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Self-management support system for renal transplant patients
Understanding adherence and acceptance

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SELF-MANAGEMENT SUPPORT SYSTEM FOR RENAL TRANSPLANT PATIENTS

UNDERSTANDING ADHERENCE AND ACCEPTANCE

SELF-MANAGEMENT SUPPORT SYSTEM FOR RENAL TRANSPLANT PATIENTS

UNDERSTANDING ADHERENCE AND ACCEPTANCE

Proefschrift

ter verkrijging van de graad van doctor
aan de Technische Universiteit Delft,
op gezag van de Rector Magnificus prof. ir. K.C.A.M. Luyben,
voorzitter van het College voor Promoties,
in het openbaar te verdedigen op
donderdag 7 september 2017 om 15:00 uur

door

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CONTENTS

SUMMARY

Computer-based support for disease self-management has been proposed for chronic patients to stimulate early awareness of disease changes, facilitate patients' autonomy, and reduce demands on health care resources. Renal transplant patients need lifelong care and can be viewed as chronically ill: they visit hospital regularly to monitor their blood level creatinine and blood pressure. They should also benefit from self-management as other chronic patients do. For the renal transplant patients, a self-management support system (SMSS) was designed and tested, with which they could conduct self-measuring regularly to check the renal function and get corresponding feedback. In the study, there were three feedback categories: (1) *alright*, and therefore patients did not have to take an extra action; (2) *mild concern*, and therefore patients were requested to measure again; and (3) *concern*, and therefore patients were advised to contact the hospital. To conduct self-management safely, it is important for the patients to follow the protocol and the system feedback. Therefore, to understand these patients' self-management behaviour, preferences, and adherence, this thesis investigates possible influencing factors for them to adhere to and accept the SMSS.

The study entailed two related research lines: a lab study line that focused on the user interface design of a SMSS, and a clinical trial line that focused on patients' acceptance and adherence of a SMSS.

In the lab studies various SMSS prototypes were systematically designed and tested with patients. In the first step, we derived three design principles for a SMSS based from relevant literature. These principles convey information about the renal function differently: (1) empowering the patients by providing more insight into the status of their renal function, (2) simplifying communication to reduce patients' effort to manage their health, and (3) providing empathic support to address patients' emotional needs. In the second step, each principle was worked out in a user interface design. These designs were evaluated with 16 renal transplant patients. The main finding of this evaluation was that patients' adherence to and preference for a specific type of the user interface design depend on the state of their renal function. When confronted with a mild concern situation, the level of adherence was higher for the empower interface compared to the simplicity or affective interface. When confronted with an alright or concern situation, no such difference was found.

Given that differences in renal function could influence patients' attitude, the second lab study focused on the needs of different patients: Recently or less recently operated patients. Two communication styles were designed accordingly: (1) a *guided* style that included additional information layers to provide more interpretation support and a virtual health agent showing empathy to address emotional needs, and (2) a *factual* style that showed only measurement history, medical information, and recommendations. The study found that attitude and preference towards these two styles varied between recently or less recently operated patients groups. For example, the less recently trans-

planted patients were more positive towards factual than the guided style in situations that gave no cause for concern.

The clinical research in this thesis was part of a clinical trial, in which 65 patients were recruited to use a SMSS for one year. The first research question in the clinical line was what factors influenced patients' acceptance of a SMSS. A patient technology acceptance model was designed, which had the factors of performance expectancy, effort expectancy, social influence, facilitating conditions, affect, self-efficacy, and trust. To evaluate the model, a survey was conducted among those patients who had used the SMSS for 4 months ($n = 50$). The findings revealed that this model could explain 26% of the variance between patients' intention to continue using the SMSS. Trust and performance expectancy could provide part of the explanation, but not beyond the explanation given by patients' affect towards the system. To understand the patients' one-year usage and adherence to the SMSS, the online entries and measurements recorded by the measuring devices of 47 patients were compared. Analysis of patients' adherence revealed that from the online entries that could be directly linked to single measurements (86.4%), 8.9% deviated from measured values, and 10.7% of the online entries were derived from a series of measurements. The analysis also revealed that the patients highly adhered to the measuring frequency set by the protocol, but adhered less when it came to (1) entering the measurements online on time, and (2) following the system's instructions. It implies the need for strategies that could avoid or reduce delayed manual online entry.

Concerning both research lines, we now have a better understanding about factors affecting patients' adherence to and acceptance of a SMSS: the medical health condition of the renal function affects patients' adherence and preference, the interaction between communication style of a system, patients' experience level, and medical health condition affects patients' preference, a patient technology acceptance model can partly explain patients' acceptance, patients less adhere to timely entering the measurements. Although the studies were conducted in the context of renal transplant patients, the insights obtained should also be considered for self-management of other chronic diseases, such as asthma, cancer, or HIV.

SAMENVATTING

Voorgesteld wordt door middel van computertoepassingen mensen met een chronische aandoening te ondersteunen bij het zelfmanagement van hun ziekte en om te stimuleren dat zij zelfstandig vroegtijdige veranderingen in hun ziektebeeld kunnen waarnemen en daarmee het beroep op de zorg kunnen verminderen. Nierpatiënten, waarbij niertransplantatie heeft plaatsgevonde, hebben levenslang zorg nodig, net als bij een chronische aandoening bezoeken zij regelmatig het ziekenhuis om hun creatine niveau in het bloed en hun bloeddruk te monitoren. Zij zouden net als andere chronische patiënten baat kunnen hebben bij zelfmanagement. Voor de nierpatiënten is een zelfmanagement support system (SMSS, een Engelstalige afkorting) ontworpen en getest waarmee zij zelf regelmatig het functioneren van hun nier(en), op basis van zelf gemeten waarden, kunnen controleren en daarover feedback kunnen krijgen. In het onderzoek werden drie feedback categorieën onderscheiden: (1)*veilig,* geen extra actie was noodzakelijk; (2)*enigszins zorgelijk,* de patiënten werd gevraagd opnieuw te meten; en (3)*zorgelijk,* de patiënten werd geadviseerd contact op te nemen met het ziekenhuis. Om zelfmanagement veilig uit te voeren, is het voor patiënten van belang dat zij het protocol alsmede de gegeven feedback vanuit het ondersteunende SMSS opvolgen. Om het zelfmanagement gedrag, de voorkeuren en de gebruikerstrouw te kunnen begrijpen worden in deze thesis de factoren onderzocht die van invloed kunnen zijn op de acceptatie en het blijven gebruiken van een SMSS door de patiënt.

Het onderzoek bestond uit twee aan elkaar gerelateerde onderzoekslijnen: een laboratorium studie met de focus op het ontwerp van de gebruikersinterface voor een SMSS, en een klinisch onderzoek dat zich richtte op de acceptatie en gebruikerstrouw van een SMSS.

In laboratorium studies werden verschillende prototypen voor een SMSS systematisch ontworpen en getest met patiënten. In de eerste stap ontwikkelde wij drie ontwerp principes voor een SMSS op basis van relevante literatuur. Deze principes brachten informatie over de nierfunctie op verschillende wijze over: (1) door de patiënten te 'empoweren' door hen meer inzicht te geven in de stand van zaken van hun nierfunctie, (2) door middel van simpele informatie waarmee patiënten zonder inspanning hun gezondheid kunnen managen, en (3) door hun op empathische wijze te ondersteunen waarbij rekening gehouden wordt met eventuele emotionele behoeften. In de tweede stap werd elk genoemd principe uitgewerkt tot een ontwerp voor een gebruikersinterface. Deze ontwerpen werden met 16 nier transplantatie patiënten geëvalueerd. De belangrijkste bevinding uit deze evaluatie was dat de voorkeur van de patiënt voor een specifiek type gebruikersinterface ontwerp en de daarbij verwachte gebruikerstrouw afhangt van de stand van zaken van het functioneren van de nier(en). Indien geconfronteerd met een enigszins zorgelijk situatie was het niveau van de verwachte gebruikerstrouw hoger bij gebruik van de "empowerment" interface vergeleken met de "simpele" of de "affectieve" interface. Indien geconfronteerd met een veilig of zorgelijk situatie, werd er geen verschil

gevonden.

Gegeven, dat het verschil in functioneren van de nier(en) ook invloed kon hebben op de reactie van een patiënt, ging de tweede laboratorium studie over de verschillende behoeften van twee typen patiënten: recent getransplanteerde of minder recent getransplanteerde patiënten. Twee communicatie stijlen werden achtereenvolgens ontworpen: (1) een *geleide* stijl waarbij aanvullende informatie lagen toegevoegd werden om te voorzien in meer ondersteunende uitleg, aangevuld met een 'virtuele gezondheid assistent' die empathisch reageerde om emotionele behoeften te ondersteunen, en (2) een *feitelijke* stijl die alleen maar de gemeten waarden toonde, medische informatie gaf en aanbevelingen. De studie toonde aan dat de reactie en de voorkeur ten aanzien van deze twee stijlen varieerden tussen recent en minder recent getransplanteerde patiëntengroepen. Bijvoorbeeld, de minder recent getransplanteerde patiënten waren meer positief over de stijl waar de 'feiten' werden gegeven dan de 'geleide' stijl in situaties waarin de meetresultaten geen aanleiding tot zorg gaven.

Het klinische onderzoek in deze thesis maakte onderdeel uit van een 'clinical trial', waarin 65 patiënten werden geworven om een SMSS te gebruiken voor een jaar. De eerste onderzoekvraag in de klinische onderzoekslijn was: welke factoren beïnvloeden de acceptatie van een SMSS door een patiënt. Een 'patiënt technologie acceptatie model' werd ontworpen, gebaseerd op de factoren: prestatieverwachting, inspanningsverwachting, sociale invloed, facilitaire condities, gevoel, zelfvertrouwen en vertrouwen. Om het model te evalueren werd een vragenlijstonderzoek uitgevoerd onder de patiënten (n=50) die het SMSS voor een periode van 4 maanden hadden gebruikt. De bevindingen toonden aan dat dit model 26% van de variantie kon verklaren in het voornemen van de patiënt om het SMSS te blijven gebruiken. De factoren vertrouwen en de prestatieverwachting konden dit gedeeltelijk verklaren, maar er was geen verklaring rond het 'gevoel' dat patiënten hadden ten opzichte van het systeem. Om het gebruik en de gebruikerstrouw van het SMSS over een jaar door de patiënt in kaart te brengen, werden de 'online' ingevoerde meetresultaten en de meetwaarden zoals opgenomen in de meetinstrumenten met elkaar vergeleken. De analyse van de gebruikerstrouw van de 'online' ingevoerde gemeten waarden toonde voor 86,4% aan dat deze direct 'gelinkt' konden worden aan een enkele meting uit het meetinstrument, 8,9% week af van de werkelijk gemeten waarde, en 10,7% van de 'online' ingevoerde meetresultaten waren afgeleid uit een reeks van uitgevoerde metingen. De analyse toonde ook aan dat de patiënten zeer trouw de ín het protocol aangegeven frequentie van uit te voeren metingen met het meetinstrument opvolgden, maar dat zij minder trouw waren in (1) de meetwaarden in te voeren en (2) de 'feedback' instructies op te volgen. Dit houdt in date r behoefte is aan strategieën die voorkomen of verminderen bij handmatig 'online' invoeren van meetresultaten.

