

The 'Self' as Barrier for Self-Management Technologies in Healthcare?

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ABSTRACT

Self-management technologies are promising in healthcare. In the name of patient empowerment, they can address an important challenge: how to meet an increasing demand for care without additional resources. We designed and evaluated the PICASSO-Tx system: a technology solution to support transplant patients and their self-management of diet, physical activity and medication adherences. In a field study, 19 patients used the system for two weeks at home. We discovered that although we intended patients to become actors in the management of their own health, they saw themselves rather as a subject, leaving the active role for caregivers. In this paper, we describe how patients expected their data to be shared with others, how they perceived the system as a tool for monitoring by caregivers, and what expectations towards these caregivers this perception brings. Furthermore, we discuss the barriers we encountered caused by the 'self' and conclude with design recommendations for

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self-management technologies in healthcare related to these expectations, perceptions, and barriers.

CCS CONCEPTS

• **Human-centered computing** → **User studies** • **Applied computing** → **Health informatics**

KEYWORDS

Chronic health conditions; healthcare; patients, personal informatics; quantified self; self-management; user experience

1 INTRODUCTION

Evolutions in healthcare make people live longer, yet, with increasing age, the prevalence of chronic diseases is steadily rising. In order to prevent or manage chronic diseases, a healthy lifestyle is required, especially after life-saving interventions such as organ transplantation. Patients are not cured after transplantation but remain in long-term follow-up within the transplant center with regular check-up visits taking place. Moreover, patients need to adhere to a complex therapeutic regimen. For example, patients have to take immunosuppressive drugs at fixed time points. Omitting doses or irregular time of intake might endanger the patient, as transplant rejection and eventually loss of the transplanted organ might occur. Not only poor medication adherence, but also the lack of sufficient physical activity and a healthy diet have a substantial influence on the long-term survival rate.

Inspired by the quantified self movement, technology can be deployed to provide people with data about their own behavior. Providing personalized feedback on their monitored

data can make people more aware of their behavior and enable them to improve or maintain a healthy lifestyle. Self-management is an attractive approach for hospitals to empower patients [35, 36] and it could help save resources as patients are less dependent on the availability of caregivers [37].

Self-management in healthcare puts responsibility of adherence with patients. Hence, it is of utmost importance to design self-management technology that is being accepted by the patients¹. Therefore, we investigated how self-management technology is adopted and perceived by patients. We aimed to answer this research question by designing and evaluating a platform to support solid organ transplant patients (heart, lung, liver, and kidney) with the self-management of their diet, physical activity and medication adherences.

We followed a human-centered design approach in the design and development of the user interface. First, we learned about the daily habits of the user regarding diet, physical activity and medication adherences through diary studies and contextual interviews. Next, the user interface was designed through iterative prototyping. Finally, a field usability study wrapped up the design phase.

We intended the patient to be an actor in the management of their own health and explained the aims of the technology to all of our patients. However, in the concluding interviews we discovered that patients interpreted the system as a tool for monitoring by caregivers and perceived themselves rather as a subject, leaving the active role for caregivers. In contrast with our expectations this was not perceived as something negative by the patients.

We argue that this mismatch between design intentions and patients' perceptions can lead to the abandonment of the technology or even non-use, which is by no means the fault of the patient. The contributions of this paper are insights in how patients perceived self-management technology and their expectations towards these technologies. Moreover, we describe the context-specific barriers for self-management technology we encountered and we give design recommendations for self-management technology in healthcare based on our findings.

2 RELATED WORK

In this section, we discuss quantified self, the availability of health information, and the paradigm shift in healthcare towards patient empowerment. We describe how this inspired self-management technologies in HCI research and

conclude with related work about technology appropriation and non-use of technology.

2.1 Quantified Self, Health Information, and Patient Empowerment

Quantified self (QS) refers to collecting information about people's body vitals and daily habits on a regular basis [27]. The information can be biological, physiological, behavioral, or environmental and is collected in a proactive way [39]. One example of self-quantification devices is the weight scale. Since the late 19th century it has enabled people to reflect upon their weight [39].

More recently the number of tools and devices used for self-quantification that people wear (wearables) or carry with them (including smartphone applications) has grown rapidly. Wearables are worn on the body and they automatically collect data such as physical activity, pulse, heart rate, body temperature, calories burned, and sleep patterns [30]. Fitbit is known for creating wearable technologies. In 2008 they launched a clip-on device used to measure steps, calories, activity intensity, and sleep; Later in 2013 they launched a wristband version and other companies such as Nike and Jawbone created similar technologies [9]. Also clothes are equipped with sensors to measure body vitals [8]. The adoption of the smartphone has facilitated people to quantify themselves using smartphone applications (apps). These apps enable people to automatically or manually monitor sport exercises and performances, daily steps, sleep patterns, and food intake [30].

