

Value Tensions in Telecare: An Explorative Case Study

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ABSTRACT

We describe the results from a Norwegian case study of the attitudes of community-dwelling lung patients and health response center personnel toward a telecare service for such a patient group. The telecare service was intended to prevent exasperations in patients and employed a digital self-report application for remote monitoring of patients' health condition. Based on interviews conducted after a service trial of ten weeks, patient and provider-perceived benefits and concerns related to the service are described. Comparing the data from the two stakeholder groups, we highlight key tensions related to *patient safety*, what it constitutes as a value, and views on how it can be promoted or undermined through telecare. The way potential technology-embedded value biases can fuel patient-provider tensions are also discussed.

Our objective is to inform value-centered design of telecare technology and services by providing an in-depth empirical understanding of relevant value perspectives and tensions.

Author Keywords

Human values; Patient safety; Telecare technology and services; Value bias; Values in design.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

J.3. Life and Medical Sciences: Health.

INTRODUCTION

The aging population in many countries is expected to cause a significant growth in the prevalence of age-associated chronic illnesses, such as lung diseases, heart and coronary conditions, and cancer [2, 20]. Chronic illnesses in seniors are therefore considered to pose an increasing burden on health care resources in decades to come [24]. To help reduce this burden, and to provide sustainable services for various patient groups in the future, health care is increasingly turning toward *telecare*, i.e.,

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technology-enabled remote health monitoring and follow-up. Enabling technologies, such as biometric sensors, medical alert systems and digital self-report tools come with promises of added values for both patients and their health care providers [28-30, 33]. For patients, telecare interventions are typically expected to offer increased safety and security, and to enable an independent life at home longer. For health care providers, such interventions are envisioned to improve the quality of care in cost-effective manners, e.g., by providing awareness about the patient's health situation and inform decisions concerning when and how to intervene.

While telecare arguably has a great potential to help realize human values typically associated with health care (e.g., safety, security, autonomy), we hold that telecare value propositions tend to build on two implicit assumptions. Firstly, the vision of telecare as mutually and constantly beneficial for both patients and providers, often take for granted that the two stakeholder groups have a shared view of what values are important in the context of care, and what each value of importance constitute. Secondly, the above promises implicate that the employed technology mainly plays an instrumental, rather than a determinative (value-shaping) role in the realization of care values. Telecare technology is, in other words, typically understood as a passive mediator of care values across the physical distance separating a health care provider, and, for example, a community-dwelling patient.

In this paper, we argue that there is a potential gap between the promises of technology-enabled remote care, on the one side, and how various stakeholders may *experience* real-world telecare applications, on the other. Given the strong emphasis in many countries on reforming and modernizing health care by means of telecare technology, this gap forms an intriguing space for Human-Computer Interaction (HCI) and value-centered research. To help understand value tensions that can arise in the context of remote health monitoring, we conducted an empirical, qualitative investigation of patients' and providers' attitudes toward a specific telecare intervention. We report here on key findings from an explorative case study of a telecare service offered by a Norwegian municipal health response center to community-dwelling patients with Chronic Obstructive Pulmonary Disease (COPD¹). The study was part of a

¹ COPD (ICD-10 Code J40-J44) is a collective term for a number irreversible and progressive lung disorders.

municipal health service project exploring the feasibility of new technology-enabled services for patients with COPD living at home. The project aimed to investigate stakeholder-perceived benefits and challenges related to remotely assisted disease management as a means to prevent exacerbations in patients and reduce related hospital readmissions. The service was based on the concept of digital self-reporting. This meant that patients were expected to answer a predefined web questionnaire regarding cardinal COPD symptoms based on self-assessments, and report to the response center on a daily basis. The objective of the service was that the digital self-reports would enable the health care personnel to monitor changes in relevant symptoms and provide telephone-based follow-up assistance in case of identified aggravations.

To garner data on patients' and providers' attitudes toward the telecare service, we conducted a series of post-trial interviews.

The main contribution of this paper is an empirical, nuanced understanding of patients' and providers' attitudes toward technology-enabled remote health monitoring and follow-up, with a focus on perceived benefits and concerns. Based on our findings, we highlight emerging value tensions between the two stakeholder groups, particularly with respect to the concept of *patient safety* and the telecare service's role in providing safety. We also discuss how potential value biases, or tendencies, embedded in the self-reporting tool may give rise to, or fuel, value tensions.

Through our case study, we aim to inform value-centered design of telecare technology and services.

DEFINING VALUE AND VALUE TENSION

Value, in the context of design, is a contended notion [6]. In this paper, we use the notion to refer to what Rokeach [35, p. 5] defined as “*an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preference to an opposite or convers mode of conduct or end-state of existence*”. “Modes of conduct” thus refer to ideas about *how* one should act, while “end-state of existence” refers to the *long-term goals* or *conditions* that one wants to achieve. For example, a person may hold that one should use remote monitoring technology (mode of conduct) to help ensure the welfare of people in need of care (end-state of existence).

