



## Technologies of Compliance?

### Telecare technologies and self-management of COPD patients

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#### Abstract

In current healthcare discourses self-management has been articulated as one of the major aims of telecare technologies for chronic patients. This article investigates what forms of self-management are inscribed during the design of a telecare system for patients with COPD (Chronic Obstructive Pulmonary Diseases) and enacted during its use. Based on an analysis of the design and use of this telecare system, the paper shows that there are important differences between self-management approaches incorporated in the telecare system and the self-management strategies adopted by patients. The telecare equipment was designed in such a way that it incorporated forms of self-management based on compliance. It disciplined patients to adhere to medical treatment and an activity regime rather than involving them in shared decision-making with healthcare professionals. However, the used practices reflected self-management approaches based on collaboration and concordance between healthcare professionals and patients, including integration of their experience based knowledge. Patients domesticated the devices in such a way that they became adjusted to their daily routines and embodied experience with managing their illness<sup>1</sup>.

#### Keywords

Telecare technologies, self-management, COPD patients, design and use practices, scripts.

<sup>1</sup> See Maathuis (2015) for a more detailed analysis of the ways in which telecare technologies shape self-care of chronic patients.

## Technologies de la conformité ?

### Technologies d'auto-gestion et de télésoins des patients atteints de MPOC\*

#### Résumé

Les discours actuels sur la santé présentent l'auto-gestion comme l'un des principaux objectifs visés par les technologies de télésoins pour les patients chroniques. Le présent article examine les modes d'auto-gestion qui sont intégrés au stade de la conception d'un système de télésoins pour les patients atteints de MPOC (maladie pulmonaire obstructive chronique) et qui sont mis en œuvre lors de l'utilisation de ce système. Prenant appui sur une analyse de la conception et des usages de ce système de télésoins, cet article pointe les différences majeures qui existent entre les approches d'auto-gestion intégrées au système de télésoins et les stratégies d'auto-gestion adoptées par les patients. L'appareillage de télésoins a été conçu de manière à intégrer des modes d'auto-gestion fondés sur la conformité. Il discipline les patients afin que ceux-ci adhèrent au traitement médical et à un régime d'activité en ne participant pas à un processus de prise de décision partagée avec les professionnels de santé. L'analyse des pratiques d'utilisation donnent cependant à voir des modes de gestion fondés sur la collaboration et l'entente entre les patients et les professionnels de santé, en particulier dans le domaine de l'intégration de savoirs acquis par l'expérience. Les patients ont donc apprivoisé les appareils de manière à ce que ceux-ci s'adaptent à leur quotidien et à leur expérience physique de la gestion de leur maladie.<sup>2</sup>

#### Mots-clés

Technologies de télésoins, auto-gestion, patients atteints de MPOC, pratiques de *design* et d'utilisation, scripts.

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<sup>2</sup> Voir Maathuis (2015) pour une analyse approfondie de la manière dont les technologies du télésoin façonnent le soin de soi des patients chroniques.

## ¿Tecnologías de conformidad?

### **Tecnologías de cuidado a distancia y autogestión en pacientes con enfermedad pulmonar obstructiva crónica (EPOC)**

#### **Resumen**

En los discursos actuales de la atención de la salud se reconoce a la autogestión como una de las metas principales de las tecnologías a distancia para pacientes crónicos. Este artículo investiga qué formas de autogestión se inscriben durante el diseño de un sistema a distancia (telecuidado) para pacientes con EPOC (enfermedad pulmonar obstructiva crónica) y se representan para su uso. Basado en el análisis del diseño y uso de este sistema a distancia, el trabajo muestra que existen diferencias importantes entre los enfoques de autogestión incorporados en el sistema a distancia y las estrategias de autogestión que son adoptadas por los pacientes. El equipamiento de telecuidado fue diseñado de manera tal que incorporara formas de autogestión basadas en la conformidad. Disciplinaba a los pacientes para que éstos adhirieran a un tratamiento médico y a un régimen de actividad en lugar de involucrarlos en un proceso de toma de decisiones compartido con los profesionales de la salud. Sin embargo, las prácticas de uso reflejaron la existencia de enfoques de autogestión basados en la colaboración y en el acuerdo entre los profesionales de la salud y los pacientes, incluyendo la integración de su conocimiento basado en la experiencia. Los pacientes domesticaron a los dispositivos de forma tal que los hicieron ajustar a sus rutinas diarias y a su experiencia física de la gestión de su enfermedad.

#### **Palabras clave**

Tecnologías a distancia, autogestión, pacientes con EPOC, prácticas de diseño y uso, guiones.

## 1. Introduction

In many industrialized countries, the development of telecare technologies is considered to be one of the solutions for decreasing financial and social pressure on the healthcare system in the future (European Commission, 2007). Telecare technologies can best be described as “devices that can monitor, diagnose or treat people at home or on the move by applying advanced information and communication technologies (ICTs)” (Oudshoorn, 2011). Most telecare devices are aimed at providing care at a distance for chronic patients suffering from diabetes, heart failure or chronic pulmonary diseases (COPD) and include wireless measurement equipment, automated sensors, electronic diaries or interactive video-systems. By re-distributing tasks and responsibilities from expensive to less-expensive healthcare professionals to patients and technological devices, telecare technologies are expected to make healthcare more cost-effective and efficient. The introduction of these new technologies thus implies a transformation in the order of who cares consisting of a displacement of treatments from hospitals, clinics and expert users to domestic (or remote) environments, telecare nurses, patients, and technical devices (Mort, May & Williams, 2003; Oudshoorn, 2011; Pols, 2012). In this changing landscape of healthcare self-management by patients is often articulated as an important aim of telecare technologies.