Self-quantification enables people to collect information about themselves and act upon this information. This facilitates self-knowledge, awareness, self-control, self-improvement, and self-reflection. People use their data to improve sleep, increase concentration, and improve performance. They can share their data easily with peers, sports coaches, and medical staff.

Here, people's experience of their self is (partially) shaped by the use of technology applications that measure body vitals and daily habits. In the design process, social, political, economic, and technical influences, shape the features and functions of technology applications [5]. They assume functions and desires of users, and force meaning and subjectivity on the users by interpreting data about descriptions of the body [25]. Also, health promoters may contribute to negative feelings of shame and guilt by forcing an ideal of a healthy lifestyle on users through technology applications [26].

While quantified self is about people gathering their own information, health information in general is becoming more accessible to patients as well through the growing use of information technologies and online technologies in healthcare. Information that used to be available only via

¹ For clarity, we consistently use the word 'patient' throughout this paper for technology users and participants in this study as well.

medical specialists, is now widely available online. [26]. Health information is one of the topics that is most frequently searched for online. It can improve a patients' understanding of their medical condition [29].

The disclosure of health information has facilitated a paradigm shift in healthcare. Traditionally a paternalistic model was common in which the patient passively accepts the doctor's authority and choice of treatment. New forms of healthcare delivery models are developed that are grounded in collaboration and in which a partnership between the doctor and the patient is established [6, 10, 29]. The old thinking in which patients placed the responsibility of their health with the doctor is changing to a new thinking in which patients take responsibility to manage their own health and they have the tools to do so [38].

2.2 Self-Management Technologies in HCI

Self-management technology is widely discussed, both in medical as well as in HCI literature. Several barriers for the sustainable use of self-management technologies have already been identified:

The work of Bhachu et al. [3] showed that elderly people are willing to accept technology for self-managing chronic health conditions, if it benefits their health condition.

Simm et al. [35] presented Snap, a wearable to self-manage anxiety for people with autism. The authors suggest a DIY co-development approach to design technology for self-management of anxiety, as it removes the focus from the diagnosis and emphasizes a holistic approach to the user.

Other examples include the work on diabetes self-management by Maniam et al. [28] that identifies financial and privacy aspects for technology acceptance and the work of Doyle et al. [13] on smart home data for ambient-assisted living that emphasized the importance of education and goal-setting.

Harrison et al. [19] described how accuracy and aesthetics are important barriers for quantified selfers using activity trackers. Li et al. [23,24] studied lead users—early adopters of technology, who might not be representative for a whole population—and identified barriers and design recommendations for personal informatics. They present an iterative stage-based model (including reflection and action) and found that barriers such as accuracy, time constraints, and difficulties understanding visualizations, cascade through stages.

Despite this knowledge on barriers, sustainable use of quantified self tools in the long-term remains difficult, even for lead users [2]. Furthermore, when introducing quantified self approaches to atypical audiences (other than middle-aged white men) new challenges emerge as these atypical end-users often lack required resources in their natural

environment [22]. Also, there might be a misalignment between designer intentions and end-user views when thinking about a quantified life [18].

Next to the known barriers, we argue that in binding applications of quantified self such as self-management applications in healthcare, the inherent curiosity of quantified selfers might be lacking as compared to non-binding applications of quantified self such as sports activity trackers or mindfulness training. Non-binding applications start with a deliberate choice and freedom as they are aimed at healthy individuals that want to initiate or keep up a certain lifestyle. Whereas most of this related work involves the caregivers' perspective, or used focus groups as method, we focus on patients' experiences after they use the self-management technology for two weeks in their own home. We are interested in how patients perceive the technology after using it, and the barriers they encounter.

2.3 Technology appropriation and Non-use

Ever since products are designed they are used in ways they are intended to and in new ways [4]. Appropriation is a creative use of a product where the user adopts a new use of the product [33]. Appropriation is found in a variety of products such as digital camera's [33], online learning platforms [11], and mobile banking [31].

Users' values affect their experiences with products or services [21]. Every product, whether intentionally designed or not can trigger associations that depend on social and cultural norms [4] and through use, users construct new meanings on the technologies they use [11].