We use the term *value tension* to denote conflicting, enduring beliefs that individuals or groups of people may hold about modes of conduct or end-states of existence. For example, a person who holds that the welfare of people in need of care requires collocated patient-provider interaction (and thus rejects the idea of using remote monitoring technology for such purposes) advocates a mode of conduct which is in conflict with the one from the given example above. As such, the two modes represent a value tension.

BACKGROUND

Value-centered Studies of Telecare

As telecare applications have become increasingly technologically feasible, value issues related to and stakeholder attitudes toward such system have gained growing attention in HCI-related research literature. A number of relevant studies have focused on how care receivers, or patients, perceive telecare interventions (e.g., [1, 12, 25, 36]). Some of these more “patient-centered” studies have focused on how values held by marginalized patient groups can be taken into consideration in telecare designs [1, 12, 25]. This to prevent potential biases (e.g., assumptions, approximations, prejudice) held by other stakeholders, such care providers and technology developers, from dominating the design. Such value biases may have unforeseen and often negative consequences for the care receiver [10]. Studies which fall into this category have highlighted the need for technology which focuses beyond illness and symptoms-specific aspects, taking into account, for example, the need for personal tailored solutions, the significance of routine in everyday life, and concerns about stigma associated with telecare devices [12, 25].

Another category of relevant studies has focused primarily on health care providers' perspectives on, and attitudes toward, telecare solutions. Examples of such studies can be found in Refs. [9, 14, 17, 22]. These studies typically describe aspects of telecare solutions that affects (positively or negatively) the work of health care providers, such as care efficiency, purpose and routines for use and required knowledge about individual patients [9]. Some of these studies also draw attention to providers' perspectives on ethical issues related to, for example, remote surveillance and privacy [9, 14, 22].

Yet, another category of studies has drawn specific attention to the diverse, and sometimes conflicting, views and value stances patients and their care providers may hold with regard to telecare (e.g., [3, 7, 8, 11, 18, 19, 34, 39]). These studies have helped reveal conflicting perspectives or value tensions between care stakeholders on issues such as the patient's rights to freedom and safety versus risk reduction and on patient *enabling* versus patient *controlling* technology. The current study falls into this latter category of comparative studies of patient-provider attitudes toward telecare.

Theoretical Basis

While the main contribution of the current study is empirical, it takes much of its inspiration from technological mediation theory [37, 38]. Mediation theory holds that technology, when put to use, shape the relation between humans and the world (including other humans). From such a perspective, telecare technology also shapes the relationship between, for example, a patient and his or her health care providers. Mediation theory thus sees technology as a *mediator* of human-world relations, as

opposed to merely material objects or extensions of human beings.

The idea that technological design mediates relations, and thus influence, for example *what*, *whose*, and *how* human values are realized is also reflected in value-centered design frameworks such as Value Sensitive Design (VSD) [15, 16] and the embedded values approach [31, 32].

Positioning the Current Study

The value-centered telecare studies cited earlier in this section are by no means intended to form a complete nor extensive overview of related work. Together with selected methodologically oriented articles on value-centered design, they nevertheless serve to pinpoint the main scientific contributions of our work.

Firstly, we provide a *qualitative and contextually grounded understanding* of stakeholder values and value-tensions in telecare, as the values and tensions arise from the case rather than being identified a priori. Existing work on value-led design [4, 23, 27] argue that values of import in a given design case, as well as stakeholders' interpretations of such values, is contextually and culturally conditioned. As such, the understanding of values (and value tensions) need to emerge from the particular context or culture being studied. Acknowledging the above recommendation, we attempt to form an empirically grounded, qualitative understanding of stakeholder values and value tensions in a particular socio-technical context (telecare for community-dwelling COPD patients in Norway).

Secondly, we seek to *convey the voice of the participants* (patients and care providers) when describing their attitudes toward the evaluated telecare solution. We do so by giving particular emphasis to participants' quotes when accounting for the results from our study, and thus reducing our own (the researchers') voices as interpreters. Borning and Muller [4] have requested more emphasis on allowing participants in value-centered studies "speak for themselves" when value stances are accounted for, as researchers' interpretations risk altering aspects that may be important for understanding a participants' viewpoint. Strong commitment to the "voices" of participants is something we find lacking in much of the existing research literature on telecare and human values.

Thirdly, by allowing participants to use and experience telecare technology over time, we are able to *link stakeholders' expressed attitudes to particular experiences*, and thus contribute a richer understanding of factors and events, that shape their perspectives. Our *technomethodological* [5] approach thus help provide insights to how users act out values they hold through the use or, sometimes, rejection of telecare technology.

THE TELECARE SERVICE

This section provides a brief description of the telecare service including how it was organized and the remote monitoring technology (i.e. the digital self-reports).

The response center where the telecare service was implemented and trialed also offered other municipal telecare services for community-dwelling care receivers. This included emergency alerts (from push-button alarms), and electronic tracking services. All patient services were based on a formal resolution of need made by the local health authorities. The services were delivered free of charge.

