

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-teleconsultations. 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 week¹. 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

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

midwives, a diabetes doctor, a dietician and two nurses) participated in these workshops.

Dates	BLOOSUKKER DOKUMENTERINGSBOK														BEMERKNINGER	
	PROVE 2		PROVE 3		PROVE 4		PROVE 5		PROVE 6		PROVE 7		REINSLING	Regulering blod-sukker		
	tid	mmol/l	tid	mmol/l	tid	mmol/l	tid	mmol/l	tid	mmol/l	tid	mmol/l				
8/7	5 ⁰⁰	4,7	8 ⁰⁰	5,1	10 ³⁰	5,7	14 ⁰⁰	4,5	19 ⁰⁰	10,8	21 ⁰⁰	5,1	22 ⁰⁰	6,8		
9/7	5 ⁰⁰	1,5	8 ⁰⁰	2,9	12 ³⁰	14,9		4,5	17 ⁰⁰	1,6	19 ⁰⁰	13,1				
10/7	9 ⁰⁰	3,1		12 ⁰⁰	2,4	18 ⁰⁰	6,2	8 ⁰⁰	12,0	20 ⁰⁰	8,2	21 ⁰⁰	6,9			
11/7	7 ⁰⁰	1,9	10 ⁰⁰	7,9	13 ⁰⁰	9,3	19 ⁰⁰	13,2		20 ⁰⁰	6,4	22 ⁰⁰	8,4			
12/7	7 ⁰⁰	2,0		12 ⁰⁰	7,5	15 ⁰⁰	4,5	18 ⁰⁰	2,6	20 ⁰⁰	15,2	22 ⁰⁰	12,2		19 mat ins. + 6 ins. morgen	
13/7			10 ⁰⁰	12,8	14 ⁰⁰	18,4	16 ⁰⁰	5,4	19 ⁰⁰	5,1	21 ⁰⁰	9,9			+ 6 ins. morgen	
14/7	7 ⁰⁰	1,6	9 ⁰⁰	7,4	11 ⁰⁰	5,1	14 ⁰⁰	7,2	18 ⁰⁰	2,6	20 ⁰⁰	14,1	23 ⁰⁰	5,6		+ 6 ins. morgen
15/7	2 ⁰⁰	2,6		15 ⁰⁰	7,8	15 ⁰⁰	3,8	18 ⁰⁰	12,3	20 ⁰⁰	3,8				+ 6 ins. morgen	
16/7	5 ⁰⁰	2,8	12 ⁰⁰	5,6		14 ⁰⁰	5,7	18 ⁰⁰	2,9	19 ⁰⁰	6,2	23 ⁰⁰	14,5		+ 6 ins. kl. 14.00 + mat kl. 01.00	
17/7	5 ⁰⁰	2,2	8 ⁰⁰	2,2	11 ⁰⁰	9,2	12 ⁰⁰	3,0	18 ⁰⁰	5,9	19 ⁰⁰	12,9	21 ⁰⁰	13,1	22 ⁰⁰	9,2 mat kl. 1.30 0,15 7 + 6 ins. kl. 9.00
18/7	6 ⁰⁰	2,7	8 ⁰⁰	10,4	10 ⁰⁰	5,2	15 ⁰⁰	6,2	17 ⁰⁰	6,6	20 ⁰⁰	8,1	23 ⁰⁰	5,9		
19/7	6 ⁰⁰	1,8	9 ⁰⁰	9,8												

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 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