Designers have specific intentions when designing products, these intentions are embedded in the product as features and affordances [11]. When a product is designed, the features and functions are shaped by social, political, economic, and technical influences [5]. Also, technologies are designed around assumptions about what needs to be done to establish an action, but often they are wrong [17]. Appropriation is critical to the adoption and thus success of a technology. Therefore it is crucial to understand appropriation for those who develop technology [12].

New appropriations of design do not necessarily need to be a problem. It can be seen as a phenomenon that provides opportunities to learn about the user as appropriations capture the needs of the users. Carroll [5] argues that appropriation is part of the design and that the uses' appropriation of technology may be viewed as a completion of the innovation cycle. From a technology perspective appropriation can provide user requirements for future products or versions [12]. However, in certain domains such as banking where a system may be used for fraud or in healthcare where a doctor may need to use a tool the way that

it is intended to, appropriation is not desirable as the anticipated outcome is something that is relied upon.

An important field of study in this light is non-use. If technologies do not get appropriated or adopted in the long term, why are they abandoned, or not even considered for use in the first place? As Satchell and Dourish [34] argue, use is only one kind of relating with technology and non-users are not bad users. The study of non-use can equally bring up insights regarding the design of technology [34]. Fuchsberger et al. [16] consider non-use as an activity. They too call for a different way of seeing non-users, as if these users are in need for something [16]. As Baumer et al. [1] describe, use and non-use could even be considered as a non-binary spectrum.

Havlucu et al. [20] studied the abandonment of wearables with tennis players; They found that generic feedback that lacks qualitative interpretation of the data and the absence of coaches on the platform leads to this abandonment.

Epstein et al. [14] studied abandonment of personal informatics too; They identified the cost of tracking, discomfort with the information, and concerns regarding data quality as reasons for abandonment. Furthermore, they studied what happens after abandonment: Their findings point at feelings of guilt and frustration, but also at freedom after abandoning personal informatics tools. To conclude, as Clawson et al. [7] illustrate with their work on abandonment of personal health-tracking technologies, abandonment and non-use are complex stories. Abandonment can also be a consequence of people having upgraded devices or achieved their goals.

3 CASE STUDY

The PICASSO-Tx project tests a self-management intervention with or without interactive health technology

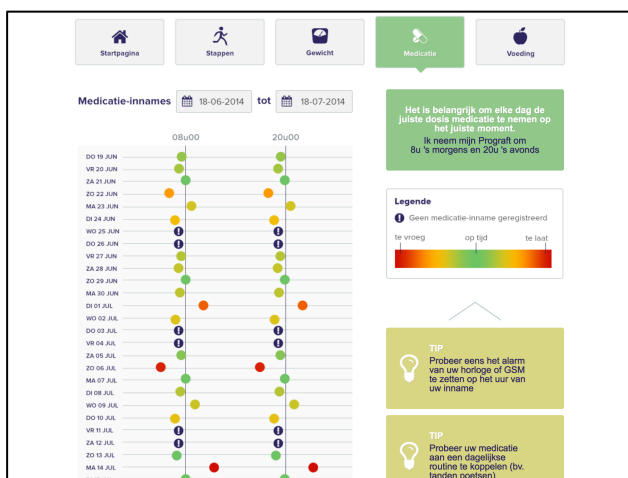


Figure 1: PICASSO-Tx website, giving feedback on medication intake

option depending on the patient’s preference. It aims to study whether patients’ preference for technology to support them and manage their condition impacts health outcomes. Self-management through technology is a promising way to provide support to patients next to the regular visits to the hospital. The system was built using off-the shelf hardware and a custom designed software component. The PICASSO-Tx platform will be deployed in a clinical trial to answer the question about preference.

3.1 System Overview

The goal of the PICASSO-Tx project was to develop an open system, that is free of any judgment. Patients can use this system to measure their own behavior and gain insights in their behavior and themselves. The system is not intended to be used by doctors in the light of self-management and considering the increasing amount of workload of doctors.

The PICASSO-Tx project combines three smart devices tracking the patient’s behavior: a Fitbit One stepcounter², a Fitbit Aria smart scale³, and a smart pill box⁴. The data that is collected with these devices is presented on a dedicated website where patients get feedback about their adherence to medication (see Figure 1 for an example about medication).

As there was a clear need for education to overcome existing health beliefs, the website’s landing page offers patients challenging true or false questions about diet, physical activity, and medication routines.