Organization of Service

At an overall level, the telecare service was organized into three subsequent steps: (1) Inclusion, (2) Start-up meeting, and (3) daily service provision.

Inclusion

Patients were offered the service during a patient consultation with a pulmonary physician at the hospital (specialist health care), or as part of a discharge process after a hospital stay related to a COPD deterioration. Patients who enrolled to the service, would get a personal treatment plan, which the pulmonary specialist would create. The plan included information about medication to be used in cases of aggravated symptoms. Each patient was further scheduled for a "start-up" meeting that would be undertaken 3-5 days later.

Start-up Meeting

Before daily service provision commenced, the patient would have an initial joint meeting, undertaken in his or her home, with a pulmonary nurse from specialist health care and a health care worker from the municipal response center. The aim of the meeting was twofold: (1) provide patient education about COPD (conducted by the pulmonary nurse), and (2) inform about the telecare service and instruct in using the tablet computer and the digital self-report application (conducted by the response center nurse). The patients were encouraged to submit their self-reports on a daily basis, and to follow their personal treatment plan.

In addition, the patients were provided with a telephone number to a contact person (nurse and service trial manager) at the response center, in case of questions or technical problems with the application.

Daily Service Provision

The service was intended to monitor trends in patient COPD symptoms, as reported daily by patients via a digital self-report application (described in further detail below). According to the initial service design, the response center personnel were to make telephone contact with patients who reported aggravated symptoms, or whose symptoms trends gave reasons for concern (e.g., patients not reporting reduced symptoms after following their personal treatment plan). The follow-up call from the response center was intended to encourage patients to follow their treatment plan and to help resolve medical questions.

The Digital Self-Report Application

In order for care personnel at the response center to remotely monitor the daily health condition of the service

users, the service employed a digital patient self-report application. The self-reports were in the form of a questionnaire (Figure 1) in a web-based application (requiring log-on procedure with name and password), which patients could access via 3G cellular-enabled tablet computers provided after service enrollment. This was a five-item questionnaire about cardinal COPD symptoms, presented to the patient in a step-by-step manner: (1) general daily health condition, (2) breathing (3) coughing (4) spit (mucus) color, and (5) psychological wellbeing. The items included in the questionnaire reflected those contained in a paper-based version developed by the local hospital as part of earlier research projects. For each item in the questionnaire the patient could select between three predefined answers, being for instance “GOOD – My condition is as normal or better”, “FAIR – My condition is not that good”, and “BAD – My condition is bad”. For most items, each option was accompanied by a matching face icon (green, smiling face for condition GOOD; yellow, indifferent face for condition FAIR; and red, unhappy face for condition BAD).



Figure 1. Screenshot of the digital self-report's user interface.

RESEARCH DESIGN

This section describes the general research design of our study, including the telecare service trial and its participants, the post-trial interviews, in addition to data collection methods and analysis.

Telecare Service Trial

The telecare service was trialed for a period of ten weeks. The purpose of the trial was to promote critical reflections among patients and providers regarding the service and the value it offered.

A convenience sample of ten community-dwelling individuals with COPD (of various severity) were enrolled in the service trial. The group consisted of two men and eight women in the age 63-87 years.

From the response center, four nurses participated. They were not specialized in respiratory nursing but had received relevant training prior to the service trial.

Post-Trial Interviews

Depending on availability, individually or group-based semi-structured interviews were conducted with the health care providers and patients in the two weeks after the trial period. The interviews were conducted by the first and the second author (either individually or jointly). The individual patient interviews had a duration of approx. 1 hour, while the group interviews lasted for 1.5 hours. The health care providers were interviewed as a group for a duration of approximately 2.5 hours. While we would have preferred to conduct individual interviews with the health care providers, we were not able to do so for practical reasons.

Data Collection Methods and Analysis

The interviews were audio recorded and transcribed verbatim. The transcriptions were then analyzed deductively by the interviewers in search of expressed benefits and concerns in relation to the telecare service.

To organize the transcribed interviews into meaningful units, we attached descriptive codes to text segments. The coding process consisted of three iterations. First, each perceived benefit or concern that emerged in the text was given a primary keyword, such as *Reliability (benefit)* or *Irregular reporting (concern)*, and combined with some words from the quote to capture the meaning as interpreted by the analyst. We then reviewed the descriptive codes for consistency by checking that the codes were used in the same way for different text segments and combining codes (using the most descriptive term) where different codes had been used to denote the same theme. Finally, the codes were grouped into thematic categories. The resulting categories are described in the subsequent section, where we account two stakeholder groups' attitudes toward the telecare service.

RESULTS

Below, we describe the patients' and providers' expressed attitudes toward the assessed telecare service in terms of perceived benefits and concerns. We also present the rationale the patients offered for their position.

The Patients' Perspective

Patient-Perceived Benefits

The patients generally expressed positive attitudes toward the telecare service. From the interviews, we learned that the main benefit patients associated with the service was the perceived *added safety* it offered in their daily lives. As further described below, the patients pointed out different, and often multiple factors as to why they considered the service to increase their perceived everyday safety.

