Interaction Design and Architecture(s) Journal - IxD&A, N.23, 2014, pp. 142-159

Telecare and self-management: a guideline for anticipating future care in scenario-based design

Ivo Maathuis[1], Valerie M Jones[2], Nelly Oudshoorn[1]

[1] Department of STePS, Faculty of Behavioural, Management and Social Sciences, University of Twente, PO Box 217, 7500 AE Enschede, The Netherlands, i.j.h.maathuis@utwente.nl, n.e.j.oudshoorn@utwente.nl

[2] Telemedicine Group, Biomedical Signals and Systems, Faculty of Electrical Engineering, Mathematics and Computer Science, University of Twente, PO Box 217, 7500 AE Enschede, The Netherlands, v.m.jones@utwente.nl

Abstract. An important aim of telecare technologies for chronic patients is supporting self-management. Although patient involvement is crucial for successful implementation, any adaptation of telecare systems to needs of users requires explicit reflection regarding which form of self-management it should support. Scenario-based methods (SBDs) are proposed to involve users in the earlier phases of development. This paper aims to extend SBDs by incorporating explicit exploration of self-management forms. We first analyzed what self-management forms were inscribed in the design of a telecare system for COPD patients. These were mainly based on compliance to medical treatment. However, our study shows that many patients thrive better on self-management based on cooperation and concordance with healthcare professionals. To overcome this discrepancy between design and use practices we developed a guideline enabling designers to anticipate and reflect on which form of self-management is desirable to incorporate in the design of telecare technologies for chronic patients.

Keywords: telecare technologies, self-management, scenario based design (SBD)

1. Introduction

An important aim of telecare technologies is to support patient self-management. Individuals are increasingly expected to take more responsibility for their own health with the objectives of reducing costs and increasing patient autonomy [1, 2]. Although patient involvement is crucial for the successful implementation of telecare services, techniques for collecting data about user needs often focus on the later phases of development. Scenario-based methods (SBDs) have been used to explore the impact, usability, and acceptance of current and future imagined telemedical applications. In a previous study SBDs were proposed as a way to involve users in the earlier phases of development of teletreatment services [3]. This paper aims to extend SBDs by incorporating explicit exploration of self-management forms. The concept of

self-management is widely used in current studies on the treatment of chronic illness. 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" [4]. Recent medical ethics literature distinguishes three dominant forms of self-management that can be supported by telecare systems (Box 1) [5].

Box 1. Three forms of self-management

The first form of self-management can be described as 'compulsory compliance'; patients take over some practical tasks of professionals and follow medical instructions blindly. It does not involve any decision making by the patient, nor are patients' personal views or preferences involved. The second form considers patients as 'proto-professionals'; patients learn to manage their disease in an almost professional manner, by following medical guidelines. The third form of self-management can be described as self-management based on cooperation and concordance with healthcare professionals, including integration of patients' experience based knowledge into the prescribed treatment. The main principle in this form of self-management is enhancement of patients' quality of life.

Given the diversity of self-management models, any adaptation of a telecare system to the needs of future users requires explicit reflection regarding which form of self-management it should support. The paper therefore develops a guideline to extend SBDs. The guideline can be used to develop scenarios that enable designers to anticipate and reflect on which form of self-management is desirable to incorporate in the design of a telecare service. We begin with a discussion of relevant studies on SBDs in which we explain the aim of the study and continue with an explanation of our case study and of the methods used. This is followed by an analysis of the self-management forms inscribed in a telecare system for patients suffering from Chronic Obstructive Pulmonary Disease (COPD) developed in the Netherlands. Based on this analysis, we develop a guideline for anticipating self-management forms during early phase development of telecare services for chronic patients.

2. Scenarios and scenario based design

Below we discuss the main approaches to scenario-based design relevant to this research and explain the aim of this study.

2.1 Scenarios

Scenarios have been described as "stories about people and their activities" [7] and "Narrative descriptions of envisioned usage episodes" [8]. They are used in software development to "explicitly envision and document typical and significant user activities early and continuingly in the development process" [9]. A scenario involves a setting (which may be explicit or implicit), actors, goals, and sequences of actions and events. Sets of user interaction scenarios can be used to make explicit the implicit assumptions about (human) actors and the tasks they perform that are "implicit in systems and applications" [7].

In 2000 the EC IST Advisory Group (ISTAG) launched a "scenario planning exercise" as a way to get an impression of the future in order to stimulate research into Ambient Intelligence (AmI), and as "a tool to help us invent our future" [10]. Four ISTAG scenarios were developed to offer "provocative glimpses of futures that can (but need not) be realized" [10]. A scenario features a persona (e.g. *Maria: Road Warrior*) and has a script that is used to envision future living and to derive the technological, societal, economic and market steps needed to reach that state. This concept of scenarios has informed many of the scenarios developed subsequently in healthcare and other domains.

