse ways. In this regard, it may be useful to compare the Dutch solution, reported on by Oudshoorn, with a Danish solution evaluated by Dinesen et al. (2007a; 2007b; 2008). The two solutions address the same issue of monitoring heart patients in the home, but do so in different ways: The Dutch solution relies on digital proximity, as described above, while the Danish one is based on physical proximity, but has moved the monitoring into the home, in the form of a visiting district nurse. The working arrangement of physical proximity in a different location also causes transformations and redistribution of work. First, work is redistributed from the ward to the visiting nurse, as she now has to participate in teleconferences with the hospital team, and will often have to learn more about cardiology. The hospital nurse experiences a transformation in her work, as she no longer has to engage in the daily monitoring of the patient who is now being treated at home, but acquires a new task, as she now has to discharge the same patient twice, once from the ward, and again from home treatment (Dinesen et al. 2007, 8). Secondly, an issue arises regarding the character of care in the home. Dinesen et al. (2008) state that the majority of home-treated cardiac patients experienced a great difference between the monitoring they underwent at the cardiology ward, and when cared for at home: At the ward, they experienced the monitoring as being under surveillance, which they found rather stressful. In contrast, they regarded the home monitoring as being looked after, and felt more relaxed (Dinesen et al. 2008, 244). However, the family caregivers experienced an invasion of privacy, as they had to alter routines in order to accommodate the schedule of the visiting nurse. Thus, even when the new working arrangement is based on physical and narrative proximity, it still implies a redistribution of work and transformations in care, and gives rise to other concerns. Wang and Barnard (2008) also touch briefly on the topic of privacy, and state that parents of ventilator-dependent children found it stressful to have nurses living in the home, as they felt it interfered with the privacy of the home and parental control (Wang & Barnard 2008, 504).

Negotiations of public and private spheres in the home are often delicate, as in Western countries the home is often regarded as a private sanctuary, making the presence of representatives of public authorities be perceived as a potential threat or invasion of privacy (Angus et al. 2005; Dyck et al. 2005)[25]. The performance of home care therefore

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[25] This tension has also been addressed in terms of privacy and security when handling and transmitting data (e.g. Meingast et al. 2006; Rindfleisch 1997).

demands much collaborative work on part of visiting nurses, home patients, and family caregivers (e.g. see Spiers 2002). Working arrangements that introduce healthcare technologies from the social world of the hospital into the home, for example, in the form of remote monitoring such as the Dutch telemedical solution, have been criticized as extending the *medical gaze*, penetrating the home with a biomedical discourse and the vision of a healthy body (Olesen 2010, 312). From this perspective, healthcare technologies continue to enhance the asymmetrical power relationship between the social world of the professional sector and that of the popular sector. In the following section, I present a critique of this power relationship, and discuss how the introduction of healthcare technologies creates opportunities for the negotiation of structures of healthcare services.

Healthcare technology as a transformative tool

The present and previous chapters address the redistribution of work and responsibility, alterations of social relationships in the family relating to the performance of homework, and conflicting concerns between the social worlds of the popular and professional sectors. These transformations, which are a consequence of negotiating working arrangements when healthcare technology is introduced to the home, are closely tied to the notion of the empowered, self-caring patient introduced in chapter 1, and are a cause for concern. Olesen argues that the redistribution of work involves the risk of imposing an overwhelming responsibility on the self-caring patient, who may not be able to mobilize the necessary resources to make qualified decisions, owing to the disease condition (Olesen 2010, 324, 329). Furthermore, Olesen notes a discrepancy between responsibility and the notion of empowerment. Often self-caring patients are restricted in their actions and in specific decisions on treatment, as they have little influence on what healthcare services are offered just as the allocation of resources within the healthcare system delimits the options of the self-caring patient. Thus, empowerment of self-caring patients may be argued to be limited, although self-caring patients assume responsibility for performing treatment (Olesen 2010, 322). Moreover, Forchhammer points out that patient schools promote the engaged, self-caring patient as a universal ideal, and thereby exclude other ideas of the patient's role. A possible consequence may be that those who, for any reason, do not become self-caring patients – whether they disagree with the existing norm, or are unable to perform the expected homework – will be marginalized, and even stigmatized (Forchhammer 2010, 99). The individualized, normative frame of reference of the empowered, self-caring patient risks placing full responsibility on the patient him- or herself, with any blame resting solely on the self-caring patient, should self-care be unsuccessful (Olesen 2010, 323).

As Ida's case illustrates, it is important to bear these concerns in mind. Ida is extremely frustrated, and feels unable to mobilize the resources necessary to perform her homework. Additionally, she is unsuccessful in rejecting the responsibility laid upon her, as the healthcare professionals deem hospitalization unnecessary, and her influence as an empowered patient is thus limited. While these issues are important, they do not stand alone, but are balanced by cases such as Maja's, for example: She experiences a sense of control and security in the same self-care treatment program. For Maja, self-care in the form of technology-supported homework provides a tool for managing the trajectory of her condition and minimizing uncertainty. The two cases emerge from the same treatment program and transformations in the redistribution of work and responsibility, but with two highly contrasting experiences of self-care and homework on the part of the home patients.

These dissimilar experiences prepared the ground for the eDiary prototype evaluated and discussed in paper 4. The eDiary is based on acknowledging that transformations in healthcare services occur when healthcare technology is introduced, and that work and responsibility are redistributed. Its development and design have attempted to take the social world of the home as a starting point, with the goal of addressing how technology may aid pregnant women with diabetes, and their husbands, in the face of extensive homework. This approach was inspired by the early visions outlined in paper 2, in which my co-authors and I argue that there is a need for supplementing the perspective of the social world of the professional sector with that of the popular sector, as disease trajectory management and homework are not solely concerns of home patients, and that healthcare technology needs to take this into account. Taking its point of departure in the social world of the popular sector, the eDiary aims to deliver healthcare technology that considers the diversity of concerns of home patients and their everyday lives; it aims to support pregnant women and their husbands in their efforts to perform patient homework, and not impose more homework upon them. The women themselves should be able to determine strategies for integrating or segmenting disease from their everyday lives, whether they want healthcare technology to be visible or invisible (paper 5). In the eDiary, this is supported by a flexible platform, where the women choose whether they wish to use their computers (e.g. at work) or their mobile phones to enter blood glucose measurements, according to their routines and individual preferences. Making consultations with a diabetes specialist available through videoconferences is another approach intended to increase flexibility of treatment, by enabling the women to choose the setting of the consultation, whether it is at work or at home. Moreover, a central goal of the eDiary is to support the strategy for sharing responsibility (paper 3), by making video recordings of consultations at the outpatient clinic available to the father.

The eDiary would probably not aid Ida and her husband in performing homework, as their situation is overshadowed by other concerns, while women like Maja may benefit from such a tool. Moreover, in keeping with the argument in this and the previous chapter, the evaluation of the eDiary indicates that the introduction of healthcare technology creates opportunities for negotiating working arrangements. Implicit in this statement is also the recognition of the transformative potential of healthcare technology that may be used to initiate discussions of the relationship between the healthcare sector and the home. The eDiary exists for the benefit of the pregnant women with diabetes, rather than the healthcare providers. It emphasizes that patient data comes from the social world of the home, that the women have ownership of the data, which the healthcare professional must ask permission to access. On a small scale, the eDiary questions the relationship between the social worlds of the professional and popular sectors, and establishes negotiations regarding the distribution of work and responsibility, raising the question of what kinds of healthcare technology and healthcare services we wish to promote. The questions of which problems to address and solve by means of new healthcare technology, and which transformations to promote will be the focus of the closing discussion.

Summing up

This chapter has addressed the collaborative aspects of new working arrangements, of moving healthcare into the home, and demonstrating how work and responsibility are redistributed and transformed. First, I noted the implications for the alteration of reciprocity in relationships within the family, as self-care and homework often involve family caregivers, which may create practical and symbolic dependence on the part of the home patient. I further argued that the collaborative effort involving the family caregiver in homework might also be seen as a strategy for sharing reciprocal responsibility, which lies implicitly in the distribution of work. Secondly, I argued that work does not disappear, but is redistributed to other persons in the work arrangement. Moreover, the new arrangement causes transformations of work and care, regardless of whether interaction between healthcare professionals and families is established by means of digital or physical proximity. Finally, I discussed technology as a transformative tool that creates opportunities for how work and responsibility are distributed between healthcare professionals and home patients, and for the negotiation of what healthcare services are, or should be.

Concluding remarks

At the beginning of this dissertation, I introduced Jens's flower arrangement, and described the contrasting esthetic orders of the home and the functionality of the workspace of the caregivers' office. My investigation has been concerned with what happens when these two contrasting orders meet, via healthcare technology. This dissertation has explored numerous ways in which the two worlds may be connected, and discussed the transformations of care and of the new working arrangements, and the redistribution of work and responsibility that may occur, owing to the introduction of healthcare technology to the social world of the home.

I have introduced you to Jens, who put great effort not only into domesticating his Tablet PC in accordance with his sense of home, but also into integrating his pills into his daily routines by creating a small, therapeutic landscape on the kitchen counter. I have presented you with dialysis machines and pills, and described how healthcare technologies may take the forms of standardized packages or boundary objects, either pushing certain procedures into the home, or being flexibly integrated into the routines of everyday life. You have met Ida and Maja, who, despite their participation in the same treatment program and use of identical healthcare technologies, had contrasting experiences of performing their homework. Whereas Maja experienced a sense of being in control and being able to manage the trajectory of her diabetes, Ida was faced with conflicting concerns, when her depression and severe nausea made it difficult for her to control her blood glucose levels, to her extreme frustration and anxiety. Finally, I have described how women with diabetes and their husbands attempt to share responsibility for carrying out homework, and have pointed out that the inclusion of family caregivers may create a practical and symbolic dependency, potentially altering social relationships within the family.

When discussing and developing new healthcare technology and services, it is important to keep in mind these stories and glimpses of disease and treatment trajectories. Technology is neither good nor bad, nor is it neutral (Ihde 2002). Transformations of care occur when healthcare technology is introduced. New working arrangements must be worked out, in which work and responsibility are distributed in new ways, creating new dilemmas. The challenge lies in how to approach this task of designing new healthcare technology: For whom and what do we design? There are health economists, who wish to calculate the potential reduction in costs, there is the professional sector, where establishing evidence of compliance and the efficacy of diverse treatment regimes is a dominating agenda, or we may seek to improve the everyday lives of home patients, who must live with and balance concerns related to disease, parenting, working, and leisure activities (Storni 2010). Throughout, I have argued that it is necessary to take into account the voices of the home patients, when developing healthcare technology. Presently, regional administrations and various public and private organizations, along with private companies, drive development. Consequently, the development of new healthcare technology and services tends to take as its starting point the perspectives and needs of the professional sector. The disadvantage of this is that home patients are addressed last in the development process, and are often presented with specific solutions which they may either accept or reject, but over which they have very little influence (Pols 2010). With my dissertation, I hope to tell a story of great heterogeneity, of multiple concerns and diverse perspectives on care and everyday life, a complexity that I believe should be reflected in the development of healthcare technology. I believe that introducing healthcare technology to the home has great potential. I also argue that in the process of developing and using healthcare technology in the home, it is important to be attentive to conflicting concerns that may exist between the social worlds of the hospital and the home. It is important to realize that the introduction of healthcare technology to the home involves work and responsibility, not only for the home patient, but also for family caregivers, who may or may not benefit from the new working arrangements.

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Part II: Analyses of case studies

This part of the dissertation concerns the empirical investigation of new healthcare technologies. The analyses of the ethnographic field studies resulted in the following five published papers, and one paper that is to be submitted for publication. The papers empirically explore the work arrangements and negotiations that occurred upon the introduction of healthcare technology during the case studies. The papers are presented in chronological order, and appear in the format of the publication.

Papers included

Paper 1: *Of Pill Boxes and Piano Benches: "Home-made" Methods for Managing Medication*

Palen, L. & Aaløkke, S. (2006) *Proceedings of CSCW'06*, 79-88

Paper 2: *Healthcare in everyday life: designing healthcare services for daily life*

Ballegaard, S., Hansen, T. R., Kyng, M. (2008) *Proceedings of CHI'08*, 1807-1816

Paper 3: *Teknologiers mellemkomst i ambulant behandling og egenomsorg. Med fokus på gravide kvinder med diabetes (The intervention of technologies in ambulant treatment and self-care: focusing on pregnant women with diabetes)*

Ballegaard, S. A. & Aarhus, R. (2009) *Tidsskrift for Forskning i Sygdom og Samfund,* Vol. 11, pp. 71-85

Paper 4: *The eDiary: Bridging home and hospital through healthcare technology*

Aarhus, R., Ballegaard, S. A., Hansen, T. R. (2009) *Proceedings of eCSCW'09*, 63-88

Paper 5: *Negotiating Boundaries: managing disease at home*

Aarhus, R. & Ballegaard, S. A. (2010) *Proceedings of CHI'10*, 1223-1232

Paper 6: *HomeHealthTour: A method for studying health and disease in the home*

Aarhus, R., Ballegaard, S. (To be submitted to Pervasive Health Conference 2011, Dublin)

Of Pill Boxes and Piano Benches: "Home-made" Methods for Managing Medication

Palen, L. & Aaløkke, S. (2006) *Proceedings of CSCW'06*, 79-88

Of Pill Boxes and Piano Benches: "Home-made" Methods for Managing Medication

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ABSTRACT

We report on the results of an ethnographic study of how elders manage their medication with the objective of informing the design of in-home assistive health technology to support "medication adherence." We describe the methods by which elders organize and remember to take their medication—methods that leverage a kind of distributed cognition. Elders devise medication management systems that rely on the spatial features of their homes, the temporal rhythms of their days, as well as the routines that occasion these places and times to help recall and prospective remembering. We show how mobile health care workers participate in the development and execution of these systems, and "read" them to infer an elder's state of health and ability to manage medication. From this analysis, we present five principles for the design of assistive technology that support the enhanced but on-going use of personalized medication management systems, and that also allow for remote health care assistance as it becomes needed.

Categories and Subject Descriptors

J.3 Life and Medical Sciences—Health, Medical Information Systems, H.5.2 User Interfaces—User-centered design, H.1.2 User/Machine Systems—Human Factors.

General Terms

Design, Human Factors.

Keywords

Assisted living, health care, elder care, medication, drugs, pharmaceuticals, adherence, compliance, distributed cognition, external cognition, intelligent environments.

1 MEDICATION MANAGEMENT IN ASSISTED LIVING

In-home health care has received research and development attention because it is believed that thoughtful innovation can extend the length of time that people stay in their homes. As the world's old-age population continues to rise, the hope is that such technological advancements can defray expensive health care costs while maintaining the dignity of citizens who can continue to manage their own care in their own homes and communities.

We report on a study of in-home health care for elders, with a particular focus on how elders and their health care providers manage medication. Taking medication at the right time and in the right amounts is an important aspect of in-home health assistance, though it is a difficult one to support. Remembering to take medication—and remembering if medication was already taken—is a challenge for many of us no matter our age, but is a particular problem for elders with compromised health [8, 10, 21]. Elders often have many medications to manage throughout their days, and forgetfulness can be an additional challenge for this population. Some health conditions are such that people who forget to take their medication will deteriorate physically and mentally, making it even more difficult to remember to take future doses. Yet, monitoring consumption is very difficult. Short of invasive measures—sampling blood or urine for example—or eye-witness confirmation, it is difficult to be assured that a person has taken the appropriate dose.

1.1 Elder versus Clinical Perspective

Our research was prompted by a third-party development and pilot deployment of a new information system intended to track elders' drug consumption and transmit this information and other health measures to remotely located health care workers. In this technology case, the system was primarily designed for the benefit of the health care workers, and therefore resulted in a design that favored clinical depictions of drug use. As such, this system relied on the ability of elders to know their medication names and dosage, as well as adhere to exact times of consumption. This problematically divorced elders' understanding of their medication from situated activity to one of post-hoc knowledge and recall [4], and resulted in a system that queried users to, for example, "Confirm that 5 mg of Novrad was taken at 0730."

Our research has instead found that daily medical management by elders in their homes leverages a kind of *socially distributed cognition* [18] that makes use of features of homes and schedules as well as other people to help with planning, organization and prospective remembering, the need to "remember to remember" [28]. Our investigation shows that people manage their medications—with only partial information about what the medication is—through a set of personalized spatio-temporal arrangements and routines that they devise in their homes. These physical arrangements and routines provide a sense, structure and rhythm to intake even when people know very little about the medication itself. In contrast to our example above, this translates into useful and reliable knowledge about medication that is encoded into external representations—physical features of the pills, their containers and the home environment, as well as temporal features of a person's

CSCW '06, November 4-8, 2006, Banff, Alberta, Canada.

day. An elder's practical knowledge that medication was taken, then, looks more like this: "The pill I already took today was in the first bottle in the row of bottles in my kitchen cabinet, taken immediately after my breakfast."

While these kinds of confirmation reports might not appear to be especially precise because they are not framed in a clinical fashion, we believe that these realistic accounts of intake can also be reliable. Our goal is to show how personalized medication management systems are intelligent even though they do not always conform to clinical standards of medical description, and that those existing systems can be leveraged with IT support to enable ongoing independence with computer-mediated remote assistance.

We also found that those same handcrafted routines and arrangements that exploit features of one's home environment also serve as resources for mobile health care workers. Health care workers are able to "read" and support the creation of these personalized systems to communicate with their clients and to assess needed levels of care. They *infer* that all is in order by talking with the elder, checking the current state of the medication (its orderliness, remaining amounts and so on), and assessing the physical state of the home.

What is important when considering the future of IT in the home for assisted health is to appreciate that IT needs to support these grounded, folksy descriptions—because that is the manner in which people think, act, and feel intelligent and autonomous. By extending existing methods for medication management through integrated IT support, the methods can be adapted to people's changing health and assistance needs over time.

1.2 Adherence Through Support

In this paper, we have largely chosen to use the phrase "medication management" as opposed to "medication adherence," "patient compliance" and "drug administration." These latter terms are what the clinical literatures tend to use; "adherence" and "compliance" speak to a clinician's perspective of keeping to intake schedules, and the term "drugs" emphasizes prescription medication. We have elected to refer to and study "medication management" for two reasons: we want to more closely identify with the elders themselves, who are more likely to refer to drugs as "medicine" and "medication." It also allows for conceptual inclusion of non-prescription drugs, including vitamins, supplements and over-the-counter medications.

However, "medication adherence" and "patient compliance" to a drug regime of course are serious concerns. Some of the most recent research in the gerontology literature [10] shows that "compliance" is at about 75% on average, meaning that, across the sample population, only three-quarters of medications are taken by elders managing their own medication. Our take on this problem is to consider how elders manage their medication with the assistance of health care workers, so that we might be able to implement IT to 1) better support the creation of and interaction with those personalized systems in order to 2) further improve dosing reliability and 3) more accurately measure and monitor medication "adherence" by 4) modelling remote, computationally-supported assistance for medication management on face-to-face assistance.

We report on the findings from our qualitative investigation of eldercare in the Danish social welfare system. We studied 10 elders who are living in their own assisted-living apartments and are visited sometimes multiple times a day by mobile health care workers. From this, we derive principles for design for IT for in-home health care, particularly with respect to medication management.

2 DESIGNING FOR THE HOME

There is a large body of work in the arena of assisted living. For example, research projects stemming from Georgia Tech's Aware Home initiative, including the reverse family portrait [24] and the cooking assistant [6], are based on making it possible for people to age "in place" by emphasizing familial social connection and providing assistance in critical everyday tasks, respectively. The multiple-partner interLiving project [19] addresses matters of intergenerational family communication. Assistive technologies for people with disabilities also are designed with the intention of enabling people to help themselves with remotely located practical and emotional support [5]. The "care in the community project" has developed a wellness index and overview, which provides caregivers with views of how elders are doing by considering what activities are truly measurable and indicative of well-being [3]. The ELDeR project has considered how elders are supported by an ecology of people, products and activities in the physical context of home and the emotional context of community [14, 17]; this perspective has helped inform ours here. These are just a few examples of the growing body of work in assisted living.

On the medication front, the gerontology literature has researched "medication adherence" and "patient compliance" to medication regimes extensively, though these investigations tend to examine quantitative aspects of management—how much medication is consumed by considering different populations, health, age, and dosing variables [8, 10, 21]. In the human computer interaction literature, there is some systems-oriented work in this area, including exploratory work at Georgia Tech using the Memory Mirror system [26]; The EQUATOR project's MediPic prototype [7]; and Wan's Online Medicine Cabinet [27]. Fishkin, Wang and Borriello [13] developed a system for medication monitoring that supports some of the real practices we observed by relying on smart surfaces that build on people's own methods for medication management. In particular they support the idea of the distribution of medication across spaces in the home. We hope our investigation of elder-centered practices complements and extends this work, as well as these other HCI-centered approaches for supporting medication management.

Our work is also guided by research that pertains to more general issues of designing for the home and households. Most notably, we draw on the findings and insights of Taylor and Swan [25], Crabtree and Rodden [9] and Edwards and Grinter [12]. No matter the target user audience (elders, parents, children, people who need additional assistance and so on), homes are special environments. As Edwards and Grinter [12] point out, people at home have different technological needs and expectations than at work, and designing for these environments is qualitatively different. The home is its own institution that operates under rules and expectations for privacy, communication, conflict and so on that might be different than workplace environments. Homes are places where any number of activities take place by different actors throughout the day, from meal preparation, to laundry, to entertainment, childcare, emotional connection and so on. Technology there is often introduced piecemeal and so needs to be compatible with devices introduced before and later. Domestic technology needs to be especially robust and reliable and allow people to continue their activities even in the event of technology failure.

Crabtree and Rodden [9] and Taylor and Swan [25] closely examine information-based activities of the home—processing postal mail and keeping track of family members' schedules, respectively—illustrating that households use features of spaces and places within homes to develop means for coordinating plans, sharing information and essentially doing the work of home. For example, mail comes into a home and is moved to different locations depending on its status, intended audience, and the set of actions it might invoke (bill paying later in the month, making a phone call for followup, writing a thank-you note). Resting in a pile next the front door, it signals one thing (unprocessed); opened at the center of the kitchen table before a meal it means another (something for the family to share perhaps); sitting unopened in front of someone's bedroom door, it means something yet again (intended only for that person). Crabtree and Rodden [9] explain that it is the routines of the family and their commonly-understood organization of the mail that create the sense and purpose for members of the household.

Taylor and Swan's work [25] on the management of things like appointments, reminders and so on in a family home extends these insights to show that with these locations of information and activity, families develop and rely on artful organizing systems that are distributed across places and artifacts within the home. The home itself offers places that generate additional meaning depending on the arrangement of materials and information there. As we hope to show, our investigation of medication management echoes some of these findings, though the extent and purpose of spatial distribution can be different, as well as the nature of collaboration in the medication case. Temporal patterning plays a central role in the management of medications as well.

3 THE ELDERTECH STUDY

3.1 Elder Care in the Danish Welfare System

Denmark is a social welfare state. Health care is available to everyone, and includes assistance in older age that strives to keep citizens for as long as possible in their own homes or "protected residences"—homes that are located close to health care professionals for more immediate care if needed. This philosophy is in keeping with Danish ideals of enabling people to help themselves in most everything they undertake no matter stage of life, and happens to accord with a growing world-wide need to find ways to care for a progressively aging population "in place."

The Danish welfare system provides a variety of services to elders that can include nursing care as well as home-help assistance like house cleaning and personal hygiene. Needs are assessed by the local municipality. Nursing care is always provided free by the municipality. Home-help and other personal services might incur a fee if the health condition is a temporary one, but not if the health condition is permanent. Elders are entitled to the same care services whether they are in their own homes or have moved into protected residences. Protected residences can be long-term homes for elders; they are not simply short-term stopping grounds before more intensive care becomes necessary [1].

Assistance for elders is organized by what is called the Local Center in their geographical area. Several professionals are employed by each Local Center: Nurses, Assistants and Helpers, physical therapists and occupational therapists. We focused on the work of the first three professions, as they have regular schedules for visiting citizens. Nurses have the most medical training, and coordinate long-term medication plans with doctors, make medical assessments, and so on. With citizen-specific training by Nurses, Assistants can provide some medical support like changing wound bandages, giving injections, changing leg support stockings, etc. Assistants visit more frequently than Nurses to provide regular care and assistance, and, in comparison to the Helpers, handle the more complex, medically-involved care cases. Helpers do little medical work, but both Assistants and Helpers assist with personal care like bathing, dressing, making beds, housecleaning, and meal preparation. In this paper, we will use these titles when we are referring to the particular professionals, but when referring to them generally, we use "health care workers" who provide health care "assistance."

Figure 1:
The nurses' office in the Local Center is located behind the protected residences

For our study, the Local Center has purview of 114 protected residences but also provides less frequent help to 600 other citizens living in regular residences in an even larger geographical area. The protected residences, where our participants live, are buildings that belong to the municipality and are situated closely to the Local Center (see Figure 1). They are apartments between 65 and 80 m^2 (or 700 to 860 f^2) modified to meet the needs of elderly people but are otherwise comparable to city center apartments. Hence, there are string-pull alarms in each room that the elder can trigger if help is needed, which are in turn answered by Local Center staff. Each has a living room, kitchen, a large bedroom and spacious bathroom. The size of the rooms accommodate special furniture and aids such as hospital beds and walkers, and for the staff to work more easily within the space of the apartment. Elders furnish the apartment with their own furniture and decor.

3.2 Participants

We worked with a nearby Local Center to find 10 elders who received at least one health care worker visit a day and were able to participate for an extended period of time. We studied health care workers out of the same Local Center. All participant names used here are pseudonyms.

3.2.1 Elders

The participants were seven women and three men between the ages of 65 and 88 years with an average age of 81 years. They all lived in protected residences, and at the time of the study, eight of them lived alone and two lived with their spouses. The length of time in their apartments ranged from one month to eight years. Four citizens made use of wheelchairs (though not necessarily inside their homes) and four used walkers. All had compromised physical health that required medical assistance but various degrees of personal care assistance. Over the entire project period of 9 months, each of the elderly participants was hospitalized for some period of time; two passed away late in the project period.

3.2.2 Health Care Workers

Six health care workers served as participants in our data collection, and included two Nurses, two Assistants and two Helpers. They have many years of specialized experience in eldercare, ranging from 11 to 25 years.

3.3 Method

We conducted field studies at the Local Centre over a period of 9 months. During the last 4 months, some of our elders had a computer system installed in their homes that was intended to record reported drug intake as well as capture different health measures. Over the whole of the project, we used ethnographic methods to study what was initially a fairly broad set of interests in the domain of elder care, with an eye to understanding how elders manage their own health, the function of the health care worker visits, means of social connection, the function of the Local Center in community-building, and the nature of work of mobile health care workers. In addition to these set of concerns, the work included an evaluation of the computer system pilot. A central issue throughout the project has been the management of medication by the elders and the health care workers—the subject of our work reported here. As the field studies evolved, we tailored our methods to capture particular activities.

Initial observations were conducted at various events at the Local Center to understand the kind of activity that happens there, and to meet citizens. This included partaking in lunch in the dining hall; attending entertainment events, fitness class sessions and an internet café class; and meeting with the weekly coffee group.

Additionally, we shadowed a Nurse, an Assistant and two Helpers—all in-home health care workers—each throughout an entire workday, which has anywhere from 6 – 11 home visits. For each day of shadowing, we began by attending the morning coordination meeting where all the Local Center's health care workers meet at the start of their shifts. Shadowing revealed how workers coordinated with each other and individually organized their appointments, paperwork and equipment throughout the day, observations that were also informed by Nilsson and Hertzum's account of the coordination work of Danish mobile health care workers [22]. We focused particularly on how care is provided within citizens' homes. We examined how health care workers oriented themselves in homes and how they and citizens interact. This observation was later supplemented by interviews with the six selected health care workers.

All ten citizens were interviewed and observed in their homes on at least one occasion prior to the computer installation. The initial interviews were open-ended and semi-structured and lasted for one and a half hours, and sometimes longer. The citizens were asked to describe their daily and weekly routines, social networks, feelings about the kind of care they receive, as well as show how they manage their medication. Two elders were videotaped while preparing their medications for the next day. In addition we studied and photographed areas of importance where medication was kept, where contact and medical information was stored, and particular places that we came to call "altars" where collections of important daily items like the telephone, remote controls, insulin syringes, and lip balm, for example, were arranged for easy access while sitting in a favorite chair.

As part of our larger research project, we observed some of the installations of the computer system for managing medication. Analytically, this allowed us to "see" otherwise more invisible matters of spatial arrangements in the home—which came to be an important focus of our study as we will explain next—that were supported or disrupted by the installation.

4 MEDICATION MANAGEMENT

4.1 The Work of the Elders

[redacted]

Figure 2:
Prepackaged doses prepared by the pharmacy

Management of medication is an important activity in the lives of the elders we studied. For some, it requires a good amount of attention to organize and consume medicine. When one has to take as many as 35 pills a day, or self-administer insulin depending on blood sugar levels, the management of medication is a foregrounded activity. For some people, management of medications can become central to one's day, and can itself serve to organize other attributes of daily schedules. Depending on individual capability, dosing may be facilitated by nurses, pre-packaged into daily dosage packets by the pharmacy (see Figure 2), or done by the elders themselves.

Figure 3:
The official municipal pillbox system

Pillbox kits, available through the local municipal government, are comprised of 7 horizontal boxes for each day of the week that fit inside in a folder that either the elder or the nurse fills. For Marie, depicted in Figure 3, the "medication-week" begins on Thursday (Torsdag), since the nurse visits every third Wednesday to distribute pills in her pillbox system. Marie shows how she takes a new week of boxes and puts them in the folder at the far left.

In our studies of elders in their homes, we found that management of their medications was personalized to each elder and their home, and developed over time. These methods are vital to the successful self-administration of medication because, we found, except for all but two cases, elders could not readily identify what all their medications were called, and only possessed partial information about what they were for. This information was often not important to them—what was important, for example, was that they took "the small pink tablet" at breakfast and dinner, but not at lunch. This is not at all to say that elders per se are incapable of learning or knowing what their medications are or what they are for; indeed anecdotal evidence suggests that many people—young and old alike—simply take medications with only partial information about its features, including name and purpose. A few of our elders, when asked what a medication was for, knew for example that it was "for the blood," and even then read the label for our benefit to find that, "Oh, this is for cholesterol." Often elders *could* know what their medications are for, but they don't *need* to know. It could also be the case that they knew at one time, but have since forgotten or, rather, deferred or reassigned or *encoded* [20] only its most salient meaning (when to take it) into an external cognitive-computational system. People use their environments to organize things and information and to be "smart" [9, 18, 23].

We found that people exploit and rely on features of their physical environment and the temporal rhythms of their day to help them organize and remember to take their medications. They spatially organize their medications, which are occasioned during the daily routines that are themselves developed over time [9]. And, because these environments are homes that reflect individual preferences, personalities, needs, and styles of living, organization of medication is also adapted to each home's affordances for storage and placement. Medicine cabinets run out of space, kitchen shelves might become too low or high as someone ages, and so on. Medication might be found in unexpected places that are for various personal or aesthetic reasons the appropriate places for the particular home's resident. In our analysis, we present the means of spatial and temporal ordering in medication management, as well as other factors and features of use that figure into this task.

4.1.1 Spatial & Temporal Orderings

People use the arrangements of things in space in intelligent ways [20] to support internal cognitive activity with cognitive artifacts and external representations [23]. Creating and manipulating external representations of information is a natural way of supporting and enhancing human ability, and happens in all aspects of human life (food preparation and cooking [11], bartending [2], air traffic control [16] are a few lively examples in the literature). We conduct our lives in a spatio-temporal context and with other people; we build external representations of our cognitive activity as ways to mark, measure and support estimations, calculations, memory and so on. Doing so supports not only ourselves, but very often is for the benefit or inclusion of other people in the activity, resulting in what Hutchins calls *socially distributed cognition* [18].

Figure 4 shows Ida's medication in her kitchen cabinet. Ida seems to have little knowledge about her medications, knowing neither the names nor the purposes of most. However, she is also one of the citizens who is fully responsible for doing her own dosing. To do this, she relies on a spatial arrangement of her medication—and the path of her morning routine to occasion the arrangement—to guide her. Just below her tea selection in her kitchen cabinet, Ida has arranged her medication in a right to left fashion exploiting the natural spatial affordance of "next" in a linear order [20]. All the medication in the cabinet is supposed to be taken each morning (and only then); her morning routine, which occasions the cabinet, reminds her to open each bottle in their linear order and sequentially take a pill from each.

[redacted]

Figure 4:
Ida's medicine in a kitchen cabinet, taken sequentially from right to left

Figure 5:
Margrethe's special heart medication (circled) is placed away from her daily medication on the first shelf

Figure 5 shows a similar linear ordering on the first shelf, but Margrethe also takes the additional prescription medication circled in the picture for her heart based on how she is feeling. This medication is kept separate from the other medication, though in the same cabinet, an example of how physical artifacts can be *symbolically marked* as distinct from others.

The simple placement of things in spaces that have particular meaning and purpose—*places*—also cues prospective remembering. For example, Marie keeps her medication on the kitchen table, since she has to take something at every meal. Jens keeps his midnight medication by the bed on his nightstand where he will remember to take it even though all his other medication is located in the kitchen. We will return to the idea of the exploitation of space and place in short order when we discuss how arrangements in particular places evoke and support routines.

The most straightforward example of temporal cueing for taking medication is the general practice of associating dosing with mealtimes. Sometimes this is necessary, because some medication needs to be taken with food, but it also serves as a way of helping people conveniently remember to take medication and of pacing consumption throughout the day. It is much more likely that one will remember to take a pill 3 times a day at mealtimes than 3 times evenly distributed across one's waking hours. One participant, Anna, used to use only temporal cues to remember to take her medication. Anna takes a great deal of pride in her home and likes to keep her health matters private—as such, she used to keep her medications tucked away in her piano bench, which happened to be located near her dining table. At mealtimes, she would go to her piano bench and take out her necessary medications. However, recently her medication schedule changed to include two additional times outside meal times—2pm and 5pm. Upon that change, Anna needed to resort to spatial placement reminders, and so began to use a pillbox that she filled every morning and (quite reluctantly) placed on her living room table to remind to her to take the medication at the odd hours that linked to nothing regularly notable in her day.

The power of using external representations and cues to support medication management comes in *linking spatial and temporal orderings*. In fact it is critical, and can distinguish medication management from other kinds of socially distributed information processing in the home.