Reliability. One central reason patients gave for why they found the service to be safety-enhancing was linked to reliability. Most patients expressed feeling a high degree of comfort in knowing that they would be followed up (via telephone) by personnel at the response center when reporting aggravations. One patient stated:

(Quote 1, Patient#1) *It feels safe in way, knowing that someone will check on you [via telephone when you report feeling ill].*

What many patients perceived as a consistent and quick response by the alarm call center appeared to play a key role in establishing trust in the service among patients. One patient, recalling his experiences from multiple incidents of interacting with alarm call personnel after reporting ill, explained:

(Quote 2, Patient#2) *If you indicate [in the self-report] that you are feeling a bit sick, they [the response center personnel] call you back immediately—And that is safety.*

The two quotes above, and other similar statements, illustrate how the patients' perception of the service as reliable was as a result of a series of (positive) first-hand experiences of how the service responded in cases where the patient reported aggravated symptoms. Rather than being an end product of the service, the safety that the patients experienced appeared to be a cumulative result of various events where interaction with response center personnel was central in promoting the patients' trust in the service.

Some patients found the service safety-enhancing due to the particular social context they were living in. For example, the following quote shows how one patient considered the service to act as a reliable aid in the absence of family care providers:

(Quote 3, Patient#3) *I don't have a husband. I live alone. I have two children, but they are working, and you don't want to bother your children. So, in one way, the tablet [digital self-report application] is my partner, or my safety, you see, and...well, it watches over me.*

External contact point. Another aspect of the telecare service, which for certain patients contributed to perceived added safety, was the appointed contact person at the response center. For some patients, disease-related problems, such as anxiety and depression, represented highly sensitive issues. We found that in many cases, patients preferred not to discuss such issues openly with family members or friends, but rather to contact the alarm call center, and particularly the contact person, to have a dialogue with an external contact person:

(Quote 4, Patient#5) *I'm a little careful when it comes to how much I tell my husband [about my medical condition], because he is so easily worried. Next, he'll call the kids, and then they get worried too...Sometimes I think it is for the better if I keep my mouth shut. So, it is simpler to use [the telecare service] and talk to an external person instead.*

Another patient also reflecting on the value he identified in having an external contact point stated:

(Quote 5, Patient#6) *My kids are the only ones who know [that I am sick]. Neither my siblings nor my mother know that I've been very ill, and that I've been hospitalized. I have no intention of telling them. My mother is 84 years old, so she doesn't need to carry such an extra burden...I would like to keep it [the illness] secret for as long as mom lives. That's what I want. I don't want her to worry. She has enough problems.*

The two quotes above illustrate the concern that some patients expressed about burdening one's spouse, relatives or friends with disease-related issues.

Discretion. The value patients identified in having an "outsider" to talk to about disease-related challenges, as described above, also suggest how some had a strong desire for discretion about their medical condition. This need for discretion appeared to be central in the patients' assessments of the digital medium (i.e. the tablet computer) used for accessing the self-reports. By being provided a "general purpose" technology, many some patients felt that they avoided the social stigma they often associated with custom-made medical or assistive devices, such as medical push-button alarm systems and oxygen concentrators. Explaining her affection for a tablet-based solution, one patient stated:

(Quote 6, Patient #3) *You know, when you have COPD...it is a disease that you're ashamed of. At least, I am. And, yes, I smoke. Therefore, I don't tell people that I suffer from COPD. And, then, if the neighbors can see, [they'll start asking questions, such as]: "Why are you wearing an emergency alarm device?"*

She further elaborated on potential negative effects that more traditional assistive devices, such as medical push-button alarms, could have on her self-esteem:

(Quote 7, Patient #3) *Emergency alarm devices, are something we associate with old people. And I don't feel that old yet. They [the response center] offered me such an alarm device...but I declined – Because I am only 63, right? That would make me feel even older. So, I don't want one.*

We also learned that some of the patients were careful to hide COPD-related items such as medication and paper-based information related to their disease when guests. This to avoid bringing attention to what one of the patients characterized as a (quote) "self-inflicted disease" (ascribing the illness a result of many years of cigarette smoking).

Patient-Perceived Concerns

What to report. Based on feedback from the patients, we learned that the performing self-assessment of symptoms can raise certain difficulties from the perspective of the patient. One patient explained that he sometimes found it challenging to self-assess symptoms and select corresponding measures in the report. He also described that he, on certain occasions, downplayed symptoms when

reporting, to avoid causing (quote) “unnecessary fuss”, referring to the follow-up call (from the response center) reported aggravations would trigger. The motivation for downplaying symptoms, as explained by the patients, was to avoid burdening the call center personnel with situations he felt comfortable handling on his own (having previously handled similar situations unassisted).