Beschouwen wij de beide onderzoekslijnen, dan kunnen wij vaststellen dat wij nu een beter begrip hebben omtrent factoren die de acceptatie en de gebruikerstrouw van een SMSS beïnvloeden: de medische conditie van de nier functie beïnvloed de gebruikerstrouw en de voorkeur voor de interactie tussen de communicatie stijl van een system. Het ervaringsniveau, en de medisch conditie hebben effect op de patiënt voorkeuren, een patiënt technologie acceptatie model kan gedeeltelijk de patiënt acceptatie uitleggen en patiënten zijn minder trouw in het tijdig invoeren van de meetresultaten. Ofschoon de studies werden uitgevoerd in de context van nier transplantatie patiënten,

zouden de verkregen inzichten ook overwogen kunnen worden voor zelfmanagement support systemen voor andere chronische aandoeningen, zoals astma, kanker of HIV.

1

INTRODUCTION

1

Two trends in society may lead to an undesirable increasing demand on healthcare resources. First, the ageing of the population in developed countries raises the need for elderly care[1]. Second, there is an increasing prevalence of patients with chronic diseases who can expect longer life spans for which they need regular care[2, 3]. Both trends require more resources over a longer period of time and for more treatments. These resources are limited; do not only referring to money, but also to the (near future) shortage of labour force.

The increasing costs and shortage of medical resources require more individuals to adapt their lifestyle to cope actively with their chronic disease[4–6]. In this context, self-management has been proposed as a solution[7]. It includes treatment management, lifestyle management, and emotion management[6, 7]. For example, patients should take medicine properly, adapt to a healthy diet, and accept their diseases emotionally[6, 8]. More generally, self-management could increase the behavioural compliance with medical standards, stimulate early awareness of disease changes, and facilitate patients' autonomy[6, 9].

To support patients with self-management, computer-based Self-Management Support Systems (SMSSs) have been proposed. These systems empower patients, giving them more control of their care process and daily activities, and thereby increasing their autonomy[10]. Current SMSSs support patients in different ways, focussing on knowledge, action guidance, or communication. Knowledge support focuses on how to conduct self-management, such as knowledge on self-monitoring or relevant problem solving skills[11]. Guidance support focuses on patient's creation, adjustment and execution of plans for their daily life, such as exercise, diet, and self-monitoring[12–14]. Communication support focuses on the information exchange with care-givers or fellow patients [10, 15]. Beneficial effects of such SMSSs have been shown for several chronic diseases, such as heart disease, chronic lung disease, and type 2 diabetes[10].

1.1. SELF-MANAGEMENT SUPPORT FOR RENAL TRANSPLANT PATIENTS

ACCORDING to our knowledge, there is not (yet) a SMSS for renal transplant patients developed, whereas this patient group could have high benefits from such systems. The transplant rate was 59.2 per million population in the Netherlands in 2014[16]. These patients had a kidney transplantation to treat the End Stage Renal Disease, and they seem to have a real need for the proposed SMSSs.

In general, kidney transplantation provides a substantial improvement of patients' well-being. Dialysis is an alternative treatment for transplantation, but has a higher risk of mortality[17]. In addition, a successful kidney transplant brings more freedom and energy than dialysis does[18]. After the transplantation, however, complications may occur, such as rejection of the transplanted kidney[19, 20]. Therefore, renal transplant patients need lifelong care and are treated as chronically ill. Usually, patients visit the hospital regularly to monitor their kidney function by measuring the *creatinine level* in their blood. In addition, *blood pressure* needs extensive monitoring too, because hypertension is both a potential indicator of decreased kidney function and an important risk factor for kidney graft failure[21–24].

To better understand the disease management and support needs of renal transplant patients, and to develop a SMSS prototype to meet these needs, the ADMIRE project (Assessment of a Disease management system with Medical devices in Renal disease) was carried out. This project developed and tested a SMSS that supported patients to learn relevant self-management knowledge and to perform self-measurements. The overall aim was to empower these patients in such a way that they can conduct daily self-management at home and visit the hospital less frequently. In addition, the SMSS should help them to be better informed about their current health status, to know their health status better, and to be more alert to detect early symptoms of graft failure. It should be noted that the SMSS has to meet a specific challenge for this patient group, i.e., its *acceptance* and *adherence* level. Unlike most other chronic patients, the risk of possible acute rejection and the tremendous consequences of losing their kidney may let renal transplant patients have more reservations towards using a SMSS and relying on its advice.

This thesis studies the factors that may affect patients' acceptance and adherence. For example, acceptance and adherence may be affected the state of the renal function and the level of experience (of being a renal transplant patient, or of using a SMSS and coping with specific medical health situations). Taking such factors into account, the thesis provides interaction design approaches to improve the user interface with feedback on the self-measured data, which invokes appropriate actions of the patients (e.g., maintaining the self-measurements routines, performing additional measurements, or consulting a caregiver). By using this system, it was expected that the patients would know their renal status better, be more alert, and visit hospital less frequently. The ADMIRE study included a randomized controlled trial among kidney transplant patients where the control group went through usual care while the intervention group conducted self-management with the SMSS for one year. This thesis reports on how patients in the intervention group used and experienced the SMSS.

1.2. RESEARCH QUESTION

RENAL transplant patients need to accept and adherence to the SMSS support, so that this support can become effective. Therefore, we need to have a good understanding of the factors that affect patients' acceptance and adherence: Patients' characteristics (like their health condition, self-management behaviour, and preferences) and the design characteristics of self-management support systems, the main research question of this thesis is:

> *What are influencing factors, concerning the patient or the design characteristics, for renal transplant patients to adhere to and accept a self-management support system?*

A further analysis of this main question shows that, three aspects of patients' self-management should be well-accommodated by the support, i.e., patient's (1) (physical) condition, (2) level of experience with his or her (evolving) disease situation, and (3) technology acceptance.

First, the thesis argues that patients' adherence to and preference for a specific type of user interface design differ as it depends on the *physical condition* (i.e., the state of the

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renal function) patients are confronted with at a certain moment (i.e., the patients can *value* the support differently, due to variations in renal function). There is a large amount of relevant literature about user interface design[25–28], but the different design guidelines seem to lack coherence, and do insufficiently address value dependencies (i.e., how to project values with their dynamics and interdepencies on user interface design solutions). Currently, there are "just" different values behind these design guidelines. In the SMSS domain, various core values can be addressed, such as a comfortable life, inner harmony, or self-control[29] leading to different user interface design that could affect patients' adherence and attitude. Besides variations between patients, the importance a patient might give to certain values might depend on situations they are confronted with[30]. An important element in the patients' life that determines how they perceive a situation is of course their health. Uncertainty, risk of imminent health complications, or a stable health situation with no indications of complications set in motion different cognitive and affective needs[31, 32]. To respond to these needs, an adaptation of the SMSS is required. For example, chronically ill patients' perception of the course of their illness proves to be a predictor of their support needs in self-management activities[33].

Continuing on the idea of variation in patients' needs, the **second** position argued for in this thesis is that patient preference on how a SMSS communicated with them changes, because of the *experiences* patients obtain during their life as chronic patients. As the model of self-regulation processes in disease prevention and management indicates, chronic patients learn over time specific strategies on how to manage their disease [34]. Sen and Spring for example observed that young people with long-term illnesses, overtime become more informed, and their confidence and capacity to cope with their condition increase[35]. Decker's findings that adolescents 1 to 3 year from diagnosis of cancer have higher needs for information about depression, death, and helping others with cancer than newly diagnosed adolescents also reflect this change over time[36]. Addressing these patients' needs can be beneficial. For example, receiving empathy from physicians has been positively associated with health outcomes, patient satisfaction, patients' ability, and reduction of patients' anxiety and distress[37]. As it has been shown that people respond to computers to some extend similarly as to other persons[38], Fogg proposed to use social cues in computer systems to express empathy and improve adherence[39]. Blanson Henkemans et al. demonstrated, for example, that computer applications with emotional responses result in better health outcomes, better adherence to self-management, and less motivation declination[40]. Therefore, to satisfy patients' need for empathy or social communication, a system could use social cues, such as a virtual agent with different facial expressions, to express empathy. However, some patients would prefer a more straightforward instruction or explanation, instead of empathy, especially if they are already familiar with the system or the situation[41]. As newly transplant patients would be more anxious or worried[42], it is likely that less experienced, i.e., less experienced, patients will prefer empathy, while more experienced, i.e., more experienced, patients will prefer conciseness.

Besides the user interface design, other factors should also be considered to understand renal transplant patients' acceptance when implementing a SMSS. Both generic and specific models have been proposed to explain users acceptance of information technology or information systems. The most well-known generic ones are the the-

ory of reasoned action[43], the theory of planned behaviour[44], the technology acceptance model (TAM)[45], and their extensions, such as TAM2[46], the unified theory of acceptance and use of technology[47], and TAM3[48]. These models are widely used and can explain 17% to 70% of the variance in peoples' intention of using information technology[47]. Meta-analysis and review also revealed that TAM and its extensions are valid and robust, that they may have more applicability, and that more factors should be integrated[49, 50]. Therefore specific models, which are often derived from generic models with more variables, have been formulated for specific domain, such as for internet commerce[51, 52], online gaming[53], and mobile commerce domain[54]. The position taken in this thesis is that a domain specific model is able to, at least for a part, explain the variation between renal transplant patients to accept a SMSS.