The time-tested pillbox provides additional support for recall and prospective remembering by mapping a temporal representation to a spatial one. Spatially, the kind of linear ordering that we saw in the line of bottles in the kitchen cabinet is used, but the pillbox is engineered to evoke a temporal pattern as well, with each cell corresponding to a time in the day (usually morning, noon, evening and sometimes night). The absence or presence of pills in a particular cell indicates past action (having taken the pills or having forgotten to) and intended future action (must still take evening pills). They provide traceability of action, and for that, Jens says, "The pillbox never lies."

4.1.2 Routines

As we have begun to see in the above discussion, spatial and temporal orderings are intertwined. As Crabtree and Rodden describe, routines are "sequences of action [that] articulate the spatial and temporal distribution of information around the home" [9, p. 209]. We now turn to some illustrations of this.

Ida, the citizen who knows little about her medication but manages her own dosing directly from their bottles by relying on a linear arrangement of them in her kitchen cabinet, uses her morning breakfast routine to cue her to take her medications. She doesn't have the traceablility of the empty pillbox cells to help remember whether she took her pills or not; instead she offloads it to her morning routine, trusting that if she conducted her morning routine, then she very likely took the medications as well.

Routines in medication management are, as we explained earlier, associated with other activities, including eating meals and bedtimes (including naptimes). Jens, who distributes his medication across his home depending on what spaces he expects to be in at certain times, relying on what Taylor and Swan might call an artful system [25], tells us:

> *In the evening I put out the pillbox for the morning. I put it on the kitchen table, where I start my day. Those that I take at night I keep by the bed. It's a routine.* [1]

Figure 6: Jens's Morning Counter:
Jens's pillbox is at the bottom right of the picture, next to his paring knives for his morning apple (located just above the pillbox), as well as a cutting board, coffee, a coffee cup, and so on.

Jens' *consumption* of his medication as well as his *organization* of his 9 different medications are routine. He stages his morning medication on his "morning counter" (see Figure 6)—what Crabtree and Rodden call an activity center [9]—which has all his morning routine supplies. The night before he makes a point of filling the pillbox with his morning medications and placing it on the kitchen table to take at meal times as an extra measure to remind. When those doses are taken, he returns the pillbox to the morning counter when cleaning up after lunch. Nighttime medication is in and on his bedside table, with the supply located in the drawer and daily doses in a pillbox placed on the nightstand.

Routines are critical in organizing medication supplies, dispensing and preparing doses, and remembering to take the pills. They are

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[1] All verbal data reported here are careful translations to English.

also the means by which people recall or at least *infer* that they have taken their medications. A person might infer—correctly or incorrectly—that if she executed her normal morning routine, for example, then she probably took her medication. When there is no traceability of past activity in routines, people could benefit—as we will discuss later—from built-in IT support of their existing systems to indicate if pills have been taken.

Routines are how people encode and conceptualize information about their medication. When our participant Ida was introduced to a new system that queried whether she took her medication at 8:00—which, clinically speaking, is only meant to be an approximation anyway, though it didn't feel that way to her—she objected to the formulation of the query. Instead she says in response, "I get up, then I have my breakfast. After that a Helper comes and makes the bed. Then I do the dishes and afterward I take my medication." Only when prompted further does she add that the time is about 8:30am by the time she takes usually her medication.

Ida's account of when she took her dose is just as accurate as a more temporally exacting report. What matters is that Ida remembers to take her medication every morning at approximately the same time, and that her next dose follows after an appropriate interval. The management of medication is not about outward signs of precision. It is about completion in a timely but not exacting manner, and in the context of the larger rhythms of one's day, and in such a way that continues to enable elder independence.

4.1.3 Conceptualization of Prescribed versus Discretionary Medication

Finally, we found that our participants treat what they call "real" or their prescribed medication differently from other types of drugs (over-the-counter pain relievers) and vitamins and supplements. This is reflected in their spatial arrangements and placements of medication. Karen keeps her "real" medication in the medicine cabinet in the bathroom (the only one of the 10 participants to do so), but keeps her vitamins in the drawer in the kitchen:

> *I keep my medication in the medicine cabinet in the bathroom. When I take my medication then I'll take out the pills from the medicine bottles in the bathroom and bring them to the kitchen where I take them with my breakfast. I keep my vitamin pills and Ginko-tablets in my kitchen drawer. They are in the drawer because there isn't space in the medicine cabinet. And then, it isn't real medication, even though I take it because I think they work.*

In another example, Kirsten keeps her prescribed medication in her kitchen cabinet by the window. In contrast, her fish oil is kept on her kitchen table, even though she takes her prescribed medications at mealtimes as well.

4.1.4 Private & Public Perceptions of Health

Elders' management of their medications occurs in their homes, of course, and not in the clinical setting of a hospital or nursing home. As such, whether people see their medical conditions and illnesses as appropriate for an audience of visitors, say, works as a backdrop to the ways they manage their medications.

Two contrasting examples highlight how medication might be treated in part by how one perceives one's home. For Peter, management of his health is a central activity in his day. He has his medications on his coffee table in his living room (Figure 7) and also on a dedicated desk in his bedroom that holds his medications and notepads where he records blood sugar levels. He makes no effort to hide his physical condition, and the systems he has devised to support it are quite visible.

Figure 7:
Peter's medications and other daily necessities are kept on his coffee table

In contrast, Anna, who lives in a nicely decorated and ordered home, curiously keeps her supply of medications well out of view in her piano bench. Even more private than the bathroom medicine cabinet (where, interestingly, only one elder in our study kept her medications), the piano bench is more like a hiding place. In a medicine cabinet, one would expect to find medicine, but in a piano bench, one expects to find music books. For Anna, her home is a place to receive visitors where there are no outward displays of compromised health. Her strategies for managing her medications reflect this preference, and relied on only temporal mappings (and therefore completely hidden medication) when it could; she only came to use spatial cues when new medication required dosing out of her natural rhythms. This desire to not have the stigma of assistive aids—in this case, assistive aids in the form of visible, spatial representations of medication dosing—parallels Hirsch et al's findings [17].

There is also the practical matter of what the space of the homes can afford, as well as one's own propensity toward being organized: Another underlying principle for organizing the medication is based on a very practical consideration, and that is the matter of available space. In Karen's case, she explains that if she had to add a new medication to her existing ones, it would have to go on one of the bottom kitchen shelves because there is no room left up top.

Home settings, then, are "imperfectly perfect" in the ways in which tasks like medication management are accomplished. Homes and their supporting information systems are tailorable and open to improvement, enabling residents to iteratively perfect placement of medications and steps in their routines, to adapt to the inclusion of new medications, and to optimize the placement of some things vis-à-vis the optimization of others (one can imagine someone thinking "I really want my tea THERE, and I'd like my medication close by, so, hmm, it looks like HERE there's space. Let's try that"). To outsiders, the "sense" of organization may appear imperfect. This has direct consequences to IT support for in-home health, which we will return to later.

4.2 The Work of Health Care Workers

Health care workers in the Danish welfare system provide in-home care with frequent visits depending on need. The monitoring of the physical, social and psychological condition of the elderly takes place in the home where the caregivers base their assessment on what they see and hear there. This includes assessment of the physical state of the home and how an elder moves within it.

> *It's best if they're in their own home. Then you can get a clearer picture of the person, who they are and get [the care giving] right. (Hanne, Nurse)*
>
> *When you know a citizen it is easy [to see how they are doing] – you keep an eye on if the place is a mess, if there is spill. If there are newspaper advertisements everywhere, or if the kitchen floor is very dirty then it's a sign of things not being the way they're supposed to be. Or if their clothes are sloppy or if there's a mess in the medicine pillbox. Then I'll tell the nurse. There are many small signs that you look for. If you've visited a new citizen and you see that it's a mess and it's dirty then you tell the group leader and talk to the regular helper about it – is this normal or is something wrong here? (Mette, Helper)*

In addition, the health care worker learns the routines and the systems each elder has in place (such as where the linens are stored and how they should be folded). This is driven out of a matter of respect and acknowledgement that worker's workplace is first someone else's home.

> *You have to respect their routines and take care of their things even though it can be difficult if they're in a wheelchair to avoid bumping into their furniture [when moving them in it]. (Helle, Assistant)*
>
> *You have to respect that it's their home but it's also my workplace. It's about getting a sense of the home - saying hello properly and not just walking right in and saying that now you have to get an awful lot done in a hurry. (Jette, Assistant)*

This is not to say that health care workers do not impose their own ideas or institutionally-led ways of organizing health-related materials in the elders' homes. This comes to play in the protected residences. The similar apartment layouts invite health care workers to suggest common placement of medication and medical equipment, which largely works to the benefit of the health care workers to help locate items across the many apartments they visit.

Though the intake of medication is done individually, the management of it for elders receiving in-home assistive care is collaborative, although usually over a protracted amount of time. Nurses may help with preparing doses on a routine but infrequent basis (like every third week), and assistants make sure things are in order more frequently (weekly or daily). Helpers might also assist on a daily basis by setting out medication when elders have difficulty remembering to take it. The health care workers provide an external check in the elders' personalized systems. In fact, care staff must learn each personalized system for the elders in their care in order to be able to provide assistance. For each elder, they know the medication is kept in the upper kitchen cabinet next to the tea, or discretely tucked away in the piano bench, or kept readily visible on the kitchen table, ordered bottle by bottle from left to right. In fact care staff use the state of medications to assess the general state of an elder. Are the usually nicely ordered medications in disarray? Are pills left in the pillboxes? Can the elder still open the plastic-wrapped pre-packaged doses? Management of medication is a cooperative activity that occurs perhaps stretched over time, and in an assistive capacity, with the elder often remaining in primary control.

These qualities of collaboration between elders and health care workers are important to call out, because it is these that would be likely subject to technological innovation. It is also these that are likely to be misunderstood, with the danger being that innovation could control an activity that is squarely in the control of elders currently, and that loss of that control could be quite damaging to the general welfare and feeling of autonomy by elders. Although technological assistance with medication certainly could provide a sense of comfort to the elders and caretakers alike, it is important to recognize that the management of illness remains highly personal—and for some people is highly private. Medication management is also an organizing activity, an ongoing and important task that elders can engage in to help themselves. Technological assistance needs to be analogous and in the form of the same kind of check that health care workers provide now.

5 DISCUSSION: DESIGN PRINCIPLES

Our analysis of elder's medication management practices and the means by which mobile health care workers support those practices—in a society with a long tradition of in-home support—suggests a set of design principles to guide development of technological support systems for assistive care. Although our principles are derived from the particular task of medication management and pertain first to this task domain, they speak to a broader perspective of what future assistive technology design might look like.

We begin with a recognition that medication management usually begins before a great deal of outside assistance is necessary—that the "home-made" systems that people put into place are first designed to remind and help themselves with medication intake *before* health care workers become involved. The **first principle,** then, is for assistive IT to *support personalized medication management systems* that can be *distributed across the home using spatial arrangements in places that support routines.* These computationally enhanced versions of people's personalized medication management systems need to be *flexible and adaptable* to changing medication and reminding needs, and should be in the form of *physical artifacts, surfaces and containers with built-in computational support.* In other words, these systems still have to remain first and foremost physically manipulable, and secondarily computational. Digital support could build in temporal dimensions (cueing and reminding) to physical artifacts.

This is because, as the **second design principle**, computation should not be viewed as first for the benefit of the clinicians who check for measures of consumption. Designing to track whether people take medication does not necessarily support actual medication intake. Hence, *computation should, as a first-order design goal, benefit elders in the management of their medication.* We believe, however, that the needs of the elders and health care workers can *both* be met if the design is based on the medication management activities of elders. By doing so, not only might it be possible to better support medication adherence, but we believe that it will also provide more accurate intake information for clinicians. Additionally, as our research community has learned with other collaborative computational systems, this will increase the likelihood of elders' use of a system, because it provides direct benefit to those using it [15]. Interaction with a technological system that, at its basis, is built on familiar physical artifacts is more manageable by users, and maintains the familiar practice of physically distributing medication across the home.

As a **third principle**, this distributed, modular, and physical-digital system should provide *windows of inference for remote assistance*, windows that can be "opened" as more and more assistance is needed. This mimics the kind of collaboration we observed in home health care, where health care workers "read" the personalized spatio-temporal medication systems to infer how an elder was doing. Health care workers also helped elders adapt the systems with the addition of new medication or dosing patterns, or when seeing when systems fail to accurately remind people to take their doses.

Such an approach is in keeping with our **fourth principle**, that of *technology by invitation,* which speaks to matters of privacy and maintaining personal dignity. If technology is introduced in a stage-wise fashion to people, first as means of supporting their individual capabilities, then—in collaboration and agreement with the elder—"turning on" features that allow for remote assistance and care, elders can maintain control over what happens in their home; they also can participate in decisions about how the management of their health should adjust in time. This is particularly important for people who view health status as a private matter.

The **fifth principle** addresses the matter of the distinction between "real" versus "other" medication. The intake of discretionary medication and supplements, while a serious issue from a clinical point of view, is not always accounted for in IT-based ideas of home health support. We see this reflected in the elders' practices that vitamins, supplements and discretionary medication—unless explicitly prescribed by a doctor—conceptually belong to the category of things that is not under the purview of medical personal. Health care workers who visit homes might very well have knowledge of supplements taken, just by visiting the home frequently. Under a certain threshold, workers might not remark on these supplements because they know that intake of these are not contraindicated. But what of remote IT support that might not have the full view of a person's dietary or health habits? This begs the question, "What is health?" *A high-level design principle for in-home health IT-based assistance needs to conceptualize "health" to be broader in scope than what occurs in the context of a doctor-patient exchange.*

6 CONCLUSION

Our work has taken an elder-centered view of medication management, with resulting observations that suggest that an approach to supporting in-home health care and reliable dosing of medication should begin with support for the personalized spatio-temporal systems and routines that people create in the context of their homes. These systems exploit spatial and temporal features in familiar environments, enhancing a person's ability to manage medication even in the presence of partial information. The systems are collaborative, where collaboration occurs between the elder and the environment, the elder and their "future" and "past" selves (in the act of recall and prospective remembering), as well as the elder and in-home health care workers. For the latter relationship, health care workers adapt their work to elders' systems, and learn to "read" those systems to make inferences about the health and well-being of the elder. They are also the things around which the elder and the worker collaborate to adapt the systems to changing health.

From these observations we introduce five design principles for IT that can help people "age in place." These principles are formulated with the recognition that medication management, as one aspect of self-care, is sometimes a central activity in people's days and can itself serve as an organizing function. We propose that through computational support of these personalized medication management systems, IT can often enhance people's abilities to manage a complex task, and support remote health care assistance without taking away personal control.

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Healthcare in everyday life: designing healthcare services for daily life

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Healthcare in Everyday Life - Designing Healthcare Services for Daily Life

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ABSTRACT

Today the design of most healthcare technology is driven by the considerations of healthcare professionals and technology companies. This has several benefits, but we argue that there is a need for a supplementary design approach on the basis the citizen and his or her everyday life. An approach where the main focus is to develop healthcare technology that fits the routines of daily life and thus allows the citizens to continue with the activities they like and have grown used to – also with an aging body or when managing a chronic condition. Thus, with this approach it is not just a matter of fixing a health condition, more importantly is the matter of sustaining everyday life as a whole. This argument is a result from our work – using participatory design methods – on the development of supportive healthcare technology for elderly people and for diabetic, pregnant women.

Author Keywords

Healthcare technology, Independent living, Tele-medicine, Design methods, Participatory design, Elderly, Diabetes, Chronic disease, Patient, Citizen.

ACM Classification Keywords

H.5.2 Information interfaces and presentation (e.g., HCI): User Interfaces: Evaluation/methodology, Prototyping, User-centered design, H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous, J.3 Life and Medical Sciences: Health, Medical information systems, K.4.2 Computers and society: Social issues: Assistive technologies for persons with disabilities.

INTRODUCTION

In a recent research project working with independent living technology for elderly we held a number of workshops with different stakeholders: One workshop with physicians and nurses, a second with homecare workers and a third with elderly people and their relatives. The workshops were part of our initial participatory design efforts and the focus of the different workshops was chosen by the participants – within the general theme of "independent living technology for elderly".

In the *first* workshop the physicians and nurses discussed how mobile technology and sensors could enable effective telemedicine, e.g. remote monitoring of vital life signs to avoid hospitalization. In the *second* workshop the homecare workers focused on how technology could help them in administering medication for the elderly and document the care given to the elderly, including the monitoring of their health condition, diet, liquid balance, and weight. The discussions in the first two workshops were in sharp contrast to the debate in the *third* workshop with the elderly people and their relatives, where the main focus was on living a normal everyday life, spending time with friends and family, continuing the activities they cherished the most. Of course the risk of getting sick or having a fall was a concern, but at this point in their life, the elderly found that they had a good health (Their age was between 60 and 77). However, they also acknowledged that this might change towards more emphasis on health related issues over time.

These three workshops illustrate the tension that exists between the approach of healthcare professionals and elderly people when it comes to designing healthcare technology. The healthcare professionals address the health and disease of a patient. By use of their professional knowledge they focus on possible diagnoses – which general risks do this type of patients face and how can this be prevented or treated? The healthcare professionals and caregivers somehow presume that the main goal for the elderly is – almost *at all cost* – to avoid diseases and health related problems.

While this approach has clear benefits and justifications it should not stand alone, as the workshop example above illustrates. The clinical approach should be supplemented with an approach that gives voice to the interests of the

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citizen[1]. For most people health and disease are just some aspects of life. The people in our case studies explain that their everyday life as a whole is what matters: e.g. spending time with their family and friends, having an interesting job or exciting hobbies. Health and healthcare technology are just small pieces that they try to fit into the larger puzzle of the everyday routines.

In the process of making the pieces fit together some people might choose to make other priorities than those recommended by their healthcare professionals or may perhaps struggle with little success to integrate the prescribed actions into their everyday routines. What might make sense from a clinical perspective might not make sense in the everyday life of a citizen.

In this paper we argue that if healthcare technology is to be successfully integrated in the lives of the citizens, it is necessary to acknowledge the knowledge and everyday life of the citizens – just as the healthcare professional's knowledge is vital for a proper treatment of a disease.

In the following, we explore two views on healthcare and healthcare technology: that of the healthcare professional and that of the citizen. In particular we address the challenge of creating healthcare technology which will be able to fit into the everyday life of the citizen.

We unfold this view by exploring the clinical notion of "a patient" and the widespread use of monitoring devices. We examine how these terms are used and how people try to integrate healthcare technology into everyday life. The work presented is both an analytical exploration of the citizen perspective based on a number of projects as well as prescriptive suggesting some implications for design.

CASE STUDIES

At Center for Pervasive Healthcare we have worked with technology and healthcare for more than five years and 15+ projects have focused on the use of healthcare technology in hospitals, in homes, at work and while being mobile. In the following we draw on our experience from most of this work, however, the reflections and implications presented in this paper are mainly based on the work in two projects: one working with elderly and one with pregnant women with diabetes.

Our work is based on a participatory design approach [9], where users-to-be play an important role both in the development of the "innovation focus" and in the actual conception, design and evaluation of new proposals.

In our projects the users-to-be are both the receivers-to-be of the healthcare being developed and the professionals involved in the delivery of that healthcare. Thus a typical project group involves a small number of diabetic, pregnant women, doctors, nurses, midwives and secretaries as users-to-be and doctors, nurses, ethnographers and computer scientists as researchers. The group discusses where innovations are most needed, and decides what issues to work with and develops proposals, mainly in the form of ICT prototypes and organizational experiments.

The primary activities of our participatory design are ethnographic field studies, qualitative interviews, idea and concept generation workshops, design of and experiments with physical mock-ups and computer-based prototypes and organizational experiments.

Elderly and healthcare technology

First of all the paper draws on findings from an evaluation of the ElderTech study where independent living technology was installed in the homes of seven elderly residents in collaboration with a nearby local healthcare centre [1, 2, 18]. The pilot ran for two months and included self and remote monitoring of blood pressure, weight and medication adherence. Problems with medical adherence have in several studies been targeted as a major issue for elderly people [4, 6, 16]. The focus of the study was the integration of independent living technology in the everyday life of the elderly participants and in the work of the healthcare workers. The project was carried out in collaboration with an international IT company and a municipality.

Ethnographic field studies were carried out over a period of nine months. Interviews were made with the elderly in their homes and with caregivers both before and after the installation. The interviews lasted for at least one hour, usually longer. Among other things, the interviewer observed the installation of the system, as well as the use of the system both by the elderly and caregivers to explore how the system influenced the life of the elderly, the work of the caregivers, collaboration between the elderly and the caregivers, and the self-care of the elderly people.

Pregnant women and diabetes

In our most recent study we work on developing pervasive healthcare solutions for diabetic, pregnant women on insulin treatment (not gestational diabetes). The treatment is crucial to avoid serious complications – such as miscarriage and malformations – but difficult, as the need for insulin changes constantly. Throughout the pregnancy the women are treated every week or every two weeks at the outpatient clinic – up to two hours drive away from their home. The focus of the project is to explore how to integrate the everyday life of the diabetic, pregnant women

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[1] We have chosen not to use the term "patient". This is done to emphasize that a tension exists between the clinical view of a person as a patient and the self-image of a person. Furthermore, as we draw on several case studies with different groups of people, a term like "elderly" is too narrow. We are in this paper, in lack of a better word, using the term "citizen".

in the network of healthcare institutions. The challenge in focus is designing technology that will support not only the professional treatment, but also provide flexibility in the life of women who lead an active everyday life with work, family and friends.

The project is carried out in collaboration with two private companies and a university hospital in Aarhus. The study included two-hour long qualitative interviews with 10 diabetic, pregnant women in their homes. Furthermore, field studies were carried out over a period of four months at the outpatient clinic, amounting to a total of 70 hours of observations and five interviews with central clinicians.

HEALTHCARE IN EVERYDAY LIFE - A CITIZEN PERSPECTIVE

Based on our work with healthcare and exemplified by our study of technology for elderly and pregnant women with diabetes we will present an alternative view on the design of healthcare technology.

We call our perspective "the citizen perspective". The perspective focuses on how healthcare technology can be integrated into the everyday life of citizens with a health condition. Our main point is that a clinical perspective on healthcare technology needs to be supplemented with a citizen perspective focusing on the everyday aspects of life in order for the technology to succeed. This is especially true when healthcare technology is introduced outside hospitals in people's home and in wearable health systems. We will argue that especially the notion of the "patient role" and the discussion around "remote health monitoring systems" need to be informed by a citizen perspective.

Figure 1. A mismatch between assistive technology, a PC, and the aesthetics of a home

This is illustrated by the ElderTech study where we evaluated a system for monitoring medication intake of elderly people living at home. The system was based on a clinical perspective focusing on name and dosage of the drug, and did not take into account the everyday routines that the elderly had constructed and relied on in managing their medication. The elderly were left with a system which was difficult for them to understand and use. As a result, the system neither supported the elderly in taking their medication nor was it able to provide the clinicians with accurate data on the actual medication intake [18]. Figure 1 shows an illustrative example from the study: It is often difficult to fit technology, e.g. a PC, into a home in an aesthetically pleasing way. In this example the laptop was hidden under a vase – and not able to function.

The expertise of citizens

Traditionally, the experts within healthcare have been the healthcare professionals. According to this *clinical perspective*, the clinician holds the role of expert who makes diagnosis and adjusts the prescribed treatment accordingly. On the other hand, the citizen holds the role of being a patient and visits the experts at e.g. the hospital and is expected to follow the advice of the expert. This division of roles is fundamental to healthcare provision and is grounded in the social and technological organization around the interaction between healthcare professionals and patients.

In this clinical perspective the healthcare professionals often have a pragmatic approach towards the patients' everyday life. If social aspects are taken into account, it is usually to consider if the social network of a patient constitutes an obstacle or can serve as a supportive tool for the patient in adhering to the prescribed treatment. In the diabetes case, the clinician could e.g. recommend sick leave if it was difficult for a woman to handle her diabetes because of her work.

Murphy describes, based on own experience and extensive fieldwork among handicapped, how such a clinical perspective can create a feeling of being trapped. Not only is a patient trapped physically at the healthcare institution, but the patient is also trapped in the specific role of being a sick person – suspending all other roles that the person normally possesses. Thus, the person is left with a highly stigmatized role, resulting in a feeling of loneliness, guilt, and loss of self-esteem [17].

We emphasise a need to revise this traditional clinical perspective. With a growing number of chronic patients and elderly and through the invention of novel healthcare technology, the treatment is no longer confined to the hospital, but also involves and impacts the citizens' everyday life in their home, at work, in public places, and when traveling. Thus, there is an everyday life to attend to as well as the health problems – and the clinical perspective of *patients* and *clinical experts* does not support or recognize this.

In this paper we present and argue for a more complex understanding of the roles of patients and healthcare professionals that take into account other roles in the everyday life of the citizens than that of being a sick person, of being a patient. We want to expand the clinical view by introducing a "multi-expert" view that includes the citizen as a different kind of expert with a different expertise, which is to be taken into account when designing healthcare technology. In our case studies we have found that the elderly and the diabetic, pregnant women each have several roles that implicate different kinds of expertise (related to healthcare). To discuss the different roles and expertise related to the different role - and in particular to discuss the tension between roles - we draw on Goffman's notion of roles in everyday life [8].

Clinical expertise and the roles of patients

All the diabetic, pregnant women and the elderly people in our case studies have diagnosed diseases – e.g. diabetes and/or hypertension. As such they all possess the role of a patient and have over the years obtained the expertise of a patient. This is not to be seen as if all patients behave similarly or have the same knowledge. On the contrary, we have identified several different ways of being an expert that are all tied to the patient role.

One kind of expertise connected to the patient role is that of clinical knowledge. The clinical knowledge is often constructed in collaboration with the healthcare professionals. In this manner, the healthcare professionals give the elderly or the diabetic, pregnant women the basic, relevant information about their condition. This can be seen as a type of transfer of expertise from the healthcare professional to the patient. The elderly or the diabetic, pregnant woman is also taught what the expected appropriate patient behavior is. We have seen many and elaborate examples on how the clinician explains e.g. the mechanism of the hormones produced by the placenta, the effect it has on the insulin level and the blood sugar and we have observed how he guides and instructs the diabetic, pregnant woman in dealing with this mechanism.

This is traditionally the kind of expertise acknowledged in relation to the patient role. However, it focuses on the situation where there is a tight link between the healthcare professional and the citizen's patient role, e.g. the situation of a consultation or hospitalization where the healthcare professionals give instructions. However, a different kind of expertise connected to the patient role exists in another kind of situation: that of everyday life. When the diabetic, pregnant women return from a consultation, the women have to turn the knowledge and instructions given by the healthcare professional into practice – they have to live with their diagnosis and manage their disease in the situation of their everyday life.

Expertise centered around everyday routines

Most of the elderly people in the ElderTech study did not apply or possess the clinical knowledge described above in their medication management. As described in [18] they seldom knew the name or dosage of their medication and did not always know what the medication was for and yet they were still assessed by the local healthcare center to be able to manage their own medication. Instead of the clinical knowledge they rather relied on the routines of their everyday life to support them in managing their medication. Many would place their morning medication with their breakfast and medication for the night on the nightstand relying on their morning and evening routines to prompt them to take their medication – all they had to remember was to put the right type and amount of pills at the right place. Thus, they would unload the information given to them about the pills and the treatment onto their routines. So, although many of the elderly had little actual clinical knowledge on their medication, they rather had much expertise at managing their disease in their everyday life using their routines. This way of creating elaborate information systems using the physical qualities of artifacts and materials is not exclusive to healthcare. [5, 20] describe how members of households use this method for processing, distributing and indicating the status of e.g. mail and other types of information.

The diabetic, pregnant women often have a well founded, clinical understanding of their disease accumulated through many years of treatment, medical checkups and training: They know how to calculate carbohydrates, they know their carbohydrate-insulin ratio and can thus calculate the amount of carbohydrates in a specific meal and how much insulin is needed. This expert knowledge is closely connected to that of the traditional patient role. However, in their everyday life many do not use these tools explicitly. On the other hand, they have integrated this (clinical) knowledge about their disease into the context of the routines of their everyday life. They now know how much insulin to take with their meal without having to think about it.They often use their kitchenware to provide measurements. E.g. one woman knows how many carbohydrates are in one glass of milk, when she uses the glasses at home. So, without thinking about it, she knows how much insulin is needed when drinking a glass of milk. Likewise, the women use the size of their plates to estimate the amount of insulin needed. Furthermore, one woman describes how she is unable to tell how much insulin she takes. Instead she describes it as punching your pin-code for your credit card: you cannot tell the number but you can punch it. She does not know the amount - rather it comes automatically to her when she prepares the insulin dosage.

The women are encouraged to keep a diary of their blood sugar level providing a tool for both the women and their healthcare professionals. The healthcare professional uses the diary to get an overview of the changes in the blood sugar level and use it to improve the overall insulin treatment. For the women the diary is a tool to get an overview, but it is also a tool for adjusting their everyday insulin intake. One woman describes how she uses her diary at meals to assess her insulin intake. E.g. at breakfast she measures her blood sugar level and compares it with the blood sugar level, insulin intake and the amount and type of breakfast from the previous morning to figure out how much insulin she will need.

Another woman explained how she could no longer feel if her blood sugar level was out of balance because of her pregnancy. She therefore felt the need to monitor her blood sugar closely, even once every night, which was more frequently than usually recommended by the clinician. To do this she relied on two different strategies. She would set her alarm clock to wake her during the night. However, this strategy often failed, as she did not always hear the alarm. The second, more reliable strategy took advantage of her existing, everyday routines. Most nights she would help her two 4-year-old sons to go to the bathroom. She would then use that opportunity to measure her blood sugar level.

While many of the women do use the diary in this way to get an overview of their insulin intake, many also describe how they rely more on a feeling. Over the years they have developed a sense of their blood sugar and furthermore rely on their memory to link specific blood sugar measurements with the situation. They describe how this implicit sense of the relation between blood sugar, diet and insulin gives them flexibility in their everyday life that allows them to lead a normal life – i.e. an everyday life where there is balance between leading a normal life and managing their disease.

The patient role thus carries two different kinds of expertise depending on the situation: the traditional expertise, where healthcare professionals give instructions and clinical explanations to the patient in the context of a consultation (or make information available e.g. on the Internet) on the one hand, and on the other hand the kind of expertise developed when turning the information given to them into routines of their everyday life.

Tensions around the patient role

As described above a person can posses a series of different roles which all influence the health and health relevant decisions. These roles may, as we will demonstrate below, conflict with one another. According to Goffman this can happen when a person is put in a situation that requires two different sets of roles and thus two different expected sets of behavior. E.g. when a person is out having fun with friends and suddenly the boss calls on the phone. Thus, the new multi-role view on healthcare expertise inherently includes – and is useful for understanding – potential conflicts of roles.

Our case studies showed that the citizens only considered their health or disease as a fragment of their life as a whole, encompassed in the routines of their everyday life. The citizens are often put in a dilemma trying to create a balance between the routines of a normal everyday life and implementing healthcare initiatives prescribed by clinicians. In our studies we have identified continuous efforts put into making the patient role fit with the remaining roles of the individual and his or her social network.

As described in [18] one of the elderly women in the ElderTech study had worked as a general physicians' secretary and she took great pride in administering her own medication. During the study her husband died, she experienced a serious fall and her own health condition deteriorated dramatically within a few months. She was prescribed a new medication, which she was to take at 2 pm. She had always kept her medication hidden in her piano bench and used the mealtimes to prompt her to take her medication. However, the new medication was to be taken outside mealtimes, rendering her time-bound prompt useless. She then had to leave out her medication on the dining table for everyone to see. The woman had always taken great pride in keeping her home neat and tidy and saw it as a place to receive guests. Leaving the medication out for everyone to see was a severe blow for her, as it would depict a sick person, which was in sharp contrast to the picture she wanted to give her guests – that of a meticulous woman living in a tidy home. The women thus experienced a great discrepancy between her expert role of a patient that was still able to administer her own medication and the more social role of a hostess who was able to manage her home and keep it neat and tidy.

Similarly, many of the diabetic, pregnant women often experience an antagonistic relationship between the demands and expected behavior of the expert patient role and the expected behavior connected to social or work related roles. Thus one of the diabetic, pregnant women describes how she sometimes ends up eating alone at work because of the need to keep her diabetes tightly regulated during the pregnancy. When preparing for lunch, she first needs to see the menu at the cafeteria to estimate how many carbohydrates she is about to consume, then she has to measure the level of her blood sugar and take the appropriate insulin dosage. Furthermore, she has to decide if she wants to take her insulin in front of her colleagues and possible guests or in private. By the time she sits down for lunch everyone else has finished and returned to work.

The same woman described how she was advised to measure her blood sugar level seven times a day once a week. The measures were to be taken immediately before as well as one and a half hours after her meals. However, one and a half hours after lunch she would be giving lessons as she had a teaching job at the local high school. She then had to choose roles: that of the teacher or that of the diabetic, pregnant woman. She created an alternative solution and carried out the seven measures on Saturdays even though it did not give as good an indication of her condition as it would on a weekday where she has a steady routine.

As the latter example illustrates, a potential conflict between roles is often reconciled. Many of the pregnant, diabetic women described how their husbands were of great help to them. Often the husband and wife would appreciate the same kind of diet and lifestyle and in many cases the husband played an active part in managing the condition of his wife. One husband explained how he often calls his wife during her lunch break to hear if she has eaten – she often forgets because of a heavy workload. The husbands would also search for information on new insulin treatments, new blood sugar meters, and in one case the husband even helps his wife measure her blood sugar level as she drives and is in need of an extra set of hands to handle the blood sugar meter. The husbands know how to identify and how to act on a low level of blood sugar. Thus, instead of a conflict between the role of a patient and the role of a wife the diabetic, pregnant women describe a relationship with their husbands based on collaboration also in regards to the patient role.

Monitoring technology in everyday life

The clinical perspective is also dominant in the design of monitoring technology within healthcare. Figure 2 shows four different examples of visualizations of sensor data created from different technological devices. These representations are designed and visualized in a way that allows only trained health professional to interpret and act upon.