2.2 Scenario-based design

Scenario Based Design (SBD) has been defined as "a family of techniques in which the use of a future system is concretely described at an early point in the development process", shifting focus away from system functionality towards how the system will be used by (human) actors [8]. SBD has been applied to support participatory design during requirements engineering [11] and HCI design (e.g., usability engineering [12]), software architecture evaluation [13], and software specification [14]. In requirements engineering, for example, scenarios featuring (fictional) users have be used as a vehicle for participatory design. A scenario tells a story of one or more users using the system in order to explain and illustrate a use case of the intended system. Designers and users can work together using a set of such scenarios to explore aspects of the putative system and gain feedback on functionality and HCI design. The fictional users or personas are usually named characters who have been created to represent different classes of user. According to Carroll SBD should be considered as complementary to analytical design approaches, which attempt to control the complexity and fluidity of the design process by problem decomposition and by filtering information [7]. In contrast SBD utilizes the complexity and fluidity of the design process by exploring the problem domain from different viewpoints and by "interacting intimately with the concrete elements of the situation" in order to "support reasoning about situations of use, even before those situations are actually created". Hence it supports reflection on and exploration of the problem space which supports our intention to explicitly encapsulate and explore management forms prospectively.

2.3 Scenario-based design in the development of telemedical applications

SBD has been applied in a variety of ways in the development of telemedical applications. Scenarios were used in the design of guideline-based clinical decision support systems for gestational diabetes mellitus patients [15] and atrial fibrillation patients [16]. Other examples are: design of collaborative working support tools in a hospital environment [17], generation of new project ideas in telehealth applications research and support of design, implementation, and evaluation [18], and in evaluation, e.g., system evaluation with patients in a laboratory setting [19], and assessment of user interests and expectations about possible future home telehealth services supporting independent living for the elderly [20]. SBD has been used to support user-centered design, for example in telecardiology [21], as part of a

standards-based operational framework for patient-centered design of self-help tools [22] and, in the context of Goal-Directed Design, in the development of a heart failure telemonitoring and assessment system [23].

In user requirements elicitation, Widya [24] applied SBD in early phase requirements elicitation for teletreatment services for chronic pain, with users and other stakeholders. Huis In 't Veld et al [3] adapted the People-Activities-Context-Technology (PACT) framework together with principles of evidence-based medicine to develop a guideline for constructing scenarios to describe new teletreatment services. This approach was further developed and applied in a telehealth application to support behavioral change toward healthier lifestyle [25] and twelve scenarios were used to illustrate future visions of AmI applied to health and wellbeing applications in the context of mobile collaborative work [26].

2.4 Aim of the study

SBD has been used to represent and explore use of both current and prospective telemedical applications, in both single user and distributed collaborative settings, and for patient as well as for professional users, as well as taking into account the influence of other stakeholders and impact of other external factors on a design. SBD has not been used explicitly in telemedicine as the prior creative step of imagining alternative future self-management forms for patients, although we believe this would be aligned with the spirit of ISTAG. We therefore propose to extend the reach of SBD in telemedicine by applying it in this new way, namely to use SBD with the explicit objective of anticipating and reflecting on which form of self-management is desirable to incorporate in the design of telecare technologies for chronic patients. In order to do so, we first introduce the COPD telecare system in the methods section after which we present the analysis of the design and use practices in the following sections. We then proceed with introducing a guideline that enables designers to incorporate different forms of self-management in the design.

3. Methods

3.1 A telecare system for COPD patients

We conducted an explorative, qualitative analysis of the evolving design and use practices of a contemporary telecare system for COPD patients.[1] The system studied was developed over the course of two consecutive research projects 'COPDdotCOM' (2008-11) and 'CoCo COPD' (2011-13) conducted by Roessingh Research & Development (RRD) in the Netherlands. Partners of RRD in the COPDdotCOM project were the University of Twente (Centre for Telematics and Information Technology (CTIT)) and the local hospital in the city of Enschede Medisch Spectrum

[1] Although an analysis of real use practices might have been relevant as well, it was a deliberate choice to investigate the use of a telecare system during randomized controlled trials, because of the ability to feedback our results to the designers of the telecare system.

Twente (MST). Partners in the CoCo COPD project were RRD, MST and two physiotherapy clinics. The study presented in this article was based on a separate research project conducted by the authors by agreement with the researchers of the two projects mentioned above.