This paper addresses the question of what forms of self-management are created during the design and use of a telecare system developed for COPD patients. COPD is short for Chronic Obstructive Pulmonary Disease and is defined as “a common preventable and treatable disease, characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients”<sup>3</sup>. Current treatment is aimed at both pharmacological and nonpharmacological interventions, although smoking cessation is the most effective treatment. Additionally, COPD patients gain from regular physical activity, distributed evenly throughout the day. This reduces the chances of hospital readmission, increases patients’ life expectancy and slows down the deterioration of lung function. Consequently, it can contribute to breaking the vicious circle leading to a reduced quality of life (Tabak, 2014, p. 10-11). Because of the related increase in healthcare expenditures, COPD patients are considered as an important target group for the development of telecare technologies. Telecare systems are expected to diminish exacerbations and hospital

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<sup>3</sup> Global Strategy for the Diagnosis, Management and Prevention of COPD, Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2014. Available from: <http://www.goldcopd.org>(accessed 05-02-2015).

(re)admissions and improve patients' quality of life (Schermer, 2009). The COPD telecare system we selected for this research can be understood as an exemplary case of this trend in developing telecare systems for these chronic patients.

The article begins with a discussion of relevant studies to elaborate the conceptual approach adopted in this research and proceeds with an explanation of the case study and methods. This is followed by an analysis of the different forms of self-management inscribed during the design of the COPD telecare system and articulated during its use. We argue that there are important differences between self-management approaches incorporated in the design of the telecare system and the self-management strategies adopted by its users.

## 2. Self-management, scripts and anti-programs

To analyze what forms of self-management are inscribed during the design of the COPD telecare system and enacted during its use, we draw on insights developed by scholars interested in self-management approaches in healthcare and the dynamics of user-technology relations. The concept of self-management is widely used in current discourses on the treatment of chronic illness<sup>4</sup>. Since the 1990s enhancing patients' ability to take responsibility for their own health has become considered as crucial in dealing with the chronic illnesses of late modernity and is encouraged by public health organizations such as the WHO (Kendall, 2001). In this context self-management is conceptualized as "an individual's ability to detect symptoms, and manage treatment, physical and psychosocial consequences, and lifestyle changes (such as exercise and diet) inherent in living with a chronic condition" (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). The increased emphasis on self-management is related to two different developments in healthcare. On the one hand, dominant discourses in healthcare policy consider patients' self-management as a way to improve clinical outcomes and as a way to enhance efficiency in the treatment of chronic diseases (Holm, 2005). On the other hand, self-management is embraced in discourses on empowerment of patients. This latter approach takes patients' perspectives rather than efficiency of healthcare as point of departure and aims to enhance patients' autonomy in making decisions about the treatment of their illness based on their embodied knowledge (Redman, 2007).

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<sup>4</sup> The concept of self-management has been introduced by Thomas Creer (1976) in his research on the rehabilitation of children with chronic diseases. Sociological studies on self-management go back to the later 1980s when Corbin and Strauss (1988) first identified all the work involved in living with chronic illness.

This dualistic view on self-management (compliance versus empowerment) has been modified by Schermer (2009) who introduced three different approaches to self-management that can be supported by telecare systems. The first form of self-management she discerns can be described as "compulsory compliance", i.e. patients take over some tasks of professionals, follow medical instructions blindly, with no place for own experiences or preferences. This might be helpful for improving patient's health but does not encourage their autonomy because they are not involved in any decision-making. The second form of self-management conceptualizes patients as "proto-professionals" (Swaan, 1990, p. 32). They learn to manage their disease in an almost professional manner for example by changing lifestyle or adapting the dosage of medication. Unlike the previous form of self-management, patients are considered as able to understand and interpret health-related bodily signals and act autonomously according to medical guidelines. With this form of self-management patients have more "executive autonomy" (Schermer, 2009, p. 689), but are not supposed to act according to their own experiences and perspectives on living with their illness. The third form of self-management can be defined as self-management based on "collaboration and concordance" with healthcare professionals. Central idea of this approach is that patients are allowed to deal with their condition based on individual preferences and insights, even if this is not the most optimal choice from a medical perspective. Enhancement of patients' own view on "quality of life" is the main principle in this self-management approach and their experience based knowledge is integrated into the prescribed treatment. With this form of self-management patients' autonomy is encouraged, with the aim to improve their health status from the patients' *individual* point of view.