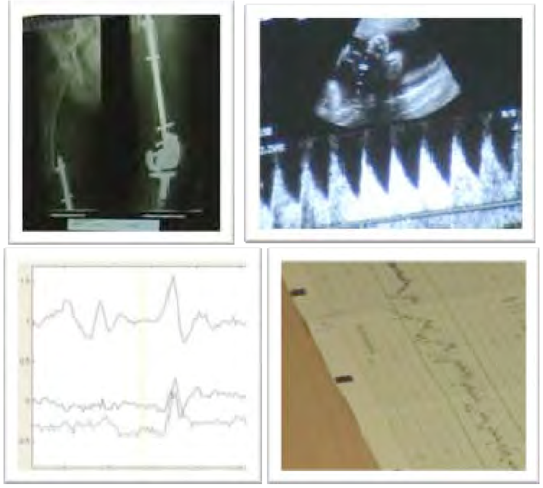

Figure 2. Top row, an x-ray of a leg and an ultrasound image and the flow in the umbilical cord of the fetus. Bottom row, accelerometer data of an elderly woman trying to answer the phone while using a walker and a cardiotocography of the fetus of a pregnant woman with diabetes.

Monitoring technology is often seen as the solution to the problem of how to move healthcare services out of the hospital and into the everyday life of the citizens – for instance caretaking of elderly in their own homes or the treatment of chronic patients. Nevertheless, when monitoring devices are moved out of the hospital a key question will be how the relationship between the monitoring technology and the citizen being monitored should be designed.

This challenge has been met in different ways. A common scenario in many suggested home monitoring setups depicts either healthcare professionals or caring family members as the ones keeping an eye on a single elderly person at a distance through the use of sensor technology [e.g. 19]. The monitoring systems will make it possible for the son, daughter or healthcare professionals to keep an eye on the health condition of the elderly – e.g. to check their nutrition and sleeping patterns [3] – or to see if the front door has been opened, if the elderly has slept more than usual, and monitor other kinds of activities. As these solutions are often automatic and invisible to the elderly, the solutions can sometimes be incomprehensible or even intimidating for the elderly. To depart from the clinical perspective, where the elderly is left as an object for monitoring, it could be suggested to convert the monitoring scenario described above giving the elderly mother or father the ability to watch their children and grand children, who they often have a great interest in keeping an eye on – as they have always done.

Common for the traditional monitoring scenarios is that very few actually focus on the relation between the person being monitored and the technology. In many designs the person being monitored is viewed as incapable of understanding the produced representation and hence this group is not the intended receiver. From our studies we have found that the elderly and the diabetic, pregnant women themselves have a strong interest in being the intended receivers of the monitoring technology. We have found a great potential in designing monitoring technology not only with a strict clinical focus, but also with a citizen view focusing on the person being monitored and this person's everyday life.

Understanding monitoring systems

In the ElderTech study the system allowed for remote monitoring of the blood pressure. The elderly measured their own blood pressure and the data was collected and made available at the local healthcare centre. This way, the nurses could monitor the condition of the elderly, many having cardiovascular and hypertension diseases. While the system was designed primarily for the healthcare workers to use, several of the elderly actively used the blood pressure meter to acquire knowledge on their own condition. E.g. if they had a headache they would use the meter to check their blood pressure to establish whether the headache was a symptom of hypertension or it could be cured by drinking a glass of water. That is, the meter was used mainly for their own benefit and only secondly to provide information to the remote healthcare professionals. The introduction and use of a blood pressure meter also led one of the participants to make logical inferences about his hypertension and his medication. A learning aspect, thus, emerges in the intersection between technology, health and the citizen.

This is closely connected with the point stated earlier, that the patient role also includes an expertise that can be developed and strengthened. Teaching the citizens how to read and understand their own data will allow them to understand e.g. how their medication is influencing the condition, follow development and progress in their treatment and distinguish special conditions that might require further professional inspection. More importantly, it will enable the citizen to gain an understanding of the condition that will allow for acting upon the data representing their condition.

This point is supported by our case study with the pregnant, diabetic women who regulated and administered changes in their insulin dosage during their pregnancy. The women were instructed in a more intense schedule of self-monitoring their blood sugar level in the shape of a special diary (see Figure 3). Additionally the healthcare professionals explained throughout the pregnancy the expected changes in the insulin dosage of the women and described to the women the cause of these changes. The combination of the knowledge on the specific condition and the new instructions for self-monitoring gave the women a tool and an understanding allowing them to monitor their own condition and behave accordingly, adjusting their insulin intake appropriately.

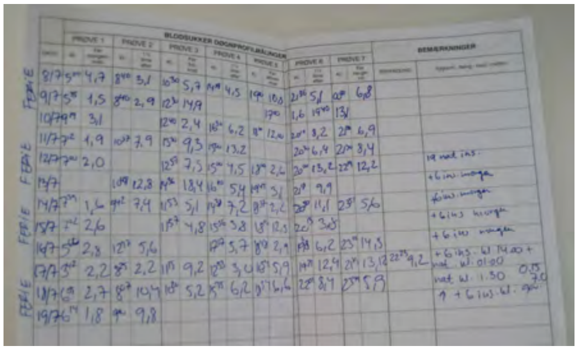

Figure 3. An example of the diary over blood sugar level and insulin intake that the pregnant, diabetic women are instructed to fill out. In the left margin the woman has added that she was on vacation ("FERIE").

Based on the information in the diary, which is a result of the women's self-monitoring , the women and the healthcare professional evaluate the prescribed treatment, as well as the women's self-treatment every fortnight. That is, the clinician and the diabetic, pregnant women use the representation of the development in her condition and treatment generated by the woman herself. This collaboration between the clinician and the diabetic, pregnant women in generating and interpreting a representation of the condition thus increases the quality of the treatment.

In sum, healthcare technology is not only about making information available to clinicians to qualify treatment. Healthcare technology is also a matter of supporting the collaboration between the healthcare professional and the citizen, just as it is about supporting the citizens themselves in their self-care, providing them with the means to act appropriately on the information made available to them.

This point is supported by the work by Mamykina et al. [15]. They compare the role of the diabetic patient to that of a detective. The patients have to identify the source for the rise and fall in their blood sugar level by following different hypotheses. In the paper it is pointed out that monitoring technology can play an important role in reflective analysis, but the paper also emphasizes that the right visualization of these data is crucial in supporting this reflection and to prevent wrong conclusion based on the data.

IMPLICATION FOR DESIGN

In the following we discuss a number of design issues and challenges that emerged in the elaboration of the citizen view. Following this discussion we will look at some methodological issues in relation to design of technology for healthcare in the citizen perspective.

Continuity and understandability

We have argued for the importance of incorporating the role of the citizen when designing technology for healthcare. From our discussion we will suggest two guidelines for design: Design for continuity and design for understandability and learning related to daily life.

Design for Continuity

From a clinical perspective new technology is introduced to fix a health-related problem. Walkers, special elevation beds, fall alarms, scanners and similar equipment are introduced to help patients. And each of these technologies is indeed useful in many situations. The disadvantage is, however, that the technologies require the citizen to change behavior, often in ways that are disruptive and/or not well understood, as when a pregnant women has to travel to an outpatient clinic every week or an elderly citizen is unsure whether or not a fall-alarm functions outside the home. In addition the technologies are based on a number of assumptions that cannot be guaranteed to hold. Fall alarm buttons cannot be worn when taking a bath; they are stigmatizing, and constantly remind people of their weaknesses. Some even refuse to use such assistive technology e.g. simply because they want to look good [12]. Many pregnant women with diabetes do not measure their blood sugar level and do not take their medicine as prescribed by their doctor e.g. due to work or sports activities.

Taking a citizen view, a main design concern becomes to minimize the disruptive nature of new technology. This line of thought will focus on the citizen's daily life and routines and try to design for continuity in the citizen's life, e.g. despite a medical condition.

Instead of searching for and presenting new devices targeted at specific needs, continuity can be supported by augmenting the technology already present in the life of most people. It could be an interactive outpatient clinic calendar realized as an enhancement of the users existing cell phone or PC based calendar. Another example is the Philips Motiva product [21]. Motiva is based on well-known TV technology augmented with extra functionality that enables it to show personalized content.

In our current work we are addressing the discontinuity introduced by the travel of the pregnant women with diabetes described earlier: they travel from their home to the hospital every week (every second week in the beginning) to spent half a day being checked. This often implies problems keeping a full-time job and huge amounts of time commuting or waiting at the hospital. Thus, we look at how to substitute a number of the outpatient visits with measurements done by the pregnant women themselves plus off-line evaluations by the doctors and on-line consultations.

Hospitalization is considered as a last example . Hospitalization is usually a major disruptive event. The hospital is a new and unknown environment with new routines. Often the required changes even include clothing – and all this comes on top of an often dramatic change in health. Furthermore, when the citizen is discharged this usually constitutes another discontinuity: the new medication regimes have to be fitted into the routines at home and at work, a diet might have to be followed etc. Therefore, we have begun to look at how to reduce the impact of these discontinuities primarily by bringing parts of the home into the hospital setting and secondly by bringing relevant aspects of the hospital setting back into the home. As a simple example consider the digital environment in the home of a citizen. ICT such as email, calendar, pictures and music as well as phone and TV channels may be transferred to the hospital – in addition to physical artifacts such as books and clothes.

In summary we may say that we should design for continuity in *space*, *time* and the *aesthetic dimension*. *In space* emphasizes that the solutions provided should preferably be usable where the citizen wants to use them, and not only in the home as e.g. many fall alarm buttons or only at the hospital as most scanners. Continuity *in time* emphasizes that when feasible new healthcare solutions should use or extend technology and routines that are already part of the daily environment. Finally, continuity in the *aesthetic dimension* implies that health technology should be able to meet the aesthetic preferences of the citizen.

Design for understandability and learning

A second design guideline is to design for understandability and learning with respect to the main elements of technology in the daily life of the citizen – albeit at different levels depending on the use and the user.

As we saw in the ElderTech study some of the elderly were able to use the blood pressure meter to learn about the relation between blood pressure and their condition and one of the seven were able to make logical inferences about his hypertension and his medication and became active in adjusting his medication.

In the ElderTech study a mobile phone was included in the setup to provide communication from the laptop. However, this role of the mobile phone was not explained and the design did not include any reasonable ways for the elderly to inspect whether or not the mobile phone was functioning and the laptop actually connected. Thus when disconnections occurred the elderly were not able to detect this and thus not able to make a reconnection. As a result the intended on-line transmission of data was often interrupted for days and even weeks. As a first step towards a solution one may consider how to explain the functioning of the system at different levels depending of the interest and ability of the user. Secondly, one should consider how the user might inspect the status of the system, e.g. “on/of”, “power/no-power” and “connected/not-connected”. For the interested user, more information could be added like “recording/transmitting/receiving blood pressure data” and a number of error conditions. Thirdly, the issue of taking action, e.g. switching on power or restarting a mobile phone with PIN code comes. However, the development of such solutions should be done in a process where new ideas are prototyped and tightly coupled to experimental use in realistic settings. Otherwise it will be unfeasible to create solutions that the citizen will be able to understand when used. This point is elaborated in the next section.

Following the discussion on expertise and monitoring we note that it is crucial also to consider the citizen as the receiver and interpreter of information and one who may take action. A simple consequence of this is that it should be possible to filter out aspects of representations requiring specialized professional knowledge. Secondly, when people begin to use data from devices monitoring their own health they often do so by making connections between such data and potentially related conditions, e.g. having a headache or being on vacation. To support this kind of use and learning it is important that the users can initiate measurements themselves and can annotate data and integrate it into other tools they are using such as a calendar.

Participatory design of technology for healthcare

Our own work is grounded in Scandinavian Participatory Design, which from its early days have been based on two lines of arguments: a democratic and a process one [13].

*The democratic lin*e of argument states that people have a right to have a direct influence on their daily lives, that compromises have to be reached, that the ICT professionals aren’t neutral and that the different groups of users have to safeguard their own interests. *The process argument* states that as ICT gets more interwoven with our activities detailed knowledge of and experience with these activities are a necessary basis for developing high quality proposals and for evaluating them [7, 10].

The interests of the users

Traditionally, the concern for the interests of the different groups of users has been related to the work sphere and especially how employees may safeguard their interests.

However, in our work with healthcare we learned that the power structure present in healthcare (re)produces many of the problems found in the workplace. First and foremost the group(s) at the top of the hierarchy are used to define the problems and solutions for the people at the bottom. In the healthcare sector this means that the doctors define problems and solutions for the patients. The outpatient clinic for pregnant women with diabetes is one such example: the decision to set up a small number of such highly specialized units were made by doctors in a government agency based on recommendations from a small group of doctors specializing in diabetes. The basis for the decision was statistics indicating that specialized units had fewer miscarriage and malformations than the non-specialized ones. No pregnant women were involved and up until our project was initiated no systematic attentions had been given to other aspects of the centralization than the numbers of miscarriage and malformations.

Thus, specific attention has to be paid to the design of the development process in order for the citizen to be able to influence on the result. Otherwise healthcare professionals, mainly doctors, and technology companies will continue to define the problems and the solutions.

In our work the different groups of citizens are involved in decisions on “innovation focus”, concepts, prototypes and new ways of organizing health services as well as in the creative process itself. This change in the way healthcare technology is designed is necessary - not only to support the citizens receiving healthcare to influence the design of that care, but – as illustrated in the previous sections – also to develop better, more useful technology.

Involving users in order to understand use

One of the key insights of participatory design is that experience with a specific type of work and ways of ‘doing’ as well as more formal understanding acquired e.g. through education is crucial in identifying important problems as well as potential solutions [9]. When we look at the development of healthcare technology this means that experience with a specific type of health condition and ways of coping in daily life are important – and only those who have that condition can provide this experience. Furthermore, this kind of experience is usually not verbalized and it is usually not possible to apply it in a de-contextualized evaluation of proposed solutions. Thus an experimental approach is needed. An approach, were the receivers or users of new healthcare solutions are involved not only in decisions as described in the previous subsection, but also in the creative process itself, e.g. in:

- problem identification in realistic settings, e.g. their homes, in relation to ethnographic field work and qualitative interviews,
- concept development in different kinds of workshops, where physical mock-ups and simulation of use plays an important role,
- evaluations of proposed solutions based on experiencing (using) prototypes of these solutions in realistic settings and redesign based on evaluating experiences with realistic use.

Thus, successful involvement focuses on evaluating and creating use experiences in realistic settings – not on detached opinions. This is not a simple thing to achieve, it requires skills in fieldwork, prototyping and setting up realistic trials, i.e. trials where the users define what to do. However, this is the kind of techniques that participatory design has been developing for several decades – albeit mainly in the context of developing solutions for work. Some recent developments in our PD methods are presented in [11, 14].

CONCLUSION

The design of healthcare technology has traditionally focused quite narrowly on what we call a clinical perspective. The citizen is placed into the role of a patient with a health problem which can be diagnosed and where technology plays a role in the treatment. In this paper, we present a supplementary view where we shift focus to the everyday life of people. This citizen view focuses primarily on daily activities, values, expertise and wishes of the citizens and hereby presents an alternate view on what it means to design healthcare technology.

We have shown, how bringing forward the *use* of health technology can challenge key concepts about how to design health monitoring systems and related healthcare solutions. Based on numerous studies we recommend designing for continuity in *time, space* and the *aesthetic dimension* and recommend focusing on *understandability* and *learning*. We argue that successful healthcare technology needs to be designed in close collaboration with the users in order to understand (future) use. However, in addition to the users numerous other stakeholders exist whose interests have to be taken into account. For most healthcare technology organizational acceptance and economic viability are crucial, and this typically involves hospital managements, technology companies, insurance companies, municipalities and government agencies.

In our work so far all of the involved users and other stakeholders have demonstrated an interest in working towards solutions as those described above – and using a process following the lines indicated. Thus, it has been relatively straightforward to organize e.g. joint workshops where pregnant women and their husbands/boyfriends together with doctors, nurses, midwives, and secretaries work on concept development. And almost equally straightforward to organize series of workshops focusing on the aspects important to the companies who will eventually develop the commercial products and services.

Currently our main challenge relates to the imbalance in organizational grounding for the different participants. The people representing the professional perspective, such as doctors and nurses, participate in the projects as part of their job. They are interested in gaining a better understanding of related technology and to contribute to development of better solutions. At the same time they are able to discuss the work in the project with interested colleagues and often to look at the project as part of an organizational development process for their work place. However, the citizens, e.g. the elderly or the diabetic, pregnant women, participate as just that, e.g. as a diabetic, pregnant women interested in gaining a better understanding of related technology and in contributing to the development of better technology. However, they do so without support from an organization such as a workplace. In this sense it is a main challenge for Participatory Design to develop methods that take the daily life of the citizen as the starting point and support development processes that fit well into the daily life of all the participants.

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Teknologiers mellemkomst i ambulant behandling og egenomsorg. Med fokus på gravide kvinder med diabetes (The intervention of technologies in ambulant treatment and self-care: focusing on pregnant women with diabetes)

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Originalartikel

Teknologiers mellemkomst i ambulant behandling og egenomsorg: med fokus på gravide kvinder med diabetes

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Vigtige tendenser i den danske sundhedssektor i disse år er centralisering af behandling og øget egenomsorg. Teknologi ses ofte som en del af denne udvikling omend der eksisterer både dystopiske og utopiske forestillinger om, hvorvidt teknologi fremmedgør eller støtter patienten. I denne artikel belyser vi, ud fra behandling af gravide kvinder med diabetes, hvordan mennesker interagerer med teknologi i udførelse af egenomsorg og i forbindelse med et ambulant behandlingsforløb. To empiriske eksempler, Maja og Ida viser hvordan der iværksættes en række strategier i forsøget på at integrere behandlingen i hverdagen og for at leve op til *behandlingsprogrammets krav. Maja indgår i en reciprok, symbiotisk relation til teknologien og oplever den som en ressource og formår omend med omkostninger at integrere behandlingen i sin hverdag. Ida oplever derimod ikke teknologien som en ressource og er på grund af sociale omstændigheder og behandlingsprogrammets ufleksibilitet ikke i stand til at integrere behandlingen i sin hverdag. Artiklen konkluderer, at hvorvidt teknologier fremtræder som en ressource afhænger af den specifikke relation mellem menneske og teknologi. En relation der kan være påvirket af individuelle, ikke-medicinske omstændigheder.*

Introduktion

Den danske sundhedssektor oplever i disse år et stigende pres på grund af stigende antal patienter med kroniske lidelser, dyrere behandlingsformer og en voksende ældrebefolkning. For at imødekomme denne udvikling er der i stigende grad fokus på blandt andet at øge patienters egenomsorg i hjemmet, overdrage flere patienter til ambulant behandling, samt at nedlægge mindre sygehuse til fordel for specialiserede, centraliserede hospitaler. Udvikling af ny teknologi ses som central for muliggørelsen af sådanne nye behandlingsformer. Forskningsprojekter har vist at det med støtte af teknologi bliver muligt blandt andet at styrke patienters egenomsorg og monitorere patienter i eget hjem (Teknologirådet 2006).

Udsigter til nye teknologiske landvindinger afføder ofte såvel utopiske som dystopiske forestillinger om hvad teknologi kan bibringe mennesket. Utopiske visioner om forbedring af mennesket og dets præstationsevne (Ihde 2002, 111) og dystopiske forestillinger om menneskets fremmedgørelse (ibid., 113). Udviklingen af teknologi til medicinsk anvendelse gøres ligeledes til genstand for utopiske forestillinger om patienter der tager ansvar og initiativ i forhold til egen sygdom som eksempelvis i begrebet 'egenomsorg' og modsat, i dystopiske anklager om at patienter pacificeres og underkastes lægevidenskabelige eller bureaukratiske regimer.

Snarere end at bidrage til den dystopiske eller utopiske retorik ønsker vi i denne artikel at belyse empirisk hvordan gravide kvinder med diabetes interagerer med teknologi i forbindelse med deres behandlingsforløb. Særligt fokuserer vi på strategier og forhandlinger, som kvinderne engagerer sig i for at opnå en god og sikker graviditet samt en succesfuld integration af teknologi og behandling i deres hverdag.

Relation mellem menneske og teknologi

Dystopiske og utopiske forestillinger om teknologiens essens og konsekvenser har Don Ihde, der har beskæftiget sig indgående med teknologi fra et filosofisk perspektiv, taget afstand fra (Ihde 2002). I stedet argumenterer han, ud fra en fænomenologisk tilgang til analysen af relationen mellem menneske og teknologi, for at hverken teknologien eller mennesket kan forstås som noget i sig selv. Verbeek forklarer det på baggrund af Ihde (1990) således: ”In the phenomenological perspective, there is no such thing as a thing-in-itself, either. If we experience things, we experience things-for-us, that is, things as they are revealed to us” (Verbeek 2001, 121). Teknologi kan derfor kun forstås i den specifikke situation og i den specifikke relation til mennesket. Omvendt er teknologi også med til at sætte rammer for og påvirke menneskets handlinger. Dermed ikke sagt at teknologi har en deterministisk indflydelse på mennesket, men at teknologi besidder en vis robusthed og nogle kvaliteter, som fordrer til en bestemt brug (Ihde 1990, 48). Teknologi kan dermed virke disciplinerende; en disciplinering der både kan udgøre en støtte og virke fremmedgørende. Teknologi er således ikke neutral, men transformerer og medierer menneskets oplevelse af verden (Ihde 1990, 75). Studiet af de gravide kvinder med diabetes, og teknologis mediering af menneskets erfaringer og oplevelser, kan medvirke til at øge forståelsen af hvordan patienter interagerer med teknologi i et behandlingsprogram. Teknologi skal i denne sammenhæng forstås som værende fysiske redskaber til støtte og monitorering af behandling, primært i form af blodsukkerapparater og skanningsapparatur. Formålet med denne artikel er således ikke at indgå i en diskussion af begrebet teknologi, men at se på anvendelsen af konkrete fysiske artefakter i et behandlingsforløb.

I tråd med Ihdes fænomenologiske tilgang, men med særligt fokus på den intersubjektive relation mellem menneske og teknologi, udfolder antropologen Michael Jackson menneskets oplevelse af nogle gange at kontrollere teknologien og andre gange at blive kontrolleret af den (Jackson 2002, 336). Føler mennesket at det kontrollerer teknologien og at den bidrager til menneskets velbefindende, opstår et reciprokt, symbiotisk forhold mellem menneske og teknologi. Hvis mennesket mister kontrollen sker der et nedbrud, og den reciprokke, symbiotiske relation brydes (ibid., 338). For at genvinde kontrollen må mennesket trække på en række kompensations- eller modstrategier. Netop disse foci på reciprokke, symbiotiske relationer samt nedbrud og strategier vil vi anvende til at belyse forskellige oplevelser af interaktion med teknologier i behandlingen af gravide kvinder med diabetes.

Om diabetes og graviditet

Denne artikel omhandler gravide kvinder med insulinbehandlet type 1 diabetes. Før vi tager fat på analysen af behandlingsprogrammet og de anvendte teknologier vil vi derfor introducere til diabetes generelt og specifikt til de omstændigheder der gør sig gældende, når en kvinde med diabetes bliver gravid.

Mennesker med type 1 diabetes kan ikke selv producere tilstrækkelig insulin og skal have tilført insulin flere gange dagligt for at kunne optage sukker i blodet. Til at beregne hvor meget insulin der er brug for, anvender diabetikeren et blodsukkerapparat, som måler blodsukkerværdien. Resultatet af blodsukkermålingen skal diabetikeren sætte i relation til mængden af kulhydrater i det måltid hun skal til at spise, og hendes fysiske aktivitet. Derved kan hun beregne, hvor meget insulin hun skal tage uden at tage for meget eller for lidt. At beregne den rigtige mængde insulin er således komplekst, men vigtigt, da der ellers er risiko for føling, insulinchok eller senkomplikationer. Føling er betegnelse for den fornemmelse diabetikere får når blodsukkeret er lavt og kan, hvis der ikke tilføres sukker, resultere i insulinchok hvor diabetikeren bliver bevidstløs. Efter flere år med diabetes sidder regnestykket om insulin ofte på rygraden og antallet af målinger skæres ned. Også overvejelser om sund kost og motion bliver efterhånden indlejret og kræver ikke bevidste slutninger. Diabetikere går til kontrol for deres diabetes hver tredje måned.

For en kvinde med diabetes betyder en graviditet et væsentligt brud i hverdagslivet da diabetesen medfører risiko for en række komplikationer for hende selv og fosteret, som kræver, at hun tildeler sin diabetes øget opmærksomhed. Blandt komplikationerne er svangerskabsforgiftning, for tidlig fødsel, misdannelse af hjertet, spontan abort og dødfødsel (Lauenborg et al 2003, Jensen et al 2004, Clausen et al 2005). Endvidere vejer diabetikeres nyfødte ofte mere end gennemsnitligt og ca. 50 % af gravide kvinder med diabetes forløses med et kejsersnit (personlig kommunikation med fødselslæge).

Grundet risikoen for komplikationer henvises gravide insulinkrævende diabetikere til kontrol og fødsel på ét af fire hospitaler med landsdelsfunktion (Aalborg, Århus, Odense, København) (Indenrigs og Sundhedsministeriet 2003). Kontrollerne på svangreambulatoriet, hvor feltstudierne har fundet sted, består af konsultationer hos specialister (diætist, fødselslæge, diabeteslæge, jordemoder) hver anden uge frem til uge 32 dernæst hver uge. Den gravide kvinde med diabetes kan ved at holde sit gennemsnitlige blodsukkerniveau på ca. seks mmol/l minimere risikoen for komplikationer (Jensen et al 2004).

Foruden specialistkonsultationerne indeholder behandlingsprogrammet derfor en omfattende egenomsorg der primært består i at holde blodsukkerniveauet lavt. Imidlertid påvirker hormoner kvindens evne til at fornemme ubalancer i blodsukkerniveauet, og hun måler sig derfor flere gange end normalt. Regnestykket om mængden af insulin, der før sad på rygraden, forandres ligeledes, da insulinbehovet ændres gennem graviditeten. Endvidere skal kvinderne være mere bevidste om kost og motion. Flere af kvinderne erfarer således at deres diabetes pludselig griber mere radikalt ind i deres hverdag. Desuden opleves graviditeten af mange som psykisk belastende og som et stort ansvar da kvindens blodsukkerniveau har stor indflydelse på, om barnet bliver velskabt.

Metode

Studiet af gravide kvinder med diabetes tager sit afsæt i en fænomenologisk tradition for studier af relationen mellem menneske og teknologi. I modsætning til tidligere teknologifilosofiske forsøg på at afsløre teknologiens essens ud fra overvejelser om teknologi generelt tager den fænomenologiske tilgang udgangspunkt i analyse af specifikke empiriske relationer (Verbeek 2001). Det etnografiske feltarbejde skaber et sådant udgangspunkt for en fænomenologisk analyse af specifikke relationer mellem individer og konkrete teknologier. Relationer mennesket ofte ikke er bevidst om, og som indeholder indlejrede og ikke italesatte praksisser.

Artiklen er derfor baseret på et fire måneders feltarbejde udført i foråret 2007 på et svangreambulatorium og hjemme hos ti gravide kvinder med diabetes. Feltarbejdet havde fokus på hvordan det opleves at være gravid diabetiker og var desuden en del af et projekt med fokus på udvikling af teknologi til støtte af samspillet mellem hjem og hospital (1). Feltarbejdet på svangreambulatoriet bestod af deltagerobservation (Bernard 1995) med vægt på observation af konsultationer, ventetid og booking samt semistrukturerede interviews (ibid.) med de implicerede behandlere. Alle interviews blev optaget og transskriberet. Observationerne på ambulatoriet havde forskellige foci; i nogle tilfælde fulgte vi de gravide kvinder med diabetes rundt til de forskellige behandlere, mens vi i andre sad med hos en af behandlerne og videofilmede konsultationen, ligesom vi også observerede og foretog etnografiske samtaler i venteværelset. I hjemmene hos de ti gravide kvinder med diabetes havde feltarbejdet karakter af primært semistrukturerede interviews samt observationer. Interviewene, der varede omkring to timer, blev optaget og efterfølgende transskriberet og i fire tilfælde deltog den gravide kvindes mand i interviewet. Observationerne havde fokus på praktiseringen af diabetes i hverdagen; herunder de forskellige teknologier kvinden anvender.

Maja og Idas interaktion med teknologi i behandlingsforløbet

I det følgende præsenteres to kvinder, Maja og Ida, som vi mødte på ambulatoriet. Præsentationen og den efterfølgende analyse baseres primært på interview med kvinderne i deres hjem og sekundært på observationer fra hjemmet og ambulatoriet. Maja og Idas fortællinger repræsenterer to kvinders forskellige forsøg på at skabe kontrol i deres graviditet for at sikre et velskabt barn. De to cases skal samtidig ses som dele af en større helhed, og analysen af dem omfatter således også det øvrige materiale fra feltstudiet.

I de to cases beskriver vi hvordan Maja og Ida anvender teknologier i forbindelse med deres egenomsorg, og hvorledes de forholder sig til de teknologier, som de møder på ambulatoriet. Dette med henblik på at vise hvordan de forsøger at integrere teknologierne og behandlingsprogrammet i deres hverdag. Både Maja og Ida oplever nedbrud i forbindelse med brug af teknologi og arbejder begge på at integrere teknologi og behandling i deres hverdag. De to kvinder besidder forskellige sociale, økonomiske og uddannelsesmæssige ressourcer og deres historier viser forskellige muligheder for at håndtere nedbrud og opnå et symbiotisk, reciprokt forhold til den teknologi, der anvendes i behandlingsprogrammet. Ved at udfolde empirisk hvorledes etableringen af et symbiotisk, reciprokt forhold til teknologi er afgørende for kvindernes oplevelse af behandlingsprogrammet, udfordrer de to cases dermed de enten dystopiske eller utopiske forestillinger, der ofte er gældende for, hvad teknologi kan bibringe mennesket i forbindelse med medicinsk behandling.

Maja: Teknologiers bidrag til støtte og tryghed

Maja og Thomas bor i en provinsby ca. en times kørsel fra svangreambulatoriet. På trods af transporttiden og vanskeligheder med at få den og konsultationerne passet ind i deres arbejdstider, synes de at det er en stor fordel at komme til kontrol på hospitalet. Maja er gravid med deres første barn. Det er et ønskebarn, der har været undervejs længe. Da parret var i gang med fertilitetsbehandling, fik Maja konstateret type 1 diabetes. Tre måneder efter diagnosen lærte hun på en diabetesskole at håndtere og leve med sygdommen. Inden havde hun været meget ked af det fordi det var svært for hende at styre sit blodsukker. Både før og under graviditeten har Maja og Thomas grundigt sat sig ind i viden omkring diabetes og graviditet så Maja kunne handle mest hensigtsmæssigt. Maja er gymnasielærer og hendes mand læge og de forklarer, at de derfor godt kan lide at basere deres handlinger på fyldig information. Alligevel har Maja oplevet, at det har været svært at styre blodsukkerværdierne og har sat pris på rådene fra diabeteslægen.

Teknologiers medierende funktion på svangreambulatoriet

For Maja består en dag på ambulatoriet oftest af besøg hos flere af specialisterne. Varigheden af ambulatoriebesøget afhænger af antallet af konsultationer og kan således strække sig fra 15 minutter til flere timer plus transport. Det betyder at Maja er nødt til at flytte sine undervisningstimer de pågældende dage. Thomas er med på ambulatoriet så ofte det kan lade sig gøre med hans arbejde for at være to, der hører de vigtige beskeder.

Til konsultationerne hos diabeteslægen medbringer den gravide den bog hun noterer sine blodsukkermålinger i. Diabeteslægen bruger den samt en såkaldt langtidsprøve, som fungerer som en sladrehank ved at angive den gennemsnitlige blodsukkerkoncentration for de sidste tre måneder, til at basere sine anbefalinger på. Maja har ligesom mere erfarne diabetikere, stor glæde af diabeteslægens anbefalinger, da graviditeten får blodsukkerværdierne til at være ustabile. Maja fortæller hvordan en diabeteslæge, som hun omtaler som 'den aggressive', forklarede hende, hvordan hun kunne gøre sit arbejde med blodsukkeret bedre ved at lave ekstra målinger. Denne evaluering af hendes egenomsorg og de nye krav oplever Maja som en støtte til at opnå det ønskede resultat, "selv om man bliver lidt træt af, at der er nogen der kommer og stikker til en og siger, det der, det kan du godt gøre bedre."

Fra otteogtyvende graviditetsuge bliver der regelmæssigt foretaget ultralydsskanninger enten hos en fødselslæge eller en skanningssygeplejerske. Maja og Thomas er spændte før en skanning, Fordi skanningen viser om der er tegn på uregelmæssigheder, og fordi et computerprogram giver en anslået vægt, og tegner en kurve over barnets udvikling. Især sidst i graviditeten kan barnet på grund af moderens diabetes tage meget på i vægt og lagre en bræmme af fedt om maven hvilket gør det vanskeligt at føde barnet. Derfor oplever mange gravide at fødselslægen opfordrer dem til ikke at lade blodsukkerværdierne stige, og de mindes derved via skanningen om deres ansvar.

Maja oplever, hvordan hun via skanningsapparatet får vished om, at hendes ufødte barn har det godt. Skanningsapparatet medierer Majas oplevelse af at være gravid og have diabetes ved at synliggøre det, der ellers er usynligt; barnet og for eksempel fedtbræmmen. Med Ihdes ord (1990, 80) så indgår Maja i en hermeneutisk relation med teknologien, hvor det ikke er teknologien i sig selv, men den verden den afslører, som Maja er involveret med. Maja er optaget af barnet der via skanning og grafer bliver synliggjort, og ikke af selve teknologien. Ved hjælp af teknologiens mediering og lægens fortolkning kan Maja skabe en forståelse af hvordan barnet har det, og hvordan hun bør regulere sine blodsukkerværdier. En forståelse hun ellers kun delvist kan opnå via den såkaldte langtidsprøve, der med 'mindre kontrast' (Ihde i Veerbeek 2001, 128) end skanningsapparatet afslører barnets tilstand.

Teknologiens mediering og lægens fortolkning af denne får Maja til at føle sig tryg i en tid, hvor diabetesen forårsager mange usikkerheder. Maja har brug for at føle at hun har kontrol over sin sygdom og dermed over graviditetens forløb. På interviewtidspunktet er Maja i stand til at holde sit blodsukkerniveau lavt og teknologierne på ambulatoriet underbygger hendes følelse af kontrol, da hun bekræftes i, at hun gør det rigtige. Hvorvidt Maja rent faktisk er i kontrol eller kontrolleres, er ikke så vigtigt, da det vigtige her er Majas oplevelse af at være i et reciprokt, symbiotisk forhold til teknologien; altså at opleve at skanningen giver hende et brugbart resultat. Også teknologierne anvendt hos diabeteslægen; langtidsprøven og diabetesbogen, optræder medierende og giver Maja mulighed for at forholde sig til sine blodsukkerværdier på konkret vis.