The COPD telecare system discussed here included enhancing self-management strategies of patients: "The objective of COPD dot COM was to design, develop and demonstrate a prototype system for supporting disease management of COPD. This involves the increase of self-management of the patient by 1) self-treatment of exacerbations and 2) coaching in daily life to improve activity behavior"[2]. The telecare system includes 1) an electronic triage diary and 2) devices for activity monitoring and feedback (Figure 1)[3]. Both the electronic triage diary and the devices for activity monitoring and feedback were also present in the CoCo COPD system.

Figure 1: Activity sensor and PDA

3.2 Methods of data collection

The empirical data concerning the design practices was analyzed by means of script analysis, an approach developed in the field of sociology of technology to analyze how the future use of technologies is pre-structured and anticipated during their design. During the design phase developers inscribe specific programs of action into the design based on the expected behavior and skills of the future users, which results in a script: the design attributes and delegates competences, tasks and responsibilities to the users [6]. The script analysis was aimed at investigating what programs of action were inscribed in two telemonitoring devices: a motion sensor combined with a PDA and a web based portal giving access to web applications for viewing personal activity behavior or using an electronic triage diary. These telecare devices were used

[2] http://www.copddotcom.nl (accessed 15-10-2014)

[3] Source: Hermens, H. (2010). COPDdotCOM: Innovatieve coaching van COPD patiënten. [COPDdotCOM: Innovative coaching of COPD patients]. Presentation at the 4e COPD ketenzorg congres, Utrecht, November 15, 2010

in a randomized controlled trial (RCT) conducted in the context of the COPDdotCOM project at MST between October 2010 and April 2011 [27]. More specifically, the analysis focused on how the programs of action inscribed in these devices pre-structured the interactions between patients and healthcare professionals and the forms of self-management implied in these interactions.

The empirical data used in the analysis of patients' use practices was gathered by conducting semi-structured interviews with patients (n=8) who took part in an RCT to evaluate the use of the CoCo COPD application and to investigate the effects of use of the application on patients' health status.[4] The interview questions were clustered around specific themes concerning self-management in telecare systems. Patients were asked how they experienced the use of the telecare system, how it influenced their relation with healthcare professionals and how using the telecare system influenced the perception of their illness. The interviews were recorded and transcribed verbatim. For the analysis we coded fragments of text of the transcription to associate common themes, after which they were clustered into theoretical notions relevant for the case study. Atlas.ti 6.2 software was used as a supporting tool.

The interviewees were a heterogeneous group of patients who participated in the RCT from April 2012 to June 2013. This group forms a representative sample of the target population. The age range of the sample was 50-80 years, with three females and five males. All patients were diagnosed with COPD, with four still working and four retired. The patients varied in physical capacity; some were quite fit and could walk their dog or ride a bicycle, while others could barely walk to their front door, or had to carry oxygen all day. The educational background of the patients ranged from primary school to university level. All lived in the city of Enschede, the Netherlands. The nationality of the patients was Dutch. All the interviews were conducted in their native language. Saturation was reached after eight interviews, meaning that no new information was collected, and hence no more patients needed to be interviewed.

Next to the interviews participative observations were conducted during two consecutive self-management courses the patients followed prior to the trial. For the data collection an observation scheme was used. The self-management courses took place in the summer of 2012 at MST. Based on these analyses we developed a guideline for scenario-based design to support developers in anticipating which self-management form is most appropriate to incorporate in the design.

4. Analysis of design and use practices of the COPD telecare system

4.1 Analysis of the design of the COPD telecare system

Below we describe both telecare applications and analyze what forms of self-management are inscribed in the design of these applications.

[4] The study is registered in the Netherlands Clinical trial register no.NTR3072

4.1.1 The electronic triage diary

The electronic triage diary plays a central role in supporting patient self-management. For this purpose patients are asked to fill in one or more multiple choice questions about their condition (Table 1)[5]. The computer algorithm behind the electronic triage diary dictates it should be used on a daily basis.

Table 1: Multiple choice questions of the electronic diary

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

The use of multiple choice questions pre-structures the way patients will report their illness, i.e. patients cannot enter their experience with their disease in their own words, make their own sentences or express their feelings in the way they would like. The questions posed are all related to medical facts about their condition and do not include questions of a psychological or social nature. When patients have answered the question(s) the system produces a (medication) treatment advice generated by a computer algorithm. In this way the patient becomes immediately responsible for the use of medication. The design of the electronic diary eliminates aspects such as free text expression usually associated with a paper diary. It is restricted to a multiple-choice clinical application.

We conclude that the first form of self-management is dominantly inscribed in the electronic triage diary. The frequency of use is based on the requirement to collect more or less continuous data. There is no freedom for patients to give information about their health status outside the scope of the medically oriented multiple choice

[5] Source: Hofs, D. (2010). Architectuur COPDdotCOM. RRD, Enschede. (Own translation). Document received during interview with Dennis Hofs, June 23, 2010.

questions. A small element of the second form can be discerned, since patients have to interpret their condition in order to fill out the diary. The diary might improve patients' wellbeing, but it does not increase their autonomy. The third form of self-management is not inscribed in this part of the telecare system as there is no option for personal contact from within the diary.

