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RESEARCH-ARTICLE

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.

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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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citizen¹. 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

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 possess 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.

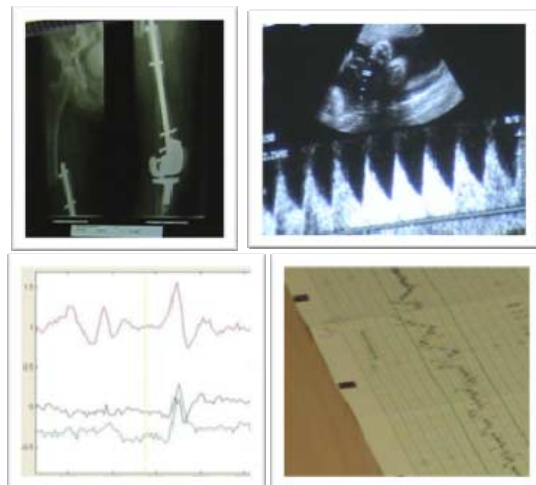


Figure 2. Top row, an x-ray of a leg and an ultrasound image and the flow in the umbilical cord of the fetus. Bottom row, accelerometer data of an elderly woman trying to answer the phone while using a walker and a cardiotocography of the fetus of a pregnant woman with diabetes.

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.

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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 line 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, where 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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