When to report. The question of when, or how frequent, digital self-reports should be submitted was a recurring topic in the patient interviews, and the respondents expressed different opinions in this regard. The majority of patients expressed that they did not find it meaningful to submit reports on symptom-free days, and therefore had adjusted their reporting routines throughout the trial accordingly. One patient gave the following account for why she chose not to report on a day-to-day basis:

(Quote 8, Patient#7) *Basically, I know both myself and the disease so well that I don't see the necessity of having to report. I feel very restrained [by the service] as it is now...I almost think that it's a bit uncomfortable to [submit reports]. I'm feeling fine. Darn! I'm not feeling any different...If you're feeling sick, then you report!*

Only one of the patients expressed a personal benefit of submitting self-reports on a daily basis. According to the patient, the routine (quote) “promoted a sense of self-awareness toward potential exacerbations”. Another stated that she strived to submit self-reports on a daily basis because she (quote) “had been encouraged to do so” at the start-up meeting.

To avoid causing undesired attention from the response center, some patients explained that they tended to postpone reporting on mornings when feeling ill, to see if their condition would improve later, after taking medication.

Summing Up the Patients' Perspective

The interviews with the patients revealed that perceived *added safety* in daily life was the main value they identified in the telecare service. Key factors which contributed to this perception included:

- **Reliability:** The *experience-based* confidence in knowing that one will be contacted quickly by one's care providers and receive assistance in a satisfying manner when reporting ill.
- **External contact point:** Having the possibility to contact and talk to someone outside the one's family or social network about disease-related issues such as depression and anxiety.
- **Discretion:** Being able to use technology, which from a patient perspective was considered non-stigmatizing.

The main concerns patients raised with respect to the service were related to the following issues:

- **What to report:** Assessing symptoms and selecting the corresponding category in the self-report may be challenging. Most of the patients did not want attention from the response center in situations they felt comfortable handling themselves.
- **When to report:** Daily reporting were considered to compromise patient autonomy. The majority of the patients adopted routines of only reporting on days when feeling ill.

The Providers' Perspective

Provider-Perceived Benefits

Patient safety also emerged as a central concept in the group interview with the health care providers at the response center. As noted earlier, the main added value the patients associated with the service, was increased safety in their everyday lives. From the patients' perspective, then, how the telecare service fitted into their current social life situation, was central in their value assessment. The response center personnel, while expressing deep sympathy with the patients' desire for wellbeing and feeling safe, generally considered the patient-perceived or “felt” safety to be a positive by-product of the telecare service, rather than its main value proposition. From the personnel's, the primary value of the telecare service, was related to its *preventive potential* in a medical sense, i.e., the possibility to reduce the risk of exacerbations, hospitalization and even fatalities related to COPD. As such, the response center personnel focused primarily on aspects, which from their perspective, promoted or negated the potential of the telecare service to safeguard the patients from the above risks.

Trend monitoring. From the providers' perspective a central contributing factor to the preventive potential of the service, was linked to the possibility of careful monitoring of changes in symptoms over time.

(Quote 9, Provider # 2) *There may be a number of patients who report “green” [no aggravated symptoms], but you have constantly to check back [on previous reports]...In order to deliver a good service, the service providers need to be capable of providing quality assistance. Hence, I need to know how you [the patient] have been lately. I can't take it for granted that you're OK, even if you report you're OK.*

Trend monitoring of symptoms was an important part in forming a more complete picture of the patient's health situation and his or her relative safety. This promoted the response center personnel to take a more proactive approach to safeguarding of patients, for example, by contacting them via phone to check on their situation.

Patient engagement. Another factor contributing to the preventive potential of the telecare service, was the way the providers regarded the digital self-report solution to encourage patients to take an active part in managing their own health situation. The response center personnel

considered self-assessment to form an important part of reinforcing awareness in patients toward COPD symptoms. Comparing the self-report application with the medical push-button alert system used as part of other telecare services delivered by the response center, one of the providers expressed:

(Quote 10, Provider# 1) *It's about actually not making them [the patients] sicker than they are. It's about making them accountable to some extent for mastering their own situation. They need to somehow take action and preventive measures themselves. Thinking through the symptoms [listed in the digital self-report] is about mastering one's situation and can be sort of a kick in the butt. So, in terms of mastering the situation and preventing exasperations, I believe they [the patients] need more than an alarm button. They need to become mindful about exasperations and symptoms and their treatment plan. I believe that [these elements] taken together can help prevent revolving-door patients.*

Provider-Perceived Concerns

Irregular reporting. As described above, the personnel at the call center identified the preventive potential, i.e., the possibility for early intervention and prevention of exasperations and further complications, as the main values offered by the service. For the personnel, the digital self-reports were considered a key enabler in this context, as they provided the means for close monitoring of the patients' health condition and deciding when to follow up. Hence, one of the primary concerns with regard to realizing the preventive potential of the service, was irregular reporting by patients:

(Quote 11, Provider#1) *There is much focus on the daily reporting and how important it is that we hear [receive reports] from them [the patients] each day. It [reporting] is voluntary, of course, and we cannot force them. We really hope to hear from everyone on a daily basis, but we don't. It has been thirteen days since we [received reports] from one of the patients.*