4.1.2 The activity monitoring devices

For monitoring and managing their physical activity, patients use an activity sensor, a Personal Digital Assistant (PDA) and a computer to access the web portal of the telecare system.

The rules about frequency of use follow the requirements of the minimum set of data that should be collected. They do not allow flexibility based on daily routines or own judgment of patients. This is reminiscent of the self-management form based on "compulsory compliance". Patients are encouraged to follow these rules otherwise the system will not be able to collect useful data. Patient autonomy is not supported here.

Feedback on activity monitoring is given via text messages on the PDA (Table 2)[6] and graphs of activity levels on both the PDA and on the personalized web portal (Figure 2)[7].

Table 2: Feedback messages for PDA

#	Message	#	Message
1	Try to relax	13	Have you read the newspaper?
2	Have a seat	14	Have a seat for 10 minutes
3	Keep going!	15	Try to walk up and down the stairs a few times
4	Bravo	16	Stop with what you are doing for a while
5	Excellent	17	Maybe you can have a seat?
6	You are doing fine!	18	Have you seen today's newspaper?
7	Take some time for yourself	19	Do you need something from town?
8	Take a nice magazine	20	It's time for a brisk walk!
9	Go for a walk	21	Try to take a long nice walk
10	Have a nice cup of coffee	22	Go for a nice long ride on your bike
11	Go for a nice ride on your bike	23	Have you already been outside today?
12	Go for a nice long walk	24	Get some fresh air

[6] Source: Hofs, D. (2010). Architectuur COPDdotCOM. RRD, Enschede. (Own translation). Document received during interview with Dennis Hofs, June 23, 2010.

[7] Source: Hermens, H. (2010). COPDdotCOM: Innovatieve coaching van COPD patiënten. [COPDdotCOM: Innovative coaching of COPD patients]. Presentation at the 4e COPD ketenzorg congres, Utrecht, November 15, 2010

The text messages do not involve decision-making by patients and are not aimed at enhancing patient autonomy. Hence they reflect the first form of self-management.

Figure 2: COPDdotCOM web portal – Activity monitoring and feedback.

The use of graphs to display activity levels points to the second form of self-management. Patients are expected to take over interpretative tasks of professionals and take action accordingly. Patients are not supported to develop behavior that might enhance their quality of life if this means behaving contra to medical guidelines. The script of the PDA application thus contains a mixture of the first and second form of self-management. The script of the web portal contains the second form of self-management. The third form of self-management is not promoted by the scripts. Patients are not stimulated to find their own way to live with their condition.

4.2 Analysis of the use practices during the testing of the telecare system

As demonstrated above, the design of the telecare system studied primarily resulted in inscription of the first and second self-management forms. Of course, programs of action inscribed in a technical system may not necessarily be followed by users. Studies of user-technology relations have shown how users often modify or reject the scripts of technologies [28]. Some examples of instructions given at the self-management course where patients received training on how to use the system and how to interpret data are given below. Additionally patients' experiences with the telecare system are presented.

4.2.1 The self-management course

During the self-management course where patients received training on how to use the system and how to interpret data they were taught to manage their condition in an almost professional way. Patients were trained to follow the second form of self-management. Moreover, they were allowed a certain amount of freedom in using the system. The course included the instruction that patients did not have to fill in the electronic triage diary every day. They did not have to go for a walk, for instance if it was raining, even if the telecare system advised them to. Patients were instructed not

to follow the advice of the electronic triage diary blindly but to contact professionals if they had second thoughts about a generated advice. These instructions point to the third form of self-management, based on concordance and collaboration. During the course patients were advised to trust on their experience based knowledge of their illness above that of the 'knowledge' or advice of the electronic triage diary. They were stimulated to find their own way of living with their condition and not follow the advice of the electronic triage diary automatically. The analysis of use practices of the telecare system thus shows that patients were taught to modify or even reject some parts of the script of these devices.

4.2.2 Patients' experiences during the trial

Patients' use of the telecare system also reflected the third form of self-management. Patients did not follow the advice generated by the activity devices blindly, but incorporated them in their daily life pattern. Compliance to the medication advice varied. Patients mentioned that they listened to their body and considered the advice of the diary as complementary to their own experience. Patients felt reluctant to follow the medication advice without contacting their healthcare professional first. Some patients developed anti-programs because the prescribed use of medication conflicted with their embodied experience. 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.