For self-monitoring to be useful, the self-monitored data need to be accurate and reliable. Different levels of accuracy and reliability of self-monitored data have been found in studies of other diseases. Most studies have been performed on self-monitoring blood glucose, with reliable logbook entries ranging from 46-79%. Interestingly, when patients knew the logbook data would be compared to device memory, the reliability increased considerably[55]. For self-monitoring blood pressure, reliability was found higher on average[56–58]. However, one study found serious deviations in that 20% of the logbook entries were > 10 mmHg different than actual values[57]. Among the highest level of reliability was found for self-monitoring of international normalized ratio, a measure for blood coagulation; the majority of patients had a 100% accuracy[59]. Besides reliability of reporting measured data, adherence to measurement protocol is also essential to ensure the self-monitoring to be safe. One pilot study (van Lint et al., 2015) showed that adherence to self-monitoring creatinine was high in the first months after transplantation, with the majority of renal transplant patients reporting more measurements than required[60]. However, differences between patients were large and seemed to increase over time[60]. In other disease populations, level of adherence ranged from 52-92%[58, 61–66] and decreased over time[67]. More insight into the reliability and adherence to self-monitoring protocol using a SMSS is still needed. To conclude this section, from the main research question and the main tenets introduced, it is now possible to derive the following three hypotheses that are addressed and discussed in this thesis:

H1. Renal transplant patients' adherence to and preference for a specific type of the user interface design- depend on the state of their renal function they are confronted with.

H2. Renal transplant patients' preference for a specific communication style depends on their level of experience (of being a renal transplant patient, using a SMSS, and coping with specific medical health situations).

H3. A domain specific patient technology acceptance model can partly explain renal transplant patients' acceptance of a self-management support system.

Besides these theoretically founded hypotheses, the thesis also has an explorative character, in that it tries to answer the following research question:

Q1. How do renal transplant patients use and adhere to a self-management support system?

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1.3. METHOD AND THESIS STRUCTURE

T O test the hypotheses and answer the explorative research question, the work was done in two parallel branches: one focussing on the design of the SMSS with studies in the lab, the other focussing on patients' acceptance and adherence of a SMSS in the context of the clinical trial (Figure 1.1). To test the first hypothesis, an iterative cognitive engineering approach was followed[68]. Each iteration included designing and then evaluating the SMSS interface, with the exception of the first iteration. This approach led to improved designs based on insights gained in previous iterations. In the first iteration, three different design concepts were formulated based on several design principles. Each of the design concepts was then used to develop a paper prototype that was evaluated with non-patients in the second iteration. In the third iteration, the prototypes were modified and evaluated with a group of renal transplant patients. This led to one adjustable prototype in the fourth and final iteration. Here the prototype was reviewed by a group of renal transplant patients in a focus group setting. In addition to the usability insights, the review also provided a better understanding of patients' underlying values and concerns. The iterations and corresponding results are described in Chapter 2.

The study continued with testing the second hypothesis regarding the effect of patients' experience. Based on patients' different experience levels, two communication styles were designed and implemented as a web-based prototype. One style, the guided style, provided additional information layers with more interpretation support and a virtual agent showing empathy to address emotional needs. The other style, the factual style, only presented measurement history, medical information, and recommendations. Fifty-one renal transplant patients with three different experience levels (recently transplanted and no SMSS experience, not recently transplanted and no SMSS experience, not recently transplanted and with SMSS experience) were recruited to interact with the prototype. Their understanding, adherence, and attitude towards the two communication styles were examined and compared. Chapter 3 describes this study in detail.

Paralleled with the lab experiments, 68 patients were recruited and allocated to the intervention group of the clinical trial. Here the renal transplant patients used a SMSS for one year. Their response to questionnaires and their behaviour were the source to test the third hypothesis about the acceptance model and explore their use and adherence behaviour. First the literature was reviewed to identify possible factors that could explain patients' acceptance of the SMSS. This led to the formulation of a domain specific acceptance model. Generic questionnaire items to measure each factor were obtained from the literature and, subsequently, adapted to the application domain. This domain adaptation was done in focus group discussions with experts and patients. The resulting questionnaire was given to patients in the clinical intervention group, who were asked to complete it twice: once at the start of the trial and once after using the SMSS for four months. The data from this questionnaire were used to test the domain specific patient technology acceptance model. A detailed description of this study and the results are presented in Chapter 4.

Patients' self-management behaviour in the clinical trial was also analysed to answer the explorative research question regarding patients' reliability and adherence of using

Chapter 1. Introduction

Lab experiments on
prototypes to
provide advice

Chapter 2. Design of
patient support

Chapter 3. The effect of
patient experience

Clinical trial
of the SMSS

Chapter 4. Acceptance
of the SMSS

Chapter 5. Behaviour
with the SMSS

Chapter 6. Conclusion
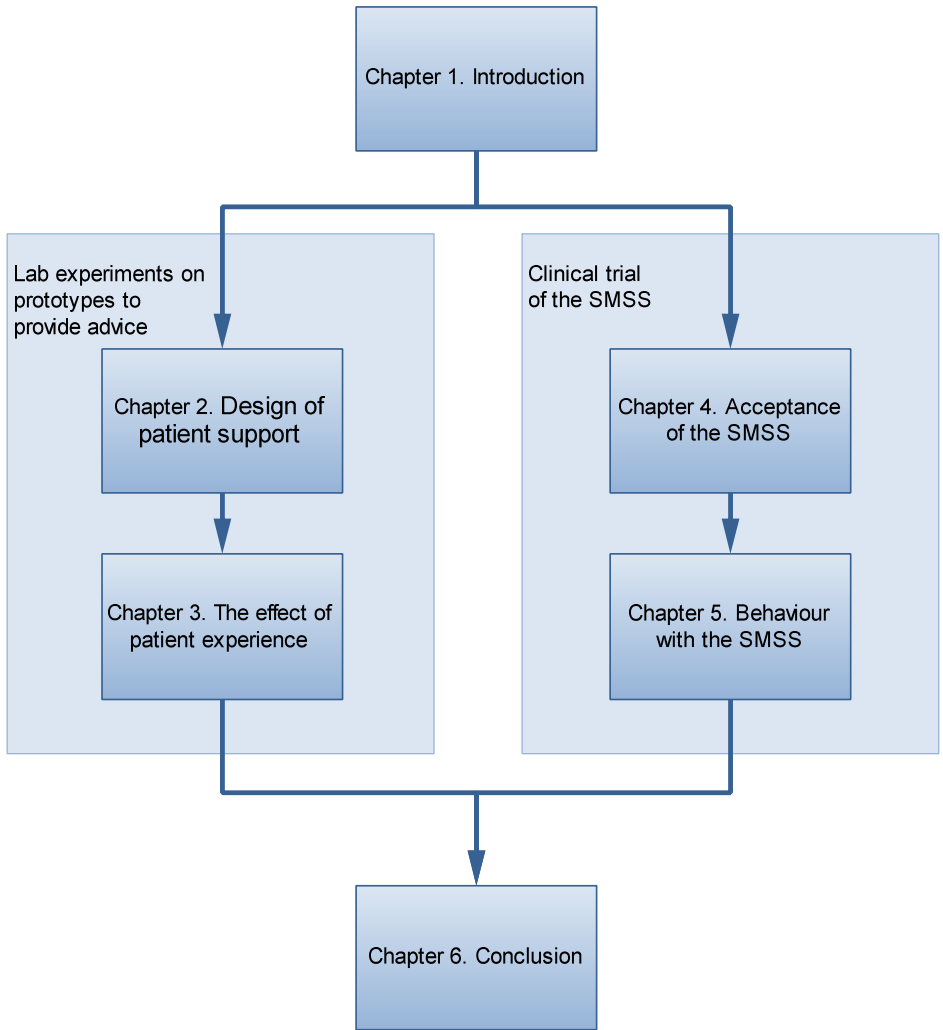
Figure 1.1: Thesis Outline

a SMSS. Two types of data were recorded and compared: the (1) creatinine level that the mobile device measured and (2) the creatinine level that the patients entered into the online monitoring system (this system provided the patients with feedback and advice). As the system could also advice patient to contact the hospital, the record of hospital visits was also examined to see how well patients followed up this advice. Detailed analyses of this data can found in Chapter 5.

The conclusions that can be drawn from all these studies are presented in the final chapter, chapter 6. Here the limitations, suggestions for future work, and the contribution of the work presented in this thesis are discussed.

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2

HOW TO SUPPORT RENAL TRANSPLANT PATIENTS WITH SELF-MONITORING AND TAKING APPROPRIATE ACTIONS

Previous chapter introduce the background of this thesis. This chapter aims to improve patients' adherence to a self-management protocol. To achieve it, different presentations of the renal function with relevant explanation and advice were developed in this chapter. We aimed to propose appropriate design rationales by examining patients' reaction to each presentation. This chapter consists of four iteration cycles. In the first iteration (section 2.2), three different design concepts were formulated. Based on the design concepts, three paper prototypes were develop and evaluated with non-patients in the second iteration (section 2.3). In the third iteration (section 2.4), the prototypes were modified and evaluated with renal transplant patients. Section 2.5 presents the final iteration. It led to a single adjustable prototype that a group of renal transplant patients reviewed in focus group setting. Section 2.6 concludes that patients behave and value differently depending on the state of their renal function and on their post-transplant lifestyle adaptation stages.

ABSTRACT

R ENAL transplant patients might benefit from reducing hospital visits by a self-management support system (SMSS) that helps them to self-monitor at home. This paper presents the development of different presentations of the monitoring feedback to improve patients' attitude and reaction.

This study follows an iterative cognitive engineering approach. The first iteration identified three design concepts: simplicity, affection, and empowerment. The second iteration instantiated and tested these concepts in an experiment with non-patients ($n = 12$). The participants' behaviour and attitude towards the different designs were compared. The third iteration refined and evaluated the prototypes in an experiment with renal transplant patients ($n = 16$). The fourth iteration refined and evaluated the prototypes in focus groups with renal transplant patients ($n = 7$) to get in-depth understanding.

Patients showed a significant lower level of adherence in uncertain situations (i.e. recommended to re-measure) compared to certain situations (i.e. recommended no action, or to contact hospital), and in the uncertain situations they tended to adhere more to the empowerment design than to the other designs. The results also revealed different preference rating for the three designs. The focus groups revealed that patients' attention, emotions, and self-esteem needs vary according to their lifestyle adaptation stage and the renal function status.

This paper shows that patients adhere to and prefer the designs differently depending on their renal state. The renal state and patients' post-transplant lifestyle adaptation stages may affect their values and concerns. This suggests SMSSs need an adaptable way to present monitoring feedback.