According to the professionals, irregular reporting made it challenging not only to follow trends in a patient's health condition and take proactive measures to prevent potential exacerbations; Missing self-reports from patients also presented an ethical dilemma concerning whether or not to contact the patient:

(Quote 12, Provider#2) *When we know that they are experiencing an aggravation... and then it becomes silent [the patient does not submit reports] for three or four days; How long are they supposed to lie dead before we take action?*

The perceived problem of irregular reporting evoked reflections concerning the patient's role and responsibility in relation to the telecare service:

(Quote 13, Provider#2) *They [the patients] need to understand that if they want to receive this type of service, it also requires them to take some responsibility on their own. In order for us to offer them a good service, they have to report. We need to know that we can have daily contact.*

Under-reporting. Another emerging concern related to the use of digital self-reports to communicate and monitor patients' health condition was under-reporting, i.e., patients failing to report experienced symptoms or their severity:

(Quote 14, Provider#1) *I am not too confident when it comes to the credibility of some of the self-reports. I have caught some [patients] in the act; They under-report. Sometimes, when they report aggravations, they may actually have been ill two days already, but they have waited [to report], and yes, waited extensively – Because they don't like periods of exacerbations. That is the worst for them. They don't like to go on [the medication]. They would rather not... In this regard, the reporting tool doesn't work optimally – in terms of the disease specific – to help discover exacerbations at an early stage. Too the patients, it is the safety which is important, not the diagnosis.*

For the providers, under-reporting from patients created in many ways similar problems and dilemmas as irregular reporting.

Inappropriate support systems. Since monitoring trends in the symptoms of patients was an important part of the service, all the provider informants expressed concerns about what they considered lack of appropriate computer tools to support such activities. In particular, the absence of user interfaces which could present trends in one screen view, and preferably as a graph, was regarded as a problem. The current solutions which were used for reviewing self-reports from patients required extensive navigation between different screen views in order to trace trends. Lack of integration between different systems used at the response center, e.g., between the patient health record system and the system for accessing submitted self-report also required the personnel to frequently switch between different applications.

Unexpected work demands. As pointed out earlier, some of the patients appreciated the possibility to call their dedicated contact person for various reasons. Especially, patients who struggled with anxiety or depression valued the opportunity to talk to someone outside the family. While the care providers were aware that some patient were in need of psychological support before the telecare service trial, they had not anticipated the extra work demands phone calls related to such issues would involve.

(Quote 15, Provider#1) *They [the patients] have phoned a lot – At all hours. I did not expect to become a 24/7 telephone service, which I have been for certain periods [of the service trial]. But they call about real issues.*

Elaborating some of the typical issues the patients often made contact about, the provider who served as contact point explained:

(Quote 16, Provider#1) *[The patients call about] their anxiety. Some feel that they, to some extent, have exhausted many of those who they surround themselves with – one’s spouse, children, grandchildren. Some describe having mood swings, which make them not very pleasant to live together with, under the same roof. In many ways, it’s simpler for them to make a phone call [to me]. So, I’ve almost become kind of a psychology service, as well...I think that the patients who have received the service up until now, and who have been diagnosed very recently, are among those who phone [me] the most. They have an intense need for safety given their illness. They don’t quite know how to deal with the situation, and this has made them very insecure.*

Summing Up the Providers’ Perspective

The health care providers considered the primary value proposition of the service to be its potential to reduce the risk of exacerbations, hospitalization and fatalities in COPD patients. Patient safety, then, was mainly considered a function of the telecare service’s possibility to continuously safeguard the patient.

The providers especially found the following two aspects to play an important role in the safeguarding process:

- **Trend monitoring:** Careful monitoring of changes in cardinal COPD symptoms over time.
- **Patient engagement:** Reinforcing awareness in patients toward changes in symptoms through self-assessment, was considered an important part of making patients accountable for their own health situation.

The main concerns the providers expressed with regard to ensuring the patients safety can be summarized as follows:

- **Irregular reporting:** Patients who did not submit self-reports on a daily basis generated uncertainty in providers about the patients’ health and safety.
- **Under-reporting:** Under-reporting was considered to severely compromise the telecare service’s potential for early detection of exacerbations.
- **Inappropriate support systems:** Lack of integration between digital systems employed at the response center and reduced support for trend monitoring were factors considered counterproductive to the safeguarding process.
- **Unexpected work demands:** Patients with anxiety or depression problems put an increased and unexpected demand on the appointed service contact person.

DISCUSSION

Emerging Value Tensions

Both the patients and the providers considered increased patient safety to be the primary value offering of the telecare service. However, the results presented above also show that the two stakeholder groups, in some respects, held diverse views with regard to what *patient safety* constitutes, and the telecare service’s role in promoting such a value. Below, we draw attention to three ways in which the patients’ and the providers’ attitudes toward the telecare service, and perspectives on patient safety, conflicted. Our motivation for focusing on tensions between the viewpoints of the two stakeholder groups is that such contradictions represent challenging issues for designers to deal with [4]. Hence, such issues are likely to require careful consideration.