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

DATE	Før morgenmad		1½ time efter		Før frokost		1½ time efter		Før aftenmad		1½ time efter		Før sengetid		Om natten		Kommentarer					
	Kl.	BS	Insulin	Kl.	BS	Insulin	Kl.	BS	Insulin	Kl.	BS	Insulin	Kl.	BS	Insulin	Kl.		BS				
1/10	06:30	18,1		09:00	8,2		12:00	6,9		14:30	5,8		17:30	8,3		20:00	9,6		21:00	14,8		Syg 10^A-2-7-2-7-2-11^A
2/10	06:00	18,2		09:00	5,4		12:00	6,7		17:30	8,7		21:30	9,1					21:30	9,1		10^A-9-7-8-11^A
3/10	07:00	8,0		09:00	3,9		12:30	7,4		14:30	5,2		17:30	5,1		20:00	4,7		21:30	6,6		10^A-8-7-7-11^A
4/10	8:00	8,2					12:00	4,9		14:00	4,4		17:30	3,3		20:00	3,1		21:30	10,6		10^A-8-7-7-12y^A
5/10	08:00	6,2					12:00	9,7		14:30	6,2		18:00	15,4		20:00	11,2		21:30	8,6		10^A-8-8-2-9-12^A
6/10	07:00	3,3		09:00	9,2		11:20	10,2		14:30	3,3		17:30	6,9		20:00	5,0		21:00	4,6		2,00-4,9. 10^A-7-8-8-2-12^A
7/10	07:00	5,1		09:00	8,2		12:00	9,2		18:00	9,1		18:30	13,6		20:00	9,4					10^A-8-8-3-8-12^A
8/10	06:30	5,4		09:30	3,3		11:30	9,1		14:00	3,6		17:30	5,7		20:00	5,4					10^A-8-8-8-2-8
9/10	06:00	8,3		09:30	17,4		12:30	2,7		14:30	2,4		17:30	9,4		19:30	2,4		21:30	6,6		10^A-8-8-8-12^A
10/10	06:30	6,4		09:30	6,7		12:30	5,8		14:30	2,8		18:00	6,5		20:00	1,9					10^A-8-8-8-12^A
11/10	07:30	5,3		10:00	6,3		11:30	6,0											21:30	5,7		
12/10	06:30	11,4					12:30	12,3														

Screenshot 1

Screenshot 2

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.

		<i>Obstetrician</i>	<i>Diabetes doctor</i>	<i>Mid-wife</i>	<i>Scanning</i>	<i>Dietician</i>	<i>Tele-consultation</i>
<i>Martha</i>	13-Nov-08	X	X				
	26-Nov-08						X
	27-Nov-08	X	X		X		
<i>Vicky</i>	13-Nov-08		X	X			
	26-Nov-08						X
	27-Nov-08	X	X		X	X	
<i>Emma</i>	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



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

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*

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.

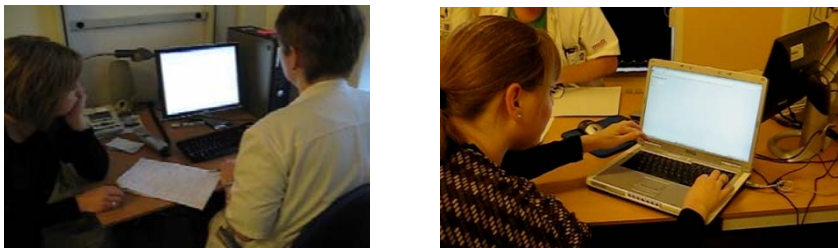


Figure 5. Left picture: Using hospital computer the doctor controls the keyboard and mouse, leaving Vicky as a spectator. Right picture: Martha logs on the dedicated computer to use the eDiary in the consultation. Behind the dedicated computer is the computer of the healthcare provider.

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 losing 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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References

- AccuCheck: (Accessed on March 1st 2009) http://www.accu-check.com/us/rewrite/content/en_US/2.4:40/article/ACCM_general_article_2549.htm
- Alonzo, A. (1979): 'Everyday Illness Behavior: A Situational Approach to Health Status Deviations'. *Social Science and Medicine*, 13A, 4, June 1979, p. 397-404
- Ballegaard, S., Aa., Aarhus, R. (forthcoming 2009): 'Teknologiers mellemkomst i ambulant behandling og egenomsorg' [The intervention of technologies in ambulant treatment and self-care: the case of pregnant women with diabetes], in *Tidsskrift for Forskning i Sygdom og Samfund* [Journal for research in sickness and society].
- Ballegaard, S. Aa., Hansen, T. R., and Kyng, M. (2008): Healthcare in everyday life: designing healthcare services for daily life. In *Proceeding of the Twenty-Sixth Annual SIGCHI Conference on Human Factors in Computing Systems*. CHI '08. ACM, New York, NY, 1807-1816.
- Bardram, J., Bossen, C., and Thomsen, A. (2005): Designing for transformations in collaboration: a study of the deployment of homecare technology. *Proceedings of the 2005 international ACM SIGGROUP conference on Supporting group work*, pages 294-303, New York, NY
- Clausen, T.D., Mathiesen, E., Ekbom, P., Hellmuth, E., Mandrup-Poulsen, T., Damm, P. (2005): 'Poor pregnancy outcome in women with type 2 diabetes', *Diabetes Care* 28(2), Feb. 2005, pp. 323-328.
- Danholt, P. (2008): *Interacting Bodies: Posthuman Enactments of the Problem of Diabetes*, Roskilde Universitetscenter, Roskilde
- Diabetes Logbook: (Accessed on March 1st 2009) <http://www.nesfield.co.uk/diabeteslogbookx/>
- Diabetes pilot: (Accessed on March 1st 2009) <http://www.diabetespilot.com>
- Dinesen, B. (2007): Implementation of telehomecare technology: impact on chronically ill patients, healthcare professionals and the healthcare system, *International Journal of Integrated Care*. 2007; vol. 7.
- Dourish, P. (2004): What we talk about when we talk about context. *Personal Ubiquitous Comput.* 8, 1, Feb. 2004, pp. 19-30.
- Grudin, J. (1989): 'Why groupware applications fail: problems in design and evaluation', *Office: Technology and People* 4 (3), pp. 245-264.