The website offers patients insight in their step count on a bar graph in a seven-day timeframe. This timeframe allows bad days to be compensated, but does not highlight when a patient’s condition gets worse (e.g. due to a relapse).

Below the seven-day graph, the cumulated distance of their steps is presented on a map. The platform allows patients to set a goal for them to reach, e.g. Santiago De Compostela [40]. Then on a traditional weight graph, patients can track their weight. The graph highlights zones based on BMI by default, but can be customized by the doctor if required.

For medication adherence, the platform can be customized per patient. Most patients need to take their medication every twelve hours, within a window of one hour. We plot the times they took their medication and added a color gradient to indicate the deviation from the prescribed moment (see Figure 1). The more accurate, the greener the dot gets. Once the medication was taken too early or too late, the dots turn red. The gradient emphasizes the fact that it there is some margin, but the more accurate, the better.

² <http://www.fitbit.com/one>

³ <http://help.fitbit.com/?p=aria>

⁴ <http://www.aardexgroup.com/products/mems-cap>

Finally, the website also gives recommendations on healthy diet. This consisted of general diet recommendations based on the Belgian diet guidelines. This information was also shared after transplantation by a dietician and patients received a hard copy of this information once.

3.2 Human-Centered Design Process

We designed the PICASSO-Tx platform in close collaboration with the academic center for nursing. We started the project collecting insights about the current practices of patients using diary studies and contextual interviews. Based on the behavior model of BJ Fogg [15], we asked 19 patients to keep track of their self-management practices related to our PICASSO-Tx project. In a booklet, patients tracked their activities and experience during one week and on dedicated forms patients tracked their diet, physical activity, and medication adherence. We concluded the diary study with a contextual interview at patients' homes to discuss their current practices.

The results showed that the main reason for non-adherence to medication was the interruption of daily routines. For example when the weather is good patients leave their house to go out but forget to bring their medication. Another insight was that people hold false beliefs about diet.

Based on the insights collected with the diary study and the contextual interviews, we started an iterative prototyping phase and made our first sketches of the PICASSO-Tx website. We invited patients to our lab, to test different approaches to give feedback on steps, weight, medication adherence, and healthy diet. We repeated this process using digital sketches and an interactive mockup. In total, we included 12 patients in 3 rounds. All evaluations were conducted in our lab at the university campus.

After the developers implemented our findings, we conducted a field evaluation of the PICASSO-Tx platform. Initially, 20 patients were recruited to use the PICASSO-Tx platform at home. One patient was excluded, as he did not have a working internet connection. Finally, 19 patients were included in the study. The findings presented in this paper are based on this final phase of the project.

All studies within the project were approved by the medical ethical board of the university hospital in Leuven. As most patients were willing to participate the project, we included new patients for every study or round. In every round, we balanced patients from the different solid organ transplant departments (heart, lung, liver, and kidney), as well as condition related variables such as time since transplantation and demographic variables were balanced.

4 METHOD

4.1 Sample

We conducted a field evaluation with 19 patients (11 males, 8 females; aged 21–69 with an average age of 52). The patients in this study were recruited by the academic center for nursing. We included five patients of the heart, kidney, and lung transplant departments, and four patients of the liver transplant department. We balanced patients who claimed they do or do not self-manage one or multiple of our target behaviors (diet, physical activity, and medication adherence). Next to that, we aimed to balance time since transplantation, sex, age, marital status, education, and employment. We used several inclusion criteria: patients needed to be fit enough to participate, live in or close to Leuven (Belgium), and be able to understand and sign the informed consent forms.

4.2 Procedure

We first visited patients at home to install the equipment and explain the platform to the patients. During this first visit, we also conducted a usability evaluation of the final system. This allowed us to tweak the platform before deploying it on large scale in a clinical trial. This visit took one to two hours per patient.

Patients used the PICASSO-Tx platform for two weeks at home. The platform supported their self-management of physical activity, healthy eating, and medication adherence.

After 10 days they were contacted to arrange a second home visit. During that visit, the equipment was uninstalled, and we conducted a closing interview. The interview focused on the patients' user experience after using the platform for two weeks.

4.3 Analysis

The interview data were analyzed using content analysis while specifically focusing on the barriers and enablers that the patients encountered while using the PICASSO-Tx system. During the analysis, we noticed that patients formed mental models of the platform that differed substantially from how we designed the platform. This resulted in a new approach for the analysis to answer the question: *What are expectations patients have about the platform and how do they perceive the system?* We revisited the recordings of the closing interviews and coded the interviews from that perspective. The results below discuss the outcomes of this selective coding of the closing interviews.