Skanningsapparatet, langtidsprøven og diabetesbogen bidrager desuden til at disciplinere Maja ved at udstikke en ramme for handling, det vil sige, hvad hun bør gøre og eventuelt har gjort forkert. Disciplineringen skal i Majas tilfælde ikke forstås negativt. Maja anser disciplineringen som en ressource, idet hun oplever at have et reciprokt, symbiotisk forhold til teknologierne og er i stand til at inkorporere behandlingen og særligt egenomsorgen i sin hverdag, hvilket vi belyser i det følgende.

Inkorporering af teknologistøttet egenomsorg i hverdagen

Også i egenomsorgen interagerer gravide kvinder med diabetes med teknologi, særligt blodsukkerapparatet. I det følgende vil vi beskrive hvordan Maja anvender teknologier i udførelsen af egenomsorgen og vise, hvordan hun formår at integrere dem og behandlingsprogrammet som helhed i sin hverdag.

Den vigtigste opgave i egenomsorgen er via daglig håndtering af diabetes at holde blodsukkerniveauet lavt. Dette er en meget kompleks opgave som Maja forsøger at udføre på bedst mulig vis. Majas vigtigste redskab i dette er blodsukkerapparatet der ligesom skanningsapparatet medierer hendes erfaringer og giver hendes blodsukkerværdi en form, hun kan handle ud fra. Når Maja har indlæst en bloddråbe i apparatet viser det efter ca. 5 sekunder et tal, som hun på diabetesskolen har lært at fortolke og beregne insulinmængde ud fra. Tallet fra blodsukkerapparatet noterer hun i sin diabetesbog, hvilket også gælder mængden og typen af insulin, hun tager. Maja opnår derved et overblik. Hun kan anvende i håndteringen af sin diabetes. Majas udførelse af egenomsorgen bliver som vist, evalueret af specialisterne på ambulatoriet.

På grund af graviditeten har Maja mistet evnen til at fornemme om blodsukkeret er lavt, og hun er nødt til at foretage mellem otte og tolv målinger dagligt. Maja føler sig derfor afhængig af sit blodsukkerapparat og forklarer, at hun føler sig nøgen uden det. Maja oplever at målingerne giver hende et resultat, hun kan omsætte til praksis, og som giver hende et godt gennemsnitligt blodsukkerniveau og en følelse af kontrol. De mange målinger er dog ikke altid nemme at få integreret i hverdagen som gymnasielærer, og Maja må foretage justeringer for at opretholde den reciprokke, symbiotiske relation. Hun bør måle sig halvanden time før og efter hvert måltid, men hun understreger, ”jeg går ikke ud i en time, når jeg underviser for at måle mit blodsukker, det gør jeg simpelt hen ikke”. Da den ’aggressive’ diabeteslæge påpegede at netop disse målinger ville støtte hende i at opnå et mere stabilt blodsukkerniveau, besluttede Maja, at eftersom det var umuligt at foretage målinger i hverdagen, så måtte hun gøre det i weekender og ferier, selvom weekendens og hverdagens forskellige rutiner ville påvirke resultatet. Maja har ofte svært ved at huske at foretage de mange målinger. Hendes mand forsøger at minde Maja om målingerne mens andre gravide bruger strategier som for eksempel at få en påmindelse på mobiltelefonen.

Også kost er et vigtigt element i egenomsorgen. Af diætisten er Maja blevet opfordret til at veje sin mad før hun spiser, og derefter via en omregningstabel, får hun et nøjagtigt mål for mængden af kulhydrater til brug i beregningen af insulin. Omregningstabellen giver Maja et redskab til at beregne mængden af insulin og den har således en medierende funktion for hende. For en nybegynder kræver det dog en række komplicerede og tidskrævende udregninger. Maja bruger ikke længere omregningstabellen, både fordi det tog for lang tid, men også fordi hun nu kan klare sig uden. Hun skal dog stadig være påpasselig med at spise ofte og regelmæssigt, hvilket kan være svært som gymnasielærer, ”der er situationer, som man kommer i, hvor man ikke kan komme til at spise, og hvor man så er nødt til at gøre det alligevel, for eksempel når man sidder og er censor”. Selvom hun ikke bryder sig om det så må hun bryde de uskrevne regler ved et eksamensbord for at udføre egenomsorgen.

Egenomsorgen som hjemmearbejde

Egenomsorgen er krævende og omfattende, men Maja lykkes i at integrere den i sin hverdag via forhandlinger, strategier og justeringer, da hun selv og hendes mand har de nødvendige ressourcer til at imødekomme udfordringerne. Derved er hun fortsat i stand til at passe sit arbejde samtidig med at hun lever op til ansvaret for det ufødte barn. Egenomsorgen griber dog stadig ind i hverdagslivet; Majas mand minder hende om målingerne og tager med på ambulatoriet. Hun må ændre sine undervisningstimer og hun er konstant usikker på, om hun gør det godt nok.

Grøn et al (2008) påpeger at det arbejde patienter laver i hjemlige omgivelser i forbindelse med deres sydom er komplekst og bedst kan indfanges ved en hjemmearbejdsmetafor. Hjemmearbejde implicerer at nogen giver nogle lektier for. Maja får lektier for af behandlerne og de tjekker, at hun har gjort dem godt nok ved næste ambulatoriebesøg. Samtidig er udførelsen af arbejdet ikke løsrevet fra hjemmets øvrige liv; det skal tilpasses eksisterende rutiner, nye rutiner skal opbygges, og hjemmets andre beboere bliver involveret i udførelsen af arbejdet. Men lektierne er udstukket af behandlerne i et hospitalsmiljø og bliver ligeledes vurderet i et hospitalsmiljø, hvor fokus er på skanningens eller langtidsprøvens resultat og ikke på omstændighederne bag resultatet. Ihde (i Verbeek 2001, 129) beretter netop om hvordan teknologier i deres medierende funktion kun afslører dele af verden, mens andet forbliver skjult. I dette tilfælde skjuler teknologierne egenomsorgens reelle omfang. Selvom behandlerne er bevidste om at det kræver en stor indsats af kvinderne, så er deres primære fokus ikke indsatsen, men resultatet af den. Udover at udføre selve opgaverne i egenomsorgen så bliver det også den gravides opgave at skabe rutiner der kan integrere dem i hverdagen. Både de direkte og de indirekte krav der stilles af behandlerne og behandlingssystemet, indfanges med hjemmearbejdsbegrebet. Implicit i begrebet hjemmearbejde ligger således et potentielt spændingsfelt mellem de forventninger som behandlere har til patienten om at lave lektier, og det hjemmearbejde, som patienten er i stand til at udføre derhjemme. Hjemmearbejdsbegrebet sætter dermed fokus på at egenomsorgen ikke nødvendigvis er enkel at udføre, og at sociale dilemmaer kan være afgørende for, om patienten kan udføre sit hjemmearbejde, som vi skal se i Idas fortælling.

Ida: Behandlingsprogrammets ufleksibilitet

Ida er på kontanthjælp og hendes mand, Peter, er sygemeldt. Deres søn Lucas er otte år og multihandicappet. Handicappet skyldes komplikationer under fødslen blandt andet på grund af fejlvurdering af barnets størrelse hvilket resulterede i iltmangel og hjertestop hos Lucas. Graviditeten er meget belastende for Ida både fysisk og psykisk. Hun er plaget af svær kvalme og har vanskeligt ved at spise uden at kaste op, hvilket gør det svært for hende at regulere sit blodsukkerniveau så godt som hun gerne vil. Hun har bedt om at blive indlagt for at få hjælp til styre sin diabetes, men det er ikke skønnet lægefagligt nødvendigt. Samtidig kæmper Ida med en depression, og i perioder magter hun ikke at komme ud af sengen. Peter kører Ida til ambulatoriet som ligger ca. en time væk. Køreturen er belastende for hende på grund af kvalmen, og det er ubehageligt for hende at sidde i venteværelset med de andre gravide, da kvalmen forværres af lugtene i venteværelset. Hun har ikke tiltro til behandlingen på grund af oplevelserne ved sin første fødsel, men omvendt ser hun ikke andre muligheder end at blive ved med at komme til kontrollerne, da hun ellers vil stå helt alene med ansvaret.

Nedbrud i relation til teknologier

Da interviewet finder sted er Ida gravid i ottende måned og venter på, at barnet snart skal forløses ved kejsersnit. Selvom det har været en fysisk og psykisk udfordring for hende, har hun gjort sig stor umage og er mødt op til de fleste kontroller. Hun føler ikke at behandlerne kan hjælpe hende, men at hun tværtimod bliver mødt med en række krav til egenomsorg i hjemmet, som hun grundet sin situation ikke kan efterleve. Trods deltagelse i kontrollerne oplever hun ikke en større tryghed da hun ikke har tiltro til, at teknologierne viser, hvorvidt hun faktisk ender med at få et velskabt barn. Selvom skanningerne ved første graviditet viste et barn, der bevægede sig og havde det godt, så er Lucas handicappet i dag (2). Ida oplever derfor ikke skanningsbillederne som nogen garanti for, at hun får et velskabt barn. Det er først i det øjeblik hun ser barnet i virkeligheden, at hun vil opnå vished om, at alt er gået godt. Den samme mistro har hun i forhold til vægtskanningerne. Nu hvor hun er otte måneder henne, har hun fået at vide, at barnet vejer 3,5 kilo, men Ida er skeptisk. Ved hendes første fødsel havde de anslået Lucas til at veje 3,3 kilo, men det viste sig, at han vejede næsten fem kilo.

Der eksisterer således en uoverensstemmelse mellem den måde som Ida og lægerne fortolker teknologierne på. Selvom både lægerne og Ida indgår i en hermeneutisk medieret relation til de samme teknologier, så oplever lægerne, at de ved brug af teknologierne får vished om barnets størrelse. Dette hjælper dem til at udføre deres arbejde korrekt og de indgår således i et reciprokt forhold til såvel skanningsapparatet som til de tal og grafer, der genereres om barnet. Ida derimod, oplever et nedbrud i disse relationer. Dette står i modsætning til hendes første graviditet hvor hun ikke stillede spørgsmålstegn ved eksempelvis billederne af et sundt barn, og hvor hun havde en forventning om selv at kunne føde barnet. Ved den anden graviditet formår hun ikke via teknologiens mediering at genskabe dette reciprokke, symbiotiske forhold til teknologierne; vægtskanningerne er utroværdige og billederne af et sundt og rask barn optræder løsrevet fra det barn, som vil blive forløst. Teknologierne er ikke med til at skabe en følelse af kontrol over situationen og dette nedbrud er derved medvirkende til, at Ida fravælger fødslen og vælger en anden strategi i form af kejsersnit for at forbedre sine chancer for at få et velskabt barn.

Udfordrende sociale omstændigheder i egenomsorgen

Idas første graviditet var præget af svær kvalme, værre end nu, og hun gik gentagne gange i insulinchok. Dengang indlagde diabeteslægen hende i en længerevarende periode. Under dele af indlæggelsen fik hun glukose-drop. Hun har forklaret både diabeteslæge og fødselslæge om sin kvalme og om de problemer det giver hende i at styre blodsukkeret, og har som nævnt efterspurgt en indlæggelse. Hun ved godt at en indlæggelse ikke er en langsigtet løsning, og understreger, at det kun er for en periode, hun har brug for det. Én af diabeteslægerne har noteret i journalen at en indlæggelse bør overvejes for at aflaste såvel Ida som familien, men da indlæggelsen ikke er blevet iværksat, oplever Ida det som en kraftig afvisning af at ville hjælpe hende.

Der er således en uoverensstemmelse mellem de behov, Ida har for behandling og de muligheder der stilles til rådighed gennem det standardiserede behandlingsprogram. Ida har vanskeligt ved at overkomme transporten og selve det at være på ambulatoriet og deltage i kontrolforløbet. Samtidig føler hun at det overvejende er barnet, der er i fokus, selvom hun også selv har brug for hjælp. Ida har gennem graviditeten forsøgt på forskellige måder at forhandle med behandlerne for at få tilpasset behandlingsforløbet uden, at det dog har resulteret i ændringer. På trods af alle skuffelserne og ubehaget ved ambulatoriebesøgene tør hun ikke blive væk fra kontrollerne: Hvis hun bliver væk, står hun og hendes mand alene med ansvaret for barnet, og det vil være hendes skyld, hvis noget går galt.

Ida oplever at hun bliver mødt med en række krav fra behandlerne, som hun føler hun ikke kan leve op til. Kvalmen gør det vanskeligt for Ida at holde et stabilt blodsukkerniveau. At hun ikke kan spise betyder at hun heller ikke bør tage insulin, da det vil forårsage at blodsukkeret bliver alt for lavt, og hun vil dermed risikere at gå i insulinchok. Det er en svær situation for hende at håndtere og da hun ikke længere kan mærke når blodsukkeret bliver for lavt, bliver hun nødt til lave hyppige målinger og bede Peter holde øje med symptomer på et for lavt blodsukkerniveau. På ambulatoriet er hun blevet rådet til at forsøge at spise lidt mere for at få bedre styr på sit blodsukkerniveau, men det er meget vanskeligt for hende, og hun har dermed svært ved at leve op til behandlernes anbefalinger.

Udover at det fysisk er vanskeligt for Ida at imødekomme kravene om at regulere sit blodsukkerniveau, så har hun det psykisk dårligt på grund af depressionen hvilket er medvirkende til, at egenomsorgen er uoverkommelig for hende at udføre præcist som forlangt af behandlerne. Idas situation påvirker også familien. Peter har været sygemeldt tre gange på grund af stress, både fordi det psykisk er en belastning at se Ida have det så dårligt, og fordi han er nødt til at overtage de praktiske gøremål i hjemmet.

Idas historie viser hvordan det er omstændigheder, der ikke er knyttet til hendes diabetes, der har indflydelse på hendes evne til at udføre egenomsorgen. I modsætning til Maja har hverken Ida eller hendes mand tilstrækkelige ressourcer til at overkomme egenomsorgens forhindringer. Grøn et al (2008) påpeger som nævnt, at det ofte er ikke-medicinske omstændigheder der har indflydelse på en patients udførelse af behandling i hjemmet. Som vist i fortællingen om Maja er hjemmearbejdsbegrebet brugbart til at belyse de problematikker der ligger i, at patienter skal udføre en behandling i hjemmet, samt de iværksatte strategier. Idas strategi er blandt andet at involvere hendes mand, men hendes situation betyder, at hun alligevel ikke er i stand til at inkorporere hjemmearbejdet i hendes hverdag og dermed lykkes i at gøre den indsats, hun gerne vil i forbindelse med graviditeten. Kravet om egenomsorg virker således ikke som en hjælp eller som en ressource til selvdisciplinering. Tværtimod udgør det en belastning og giver Ida et nederlag, da hun ikke føler, at hun kan disciplinere sin krop, som hun selv og behandlerne ønsker det.

Konklusion

I denne artikel har vi vist, hvordan gravide kvinder med diabetes interagerer med teknologi i form af fysiske redskaber til støtte og monitorering i et standardiseret behandlingsprogram. Maja og Idas fortællinger viser forskellige måder at interagere med teknologi og at opleve behandlingsprogrammet på. Maja indgår i et reciprokt, symbiotisk forhold til teknologierne, idet de giver hende brugbare billeder og resultater, og hun opnår dermed en følelse af kontrol. Den disciplinering behandlingsprogrammet og teknologierne påfører Maja, oplever hun som en ressource, da den øger hendes tryghedsfølelse i graviditeten. Maja er ressourcestærk og disse ressourcer kan hun iværksætte, når/hvis hun oplever nedbrud i forhold til teknologien. Ida derimod besidder ikke de samme ressourcer som Maja, og hendes sociale og øvrige medicinske omstændigheder gør det svært for hende at leve op til de stillede krav. Teknologierne giver hende ikke redskaber til at mindske kvalmen og de reducerer heller ikke angsten for, at hendes ufødte barn bliver handicappet. Ida indgår således ikke i en reciprok, symbiotisk relation med teknologierne og opnår ikke den ønskede følelse af kontrol. Disciplineringen via teknologierne og behandlingsprogrammet virker fremmedgørende på Ida frem for støttende, som det var tilfældet med Maja.

Med artiklen gør vi således op med dystopiske forestillinger om at ny teknologi til støtte af egenomsorg vil invadere hjemmet og gøre hjemmet til et hospital, samt med utopiske forestillinger om at teknologi per definition og ganske gnidningsløst giver empowerment til patienten. Studiet viser at teknologi har en disciplinerende effekt, idet den fordrer en særlig brug. Afhængig af den specifikke interaktion mellem menneske og teknologi, den ramme teknologien sætter, samt de strategier mennesket har mulighed for at udvikle og anvende, er det muligt for nogle patienter at opnå en positiv disciplinering, hvor teknologien opleves som en ressource, hvorimod andre ikke formår at leve op til kravene, hvorved disciplineringen opleves negativt.

Mens de dystopiske og utopiske forestillinger har vist sig ikke at være fyldestgørende i deres dikotomiske form så har vi med artiklen peget på, at det er interessant at fokusere på mulighederne for at skabe en reciprok, symbiotisk relation mellem menneske og teknologi. Dette er relevant ikke blot i behandlingsprogrammet for kvinder med diabetes, men også i andre behandlingsprogrammer, der indeholder teknologistøttet egenomsorg, for eksempel hjertepatienter, der monitoreres i hjemmet. Opnås en reciprok, symbiotisk relation øges chancerne for at patienten opnår et godt medicinsk resultat, da denne lader sig disciplinere, samtidig med at udførelsen af egenomsorgen giver en følelse af kontrol.

Såfremt en reciprok, symbiotisk relation opnås, kan teknologi og nye behandlingsprogrammer med øget egenomsorg kompensere for at hospitaler og behandlinger centraliseres og derved kommer længere væk fra borgerne. Ikke alle formår at opbygge en sådan relation og der er i stedet behov for mere fleksible behandlingsformer.

Noter

Et tværfagligt team af forskere har medvirket i gennemførelsen af feltstudierne. Stinne Aaløkke Ballegaard har været den gennemgående person under feltarbejdet og har lavet alle interviews.

På daværende tidspunkt var behandlingen af gravide diabetikere endnu ikke centraliseret, og såvel kontroller som fødsel foregik på det lokale sygehus.

Tak

Vi vil gerne takke de gravide kvinder med diabetes og deres pårørende samt personalet på svangreambulatoriet. Også stor tak til ISIS Katrinebjerg, som har ydet støtte til forskningsprojektet.

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The eDiary: Bridging home and hospital through healthcare technology

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The eDiary: Bridging home and hospital through healthcare technology

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Abstract. The main contribution of the paper is to present challenges relating to the use of new healthcare technology, the eDiary, which seeks to create a better integration between home and hospital. To minimise risks of malformations and other complications, pregnant women with diabetes are enrolled in an extensive treatment regime, which requires frequent visits to an outpatient clinic as well as a high degree of self-care. The eDiary is designed to assist the women in this work, primarily by allowing the women to register their glucose values, record video consultations, and support video-tele-consultations. This paper reports on a pilot study during which pregnant women with diabetes and their healthcare providers make use of the eDiary. The pilot study indicates that such healthcare technology not only allows the women to achieve a better integration of the management of their diabetes into their everyday life, but may also challenge existing power relations between patients and healthcare providers.

Introduction

The demand for hospital services is increasing as new treatments, lifestyle related diseases and a growing elderly population require more interventions. To move treatment from hospitals to the patients' home and to empower the patients are considered possible responses to this challenge. However, moving hospital services into the homes and everyday lives of patients has a number of consequences for patients in how they manage their disease. It also has consequences for the healthcare providers because it changes organisation of the healthcare services, collaboration between different healthcare providers, and the collaboration between patients and healthcare providers (Dinesen 2007).

The focus of this paper, and the project HealthyHome it is based on, is to enquire into challenges related to the implementation of new healthcare technology that integrates home and hospital. HealthyHome was a two-year, Danish research project focusing on the design of healthcare technology to be integrated in the everyday life of people living at home with a health condition. A secondary focus was to bridge health-related activities in the homes with activities at the hospital. The project was a joint project between a university, two industrial partners and a hospital. One of the industrial partners specialized in electronic health records and the other in wireless technology. The case studied in the project was pregnant women with diabetes. They matched our objective of working with patients that required extensive health support from the hospital, but still spent most of the time out of the hospital. The participating healthcare providers and secretaries were from the outpatient clinic where pregnant women with diabetes are treated.

Based on the development, implementation and pilot study of a web-based tool, the paper points to aspects related to shift in workload, responsibilities and power relations between the home and the hospital. First, we will briefly introduce the case, the developed tool and the pilot study, and then discuss the findings from the pilot study.

Pregnant women with diabetes

A pregnancy is a complicated condition for women with diabetes as diabetes causes risks of pre-eclampsia, hypertension, premature birth, malformation of the heart, miscarriages, and stillbirth (Lauenborg et al 2003, Jensen et al 2004, Clausen et al 2005). According to one of the obstetricians involved in the project, approximately 50 % of the pregnant women with diabetes have a Caesarean birth as their foetuses weigh too much for a normal delivery.

To reduce the risk of complications, the pregnant women with diabetes are closely observed by a specialised interdisciplinary team of healthcare providers (dietician, diabetes doctor, obstetrician, and midwife) during pregnancy and birth. Since 2001, the treatment has been centralised at four specialised units in Denmark (Indenrigs og Sundhedsministeriet 2003). The treatment consists of consultations with the team of specialists at one of the four units every second week until week 32 and then every week[1]. In addition to the hospital-based treatment extensive self-care is required to keep the blood glucose low. Due to the pregnancy the need for insulin fluctuates making it difficult to keep blood glucose stable. The self-care includes exercise and a healthy diet.

In the beginning of the project, a field study was carried out focusing on this double-sided treatment of diabetic pregnancies. The study lasted four months and included approximately one hundred hours of observations at the outpatient clinic as well as interviews. Ten pregnant women with diabetes were recruited at the clinic and interviewed in their home. Four healthcare providers were interviewed at the hospital. The ten pregnant women all had type 1 diabetes, as opposed to the type 2 diabetes lifestyle related, and the majority of the women have had diabetes

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[1] A normal pregnancy is expected to last 40 weeks, however labour in diabetic pregnancies is often induced during week 37.

for several years. The field study revealed the main challenges within the existing treatment programme and of being a pregnant woman with diabetes. In particular the amount of work required by the women in carrying out their self-care and attending the consultations at the outpatient clinic informed the further design process.

Related work

Easy and correct management of blood glucose is generally a huge challenge for people with diabetes and hence a large number of both commercial systems and research projects address this area. This section will briefly discuss some of the software solutions and systems that address everyday management of diabetes.

A comprehensive list of a couple of hundred freeware and commercially available systems are listed and briefly commented by David Mendosa (Mendosa, web 2009). Most systems provide similar functionality and are mainly focused on visualising glucose level, insulin doses, calorie intake and exercise information. A challenge for the use of these systems is to enter the required information into the system. To address this a number of the solutions provide extensive information about different types of foods (DiabetesPilot, web 2009), support mobile data entry (SiDiary, Mendosa, OneTouch, web 2009), or allow synchronization of data from for instance a glucose meter (AccuCheck, Onetouch, web 2009). However, even though the data entry is easier with some of these solutions, they still require extensive data entry activities from the user, which reconfigure some of the solutions from being about decision support and overview to a registration tool as discussed by Danholt (2008).

A number of the commercial systems also use the title diary or logbook to emphasise the continuous use of these systems, but still they focus strongly on health or diabetes and do not mix everyday events with the clinical purpose of collecting data (SiDiary, MyNetDiary, DiabetesLogBook, web 2009).

A number of research projects have also worked on the management of diabetes. A larger endeavour is the MAHI research project by Mamykina et al (Mamykina, 2006, 2008). The MAHI project extends a previous project called CHAP within this area and focuses on people newly diagnosed with diabetes. In the MAHI project 25 people used a combination of a camera-phone and a glucose meter for four weeks to record glucose levels and take pictures relevant to their diabetes. The main focus of the project was to help people reflect on how to manage their diabetes. It is a different challenge from the pregnant women with diabetes where most have had diabetes for several years.

A related project investigates the relation between digital photos and glucose data. In this project a system with a glucose meter and a camera was tested in a pilot study (Smith, 2007). And while the focus is on creating a tool to support reflection, the project shares the same challenge as the previous project. To really make sense of the collected data, the data needs to be coupled to the context. For instance the interpretation of a blood glucose figure depends on whether the data is taken before or after lunch. And though photographing events such as eating lunch might help the interpretation this might not be a viable solution for the everyday use of the software to manage the blood glucose.

Design, implementation and evaluation of the eDiary

In line with Mamykina et al (2008), we believe that rethinking health records is relevant with the rise in chronic diseases where being ill is an aspect of everyday life and with the increasing number of treatments being moved from hospital to home entailing collaboration between patient and healthcare provider outside the hospital. Management of disease and treatment becomes a matter of supporting the integration between hospital and home and facilitating the treatment at home. In this section, we present the process of design as well as the eDiary developed to achieve just this.

The field study showed that pregnant women with diabetes generally experienced that the management and treatment of their disease took up much space and time and were, to some extent, what their everyday life evolved around during their pregnancy (Ballegaard & Aarhus 2009). The purpose of the eDiary is hence to be a tool for supporting the pregnant women with diabetes to manage their diabetes in their everyday life, but also a tool for supporting their collaboration with their healthcare providers in a hospital setting, as this was another point from the field study. The eDiary mixes the concept of a diary and a personal health record to achieve this objective. A diary is often a personal item for recording everyday events relevant to the owner. In contrast a personal health record is often the outcome of clinical systems of medical devices and contains everyday information about the patient’s health condition.

The concept and the following prototype implementation were developed on basis of the early field studies and on a series of workshops with participation of project partners, healthcare providers and pregnant women with diabetes. Based on the early field studies, ten different concepts were presented in an initial design workshop with healthcare providers, two pregnant women with diabetes and the research team. Among the concepts were: specially designed handbags for pregnant women with diabetes, an intelligent booking system, and novel consultation rooms. Based on the discussions at the workshop, the concept of the eDiary was selected and further developed.

To validate our discussions, a second workshop was designed to get feedback of the eDiary from a larger number of patients. The workshop took place in the waiting area at the outpatient clinic. A third and fourth workshop explored a mock-up of the eDiary and tested a prototype of the system. Four pregnant women with diabetes and their healthcare providers (an obstetrician, two midwifes, a diabetes doctor, a dietician and two nurses) participated in these workshops.

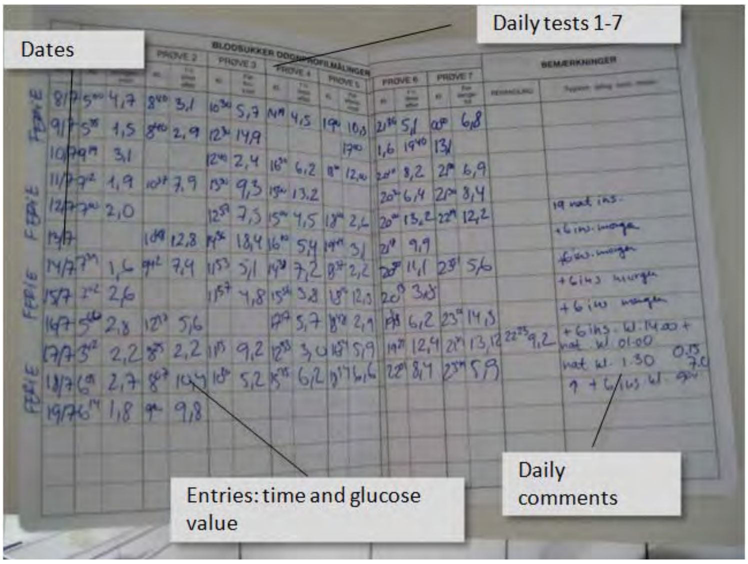

Figure 1. A traditional diabetes book. Each row presents the blood glucose development during a single day, along with insulin dose and comments.

The eDiary prototype

The eDiary consists of a web portal, which offers various services. First, the portal allows users to manually type in blood glucose measurements from their preferred glucose meter and add additional comments to specific measurements. The field study revealed that comments were vital for understanding the circumstances of a specific measurement – if eating birthday cake caused a high figure or if it indicated a shift in the need for insulin (see (Dourish 2004) for a discussion of the use of contextual data in system design). Furthermore, the portal contains a monthly overview of blood glucose measurements similar to the traditional diabetes book that the pregnant women receive from their doctor shown in Figure 1Figure 1. A traditional diabetes book. Each row presents the blood glucose development during a single day, along with insulin dose and comments. In this book they register their blood glucose values approximately seven times a day, note their insulin dose, and add comments, if necessary. They use the book in their daily evaluation of their blood glucose and in the discussion with the diabetes doctor at the outpatient clinic. Apart from this, the portal can automatically highlight with colours women, e.g. all figures below 3.5 or higher than 10.[2] Some blood glucose meters allow automatic upload of data, however, this approach was not selected because there was no easy way of attaching

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[2] During the pregnancy, six mmol/l is the recommended blood glucose average (Jensen et al. 2004).

comments to the individual readings and because the women used devices of different brands, many of them not able to connect to a computer.

Second, the eDiary allows the user to record and play videos directly from the web site with the use of Adobe Flash. By means of the eDiary and a webcam, video recordings of the women's consultations are easily produced by the women in the outpatient clinic and played at home.

Finally, a collection of links about specific topics relevant for pregnant women with diabetes is accessible from the web portal. The links were selected in collaboration with the healthcare providers who were also encouraged to add links throughout the pilot test. The links were made available through the commercial service, Delicious.

Figure 2 shows screenshots from the prototype. On Screenshot 1, the services (blood glucose, video and links) are listed in the left column. The right column shows an excerpt of the table listing the different glucose measurements along with a timestamp and insulin doses. The last column allows for comments, which this woman used to summarise her daily insulin doses. The recording of blood glucose and insulin intake is focused on predetermined key points around the meals in line with medical advice and the traditional diabetes book. Screenshot 2 shows a list of recorded videos along with a short editable title – pressing the title of the existing video will play the specific video. Furthermore, by activating the

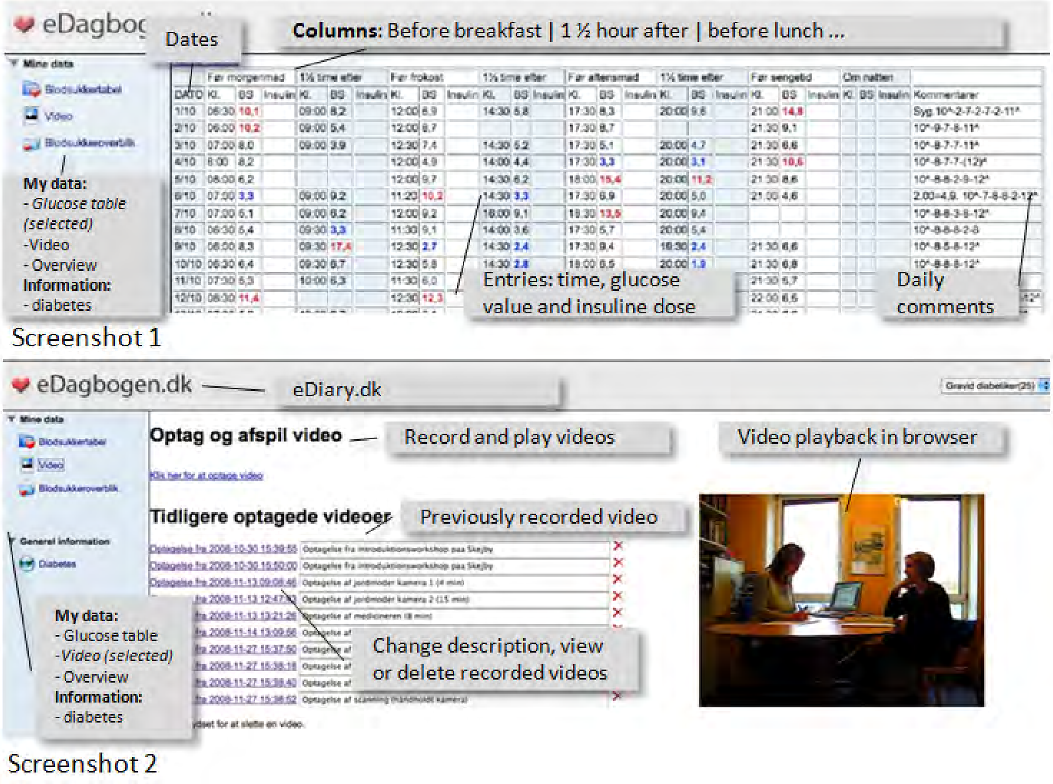

Figure 2. Screenshots from the eDiary.

top link, new videos can be recorded in the browser from this screen within the eDiary, making recordings of consultations or home video easy for the women.

The main objectives of the eDiary were to support the women in their everyday life and to allow for tele-consultations between the woman and the healthcare providers. Accordingly, choosing a web-based approach allowed the pregnant women with diabetes and their healthcare providers to access the eDiary from any computer without installing extra programs (except Adobe Flash Player for watching video). The system runs and has been tested on all major browsers and platforms. The user interface is developed using Google Web Toolkit Framework. Furthermore, a mobile version is developed to ensure mobility. The Nokia Widget Framework is used to present a compact version of the eDiary on a mobile phone. On the Nokia mobile phone a service makes it possible to enter blood glucose values and also access daily overviews.

While the prototype is aimed at pregnant women with diabetes, the overall architecture is designed to allow the plug in of different services to the system. A modular service-oriented approach was selected to ensure that the diary could easily be reconfigured to support other types of health problems by adding new or removing existing services. In addition, the architecture is highly distributed enabling various vendors to develop different services for the eDiary.

The pilot test

To test the eDiary prototype three pregnant women with diabetes, Martha, Vicky and Emma, were recruited voluntarily in the waiting area at the outpatient clinic. They had type 1 diabetes, Emma only for about one year, the others for more than 10 years. Emma was in her late twenties, Vicky and Martha in their early thirties. The test lasted one month and was designed to support the pregnant women in already existing routines and activities related to the management of their diabetes. Rather than utilising the traditional diabetes book the women used the eDiary to key in their blood glucose value, the amount of insulin, and comments. During the test the women on average had seven daily entries using either the web page or the mobile phone. They did this either during the day or at the end of the day depending on their other activities and engagements.