4.3 Discrepancy between design and use practices

Whereas major parts of the script of the telecare system thus reflected the first and second form of self-management, the dominant form taught in the course and which became visible via the use practices of the telecare system during the trial was aligned with the third form. We therefore conclude that there was a discrepancy between the self-management forms inscribed in the technology of the telecare system and exerted in the training and use of the system. Equally important, the analysis of the design and use practices shows how the ways in which the telecare system supports specific forms of self-management highly depends on design choices about frequency of use (section 4.1.1 and 4.1.2.), presentation of data (4.1.2); feedback on activity levels (section 3 and 4.1.2.) and treatment/medication (section 3; 4.1.1. and 4.2.2).

5. Results and Discussion

Based on the analysis of the design and use practices described above we developed a list (Table 3) for designers guiding the process of building a scenario which enables anticipating what forms of self-management are most appropriate to incorporate in the design of a telecare system for chronic patients. By using the guideline discrepancies between the self-management forms inscribed in the design of a telecare system and exerted during the training and use of the system can be avoided. Table 3 represents a list which can be used to guide the making of scenarios incorporating specific forms

of self-management. See Box 2 for an example of a scenario for designing a telecare system based on the first form of self-management.

Box 2: Scenario based on the first form of self-management

John has been diagnosed with COPD in stage gold 2. To support John to self-manage his condition he is coached by a telecare system to improve his activity behavior and apply self-treatment of exacerbations. For monitoring his activity behavior a more or less continuous data stream is required: John has to wear wireless on body sensors during the day, and is not allowed to take these off. When John's activity level is too low the system automatically generates a message he should become more active. Since John is not educated nor used to reading science based representations of his activity level, he receives text messages and/ or alert icons to motivate him. The feedback he receives is based on a computer algorithm only, not on his own embodied knowledge. John's is not allowed to tinker with the devices to make them fit into his daily live pattern. To prevent potential inflammations of his condition, John has to fill out multiple choice anamnesis questions on his physical condition every day via a personalized web portal. The system generates an advice which is based on a computer algorithm whether John should take medication or not. John's experience based knowledge is not integrated into the advice. He is directed always to follow this advice.

Based on the system we studied we distinguish five key features that should be taken into account in this scenario-based design: 1) frequency of use; 2) presentation of data; 3) feedback on activity level; 4) monitoring health condition; and 5) treatment/medication. We have selected these features because they are important aspects of contemporary telecare systems for chronic patients, including the system investigated in this paper (see section 3; 4.1.1; 4.1.2; and 4.2.2).[8] Most importantly, all five features are highly relevant in design choices of how to incorporate the three forms of self-management described in this paper. To avoid discrepancies between design and use as described above telecare systems should be able to vary the implementation of these features in their design. First, explicit consideration of frequency of use of the telecare system is important to take into account because it can be based on different requirements varying from the collection of more or less continuous data, to daily routines of patients, or patients' free choice, which support respectively the first, second and third form of self-management. Second, the anticipation of what form of self-management is desirable to incorporate in the design should address the ways in which the monitoring data are presented. A science-based presentation of data may be appropriate for science-educated patients to support them to become proto-professionals, the second form of self-management, whereas a system that invites patients to comment on the data is useful to support the third from of self-management. Third, anticipation of appropriate forms of self-management should include an explicit reflection on the forms of feedback on patients' activity levels. Automatically generated feedback based on algorithms is appropriate to support the first form of self-management because it disciplines patients to comply with the activity regime. In contrast, advice generated by an interactive feedback

[8] For a more detailed analysis of the importance of these features for incorporating forms of self-management in design see Maathuis, I.J.H., "Technologies of Compliance? Telecare Technologies and Self-Management of Chronic Patients" (Doctoral dissertation). University of Twente, Enschede, the Netherlands (2015).

system supports patients in taking responsibility for their behavior and educates them in balancing the advice of the system against their own experience (the third form of self-management). Fourth, the guideline we developed includes anticipation of the requirements for monitoring patients' health condition. Monitoring based on multiple choice anamnesis questions on the physical condition inscribed in a triage system is appropriate to support patient compliance (the first form of self-management). Designing a telecare system to support the third form of self-management would require anamnesis questions based on physical, psychological, and social parameters as well as creating space for patients to report on their experiences with their illness. Finally, an anticipation of what form of self-management is most desirable for the targeted patient group should reflect on the requirements for the advice on treatment/medication generated by the system. An automatically generated advice on medication or other treatment based on anamnesis of the triage system is desirable to support the first form of self-management because an automated, compelling advice disciplines patients to follow the instructions blindly. In contrast, an interactive software system enables healthcare professionals and patients to change medication in a shared decision-making process. This design supports the third form of self-management because it makes patients co-responsible for decisions on medication thus enhancing their autonomy. In Table 3 we present the full overview of the guideline. Although the guideline is aimed at developing telecare systems for COPD, they can be applied to other diseases that require monitoring of physical activity as well.