5 RESULTS

During the analysis of the closing interviews we focused on patients' expectations towards the system and its implementation, perceptions of the platform, and potential barriers related to these expectations and perceptions after using the PICASSO-Tx system for two weeks at home.

5.1 Patients' Expectations

5.1.1 Expectations towards the system. Patients expected their data to be shared with others such as caregivers, although we were explicit about the fact that only the patient could see their data. They perceived the PICASSO-Tx system as a tool for monitoring by the caregiver and talked about how it would be used by physicians or nurses for follow-up. Although we expected strong and negative opinions about the idea of monitoring by the caregiver through the technology, patients perceived this to be rather positive: *"Now the doctor can see the evolution of a patient [...] What an improvement! Now they can rely on technology to follow-up on patients."*—P13

Our patients saw little problems regarding privacy about sharing this behavioral data. The caregivers in the hospital already ask how things are going, and they are expected to be honest about their adherence, so why would anyone bother about this? *"It's a fundamental principle to help the patient. If it can't happen openly, then the patient should not engage in it."*—P19

However, we did notice that our patients were hesitant about sharing the aspects they had most difficulties with: *"Maybe the number of steps shouldn't be shared, otherwise the doctors become too much like the police. Of course, weight and medication would be fine, as you have to do these things anyway."*—P5

This patient did not have problems with taking medication and used the scales every day, but found it hard to be physically active. With other patients, we encountered objections against different aspects of the platform being shared with caregivers, mostly depending on how well (or bad) they did.

5.1.2 Expectations towards caregivers. Since our patients understood the platform as a way to organize monitoring, they had certain expectations towards caregivers related to this as well. Our patients expressed how they totally understood why physicians would want or even need to have access to the data. In the interviews, they described how physicians would benefit from their data being included in their patient file: *"It would be nice if they, from the hospital, would be able to track when things go wrong. For example when you've had enough and no longer take the medication."*—P8

Patients also saw how the platform would make the contact between caregivers and patients more time-efficient while using it for monitoring them and follow-up: *"If I become ill, I call the hospital. These are long and technical conversations because I have to go through everything I did in the previous days. Now they could look at this system. It's interesting because all information is at one place."*—P19

Next to monitoring and follow-up, patients expected an active role for caregivers in the implementation of the system. The patients expressed their appreciation for physicians, how the caregivers would coach patients and how the system would support the dialogue between the patients and their physicians: *"I think I've done bigger blunders than what is on there, no, the better I got coached, the more I'll gain"*—P19

Some patients even expressed their disappointment because this interaction with caregivers was not implemented in our prototype *yet*—while we deliberately never intended to implement this in the light of self-management. When evaluating the system as an improvement of the current situation, they assumed the interaction with physicians would be available in the 'real' platform. The patients found that the presence of these caregivers on the platform would add credibility to it.

Patients appropriated the system as a tool for monitoring by the caregivers in their treatment. When we use appropriation as a tool to learn more about the users' needs, this shows how patients value a strong role of their caregivers in their treatment. Patients expressed their respect for the professors and their teams at the university hospital, as they the reason they were still alive.

5.2 Patients' Perceptions

Patients perceived themselves as a subject, leaving the active role of monitoring by the caregiver. This was not necessarily a bad thing, as patients expressed how they believed this would improve their situation. They mentioned how the platform helped them to adhere to the therapy and the benefit of a caregiver monitoring their behavior: *"You are more careful when you're being monitored. I woke up at 7:30 am to take my pills. I thought, I have to make sure everything's fine while they monitor me. It certainly makes you more aware."*—P8

The perception of the system in which the patient is being monitored by the caregiver, with an active role for caregivers was articulated in the tendency of our patients to justify their data. Throughout the field evaluation study, patients made notes about the recorded data. As this functionality was not part of the system, to minimize the burden on patients in long-term, several patients used the paper booklet we gave them to note feedback on the system to annotate the data.

In several situations, our patients wanted to clarify why they did not follow the dietary advice (e.g. because they

celebrated a birthday at a restaurant), why they had fewer steps (e.g. because they forgot the stepcounter, or they were ill), or how they actually took it from their other pillbox and not through the new system. *"One time, it said I did not take my medication while I did. Another time, I took my medication from my other pillbox, so not from yours. I would like to add this feedback to the system. The system says that we did not take it, but I would like to indicate that I did take it, so we can cover ourselves."*—P8

Most patients automatically started justifying their data to us and wanted to do so to their caregivers as well (with the expectation that the caregivers would also be able to see the data). When we asked patients why they would want to justify their data, they responded that the physicians might draw the wrong conclusions based on the recorded data: *"If you visit the doctor after three months and he asks why you did not take your medication or why you were too late, he doesn't know what really happened."*—P5

This tendency to justify the data to others emerged persistently throughout the interviews, as patients felt caregivers would monitor the patients' behavior through the system.