Up until now, there are no empirical studies on how different forms of self-management are incorporated in the design of telecare devices and what happens to them during the use of these technologies. Do patients follow the prescribed self-management approach or do they rely on their own strategies of coping with their illness? In order to understand what forms of self-management are created by designers and enacted by users of telecare technologies, conceptualizations of user-technology relations developed in the field of Science and Technology Studies (STS) are useful, particularly the script approach. The script approach has been introduced by STS scholars to analyze how the future use of technologies is pre-structured and anticipated in their design. During the design phase developers inscribe specific programs of actions based on the expected behavior and skills of the future users in the technical devices which results in a script: the devices attribute and delegate specific competences, tasks and responsibilities to its users (Akrich, 1992). In the case of telecare technologies, the script of these devices may also pre-structure the interactions between patients and healthcare professionals and the self-management approaches implicated in these relations. Although

engineers thus play an important role in shaping the future use of technological objects, the fate of technologies is not solely in the hands of designers.

As STS scholars have pointed out, the development of technological artefacts is never a linear process from design table to end-use. The process is widely influenced by all kinds of aspects, including the influence of users (Oudshoorn & Pinch, 2003; 2008). Users do not necessarily adopt the scripts constructed by the engineers. They can accept the built-in norms and ideas of engineers about the “foreseen” use of a device, but they can also slightly modify the scripts, drastically adjust them, or even reject the programs of actions inscribed in the technology. Consequently, users may develop “anti-programs” (Latour, 1991, p. 261) by which they counter the original intentions of the design of the technology. In a similar way, scholars in cultural and media studies have emphasized how new technologies must be culturally appropriated to become useful for its intended users (Bourdieu, 1984; Miller, 1995). People will have to domesticate the technological devices to incorporate them in the practices and routines of daily life (Silverstone & Hirsch, 1992).

In this research we use these conceptualizations of user-technology relations to analyze what forms of self-management are inscribed during the design and enacted during the use of a telecare system for COPD patients.

### **3. Case study and methods**

We conducted an explorative, qualitative analysis of the design and use practices of a telecare system for COPD patients. The system studied was developed over the course of two consecutive research projects “COPDdotCOM” (2008-11) and “CoCo” aimed at the treatment of COPD (2011-13) conducted by Roessingh Research & Development (RRD) in the Netherlands. Partners in the “COPDdotCOM” project were the Telemedicine Group of the University of Twente and a hospital in Enschede, Medisch Spectrum Twente (MST). Additional partners in the CoCo project for the treatment of COPD were two physiotherapy clinics.

The analysis of the self-management forms inscribed during the design of the telecare system was based on the script approach. We focused our script analysis (Akrich, 1992) on the

prototype of the system that has been tested in May and June 2010 in the MST hospital<sup>5</sup>. In the context of this research we made a distinction between scripts of hardware and software of the telecare system because it provides a much more detailed account of the various ways in which the technology supports specific forms of self-management of patients.

For the analysis of use practices we conducted interviews (n=8) with patients who used the telecare system as part of a pilot randomized controlled trial (Tabak et al., 2014) for at least a few months. The trial took place in the MST hospital in the Netherlands from April 2012 to June 2013 and the interviews were conducted in January 2013<sup>6</sup>. The interviews included a heterogeneous group of COPD patients, ranging in age from fifty to eighty years, three of them were female and five of them were male, with different demographic backgrounds.

#### **4. Self-management forms inscribed in the telecare system**

As with other telecare technologies, enhancing self-management was identified as one of the major aims of the COPD telecare system. According to the project description, the objective was to increase patient self-management by 1) self-treatment of exacerbations and 2) coaching in daily life to improve activity behaviour<sup>7</sup>. To achieve these goals the telecare system consisted of respectively an electronic triage diary and devices for activity monitoring and feedback. To investigate the forms of self-management inscribed in these devices, we first focus on the hardware and software components of the activity monitoring and feedback devices and continue with an analysis of the electronic triage diary.

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<sup>5</sup> See website <http://www.copddotcom.nl>. Although some parts of the telecare system are developed for healthcare professionals as main users, we restricted the analysis to those parts of the technology that patients are expected to use for self-management of their disease.

<sup>6</sup> Permission for these interviews was granted by the medical ethical committee of the hospital and based on an informed-consent procedure.

<sup>7</sup> COPDdotCOM (2015). Project Summary. Retrieved on February 4<sup>th</sup>, 2015 from [http://www.copddotcom.nl/html/project\\_summary.html](http://www.copddotcom.nl/html/project_summary.html).



#### 4.1. SCRIPTS OF THE ACTIVITY MONITORING & FEEDBACK DEVICES

For monitoring and managing their activity, patients were expected to use the following hardware: an activity monitoring device (i.e., on-body sensors), a personal digital assistant (PDA) and a computer with Internet connection to access the personalized web portal of the telecare system. To collect more or less continuous data, patients had to wear the devices throughout the day; they were not supposed to switch the devices off for a period of the day. Moreover, patients were supposed to wear the on body sensors on a specific part of the body (their waist) for a reliable measurement of their bodily activity (see Figure 1).



**Figure 1:** Activity sensor and PDA (Hermens, 2010)

These specific rules about the proper use of the devices support the first form of self-management based on “compulsory compliance”. Patients have to follow these rules otherwise the devices will not be able to collect useful data. Their use does not involve any decision making by patients, nor any possibility to express their own views and preferences. Patients’ autonomy is thus not supported by the prescriptions for using these devices. The rules about frequency of use and where to wear the on-body sensors are not based on daily routines or on patients’ own judgment but rather follow the technical requirement of a minimum set of more or less continuous data that should be collected.