KEYWORDS
User interface design, costumer health, self-management support system, feedback, attitude, adherence

2.1. INTRODUCTION

T HE combination of an aging population and increasing prevalence of chronic diseases requires more individuals to adapt their lifestyle to cope actively with their chronic disease[2–4]. In this context, self-management, i.e., the process of managing symptoms, treatment, physical and psychosocial consequences, has been proposed for chronic patients[5]. It is believed that self-management could increase compliance with medical standards, stimulate awareness of early physical changes, and facilitate patients' autonomy[4, 6]. Computer support has been suggested as a mean to support patients with self-management[7]. These computer systems, referred to as self-management support systems (SMSSs), can help empower patients by giving them more control of their care process and daily activities, thereby increasing their autonomy[7]. Beneficial effects of SMSSs have been shown for chronic disease such as heart disease, chronic lung disease, and type 2 diabetes[7]. Self-monitoring is often a component of self-management, and is meant to improve self-management[8]. It is considered to be comprised of two central components: 1) bodily awareness and 2) measurements, record-

ings, and observations. Quite some tools have been developed for self-monitoring, particularly for measurements, including objective measures and subjective data, like diaries, and checklists[8, 9]. Most of the studies that have been conducted in the area of self-monitoring have focused on behavioural health change[10, 11]. In principle, self-management could also be beneficial to renal transplant patients, who need to be monitored for the rest of their life. This monitoring is vital because complications and rejection can occur after renal transplantation[12, 13]. Indeed, the fear of rejection was reported as the most common stressor among kidney transplant patients[14–17]. Hopes are that a SMSS for renal transplant patients could guide them conducting daily self-management, such as self-measuring, getting feedback, and taking appropriate action [18]. Furthermore, if patients have the ability to monitor their renal function at home, this would potentially reduce the need of hospital visits for measuring creatinine in their blood. A key success factor would therefore be the SMSS ability to support these patients with entering monitoring data, interpreting the results, and taking appropriate actions, for example contacting the hospital if there are indications that the renal function deteriorates. Therefore, a SMSS that can support such patients to conduct appropriate actions is needed.

The study reported in this paper followed an iterative cognitive engineering approach [19] to develop the user interface of a SMSS. This interface had to support patients in their ability to self-monitor their creatinine level and to take appropriate actions based on monitoring data. As Figure 2.1 shows, the study consisted of four iteration cycles. Each included a design and an evaluation component, with the exception of the first iteration. This approach led to consecutive design improvements that were based on insights established in previous iterations. In the first iteration, three different design concepts were formulated. These were based on several design principles taken from the literature. The design concepts were again used to develop three paper prototypes that a group of non-patients evaluated in the second iteration. In the third iteration, the prototypes were modified and evaluated. A group of renal transplant patients participated in the evaluation this time. The fourth and final iteration led to a single adjustable prototype that a group of renal transplant patients reviewed in focus group setting. This also provided insight into patients' values and concerns underlying their behaviour and attitude towards the design of a SMSS.

2.2. ITERATION 1: DESIGN CONCEPTS

THE aim of the first iteration was to establish a rationale underlying the design of the SMSS user interface. As explained in the introduction, the focus was on self-monitoring and recommending appropriate actions. There exists an extensive body of literature about the design of user interfaces that could be relevant[20–23], but the accumulation of design guidelines and solutions seems to lack coherence at first glance. This is often caused by the different values these design guidelines and solutions might try to address. For our research domain, SMSS user interfaces can target at different core values, such as a comfortable life, inner harmony, or self-control[24]. Therefore instead of exploring a single design solution, three different design concepts were examined, each with a specific value connotation. This allowed for the exploration of different underlying psychological mechanisms that could affect patients' attitude towards, and the use

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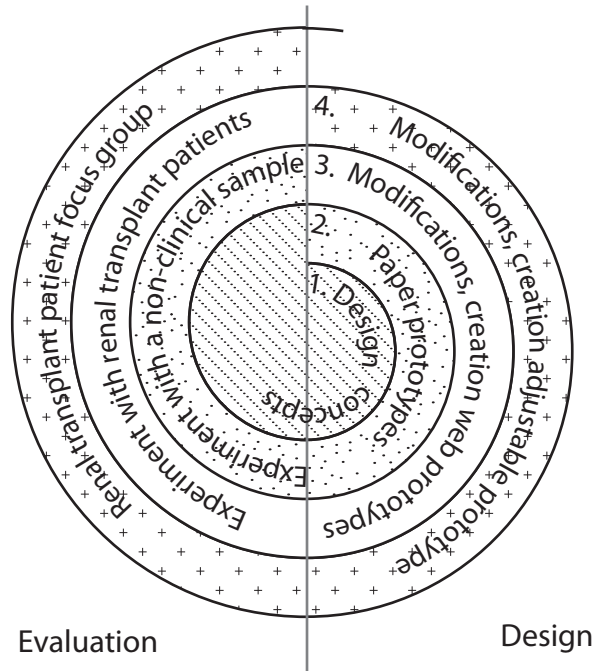
Figure 2.1: The four design and evaluation iteration cycles of this study

of, a SMSS. The three mechanisms explored were: minimising effort (i.e. the simplicity design), affective empathy (i.e. affection design), and cognitive support (i.e. empowerment design).

2.2.1. SIMPLICITY

The simplicity design concept aims at minimising patients' physical and cognitive effort to accomplish their self-management task. It tries to accomplish this by limiting the reported information by only providing the main conclusion that can be derived from the monitoring data combined with instructions for appropriate goal-oriented actions. This concept can be traced back to the minimal manual design principle for training manuals[25]. It emphasizes the importance of short manuals that focus mainly on the user task. Similar principles and guidelines have been proposed for system design. For example Nielsen argues that simple and natural dialogue user interfaces should be used, as every additional piece of information could potentially be misunderstood and could distract from essential elements[21]. Limiting user effort can also be used as a persuasive strategy to stimulate desired behaviour. For example Fogg argues that by simplifying a complex activity into simple tasks, the benefit-cost ratio is raised, and therefore target behaviours are easier and more likely to be performed[26].

In a similar vein, the simplicity design might be applied to the SMSS as a mean to guide or coach patients' self-monitoring behaviour after renal transplantation. Moreover, the simplicity concept fits the principles underlying the goal-focused or the solution-

focused coaching style to raise performance and support effective action[27]. The goal-focused coaching style mainly focuses on fostering coachees' self-regulation, whereas the solution-focused coaching style aims at achieving goals in a relatively short time by moving coachees' attention to the solution level. Likewise the simplicity based SMSS focuses patients' attention to the main conclusion and the related action they should take, i.e. the solution to their current renal situation. In contrast, only little attention is given to insight-oriented information and problem-analysis, for example about identifying and understanding possible causes[28]. In this behavioural perspective on coaching people, insight-oriented questions are not regarded at the heart of coaching[29]. Similarly, Grant suggested that coaching supports solution construction more than problem analysis[27]. Likewise in the simplicity design concept the focus is on instructing patients on what they should do and less on why they should do it; for example, redo the measurement to confirm an unexpected high creatinine level.

2.2.2. Affection

The affection design concept aims at responding appropriately to the patient's emotional state by showing an emotional response. The SMSS can accomplish this by using affective text in the user interface or by using anthropomorphic user interface elements, such as a virtual human. The effect of the emotional response is twofold. First, relying on patients' empathic ability, an emotional response is easily understood by the patient. For example, when emotions are expressed by virtual characters through facial expressions humans can successfully distinguish the six basic emotions as identified by Ekman and Friesen, i.e. joy, anger, sadness, surprise, disgust and fear[30], and even blend emotions such as enthusiasm or frustration[31]. Furthermore, positive or negative valence expressions by a virtual human in a dialogue can elicit similar emotions in a human conversation partner[32]. Computer users have also been shown to be well capable to provide affective feedback by selecting iconic facial expressions on a computer[33]. The second effect of an emotional response is the acknowledgement of the patient's emotional state, which is seen as an essential part of clinical empathy[34, 35]. In psychotherapy, communicating the therapist's empathic understanding is seen as a necessary condition to initiate constructive personal change[36], and is linked with patient satisfaction, the reduction of stress, patient commitment, and ultimately with treatment adherence[37]. In a similar way, physician empathy has also been positively associated with health outcomes, patient satisfaction, strengthening patients' ability, and anxiety and distress reduction[38]. The physician-patient relationship has also an important persuasive element, as people are more willing to comply with the requests of individuals they like[39]. As humans have shown to respond to computers in a manner similar to how they would towards other humans, Fogg hypothesizes that computer systems that use social cues, for example, emotional facial expression, have more persuasive power[26, 40]. It has already been shown that computer applications that include emotional responses in their communication towards an individual result in better health outcomes, better adherence to self-management, and less decline in motivation[41]. The affection design concept therefore aims at utilising emotion expression to communicate affective consequences, and to establish a positive relationship towards the system.

2.2.3. Empowerment

The empowerment design concept aims at supporting patients in taking control of their own health. It does so by helping patients understand their own monitoring data and how conclusions can be drawn in depth. This concept aims at teaching patients about their health conditions, to reason about appropriate actions, and to facilitate well-informed patient-physician interaction. Less informed patients have been associated with decreased treatment adherence[42], and increased distress[43]. Furthermore, feeling powerless has been related to health deterioration, whereas empowerment may enhance health[44]. Key concepts of empowerment are self-determination and self-efficacy. Self-efficacy, i.e. the belief in one's own capability of self-managing health, is strengthened by positive experiences and observational learning[45]. Therefore, an empowerment SMSS should provide insight into data interpretation, demonstrate the rationale for drawing conclusions, and thereby support observational learning. This should allow patients to understand future events more easily and take appropriate actions, even without guidance of the system. Likewise, the empowerment SMSS might lead to more elaborated cognitive processing of information which will lead to more sustainable behaviours, as these behaviours are more likely to be retrieved when encountering a similar situation [46]. The empowerment design concept can also be linked to the cognitive behavioural coaching tradition[47], which aims at improving peoples' problem-solving skills by providing people solution-seeking strategies. Internet is also an important enabler of patient empowerment. Web-based interventions have shown to enhance empowerment, self-efficacy and mastery, i.e. the patients' feelings of being in control of events among a clinically heterogeneous patients sample including mental health patients, chronic diabetic patients, and cardiac patients[48].