The women attended the outpatient clinic every two weeks as part of the ordinary treatment and hence twice during the test (see Figure 3). These consultations were video recorded in the eDiary by the women. In the pilot test, a separate computer was in most cases used at the hospital to access the eDiary to avoid using the IT-infrastructure of the hospital. Emma and Vicky each saw their recordings with their husband once, Martha saw her recordings several times on her own, once with her husband, but faced technological difficulties when showing them to her mother. Vicky showed her recordings to her mother.

The eDiary was used in all but one consultation (due to initial hesitation of the diabetes doctor) with the diabetes doctors to discuss the blood glucose values.

The other healthcare providers also had the possibility to look at the blood glucose values, but this only happened a few times which corresponds to the frequency in which they would have used the regular diabetes book. In addition to the ordinary treatment, each woman had one tele-consultation with a diabetes doctor using a Skype video application. Each woman got a scheduled time the day before a check-up at the hospital, but was free to decide from where to have the tele-consultation. A support hotline and support e-mail were available during the test. The women received an eDiary manual and a web camera.

		Obstetrician	*Diabetes doctor*	*Midwife*	*Scanning*	*Dietician*	*Tele-consultation*
Martha	13-Nov-08	X	X				
	26-Nov-08						X
	27-Nov-08	X	X		X		
Vicky	13-Nov-08		X	X			
	26-Nov-08						X
	27-Nov-08	X	X		X	X	
Emma	13-Nov-08		X				
	26-Nov-08						X
	27-Nov-08		X	X			

Figure 3. Overview of the ordinary consultations (13th and 27th Nov.) and tele-consultations (26th Nov.) during the pilot test.

To collect data we used three different methods during and after the pilot test. First of all, the interaction with the system was logged and data concerning which device was used and when were recorded. Secondly, we wrote extensive field notes and had follow up conversations after each visit to the outpatient clinic. Thirdly, each of the pregnant women, and in two cases also the husband, was interviewed after the test period. Also two diabetes doctors, one dietician, and one obstetrician who all had been involved in the test were interviewed. All interviews were recorded, transcribed and later analysed with the other data. In the following section, we will present indicative findings from the pilot test.

Findings from the eDiary pilot study

The findings we present here are from a limited pilot study with three women lasting one month. The findings are hence indicative rather than definitive. The starting point of the analysis is the three main services of the eDiary: ‘blood glucose’, ‘video recordings’ and ‘tele-consultation’. Vicky, Emma and Martha, the three pregnant women with diabetes, were the main users as well as the healthcare providers who treated them. The three women described themselves as experts in diabetes management and successful in managing their diabetes both prior to and during the pilot test. Whether the findings would also be representative of pregnant women who experience difficulties in the management of their blood glucose remains to be tested. The women did not consider themselves expert users of technology. Martha was a clerk and despite her daily use of computers she had only little interest in technology. As a school teacher Vicky also had basic knowledge of computers. She had only little interest in technology, and her husband was the system administrator at home. Emma, who was a PhD student within the field of archaeology, was a more confident user of computers and other technological devices that she used almost on a daily basis.

Using the eDiary to manage blood glucose

> *Vicky has had diabetes for 11 years, she is married and expects her second child. She is successful in keeping her diabetes tightly regulated and experiences that the eDiary constitutes a useful tool in this. She types in her blood glucose numbers on the mobile phone when she makes the measurement, but feels that the web solution provides a better overview.*

Integration in everyday life and work routines

Blood glucose management was a central activity for the pregnant women with diabetes. Figure 4 shows how the women and their relatives used the eDiary at home. Vicky described how she used the eDiary to enter and access her blood glucose figures. Usually she used her diabetes book to write down the figures, but Vicky explained that during the pilot test it quickly became obvious that it was easier to bring her mobile phone than the traditional book and a pen: *'you always bring your phone anyway'*. Likewise, Martha preferred the mobile phone and both agreed that the web portal was excellent for getting an overview. In contrast, Emma preferred to enter the figures via the web solution: *"I'm online everyday so it makes sense to use it"*. She had only used the mobile phone on a few occasions, e.g. when she went away for a weekend, making new entries easy despite being out of daily routine and away from her computer. During the pilot test Emma experienced a change in her need for insulin and used the eDiary in the process of adjusting the dose: *"It's very smart that you can colour the numbers above and below a certain value so you can see if there is a system.* (…) *During the period where I had to take more insulin it was very pedagogic that I could see exactly where it went wrong"*. Vicky also expressed that the eDiary gave her a feeling of security; *"I don't have to bring my book and if I have forgotten it, then it's just there. And they* [the healthcare providers] *can find it* [blood glucose list] *even if*

Figure 4. The use of the eDiary by the women in their homes.

I'm not there". None of the diabetes doctors had preferences on whether to utilise the traditional diabetes book or the eDiary when treating the pregnant women with diabetes. However, it was crucial that the eDiary could provide them with the standardised overview, as it would be highly time consuming to decipher various systems.

The women's experiences with the eDiary indicate that it integrates well with existing routines, both at the outpatient clinic and in the everyday lives of women. The three women found the eDiary easy available and had each adopted it in a manner compatible with routines of their everyday life and working patterns.

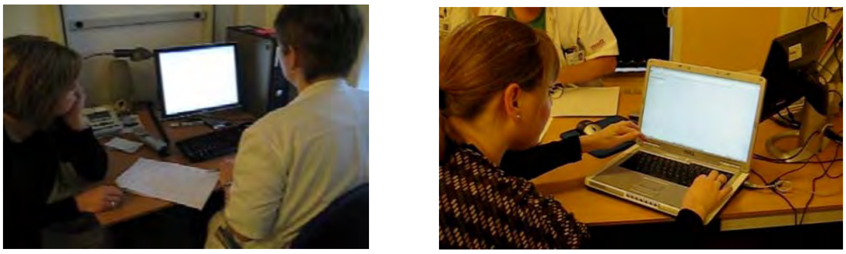

Figure 5. Left picture: Using hospital computer the doctor controls the keyboard and mouse, leaving Vicky as a spectator. Right picture: Martha logs on the dedicated computer to use the eDiary in the consultation. Behind the dedicated computer is the computer of the healthcare provider.

The eDiary at the hospital

The collaboration between the women and their diabetes doctors centered around blood glucose levels, and in the pilot test eDiary served as a collaborative object. Two different approaches for accessing the eDiary were tested. During most consultations a dedicated laptop with a 3G connection was used. Due to problems with the 3G Internet connection the hospital computer was used instead in two instances. The two different ways of accessing the eDiary web portal produced - through collaboration and negotiation between the women and the diabetes doctor - two different usages (see Figure 5). With the use of the hospital computer the diabetes doctor got the username and password from Vicky, thus gaining control of the situation: deciding when to look at the blood glucose and when to shift to hospital systems, such as the laboratory system. In this situation the women lost control in comparison with the traditional diabetes book where they themselves held the book and could point out important figures.

In contrast, using the dedicated laptop the women themselves logged in and navigated to the appropriate web page with the diabetes doctor as a spectator who should negotiate with the women to access relevant data. Although the situation does not appear to be much different from consultations where the women bring their traditional diabetes book, introducing a new technology opened up for negotiations of the structure of the consultation in the pilot study. A diabetes doctor explained that she often performs various tasks simultaneously and that she preferred to be in control of which tasks to carry out: *"I choose the blood* *samples and I choose to look in the record or I choose to look at the blood glucose figures".* However, giving the women a dedicated technology of which the diabetes doctor had no control interrupted the traditional structure where the diabetes doctor sets the agenda, opening for negotiation of the structure of the consultation and the position of both the diabetes doctor and the women. Both Vicky and her diabetes doctor agreed that the eDiary in the pilot test belonged to Vicky. Vicky says, *"it's my numbers and it is I who can help interpret them – there is a story behind these numbers".* Her doctor agreed, *"when you access the eDiary then you are on the patient's turf (...) it's something we are given permission to look at".* The concept and design of the eDiary highlighted that the data originates in the home and thus belongs to the women.

Video recording of consultations

> *Since her first pregnancy Martha's husband has gotten a new job, making it more difficult for him to attend the consultations of this second pregnancy at the outpatient clinic and thereby share the responsibility. During a single visit to the outpatient clinic, Martha has several consultations, and receives much information, which she often finds difficult to remember.*

The pregnant women with diabetes were to a large extent carriers of information both between different healthcare providers at the outpatient clinic, and between daily life and hospital. Being able to remember and to incorporate all information was a critical task to ensure a healthy pregnancy and to feel secure. A day at the outpatient clinic typically consisted of appointments with several healthcare providers making it difficult to take in all information. Martha explained, *"You don't store all information, only the most important things. But who knows, maybe some of the things you didn't store could be important too".* While watching one of the video recordings with her husband and two researchers, Vicky realised that she was not able to remember everything: *"did she say 3,600 to 3,700 gram? I didn't tell you* [husband] *that* (…) *I am totally surprised".* The pilot test indicates that through the recordings, the eDiary can support pregnant women with diabetes in encompassing and remembering much information.

For Martha, the recordings improved her husband's ability to participate in the consultations despite the shift of time and space facilitating their sharing of responsibility. To Vicky and her husband, the recordings improved their exchange of information, her husband explains: "*because when I ask you... it's always the same to you, so you tell me the same things always. And you can't remember even half of it. So it's at good thing to be able to see what happened".* The healthcare providers also pointed to the potential positive effect of a recording in making the pregnant woman aware of what the healthcare provider really said rather than what they thought he said thereby reducing the level of uncertainty. The women and their husbands agreed that the most interesting recordings were consultations with obstetricians, dieticians, midwives, and scannings as they centered on the baby and provided information new to them.

The pilot test points to the potential of recordings as a supportive tool for both pregnant women with diabetes and their husbands.

Responsibility and system administration

The experiences of the pregnant women with diabetes and their husbands were that both sound and picture should be recorded, that all participants in the consultation should be seen and that gestures should be visible. As the place of a consultation may move from desk to couch and back again, the equipment should ideally be flexible to allow the filming of this automatically.

During the pilot test the healthcare providers reserved the right to refuse to be filmed. On several occasions the healthcare providers discussed the risks of being filmed and perhaps subsequently criticized in public. Most often they came to the conclusion that the advantages were bigger for the pregnant women of having the recordings than the risks they as providers faced being in a Danish context with no or only little tradition for running lawsuits against doctors. However, they came to this conclusion within the context of a pilot study and thus these legal aspects should be further discussed and examined.

Overall the recording of consultations at the outpatient clinic was to the pregnant women’s benefit, raising the question whether the women should also become system administrators, e.g. activating recordings and responding to software updates, rather than the healthcare providers. However, the women are already focused on and engaged in what happens at the consultation and handing over the responsibility to them may be experienced as an extra burden. On the other hand, the women might accept this extra work as it empowers them, This discrepancy between being recorded and getting the benefit is a challenge to the success of using video recordings in this setting (cf. Grudin 1989). In a related project on video recordings of surgical rehabilitation Sokoler et al present explicit interaction as a way of sharing the responsibility of setting up the consultation and making it explicit when something is being recorded (Sokoler 2007).

The role of tele-consultations

> *Emma is pregnant with her first child. The frequent visits at the outpatient clinic interrupt her busy workday. She insists on not letting her disease control her and her husband’s life. Emma is open about having diabetes and does not consider it a problem to have a tele-consultation with the diabetes doctor from her office that she shares with a male PhD student.*

During the pilot test all three women had one tele-consultation with a diabetes doctor. Potentially, tele-consultations can save much time on transportation for the women, and while others have provided larger tests (see (Verhoeven et al 2007) for a literature review), this small scale experiment was set up to explore the outcome and implications of carrying out such consultations in the context of the eDiary.

Emma experienced a delay in the doctor calling her for the tele-consultation, but waiting at her desk she could continue her work. Emma and her diabetes doctor used the web-application of the eDiary to exchange information of blood pressure and blood glucose in the tele-consultation. As they could both see the figures, they were able to discuss them as they would at the outpatient clinic. Since her last visit at the outpatient clinic Emma had experienced a sudden increase in insulin need and was reassured by the diabetes doctor that she had made the right adjustments.

Changing the setting of the consultation

In line with other pregnant women with diabetes who had a stable blood glucose level, Emma thought of the consultations with diabetes doctors as trivial. Rather than getting all the answers from an expert she felt that she and the doctor had discussions where they both had an equal saying. Emma, as with the other pregnant women at the outpatient clinic, often does not see the same diabetes doctor from one consultation to the next. The consultations with the different diabetes doctors do, however, follow the same recognisable structure, where the same topics are discussed and the doctor takes the initiative, which eases the women's interactions with different doctors. The tele-consultation came to follow the same structure making it easy for Emma to interact with a diabetes doctor she had not met before in a way previously not known to her.

However, Martha preferred the consultations at the hospital; *"I prefer to be face to face with the doctor as it's easier to have a conversation"*. To her, the physical atmosphere of the consultation influenced the flow of the conversation. A healthcare provider also expressed her worries about the change of setting, *"I think there might be a risk that it will not be as quiet as needed. You will not put a stop to everything at home to have this consultation. The phone may ring, somebody may ring the bell. All kind of disturbances may happen"*. Compared with the disturbances of the consultations at the outpatient clinic, the healthcare providers were not in control of them in the case of tele-consultations.

From several observations at the outpatient clinic it is clear that the pregnant women seize breaks in the consultation to ask questions. Emma explained that when*"you see that she finds her dictaphone and is finishing up. Then it is about time to ask your question"*. The three women experienced the tele-consultation to be less calm and shorter compared to the consultations at the outpatient clinic, possibly reducing the opportunity of seizing a break. Martha elaborated that it was not only about timing but also about *"remembering a question while leaving the room"*. By having a tele-consultation, the women risk loosing the chance to ask a remembered question while leaving the room. These observations are to be considered when changing the setting with a tele-consultation.

As all patients were not as well regulated as Emma, Martha and Vicky the healthcare providers insisted on the possibility to differentiate among their patients in offering this service. In addition, a tele-consultation should be accompanied by a possibility of having a consultation at the outpatient clinic if either the healthcare provider or the patient experienced a need.

Integrating or disturbing

Emma made the tele-consultation from her work. She said that *"if the diabetes should take up as little room in my life as possible, then I need to do all these* [diabetes related] *things in the situation I am in"*. Vicky also integrated the tele-consultation in her workday. Being a teacher, she prepared herself for the next day's work from her home while having the tele-consultation. Neither Emma nor Vicky experienced that having a tele-consultation in the midst of their everyday life mattered or influenced the outcome. They did not feel that the technology made their diabetes more dominant but appreciated the integration of their treatment in their everyday life. Martha on the other hand did not want to cross the boundary between work and private life; *"I would not like to sit in front of my colleagues* (…) *I don't proclaim that I'm a diabetic"*. Having the tele-consultation from her home, she was able to keep her private life and work apart.

Tele-consultations might address some of negative aspects, e.g. transportation and time used, of the trend towards centralisation within the healthcare sector. The women in the pilot study inferred that the tele-consultation did not compromise their feeling of security, a feeling they usually got by the many consultations at the outpatient clinic. The pilot test indicates that the eDiary might be a supportive tool to be used in tele-consultations to facilitate exchange of data between healthcare provider and patient.

The eDiary between home and hospital

While the scope of the study is limited, the pilot test revealed indications of minor changes which, in sum and seen in a larger perspective, point to general discussions important for future work attempting to integrate hospital and home. That the introduction of new technology causes changes in practices and collaboration in a working setting is not a new insight within CSCW (Heath & Luff 1996). In our study, however, we focus on changes from introducing technology that connects two very different settings, that of the home and of the outpatient clinic. In the following, we will discuss how the eDiary facilitated the integration and its effects.

The eDiary as an integrating element

The management of a disease requires much work, not only in response to the physiological unfolding of a disease, but also includes the total organisation of the work done, including the impact on those involved with that work and its organization, what Strauss et al has defined as an illness trajectory (Strauss et al 1997, 8). While the term originates in studies of organisation of work in a hospital setting, we believe that the concept also applies to that of the home. Both the pilot study and the initial field study revealed that to have diabetes while being pregnant required the women not only to do an extensive self-care of monitoring their blood glucose but also that it involved a complex organisation of this work, constituting problematic trajectories. For example one woman had a depression in addition to her diabetes and another had work hours that made it difficult to measure the blood glucose at the advised hours. To accomplish the self-care the women used different strategies and at times also involved their husbands (see Ballegaard & Aarhus 2009). Grøn et al (Grøn et al 2008) introduce the concept of homework to broaden the notion of self-care to include the organizational work embedded in illness trajectories that influence the process and outcome of the self-care and hence that medical advice is not always easily followed outside a medical setting.

Much existing diabetes-related technology increases rather than supports or removes the homework, as it requires the user to type in much information (Danholt 2008). The initial field studies drew our attention to the amount of work in self-care and hence the notion of homework and it was a design principle not to add to the amount of homework of the pregnant women with diabetes. As described earlier, the three women in the pilot test did not experience that the eDiary removed their homework nor that it extended their homework. Rather they experienced the eDiary as a support in doing their homework and a tool to ease the integration in everyday life. In developing healthcare IT for the home with the aim of integrating disease management in everyday life, it is hence beneficial to take into account the concept of homework rather than self-care to include the non-medical factors and the actual work done to manage a disease in the home and in collaboration with healthcare providers.

The role of technology in concealing a disease

An aspect of the pregnant women's wish to integrate the disease management in everyday life was to reduce the space the disease took up. As is often the case with chronic patients (Robinson 1993), the pregnant women with diabetes did not want their disease to control their life and preferred not to be identified solely through their disease, i.e. as a diabetic. As Martha explained earlier, she did not wish to proclaim to have diabetes. To have a chronic disease is to live with your disease the rest of your life. Alonzo (1979) uses the concept 'side-involvement' to shed light on the space a disease takes up in a person's life. As long as you can keep your disease a side-involvement, it does not govern your other activities and is not the lens through which you see the world. Our early field studies revealed that when not pregnant, most of the women with diabetes experienced their diabetes a side-involvement. During pregnancy, it was more difficult for them to keep their diabetes a side-involvement as they were required continuously to do extensive homework. However, they sought to downplay the role of their disease by using different strategies, e.g. concealing artefacts related to their disease or integrating the diabetes related homework in their everyday work.

An objective of the eDiary was hence to support the women in keeping their diabetes a side-involvement. The means to do this were to support homework and to ensure that the technology could be integrated in everyday life without drawing attention to their chronic condition. In creating the eDiary we thus worked with how technology designed for disease management could have functionalities not related to healthcare. While the test focused on disease management, the concept of the eDiary was to merge different spheres of life while still having the opportunity to keep them separate, e.g. to not be reminded of disease when watching private photos. The eDiary was built on technology already integrated in the lives of the pregnant women with diabetes as well of healthy people and hence did not in itself indicate disease. The eDiary provided the pregnant women with a choice to conceal their diabetes status, and its integration helped them keep the diabetes a side-involvement. The pilot test drew attention to the dilemma of integrating while at the same time concealing, and that a healthcare technology should not only take the everyday life of the future users into account but also the perception and nature of the disease.

Bridging home and hospital

While the eDiary integrated disease management in everyday life, the question remains whether it bridged home and hospital in order to create greater coherence in the pregnant women's lives? Field studies established that hospital and home existed as two different spheres, which had an effect on the women's ability to integrate everyday life with disease management. On the other hand, the segregation gave them instruments to choose different identities in different situations; at the hospital they were patients while at home they were people. The division also affirmed that treatment occurred on the premises of the hospital; it was the pregnant woman who should adapt their work to the consultation hours and the work done in the home was scarcely acknowledged in the hospital sphere. The aim of the eDiary was thus to address the division between home and hospital by making the solution relevant and available for both patient and healthcare provider.

Healthcare technology often belongs to only one domain, either hospital or home. However, the eDiary transcended the domains by placing itself somehow betwixt and between, as both the healthcare provider and the pregnant woman were supposed to use it even if the women were the primary users. In this sense, the eDiary was a boundary object (Star & Griesemer, 1989) inhabiting both home and hospital, although its use and meaning varied between them. The eDiary, as was the case with the diabetes book, bridged the two spheres by bringing information from the home to the hospital and advice from the hospital to the home. In addition, the eDiary bridged home and hospital in making consultations available from home either through recordings or tele-consultations.

A challenge with the design of a technology that can be used in more than one domain is that the user-group is extremely heterogeneous having different needs and routines in which the technology should be integrated. The challenge is to make it plastic enough to match both groups as well as robust enough to be recognizable by both groups, as characterises a boundary object. The eDiary matched the women's needs better than the healthcare providers'. One of the obstetricians said in an interview that he only delivered information to the eDiary, but that he was not involved in the actual use. It could prove to be a weakness of the eDiary as the acceptance and use of a technology, as Grudin (1989) points out, largely relies on the users' ability of seeing benefits in it.

Through the eDiary, the home sphere was strengthened, not at the expense of the hospital domain but as a supplement to it. Neither the pregnant women nor the healthcare system had in this case any interest in abandoning the hospital treatment. Instead, the eDiary augmented the treatment increasing its flexibility of moving between home and hospital.

Structure and hierarchy within the healthcare sector

The healthcare sector today is based on a power relationship that to a large extent is asymmetrical in its structure as it is the healthcare system and providers that set the agenda for the treatment and hence treatment is delivered largely on their conditions. Both patient and healthcare provider recognize their roles and play their role ensuring the status quo of the situation. The asymmetrical relationship is seldom questioned as both parties take it for granted and hence are not conscious about it or its possibility of being different. However, as argued by Bardram et al (2005) changes may occur in this underlying power structure by the introduction of new healthcare technology. In their study, tele-medical solutions produce new practices, which change not only the communication between healthcare provider and patients, but also the division of work between the two parties where knowledge is collected and interpreted. Similarly it has been argued that to move technology into the homes questions the power relation between clinician and patient and reconfigures the role of being an expert (Ballegaard et al 2008).

The pilot test of the eDiary indicates that the introduction of the eDiary might introduce changes in the practices concerning the treatment that potentially open for a re-negotiation of the underlying power structure within the healthcare system. In our analysis we described how the eDiary offers a new physical space of treatment, new treatment technology, and an empowered patient role: Changing the physical space through the tele-consultation might question the asymmetrical power relation as a consultation from home left the diabetes doctor with little possibility to control the situation as he could in a consultation room and even opened up for disturbances affecting the consultation. Furthermore, being on one's home ground might increase the patient's self-confidence. The possibility of watching recordings of consultations was experienced to be an empowering tool of the patient, as she got the chance to improve her knowledge through seeing the consultation again. Additionally, the women were given the opportunity to question the healthcare providers if she found contradictory information in the recordings. The healthcare providers on the other hand might be more thorough in their utterance as they knew that it could be reheard and discussed at home. The recordings may in extreme cases change the structural power relation drastically as the patient may distribute recordings and use them for lawsuits as previously discussed. Finally, bringing in new technology at the outpatient clinic, over which the women had control in the shape of the necessary passwords and data ownership initiated a potential re-negotiation of the situation.

The structure and hierarchy did not change substantially during the limited pilot study. Nevertheless, the eDiary prompted new routines at the outpatient clinic as the pregnant women with diabetes became users of technology in the consultation rooms and as consultations were also made outside the hospital. The eDiary could provide the healthcare providers with the possibility to organise the work around pregnant women with diabetes in a new manner that to a larger extent could accommodate the wishes and needs of the women. While we acknowledge that the present study is too limited to give any firm conclusions, we find the possible re-negotiation of the underlying power structure to be of vital importance to future work in the design of healthcare solutions that connect home and hospital. It is thus something to be studied further as the implications may hold great potential for rethinking the structure of healthcare services in the future.

Conclusion

Through the design, development and pilot test of the eDiary we have explored effects of introducing technology that supports pregnant women with diabetes in their everyday life. In particular, we have explored the emergence of new practices related to the use of the eDiary and have discussed how new healthcare technology can serve to support patients in the management of their disease in everyday life, and how the introduction of new technology has the potential to open a re-negotiation of the underlying asymmetrical power structure within the healthcare sector.

While the pilot study and the complexity of the eDiary was limited, the study revealed how moving treatments from one setting to another opens a more complex discussion about homework, power relations, different interest in the design of healthcare technology and the challenge of designing and fitting the technology to the everyday life of both healthcare providers and patients. In the case of the eDiary, questions emerged regarding the future of a system, which tend to support and favour the patient and not the healthcare provider, most obvious in relation to the recording of consultations which not only expose the performance of the provider but also is to be used exclusively by the patient. These questions remain open but are highly relevant for future work.

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Negotiating Boundaries: managing disease at home

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Negotiating Boundaries: Managing Disease at Home

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ABSTRACT

To move treatment successfully from the hospital to that of technology assisted self-care at home, it is vital in the design of such technologies to understand the setting in which the health IT should be used. Based on qualitative studies we find that people engage in elaborate boundary work to maintain the order of the home when managing disease and adopting new healthcare technology. In our analysis we relate this boundary work to two continuums of visibility-invisibility and integration-segmentation in disease management. We explore five factors that affect the boundary work: objects, activities, places, character of disease, and collaboration. Furthermore, the processes are explored of how boundary objects move between social worlds pushing and shaping boundaries. From this we discuss design implications for future healthcare technologies for the home.

Author Keywords

Healthcare technology, home, disease management, self-care, boundary work, boundary objects, compliance.

ACM Classification Keywords

J.3 Life and Medical Sciences, Health, Medical Information Systems; H.5.2 User Interfaces, User-centered design; H.5.3 Group and Organization Interfaces, Computer Supported Cooperative Work.

General Terms

Human factors, Design.

INTRODUCTION

In recent years, we have experienced an increasing move of healthcare services from the hospital to the home. The healthcare sector is under pressure in many Western countries due to demographic developments and an increase in the occurrence of chronic diseases [8]. Consequently, trends are toward increased self-care and disease management in the home [36]. This has caused an increasing focus on healthcare technology, because technology is believed to be a vehicle for the movement. A similar tendency occurs within the fields of CHI and CSCW. Traditionally, focus has been on studying healthcare technology within a hospital setting, focusing on collaboration between healthcare providers, e.g. with focus on spatial dimensions [3, 7] and consequences of standardization, e.g. in relation to electronic patient records [4, 5, 35]. More recently, attention has been directed toward healthcare technologies used by health workers in the home [27, 29], and numerous prototype tests have been carried out in the home [6, 31]. Only few studies, however, examine the use of prototypes, e.g. tools for self-care or therapy, intended for the resident [23, 34].

This body of work has identified several challenges for the design of healthcare technology when moving healthcare services and technologies to the home. Firstly, the transition poses several types of technical challenges, e.g. infrastructure and user interfaces [11]. Secondly, the change in setting occasions technology to take the particular routines into account to support people in their self-care in the home [18]. This paper contributes to the latter field of research.

The purpose of this paper is to explore how people manage disease in the home including how healthcare technologies are employed and organized. The purpose is also to discuss challenges for the design of future home-based healthcare technology. In our analysis we draw on empirical findings from qualitative studies focusing on disease management in the home [e.g. 1, 28]. We show how people create order by engaging in boundary work in dealing with their condition and sick role in the home. We introduce two continuums; visibility-invisibility and integration-segmentation, which, we argue, people move along when managing disease at home. We will show that the continuums are useful tools to understand how people use healthcare technologies in the home.

We use the term self-care to denote the tasks a person has been requested to do outside a clinical setting by healthcare providers. A great deal of patient work [33] is required to perform the self-care as requested. Also, many non-medical factors, including collaboration with others, influence the possibility to live up to the requirements [15]. While we use the term ‘self-care’ to contrast the work done in the home to that of the hospital, we do not consider self-care to be an individual task and neither to be tied to the home. To

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demarcate our paper, however, we focus on the home, although findings may be applicable to other settings.

Disease management in the home: Creating order

Within CHI and CSCW there is a long tradition of using the concept of boundary object to address how objects are used across boundaries of different social worlds [32]. Healthcare technologies may act as boundary objects inhabiting several worlds either due to their use in multiple contexts or by multiple users, or due to their capabilities stemming from one context and used in another.

However, criticism has been raised toward what has become the traditional use of the concept. The critique points out that the traditional use focuses on standardized boundary objects used routinely and neglects the processes involved in the negotiation of meaning, referring back to Star and Griesemer's idea of methods standardization [20, 22]. Thus, in line with Lee [20], we argue that a negotiating process that pushes and shapes boundaries, rather than just crossing them, takes place when objects move between worlds. Introducing disease management by help of a healthcare technology in the home thus involves a pushing and shaping of boundaries, or a process of re-creating the order of the home.

Creating and maintaining order by placing people, ideas and objects into categories is a way to avoid chaos [16]. Classifications and categories are often value-laden and tell of "…things to do or not to do. Kinds of people to be or not to be" [16] affecting the way people navigate in the world. In a home, continuous negotiations or ordering takes place, for instance in terms of which activities can be done in which room and which people and objects are considered natural to a home. Therefore, objects, persons or ideas that do not fit into a category of for instance place stand out and are considered dangerous [10] challenging the current way of navigating in the world. As such, the category of patient has traditionally belonged within a hospital setting, but with the current trend to move treatment to the home, the content of this category may change, possibly challenging the self-perception of the resident or patient. The order of the home may also be challenged if the objects do not easily fit into existing categories and notions of aesthetics. In addition, the distribution of responsibility between healthcare provider and patient and the involvement of relatives are negotiated [25].

While disease, treatment and healthcare technology challenge the order of the home, people are not passive and helpless in reducing the chaos [9]. Rather they are active agents who can either seek to reestablish the existing order, e.g. by hiding the objects, or seek to establish a new order, e.g. by displaying the objects. A home is a social arena and the creation of order may take place either individually or through negotiations with relatives and/or health workers. Therefore, to move treatment and management of disease from the hospital to the home does not only require individual or collaborative work to carry out self-care, e.g. to inject insulin, but also to establish order, e.g. to take insulin only in the bedroom.

The processes of negotiation, the pushing and shaping of boundaries, will be explored in our analysis showing that order influences and is influenced by technologies, activities and roles a resident takes on in dealing with disorder.

METHOD

The qualitative studies, which provide the basis for the findings, have been carried out over a period of four years in relation to different studies connected to projects at Centre for Pervasive Healthcare. The projects have focused on different kinds of medical conditions and therapies, all involving the home: blood pressure monitoring, vestibular dysfunction, diabetes, hip replacement, and lifelong anticoagulant treatment. In addition, we have made home visits focusing on assistive technologies and health and disease management at home. The projects aimed at different age groups ranging from participants in their twenties to participants in their nineties. All together, either one or both authors have visited more than 50 homes. We have employed different methods ranging from ethnographic field studies with participant observation and semi-structured interviews [30] over several months to shorter tours [24] in the home. Observations have been documented through extensive field notes, and video or photos. Most interviews have been recorded and later transcribed, while others have been written out based on elaborate field notes.

While the studies did not have identical research foci, they all focused on health and health IT in the home. They had a technological perspective as most projects involved the development of assistive healthcare technologies. Furthermore, they had a user perspective to gain a broad understanding of the users, their practices and the domain.

The theme we explore in this paper; strategies for managing disease at home, has emerged from the different studies. While we initially did not go looking for practices of hiding or displaying objects or segmenting or integrating healthcare activities, these aspects reoccurred in our analysis of the different studies [30]. We therefore decided to go through transcripts and field notes making a more focused coding [12] of such strategies. We have carried out a thematic analysis [30] where we have grouped data into themes and searched for instances of interrelationship while relating it to relevant existing literature on disease management and boundary work.

CONTINUUMS AND BOUNDARY WORK

Through our analysis it became apparent that the different strategies to handle self-care in the home could be conceptualized as movements on two different continuums: *visibility-invisibility* and *integration-segmentation* of disease in the home (see figure 1). After an introduction to the notion of continuum and the connected boundary work, we will give empirical examples of movements on the continuums to maintain or create the order of the home. Next, we will describe factors that influence the negotiations in the boundary work and hence the movements on the continuums, which help us to understand how people manage their disease in the home.

The notions of continuums and boundary work

Nippert-Eng [26] introduces an analytic framework to conceptualize movements on continuums. It is based on studies on how people engage in boundary work of home and work. Some integrate, or make no distinctions between, their home and work, while others segment the two realms fully and conceive of them as separate worlds. Nippert-Eng argues that these extremes are seen only rarely and that most people relate home and work somewhere in between. She calls the work done to either segment or integrate ‘boundary work’. In the boundary work, objects as well as ritual or mental maneuvers can serve to create or maintain the boundary between home and work. Either integrating or segregating work and home or placing oneself somewhere in between is a means to create an order that guide one’s navigation in the world. By engaging in boundary work people create and redefine categories of home and work [26].

While we do not talk about home and work, our empirical studies have shown that people are engaged in similar boundary work as they try to either integrate or segment the management of disease from other activities, places and objects in the home in order to maintain or create order. By increasing self-care and moving healthcare services and technologies from the hospital to the home, the traditional ways of segmenting the two realms are challenged. Boundaries between the two realms, which used to be clear, are now open for negotiation: when to embrace the role of a patient, where to perform the self-care and how to organize routines around the self-care and technology use.

In their boundary work people are, either individually or in collaboration, engaged in such negotiation. For some people, the management of disease plays a central role in activities in the home; they embrace the role of being a patient, organize their daily routines around the management of the disease and surround themselves with objects related to it. Others engage in boundary work with the purpose of segmenting the disease by spending little time on it and giving it little thought. They distance themselves from the disease and reject the role of patient. Analytically, such people can be placed on different ends of the continuum of integration-segmentation as they engage in different kinds of boundary work to maintain or create order.

Furthermore, a continuum related to the visibility or invisibility of the management of the disease is played out in the maintaining or creation of order in the home. Often the home is considered to have areas that are mostly private and some which are more public [2]. Our field studies showed that people would engage in boundary work with other residents to maintain the order of the home by making disease visible or invisible. In public areas of the home, objects related to healthcare are often concealed in drawers or behind flowers on the dining table. In the bedroom, often considered a private area, objects may be more visible, e.g. leaving medication and wigs on the nightstand.

The conceptualization of movements on the continuums of visibility-invisibility and integration-segmentation provides a tool to simplify and create a systematic account of the empirical diversities encountered during our field studies. It allows us to position people analytically on the two continuums (figure 1) to understand how disease is managed in the home.