The design of the feedback system shows a similar reliance on the compliant form of self-management. Patients received feedback on their activity level via text messages and graphs. By touching their PDA screen patients could see a text message with the latest advice. The first sentence of the advice noted the deviation between the user's activity level and the desired activity level in terms of percentage. It was accompanied by a text message, summarizing the measured activity level, for example that the user had taken some rest or had been more active recently. A third text message on this screen contained the actual advice regarding what to do to come closer to the desired activity level (see Table 1 for a list of possible feedback messages of the activity monitoring and feedback application).

#	Message in Dutch	Message in English
1	Probeer wat te ontspannen	Try to relax
2	Gaat u even zitten	Have a seat
3	Blijf zo doorgaan!	Keep going!
4	Goedzo	Bravo
5	Prima	Excellent
6	Het gaat goed!	You are doing fine!
7	Neem even de tijd voor uzelf	Take some time for yourself
8	Pak even een leuk tijdschrift	Read a nice magazine
9	Ga even een blokje om	Go for a walk
10	Zet een lekker kopje koffie	Have a nice cup of coffee
11	Gaat u even een lekker stukje fietsen!	Go for a nice ride on your bike!
12	Maak een lekkere lange wandeling	Go for a nice long walk
13	Heeft u de krant al gelezen?	Have you read the newspaper?
14	Gaat u even 10 minuten zitten	Have a seat for 10 minutes
15	Probeer de trap een paar keer op en neer te lopen	Try to walk up and down the stairs a few times
16	Stop even met wat u aan het doen bent	Stop with what you are doing for a while
17	Misschien dat u even kunt gaan zitten?	Maybe you can have a seat?
18	Heeft u de krant van vandaag al gelezen?	Have you seen today's newspaper?
19	Heeft u nog iets uit de stad nodig?	Do you need something from town?
20	Tijd voor een sportieve wandeling!	It's time for a brisk walk!
21	Maak bijvoorbeeld een lekkere lange wandeling	Try to take a long nice walk
22	Ga bijvoorbeeld even een lekker stukje fietsen!	Go for a nice long ride on your bike!
23	Bent u vandaag al buiten geweest?	Have you already been outside today?
24	Ga even een frisse neus halen	Get some fresh air

**Table 1:** Feedback messages of the activity monitoring and feedback application for the PDA.<sup>8</sup>

<sup>8</sup> Source: Hofs, D. (2010). *Architectuur COPDdotCOM*. RRD, Enschede. (Our translation). Document received during the interview with Dennis Hofs, June 23, 2010.

Since the text messages did not involve any decision-making by patients, nor aimed at enhancing their autonomy, their format supports the “compulsory compliance” type of self-management. The script built in this part of the software presupposed a patient that follows advices blindly.

In addition to feedback via text messages patients received feedback on their activity level via graphs. The PDA screen displayed two graphs: one that indicated patients’ activity level and one symbolizing a reference activity line. A similar graph was included in the personalized web portal of the system (see Figure 2).



**Figure 2:** Screenshot of COPDdotCOM patient portal – Activity Monitoring and feedback (Hermens, 2010).

The use of graphs pre-supposes a certain education level and prioritizes a science-based representation of data as feedback to users and represented knowledge from a medical perspective only. We therefore conclude that the use of graphs implied the inscription of the “proto-professional” type of self-management. Patients were expected to take over interpretative tasks of professionals and take action accordingly, e.g. by changing their physical activity. However, patients were not stimulated to find their own way to live with their condition, nor was the knowledge of their illness enhanced by the system. This is for instance reflected by the absence of a help-file and explanations of the technical terms.

To summarize we conclude that the script of the hard- and software for enhancing the activity level of patients was predominantly based on a combination of the “compulsory compliance” and “proto-professional” types of self-management. The “collaboration and concordance” model was not supported by the script of the activity monitoring and feedback devices.

#### 4.2. SCRIPTS OF THE ELECTRONIC TRIAGE DIARY

As aforementioned, the electronic triage diary of the telecare system was designed to also support self-management, by focusing on the self-treatment of exacerbations. The actions and responsibilities inscribed in this part of the system show how the work usually conducted by health care professionals is delegated to patients and technical devices to manage their illness. Patients were instructed to fill in the diary on a daily basis by answering multiple choice questions about their health status (see Table 2).

<b>Q</b>	Did you have more complaints than normal the past 24 hours		
<b>A</b>	Yes	No	
<b>Q</b>	Did you have complaints of shortness of breath?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Did you have complaints of coughing up mucus?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	What was the color of the coughed up mucus?		
<b>A</b>	Normally	Different than normally	
<b>Q</b>	Did you have complaints of coughing?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Did you have complaints of wheezing?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Did you have complaints of a runny nose?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Did you have complaints of a sore throat?		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Have you used metered-dose inhalers		
<b>A</b>	Normal	Slightly more than normal	Clearly more than normal
<b>Q</b>	Did you have a fever the past 24 hours? (more than 38,5 degrees)		
<b>A</b>	Yes	No	

**Table 2:** Multiple choice questions for the electronic triage diary<sup>9</sup>

<sup>9</sup> Source: Hofs, D. (2010). *Architectuur COPDdotCOM*. RRD, Enschede. (Our translation). Document received during the interview with Dennis Hofs, June 23, 2010.