2.3. Iteration 2: Paper Prototypes and Experiment with a Non-Clinical Sample

In the second iteration, the three design concepts were worked out into three concrete SMSS user interface prototypes. This made it possible to examine how people adhere to SMSS recommendations, and what design they prefer. As the study was still in an early, explorative stage, an experiment with only a non-clinical sample was conducted in this iteration.

2.3.1. Paper Prototypes

The SMSS focuses on monitoring the creatinine levels in patients' blood. Among all measurements, creatinine level is regarded the most commonly used indicator of the renal function and, therefore, possible renal rejection[49]. A rejection is unlikely to occur if the creatinine level is stable or decreases; on the other hand, there may be rejection when the creatinine level increases obviously[50]. Therefore, based on patients' creatinine values, the SMSS was designed to inform patients about three distinct situations and instruct them to take appropriate actions. Patients were instructed (1) to take no action if creatinine level was stable or decreased (all right situation); (2) to measure again if creatinine level had increased a little (some level of concern situation); or (3) to contact the hospital if creatinine level had increased substantially (alarming situation). Based on the design
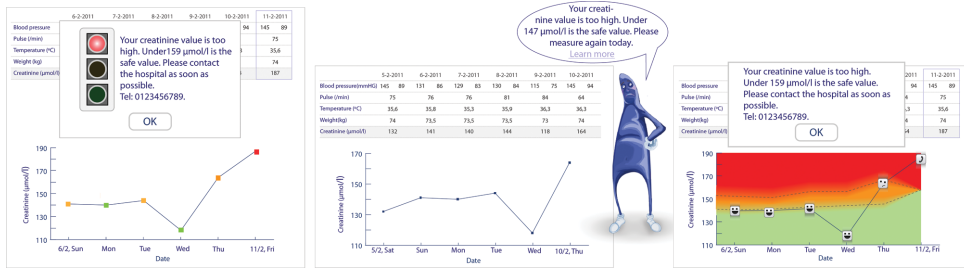
Figure 2.2: Paper prototypes based on the three design concepts. Left: Simplicity, centre: Affection, right: Empowerment

concepts, three prototypes were made (Figure 2.2). All prototypes included a creatinine level graph and explanatory texts including a recommended action that patients should undertake. In the simplicity prototype, a traffic light metaphor was used to present the three renal statuses. As patients are familiar with the concept of traffic light, it was assumed that they could easily understand the three specific situations. Each measure point in the creatinine level graph was also coded with a coloured dot, with green indicating 'all right', orange indicating 'some level of concern', and red indicating 'alarming'. The affection prototype employed a kidney-shaped virtual character to convey an emotional response to a patient's renal status. The virtual character could show two different facial expressions, combined with three different gestures: smiling and thumbs-up indicated all right, worried and akimbo indicated some level of concern, and worried and making a phone call indicated alarming. The empowerment prototype showed the thresholds between the three distinct situations in the creatinine level graph. From this, patients learn that these thresholds are not fixed, but vary depending on previous measurement and by using colour gradients between different zones patients learn that these are soft instead of strict thresholds. The measure points in the graph were represented by emoticons, e.g. happy smile and worried face, and an icon of a phone, giving an interpretation of the measurement.

2.3.2. METHOD

The experiment had a within-subjects design. All three kinds of user interfaces were shown to each participant in the form of a paper prototype. The order of the designs and of the tasks was counterbalanced to control potential learning effects. The experiment was approved by the university ethics committee. Participants were recruited from the Delft University of Technology community. The study population consisted of 12 (9 male and 3 female) Dutch-speaking non-patients of 22 to 38 years old ($M = 29, SD = 4$). They all had a bachelor's or higher educational level in science or engineering. At the start of the experiment, participants received an introduction about the experiment and signed a consent form. After this, they completed a basic personal information questionnaire about their gender, age, and educational level. This was followed by an explanation about the relation between creatinine level, renal function, and the required actions for changes observed in the creatinine levels. They were asked to imagine themselves to be a renal transplant patient. They were asked to think aloud during the main part of the

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Table 2.1: Number of task classified according to the degree of action deviation

Task	Prototype	Action deviation		Total
		severe	no	
what should you do now	Simplicity	0	12	**12**
	Affection	1	11	**12**
	Empowerment	0	12	**12**
	Total (%)	**1 (2.7)**	**35 (97.3)**	**36 (100)**
what should you have done previously	Simplicity	2	10	12
	Affection	8	4	12
	Empowerment	2	10	12
	Total (%)	**12 (33.3)**	**24 (66.7)**	**36 (100)**

experiment, which consisted of three sessions. In each session one of the three designs was presented, and the participants were asked to answer two questions: (1) what action they should take now and (2) what action they should have taken in the last measuring day when considering the measurements. The randomly assigned situations were an all right situation, a situation with some level of concern, and an alarming situation. Besides thinking aloud, they were asked to tell how they interpreted the information. After each session, participants completed a preference questionnaire consisting of 7-point Likert scales asking them how much they liked and trusted the concerning prototype, and considered the prototype easy to use (1 being the lowest and 7 being the highest score). At the end of the experiment, participants were debriefed about the experiment. The entire experiment took around one hour.

2.3.3. Results
Adherence to System Recommendations
The adherence in each task was classified into two groups: (1) severe deviation, if the participant did not formulate the recommended action, or if they formulated an action for another renal status; or (2) no deviation, if the participant formulated the recommended action. If participants did not specify what their action would be, they were regarded as to take no action. Friedman tests taking prototypes as independent variable and the action deviation classification as dependent variable showed no significant difference between the prototype in the current measurements task ($\chi^2(2, n = 12) = 2.00, p > 0.99$), but showed a significant difference for the previous measurements task ($\chi^2(2, n = 12) = 7.20, p = 0.04$). For the latter, Table 2.1 shows that the participants' suggested actions deviated from recommended actions, especially for the affection prototype. Wilcoxon signed ranks tests showed that compared to affection prototype the participants suggested fewer deviating actions when they used the simplicity ($z = 1.84, p = 0.045$) or the empowerment ($z = 2.18, p = 0.022$) prototype. No significant difference was found between simplicity and empowerment prototypes ($z = 0.45, p = 0.50$).

Preference
Figure 2.3 shows the median score regarding participants' preferences for each prototype. Friedman tests showed no significant differences in the liking rating ($\chi^2(2, n = 12) =$
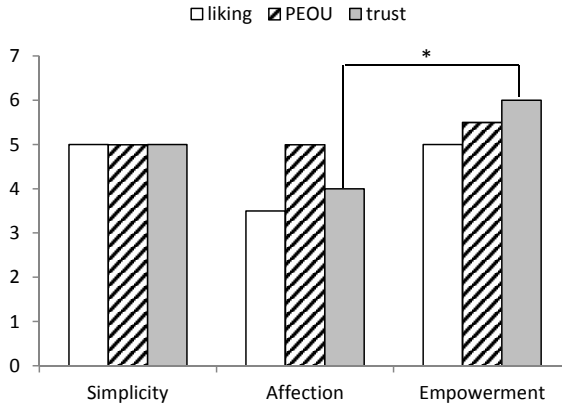
Figure 2.3: Median preference of the three prototypes

4.54, $p = 0.10$) or in the perceived ease of use (PEOU) rating ($\chi^2(2, n = 12) = 1.24, p = 0.54$). However, a significant difference in the trust rating ($\chi^2(2, n = 12) = 6.44, p = 0.040$) was found. Wilcoxon signed ranks tests showed that trust was only found significantly higher ($z = 2.25, p = 0.031$) in the empowerment design ($Mdn = 6.0, IQR = 2$) than in the affection design ($Mdn = 4.0, IQR = 4$, Figure 2.3).

2.3.4. DISCUSSION

The main conclusion that can be drawn from this iteration is that these participants on average were capable in formulating the appropriate actions after new creatinine data was entered. Only in 1 occasion out of 36 (3%) did the participant severely deviate from the recommended action. This deviation occurred with the affection user interface in the situation with some level of concern. The participant said that he would measure again the next day, but would also contact the hospital. The affection user interface also led to action deviation with regards to formulating appropriate actions based on previous renal data. The high number of action deviations with the affection prototype can be explained by a lack of information about how to interpret the previous measure points in the creatinine level graph. This information was presented in the graphs of the other two prototypes. Therefore adding this information will probably reduce the number of action deviations, and might also partly increase the level of trust, as this was significantly lower than the level of trust towards the empowerment user interface. Another reason for the reduced trust in the affection user interface was the emotional expression of the virtual character. As some participants mentioned, the facial expression and gestures were confusing and sometimes conflicting with each other. For example, the virtual character had a sad expression with one hand calling and the other hand thumb up while the text read 'your creatinine value is too high…Contact the hospital immediately.' Furthermore, the kidney-shaped character was also perceived as weird by some participants. Although with hindsight these issues might seem obvious, it shows that emotion expressions have an impact and should be used appropriately.

A number of participants explicitly mentioned the advantage of the thresholds in

the empowerment graphs. As they pointed out the thresholds were dynamic, the same measured value can be sometimes fine while sometimes not and they also gave them indication about how far away their measurement was from the threshold. Some participants explicitly stated that insight into these thresholds gave them a better understanding, while others wondered why the thresholds were dynamic. This therefore seems to support the hypothesis that the empowerment concept does stimulate reflection. The ideas behind the simplicity concept was also confirmed as some participants mentioned that this design was quite direct and required little effort to understand. Like any experiment, the experiment was also subject to some limitations. For example, the number of participants was relatively small. In addition, they were non-patients and were younger than most patients with end-stage renal disease in the Netherlands ($M_{age} = 59, SD_{age} = 16$[51]). As usability issues can differ between age groups[52], these findings may not be generalizable to renal patients.