5.3 The 'Self' as Barrier for Self-Management Technologies

In our field study, we observed several situations where patients became a barrier for their own self-management. Our analysis showed several barriers for self-management technologies related to the 'self':

1. Confrontation with the self
2. Feelings of shame
3. Lack of identification

5.3.1 Confrontation with the self. In several situations, a gap between the system and the 'self' emerged, opposing each other and raising barriers. Patients have to deal with their condition and its consequences 24/7. Patients acknowledged that therapy adherence was challenging. Also, as patients often were in a very bad condition before they received a transplant organ, their current situation is experienced as better. Several patients acknowledged how time softens memories about their pre-transplant condition: *"We feel good and we feel healthy, then it's easy to forget where we came from."*—P19. But non-adherence could bring patients back to similar or even worse conditions. On top, most patients experience severe side effects from their medication, while the benefit of not becoming ill is something you cannot feel. On the contrary, patients often feel better when they don't take their medication: *"There is no immediate effect of the medication, I feel nothing if I don't take it. At a certain moment,*

you feel good, and you just forget it."—P8. Therefore, patients doubted that putting more responsibility with the patients themselves would improve therapy adherence. As we discussed earlier, the patients call for an active role for caregivers.

Quantifying patients' behavior confronted them with their condition, which was often worse than it used to be. Patients indicated that they experienced the system as an additional reminder of their condition, which was not desirable. Generally, when using QS applications people will feel confronted with their self. In the case of healthy people, they may be able to improve their situation, however in the case of transplant patients their situation is more chronically and there may be a lot harder to improve the situation.

Most patients felt disappointed about their step count, when comparing it to others by asking fellow patients, caregivers, or us during the interview. Also, most patients were aware of the general advice of taking 10.000 steps a day, which was far more than their personal step count which was typically 2.000 to 4.000 steps a day, with some exceptions taking 18.000 steps a day. *"I felt the tendency to be more active while wearing the step counter, because I found the number of steps I took rather small. Is that a positive or negative thing?"*—P1.

This seems positive at first, because our patients are motivated to do more steps. However, the initial disappointment might be reinforced in the long-term, as it is unlikely that the patients' condition will improve substantially due to the nature of the condition. Generally, people in may be disappointed initially when confronted with the number of steps. However, for healthy individuals it will be easier to increase the number of steps whereas in the case of transplant patients, it is unlike that the initial steps might be reinforced in the long term due to the nature of the condition.

Although we encouraged small changes, as these are more sustainable than sudden big changes, this does require some patience: *"The weight is far above the upper limit, but in a downward trend. It should be green instead of red, because red is demotivating while it is actually going down. This should be encouraged! [...] If the graph is not good, it will not be pleasant to use it."*—P6. This patient had a BMI over 40, so his graph was colored dark red. He found the graph demotivating because it confronted him time and time again with the fact that he should lose a lot of weight, which felt unreasonable to him.

Other patients set irrational goals for themselves: *"I had my goals, but it doesn't work in such a short timeframe [disappointed]"*—P11. These disappointments of not meeting (unreasonable high) targets could lead to non-use of the system in long-term.

The system was designed as a companion for the patients in their daily endeavor of managing their health. In constructing new routines by using the system, patients felt it becoming compulsory and the initial excitement of starting to use a new system faded. was replaced by some reservations. *“In the long run it becomes compulsory, we have to do this and then that. It becomes too much for the patient.”—P4*

5.3.2 Feelings of shame. In some cases, patients were reluctant to use the technology due to feelings of shame. *“I now paid attention, but I know that this won't solve anything in the long term. Maybe it would help if my bowel problems [side effect of medication] would be solved. I already experimented a lot with medication, for example by not taking it for weeks. At a certain moment I decided to tell it anyway in the university hospital, because you can't keep walking around with it.”—P14.* In this example, the patient used to hide information from his caregivers by not telling them specific details.