Patients received a minimum of one and a maximum of ten questions, depending on the response they gave to the first question (whether they experienced more complaints than normal). The use of multiple choice questions pre-structured the way patients were expected to report about their illness: they could not enter their experience with their disease in their own words. It was up to the patients to decide what complaints were normal, what color of mucus was normal or what shortness of breath was normal for their condition.

Remarkably, the electronic triage system for the self-treatment of exacerbations was called a *diary*. One would expect that a diary would enable its users to write down their feelings, emotions, or experiences in their own words. However, the script of the electronic triage diary only allowed patients to enter information about their medical status, and whether their condition was "normal" or not. There was no room for adding personal remarks. This possibility to support the "collaboration and concordance" type of self-management was not included in the system.

When patients had answered the question(s) from the electronic triage diary, the system would come up with an advice for the treatment of the patient's condition (see Table 3). Which advice was applicable to which sequence of responses depended on a computer algorithm. By using the electronic triage diary patients thus became directly responsible for their own treatment. The design of this software includes a script in which tasks that used to be done by healthcare professionals are delegated to the telecare system and patients. The electronic triage diary is made responsible for producing an anamnesis and decisions about medication, whereas patients are made responsible for changing medication.

#	Advice
1	Do not start a cure (yet).
2	Start with a prednisolone cure.
3	Continue the prednisolone cure.
4	Start a cure of antibiotics and continue the prednisolone cure.
5	Continue the cure of antibiotics and continue the prednisolone cure.
6	Continue the cure of antibiotics.
7	Contact your doctor.

**Table 3:** Possible advices of the electronic triage diary<sup>10</sup>

<sup>10</sup> Source: Hofs, D. (2010). *Architectuur COPDdotCOM*. RRD, Enschede. (Our translation). Document received during the interview with Dennis Hofs, June 23, 2010.

In addition to giving medication advice, the electronic triage diary also provided an overview of how patients previously filled in the diary in the form of a table, combined with the medication advice generated that day. This overview could also be accessed via the personalized web portal. Similar to the use of graphs for the activity monitoring and feedback application, the use of tables also pre-supposes a certain education level on the part of its users and prioritizes a science-based representation of data.

To conclude, similar to the script of the activity monitoring and feedback application, the “collaboration and concordance” form of self-management was not promoted by the electronic triage diary. Patients were not stimulated to find their own way to self-manage their condition. The use of multiple choice questions and representations of patients’ conditions in graphs and tables exemplifies how the system prioritizes the medical-expert approach to understanding and monitoring illness. Equally important, the electronic triage diary did not include any psychological or sociological aspects of living with a chronic disease. We therefore conclude that the script of the electronic triage diary was predominantly based on the “compulsory compliance” form of self-management. To a more limited extent the “proto-professional” form could be discerned, because patients had to interpret their own condition (What is normal for me?) to fill in the diary.

## 5. Self-management approaches during use practices

Given the self-management approaches inscribed in the system it becomes intriguing to follow what happened when patients were actually using the telecare system<sup>11</sup>. What forms of self-management were enacted during these use practices? To analyze these practices we combined concepts from Actor Network Theory (ANT) with concepts from Domestication Theory. While ANT focuses on how technologies shape human action by their script (Akrich & Latour, 1992), Domestication Theory focuses on how the use of technologies is shaped by interpretive frameworks rooted in daily routines or culture at large (see e.g., Oudshoorn & Pinch, 2008; Lie & Sørensen, 1996). This latter approach could also contribute to analyze how telecare technologies shape patients’ perceptions of their disease and their autonomy.

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<sup>11</sup> Before patients started using the telecare system in a medical trial they had to attend a self-management course where they were taught about the physiological and medical background of their disease and how to use the electronic triage diary.

## 6. How the telecare system shaped patients' actions

### 6.1. DOMESTICATING THE ACTIVITY MONITORING DEVICE

The ways in which patients used the activity device, including the feedback application via the PDA, provides a varied picture in use that stretches from following the script of the equipment as best as possible to non-use of the equipment. This difference in use seems to be related to the amount of trust patients have in the correct functioning of the devices. Their experiences as articulated during the interviews illustrate how four patients domesticated the newcomer. They only followed the advice included in the feedback message of the PDA when they could fit it into their daily activities:

If it is possible, I will do it. However, when I am at work, I cannot follow the advice. If it indicates that I have done too much and should take some rest during work, I cannot follow that advice (patient G, interview, January 22, 2013).

Four other patients experienced quite some difficulties using the activity monitoring devices. They developed different strategies such as following the script partially or even not using the devices at all. For two patients the activity devices did not generate feedback at all, or at least, it was not visible to them:

Yes, that is what my physiotherapist said the other day: "Have you never received a message that your activity level was too low?" I said: "Not that I know of" (patient C, interview, January 31, 2013).

Two patients who had trouble with the activity monitoring device *did* receive feedback messages but had other problems. For one patient the generated feedback was totally not in accordance with his own bodily experience of his activity:

I have the measuring device [the activity monitoring and feedback devices] right here, and it should measure movement, but to be honest, I do not have much faith in it. Well, I have been busy the whole day, but it still says...(…) The first time I got it my activity level

was at 350/400 percent, now it continuously says I am too low (patient A, interview, January 27, 2013).