Table 3: Guideline for creating scenarios incorporating different self-management forms in telecare systems

SM-form	Key features of the telecare system	Guideline	Motivation
	Frequency of use		
1	Frequency of use is based on the requirement to collect more or less continuous data	Describe why continuous use is required Describe what activities need to be executed by patients and health-care professionals	Disease management or research requires more or less continuous data. If patients don't comply with the regimen of use, the collected data will be much less useful
2	Frequency of use is based on daily routines of patients	Describe the benefits of integrating use into the daily life of patients Describe what activities need to be executed by patients and health-care professionals	If continuous monitoring or data collection is not required, adjustment of system use to daily routines of patients will increase acceptability and use of the system

3	Frequency of use is based on patients' free choice	Describe the relevance of patients' autonomy in deciding on frequency of use Describe what activities need to be executed by patients and health-care professionals	Delegating the choice when to use the system enhances patients' responsibilities. This is preferred over daily use because the latter creates a constant awareness of the disease which may have a negative impact on quality of life
	Presentation of data		
1	Science-based presentation of data or directive text messages and/or alert icons	Describe patients' level of education and decide which way of presenting data is most effective Describe how a help-desk can support patients in interpreting data	Patients' use of data on activity levels depends on the ability to read and interpret these data, which depends on their education. The use of a science-based presentation of data may hamper compliance, particularly among patients who are not educated in science.
2	Science-based presentation of data	Describe the level of education of patients that is required for reading graphs and tables. Explain how the user should read them.	The use of a science-based presentation of data is useful for science-educated patients to support them to become proto-professionals
3	Style of presentation of data on patients' demand and possibility to add comments on the data	Explain to patients why checking data on activity level is useful for self-management and that patients can choose to view graphs and tables, or icons and text messages Describe how patients can add comments	Inviting patients to comment on the data provides an incentive to check the data. The comments provide an extra source of information for health-care professionals
	Feedback on activity level		
1	Automatically generated feedback based on an algorithm	Describe how feedback on activity levels is inscribed in the telecare system	An automated, univocal advice disciplines patients to comply with the activity regime
2	Automatically generated feedback based on an algorithm	Describe how feedback on activity levels is inscribed in the telecare system Explain to patients how the advice is derived from the data	An explanation of how the telecare system generates advice is important in educating patients to become proto-professionals
3	Advice generated by an interactive feedback system	Describe how feedback is based on interactions between the advice of the system and the input of patients	An interactive system supports patients to take responsibility and educates them in balancing the advice of the system against their own experience
	Monitoring health condition		

1	Monitoring is based on multiple-choice anamnesis questions on the physical condition and inscribed in a triage system	Describe what questions are used in the triage system and how they can be formulated in a compelling way Describe what activities need to be executed by patients to fill out the anamnesis questions	Monitoring based on a triage system supports patients' compliance
2	Monitoring is based on multiple-choice anamnesis questions on the physical condition and inscribed in a triage system	Describe what questions are used in the triage system and how they can be formulated in an educating way Explain to patients why these questions are important for monitoring their health condition	An explanation of the rationale underlying the anamnesis questions enhances patients' knowledge of their disease
3	Anamnesis questions are based on physical, psychological and social parameters The electronic diary includes space for patients to report on their experiences with their illness	Describe what questions about the physical, psychological and social wellbeing of patients will be included in the electronic triage diary Describe the activities of patients, i.e. filling out the questionnaire and reporting their own experiences with their illness Explain to patients why it is relevant to report their own experiences	Including psychological and social parameters will enrich the sources for anamnesis and support patients to learn to live with their disease Creating space for reporting their own knowledge and experiences enriches the sources for anamnesis and enhances patients' autonomy in coping with their disease
	Treatment/medication		
1	Automatically generated advice on medication is based on the anamnesis of the triage system	Describe how changes in medication are decided by the telecare system Describe the activities of patients, i.e. that they always have to follow the advice	An automated-, compelling advice disciplines patients to follow the instructions blindly
2	Automatically generated advice on medication is based on the anamnesis of the triage system	Describe how changes in medication are decided by the telecare system Inform patients about the rationale for taking specific medication Describe the activities of patients, i.e. that they should contact their physician to discuss whether they should change their medication or not	An explanation of the rationale for changing medication enhances patients' knowledge of medication and their disease

3	Changing medication is based on a shared decision by healthcare professionals and patients, supported by an interactive software system The decision on changing medication is based on cooperation between patients and professionals	Describe how decisions on medication decided by the patients in consultation with their physician	Making patients co-responsible for decisions on medication creates a positive attitude towards taking medication and enhances patients' autonomy

