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

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

Disease management in the home: Creating order

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

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

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

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

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

METHOD

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

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

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

CONTINUUMS AND BOUNDARY WORK

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