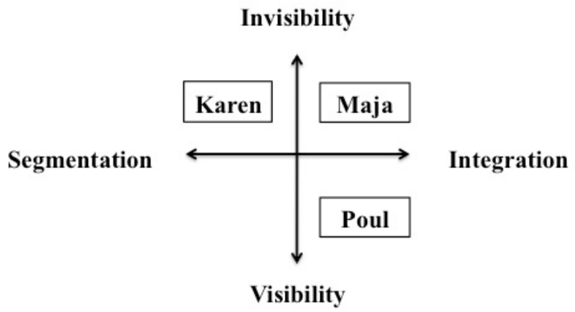

Figure 1: The two continuums form a matrix in which people’s strategies for creating order can be pointed out.

Empirical examples of movements on the continuums

Boundary work related to creating order and the management of disease is highly complex. It involves both continuums which are intertwined and combined in different ways by different people, as we will demonstrate below. In the following, we will describe three cases and the boundary work involving the two continuums. The cases of Karen, Maja, and Poul are examples of different positions on the matrix. Other cases could have shown other or similar positions, but it is our conviction that the three cases provide diversity in position and richness in detail to unfold the movements on the continuums and thus provide an understanding of how disease is managed in the home. We have not encountered an example of the position *visible* and *segmented* that also contains self-care. We have, however, examples of people living in nursing homes, but as there is no element of self-care, they are not included.

The case of Karen

To some extent, a correlation exists between keeping management of disease *invisible* and *segmented*. Karen has suffered from a heart defect since 2001 and faces an elevated risk of having a blood clot in the brain. We met Karen and her husband, Peter, in the summer of 2008 where Karen participated in a study on home-based anti-coagulant treatment. Karen was then 63 years old. When her condition was diagnosed she came into anticoagulant therapy to prevent blood clots. Soon this therapy became self-managed and once a week Karen measures her INR value[1] with a special meter and adjusts her daily medicine intake accordingly. Peter does not take part in the weekly

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[1] The INR (international normalized ratio) value indicates the time it takes the blood to clot compared to an average.

measurements but once every three months he emails the INR to the hospital for commenting.

Karen and Peter often go away for the weekend and she makes her measurement on a weekday to avoid bringing the meter. However, she refuses to routinize the measurement and does not make it at a certain time in order not to interfere too much with her other activities. She keeps her medicine in a kitchen cabinet. Peter has made it a habit to remind Karen to bring her pills wherever they go as Karen often forgets them.

Karen and Peter lead an active life with travels, grandchildren and social activities. Karen dislikes doing nothing and explains, "it unsuited my way of living to be sick". When diagnosed with the heart defect she denied being sick both to herself and to her surroundings and conceived of it as a virus to disappear within a year. She worked hard to maintain the idea of herself as an active person and to avoid the image of being a patient, even increasing her working hours. When her condition aggravated Karen and Peter's daughter arranged a meeting with a doctor to have the consequences clarified of not taking the condition serious. She was tired of feeling worried and not being able to get her mother to accept her condition.

As a result of the negotiations on how to deal with her condition, Karen strives in her boundary work to *segment* activities. She does not routinize the measurement while still doing it on a specific weekday and makes objects *invisible* as she conceals her medication and the meter that is only app. 10 by 15 cm in a cupboard (see figure 2). She thereby meets the demands of her daughter while avoiding the patient status.

Figure 2: A meter used in anticoagulant therapy is kept in a drawer together with other electronic equipment.

The case of Maja

Maja engages in boundary work to make her management of disease *invisible* but at the same time *integrated* with other daily routines and activities. We met Maja in 2007 as she participated in a project with the aim of developing healthcare IT to support pregnant women with diabetes in their disease management. Maja is a woman in her early 30s who works as a teacher and was diagnosed with type I diabetes a few years ago. She is married to Thomas and they expect their first child. The couple likes to be well informed and has retrieved extensive information on diabetes and pregnancy. Thomas attends the consultations at the outpatient clinic whenever possible as it is easier to remember the important information when they are two.

Maja needs to take insulin with her meals and before bedtime to regulate her blood glucose levels. With the pregnancy it has become difficult for Maja to feel whether her blood glucose levels are too low, which can cause hypoglycemia. She therefore measures herself up to 12 times a day. Thomas knows that Maja often forgets to do the measurements when at work and he therefore calls her to remind her. Also Maja's brother worries about her. He reacts strongly when he sees Maja eat sugary food despite Maja ensuring him that she has her sugar intake under control. A few times, he has been directly involved in Maja's disease management taking her to an eye specialist.

In the work to manage her diabetes, Maja depends on a series of tools, primarily a blood glucose meter, strips, punctuation device, and insulin pen. She has gathered the tools in what she calls her 'diabetes purse' (see figure 3). It is very important for her that the diabetes purse is chic and exquisite apart from its ability to contain all her necessities. Maja thus strives to make her tools *invisible* by concealing them in a nice purse that does not signal sickness. However, the purse is highly *integrated* in her daily activities as she brings it everywhere, both inside and outside the home. Maja explains that she feels naked without her purse. She knows that her regulation of the diabetes is crucial for the health of her unborn child, and she therefore needs to be almost constantly aware of her blood glucose level.

Figure 3: An example of a diabetes purse, which contains blood glucose meter, strips, punctuation device, insulin pen, glucose tablets, extra needles, and gum.

The case of Poul

Management of disease may also be highly *visible* and *integrated* in the home. Poul was 65 years old when we met him in 2005 in his two-room apartment in a sheltered housing unit for elderly people where he lives alone. He participated in a project on monitoring of blood pressure and medication intake. He has suffered from diabetes for many years and due to diabetes-related complications he has had one leg amputated and therefore uses a wheelchair. His apartment is located on the first floor but he can exit the building via an elevator. However, he does this only once a week when going to a physiotherapist as it is demanding for him to handle the manually operated wheelchair. Inside the apartment Poul is also affected by his diminished mobility and he spends most of his time on his couch watching TV. To avoid the difficulties of moving, he has arranged his daily necessities related to his diabetes and general wellbeing at the small table next to his couch (see figure 4).

Poul has a limited social network. He is divorced and his ex-wife and children live in a foreign country and except from occasional phone calls, Poul has no contact with them. Health workers visit Poul on a daily basis to offer their assistance to his diabetes management and to monitor a record of his blood glucose figures. They also give him a bath and clean his apartment. Poul has his ready-made meals and groceries delivered and also his general practitioner and foot therapist come to him in his apartment.

Figure 4: Objects on Poul's table: cigarettes, cup, remote control, telephone, medication and container, shaver, pencils to note blood glucose levels, alarm to get help, insulin injection pens, magnifier, and cookies boosting low blood glucose levels

Poul is very attentive to his diabetes management and keeps a meticulous record of his blood glucose levels. Having *integrated* his diabetes treatment in his other activities, Poul's daily routine now evolves around his diabetes. The diabetes related objects are highly *visible* both to Poul and his visitors, no matter if he uses them.

Negotiations in boundary work

Above, we have presented three examples of how people can be positioned on the matrix between integration/segmentation and visibility/invisibility of disease management. Although their positions seem rather static, it is important to emphasize that the positions may alter over time and that one person, in principle, could embrace all four positions simultaneously in the management of diverse objects or types of disease-related activities. Different strategies are deployed in the three cases to create or maintain order through boundary work when treatment has been moved from the social world of the hospital to the social world of the home.

In line with the call for focus on the processes regarding objects in the border area between social worlds [20, 22], we explore factors that are vital in the negotiation of boundary work in self-care: *objects, activities, places, the character of the disease* and *collaboration.* We argue that these factors both affect and are affected by the negotiations involved in the boundary work to create order. On the one hand, the culturally defined meaning of objects affects how people adapt their use of the object to the specific order of the given social world. On the other hand, the use of the objects in return shapes and pushes the meaning of the objects and the order of the social world.

Although people attempt to deploy different strategies to create order in the home, we find that these strategies and the outcome of them are highly dependent on the role of the five factors in the negotiations. In the following, we will elaborate on the role of the five factors in how people engage in boundary work. The five factors are not listed in a prioritized manner. They are all equally influential and intertwined. However, for our analytical purpose we here investigate them separately.

Objects

The physical properties of an object, e.g. size and dependency on power sockets, pose practical challenges as to how an object can be made (in)visible, integrated or segmented. As such the physical properties may affect how people can obtain a certain order and may foster a change in the current order of the home, e.g. if the object needs to be attached constantly to the person as in the case of a ventilator [21]. However, people respond not only by adjusting their use according to the physical properties, they also engage in elaborate boundary work to maintain the order of the home by altering or working around the unwanted properties, e.g. by placing large objects in secluded or private areas of the home.

More importantly, ordering of objects is affected by their cultural meaning. Within the CHI community, it is widely recognized that technology is not neutral but has consequences for how people experience the world [17]. Similarly, objects are not neutral but loaded with values either defined individually or socially. Some are loaded with positive values while others are highly stigmatizing, such as ostomy bags or catheters. This makes the ordering of objects important, as the use of an object will reflect upon the user and the identity of the user. Distancing oneself from stigmatizing objects by making such objects invisible or not using them is a way to avoid the stigmatization which is closely, either in general or in your opinion, linked with the object [14]. As such, Karen thinks of her INR meter as stigmatizing and not fitting into her order of life as it reminds her of being sick. She thus attempts to segment and make it invisible. Her husband, on the other hand, acknowledges to a larger extent that Karen is sick and does not attach the same stigmatizing values to the meter despite him sharing the ideas of a non-sick lifestyle with Karen. Poul neither attaches negative values to his diabetes objects; rather his diabetes has become his most important identity [13], and they thus fit well into his way of life at the time being.

Note that the cultural categories and values related to a given object are socially constructed. Thus, an object may be defined differently in diverse social worlds. This makes the work of dealing with the cultural meaning of an object particularly important when crossing boundaries, e.g. between hospital and home. In the case of Karen, the specific meaning of the objects involved is affected by the cultural order of the social world in which they are used. To her, the pills and meter fit in perfectly with the cultural order of the hospital. However, when moved to the home, these objects take on a different meaning to Karen and do not fit into her preferred way of life. Through processes of pushing and shaping of boundaries, she finds a way to deal with them at home making them invisible and segmented. Similarly, Maja's diabetes purse acts as a boundary object which functions in diverse social worlds. By revealing or concealing the contents of her discrete diabetes purse, Maja is able to highlight or downplay her diabetes identity in accordance with the cultural order of the different social worlds in which she engages.

Introducing a healthcare technology into a certain social world, its cultural meaning may alter as the boundary object moves between social worlds. At the same time, the cultural order of a social world may be altered by the introduction of the object.

Activities

Similarly, activities related to the management of disease are affected by both the cultural meaning connected to the activity and to the timeframe and scope of the activity.

Some activities related to the management of a certain disease take more effort and time than others which affect how an activity may be integrated or segmented, made visible or invisible. With the regulation of blood glucose levels it is advised to measure the blood glucose level before each meal in order to adjust the insulin dose. Being pregnant Maja is further recommended to measure her blood glucose level an hour and a half after a meal to ensure that she has taken the correct dose. However, an hour and a half after her lunch she gives lectures and does not want to interrupt to make the measurement. Maja chooses to segment her disease management in this situation, despite the fact that she generally seeks integration. Poul, on the other hand, is retired and spends most of his time at home having sufficient time to comply with the recommended self-care. He explains that his day evolves around managing his diabetes, striving for complete integration.

Although the two cases point to a strong relation between the scope of the activity and the possible strategies people can deploy, Karen's case demonstrates that the relation is not determined. Karen's blood test only has to be carried out once a week and she chooses freely the time of the day to make it. Ostensibly, these circumstances allow an easy integration of the measurements with her other activities, but Karen chooses to segment the measurements. Consequently, there is not per se a causal relation between the scope of an activity and the preference of segmentation/integration, visibility/invisibility.

Places

As described earlier, the home is often structured in accordance with a certain order, for instance the distinctions between public and private. Things that may be appropriate in a hospital setting may be out of place in the home, and things that may be thought suitable in the private bedroom will stand out in the public living room thereby becoming highly visible.

Poul has arranged his objects within reach at his coffee table. Whatever his reasons, by putting them on display he shapes the categories and norms of public and private in a room where he receives guests. To him the arrangement is, or has become over time, in accordance with his understanding of public and private and his notion of order that again affects his way of life. To others, for instance Karen and probably the health workers entering the room, the same arrangement would highlight objects out of place due to their understanding of public and private and perhaps affect their way of perceiving Poul. As such, Poul's display shapes and pushes the boundaries between social worlds and the norms for public and private, i.e. the order of the place.

Similarly, Maja's case illustrates how boundaries are negotiated and shaped when using certain objects in specific places. Although Maja in general integrates her diabetes management, she avoids using her diabetes tools in the classroom. Still, she brings her diabetes purse and injects insulin at the table during lunch in the staff room, even if it may stand out to some of her colleagues. Maja thereby challenges the norms of what is considered normal behavior pushing and shaping the boundaries between public and private and the silent agreement on what takes place during lunch in the staff room.

The character of the disease

When a person gets sick and is to perform self-care at home, the cultural order of the home might be challenged if the disease is considered not to belong there. Likewise, the way one manages the disease may be influenced by it taking place in a home rather than at hospital. The character of a disease can be divided into two; its pathological progression and its cultural meaning. They both challenge the order and are challenged by it, affecting the possible ways of managing a disease in the home.

The seriousness of a condition affects how a person can integrate or segment a disease, disclosing or hiding it. When Karen was first diagnosed with her heart defect she largely ignored it and chose a strategy toward extreme segmentation letting her prevalent notion of a good life affect her management of her disease. However, her condition proved to be too severe to be disregarded and in addition, she got a severe lung infection. The increase in seriousness together with her daughter's persistence forced her to reconsider her worldview and behavior while still aiming to segment it from other activities. Likewise, Maja experienced a pathological progression in her diabetes when she got pregnant. This forced her to increase the number of daily blood glucose measurements, which made it difficult for her to fully integrate her disease management. For Maja, it was easier to treat her diabetes at home than at work. The progression of Poul's condition has affected his possibilities in life and hence in choice of strategies as he has had his leg amputated. The implication of the character of a disease thus varies over time and may take on different faces in different contexts affecting the strategies people deploy.

Additionally, the cultural meaning of both a disease and a treatment might affect a person's choice to segment or integrate, hide or make visible. Some disorders, like HIV, have a cultural meaning that indeed stigmatizes the patient causing he or she to hide his or her status. In the case of diabetes, and especially type 2, there is a prevalent societal norm, at least in Denmark, that it is lifestyle related and thus the diabetic's own fault. This norm shapes the meaning of the disease, which then may affect the diabetic's choice of strategies in managing the disease.

Collaboration

The three cases show that self-care is highly collaborative involving not only the individual but also relatives and health workers. Collaboration with others is often an implicit part of self-care and of the boundary work to create order in the home.

Karen's attempt to segment her disease related activities from her other activities is only possible as a collaborative effort. Karen's boundary work is negotiated between her and Peter and against the current order of their home. Also their daughter became part of the negotiations when she opposed Karen's initial extreme segmentation.

In Poul's case, he collaborates with health workers in his boundary work and, although indirectly, the deliveryman and his GP. Perhaps it is the fact that Poul lives alone that allows him to display his diabetes related objects and his condition to be what his life evolves around. Health workers may be ambiguous toward his highly visible strategy of boundary work: on the one hand, this strategy clearly helps him to manage his diabetes while, on the other hand, it inhibits them cleaning his apartment and making him participate in social activities.

For Maja, collaboration and negotiation with both family and work-relations play an important role for her self-care. Where others may oppose and conceive of the strategy as interference, Maja's husband supports the integration of her self-care into their other activities. Colleagues and students constitute collaborative partners, as they have, more or less consciously, accepted her strategy for boundary work. Thus, common understanding of appropriate behavior and collaborative partners may shape the management of disease that, on the other hand, may push and shape the order of the social world.

The interplay between factors

Through the above analysis we have demonstrated how people engage in boundary work to create order when a disease is managed at home. However, as the analysis illustrates, people are not the sole actors in the practice of disease management in the home. Objects, values and norms, and humans are all actants in the boundary work of creating order (see Figure 5). Attached values and norms or cultural meaning of a disease affect the way people perceive themselves and interact with the healthcare technologies. At the same time, a health-related object may influence the meaning of a condition or the order of the home, either positively or negatively. People manipulate the objects, norms and values, but are manipulated by them too.

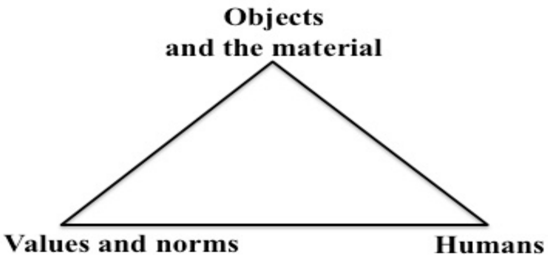

Figure 5: The triangle illustrates the interplay between objects and the material; values and norms; and humans and their actions in disease management in a home.

It is important to stress that we do not intend to make the movements on the continuums normative. Whether a person chooses to integrate or segment, hide or display is a matter of social circumstances and pragmatic considerations, and either can prove to be the most beneficial strategy. What one chooses may alter over time as one comes to accept that being a patient is part of one's identity [19]. In fact, being a patient may add value to one's life and hence, to embrace the patient identity in the home makes sense.

IMPLICATIONS FOR DESIGN

The matrix in figure 1 shows the different positions people could have when managing disease in the home. Analyzing the data behind the matrix, we have identified two main differences between hospitals and homes. The differences challenge the move of healthcare services from the hospital to the home and the technology that supports the move. The two differences are the *material environment* and *the role of patient.* The below discussion of each difference will show how the design of domestic healthcare technology can support a successful use of technology and movement of treatment.

The material environment

Differences in material environment between the hospital and home could have a bearing on the design of future healthcare technology. The physical design of the hospital differs from that of the home in several ways. At the hospital the aim of the physical environment is to promote effective working procedures of healthcare providers and provide the optimal setting for professional treatment and care. To some extent, the aim is also to improve the patient's abilities to take part in the care. The division of the hospital into areas of specialization offers a possibility to split different activities. In contrast, the environment of a home may be directed toward several other activities than disease management, and as such a home often contains a mosaic of people, objects and activities that have nothing to do with healthcare, and that are not easily split into dedicated places, timeslots or working procedures devoted to the management of disease. For instance, Maja prepares her lectures at home and Karen and her husband look after their grandchildren while Poul has dedicated his home to activities related to his condition. Rooms and places have different attached meanings of what could be done there. To Poul, a living room is a place for managing disease, while it for Karen is a place for relaxation and guests. Consequently, utilizing the same technological device might result in different use-practices in different places and for different persons. The differences between hospital and home in regard to the materiality make demands on the flexibility of the healthcare technology.

The material differences are sought responded to in several ways. As illustrated in the above analysis, a common strategy is to make healthcare technologies invisible. Invisibility (or visibility) can be achieved by working with the meanings attached to the technology and the mobility of the technology.

The different aesthetic values of a hospital and home imply that a given object takes on a different meaning in the two realms, which was what Karen experienced with her meter and pills. Also, a dialysis machine is considered natural at the hospital because there are many other similar apparatuses. In a home, on the other hand, it is a foreign object that differs from the aesthetics and design of other furniture. The aesthetics of the technology may hence affect the use of it, whether the object's representation of hospital is considered positive or negative. A strategy to keep a technology invisible is to design it in accordance with the aesthetics of a home and not a hospital. This way, the technology matches other objects in the home and does not attract special attention despite being visible.

The ability for people to make healthcare technologies invisible also relates to the mobility of an object. The wish to maintain the division between public and private spheres is met by physically moving a healthcare technology out of sight, either by storing healthcare devices in a private room or by keeping them hidden in drawers and cabinets. However, the fact that there are seldom rooms dedicated for healthcare activities in a home and that the devices are kept out of sight may increase the efforts to put the device into use. The difficulties of moving an exercise bicycle from a storing room to a room for use may cause it not to be used. Maja's blood glucose meter, on the other hand, suits well into a purse which easily allows for invisibility and integration which is where she is positioned on the matrix. The size and shape of healthcare technology should hence be in accordance with a common wish to keep it out of sight; i.e. for humans to manipulate the objects and their attached values in the disease management (cf. figure 5).

In sum, *the flexibility of the technology should give the resident a choice in terms of mobility and appearance of where to place it as to maintain the order of the home.*

The role of patient

Being a patient also differs whether you are at a hospital or in the home despite of parallels in terms of knowledge, technology and other resources. When hospitalized, Karen could concentrate on being sick while she at home is also engaged in cooking and social activities. The difference has a bearing on the design of future domestic healthcare technologies. At a hospital there is somebody to take care of the patient and to receive help from, while patients at home are more on their own. Furthermore, the meaning of being a patient may be different between a hospital and home which may affect a person's wish to take on the patient identity and use the healthcare technology. A general understanding of 'patient', which Maja and Karen share, is that it is a person who is sick and passive, and this suits well the routines and the purpose of a hospital, but not the home. A home is not commonly understood to be a place for sick people and a patient who wants to continue his or her daily life may want to downplay or discard the patient role. Poul, however, has over time changed his daily life to allow for sickness rather than discarding the patient role. The meaning of a disease can, however, change with the context. At the hospital, a disease is in an appropriate context and hence stigma may be downplayed while the disease in the home is often a matter out of place that does not belong according to prevalent norms and values. Lastly, a person often has many other roles in a home than being sick, such as spouse or grandparent. The resident of the home has to deal with the different roles while managing the disease. It is important to stress, however, that being a patient in the home is not necessarily a bad thing as especially Poul's case showed. Thus, the differences in regard to being a patient have consequences for the compartmentalization of healthcare technology to be used in the home. The technology should provide the person, who manages a disease, the possibility to either embrace or reject the patient role, while still easily being able to attend to the management of the disease.

The physical design and aesthetics of the object are important in this regard as they facilitate the invisibility of an object by not drawing attention to neither the disease nor the patient identity. Furthermore, the system design and functionalities also affect the possibilities to integrate or segment the role of being a patient. Some healthcare devices seek to support the compliance of a person suffering from a disease in regard to taking pills or doing measurements through reminders and prompts. However, this may have the side effect of drawing attention to the disease and the patient status even if the person tries to avoid the patient role. Whether you want to be reminded of your disease is an individual decision, and prompts could hence be an optional feature allowing for different positions on the matrix.

Although some degree of segmentation from the patient role is important to many, integration is also influential on the outcome of the self-care which Maja is an example of. As being a patient at home is just one of many roles, and disease management is just one of many activities, time can become an issue for use. If the device takes several minutes to start up, the person may become impatient and turn to other activities. Also mobility becomes a principle for design for integration due to the many other roles and activities a person engages in; such as work and social activities in- and outside the home. The management of disease and hence the healthcare technology should easily be integrated into those routines and activities.

In sum, *the principle of compartmentalization refers to the balance of integrating non-health related functionalities with healthcare functionalities. On the one hand, healthcare technologies serve the purpose of integrating the disease management with other activities, while on the other hand, they should also support segmentation of disease management and consider the patient role depending on the specific user.*

CONCLUSION

In this paper, we have explored how people manage their disease within the context of the home arguing that people's movements on two continuums of segmentation/integration and visibility/invisibility are important tools for us to understand the nature of disease management in the home. We have shown that to create order is an important part of managing disease and make use of healthcare technology in the home. As demonstrated, the boundary work people engage in to create or maintain order is highly complex and influenced by several factors. This poses challenges of flexibility in terms of appearance and mobility and compartmentalization for the design of healthcare technology for the home.

During our empirical studies and through our analysis it has become clear that there is a divergence between how people try to integrate or segment the management of disease from other activities in the home. On the one hand, we have often found that people have a wish to segment their disease and the role of being a patient. On the other hand, we have experienced that a way to accomplish this is to integrate the management of the disease in their other activities. To establish routines allows the disease to step into the background. Moreover, managing the disease in situ allows the person to stay in the social situation in which he or she is engaged and not have to interrupt the situation by leaving to perform the required actions elsewhere. This paradox deserves further investigation both in empirical studies of the management of disease in the home and in future work on development of healthcare technologies for the home.

The conditions and the healthcare technologies that we have focused on in this paper are rather innocuous in that the conditions are neither acute nor terminal and as neither Maja, Poul or Karen depend immediately on the technology to stay alive. Further work is needed to explore the role of the seriousness of the condition and the dependence on the technology in attempts to integrate or segment disease management. Such work will give us a broader knowledge on how people manage disease at home to base our design of domestic healthcare technologies on.

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HomeHealthTour: A method for studying health and disease in the home

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HomeHealthTour

A method for studying health and disease in the home

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***Abstract*—The aim of this paper is to describe how a method for studying health and disease in the home, the HomeHealthTour, can be deployed to understand the domain for healthcare technologies and inform the design of new technologies in participatory design processes. The method was developed to address challenges of doing field studies in the home in PD projects. The method is based on the hypothesis that a tour through a home provides an enriched understanding of context of practice and that objects prompt untold stories of practice. In the paper we describe the method and refer to two of the HomeHealthTours we have made to discuss the method's potential contributions. We argue that the method facilitates insights into broad or specific health related topics and that it enables participants' active participation in grounding design in context.**

Keywords-social factors; user centered design; pervasive computing.

I. INTRODUCTION

In this paper we introduce the HomeHealthTour; a method developed for studying health and disease in the home. The HomeHealthTour addresses the residents of a home and the everyday objects and practices related to the management of health and disease in their everyday lives. The purpose of the HomeHealthTour is to gain a contextual understanding of practices and objects related to non-professional management of health and disease in the home. Furthermore, the purpose is to provide a contextual basis for performing further design activities with participants, thereby grounding the design process in the home and in the lives of its residents. Thus, the HomeHealthTour is a qualitative approach to understanding the users' management of health and disease in the home and a starting point for designing new healthcare technology, which supports user needs.

With the description of the method and discussions of the possibilities we wish to provide fellow researchers with a tool for conducting studies in the home and with suggestions of how to make the method operational. The paper is based on our experience with four distinct HomeHealthTours of which we will outline two. Our intention is to demonstrate and evaluate the method. Analyzes, design concepts and prototypes based on the performed HomeHealthTours are reported in [1, 2, 3].

A. *Methodological challenges*

The method is a response to methodological challenges related to the study of health and disease in the home as part of a participatory design (PD) process. While PD initially often focused on professional settings [15], many PD projects have since had the non-professional home as setting. For instance, routines in the home and use of domestic and communication technologies have been the foci of many research and development projects [11, 14, 17, 30]. Accordingly, a range of methods have been applied and developed for studying the home and for including the residents as participants in PD processes, using probes, video monitoring, and interviews [e.g. 21, 25].

In the past decade, an increasingly number of PD projects has focused on management of disease and health in the home and on the delivery of healthcare services in the home [6, 18, 21, 23, 24, 27]. The increased engagement with home and health within PD projects is a response to the current development of moving treatment into the homes and to patients themselves. This development is an attempt to decrease the burden on the healthcare sector due to e.g. the demographic development with many elderly people and an increase in the percentage of chronic patients [16].

Yet, studying health and disease in the home and in the everyday life of ordinary people poses several challenges. Not so much challenges in regard to access to people's home which in many cases is easier to obtain than is the case in e.g. a private business as pointed out by Crabtree and Rodden [17]. Rather, the challenges are related to doing studies in the home. For instance, how do we make observations without making people change their practice; which role, that fits naturally into the home, can a researcher be given; and how do we built trust to facilitate collaboration between researcher and participant in PD projects which often have a short timeframe? Some of these questions are also relevant when doing PD in professional settings [e.g. 10, 19, 31], but they are often reinforced when PD takes place in a home. A home is a complex environment [8] organized different from professional settings with e.g. private and public areas [5]. Additionally, while much work takes place in a home, a home is also a place for relaxation and pleasure as opposed to a workplace. These features challenge the possibility of e.g. doing observations of people's practices

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Research grant has been removed for blind review.

around relaxation. Can you relax with a researcher in your home?

The challenges mentioned are general challenges when studying the home and not confined to health research in the home. However, there are circumstances related to health and disease that further challenge health oriented PD projects in the home. For instance, issues of health and disease may be considered private matters and may be intangible and difficult to put words on. Interviews, whether in situ, may not capture the essence of health and disease due to the intangibility, and observations may be experienced odd and interfering by researcher and participant affecting what they reveal. Long-term ethnographic field studies could ensure the close relation and trust between researcher and participant needed to get into the core of such issues but they are often not rendered suitable in design processes where the timeframe is short. Still health, disease and the home are complex topics and settings that necessitate a profound understanding before developing technologies.

In the following we outline our source of inspiration, and describe the method and its application. We then explore the possibilities of the method and compare it to other methods used to study the home, especially focusing on the participation of the participant.

II. TECHNOLOGY TOURS

The HomeHealthTour is placed within a tradition of qualitative research methods and relies on both observation and interviews [12, 26]. Qualitative methods can have broad exploratory approach or be rather focused on particular aspects of a given phenomenon. A number of studies have focused on the home and the use of domestic technologies by carrying out a 'technology tour'. Development of the HomeHealthTour is highly inspired by the structure of the technology tour, but is focused on health and disease.

When Mateas, Salvador, Scholtz, and Sorensen [25] visited different homes their aim was to obtain a model of daily home life in order to design future domestic technologies. They made a home visit where they talked informally over dinner with the family members and then took a tour through the home. Next they worked separately with adults and children asking them to lay out their house on a board by going through daily activities.

Baillie, Benyon, Macaulay, and Petersen [7, 8], referring to [25], also work with methods for studying technology in the home and involving residents in designing new domestic technology. The home visits carried out by them consist of a technology tour, discussion of scenarios and future devices, discussion and design, and critique and redesign. The technology tour consists of a series of tours through the home with the family together and with each individual focusing on: the present technology in each room; the location of the technology; the users of the technology; activities supported. In the analysis conflicting views on technology (ownership, physical organization and use) between different household members were identified, and represented in the shape of maps of the home as perceived by individual household members and a consolidated map.

Also Blythe and Monk [14] study the home through home visits consisting of a technology tour, last time questions, a personal history interview, a guided speculation on future developments and three wishes for products. Their aim was to gain an understanding of use and limitations of domestic technologies to develop new products.

We were inspired by this body of work in the development of the method presented in this article. Hence the HomeHealthTour method is an adapted but also refined version of the outlined approaches focusing on health and disease rather than domestic technologies as such. The focus of HomeHealthTour is on objects, which might be a technology but can also be a stone collected at the beach. Furthermore, we do not only focus on the practical use of objects or their ownership in the HomeHealthTour. Rather, we want the objects to be catalysts for stories about health and disease, which generate knowledge on how health and disease are managed in the home, and to inspire future designs. While the HomeHealthTour resembles technology tours in structure, the focus and approach are not similar.

III. THE HOME HEALTH TOUR METHOD

The HomeHealthTour is a method that has a broad scope in regard to who can participate, cutting across age, educational background, and physical abilities. The tours can have just one or several participants as guides depending on how many people live in the home.

Although there is clearly a point in conducting both individual and collective tours in a home as is the case in technology tours, we believe that this could frame the HomeHealthTours as a struggle over resources and could overemphasize conflicts rather than the family as a collective and its mutual intelligibility. We believe the collective aspect of healthcare to be vital as issues and activities regarding health and disease often are collaborative; from food preparation to the planning of sports activities and from visits to the doctor to assistance in rehabilitation exercises.

A HomeHealthTour consists of five phases 1) preparation, 2) briefing, 3) guided tour, 4) creative activities, and 5) debriefing, which will be described in the following.

A. Preparation

Before commencing a HomeHealthTour several issues needs to be considered. First, the team of researchers must define the objective of the HomeHealthTour. What are the guiding research questions to be answered? These research questions may go through several iterations and evolve over time as the PD process takes its course.

Second, having decided on the research objective, sampling becomes important. As in other qualitative research, it is crucial for the validity of the findings that the profile of the participants (e.g. age, civil status, possible diagnosis) matches the objective. Neither do the sampling methods differ from other research designs and hence participants can be recruited through for instance relevant organizations (e.g. patient associations), on the street randomly or through the snowball effect [12]. However, using close friends or relatives as participants is not advisable to avoid limitation in what is shown and seen on the tour due to existing knowledge on the participant and/or the home. In regard to participants, it is also important to consider possible agendas or (conflicting) interests of participants to be able to respond to them when interacting with the participant to ensure the drive of the tour.

Third, the home as a setting sets a limit to the number of researchers that can participate. Both due to spatial circumstances, but also not to overwhelm and outnumber the participants leading to an unbeneficial shift in the power relation between participant and researcher, host and guest. This does not exclude software designers, project partners representing companies and others to participate, rather it will strengthen the multidisciplinary approach, but it must be done in consideration of the balance between guests and hosts.

B. *Briefing of Participants*

Each tour or visit in a home begins with a briefing, which has several purposes: First, it informs the participant on the researchers' agenda, goal and success criteria. Second, it allows the researchers to obtain an informed consent from the participants. Third, it works as a matching of expectations and finally, it establishes rapport between participants and researchers. While these aspects are essential in all participatory research, they are indeed important here as the study takes place in the participant's private domain rather than a neutral place.

A briefing can take place while eating dinner or having cake paving the way for a good time, showing the participants that the researchers are willing to bring something, however symbolic, into the relationship and not only expect to receive. A briefing also establishes mutual trust and understanding. A careful briefing is vital to avoid or overcome a dismissive attitude of the participant and ensure collaboration between participant and researcher.

C. *The Tour*

After the briefing, the family members and the researchers take a tour around the home guided by the family members. A tour lasts approximately one to two hours. During the tour the participants are encouraged to point out and describe objects that in their opinion directly or indirectly relate to the defined research topic. Pointing out the objects participants are prompted to explain: 1) relation to research topic, 2) reason for location 3) routines and use 4) who are the users 5) the history of the object, 6) stories connected to the object, and 7) relations that transcend the home.

While being respectful, researchers should not withhold questions regarding what may be considered private issues or about objects not immediately pointed out by participants. Sometimes an open discussion, which allows the participant to explain the context of the object, eases the potential tension, bringing normalcy to the situation. In addition, all explanations or answers of the participant should not per se be taken at face value but can be questioned by the researcher as the HomeHealthTour progresses. This incites the participant to reflect on their statements and hence improves the validity of the input. A balance, however, must be obtained between pursuing questions on the on hand while being aware of ones own position, bias and role on the other hand.

To be able to make a preliminary analysis with the participants immediately after the tour, the objects singled out should be summarized. Researcher might for instance bring a Polaroid camera or ask the participant to note down the identified objects (figure 1).

Figure 1. One of the participants in a HomeHealthTour with a notepad to note down the objects singled out through the tour.