Discussion

This article suggests that SBD can be enriched by anticipating self-management forms. The guideline introduced above can be considered as a first attempt to support designers to extend the reach of SBD by creating scenarios that anticipate and reflect on which form of self-management is desirable to incorporate in the design. Building scenarios that explicitly address the five key features of telecare systems described above may contribute to an explicit reflection on key aspects of design that are often taken for granted but nevertheless shape the ways in which telecare systems can support self-management. The analysis of the case study confirms previous research findings that current telecare systems are mainly based on the first, and to a lesser extent, the second form of self-management [5]. This (implicit) prioritization of the first form, supporting compliance of patients, may not be appropriate for all patients and diseases. Given differences in physical capacity, educational background and attitudes toward coping with disease, the design strategies of telecare systems should be aimed at developing a variety in scripts of technical devices, which may include different feedback systems and different degrees in control and autonomy delegated to users. Most importantly, telecare systems that support the first form may be less effective because patients may reject the compulsory character of the feedback which may result in selective use or non-use [2]. Also, disciplining patients to comply with medical regimes may be counter-productive in terms of encouraging patients to become more responsible for managing their disease because this takes away too much of the patient's own responsibility. Instead, telecare systems which are less coercive and put more trust in patients' and healthcare providers' practical knowledge, experience, common sense and creativity may prove to be more complete (and better accepted) tools for supporting patients in playing an active role in their healthcare management. We thus hypothesize that designing systems to support patients in becoming more actively engaged in managing their disease may be more effective than systems in which patients are transformed into subjects that are acted upon and made dependent on the telecare devices [2].

We observed that SBD can be used to make explicit the implicit assumptions about actors and the tasks they perform that are implicit in systems and applications. With this in mind, and following [3, 24] and the guidelines above, one way to proceed is to create alternative scenarios for the same clinical application, each explicitly aligned with a particular management form so that the implicitly inscribed forms are made explicit and become open to experimental method. These alternative scenarios can be

used as a basis for participatory design, allowing users to "try out" and give feedback on the different forms as realized in the alternative scenarios. The enaction of the scenarios could be low-tech, e.g. by (manual) walk-throughs of the scenarios or role play, or by means of animation or rapid prototyping of system functions and interfaces so that users can interact with and give feedback on a running prototype.

We believe that the outcomes of the tensions currently playing out between the importance of compliance and moves towards more patient responsibility and empowerment deserve continuing research effort. The guideline developed in this paper provide a starting point for designing telecare systems that make explicit choices of which self-management form is most appropriate for the targeted patient group.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this article.

Acknowledgements

This research was funded by the program Societal Responsible Innovation of the Netherlands Organisation of Scientific Research (NWO). We would like to thank the employees of RRD, MST and the anonymous patients for sharing their experiences with the COPD telecare system.

References

1 Nettleton, S., Sociology of Health and Illness. 2nd ed. Cambridge: Polity Press, p. 238 (2006)

2 Oudshoorn, N., Telecare Technologies and the Transformation of Healthcare. Palgrave Macmillan (2011)

3 Huis in 't Veld, R.M.H.A., Widya A., Bults, R.G.A., Sandsjo, L., Hermens, H.J. and Vollenbroek-Hutten, M., "A scenario guideline for designing new teletreatments: a multidisciplinary approach." Journal of Telemedicine and Telecare, vol. 16, pp. 302–307 (2010)

4 Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. "Self-management approaches for people with chronic conditions: a review." Patient education and counseling, 48(2), pp. 177-187 (2002)

5 Schermer, M., "Telecare and self-management: opportunity to change the paradigm?" Journal of Medical Ethics, vol. 35, pp. 688-691 (2009)

6 Akrich, M., "The de-scription of technical objects." W. Bijker and J. Law (eds), Shaping technology/building society, pp. 205-224 (1992)

7 Carroll, J.M., "Five reasons for scenario-based design." Interacting with computers, vol. 13, pp. 43-60 (2000)

8 Rosson, M.B. and Carroll, J.M., "Scenario-based design." The human-computer interaction handbook, L. Erlbaum Associates Inc., pp. 1032-50 (2002)

9 Carroll, J.M. "Making use: a design representation." Communications of the ACM, vol. 37, pp. 28-35 (1994)

10 Ducatel, K., Bogdanowicz, M., Scapolo, F., Leijten J. and Burgelman, J.C., ISTAG scenarios for Ambient Intelligence in 2010, Final Report., European Commission, IPTS-Seville (2001)

