

Negotiating Boundaries: Managing Disease at Home

Rikke Aarhus

Centre for Pervasive Healthcare, Department
of Computer Science, Aarhus University
Aabogade 34, 8200 Aarhus N, Denmark
raa@cs.au.dk

Stinne Aaløkke Ballegaard

Centre for Pervasive Healthcare, Department
of Information and Media Studies, Aarhus University
Aabogade 34, 8200 Aarhus N, Denmark
imvsab@hum.au.dk

ABSTRACT

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

Author Keywords

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

ACM Classification Keywords

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

General Terms

Human factors, Design.

INTRODUCTION

In recent years, we have experienced an increasing move of healthcare services from the hospital to the home. The healthcare sector is under pressure in many Western countries due to demographic developments and an increase in the occurrence of chronic diseases [8]. Consequently, trends are toward increased self-care and disease management in the home [36]. This has caused an increasing focus on healthcare technology, because technology is

believed to be a vehicle for the movement. A similar tendency occurs within the fields of CHI and CSCW. Traditionally, focus has been on studying healthcare technology within a hospital setting, focusing on collaboration between healthcare providers, e.g. with focus on spatial dimensions [3, 7] and consequences of standardization, e.g. in relation to electronic patient records [4, 5, 35]. More recently, attention has been directed toward healthcare technologies used by health workers in the home [27, 29], and numerous prototype tests have been carried out in the home [6, 31]. Only few studies, however, examine the use of prototypes, e.g. tools for self-care or therapy, intended for the resident [23, 34].

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

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

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

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee.

CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.

Copyright 2010 ACM 978-1-60558-929-9/10/04...\$10.00

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

Disease management in the home: Creating order

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

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

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

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

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

METHOD

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

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

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

CONTINUUMS AND BOUNDARY WORK

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

which help us to understand how people manage their disease in the home.

The notions of continuums and boundary work

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

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

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

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

considered a private area, objects may be more visible, e.g. leaving medication and wigs on the nightstand.

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

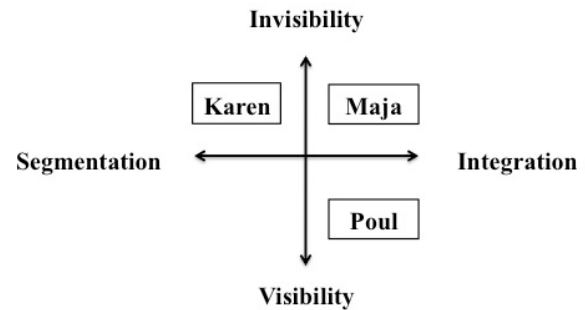


Figure 1: The two continuums form a matrix in which people’s strategies for creating order can be pointed out.

Empirical examples of movements on the continuums

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

The case of Karen

To some extent, a correlation exists between keeping management of disease *invisible* and *segmented*. Karen has suffered from a heart defect since 2001 and faces an elevated risk of having a blood clot in the brain. We met Karen and her husband, Peter, in the summer of 2008 where Karen participated in a study on home-based anti-coagulant treatment. Karen was then 63 years old. When her condition was diagnosed she came into anticoagulant therapy to prevent blood clots. Soon this therapy became self-managed and once a week Karen measures her INR value¹ with a special meter and adjusts her daily medicine intake accordingly. Peter does not take part in the weekly

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

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

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

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

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



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

The case of Maja

Maja engages in boundary work to make her management of disease *invisible* but at the same time *integrated* with other daily routines and activities. We met Maja in 2007 as she participated in a project with the aim of developing healthcare IT to support pregnant women with diabetes in their disease management. Maja is a woman in her early 30s who works as a teacher and was diagnosed with type I diabetes a few years ago. She is married to Thomas and they expect their first child. The couple likes to be well informed

and has retrieved extensive information on diabetes and pregnancy. Thomas attends the consultations at the outpatient clinic whenever possible as it is easier to remember the important information when they are two.

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

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



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

The case of Poul

Management of disease may also be highly *visible* and *integrated* in the home. Poul was 65 years old when we met him in 2005 in his two-room apartment in a sheltered housing unit for elderly people where he lives alone. He participated in a project on monitoring of blood pressure and medication intake. He has suffered from diabetes for many years and due to diabetes-related complications he has had one leg amputated and therefore uses a wheelchair. His apartment is located on the first floor but he can exit the building via an

elevator. However, he does this only once a week when going to a physiotherapist as it is demanding for him to handle the manually operated wheelchair. Inside the apartment Poul is also affected by his diminished mobility and he spends most of his time on his couch watching TV. To avoid the difficulties of moving, he has arranged his daily necessities related to his diabetes and general wellbeing at the small table next to his couch (see figure 4).