Tension 1: Episodic vs. Continuous Safety Needs

The first tension we pay attention to relates to how the patients and the care providers tended to think differently about patient safety needs and the role of the telecare service in this context. Feedback from the patients (e.g., Quotes 2, 3 and 8) suggested that they tended toward an *episodically* oriented view of their safety needs and their needs for assistance from the response center. Episodes in which the patients found it beneficial to interact with personnel at the response center were mainly situations which the patient personally experienced as “acute” or too unsafe or stressful to handle on his or her own. This typically included stronger aggravation of respiratory symptoms, or symptoms related to anxiety or depression upon which the patients often would phone the contact person at the response center (thus using the contact person for different purposes than what the response center originally had intended).

The patients’ episodic view of safety needs was in many ways also reflected in how many conceptualized the telecare service and the used the self-report application. The responses from the patients, particularly with respect to their reporting routines, suggested that they tended to regard the telecare service to serve a similar role as traditional medical emergency services, i.e. an external part which a patient can notify when he or she is in need of acute assistance. Patient accounts also showed that the self-report application in many ways were understood as the equivalent of a medical push-button alarm (see for example Quote 8 (“*If you’re feeling sick, then you report*”), and Quote 2 (“*If you indicate that you are feeling a bit sick, they call you back immediately*”).

As opposed the patients’ episodically oriented view of care needs, the care providers considered the safety needs of the patients a *continuous* and *proactive* process. From the care providers’ perspective, daily monitoring of symptoms and proactive follow-ups were considered key components of the process and seen as fundamental in safeguarding patients from exasperations and potential hospitalization.

Tension 2: Psychosocial Wellbeing vs. Safeguarding

The second tension emerging from the collected interview data, concerns how the patients tended to use a wider frame of reference than the care providers when assessing the telecare service and the safety it offered. The patients tended to assess the service and the perceived safety it offered from a psychosocial perspective, i.e., according to personal life circumstances. Examples of such circumstances included, for example, if the patient was living alone (cf. Quote 3), the need for having an external person to talk to about the disease (cf. Quotes 4 and 5), and personal desire for discretion (cf. Quotes 6 and 7).

The care providers, in contrast, appeared to assess the service and how it could affect the patients' day-to-day safety situation from a disease, or symptoms-oriented, perspective, i.e. what symptoms data indicated with regard to a patients' current health condition and risk of exacerbations. As we pointed out earlier, this focus does not imply that the providers did not acknowledge many of the patients' perspectives on safety.

In daily operation of the service, however, the digital self-report formed the providers main decision support tool in terms of determining whether to intervene or not. The "symptoms/disease" focus held by the providers also explains their concerns with respect to irregular reporting from patients. Without the daily self-report, they were left "clueless" about the patient's current health condition (cf. Quotes 11 and 13), which again gave raise to ethical dilemmas (cf. Quote 12). A patient who did not submit digital reports on a regular basis could not be properly safeguarded by the service. From a provider's point of view, then, the patient was "unsafe" independently of the patient's own assessment of his or her safety situation.

Tension 3: Patient Autonomy vs. Patient Responsibility

The third and last value tension we pay attention to in this discussion concerns the conflicting views between the two stakeholder groups regarding the patient's role in the service. For the patients, personal autonomy and avoiding becoming too restrained by the service was important. As illustrated in Quote 8, some of the patients felt that the cost-benefit of the service (i.e., the perceived stress associated with submitting reports versus the perceived added safety offered by the telecare service) was questionable.

The care providers, on their part, considered that in order for the telecare service to work according to its purpose, the patients had to be held accountable with respect to meeting certain compliance requirements. In particular, the health care providers saw it as the patient's responsibility, as recipients of a free service, to answer the questionnaire in the self-report to the best of their ability and submit self-report on a daily basis (cf. Quote 13). Negligence from the patient would essentially prevent the telecare service from thoroughly safeguarding him or her. Not only did the providers consider it the patients responsibility to submit reports; We also described how the providers regarded self-

assessment of symptoms an important part of patient engagement, i.e., encouraging patients to take an active role in managing their situation.

Technology-Embedded Value Biases

There are potentially several factors that led to the differences in the stakeholder groups' assessment of the service, some which we will point out later. As suggested in related work on value-centered design (e.g. [10]), value biases harbored in technology may also play a role in giving rise to such tensions.

Assessing what aspects of the care situation the digital self-report application "enhanced" and what aspects it "diminished" may be particularly valuable in this context. As shown below, such an assessment may help us understand how the design shaped the two stakeholder groups' attitudes toward the service, and to some extent, toward each other. The following assessment is not intended as a complete or extensive analysis of the mediating role of the digital self-report application. Rather, it serves to exemplify the potential impact of value predispositions embedded in technology on patient-provider relations.