Moreover, the script of the device did not match his daily life pattern. When he walked his dog at six in the morning the device did not register his activity because it only started measuring at eight in the morning. These negative experiences made this patient lose trust in the device which ultimately lead to complete non-use of this component of the activity monitoring device.

To conclude, patients' use of the activity devices can best be described by the "collaboration and concordance" type of self-management. Patients did not follow the advices generated by the activity devices blindly. They took their personal circumstances and experiences as reference to decide whether it was appropriate to follow the advice, to execute it later, or not to follow it at all. Patients thus domesticated (Lie & Sørensen, 1996; Silverstone & Haddon, 1996) the devices in various ways to fit them into their daily life.

## **6.2. APPROPRIATING THE ELECTRONIC TRIAGE DIARY**

As with the activity device, the electronic triage diary shows a variety of use practices. Although most patients tried to follow the script of the electronic triage diary concerning the filling in of the questions about their health status, there were also patients who deviated from the "daily basis" rule of the script. Some patients did not fill in the diary because of its script on *when* to complete it:

No, I think it works until 12 o'clock at night, but I am a night owl so ... sometimes I end up late before my computer, and then I'm too late to fill it in on time (patient G, interview, January 22, 2013).

These use practices illustrate a mismatch between the script of the diary and the patients' daily life pattern. Most importantly, the compliance to the medication advice varied per patient. Some patients mentioned they did not take medication without the advice of the diary, even when, according to their bodily experience, they wanted to start with a course of medication:



Q: Does it occur that you want to start taking medication, but that the system does not yet advise you to, but that you start anyway?

A: No, most certainly not. Otherwise, you should not participate in this test, I think (patient D, interview, January 22, 2013).

Other patients mentioned they listened to their body and started to take medication, even though the electronic triage diary did not (yet) advise them to:

Sometimes I start a day earlier, or else I will not make it. Even today, the system said: "Do not continue with the prednisolone," but I did start, otherwise I would not be here (patient B, interview, January 16, 2013).

Other patients again decided not to follow the advice for other reasons:

Q: Do you follow the advice of the electronic diary?

A: Not always, but when I don't I discuss this with my nurse practitioner why not.

Q: And what is the main reason?

A: Pre-dominantly my aversion against Prednisone (patient C, interview, January 31, 2013).

These patients thus acted more autonomously regarding the treatment of their illness. Although all patients acknowledged the validity of the anamnesis questions, they felt reluctant to follow the medication advice without contacting their healthcare professional first:

A: "Start a course," or "Do not start a course."

Q: And do you follow that advice?

A: Yes, this week I got advice and indeed, I felt really sick and when I got the advice to start with the treatment, I called the lung specialist and he prescribed me a course [of medication].

Q: But you do not start a course yourself when you do not feel well?

A: No, not yet, so far (patient E, interview, January 18, 2013).

Apparently, human contact is still essential for patients before making decisions. However, in the electronic triage diary, or any other component of the telecare system, there was no option to contact healthcare personnel. Some patients mentioned they had the e-mail address or cell phone number of a healthcare professional “accidentally” at their disposal and would use this to work around the script of the diary<sup>12</sup>. Adjacent to the absence of any form of communication via the telecare application the majority of the patients mentioned they missed the option to add information to the standardized responses they could enter into the electronic triage diary. Often they felt that their experience with their illness or general health condition could not sufficiently be described by answering the pre-structured questions in combination with the limited number of multiple choice answers of the diary:

I find it very unfortunate you can't add a small remark. There are a few options for a few questions: “Do you have more or less complaints of coughing?” I sneeze quite often, but I cannot make note of that anywhere (patient B, interview, January 16, 2013)

What patients mentioned as a positive aspect of using the electronic triage diary was the ability to start taking medication the minute they wanted to (either because of their own decision, or supported by the advice of the electronic triage diary). With the use of the telecare system, patients were allowed to have their medication at home before they began to feel ill, and start with a course without going through the difficult procedure of getting their medication at their disposal:

You realize that when you already have medication, and the diary says you should start, you indeed start taking them earlier, which helps to reduce complaints earlier (patient G, interview, January 22, 2013)

To sum up, the use practices of the electronic triage diary reflect a mixture of the “compulsory compliance”, “proto-professional” and “collaboration and concordance” forms of self-management since not all patients enacted the script of the telecare application in the same way. Some of them strictly followed the script, i.e., the medication advice of the diary. This group of patients can best be described as *compliant* patients since they adhered to the medical

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<sup>12</sup> For a similar analysis, see Oudshoorn (2011, p. 192; p. 206) who describes how telecare workers use the regular phone to work around the script of a telecare device for heart patients.

advice of the diary. They are compliant either because the advice matches with their own bodily feelings, or that they feel that the advice of the electronic triage diary is more important than their own assessment of their condition<sup>13</sup>. This group of patients thus interpreted the advices as an *order*. In contrast, patients who considered their own bodily feelings equally or more important than the advice of the diary interpreted the latter as an *advice*. This group can best be described as *self-conscious* patients. For these patients the use of the diary *in practice* supported the 'collaboration and concordance' form of self-management.