2.4. ITERATION 3: WEB PROTOTYPES AND EXPERIMENT WITH RENAL TRANSPLANT PATIENTS

THE main insight obtained from the previous iteration was that a young, highly educated non-patient population would be capable in formulating an appropriate action. The third iteration therefore extended the evaluation towards the actual renal transplant patients. The previous iteration also provided insights for possible improvements to the prototype, specifically the implementation of the affection design concept, i.e. the appearance and behaviour of the virtual character. Human appearance can influence motivation, attitude, and future behaviours of another person[45]. Similar results have been reported for the appearance of a virtual character[53]. Indeed, different appearances of a virtual character can also lead to different reactions from individuals towards the character due to, for example, social influence and racial bias[54, 55]. Several principles have been suggested that govern users' attitude and behaviour towards virtual characters. First, according to the principle of similarity[56], people become more motivated and are more easily persuaded by a character that is more similar to themselves[26, 39]. A potential influencer who is more similar to a certain person is considered to be more attractive[57], is more likely to make a sale[58], and is more likely to receive altruistic help in a dire situation[59] than a less similar influencer. The similarity can be present in different aspects of the agent's appearance such as gender, age, human race, and clothing. Still, the persuasive effect of a virtual character, who is similar to the individual, can in some cases be overwritten by the specific context of the application[53]. For example, Baylor and Plant reported that females were more motivated to learn engineering by a male instead of a female virtual character[60]. Therefore, another principle that explains the influence of a virtual character is to present the character as a specific social character[26]. For example, in a learning context, a character can represent a motivator (e.g. providing motivational messages), an expert (e.g. providing informational support), or a co-learner (e.g. providing a learning together feeling)[61, 62]. Similarly, in the context of self-management, a virtual character may play a role of a health care provider, a motivator, or a fellow patient. The work of Pagliari et al into the design of virtual coaches for an online depression therapy showed that patients preferred a vir-

tual character that looked trustworthy[63]. They also found that the health professionals involved thought that the virtual character should look like someone who could be a member of their health care team[63]. Besides humanoid virtual characters, iconic characters and robots have also been suggested to increase the social influence of a system, such as the iCat and kismet[64, 65]. Systems with this kind of robot or iconic characters were used more frequently, resulted in better (self-reported) performance, and were rated as more motivating, easier to use, and more preferred than systems without characters[41, 66]. A study on robots and a virtual agent showed that a more serious and agreeable appearance improved the perceived performance of an agent, and that the perceived facial realism appeared to be important for trust, social presence, perceived sociability and perceived enjoyment[67]. Still, knowledge on humans' attitude towards iconic versus humanoid agents is lacking.

2.4.1. WEB PROTOTYPES

The paper prototypes created in the second iteration were implemented as web pages in this iteration (Figure 2.4 for some example). In addition, a number of small modifications were made to the design to adhere more strictly to the design concepts and to overcome identified problems. For example, the simplicity prototype followed its underlying design concept more closely by showing only the relevant information, i.e., interpretation of patients' creatinine level and recommended action. Data interpretation and recommended action was only illustrated by traffic lights and text, without explanation or any additional information. Previous renal conditions were no longer colour coded. Only a phone icon was included in the graph when data suggested that a patient should have contacted the hospital. For the affection prototype, the kidney-shaped character was replaced by a more neutral, iconic character. The facial expression of this character was based on facial action coding[33]. This meant that in the alright situation, the character showed a happy face, i.e. lip corners drew back and up, and eyebrows remained in a neutral position (Figure 2.5, left)[30]. When there was reason for concern, patients might be concerned, frightened, or sad. Concern is, however, a blended emotion and not one of basic emotions, which makes it less easy to recognize. Fear on the other hand coincides with high arousal[68], which is undesirable as patients ideally should remain calm. Therefore the character expressed sadness. Sadness is also a state of negative valence, but it has the advantage that it coincides with low arousal. The character showed inner corner raised eyebrows and a corner down mouth (Figure 2.5, centre)[30]. Though sadness was expressed when there were reasons for mild or serious concern, the expression was more intensified by raising eyebrows more and drawing mouth corners more down to distinguish between two levels of concern (Figure 2.5, right). The gestures of the character were designed to match the facial expression. The happy face coincided with thumbs up and sadness with arms drooping. In the empowerment prototype, the emoticons in the graph were replaced by more emotion neutral circles: complete white circles when everything was all right, half black half white circles when there was some level of concern, and complete black circles for alarming situations.
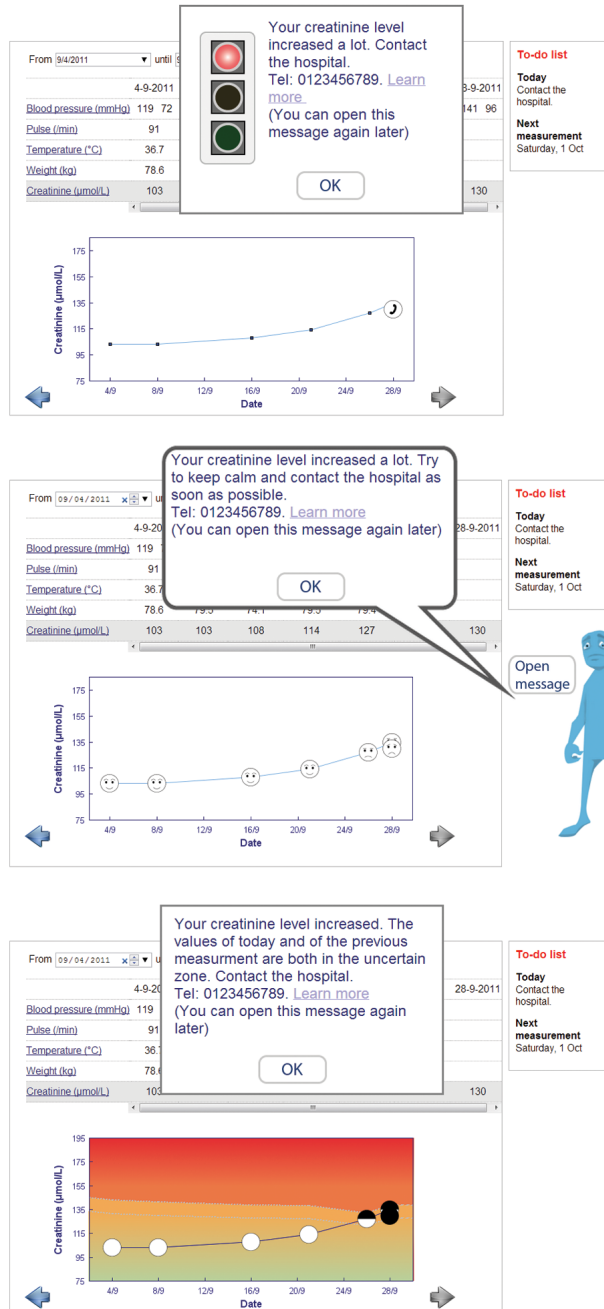
Figure 2.4: Screenshots of the three web-based prototypes. Top: Simplicity, middle: Affection, bottom: Empowerment
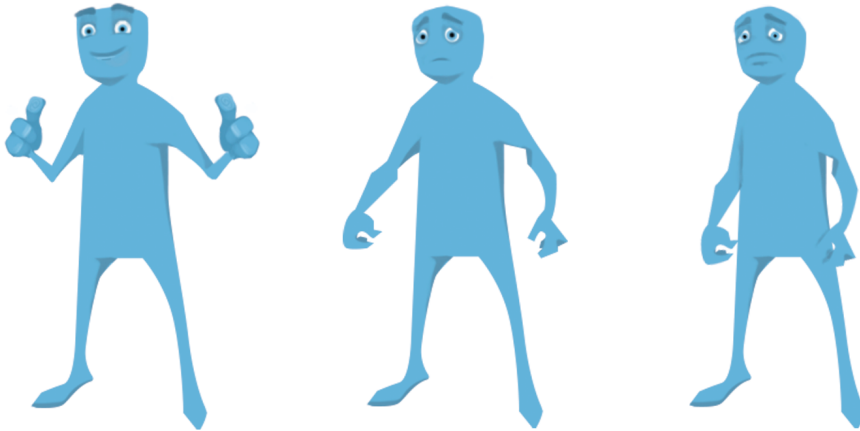
Figure 2.5: Virtual character indicating three renal status. Left: Alright, centre: Some level of concern, right: Alarming

APPEARANCE OF VIRTUAL CHARACTERS

To investigate the attitude towards the appearance of a virtual character in a SMSS for renal patients, twelve humanoid virtual characters were selected from the Vizard character set[69]: two genders, three age groups (young, middle-age, and old), and two clothing styles (formal and informal). To evaluate the social role of the character, the clothing style was extended with characters dressed as a care provider, wearing a white doctor coat with a stethoscope (see Figure A.1, Appendix A). To explore the difference between humanoid agents and iconic ones, two iconic characters were also included in the evaluation set – the iCat[70] and the cartoon figure representation especially designed for this experiment (see Figure A.2, Appendix A). To validate the age appearance of the character set, 15 participants were asked in advance to estimate the age of each humanoid agent. These participants were recruited from Delft University of Technology, 11 male and 4 female, 25 to 39 years old ($M = 29, SD = 4$). They were shown the characters and asked to write down an estimation of their ages. The rated ages of characters of the same gender and clothing style were compared in pairs in successive order. Paired-samples t-tests showed that all successive pairs were attributed with a significant older age (all $p < 0.05$), except the young and middle-age white-coat female pair ($p = 0.36$) (Figure A.1, Appendix A). Note that the white coat females were the same characters as the characters in the informal clothes where age was perceived differently. A possible explanation might be that age was not only judged by the character's face, but by its body and clothes as well.

TEXT

To investigate patients' attitude towards the texts in the SMSS, three types of texts were written following the ideas of three design concepts. The simplicity texts consisted of current creatinine level status and instructions for the follow-up action. The affection text added an extra affective sentence, such as 'don't worry immediately', whereas em-

Table 2.2: Examples of different types of texts

Simplicity	Affection	Empowerment
Your creatinine value has increased this time. Measure again now.	Your creatinine value has increased this time. Do not worry immediately. Please measure again now.	Your creatinine value has increased this time. The value is in the uncertain zone. Measure again now.

powerment texts added explanations of why a patient should conduct the instructed actions. Examples of the texts are presented in Table 2.2. Apart from the three types, affection texts had formal and informal Dutch variations. The formal one used a honorific personal and possessive pronoun 'you' ('u') and 'your' ('uw') and 'please', while the informal one did not use 'please' and used the informal personal and possessive pronoun, i.e. 'je' and 'jouw'.

2.4.2. Method

Participants

The patient population consisted of renal transplantation patients who had previously participated in a pilot study on self-management. In this pilot study, they had measured their creatinine values and used a web-based application during the first three months after renal transplantation. A recruiting letter was sent to all the 30 patients, and all those who were willing and able to attend the experiment were recruited. The 16 participants, 11 male and 5 female, were 28 to 72 years old ($M = 51, SD = 12$) renal transplant patients with various educational levels, ranging from primary school to master's degree, and diverse working backgrounds.