In the digital self-report application, the patient corresponded to a set of selected symptoms indicators. These indicators were, in other words, the telecare technology's (abstract) representation of the patient. As our results show, the main attention of the care providers was directed towards patient-reported changes in the symptoms indicators. Failure of the patient to provide such data conversely raised concerns in the providers (cf. Quotes 11-13). In many ways, then, the design reflected the provider's conceptual model of the service.

While focusing on the patients' COPD symptoms, the design solution diminished other, potentially important, aspects relevant for the telecare service to work as originally intended. For example, the results suggest that many of the patients failed to realize the role the reported symptoms data played in the providers' proactive safeguarding of the patients (cf. Quote 8). The solution left the patients, figuratively speaking, "in the dark" regarding how the care providers worked with the data, for example, by analyzing trends over time, in order to decide whether to follow patients up more closely. Steps taken at the service start-up meeting, such as informing the patient about the role of the digital-self reports and encouraging daily reporting did not appear sufficient to make many of the patients adhere in practice. The lack of feedback to patients, for example on trends can be considered a potential reason why many patients regarded it an equivalent to that of a medical alarm-button and decided not to report on a daily basis.

For the providers, the strong symptoms-oriented focus of the design solution can be considered to have contributed to an initial "blindness" toward other ways of understanding

patient safety than symptoms monitoring and safeguarding from exasperations. This may potentially explain why the service appeared unprepared and understaffed to deal with phone calls from patients struggling with anxiety or depression. The results described earlier also reveal other “blindspots” embedded in the telecare solution, such as the lack of possibilities for providers to understand the rationale for why a patient reported in a certain manner. As described earlier, patients gave various reasons for underreporting, postponing the report, or choosing not to report.

Value-Centered Design of Telecare Technology and Services

In what way, then, can the current study inform value-centered design of telecare technology and services? Below, we outline three key takeaway points in this regard.

Firstly, based on our results, we recommend that designers of telecare technology and services pay specific attention to values and value tensions through practice-oriented, hands-on approaches. Providing patients and providers real-world use experiences with telecare technology can potentially evoke rich reflections about how such interventions accommodate (or fail to accommodate) their values, and how central values, such as *patient safety*, are conceptualized and *acted out* by differently stakeholders. Given that value tensions potentially can affect the acceptance of telecare technology and services among stakeholders, we highly recommend that such conflicts are paid explicit attention in early phases of technology and service design.

Secondly, identified value tensions between patients and providers may serve as a suitable starting point for considering how technology and service design solutions may cause, or fuel, tensions. Our findings illustrate how telecare technology and services can come with certain implicit, and possibly wrongful, assumptions (biases) about patients’ use, and about patient’s information and service needs. For example, we have highlighted issues that can arise when patients are left unaware about how safeguarding is accomplished and how their health data are used in the safeguarding process. In a sense, then, telecare technology may enhance certain aspects of the patient’s situation, but at the same time cause a “blindness” toward other aspects. Perhaps most importantly, such shortcomings implicitly raise the question if patient-perceived safety reflects the actual capability of a telecare service to safeguard.

Thirdly, a qualitative understanding of value tensions between stakeholders, along with assessments of value biases embedded in telecare technology, may help inform potential solutions. With respect to socio-technical systems, such as telecare interventions, it is important to note that the answer to identified challenges is not necessarily technological in nature. Aspects such as service provision criteria (i.e. who the service is suited for) and individually tailored agreements on how often self-reports should be

submitted are examples of service design steps that potentially may help deal with some of the tensions we identified. In terms of technological design, providing patients incentives or rationales for submitting health reports, for example, by means of game-based mechanisms and/or patient educational means [21], are examples of technology approaches, which also may potentially reduce tensions.

Having pointed out some hypothetical ways of dealing with value-related issues identified in our study, we nevertheless recommend cautiousness against naïve ideas about how design may resolve value tensions. Value tensions may be deeply rooted in patients’ and providers’ potentially distinct value systems, and reflect differences in life experiences, environments and background. As stated earlier, values are *enduring* (per definition [35, p. 5]) and slow to change. Attempting to eliminate value tensions between patients and health care providers, in the context of telecare, may consequently be an unrealistic aim in many cases. We suggest that a more feasible goal of value-centered design of telecare technology and services is to focus on how to reduce the potential negative and even harmful effects of stakeholder value tensions when telecare solutions are put to use.

CONCLUDING REMARKS

In this paper, we have taken a critical view on telecare and its role in realizing central values we associate with care, such as patient safety. In particular, we have focused on value tensions between patients and providers, which can be considered to question the rhetorical “gospel” that often surrounds technology-mediated care. Our point here, however, is not to reject telecare interventions. Telecare has, for example, been found to reduce the stress and strain of care providers [13], and also add benefits on a societal level [26]. Currently, however, there is little evidences indicating benefits on, for example, a patients quality of life [13]. Our motivation in this paper has been to bring attention to the need for focusing explicitly on the value tensions that may emerge between stakeholder groups in the context of telecare interventions. It is only by identifying and understanding the nature of such tensions that we can hope to realize the full potential of telecare.

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