- Grøn L., Meinert, L., Mattingly, C. (2008): 'Kronisk hjemmearbejde. Sociale håb, dilemmaer og konflikter i et hjemmearbejdsnarrativ i Uganda, Danmark og USA' [Chronic homework. Social hope, dilemmas and conflicts in a homework narrative in Uganda, Denmark and USA], in *Tidsskrift for Forskning i Sygdom og Samfund* [Journal for research in sickness and society], Nr. 9, pp. 71-95.
- Heath, C, Luff, P. (1996): Documents and Professional Practice: "bad" organisational reasons for "good" clinical records. *Proceedings of the Conference on Computer Supported Cooperative Work*, 1996, p. 354-363
- Jensen, D.M., Damm, P., Moelsted-Pedersen, L., Ovesen, P., Westergaard, J.G., Moeller, M., (2004): 'Outcomes in type 1 diabetic pregnancies: a nationwide, population-based study'. *Diabetes Care*, 27(12), Dec 2004, pp. 2819-2823.
- Lauenborg, J., Mathiesen, E., Ovesen, P., Westergaard, J.G., Ekbom, P., Molsted-Pedersen, L., (2003): 'Audit on stillbirths in women with pregestational type 1 diabetes'. *Diabetes Care*, 26(5), May 2003, pp.1385-1389.
- Mamykina, L., Mynatt, E. D., and Kaufman, D. R. (2006): 'Investigating health management practices of individuals with diabetes', in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. CHI'06, ACM, New York, NY, pp. 927-936
- Mamykina, L., Mynatt, E., Davidson, P., and Greenblatt, D. (2008): 'MAHI: investigation of social scaffolding for reflective thinking in diabetes management', in *Proceeding of the Twenty-Sixth Annual SIGCHI Conference on Human Factors in Computing Systems* CHI '08. ACM, New York, NY, pp. 477-486.
- Mendosa: (Accessed on March 1st 2009) <http://www.mendosa.com/software.htm>
- Ministry of the Interior and Health (2003) *Handlingsplan for diabetes* [Strategic plan on diabetes]. (Accessed Oct. 31st 2008) www.sum.dk/publikationer/diabetesbeh/handlingsplan.pdf
- MyNetDiary: (Accessed on March 1st 2009) <http://www.mynetdiary.com/>
- OneTouch: (Accessed on March 1st 2009) <http://www.onetouchdiabetes.com/ultrasmart/index.html>
- Robinson, C. A. (1993) Managing Life with a Chronic Condition: The story of Normalization. *Qualitative Health Research*, vol. 3, no. 1, Feb. 1993, 6-28
- SiDiary: (Accessed on March 1st 2009) <http://www.sidiary.org/>
- Sokoler, T., Löwgren, J., Eriksen, M. A., Linde, P., and Olofsson, S. (2007): Explicit interaction for surgical rehabilitation. In *Proceedings of the 1st international Conference on Tangible and Embedded interaction*. TEI '07. ACM, New York, NY, 117-124.
- Smith, B. K., Frost, J., Albayrak, M., and Sudhakar, R. (2007): 'Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices', in *Personal Ubiquitous Comput.* 11, 4 (Apr. 2007), pp. 273-286.
- Star, S., L. & Griesemer, J. R. (1989): 'Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', in *Social Studies of Science*, 19, pp. 387-420.
- Strauss, A., Fagerhaugh, S., Suczek, B., Wiener, C. (1997): *Social organization of medical work*. Transaction Publishers: New Brunswick, New Jersey, USA
- Verhoeven, F., Gemert van, L., Dijkstra, K., Nijland, N., Seydel, E., and Steehouder, M. (2007): The Contribution of Teleconsultation and Videoconferencing to Diabetes Care: A Systematic Literature Review. *Journal of Medical Internet Research*, 9 (5). e37.