Experimental Design

The experiment had a within-subjects design; each participant interacted with all three prototypes. Each time participants interacted with a prototype, they entered a pre-defined creatinine value, which led to one of the three situations. For both the alright situation and the alarming situation, the data sets were artificially created and were the same for every participant. For the situation with some level of concern, the data were obtained from the participants' own values gathered during the pilot study. Participants encountered different situations when interacting with the three prototypes. Because of time limitation, the experiment was not setup as a full factorial design, and therefore participants were not exposed to all nine prototype-situation combination. Instead, participants were only exposed three times in total, each time with a different prototype and with a different situation. The three mutually exclusive prototype-situation combinations were randomly selected. To avoid learning effects, the order of the prototypes was counterbalanced, while the order in which the three situations were encountered was randomly assigned. The experiment was approved by the medical ethics committee of the Leiden University Medical Center and the ethics committee of Delft University of Technology.

2

PROCEDURE

Figure 2.6 shows a flowchart of the procedure followed in the experiment. At the start of the experiment, participants received explanation about the experiment, signed a consent form, and completed a basic personal information questionnaire. After this, they entered the three session cycles in the experiment. In each cycle, participants followed a different prototype track (A, B and C) though the flowchart. The three prototypes were randomly assigned to the three prototype tracks. A session consisted out of an initial phase and an final phase. The initial phase started by entering the monitoring data, after which the prototype first provided feedback that indicated that the situation was either alright (the prototype track A) or gave cause for some level of concern (the prototype track B and C). Note that participants were never confronted directly with an alarming situation, but initially only with a situation that causes some level of concern. Then the session moved on to the final phase. For prototype track B and C, participants were asked to enter a second pre-defined measurement, which led to either some level of concern for the prototype track B or alarming situation for the prototype C track. For the prototype track A, the all right situation, no re-measurement was requested. At the end of the session, the system made the following action recommendations: for prototype track A (all right), no action was recommended; for prototype track B (some level of concern), to re-do the measurement the next day; and for prototype C (alarming), to contact the hospital. Each time after entering monitoring data and receiving feedback in the initial or the final phase, the participants were asked what action they should take. In the final phase, participants were also asked what action they should have taken two days ago when considering the monitoring data from the previous days. Throughout the sessions participants were asked to think aloud. After going through all three prototype-tracks, participants completed a questionnaire on their preferences for the prototypes, virtual characters, and texts. Finally there was a debriefing to let participants reflect on what they had done or thought.

MEASURES

Before the interaction with the prototypes, participants completed a questionnaire about basic information such as gender, age, and educational level. After interacting with the prototypes, they completed a specifically designed questionnaire with 7-point Likert scales regarding their attitude towards each prototype, each virtual character, and each text message (see Appendix B for questionnaire). The orders of the texts and virtual characters were random and different for each participant. Besides subjective data, behavioral data of the recommendation adherence was also collected.

The adherence in each task was classified in a similar way as in the first experiment, that no deviation (coded as 0), severe deviation (coded as 1), and three additional categories: (1) slight deviation, if the participant suggested the recommended action implicitly, but did not formulate it explicitly (e.g., when they needed to re-measure, participants said that they would not contact the hospital yet or would keep an eye on the creatinine level, without explicitly stating to re-measure, this was coded as 0.5); (2) a missing category, if the participant had not entered monitoring data correctly, and therefore was not confronted with the task; and (3) a not available category, if in the initial phase participants were confronted with an alright situation, they were not confronted with re-measurement situation in the final phase. Because of the experimental set up, each par-
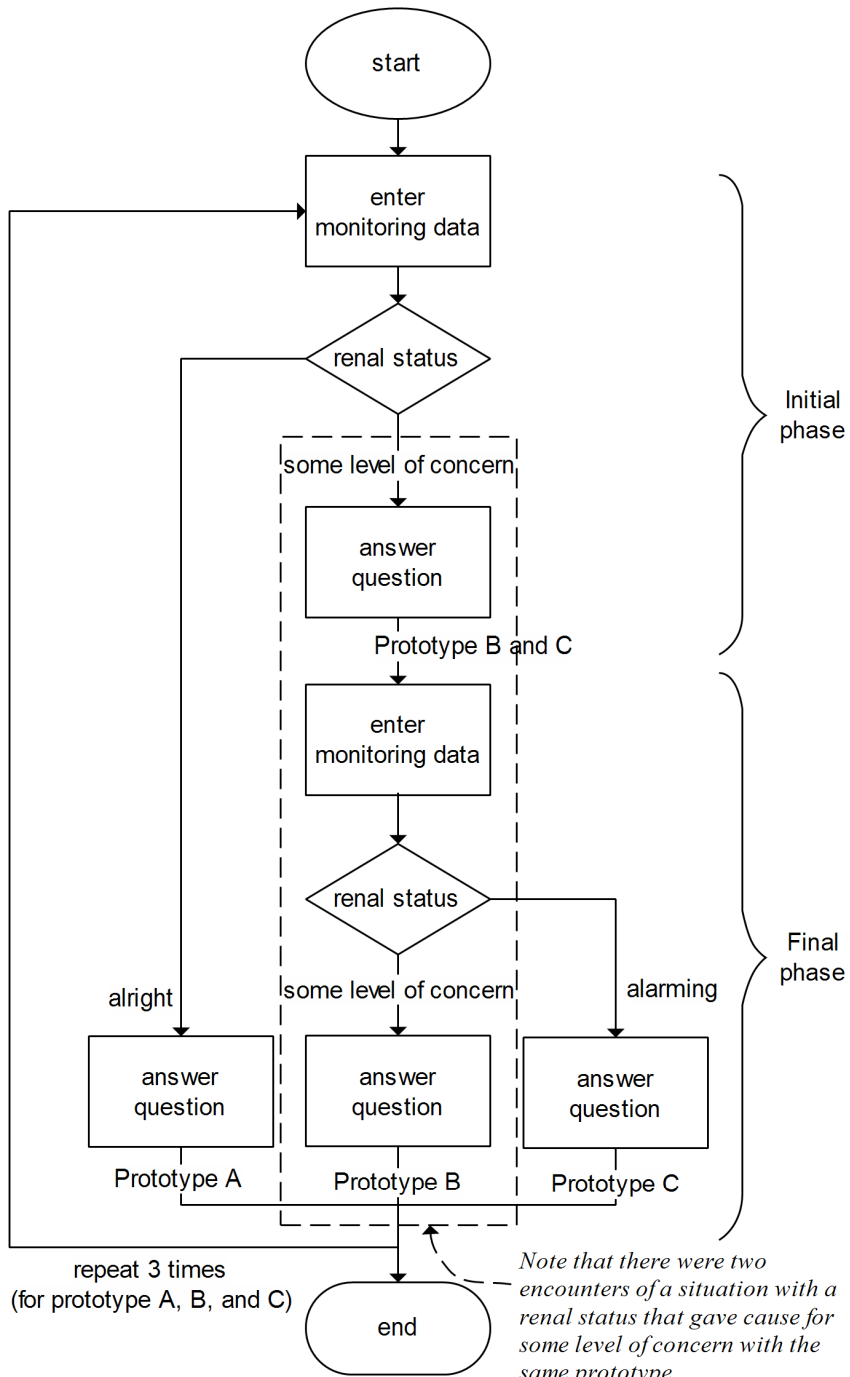
Figure 2.6: Flowchart of the experiment procedure. Note that the simplicity, affection and empowerment prototype were randomly assigned to prototype track A, B or C

Table 2.3: The number of tasks classified according to the degree of deviation from the recommended action by the system

Task	Prototype	Action deviation					Total
		severe	slight	no	missing	NA*	
	Simplicity	5	0	11	0	0	**16**
what should	Affection	7	1	8	0	0	**16**
you do now	Empowerment	4	1	10	1	0	**6**
	Total (%)	**16 (33.3)**	**2 (2.4)**	**29 (60.4)**	**1 (2.1)**	**0 (0)**	**48 (100)**
after re-	Simplicity	6	0	4	0	6	**16**
measuring,	Affection	0	1	8	1	6	**16**
what should	Empowerment	1	0	10	1	4	**6**
you do now	**Total (%)**	**7 (14.6)**	**1 (2.1)**	**22 (45.8)**	**1 (2.1)**	**2 (4.2)**	**48 (100)**
what should	Simplicity	4	0	12	0	0	**16**
you have	Affection	6	1	9	0	0	**16**
done two	Empowerment	9	0	7	0	0	**6**
days ago	**Total (%)**	**19 (39.6)**	**1 (2.1)**	**28 (58.3)**	**0 (0)**	**0 (0)**	**48 (100)**

*NA: not available.

ticipant was confronted only twice (prototype track B and C) with a renal status that had some level of concern, both cases with another prototype (Figure 2.6). This also meant that for each participant data was lacking about their action with a third prototype in such a situation. This missing data was replaced in the analyses on how each participant had acted with the three prototypes in a situation that caused some level of concern. The missing data was replaced by taking for each participant the average of the action deviation value observed in that situation with the two other prototypes. Similarly, each participant interacted with only two prototypes after re-measuring. This missing data for the third prototype was also replaced by the average of the action deviation value of the other two prototypes.

2.4.3. RESULTS

ADHERENCE TO SYSTEM RECOMMENDATIONS

Table 2.3 shows the action deviations observed. First patients' and non-patients' adherence was compared. When ignoring the one case that was classified as missing, Mann-Witney tests found a significant difference ($U = 21.0, z = 3.63, p < 0.001$) between this patients group and the non-patient group of the first experiment with regards to current data, but no significant difference ($U = 75.5, z = 1.01, p = 0.34$) with regards to data measured two days ago. When looking only at the initially suggested action (i.e. without considering action after re-measurement), only 60% of the time patients did suggest the recommended actions, whereas for the non-patient group this was 97%.