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



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

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

Negotiations in boundary work

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

In line with the call for focus on the processes regarding objects in the border area between social worlds [20, 22], we explore factors that are vital in the negotiation of boundary

work in self-care: *objects, activities, places, the character of the disease and collaboration*. We argue that these factors both affect and are affected by the negotiations involved in the boundary work to create order. On the one hand, the culturally defined meaning of objects affects how people adapt their use of the object to the specific order of the given social world. On the other hand, the use of the objects in return shapes and pushes the meaning of the objects and the order of the social world.

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

Objects

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

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

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

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

Activities

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

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

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

activity and the preference of segmentation/integration, visibility/invisibility.

Places

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

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

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

The character of the disease

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

The seriousness of a condition affects how a person can integrate or segment a disease, disclosing or hiding it. When Karen was first diagnosed with her heart defect she largely ignored it and chose a strategy toward extreme segmentation letting her prevalent notion of a good life affect her management of her disease. However, her condition proved to be too severe to be disregarded and in addition, she got a severe lung infection. The increase in seriousness together with her daughter's persistence forced her to reconsider her worldview and behavior while still aiming to segment it from other activities. Likewise, Maja experienced a pathological

progression in her diabetes when she got pregnant. This forced her to increase the number of daily blood glucose measurements, which made it difficult for her to fully integrate her disease management. For Maja, it was easier to treat her diabetes at home than at work. The progression of Poul's condition has affected his possibilities in life and hence in choice of strategies as he has had his leg amputated. The implication of the character of a disease thus varies over time and may take on different faces in different contexts affecting the strategies people deploy.

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

Collaboration

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

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

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

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

The interplay between factors

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

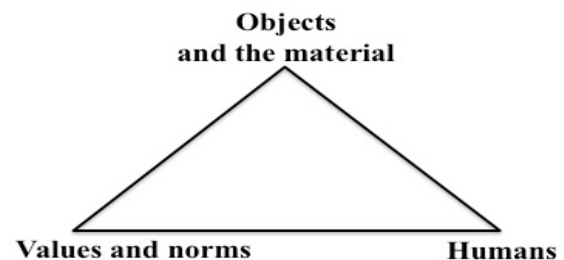


Figure 5: The triangle illustrates the interplay between objects and the material; values and norms; and humans and their actions in disease management in a home.

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

IMPLICATIONS FOR DESIGN

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

The material environment

Differences in material environment between the hospital and home could have a bearing on the design of future healthcare technology. The physical design of the hospital differs from that of the home in several ways. At the hospital the aim of the physical environment is to promote effective working procedures of healthcare providers and provide the optimal

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

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

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

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

accordance with a common wish to keep it out of sight; i.e. for humans to manipulate the objects and their attached values in the disease management (cf. figure 5).

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

The role of patient

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

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

prompts could hence be an optional feature allowing for different positions on the matrix.

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

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

CONCLUSION

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

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

The conditions and the healthcare technologies that we have focused on in this paper are rather innocuous in that the

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

ACKNOWLEDGEMENTS

We would like to thank Maja, Karen and Poul and the other participants who allowed us into their homes and shared their experiences with us. Thanks to our colleagues at Centre for Pervasive Healthcare who have participated in the projects this paper is based on. We would also like to thank ISIS Katrinebjerg and the Danish Agency for Science, Technology and Innovation for funding.

REFERENCES

1. Aarhus, R., Ballegaard, S. A., Hansen, T.R. (2009) The eDiary: Bridging home and hospital through healthcare technology. *Proceedings of eCSCW'09*, Vienna, Austria.
2. Angus, J. et al (2005) The personal significance of home: habitus and the experience of receiving long-term home care, *Sociology of Health and Illness* Vol. 27, no. 2: 161-187.
3. Bardram, J., Bossen, C. (2005) Mobility Work: The Spatial Dimension of Collaboration at a Hospital, *Computer Supported Cooperative Work* 14:131-160.
4. Berg, M. (1999) Accumulating and Coordinating: Occasions for Information Technologies in Medical Work, *Computer Supported Cooperative Work*, Vol. 8, no. 4:373-401.
5. Bossen, C. (2006) Representations at work: a national standard for electronic health records *Proceedings of CSCW '06*, Banff, Canada.
6. Brown, S. et al (2004) Care in the community, *BT Technology Journal*, vol. 22, no. 3:56-64.
7. Ciolfi, L., Fitzpatrick, G., Bannon, L. (2008) Settings for Collaboration: the Role of Place. *Computer Supported Cooperative Work* Vol. 17:91-96.
8. Davis, R., Wagner, E., Groves, T. (1999) Managing chronic disease. *BMJ* 318:1090-1.
9. Dewey, J. (1984). The quest for certainty. In: Boydston (ed.) *John Dewey: The Latter Works, 1925-1953. vol. 4: 1929*. Carbondale: University of Southern Illinois Press.
10. Douglas, M. (1966) *Purity and danger: an analysis of concepts of pollution and taboo*. Routledge & Keagan Paul: London.
11. Edwards, K., Grinter, R. (2001) At home with ubiquitous computing: seven challenges, *Proceedings of the Conference on Ubiquitous Computing*, 256-272.
12. Emerson, R., Fretz, R, Shaw L. (1995) *Writing ethnographic fieldnotes*. The University of Chicago Press: Chicago and London.