Several patients indicated that they saw the system as a new way to hide or manipulate information for the caregivers: *“I hear so many lies patients tell to their doctors. They can manipulate this system, so it's useless.”—P13*

Some patients felt ashamed about aspects of their condition. We received a lot of feedback from patients on the size of the pillbox, and how it exposes them as a patient to the outside world: *“The pill box is too big. I like to have a little privacy, and you don't flaunt with all the medication you need to take.”—P5.* Several patients searched for workarounds to deal with the conflict between the desire to perform well on the platform and the desire of hiding their condition in social situations. In this example, the patient took his medication at home before he left, so he did not have to take the pill box with him. This patient also requested the functionality to add comments to the tracked data, so he could indicate it was a deliberate action. He would also consider this intake as ok, as to him he had no other choice than taking it early. The system left him no choice.

5.3.3 Lack of identification with the system. Patients often felt that the system did not apply to them and they could not identify themselves with the target audience of the system.

Throughout the whole project, including the field evaluation study, we encountered patients declaring they did quite well. Other patients had troubles adhering to the prescribed therapy, so they were happy to help us with the design of this system, so these other patients could be supported. After using the system, the numbers were not always in accordance to what the patients told us during the first home visit, but they could explain this. Patients told us they were not impressed by the system, as they were aware of their behavior already. Also, patients had very specific or complex guidelines that did not match the system, so even if

they wanted to use the system, it would not work out. But, most patients had no difficulties in coming up with other groups of patients who would benefit from using the system. In their conviction that they did well, our patients often expressed how they did not understand how someone could not adhere to the therapy, considering how important it is— their lives depend on it. *“The death rate seems to be above 20%, because of people not taking their medication correctly or alcohol abuse. Then I think, but that's in your own power! [...] I wonder, what is the kind of people who don't adhere to their therapy?”—P19*

When the tracked data was not as perfect as our patients predicted them to be, they had all kinds of explanations: *“Having few steps does not mean you're not active. For example, after cleaning the house, I had less steps but was more tired. If you would track this, you would think I wasn't active, but I was busy the whole day.”—P2.* They interpreted this as that it wasn't meant for them or stated that the system was inaccurate.

Other patients found conflicts in the provided information on the system and their personal prescribed guidelines. *“The section about nutrition does not appeal to me. You would have to adapt it for every person, because one person has this guideline and the others that guideline. I don't have to worry about sugar, but I can't eat crudités. [...] Also, this changes over time. Earlier, I could eat crudités though, that was ok for both my liver and my kidney.”—P15*

Also, in their final verdict, our patients doubted whether the system was meant for them. Although some patients admitted they were surprised at some time during the study, it was often attributed to inaccuracies of the system. Our patients indicated that they actually were aware of their behavior, and that the system did not change much about this: *“I won't use the step counter, I know what I do.”—P5; “Eventually, you know what you do. It's your own body.”—P6*

As patients were talking how this monitoring by the caregiver system would improve the situation in general, we were wondering how they saw it working for themselves. As most patients believed they did well on the aspects that really mattered, they saw the platform of little use for themselves. However, patients could think of different other groups of our patients like elderly or new patients for whom it would be useful: *“I don't think it would be useful for me, but what if I can't do it anymore in ten years? [...] I think it could be very useful for people who can't check upon their own behavior”—P13*

This feedback returned throughout the project and our interviews in the field study. Our patients did come up with groups of our patients who might benefit from using the system. The overall suggestion by patients was to focus the project on these groups. The most commonly heard suggestions were new patients – also from patients who were

only recently transplanted patients – and elderly – again, even our oldest patients stated that older patients would need this. *“I would recommend it for someone who is starting. For me, who has her routines, I don't think we should be forced to change it. But they could follow-up on new patients using the system right away.”*—P2

“It can only serve people who aren't able to control themselves anymore”—P13

6. DISCUSSION

The field evaluation showed that using self-management technology, patients hold expectations towards their caregivers: they expect their caregivers to look over their shoulder at the data and even intervene when things go wrong. In this way, the technology is considered as a companion to the caregiver rather than to the patient. Comparing this with our initial perspective on self-management (the patient as actor in his or her own care), patients see themselves rather as subject and in a more passive role. In patients' perceptions, caregivers still have an important active role. There is a discrepancy between the patients' mental model the self-management technology assumes and the mental model that the patient has.