Comparing these use practices with patients' practices of domesticating the activity monitoring device, we can conclude that there is more at stake than trying to overcome mismatches between the script of the device and patients' daily routines. Importantly, some patients developed anti-programs because the prescribed use of medication conflicted with their embodied knowledge and experience about how their bodies reacted to specific medication. They resisted the script in which decisions about medication were delegated to the telecare system and decided to take the responsibility back into their own hands. These use practices thus illustrate how the appropriation of telecare devices may entail severe clashes between patients' needs and experiences and the medical regime inscribed in the telecare system.

## 7. Conclusions

Based on our analysis we conclude that there is a gap between what designers inscribed into the COPD telecare system and how users reacted to these inscriptions. Whereas the script analysis of the telecare devices illustrates that the "collaboration and concordance" form of self-management is not inscribed in the system, our analysis of how patients' actions were shaped by the script of the telecare system and how it was integrated in daily routines shows a different picture. Patients incorporated the use of the activity monitoring and feedback devices in their daily lives and ignored or postponed feedback advice if they did not come in handy. Moreover, patients decided to deviate from the advice of the electronic triage diary and act according to their own preferences. Additionally, the telecare system enabled patients to gain more "executive autonomy" (Schermer, 2009, p. 689) with respect to taking medicine. The use practices thus reflect that patients reacted very differently to the self-management approach inscribed in the telecare system. This is in accordance with other studies that illustrate how self-

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<sup>13</sup> So, in this sense compliance does not automatically mean less autonomy.

management can vary across socio-economic and demographic backgrounds, daily life circumstances, and patients' illness trajectory (Udlis, 2011).

The script analysis of the COPD system confirms the suggestion made by Schermer (2009) that current telecare technologies are designed in such a way that they merely support the compliant form of self-management (Schermer, 2009, p. 690). Although some instrumental tasks involved in managing illness are delegated to patients and technological devices, adherence to medical regimes is prioritized at the cost of patients' active involvement in shared decision-making. Instead of supporting patients to take responsibility for coping with their illness, the telecare system takes away responsibility from the patient. Telecare technologies thus participate in introducing specific "technologies of self" (Foucault, 1988) in which self-management is constituted as a compliant rather than a collaborative act<sup>14</sup>. This, often implicit, preference for compliant self-management approaches is in sharp contrast to the trend described in the self-management literature that emphasizes collaboration and shared decision-making as key aspects of self-management<sup>15</sup>. Based on ethnographic studies of telecare practices, Pols (2012) argues in a similar vein by suggesting that care practices supported by telecare systems can best be portrayed as "together-management" (p. 75). Whereas the term self-management seems to suggest that this kind of care is an individual endeavor, the notion of together-management portrays these care practices as a collective endeavor shaped by health-care professionals, technologies and relevant others jointly.

Reflecting on our findings we may conclude that design practices of telecare technologies do not follow this paradigmatic shift and can be portrayed as "outdated" (Schermer, 2009). The telecare system investigated in this paper disciplined patients to adhere to medical treatment and an activity regime rather than involving them in shared decision-making with healthcare professionals based on their own experience-based knowledge. The technology thus contributed to reducing the "self" in self-management. However, instead of blaming designers for not keeping up with the literature we think it is more productive to talk about a missed opportunity. Given the inherent flexibility of ICTs, telecare devices can be designed in such a way that they incorporate multiple scripts supporting various forms of self-management<sup>16</sup>. For designers the challenge is to embrace this flexibility and design systems that anticipate the

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<sup>14</sup> See Oudshoorn (2011) for a similar conclusion about a telecare system for heart-failure patients.

<sup>15</sup> The latter approach has been developed because patient-compliant approaches did not result in improved clinical outcomes (Koch et al., 2004).

<sup>16</sup> See Maathuis, Jones and Oudshoorn (2015) for a guideline to develop scenario's enabling designers to anticipate and reflect on which self-management approach is most appropriate to incorporate in the design of a telecare system.

various ways in which patients relate to their bodies and medical treatments and support a more mutual relationship between patients and healthcare professionals. This paper illustrates that healthcare professionals and patients expect telecare devices to act this way.