Furthermore, premade cards with pictures of e.g. running shoes and medication and some empty cards, where unanticipated objects could be noted or drawn, could be utilized as documentation. A box for collecting the objects or parts of them could also serve as documentation to use in the subsequent analysis although a risk is that many of the objects do not fit into a box.

The tours are videotaped by one of the researchers or one of the participants. The recording is the researchers' tool to base the subsequent analysis on and to share the HomeHealthTour with fellow researchers. Video recording should be sensitive to participants (figure 2) who may feel uncomfortable being videotaped, e.g. by directing the camera exclusively at the objects.

Video recording of all phases is important, as it will facilitate multidisciplinary collaboration at later stages in the design process and enable knowledge sharing with project participants who were unable to take part in the HomeHealthTour.

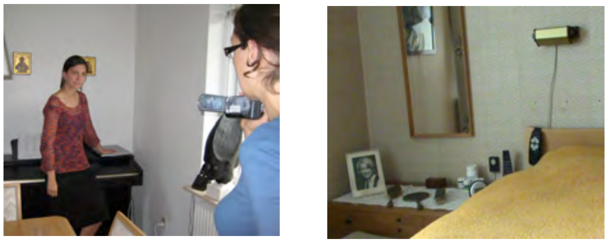

Figure 2. The researcher points the camera directly at Sarah, on the left. Anna, on the right, feels uncomfortable and hence the camera is pointed at the object in question, the bed.

D. *Creative Activities*

Following the guided tour participants and researchers engage in creative activities to initiate an analysis of the data and/or to generate design concepts. The creative activities are recorded on video for later analysis. The active participation of participants is inherent in different stages in PD processes. The HomeHealthTour method ensures that these activities are grounded in the home, in the lives of the residents and in their understanding of their practices. In this phase, the participant may be pivotal in the development of a new design concept, which can spring from an exploratory tour. Or, the participant may be introduced to existing design concepts, which is to be adjusted in a second iteration with the aid of the participant.

The creative activities, whether aimed at analyzing the tour or at generating design concepts, may be inspired by general PD techniques as for example the Inspiration Card Workshop [20]. The cards utilized could either be premade (figure 3), cards manufactured during the tour, physical objects or other artifacts that document the discussions from the guided tour.

Figure 3. A participant in a HomeHealthTour uses premade cards to inform a design concept.

A way to analyze data can be to categorize the dataset identifying key themes and the differences, similarities and relationship between them. Such analytical activity may take the shape of a card-sorting [28]. When the participant goes through the cards, he or she makes a new pile when an object that does not belong to the rest is identified. The resulting piles provide an overview of themes in the data and point out areas that need further investigation or discussion. Using a string to visualize connections will highlight relationships e.g. in terms of who uses the objects. A different approach may be to create maps of e.g. the organization of a special category of objects as inspired by the technology tours [8].

Note, that we make a distinction between the purpose of the guided tour and the following creative activities. The aim of the guided tour is to obtain an understanding of the field or topic in question while the aim of the creative workshops is to create solutions to identified problems. We believe that it is important to separate the two phases to allow a broad understanding of the domain before seeking solutions to the challenges through PD activities thereby avoiding the identified solution to govern the remaining part of the tour.

E. Debriefing

Each tour ends with a debriefing with all participants, which is videotaped. A debriefing has several purposes. One is to make room for reflection on the content of the tour and another is to discuss and validate the provisional findings. The debriefing may take place immediately after the tour but can also take place a couple of days later. Debriefing directly after the tour allows for more immediate comments on the tour while a later debriefing gives the participants time to reflect on central topics and the researcher to do additional analysis.

IV. HOME HEALTH TOURS WITH SARAH AND ANNA

As mentioned, we have, so far, made four different HomeHealthTours. They all had dual focuses, as they should inform our ongoing research but also should allow development and test of the method. We therefore selected participants who were different in terms of age, gender, diagnosis and family relation to explore the method's adaptability to different types of participants.

The two HomeHealthTours we present below, Sarah and Anna, represent diversities in terms of the participants' characteristics and in the use of the method. The two HomeHealthTours were made in connection to two projects. The (omitted for review) project, which Sarah participated in, is now completed and explored the possibilities of supporting pregnant women with diabetes with technology in their disease management and collaboration with healthcare professionals. The project (omitted for review), Anna participates in, is ongoing and aims to develop technology to support seniors in doing the home-exercises in a rehabilitation program for chronic dizziness. Both projects focus on the home as an arena for health related activities and on non-supervised healthcare activities in the home.

A. The Two Tours

1) Sarah

Sarah is a woman in her 30s who lives with her husband and four-year-old daughter. She has type 1 diabetes. Sarah and her husband both work outside the home and their daughter is in kindergarten. In (omitted for review) project, Sarah participated in one workshop beside the HomeHealthTour.

The HomeHealthTour at Sarah's home took place from 5 pm to 10 pm. Besides the two researchers, Sarah's daughter participated during the first part of the tour and Sarah's husband, who came home during the tour, participated in the final discussion. Sarah's husband was unable to care for their daughter as planned because he had to go to see his mother who had been admitted to the hospital. In consideration for their daughter's needs, we therefore conducted the tour at intervals, prolonging our stay in the home.

The purpose of the tour was to gain an understanding of how disease and health are managed in the home. As such we did not focus on diabetes but rather situated it in the broader context of health, disease, and home. A second purpose was to inform and qualify a design concept that already had been developed in the (omitted for review) project.

The HomeHealthTour with Sarah began with dinner brought by the researchers. During dinner we also briefed Sarah about the content and the purpose of the tour. We began the guided tour in the living room and continued from room to room following the physical structure of the home ending in the bedroom one and half hour later. Sarah's daughter accompanied us but eventually became tired and whiny. Now and then we took a break for Sarah to take care of their daughter. Before ending the tour, Sarah's husband came home and tucked her in. The guided tour was videotaped.

After finishing the guided tour we went back to the living room to work with the identified objects in relation to a design concept, which we introduced to her when we began the creative activity. We had brought premade cards symbolizing health related objects and empty cards to fill out for the objects we had not anticipated. Sarah selected the cards symbolizing the objects we had identified during the guided tour and categorized them in a sense that was logical to her when considering the design concept (figure 4). We provided her string, scissors, and other utilities and with this she created her own (omitted for blind review). This activity informed our design process and lasted approximately one hour.

Figure 4. Sarah engaged in a card-sorting activity of the objects identified through her tour with the purpose of informing a design concept.

Upon departure we arranged that one of the researchers could come back for a debriefing later. The fact that the debriefing did not take place immediately after the tour had made Sarah reflect profoundly on the tour and allowed the researchers to discuss a preliminary analysis with her. The video-recordings were later transcribed and analyzed with other data and the result of this process was presented in (omitted for review).

2) *Anna*

Anna is in her 90s and a widow who lives alone in the house where her three children grew up. While Anna generally takes care of herself, a gardener and a cleaning lady come every week. Besides from being dizzy, Anna has a pacemaker and depends on a hearing aid. At the time of the HomeHealthTour Anna had not participated in other PD activities in the (omitted for review) project.

Anna and two researchers were present at the HomeHealthTour in Anna's home, which lasted from 3 pm to 6 pm. The purpose of the HomeHealthTour with Anna was to gain an initial understanding of how it is to manage chronic dizziness at home. The tour began with a briefing together with coffee and cake brought by the researchers. The briefing consisted of small talk and an explanation on the tour and its purpose. The briefing created a good feeling among the three participants and provided the researchers with substantial background information on Anna in terms of an overview of her life story.

The guided tour began in Anna's bedroom and continued through all rooms of the home following the physical structure until we ended in the living room. While in the living room we also talked about her garden, which could be seen through large windows and which Anna related to health and disease as it gave her joy, but also as she fell in the garden when suffering a blood clot. The guided tour lasted approximately one hour.

Initially we wanted Anna to collect the objects or parts of them in a box to capture the objects and facilitate a subsequent collaborative analysis. However, we soon gave this thought up as Anna e.g. pointed out her late husband's bed and referred to routines, neither of which fitted into a box. Consequently, neither Anna nor we captured the objects and hence we did not carry out the planned collaborative analysis with her. The HomeHealthTour ended with a debriefing that took the shape of an explorative talk about some of the themes from the tour. We videotaped the guided tour and the debriefing. As with Sarah, the video-recordings were transcribed and analyzed with other datasets.

V. POTENTIAL OF THE HOME HEALTH TOUR

In this section we will elaborate on our experiences with the method and reflect on its possible contributions based on our tours with Sarah and Anna.

A. Being Guests in the Home

A central point, inherent to conducting studies in a home, is that the researchers are guests. This causes ethical considerations on behalf of the researchers in respecting the participant's time, sensibilities and family relations. Doing research in a home is to do research on private and intimate ground and it has to take place on the premises of the home and the home life. If the doorbell rings or a child needs to be tucked in, we as researchers must be sensible to the situation and put the activity on standby or even end it. Our experience is, cf. Sarah's case, that this is also due when conducting HomeHealthTours.

The guest/host relationship is one of the foundation stones in the HomeHealthTour. As with other guests who have not been in the home before, the researchers receive a guided tour in the home. Our experience is that this tour provides a degree of normality to the research activity, as there is a predefined and well-known role the researchers can take. Furthermore, the host/guest roles stress that one of the parties is on home ground and that he or she is the one with the greatest knowledge within this field. Thus, the research activity can be boxed into a well-known category by the tour and host/guest roles allowing participants to relate to it and feel comfortable about participating which is one of the challenges of these short-term investigations with the field.

However, despite being guests, the researchers have a specific goal with being in the home; they outline the visit and bring a range of somewhat invading artifacts such as video camera and utilities for the creative workshop. The researchers thereby transcend the normal role of a guest. To avoid participants to become uncertain as their home and role as host are challenged, it is our experience that it is vital that, although implicitly, researchers and participants reach an agreement on the tour and the roles in the briefing.

B. *An Explorative or Specific Approach*

The HomeHealthTour is a flexible method, which can be applied at different stages in a research project. At early stages of a project, the method can have an explorative approach where researchers and participants engage in a dialogue from which the topic of the tour evolves depending on what is particularly relevant to the participants, and how they interpret the topic. Similarly, the tour may evolve unexpectedly if researchers identify an unanticipated topic of interest. At later stages in a project, the HomeHealthTour can serve as a method for elaborating on a more specific, pre-determined topic, for instance in order to ground creative work in the home setting.

Planning the HomeHealthTours we have conducted so far, we were interested in getting a broad understanding of how health and disease are practiced in the home and thus planned the tours to be explorative in nature. When the first tour had drawn our attention to the topic of visibility and invisibility, this topic became a key theme in the following tours, while also having an explorative purpose.

Furthermore, the HomeHealthTour allows for continuous shifts in the levels of abstraction. Stories about specific objects often lead to reflection and discussion on a conceptual level. The strength of the method is that while the discussion explores concepts on a highly abstract level, it will be grounded and keep its connection to a specific object, related story and context rather than having the discussion making generalizing and speculative statements.

C. *Objects as Catalysts*

We found the focus on objects highly valuable, as the objects would prompt participants and help them articulate otherwise embedded, tacit practices and knowledge. During the tour, Sarah for instance found a box put away containing her first blood sugar meters, old records of blood sugar levels and information flyers. The objects helped her describe how her way of managing her diabetes has evolved from keeping a meticulous record as a way to learn to treat her diabetes to not keeping record at all when she became more experienced.

Similarly, in their search for objects participants may come to remember practices and tell stories they otherwise might have been left out. While standing in her spare room where Anna kept all her paperwork from the bank etc., we inquired into if she also kept records from the hospital: “In general, no. After a while I think: why on earth should I keep it? All the unpleasant stuff, you might as well throw it away”. Later however, while standing in the kitchen, she came to realize that she did have an envelope tugged away in the kitchen drawer with papers from the time when she came into anti-coagulant treatment.

While objects missing from the home are difficult to encompass, we experienced that the HomeHealthTour reminded the participant of such objects. When Sarah guided us around she opened a door to a cabinet stating: “There should have been red wine, which is good for you, in this cabinet. However, we drank it”. Although the object – the wine – was not available, its usual place in the cabinet reminded Sarah to mention it, which she might have forgotten if we had made an interview detached from the context.

In each home boundary objects are found which are used in different social worlds [29]. Boundary objects are interesting to investigate as they speak of connections between persons, objects and places, which can be valuable input in a design process, and remind us that a home cannot be seen as an isolated island. In our experience, the HomeHealthTour is helpful in revealing boundary objects. Sarah pointed to several such objects that had threads outside the home: her diabetes purse containing all her relevant artifacts for controlling her blood sugar levels [9], prescriptions, her phone, the family’s computer and TV. Telling us about her use of prescription on insulin in different contexts, Sarah told that she had been in doubt on how and where to keep it. Should she keep it safe at home or bring it on the road as it could suddenly be needed? The migrating feature of the prescription thus generated an insight into dilemmas and practices in Sarah’s life. Ideally, one could follow the path of the boundary objects, but to meet the time constraints in many studies, the next best option is to rely on accounts of their paths.

D. *The Lived Experience of Health and Disease*

The HomeHealthTour proved to be a valuable method to investigate everyday practices related to the management of health and disease in the home. The guided tours revealed a different perspective on health and disease than encountered in professional settings like hospitals and in dominating public health discourses. Rather we encountered a perspective that took its point of departure in the home and in the life of the participant.

During the tour with Anna, we were initially frustrated that she had misunderstood our purpose of the tour. Instead of locating objects such as medication she pointed to a picture of her son who had passed away and to small wooden figurines crafted by her late husband. As she continued to do so, despite our efforts to correct her, we began to realize that a much broader understanding of health and disease exists, interweaving health, disease and family history. Thus, beliefs and ideas about health as well as adjusted versions of medical regimens are revealed in a HomeHealthTour.

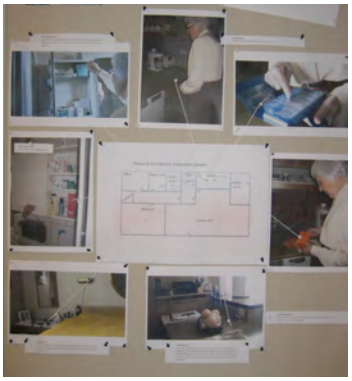

Figure 5. The mapping of Anna’s distributed medication system.

The HomeHealthTour also revealed practices and routines related to disease and health management. For instance, how and when Sarah managed her diabetes in different rooms.

Anna's tour also revealed a system Anna had invented to keep a track of her medications, to remind her to take the medicine and to have the medicine ready at hand if need should arise. As figure 5 shows, Anna had distributed her medications in several rooms. While the medication system was discussed with Anna, the researchers made the drawing afterwards to share this complex, distributed medications system with colleagues.

The broad understanding of health and disease and the insight into practices and routines that the HomeHealthTour provides are valuable if we are to design self-care technologies, as perspectives ruling in a home context, rather than in a professional setting, should inform the design.

E. Insight Into Collaborative Aspects

The HomeHealthTour also proved beneficial in regard to exploring collaborative aspects of management of health and disease. Having the participants explain who uses a given object incites them to describe how other people take part in their management of disease and health or how tasks are shared or distributed. From a hospital perspective collaboration on healthcare matters will often be thought to regard patients and their healthcare providers. However, in the home focus changes significantly pointing towards family members and social networks, even for persons like Anna living alone. Anna's daughter, for instance, was deeply involved when Anna was to have her pacemaker replaced. Furthermore, she has been inspired by friends and by the media in regard to her decision on not eating meat. Anna gave yet another example of collaborations when she pointed out the late husband's bed and explained how she collaborated with home nurses about his care before his death.

Also in Sarah's tour, the collaborative nature of health and disease was revealed. After having revealed several objects that Sarah related to her diabetes and to her husband's illnesses, a researcher asked whether her husband supported her in her diabetes management. Sarah was then prompted to talk about how her husband recognizes symptoms of hypoglycemia before she does enabling her to avoid having it.

To explore the collaborative aspects of health and disease could inform the design of technology that facilitates collaboration and enables people to collaborate around it supporting one person's disease management. Exploring collaborative aspects can also point to conflicting needs and experiences when disease is managed at home.

F. Participants Take Active Part in the Analysis

With the HomeHealthTour participants are given the opportunity to engage actively in the analysis, particularly during the creative activities and in the debriefing. Discussions with Sarah proved constructive in identifying and elaborating on what turned out to be central topics. During the design activity it became clear that when Sarah categorized the cards, she utilized concepts of segregation or integration; public or private; visible or invisible based on existing practices and regarding how her health and disease should be part of her life. During the debriefing we explored some of these themes further, but also discussed the differences of being a patient at the hospital and at home which Sarah had told us about during the tour. Sarah explained that when hospitalized upon being diagnosed with diabetes she embraced the patient identity, wanting to wear hospital clothing as a way of visualize that she was sick. However, when leaving the hospital she removed visible signs of being a patient, such as a plaster, refusing to become a patient in her own home.

Having Sarah take part in the initial analysis during the creative activity and again in the debriefing helps to ground the findings further in the context of the home informing the design for the new healthcare technologies.

G. Connection Between Context and Design Concepts

One of the advantages of the HomeHealthTour is its ability to strengthen the connection between context and the developed design concepts. In Sarah's case, doing the HomeHealthTour helped us to further develop a prototype called (omitted for review) [3]. When we held the HomeHealthTour the concept had been developed and was being redesigned in iterative processes with future users. The HomeHealthTour contributed to this work but also vindicated the identified design ideas of integrating new IT services into technologies already used by the users. The HomeHealthTours' unveiling of practices of integration or segmentation of healthcare activities from other daily activities vindicated this design idea.

The unveiling of these practices together with practices to make healthcare technologies visible or invisible also informs the ongoing project to develop technology to support home-based rehabilitation. While HomeHealthTours have not contributed with creative design activities in this project, especially the notion of invisibility-visibility has informed and do inform our development of concepts and prototypes. For instance, we currently work with a concept of an augmented flower to support seniors, as Anna, in doing their rehabilitative exercises [2]. The idea is that many elderly people have flowers in their home and value them. If we can design a supportive technology that resembles a flower, we can ensure invisibility and integration thereby respecting a common wish of many of the seniors in question to keep their condition as a side involvement [4] or 'out of sight'.

VI. CONCLUSION

The HomeHealthTour method has been developed to overcome challenges when studying health and disease in the home as part of a PD process, both in early explorative stages in a project and later when focusing on particular topics. We have found the HomeHealthTour to provide a way of conducting studies in the context of the home as it sets a stage in which both researchers and participants feel comfortable. Through the focus on objects, the method has proved valuable to generate contextual knowledge as it prompts participants to describe unarticulated practices related to their management of health and disease, including collaborative aspects.

Moreover, we believe that the HomeHealthTour can contribute to a design process with an involvement of participants in the exploration of problem areas, experiences, practices and collaborations and the motivations behind them. It can also contribute with an involvement of the user in generating design ideas, concepts or mock-ups. Thus, participants participate in the explorative phase as well as to the development process. Both types of contributions are highly embedded in the context of the home and the participants, which we find important in the development of healthcare technologies to be used in the home. We believe that the HomeHealthTour addresses one of the challenges in participatory design; namely to apply empirical knowledge in the more creative aspects of design as these two phases more easily can be intertwined. Thereby, the method serves an approach to understanding user needs and as tool for creating healthcare technologies that support the users in their management of health and disease in the home.

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List of Appendices

A: Interview guides, ElderTech study

B: Interview guides, Healthy Home project

C: Introductory letters to the research projects

D: Statements of informed consent

E: Co-author statements

F: Statement from main supervisor

Appendix A: Interview guides, ElderTech Study

Interview med borgere

Før

Dato:

Navn:

Alder	
Køn	
Ægtefælle	Samboende_____ Enlig____
Uddannelsesmæssig baggrund	
Boform	Ældre bolig__ Eget hjem __ Etage___ Villa__
Hjemmehjælp:	Hvor ofte: Hvad hjælper de med? (rengøring, pleje)
Sygeplejerske	Hvor ofte: Hvad hjælper hun med? (medicindosering, insulin, blodtryk)
Medicin	Får dosispakker fra apotek: hælder selv op: sygeplejerske hælder det op: Tager det selv: Hjemmehjælpen stiller det frem:

Vejning	Har ikke behov for at veje sig: Vejer sig sammen med sygeplejersken hver ________ Vejer sig selv hver _______
Blodtryk	Har ikke behov for at tage blodtryk: Sygeplejersken tager det hver______ Tager det selv hver______

1. Hvor længe har du boet her? (bor du her alene?)
2. Hvad kan du godt lide ved at bo her?
3. Prøv at beskriv hvordan din dag forløber – hvilke rutiner har du?
4. Hvad skal der til, for at det er en god dag?
5. Hvordan forløber din uge – er der nogle faste ting, du går til?
6. Har du kontakt med dine naboer?
7. Har du børn? – hvor bor de? Hvordan plejer du at være i kontakt med dem? Hvor mange børnebørn har du? Hvor gamle er de? Hvordan holder du kontakten med dem – ringer I sammen eller besøger I hinanden? Telefon, Besøg, Brev, mobiltelefon, e-mail
8. Bor dine venner i byen? Mødes I en gang i mellem eller taler I mest i telefon? Hvordan holder I kontakten med hinanden? Telefon, Besøg, Brev
9. Hvor skal du holde jul henne?
10. Hvor tit kommer du på lokalcenteret? Hvilke aktiviteter kommer du til? Julefesten? Cafeen? Hvad kan du godt lide ved at komme der?
11. Hvor tit får du besøg af hjemmehjælpen? – Hvad hjælper hun med? Hvad synes du om besøgene?
12. Hvor tit får du besøg af sygeplejersken? – Hvad hjælper hun med? Hvad synes du om besøgene?

13. Hvordan har I besluttet, hvad du får hjælp med? Hvordan foregår det, hvis der skal ændres på nogle ting? Er det også noget, dine børn bliver involveret i?
14. Prøv at forklare mig, hvordan det foregår, når du tager din medicin. Hvad for noget medicin får du, hvem hælder det op, hvordan husker du at tage det hver dag. Hvad gør du, hvis du opdager, at du har glemt at tage din medicin? Prøv at forklare mig, hvordan det foregår når du skal være væk hjemmefra – fx over julen?
15. Bliver der holdt øje med dit blodtryk? Prøv at forklare mig, hvordan det foregår, når du skal have taget dit blodtryk. Hvem siger, hvornår det skal tages, hvem tager det, hvorhenne?
16. Bliver der holdt øje med din vægt? ? Hvem siger hvornår du skal vejes, hvor bliver du vejet – gør du det selv, eller hos lægen?
17. Hvad gør du, hvis du har smerter – hvem kontakter du så og hvordan? Pårørende, lokalcenteret, læge via telefon, kald, når personalet kommer forbi
18. Hvor tit er du i kontakt med din læge? Hvem tager kontakt? Hvordan får han de oplysninger, som ligger her på centeret?
19. Hvem bruger din samarbejdsbog – hvad bruger de den til? Hvem læser i den? (pårørende, personale) Hvad synes du om, at dine pårørende kan læse i den?
20. Hvad synes du, er god pleje? Hvad synes du om besøgene?
21. Er du nogensinde faldet i dit hjem?
22. Kan du ikke vise mig, hvordan kaldet virker?
23. Hvad tror du der skal til, for at du er tryg ved at bo her fremover?
24. Hvordan kan det være, at du har sagt ja til at være med i det her projekt?
25. Hvor gammel er du?
26. Hvad arbejdede du som, inden du blev pensioneret?

Interviewguide - borgere

Efter installation

1. Hvad synes du om systemet?

Funktionaliteter

2. **Hvilke dele af systemet har du brugt? – hvorfor dem og ikke de andre?**
3. Hvad bruger de mest i systemet? – hvad er det mest **brugbare** for dem?
4. hvad kan du bedst lide, og hvad kan du mindst lide?
5. **Hvilke muligheder ser de i sådant et system?**
6. **Hvordan synes de at sådan et system hjælper dem til at bo hjemme? Hvad skulle der til i stedet?**

Medicinregistrering

7. Prøv at fortæl i detaljer om hvordan det foregik, da du tog din medicin i morges? Hvordan er deres rutiner omkring medicin-tagning nu/**er der sket ændringer i måden medicinen bliver taget på** pga. Roberta?
8. Hvordan passer systemet ind i deres rutiner? Passer tidspunkterne for medicinindtag med dine rutiner? Ved du, hvem der kan ændre det?
9. Hvordan passer den fysiske placering ind i forhold til medicintagningen?
10. **Giver systemet en større forståelse for hvad det er for noget medicin de får?**
11. **Tror du systemet på sigt vil hjælpe dig til at huske at tage din medicin**?
12. Når du trykker på knappen ”taget” – hvad synes du så at det betyder? Hvad har du så kvitteret for? (er det lægemidlerne eller er det, at de har taget deres medicin?)
13. Forestil dig, at du skal ud i byen og spise middag – hvad gør du med din medicin? Tager du den med? Hvad så med medicinregistreringen – hvad gør du dér?

Blodtryk

14. **Prøv at beskriv i detaljer hvordan det foregår, når du tager dit blodtryk** (er manchetten til at få på?, er apparatet til at bruge i soveværelset? Foregår det liggende eller siddende?)
15. Hvor tit tager du dit blodtryk nu? – Hvorfor?
16. **Hvad er gode blodtrykstal for dig?**
17. Ville du kunne tænke dig selv at sende dem til din læge hvis du synes de virker unormale?
18. Hvad ville du synes om hvis lægen kan se tallene fra sin praksis? Eller hospitalet?
19. **Har det betydet noget for den måde du opfatter dit helbred på? Selvovervågning? Betydning for det, du spiser? Motion?**
20. vil de gerne springe turen til lægen over og bare sende blodtryksmålingerne? – eller er blodtrykket en del af en samlet helbredsvurdering de gerne vil have foretaget? Er der noget socialt i at se lægen?

Vægt

21. **hvor tit bruger de vægten? Hvordan foregår det? Er der sket ændringer i forhold til før?**
22. hvad synes de om at bruge vægten? – er den til at bruge?
23. Hvilke muligheder ser de i det?
24. Hvad synes de om, at personalet kan se deres vægt?
25. Hvad vil de synes om, at deres læge kan se tallene?
26. Vejer de sig mere end før – **har det betydning for den måde du opfatter dit helbred på? Betydning for det, du spiser? Motion?**

Samarbejdsbog

27. **Synes du at den elektroniske samarbejdsbog gøre en forskel for din kommunikation med lokalcenteret? Hvad skulle der til for at forbedre samarbejdet?**
28. Kunne de tænke sig, hvis deres pårørende kunne se og skrive beskeder i samarbejdsbogen?
29. Kunne de tænke sig, hvis deres læge kunne se og skrive beskeder i samarbejdsbogen?

Selvhjælp

30. **Føler du, at du har større indsigt i din helbredsmæssige tilstand nu? Hvorfor – og hvad skulle der til? Hvilke parametre?**

31. **Føler du at systemet er en hjælp for dig til at klare dig selv bedre? Hvorfor (ikke)– hvilke dele af det eller hvad skulle der til?**

Monitorering

32. Hvad synes du om, at personalet kan se dine data fra deres kontor? Hvornår er det ok, hvornår er det ikke? Hvad er ok, og hvad er ikke?
33. Hvad synes du om, hvis dine pårørende kan se informationerne i systemet?

Socialt

34. Hvad kunne de mere tænke sig/funktionalitet? Sociale, kliniske?
35. Kunne de forestille sig at bruge systemet til kommunikation med pårørende: beskeder, billeder, musik
36. Kunne de forestille sig hvis man kunne se aktiviteterne i festsalen – eller busture (og at de ville vide, at man var på)?
37. Kunne de tænke sig, hvis der blev oprettet felter, hvor de kunne udveksle beskeder med andre? – med andre beboere, med venner, med pårørende?
38. **Giver systemet tryghed? Hvad skal der til for at få dig til at føle mere tryg?**

Deployment

39. kan du se, når tallene fra vægt og blodtryk kommer ind på computeren?
40. Har der været problemer med at få tingene til at snakke sammen?
41. Har du fået fejlmeldinger? – hvad gør du så?

UI

42. **Hvad synes du om at bruge computeren? Vægten? Blodtryksmåleren? Er det nemt eller svært at bruge? Hvorfor**?
43. Kan du altid finde tilbage til din side?
44. Hvad synes de om at bruge fanerne – er de nemme at bruge?
45. Er systemet nemt at bruge? Finde rundt i? Login?
46. Er det til at bruge hardwaren? Pen, skærm
47. Er skærmen mest oppe eller nede?
48. Hvad synes du om at have systemet i dit hjem?

49. **Hvordan synes de, at teknologi i hjemmet bør se ud?**

Livshistorie interview-vinkel

Omsorg i familien:

- Krise situationer
- Hjælp i hverdagen
- Sygdom i familien

Interviewguide til personalet

Før implementering

Navn:

Dato:

1. Hvor længe har du været her?
2. Hvad består dit arbejde i?
3. Beskriv din arbejdsdag i går? Typisk, atypisk?
4. Beskriv dit arbejdsmønster – hvordan forløber dagen?
5. Hvordan planlægger du din dag?
6. Hvad betyder visiteringen i dit arbejde?
7. Hvad er dine primære arbejdsredskaber? Samarbejdsbogen, vita journalen, køreplaner, overleveringssedler, telefon, computer, mail
8. Hvordan bruger du dem, og hvordan synes du, at redskaberne hænger sammen?
9. Hvornår opdateres informationerne i systemerne/redskaberne? (hvordan holdes de opdateret?)
10. Hvem arbejder du primært sammen med? Hvordan holder du dig i kontakt med dem dagen igennem?
11. Beskriv samarbejdet i gruppen – morgenmøder, gruppemøder, hvor mange uformelle møder har du på en dag? Hvor finder de sted henne?
12. Beskriv det tværfaglige samarbejde? Kommunikationen?
13. Kommunikationen med de andre skift?
14. Beskriv samarbejdet med de praktiserende læger?
15. Beskriv kommunikationen med pårørende? Samarbejdsbogen?
16. Hvad er en god pleje?

17. Prøv at beskriv et besøg hos en borger – hvad gør du, når du kommer ind, hvad gør du undervejs, hvad gør du når du går?
18. Hvordan kontakter borgerne jer, hvis de har brug for hjælp til noget?
19. Hvordan holder I øje med borgeres fysiske tilstand i øjeblikket?
20. Hvordan holder I øje med deres sociale og psykiske tilstand?
21. Hvordan er rutinerne omkring det forebyggende arbejde?
22. Hvordan hjælper I borgeren til at kunne klare mest muligt selv?
23. Beskriv rutinerne omkring medicingivning i øjeblikket? Hvordan fungerer det?
24. Beskriv rutiner omkring vejning i øjeblikket? Hvordan fungerer det?
25. Beskriv rutiner omkring måling af blodtryk i øjeblikket? Hvordan fungerer det?
26. Hvad oplever du, er den største udfordring for at borgerne kan blive boende i eget hjem længst muligt?
27. Har du computer hjemme? Hvor tit bruger du den?
28. Hvad synes du om computere i plejen?
29. Hvordan er det at have nogens hjem som arbejdsplads?
30. Alder?

Interviewguide

Personale – efter installation

Navn, stilling

1. Kommer du hos en borger, som har systemet?

Umiddelbare indtryk af systemet

2. Har du deltaget i undervisningen i brug af systemet?
3. Kommer du hos en borger, som har systemet?
4. Bruger du systemet? Hvorfor, hvorfor ikke?

Faktorer:

☐ Har ikke en borger med systemet

☐ Undervisningens længde/graden af indføring

☐ organisatoriske omstruktureringer

☐ interesse

☐ svært at bruge computeren

☐ har ikke tid

☐ Stoler ikke på data

☐ kan ikke se formålet/data er ubrugelige

☐ det giver en ekstra arbejdsgang

☐ borgeren har ikke længere mulighed for at læse i samarbejdsbogen

☐ andet: ____

5. Hvad skulle der til, for at du ville begynde at bruge det?

6. Hvilke dele kunne du bedst forestille dig at bruge?
7. Hvad ville være interessant for dig, at et sådant system blev brugt til?
8. Hvad tror du, der ville gavne borgerne, at der blev målt på?

Administration

9. Hvordan påvirker systemet dit daglige arbejde i dag?
10. Hvilke fordele og ulemper oplever du i forhold til dokumentation af sit arbejde?
11. Er der forskel på den måde du anvender samarbejdsbogen nu, i forhold til før? Fordele, ulemper?

Kommunikation

12. Oplever du at systemet ændringer din kommunikation med borgeren og pårørende? Hvordan tror du, at systemet ville kunne hjælpe til at forbedre kommunikationen?
13. Ændringer i kommunikation med kolleger? Hvordan tror du at et sådant system vil kunne forbedre denne kommunikation? på tværs af faggrupper, internt i faggrupper, mellem skift
14. Ændringer i kommunikation med den praktiserende læge? Hvordan tror du at et sådant system vil kunne forbedre denne kommunikation?
15. Ændringer i kommunikation med hospitalet? Hvordan tror du at et sådant system vil kunne forbedre denne kommunikation?

Klinisk:

16. Hvilke fordele og ulemper oplever du i forbindelse med registreringen af borgernes blodtryk?
17. Hvilke fordele og ulemper oplever du i forbindelse med registreringen af borgernes medicinindtag?
18. Hvilke fordele og ulemper oplever du i forbindelse med registreringen af borgernes vægt?
19. Synes du, at du får et bedre indtryk af borgerens helbredstilstand fra distancen? Hvorfor/hvorfor ikke? Hvad skulle der til, for at man ville opnå det?

20. Synes du, at du har bedre mulighed for at følge med i borgerens tilstand og gribe ind, hvis den forværres? Hvorfor/hvorfor ikke? Hvad skulle der til, for at man ville opnå det?
21. Giver systemet input til den forebyggende sundhedsindsats? Hvordan/hvorfor ikke? Hvad skulle der til, for at man ville opnå det?
22. Synes du at systemet er med til at højne kvaliteten af plejen?'
23. Hvordan opleves før og efter situationerne i forhold til borgeren? – Mener du, at det giver det en kvalitativ forskel i plejen? Fordele, ulemper?

Afslutning:

24. Hvilke forbedringsforslag har du til systemet?
25. Hvilke muligheder ser du i et sådant system?/ Hvis du nu ser 10 år frem – hvad kunne du så godt tænke dig, at IT bliver brugt til inden for ældreplejen?