One can argue that across countries the usage of the health care delivery model varies as the clinical decision-making process is influenced by cultural norms. The way how information about the patient and the wishes of the patient is collected and used varies across countries. For example, in Russia, a country that is authoritarian of nature, doctors tend to take into account patient's wishes less often compared to other countries such as Germany and Sweden, countries that are less authoritarian of nature [32]. Self-management in healthcare enables patients to be less dependent on their caregivers and empower the patient to take a more active role in the health care process. For the above reasons, self-management in healthcare may be more natural in cultures that are less authoritarian versus cultures that are more authoritarian of nature. In Belgium, healthcare is strongly hierarchical, which could have influenced our results. Still, we argue that taking into account patients' expectations towards caregivers should not be ignored when designing and implementing self-management technologies in any case.

In our study, patients often felt bad due to the confrontation with the fact that they are patients, who are chronically ill. Their complex therapy, which is hard to adhere to, is utterly important as it is keeping them alive. Technology to support these patients risks to isolate them even more as patients, while we heard so many times that patients just want to be normal. Also, patients often assess their own condition or behavior better than it actually is. A platform that targets patients who need support for diet, physical activity and

medication adherences often does not match patients' perceptions of themselves.

We argue that the design of self-management technology should be inclusive and flexible. By targeting its users as people, not patients suffering from a specific condition, more patients might identify themselves as target users. This connects with the modular DIY co-development approach for the self-management of anxiety by Simm et al. [35]. Also, family members could use the system as well. In our study, family members often asked us whether they could use the system to support the patient or because they were interested in their own behavior as well. In our current implementation of the PICASSO-Tx system, the whole family could use the scales, but only the weight of the patient was recorded. In several households, multiple family members reported using the scales.

We wanted to avoid that the system would resemble as a tool for monitoring and did not open up the data for anyone else but the patient, as we feared that patients would be uncomfortable with this idea. However, patients did perceive the system this way. To our surprise, they did not consider this as a bad thing. On the contrary, they perceived the system as a perfect tool for their caregivers to improve care. The system was considered a companion for the caregivers, rather than for the patient. Our patients did not bother much about the system, as long as it serves caregivers in providing care. Based on these findings, we suggest to clearly indicate what data is private for the patient, and what data is shared with other parties (even if all data is kept private, as in our system). Doing so, the privacy concerns as described by Maniam [28] can be addressed. Also, allowing patients to justify the recorded data (both for private and shared data) might increase patients' feeling of comfort with the data and enable them to reflect upon their data.

6.1 Summary: Design Recommendations

1. Specify and explicate the presence and role of caregivers on the platform. This information adds credibility to the platform and allows patients to adjust their expectations both towards the system and their caregivers. Because the system was used in the hospital context, patients assumed that all caregivers in this context were able to access the platform. When this is not the case, it is important to explicate the absence of caregivers, given that the system is used in this hospital context.

2. Allow relatives to join the platform as well. This would bring patients and relatives closer together, breaking the perceived isolation of patients as patient.

3. Indicate what information is private and what is shared with others, such as caregivers or family members. Also, allow patients to decide themselves what is being shared through the platform. Again, not sharing specific aspects also provides valuable information to the caregivers, that can be taken up during personal contacts. This will increase the autonomy of the patient and puts the needs of the patient central. Some people may feel the need to share with caregiver and family, but others not. This increases flexibility of the system.

4. Allow patients to justify the recorded data, both for themselves and for their environment. For example, by adding notes to missing data and/or outliers. This enables them to correct for errors, make mental notes and reflect upon their data and hence manage their own condition better.

6 Conclusion

In the line of research on technology appropriation, and Satchell and Dourish [34] their argument that non-users are *not* bad users, we argue there is no wrong use of self-management technology by the patient. However, design could be improved in some cases which could fit the end-user better, taking into account the patients mental model of care and how the technology fits in there. While this study is about use, we do argue our findings contain predictors for non-use or abandonment because of a mismatch of the design intentions and user perceptions. We do not call for ways to fix *'the mistake at the end-users's side'* but do argue for awareness regarding our findings when thinking about self-management technologies. In this way, the patients' expectations and perceptions of the PICASSO-Tx system can guide future design of self-management technologies.

We saw how patients still have certain expectations towards their caregivers when using self-management technologies. Based on these findings, we argue that self-management technologies can be successful in the aim for better care if the platform is not targeting its users as patients, who are ill, but as people, and if it balances the benefits for both its users and their environment.

As for the PICASSO-Tx system, this will now be evaluated in a randomized controlled trial to investigate the efficacy of the self-management technology. Also, a cost-efficiency study will examine whether the system – including the remaining human effort – is beneficial from an economical perspective. If both studies have positive outcomes, the system will be adopted in regular post-transplant care.

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