## Bibliography

- Akrich, M., & Latour, B. (1992). A summary of a convenient vocabulary for the semiotics of human and nonhuman assemblies. In W.E. Bijker & J. Law (Eds.) *Shaping technology/building society: Studies in socio-technical change* (pp. 259-264). Cambridge, MA: MIT Press.
- Akrich, M. (1992). The description of technical objects. In W.E. Bijker & J. Law (Eds.), *Shaping technology/building society: Studies in socio-technical change* (pp. 205-224). Cambridge, MA: MIT Press.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient education and counseling*, 48(2), 177-187.
- Bourdieu, P. (1984). *Distinction: A Social Critique of the Judgement of Taste*. London: Routledge.
- Corbin, J. M., & Strauss, A. (1988). *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco, CA: Jossey-Bass.
- Creer, T. L., & Christian, W. P. (1976). *Chronically ill and handicapped children: Their management and rehabilitation*. Champaign, IL: Research Press.
- Effing, T., Kerstjens, H., Van der Valk, P. D. L. P. M., Zielhuis, G., & Van Der Palen, J. (2009). (Cost)-effectiveness of self-treatment of exacerbations on the severity of exacerbations in patients with COPD: The COPE II study. *Thorax*, 64(11), 956-962.
- European Commission (2007). *Communication on Telemedicine Benefits of Patients, Healthcare Systems and Society*. Brussels: European Commission.
- Evans, H. M., (2007). Do patients have duties? *Journal of Medical Ethics*, 33, 689-94.
- Foucault, M. (1988). Technologies of self. In Martin, L. H. Gutman, H. and Hutton P. H. (Eds.) *Technologies of self: A seminar with Michel Foucault* (pp. 16-49). London: Tavistock Publications.
- Hermens, H. (2010). COPDdotCOM: Innovatieve coaching van COPD patiënten [COPDdotCOM: Innovative coaching of COPD patients]. Presentation at the 4e COPD ketenzorg congres, Utrecht, The Netherlands, November 15, 2010. Retrieved 26<sup>th</sup> April from <http://www.copddotcom.nl/html/publications.htm>.
- Holm, S. (2005). Justifying patient self-management—evidence based medicine or the primacy of the first person perspective. *Medicine, health care and philosophy*, 8(2), 159-164.
- Kendall, L. (2001). *The future patient*. London: Institute of Public Policy Research.

- Koch, T., Jenkin, P., & Kralik, D. (2004). Chronic illness self-management: Locating the "self". *Journal of Advanced Nursing*, 48, 484-92.
- Latour, B. (1991). Technology is society made durable. In Law, J. (Ed.) *A Sociology of monsters: Essays on power, technology and domination*. London: Routledge.
- Lie, M., & Sørensen, K. H. (Eds.). (1996). *Making technology our own? Domesticating technology into everyday life*. Oslo: Scandinavian University Press.
- Maathuis, I. J. H. (2015). *Technologies of compliance? Telecare technologies and self-management of chronic patients*. (Doctoral dissertation). University of Twente, Enschede, the Netherlands.
- Maathuis, I. J. H., Jones, V. M. and Oudshoorn, N. E. J. (2015). Telecare and self-management: a guideline for anticipating future care in scenario-based design. *Interaction Design and Architecture(s) Journal - IxD&A*, 23, 142-159.
- Miller, D. (1995). *Acknowledging consumption. A Review of new studies*. New York and London: Routledge.
- Mort, M., May, C. R., & Williams, T. (2003). Remote doctors and absent patients: acting at a distance in telemedicine? *Science, Technology & Human Values*, 28(2), 274-295.
- Oudshoorn, N. (2011). *Telecare technologies and the transformation of healthcare*. Basingstoke, UK: Palgrave Macmillan.
- Oudshoorn, N., & Pinch, T. (2003). *How users matter: The co-construction of users and technology*. Cambridge, MA: MIT Press.
- Oudshoorn, N., & Pinch, T. (2008). User-Technology Relationships: Some Recent Developments. In E. J. Hackett, O. Amsterdamska, M. Lynch, & J. Wajcman (Eds.) *The handbook of science and technology studies* (pp. 541–566). Cambridge, MA: MIT Press.
- Pols, J. (2012). *Care at a distance: On the closeness of technology*. Amsterdam, the Netherlands: Amsterdam University Press.
- Redman, B.K. (2007). Responsibility for control: Ethics of patient preparation for self-management of chronic disease. *Bioethics*, 21(5), 243-250.
- Schermer, M. (2009). Telecare and self-management: Opportunity to change the paradigm? *Journal of Medical Ethics*, 35(11), 688-691.
- Silverstone, R., & Hirsch, E. (1992). *Consuming technologies: Media and information in domestic spaces*. London: Routledge.

Silverstone, R., & Haddon, L. (1996). Design and the domestication of ICTs: Technical change and everyday life. In R. Mansell & R. Silverstone (Eds.). *Communicating by design: The politics of information and communication technologies* (pp. 44-74). Oxford: Oxford University Press.

Swaan, de A. (1990). *The management of normality: Critical essays in health and welfare*. London: Routledge.

Tabak, M. (2014). *Telemedicine for patients with COPD: New treatment approaches to improve daily activity behaviour*. (Doctoral dissertation). University of Twente, Enschede, the Netherlands.

Tabak, M., Brusse-Keizer, M., van der Valk, P., Hermens, H., & Vollenbroek-Hutten, M. (2014). A telehealth programme for self-management of COPD exacerbations and promotion of an active lifestyle: A pilot randomized controlled trial. *International Journal of Chronic Obstructive Pulmonary Disease*, 9, 935-944.

Udlis, K.A. (2011). Self-management in chronic illness: Concept and dimensional analysis. *Journal of Nursing and Healthcare of Chronic Illness*, 3, 130-139.

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### Related publications:

Oudshoorn, N. (2011). *Telecare Technologies and the Transformation of Healthcare*. Basingstoke, UK: Palgrave Macmillan.

Oudshoorn, N. (2011) How Places Matter. Telecare Technologies and the Changing Spatial Dimensions of Healthcare. *Social Studies of Science*, Volume 42, Issue 1, 121-142.