Appendix B: Interview guides, HealthyHome project

Interviewguide for gravide kvinder med diabetes – hjemme hos den gravide

Baggrundsinformation:

Alder, bopæl – sted og type, beskæftigelse, hvor langt er kvinden i sin graviditet, antal børn,

Sukkersyge i hverdagen:

- Prøv at fortælle lidt om din sukkersyge
    - type sukkersyge?
    - i hvor mange år?
    - hvad betyder det i din hverdag at have sukkersyge?
- Hvordan styrer du din diabetes?
    - Hvilke ting bruger du? Blodsukkermåling, dagbog, insulin pen, vægt, andet?

Sukkersyge og graviditet:

- Hvad har det betydet i forhold til din sukkersyge, at du er gravid?
    - Har det ændret noget - fx. i din hverdag?
    - Har du opsøgt info/hjælp inden du blev gravid pga. din diabetes?
- Har det været svært for dig at styre din diabetes undervejs? Hvad har været svært og hvad har hjulpet dig?
- Hvad betyder det for dig, at gå til kontrol på Skejby?
    - Fordele og ulemper? (Transport, tryghed)
    - Hvordan opleves det at have kontakt med mange forskellige faggrupper?

    - Når du får gode råd og vejledning fra personalet, hvordan får du det så integreret i din hverdag, når du kommer hjem? Kan du komme med et eksempel, hvor det kunne lade sig gøre og et eksempel, hvor det ikke lykkedes?
    - Hvilke ting har du med, når du er til kontrol? Blodsukkerdagbog? Vandrejournal? Forløbsbeskrivelse? Andet?
- Sukkersyge, graviditet og behandlingsforløb – hvordan tror du det ser ud i fremtiden? Hvordan kan forløbet forbedres? Hvilken rolle kunne du forestille dig, at teknologien vil spille? Kunne du forestille dig, at flere ting foregik hjemmefra – fordele og ulemper?

Graviditet og kontrol:

- Prøv at fortæl, hvordan din graviditet er forløbet?
- Prøv at beskriv, hvordan det foregår, når I er til kontrol på Skejby? (deres oplevelse: logistik, ventetider, flow mellem konsultationer, hvem man ser næste gang, hvor man venter henne, overlap mellem faggrupper,)

Sundhed generelt i hverdagen:

- Hvad er sundhed for dig?
- Hvad gør du for at være sund? – hvilke udfordringer oplever du i den forbindelse?
- Hvordan ser I på sundhed i din familie – har I forskellige opfattelser af sundhed og hvad betyder det? Hvad gør du for at sørge for at din familie lever sundt? Hvad gør de for dig?
- Hvordan synes du, at din egen opfattelse af sundhed er i forhold til den måde de ser sundhed på, på ambulatoriet?

(Foto)safari i hjemmet:

- Ting for sundhed og diabetes: Hvordan bruger du dem, hvorfor står de som de gør og dér hvor de gør? Hvordan synes du, de passer ind i dit hjem?
- Dit sunde sted?

- Steder for hygge?
- Teknologi i hjemmet? – ting, anvendelse, hvem er ”systemadministrator”?

Hjemmet som arena:

- Sammenhængen mellem hjem, sundhed og hygge – strider det mod hinanden eller hænger det fint sammen?

Andet:

Prøv at beskriv dagen i går (hjemmets rolle som social arena, sundhed og diabetes i hjemmet og i hverdagen)

Interviewguide for personale

Navn:

Stilling:

Dato:

Hvad består dine arbejdsopgaver i?

Hvad er dine vigtigste arbejdsredskaber? (fysiske, på computeren…)

Samarbejde med andre faggrupper

Hvad er din rolle på afdelingen?

Hvem er dine primære samarbejdspartnere i teamet?

Prøv at beskrive samarbejdet med de andre faggrupper

Samarbejde med patienten

Hvad er din rolle i forhold til de gravide diabetikere?

Hvilke udfordringer/spørgsmål hjælper du dem med?

Hvordan skaber du et overblik over patientens tilstand/hvad lægger du særligt mærke til?/Hvad spørger du til i dine løbende samtaler med den gravide/Hvad vil du gerne vide om deres tilstand mens de er derhjemme?

Forløb

Interviewguide til gravide kvinder med diabetes, efter pilottest af eDagbogen:

Dato:

Navn:

Fordel/Ulempe

- den største fordel, den største ulempe ved hele systemet

Brug i hverdag

- Rutiner; hvornår, hvilket medie
- vs. Bog, dobbelt-bogføring
- involvering af andre – fx videoklip
- telekonsultation
- sygeliggørelse i hjemlig setting
- synliggørelse/usynliggøre-skjule

Samarbejde med klinikere (vis videoklip)

- ejerskab
- vidensbærer
- hjemliggørelse i klinisk setting
- sygeliggørelse i hjemlig setting (telekonsultation)
- disciplinering? (jf. ejerskab)

Teknisk

- tillid
- praktisk til mobil, internet, webcam.
- nedbrud

Generelt/Baggrundsinformation

- diabetestype
- antal år med diabetes

- normal diabetes
- antal graviditet
- alder
- familieforhold
- arbejde

Interviewguide til klinikere vedr. test af eDagbog

1. **Hvordan har det været at bruge systemet**

   - den største fordel, den største ulempe ved systemet

2. **Hvordan har det været at være med i projektet/processen**

   - hvad har fungeret godt/hvad har fungeret mindre godt

3. **Vis video-optagelser**

   (se andet dok.)

4. **eDagbogen (log på)**
   - brug af tabel
     - 2 visninger: oversigt/overblik
     - Online
     - Integration i andet system
   - brug af eDagbog vs. Brug af almindelig bog (elektronisk vs. Papir)
   - teknologiens rolle i samarbejdet mellem gravid og ambulatorium/kliniker
   - nedbrud – incl. ejerskab
   - login/logout – incl. ejerskab
   - adgang
     - kun i konsultation?
     - hvem skal give adgang - ejerskab
   - opstilling, hvor og på hvilken computer (incl. ejerskab)
   - yderligere integration af eDagbog i konsultation
     - hvad kan lægges op på eDagbogen i konsultationen
     - hvor meget skal folk kunne huske af info i konsultation

- optagelse
    - Oplevelse af at blive optaget
    - Ændres situation (incl. den gravides ageren)
    - Etisk/retsligt problem
    - Kameravinkel
    - Hvem med på optagelse

5. **Fremtidige ideer**
    - perspektiver
    - hvad kan vi gøre bedre
    - hvad skal vi droppe
6. **Telekonsultation (diabetes specialist)**
    - Hvordan oplevede du telekonsultationen
    - Tidsperspektiv
        1. varighed
        2. integration i hverdag - tidspunkt
    - Brug af eDagbog
    - Hvordan integreres pausen (som den gravide bruger til at stille spørgsmål) i en telekonsultation
    - Telekonsultation vs. Almindelig konsultation
    - At komme ind i hjemmet (opfattelse af gravid/holistisk tilgang)
    - Sygeliggørelse
    - Ejerskab
    - Disciplinering på afstand
    - Integration mellem ambulatoriet og hjem
    - Tryghed

Appendix C: Introductory letters to the research projects

Projekt
Interaktive Ældreboliger

Tak fordi du har valgt at deltage i et spændende projekt. I denne pjece kan du læse lidt om projektet og forhåbentlig få svar på de spørgsmål, som du må have i forbindelse med deltagelsen.

Hvad er projektet Interaktive Ældreboliger?

Projektet Interaktive Ældreboliger er et forsknings- o gudviklingsprojekt. Der er tale om et samarbejde mellem:

- Aarhus Universitet (forsker i "pervasive healthcare" = IT i alting)
- IBM (udvikler ny teknologi inden for sundhed og omsorg
- Århus Kommune, repræsenteret ved Lokalcenter XXX og IT afdelingen for 3. Magistrat, som ønsker at udnytte disse muligheder i fremtidig ældreomsorg

Hvad skal der ske?

Der skal implementeres ny teknologi i 10 ældreboliger ved Lokalcenteret. Denne teknologi skal anvendes af både borgere og personalet.

Hvor længe varer projektet?

Pilotopsætning i ældreboligerne er planlagt fra 1. december 2005 til 31. december 2006. Der vil foregå forsknings- og udviklingsaktiviteter sideløbende med projektet. Der foretages en evaluering d. 1. februar 2006 og senere i projektet.

Hvordan foregår evalueringen?

Stinne Aaløkke vil komme på besøg hos dig og interviewe dig en eller to gange. Interviewet vil vare ca. én time. I interviewet vil hun bl.a. gerne høre, hvad du synes om systemet – fx om du synes, at det er nemt eller svært at bruge.

På den måde kan forskerne få oplysninger om, hvad der skal til for at forbedre systemet på et senere tidspunkt.

Stinne Aaløkke er uddannet etnograf fra Aarhus Universitet.

Hvad er det for en teknologi, som bliver installeret i boligerne?

Til pilotopsætningen hører der:

- En bærbar computer
- En blodtryksmanchet
- En personvægt
- En mobiltelefon

Blodtryksmanchetten fungerer som almindelig blodtryksmanchet, men kan sende målingen via mobiltelefonen til computeren, som gemmer resultatet.

Vægten anvendes som en almindelig personvægt, men kan sende resultatet via mobiltelefonen til computeren, som gemmer resultatet.

Mobiltelefonen fungerer som ”sender” til at sende måleresultater fra vægt og blodtryksmanchet til computeren.

Computeren skal erstatte dele af din nuværende samarbejdsbog, dvs. at det personale, som kommer i hjemmet fremover skriver notaterne i computeren.

Computeren har også en indbygget kalender, hvor besøg fra hjemmeplejen er noteret og hver der selvfølgelig kan skrives nye aftaler ind, f.eks. besøg på Lokalcenteret eller aftaler med familie eller læge.

Hvem ejer udstyret?

Udstyret ejes af Århus Kommune, som låner det gratis ud til projektdeltagerne i projektperioden. Ved afslutning af projektet skal alt udstyr tilbageleveres til Århus Kommune.

Hvordan er udstyret forsikret?

Udstyret er forsikret igennem Århus Kommune. Det betyder at du ikke selv skal tegne en forsikring eller skal have din indboforsikring til at dække ved evt. bortkomst. Vi henstiller selvfølgelig, at udstyret opbevares og behandles på forsvarlig måde.

Koster det noget at være med i projektet?

Det er vores hensigt, at projektet ikke volder udgifter til de borgere, som vælger at deltage. Det betyder, at det er Århus Kommune, der dækker udgifter for de nødvendige tekniske installationer.

Hvordan ved computeren hvilken medicin jeg skal tage og hvornår min hjemmehjælper kommer?

For at kunne vise oplysninger om den medicin du skal tage og de besøg, du får af hjemmeplejen, har computeren mulighed for at hente oplysninger automatisk fra din elektroniske Vitae Journal, som bliver ført over alle modtagere af hjemmehjælp i Århus Kommune.

Hvem får adgang til mine oplysninger?

Det er primært dig selv og personalet fra Lokalcenteret, som kan se oplysningerne. Derudover er det, for at få det nye system til at fungere, nødvendigt at forskere og udviklere fra de øvrige projektpartnere får adgang til nogle af oplysningerne. Alle oplysninger vil blive behandlet strengt fortroligt. Selve projektet er – ligesom lignende projekter – blevet godkendt af de ansvarlige myndigheder (Datatilsynet).

Hvad sker der, når projektet slutter?

Ved afslutningen af projektet vil forskere fra Aarhus Universitet skrive en videnskabelig artikel, hvor resultaterne af det samlede projekt vil blive offentliggjort. Artiklen vil blive trykt i et videnskabeligt tidsskrift. Alle oplysningerne i artiklen vil være anonymiseret og det vil ikke være muligt at finde tilbage til de enkelte deltagere i projektet.

Er det farligt at deltage?

Som udgangspunkt er det ikke farligt at deltage. Men da der er tale om et nyt system, som aldrig har været anvendt før, kan der selvfølgelig opstå fejl. Som muligt eksempel kan nævnes, at du ikke skal tage din morgenmedicin 20 gange selvom computeren beder dig om det. **Hvis dit blodtryk viser sig at være for højt, skal du aldrig selv ordinere dig flere blodtrykssænkende piller. Ordinationen af medicin må kun ændres efter du har talt med din egen læge. Computeren kan aldrig erstatte lægebesøg!**

Hvor kan jeg henvende mig, når jeg har spørgsmål?

Har du spørgsmål til projektet er du altid velkommen til at kontakte projektleder AXXXX HXXXX på tlf.: XX XX XX XX

Teknologi og sundhed

Støtte af samspillet mellem gravide diabetikere og sundhedspersonale

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Forskningsprojekt om teknologi og sundhed

En gruppe ved Aarhus Universitet er i gang med at udføre studier i forbindelse med projektet om teknologi og sundhed. Projektet handler om udvikling af sundheds-it, der kan skabe sammenhæng mellem hjemmet og netværket af sundhedspersonale, som fx fødselslæger, jordemødre, diætister, praktiserende læger m.fl. Der vil blive taget udgangspunkt i en case omkring gravide diabetikere og problemer, der kan opstå under graviditeten.

Baggrund

Der kræves en særlige tilbud til gravide diabetikere, da der kan være risiko for diabetes relaterede komplikationer i løbet af graviditeten. De gravide diabetikere har derfor tæt kontakt til sygehuset, hvor de gravide kan få eksperterne i tale. Mange gravide er trygge ved at have den tætte kontakt, hvor de kan få vejledning og få at vide, at alt går som det skal. En af ulemperne kan bl.a. være, at gravide diabetikere må rejse langt og ofte i forbindelse med kontroller relateret til deres graviditet. Samtidig har mange et job og et aktivt liv, der kan være svært at forene med den lange transport.

I projektet vil vi undersøge mulighederne for at udvikle it, der kan støtte samspillet mellem den gravide diabetiker og personalet, på en sådan måde, at trygheden bibeholdes og generne ved hyppige kontrol på ambulatoriet minimeres. Projektet opfattes som en mulighed for at udvikle løsninger til gravide diabetikere, der har lyst til at prøve en anden type behandling.

Formål

Nogle af de udfordringer, vi vil arbejde på at løse er, hvordan it kan bruges til at:

- støtte den gravide diabetiker under graviditeten
- forbedre samspillet mellem den gravide diabetiker og sundhedspersonalet

Metode

I projektet arbejder vi tværfagligt og har en bred gruppe af forskere, der har baggrund i f.eks. sundhedsvidenskab, datalogi og etnografi. Derudover vil vi gerne arbejde tæt sammen med såvel gravide diabetikere som sundhedspersonale, der har kontakt med denne gruppe. Det tætte samarbejde er vigtigt for, at der kan blive udviklet løsninger, der passer i både de gravide diabetikeres dagligdag og som kan integreres i den kliniske praksis. Samarbejdet vil betyde, at de udviklede løsninger vil kunne højne kvaliteten af behandlingen.

Derfor vil en lille gruppe af personer fra universitetet gerne have lov til at overvære konsultationer med gravide diabetikere, der kommer på ambulatoriet.

Derudover vil vi gerne tale med gravide diabetikere omkring deres oplevelser. Samtalerne kan foregå enten hjemme hos den gravide eller på ambulatoriet.

Personale og de gravide diabetikere, der har lyst, vil blive desuden involveret i workshops omkring idé udvikling og senere omkring design principper.

Mere om projektet

Hovedpartnerne i projektet er Aarhus Universitet, WM-data samt KIRK telecom.

Projektet udføres efter aftale med Skejby Sygehus og Århus Sygehus.

Hele projektet forventes at løbe over 2 år.

For eksempler på lignende projekter se: www.pervasivehealthcare.dk

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Thomas Riisgaard, ph.d. i datalogi og forsknings adjunkt

eDagbogen

Et værktøj til gravide diabetikere

Kunne du tænke dig at prøve eDagbogen?

På Aarhus Universitet har vi udviklet noget, vi kalder eDagbogen. Det er et redskab, som er designet til at kunne støtte diabetikere under deres graviditet – både i forbindelse med konsultationer på ambulatoriet og derhjemme.

eDagbogen er den første version af et helt nyt værktøj, og for at finde ud af, hvordan den kan forbedres, vil vi gerne have hjælp til at få den afprøvet. Vi efterlyser derfor gravide diabetikere, som synes det vil være sjovt at prøve et nyt redskab og som har mod på at prøve at bruge det i november måned.

Hvad er eDagbogen?

eDagbogen ligger både på en mobiltelefon og på computeren. På mobiltelefonen kan du taste dine blodsukre ind. Du vil også kunne se dem på din computer, hvor du kan få et stort overblik over dine blodsukre, ligesom du har det i bogen i dag. eDagbogen ligger på en side på internettet. Det betyder, at du let kan give andre adgang til at se dine blodsukre, også selvom I ikke sidder sammen. Det gør det muligt at lave tele- eller video konsultationer med for eksempel medicineren, hvor du giver ham eller hende adgang til at se tallene. I løbet af november vil vi prøve at lave videokonsultationer med netop medicineren. Video-konsultationen kommer til at være dagen før et normalt ambulatoribesøg og er ikke ment som erstatning for din normale konsultation med medicineren.

Vi vil også prøve at optage nogle af konsultationerne på ambulatoriet. Ofte er man alene inde til konsultationerne og det kan være svært at genfortælle til ens partner, hvad man har fået at vide. Derfor vil vi prøve at optage nogle af konsultationerne på video, fx med fødselslægen, og lægge dem på eDagbogen. På den måde kan du vise det til din partner eller andre du gerne vil dele din oplevelse med.

Desuden vil der på eDagbogen ligge forskellige links til gode sider, hvor du kan læse mere om graviditet og diabetes.

Ideen med eDagbogen er, at den på længere sigt skal ligge på ens egen mobil telefon. På den måde bliver den en del af ens almindelige hverdag og ikke kun noget, der handler om diabetes og graviditet. Tanken er, at man på den måde får lavet en slags elektronisk diabetestaske, som er en del af ens hverdag på en diskret måde. eDagbogen handler som udgangspunkt *ikke* om at erstatte besøg på ambulatoriet.

Hvordan kan jeg komme til at prøve eDagbogen?

Det vigtigste er, at du synes at det vil kunne være sjovt at prøve at bruge et helt nyt værktøj. Noget af det, du skal prøve, er, løbende at skrive dine blodsukre ind på mobiltelefonen, ligesom du plejer at gøre i din bog.

Der vil være et introducerende møde, hvor du vil lære mere om eDagbogen, og hvor du vil få udleveret forskelligt udstyr. Blandt andet stiller vi en mobiltelefon til rådighed under forsøget, men du skal selv have en computer med Internetforbindelse.

Desuden skal du have lyst til at fortælle os om dine erfaringer med at bruge eDagbogen. Vi vil gerne tale med dig, når du kommer til kontrollerne i november måned, og vi vil også gerne hjem til dig og lave et opfølgende interview, når forsøget er slut.

Nedenfor har vi lavet en oversigt over de aktiviteter, som vi regner med at lave i forbindelse med forsøget, og som vi forventer, du har lyst til at deltage i. De fleste af aktiviteterne vil ligge i forbindelse med planlagte ambulatoriebesøg og resten vil foregå hjemme fra dig selv, så det kan passe ind i din hverdag.

Plan for forsøget:

30. oktober	Introduktion til pilotforløbet på Skejby fra kl. 14.30-16.00 De gravide får udleveret udstyr. Herefter vil de gravide diabetikere registrere deres blodsukker i e-dagbogen i løbet af den næste måned.
13. november	Her vil være et normalt konsultationsforløb, hvor vi vil prøve at optage nogle af konsultationerne og lægge dem i e-dagbogen.
26. november	Her vil være en videokonsultation mellem de gravide diabetikere og medicineren om deres blodsukkertal ved hjælp af e-dagbogen.
27. november	Her vil være et normalt konsultationsforløb, hvor vi også vil optage konsultationerne, som lægges i e-dagbogen. De gravide kan også deltage i konsultation hos medicineren som normalt, hvis den står på planen. Dvs. videokonsultationen fra dagen før behøver *ikke* at erstatte dagens konsultation hos medicineren. Vi vil også følge op på erfaringerne med videokonsultationen dagen før. Vi håber på at kunne tale om dette lige efter eller under besøget på ambulatoriet.
1.-5. december	Vi tager hjem til de gravide og interviewer dem om deres erfaringer med forsøget. Samtidig henter vi det udleverede udstyr. Der vil desuden også være opfølgende interviews med personalet.

Baggrunden for eDagbogen

eDagbogen er resultatet af et forskningsprojekt, som har undersøgt, hvordan det opleves at være gravid diabetiker. I forbindelse med forskningsprojektet har der været udført en række studier af behandlingen på ambulatoriet og der er lavet interviews med gravide diabetikere i deres eget hjem.

Hovedpartnerne i projektet har været Aarhus Universitet, Logica (tidligere WM-Data) og Polycom (tidligere KIRK telecom), samt Skejby Sygehus. Projektet er tværfagligt og involverer både sundhedsfagligt personale, antropologer og dataloger. Forskerne fra universitetet er tilknyttet Centre for Pervasive Healthcare. Du kan læse om centet på www.pervasivehealthcare.dk og du kan se nogle af nøglepersonerne nedenfor:

Persongalleri

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Thomas Riisgaard, ph.d. i datalogi og post doc

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Stinne Ballegaard, mag.art i etnografi og ph.d. studerende

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Rikke Aarhus, cand.mag i etnografi og videnskabelig assistent

Carsten, B.A i datalogi og studenterprogrammør

Tobias, B.A i datalogi og studenterprogrammør

Appendix D: Statements of informed consent

ElderTech projektet

Erklæring om samtykke

Undertegnede erklærer hermed, at de [antal] vedlagte billeder taget af ____ i mit private hjem i ________________ [dato eller periode] må benyttes til illustrationer i forbindelse med formidling af forskning, f.eks. artikler publiceret i forskningsøjemed af Aarhus Universitet.

____________________________ ________________________

(Navn og adresse) (Underskrift)

SundtHjem

Erklæring om samtykke

Undertegnede erklærer hermed, at de _____ (antal) vedlagte billeder taget af _______ (person) i mit private hjem (sted) d. _______ må benyttes til illustrationer i forbindelse med formidling af forskning, f.eks. artikler publiceret i forskningsøjemed af Aarhus Universitet.

____________________ ________________________________

(Navn og adresse) (Dato og underskrift)

SundtHjem projektet

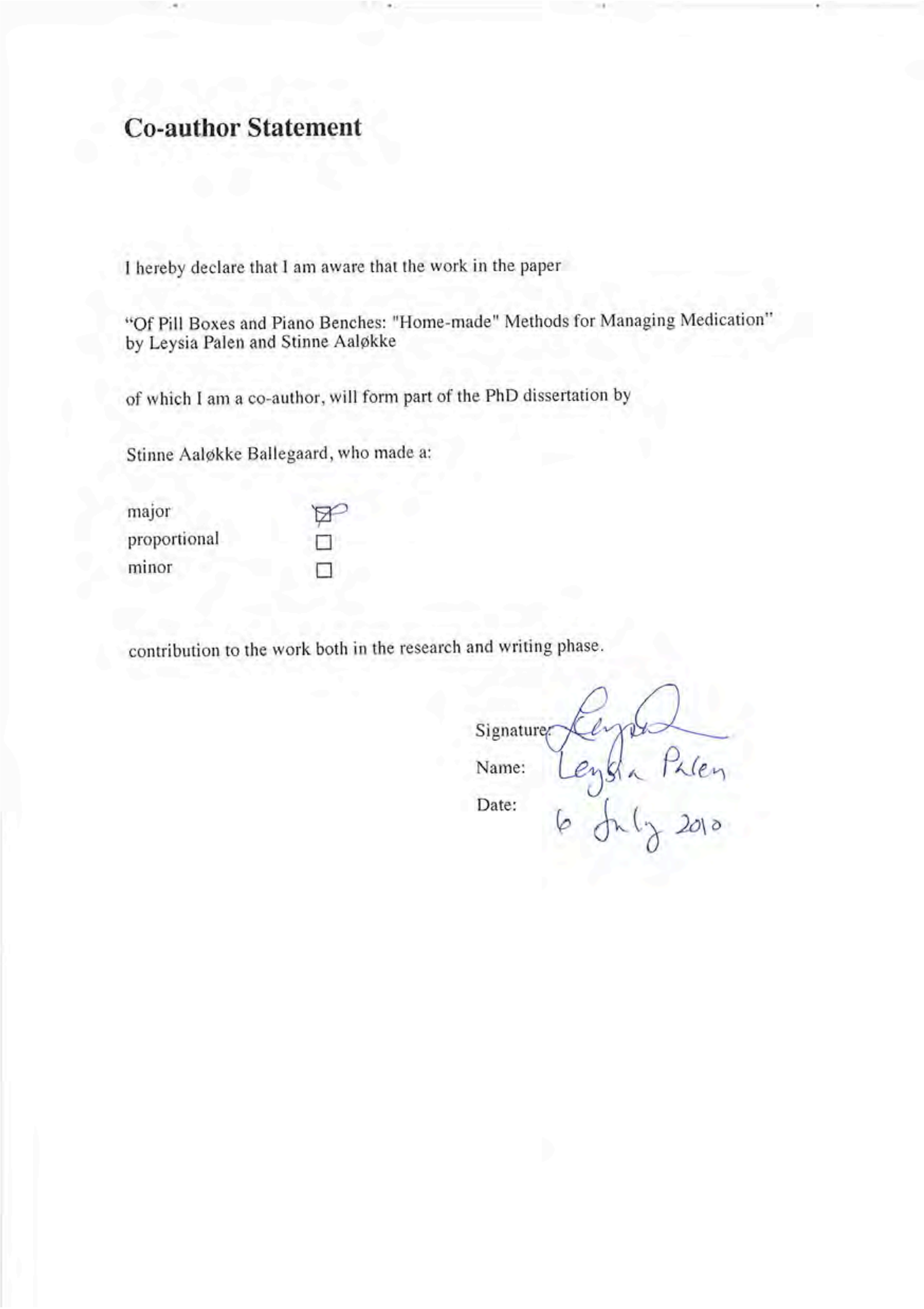
Samtykkeerklæring: Videooptagelser og billeder

Forskning og formidling

Jeg, ____ (navn), erklærer herved, at videooptagelser og stillbilleder taget i forbindelse med SundtHjem (projekt) på Skejby Sygehus (sted) 2007-2008 (dato) må benyttes i forbindelse med forskning og formidling, af medarbejdere tilknyttet Centre for Pervasive Healthcare. Billeder og videooptagelser omfatter konsultationer med gravide diabetikere samt diverse workshops.

Navn og Adresse	Dato og Underskrift
______________________________	______________________________
______________________________	______________________________
______________________________	

Appendix E: Co-author statements



Co-author Statement

I hereby declare that I am aware that the work in the paper

"Of Pill Boxes and Piano Benches: "Home-made" Methods for Managing Medication"
by Leysia Palen and Stinne Aaløkke

of which I am a co-author, will form part of the PhD dissertation by

Stinne Aaløkke Ballegaard, who made a:

major ☒
proportional ☐
minor ☐

contribution to the work both in the research and writing phase.

Signature:
Name: Leysia Palen
Date: 6 July 2010

Co-author Statement

I hereby declare that I am aware that the work in the paper

"Healthcare in Everyday Life. Designing Healthcare Services for Daily Life" by Stinne Aaløkke Ballegaard, Thomas Riisgaard Hansen & Morten Kyng

of which I am a co-author, will form part of the PhD dissertation by Stinne Aaløkke Ballegaard, who made a:

major ☒
proportional, (33 %) ☐
minor ☐

contribution to the work both in the research and writing phase.

Signature:
Name: MORTEN KYNG
Date: 26.08.10

Co-author Statement

I hereby declare that I am aware that the work in the paper

"Healthcare in Everyday Life. Designing Healthcare Services for Daily Life" by Stinne Aaløkke Ballegaard, Thomas Riisgaard Hansen & Morten Kyng

of which I am a co-author, will form part of the PhD dissertation by Stinne Aaløkke Ballegaard, who made a:

major ☒
proportional, (33 %) ☐
minor ☐

contribution to the work both in the research and writing phase.

Signature:
Name: Thomas R. Hansen
Date: 9/7-10

Co-author Statement

I hereby declare that I am aware that the work in the paper

"The eDiary: Bridging home and hospital through healthcare technology" by Rikke Aarhus, Stinne Aaløkke Ballegaard, and Thomas Riisgaard Hansen

of which I am a co-author, will form part of the PhD dissertation by

Stinne Aaløkke Ballegaard, who made a:

major ☐
proportional, (33 %) ☒
minor ☐

contribution to the work both in the research and writing phase.

Signature:	Signature:
Name: Thomas R Hansen	Name: RIKKE AARHUS
Date: 7/5 09	Date: 7/5-2009

Stinne Ballegaard
7/5-09

Co-author Statement

I hereby declare that I am aware that the work in the paper

Negotiating Boundaries: Managing Disease at Home by Rikke Aarhus and Stinne Aaløkke Ballegaard

of which I am a co-author, will form part of the PhD dissertation by

Stinne Aaløkke Ballegaard, who made a:

major ☐
proportional ☒
minor ☐

contribution to the work both in the research and writing phase.

Signature:
Name: RIKKE AARHUS
Date: 28.08.2010

Co-author Statement

I hereby declare that I am aware that the work in the paper

"HomeHealthTour: A method for studying health and disease in the home in a participatory design process" by Rikke Aarhus and Stinne Aaløkke Ballegaard

of which I am a co-author, will form part of the PhD dissertation by

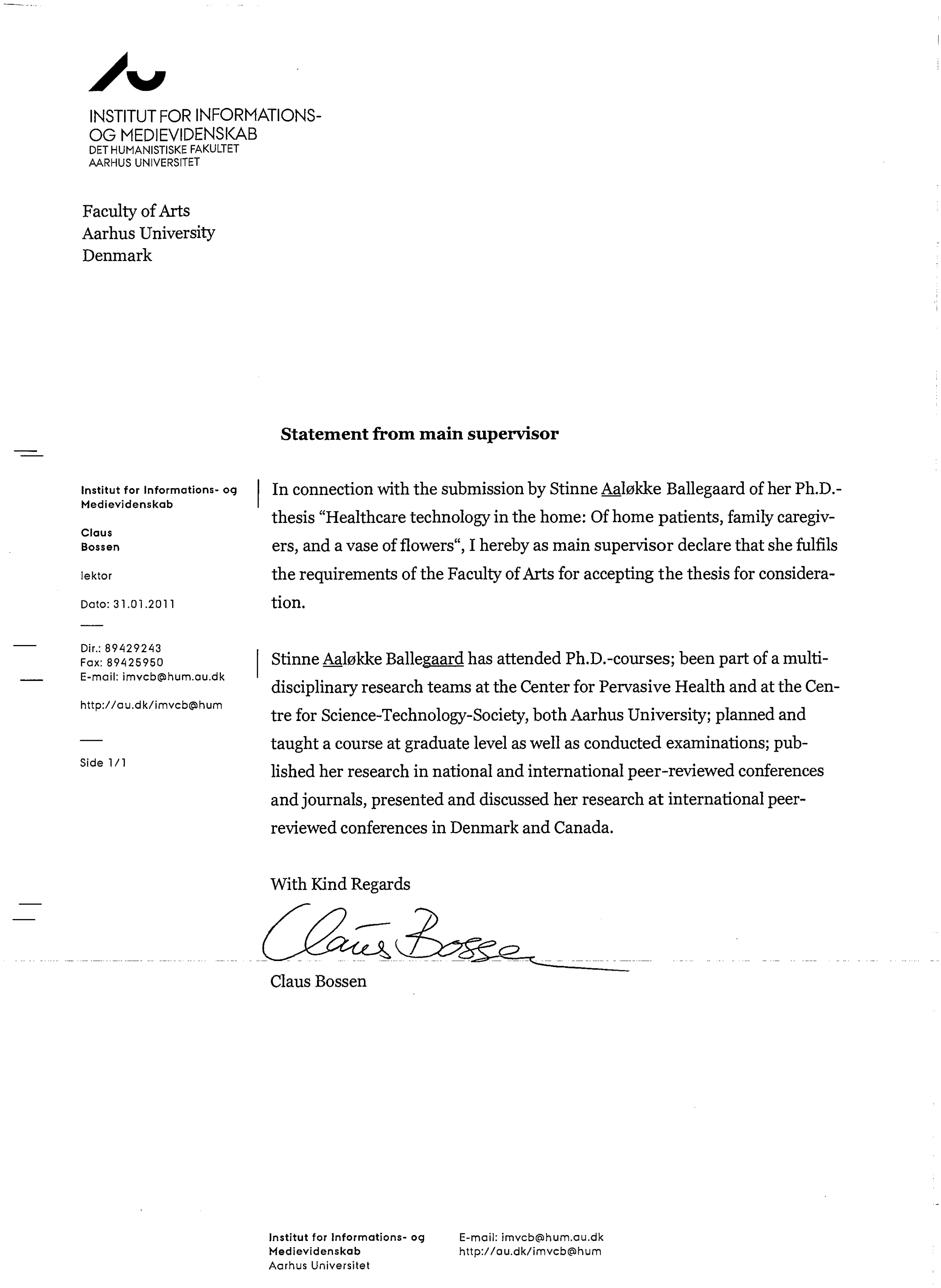
Stinne Aaløkke Ballegaard, who made a:

major ☐
proportional ☒
minor ☐

contribution to the work both in the research and writing phase.

Signature:
Name: RIKKE AARHUS
Date: 28.08.10

Appendix F: Statement from main supervisor



INSTITUT FOR INFORMATIONS-
OG MEDIEVIDENSKAB
DET HUMANISTISKE FAKULTET
AARHUS UNIVERSITET

Faculty of Arts
Aarhus University
Denmark

Statement from main supervisor

Institut for Informations- og Medievidenskab

Claus
Bossen

lektor

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Side 1/1

In connection with the submission by Stinne Aaløkke Ballegaard of her Ph.D.-thesis "Healthcare technology in the home: Of home patients, family caregivers, and a vase of flowers", I hereby as main supervisor declare that she fulfils the requirements of the Faculty of Arts for accepting the thesis for consideration.

Stinne Aaløkke Ballegaard has attended Ph.D.-courses; been part of a multi-disciplinary research teams at the Center for Pervasive Health and at the Centre for Science-Technology-Society, both Aarhus University; planned and taught a course at graduate level as well as conducted examinations; published her research in national and international peer-reviewed conferences and journals, presented and discussed her research at international peer-reviewed conferences in Denmark and Canada.

With Kind Regards

Claus Bossen

Claus Bossen

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