13. Estroff, S.E. (1993) Identity, Disability, and Schizophrenia. The Problem of Chronicity. In: Lindenbaum & Lock (eds.) *Knowledge, Power and Practice*. University of California Press: Berkeley.
14. Forlizzi, J., DiSalvo, C., Gemperle, F. (2004) Assistive robotics and an ecology of elders living independently in their homes. *Human-Computer Interaction*, Vol. 19, Issue 1:25-59.
15. 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 hopes, dilemmas and conflicts in Homework narratives in Uganda, Denmark, and US) *Tidsskrift for Forskning i Sygdom og Samfund (The Journal for Research in Sickness and Society)*. 9: 71-95.
16. Hacking, I. (1991) The Making and Molding of Child Abuse. *Critical inquiry*, 17 (winter): 253-288.
17. Ihde, D. (1990) *Technology and the Lifeworld: From Garden to Earth*. Bloomington: Indiana University Press.
18. Kientz, J. et al (2007) Grow and Know: Understanding Record-Keeping Needs for Tracking the Development of Young Children. *Proceedings of CHI '07*:1351-1360.
19. Larsen, J.A. (2005) Becoming mentally ill: Existential Crisis and the Social Negotiation of identity. In: Steffen et al (eds.) *Managing Uncertainty. Ethnographic Studies of Illness, Risk and the Struggle for Control*. Museum Tusulanum: Copenhagen.
20. Lee, C (2007) Boundary Negotiating Artifacts: Unbinding the routine of Boundary Objects and Embracing Chaos in Collaborative Work. *Computer Supported Cooperative Work* Vol.16: 307-339.
21. Lindahl, B., Sandman, P., Rasmussen, B. (2003) Meanings of living at home on a ventilator. *Nursing Inquiry* Vol. 10, no. 1: 19–27.
22. Lutters, W. G., Ackerman, M.S. (2007) Beyond Boundary Objects: Collaborative Reuse in Aircraft Technical Support *Computer Supported Cooperative Work* Vol 16:341-372.
23. Mamykina, L., Mynatt, E., Davidson, P., and Greenblatt, D. (2008) 'MAHI: investigation of social scaffolding for reflective thinking in diabetes management', *Proceedings of CHI '08*: 477-486.
24. Mateas, M., Salvador, T, Scholtz, J, Sorensen, D. (1996). Engineering Ethnography in the Home. *Proceedings of CHI '96*. Montreal, Canada.
25. Muur-Veeman, I. Eijkelberg, I. Spreeuwenberg, C. (2001) A discussion of the role of power, culture and structure in the development of shared care arrangements. *Journal of Management in Medicine*, vol. 15: 142-55.
26. Nippert-Eng, C.E. (1996) *Home and work. Negotiating boundaries through everyday life*. The university of Chicago Press: Chicago.
27. Nilsson, M., Hertzum, M. (2005) Negotiated rhythms of mobile work: time, place, and work schedules, *Proceedings of GROUP '05*, Florida, USA, pp 148-157.
28. Palen, L., Aaløkke, S. (2006) Of Pillboxes and Piano Benches: "Home Made" Methods for Managing Medication. *Proceedings of CSCW'06*, Banff, Canada.
29. Pinelle, D., Gutwin, C. (2003) Designing for loose coupling in mobile groups, *Proceedings GROUP'03*, Florida, USA: 75-84.
30. Pope, C, Mays, N. (eds.) (1996) *Qualitative research in health care*. Blackwell Publishing, BMJ Books: Oxford.
31. Rowan, J., Mynatt, E. D. (2005). Digital Family Portrait Field Trial: Support for Aging in Place. *Proceedings of CHI05*: 521-530.
32. Star, S. L., Griesemer, J. R. (1989) Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkley's Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science* Vol. 19: 387-420.
33. Strauss, A. L., et al (1985) *Social organization of medical work*. The University of Chicago Press: Chicago and London.
34. Tap, H. (2001) "You mean here?" – Video-mediated nurse-patient communication. *Proceedings from IFIP Interact01: HCI*: 124-131. Tokyo, Japan.
35. Toussaint, P., Berg, M. (2000) The electronic patient record as an organizational artifact, *Strategies for healthcare information systems*, pp. 76-89.
36. Wagner, E. et al. (2001) Quality improvement in chronic illness care: a collaborative approach. *The Joint Commission Journal on Quality Improvement* 27:63-80.