11 Sutcliffe, A.G., Maiden, M.A., Minocha, S. and Manuel, D., "Supporting scenario-based requirements engineering." IEEE Transactions on Software Engineering, vol. 24, no. 12, pp. 1072-1088 (1998)

12 Rosson, M.B. and Carroll, J.M., Usability engineering electronic resource: scenario-based development of human-computer interaction. Morgan Kaufmann (2002)

13 Babar, M.A. and Gorton, I., "Comparison of scenario-based software architecture evaluation methods." Software Engineering Conference, 2004 11th Asia-Pacific. IEEE, pp. 600-607 (2004)

14 Liu, S., "Integrating top-down and scenario-based methods for constructing software specifications." Information and Software Technology, vol. 51, pp. 1565-1572 (2009)

15 Nick Lik San Fung, Ing Widya, Tom Broens, Nekane Larburu, Richard Bults, Erez Shalom, Val Jones, and Hermie Hermens, "Application of a conceptual framework for the modelling and execution of clinical guidelines as networks of concurrent processes," Proc. 18th International Conference on Knowledge-Based and Intelligent Information and Engineering Systems - KES2014, Gdynia, Poland, September 15-17 (2014)

16 N. Larburu, I. Widya, R. G. A. Bults, and H. J. Hermens, Making Medical Treatments Resilient to Technological Disruptions in Telemedicine Systems. Proc. IEEE-EMBS International Conference on Biomedical and Health Informatics, 1-4 June, 2014, Valencia, Spain (2014)

17 Bardram, J., "Scenario-based design of cooperative systems." Group decision and negotiation, vol. 9, pp. 237-250 (2000)

18 Demiris, G., Charness, N., Krupinski, E., Ben-Arieh, D., Washington, K., Wu, J. and Farberow, B., "The role of human factors in telehealth." Telemedicine and e-health, vol. 16, pp. 446-453 (2010)

19 Blanson Henkemans, O.A., Bonacina, S., Cappiello, N., Van der Mast C.A., Neerincx, M. and Pinciroli, P., "A hybrid multi-agent system architecture for distributed supervision of chronic patients in the e-health setting." In: L.J.M. Rothkrantz, C.A.P.G. van der Mast CAPG, editors. Euromedia 2007. Ghent: Eurosis-ETI, pp. 119-124 (2007)

20 Kentta, O., Merilahti, J., Petakoski-Hult, T., Ikonen V. and Korhonen, I., "Evaluation of technology-based service scenarios for supporting independent living." Engineering in Medicine and Biology Society, 2007 EMBS 2007 29th Annual International Conference of the IEEE. IEEE, pp. 4041-4044 (2007)

21 Gil-Rodríguez, E.P., Ruiz, I.M., Iglesias, A.A., Moros, J.G. and Rubió, F.S., "Organizational, contextual and user-centered design in e-health: application

in the area of telecardiology." HCI and Usability for Medicine and Health Care. Springer, pp. 69-82 (2007)

22 Årsand, E. and Demiris, G., "User-centered methods for designing patient-centric self-help tools." Informatics for Health and Social Care, vol. 33, pp. 158-169 (2008)

23 Villalba, E., Arredondo, M.T., Ottaviano, M., Salvi, D., Hoyo-Barbolla, E. and Guillén, S., "Heart Failure monitoring system based on Wearable and Information Technologies." Journal of Communications, vol. 2, pp. 10-21 (2007)

24 Widya, I., Van Beijnum, B. J. F., Bults, R., Jones, V., Hermens, H., Sandsjö, L. and Schaake, L., "Early phase requirements assessment of a teletreatment trial." Proceedings of the 2009 ACM symposium on Applied Computing. ACM, pp. 395-396 (2009)

25 Bults, R., De Wijk, R., Loke, B., Koenderink, N., Batista, R., Jones, V. and Hermens, H., "Requirements for a Nutrition Education Demonstrator." In: 17th International Working Conference on Requirements Engineering: Foundation for Software Quality, REFSQ 2011, 28-30 March 2011, Essen, Germany (2011)

26 Jones, V. and Saranummi, N., "MOSAIC vision and scenarios for mobile collaborative work related to health and wellbeing." ICE 2005, 11th International Conference on Concurrent Enterprising, University BW Munich, Germany, 20-22 June (2005)

27 Tabak, M., Vollenbroek-Hutten, M., Van der Valk, P.D., Van der Palen, J. and Hermens, H.J., A telerehabilitation intervention for patients with Chronic Obstructive Pulmonary Disease: a randomized controlled pilot trial. Clinical rehabilitation, 28(6), pp. 582-591 (2013)

28 Oudshoorn, N. and Pinch, T., How Users Matter: The Co-Construction of Users and Technology (Inside Technology). The MIT Press (2003)