To compare the adherence to the three prototypes, Friedman tests taking prototype as independent variable and action deviation classification as dependent variable showed no significant difference between the three prototypes in participants' initially suggested action ($\chi^2(2, n = 15) = 0.38, p = 0.88$) and in their suggested actions regarding monitoring data collected two days before ($\chi^2(2, n = 16) = 2.13, p = 0.41$). However, it showed
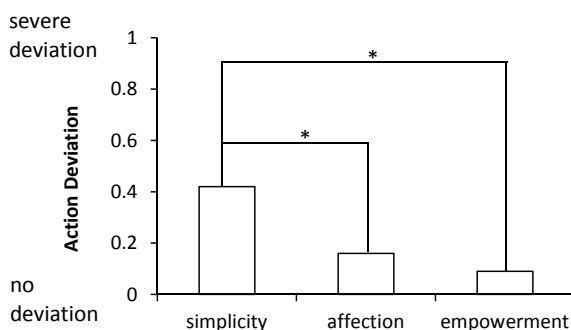
Figure 2.7: Mean of the action deviation for the different prototypes after re-measuring (with missing data replaced by mean for each participant)

a significant difference in their suggested action after re-measurement ($\chi^2(2, n = 16) = 7.55, p = 0.019$). Detailed analysis by Wilcoxon signed ranked tests showed that there were significantly more action deviations with the simplicity prototype ($M = 0.42, SD = 0.48$) than with the affection prototype ($M = 0.16, SD = 0.24, z = 2.44, p = 0.016$) and the empowerment prototype ($M = 0.09, SD = 0.27, z = 2.23, p = 0.031$). The number of action deviations in the affection and empowerment prototypes was not found to be significantly different ($z = 0.63, p = 0.77$) (Figure 2.7). There was one participant that entered an empty value in the initial phase, and therefore he did not confront any task in both the initial and the final phases.

Figure 2.8 shows the action deviation of the patients group set against the three renal state conditions in the final phase of the task (Figure 2.6). Ignoring the three cases classified as missing, a Friedman test revealed that action deviated significantly by renal status ($\chi^2(2, n = 13) = 8.72, p = 0.013$). Significantly more participants complied with recommended action in a situation where a creatinine value indicated that everything was alright (Wilcoxon signed ranks test: $z = 2.27, p = 0.016$) or was alarming (Wilcoxon signed ranks test: $z = 1.96, p = 0.035$) compared to a creatinine value that caused some level of concern (see Figure 2.8).

When confronted with an alarming renal status, 15 out of 16 (93.8%) participants suggested the recommended action, i.e. contact the hospital. The only time that a severe deviation was observed, the participant argued that he did not have to do anything because the current creatinine value was lower than the previous one. When confronted with a renal status that provided no reasons for concern, 13 out of 16 (81.3%) participants suggested the appropriate action, i.e. no action required. There were three times that some deviations were observed. Of the one case that was classified as a slight deviation, the participant suggested to save the data, although it was already saved. In both cases that were classified as severe deviations, the participants wanted to contact the hospital: one because the current creatinine value was higher than the previous one, and the other to ask why his creatinine level fluctuated.

Finally, when confronted with renal status that caused some level of concern, 6 out of 13 (46.2%) participants suggested the appropriate action. Of the one case that was classified as slight deviation, the patient said that he would keep an eye on it, but did
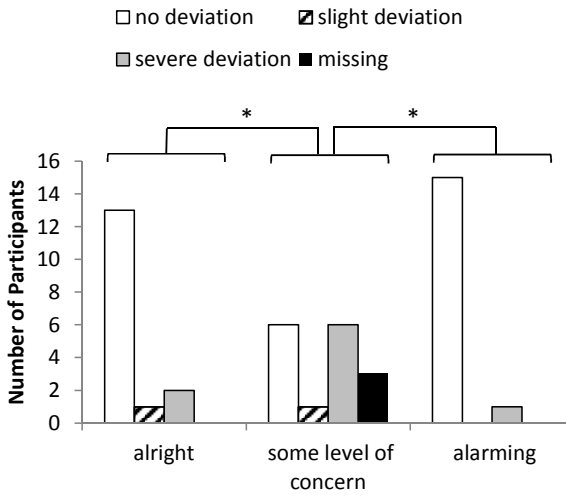
Figure 2.8: Renal status by action deviation in the final phase

not specify that he would re-measure. Of the six cases that were classified as severe deviation, three patients would contact the hospital. Two of them found the creatinine increased too much, even though one explicitly said that he knew the system asked him to re-measure, and the third would ask what the data meant. For the other three cases with severe deviations, one participant mentioned that he would measure his temperature and weight, and if either was not alright, he would also contact the hospital; one participant found everything ok and would do nothing; and one participant focused on a previous measurement, and did not say what his action would be. Besides one participant that did not enter data, there were two other cases classified as missing. In both cases, the participants entered in wrong data that led the system to indicate a renal status of either alarming or no concern, instead of some level of concern.

Because of the observed increase in deviation from the system recommendation when the renal status showed some level of concern, participants suggested actions were examined in more detail for this renal status for all three prototypes. The first step was to examine whether a learning effect occurred when participants were confronted with a renal status that showed some level of concern twice. A Wilcoxon signed ranks test showed no significant difference between the proposed actions by the participants encountering the pertaining renal status for the first versus second time within the same prototype ($z = 1.30, p = 0.38$) (Figure 2.6). The second step of the analysis focussed on the difference between the prototypes. A Friedman test, taking prototypes as independent variable and the action deviation classification as dependent variable, found a significant difference between the three prototypes if there was some level of concern in the initial phase ($\chi^2 = 16) = 6.75, p = 0.038$, Figure 2.6). Wilcoxon signed ranked tests showed that action deviations with the empowerment prototype ($M = 0.28, SD = 0.45$) were significantly less frequent than those with the simplicity prototype ($M = 0.55, SD = 0.47, z = 1.73, p = 0.05$) and the affection prototype ($M = 0.53, SD = 0.43, z = 2.13, p = 0.027$). The
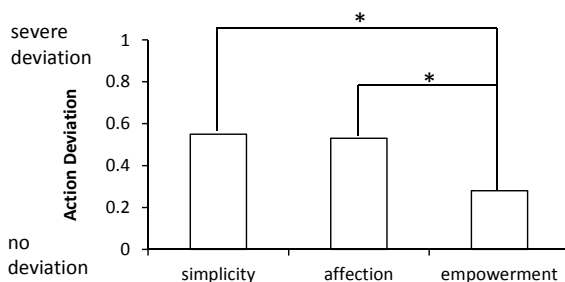
Figure 2.9: Mean of the action deviation for the different prototypes when confronted with renal status that cause some level of concern (the initial phase in Figure 2.6, with missing data replaced by mean for each participant)

Table 2.4: Mean Cronbach alpha level between attitude items

Attitude towards	Mean Cronbach alpha level
Average of three prototypes (6 question-items)	0.77
Average of the 20 virtual characters (6 question-items)	0.98
Average of 15 text items (4 question-items)	0.85

action deviation in simplicity and affection prototypes was not found to be significantly different ($z = 0.30$, $p = 0.50$, Figure 2.9).

ATTITUDE

The first step was to examine the reliability of the separate scales. Table 2.4 shows Cronbach alpha level calculated across the attitude items for prototypes, virtual characters and the text items. They all were above the threshold of 0.7 [71]. Therefore the mean scores of the Likert scales were taken as the participant's attitude towards prototypes, virtual characters, and texts, and used in the analyses.

Non-parametric tests were conducted, such as Chi-square test, Mann-Whitney U test, and Wilcoxon Signed Ranks Test on the non-transformed data, or data was first aligned rank transformed (ART) before conducting repeated-measures ANOVA and mixed design ANOVA[72].

ATTITUDE TOWARDS PROTOTYPE DESIGN

A Friedman test found no significant difference between the average attitude towards the three prototypes ($\chi^2(2, n = 16) = 0.10$, $p = 0.97$). In other words, when considering participants as a homogeneous sample the attitude did not seem to vary between prototypes. Considering participants however as a heterogeneous sample could provide insight into whether subgroups within the sample vary in their attitude towards the prototypes. To explore this, each individual patient's attitude was ranked from prototype with the highest score (first choice), the second highest score (second choice), and the lowest score (third choice). Figure 2.10 shows that the distribution of the ranked preferences for the three prototypes differs, where each tie was regarded as a half participant for either choice (e.g., a 1.5th choice was regarded as a half first choice and a half second

Figure 2.10: Rank of participants attitude choice towards the prototypes

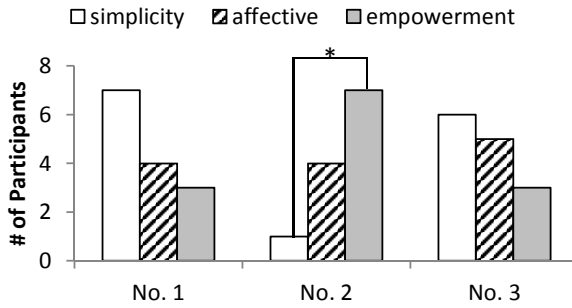choice). For homogenous sample, each prototype could be expected around 4 participants to rank it as their first, second, or third choice. However as Figure 2.10 shows, participants seems to vary in attitude. For example, the preference for the simplicity prototype has a U-shape with some participants rated it as their first choice and some as their last choice with few rated it as their second choice. The opposite can be seen for the empowerment prototype, which seems to concentrate around the 2nd choice. The preference for the affection prototype seems to have an equal distribution across the ranking of choices. Chi-square tests found a significant difference between simplicity and empowerment prototype as a second choice ($\chi^2(1, n = 16) = 3.96, p < 0.05$), but not between other prototypes or as other choices. Participants' comments showed that five participants regarded simplicity prototype as clear, three the affection prototype and two the empowerment prototype. On the other hand, the empowerment design was considered unclear by four participants, whereas both the simplicity and the affection design were mentioned as unclear by only two participants. Besides, two participants mentioned the affection prototype was childish, mostly due to the cartoon figure, but none said so about the other two prototypes.

To investigate whether attitude towards the different prototypes was related to personal characteristics, a mixed design ANOVA was conducted on ART attitude score towards the prototypes. The within-subjects variable was prototype, and the between-subjects variable was participants' educational level (primary or secondary versus higher level education). Although no significant main effect for prototype ($F(2, 28) = 0.11, p = 0.90$) or education ($F(1, 14) = 0.002, p = 0.96$) was found, the analysis revealed a significant interaction effect between prototype and participants' educational level ($F(2, 28) = 4.92, p = 0.015$). Figure 2.11 shows that the median scores for the prototype differentiated by education level. Mann-Whitney tests revealed that higher-educated patients rated ($Mdn = 7.00, IQR = 1.13$) the simplicity prototype significantly higher ($z = 2.10, p = 0.036$) than the lower-educated people did ($Mdn = 5.75, IQR = 2.50$), whereas such difference was not found for the other prototypes.

ATTITUDE TOWARDS VIRTUAL CHARACTERS

A repeated-measures ANOVA was conducted on ART attitude towards the 18 virtual characters with a humanoid appearance. The within-subjects variables were characters' gen-
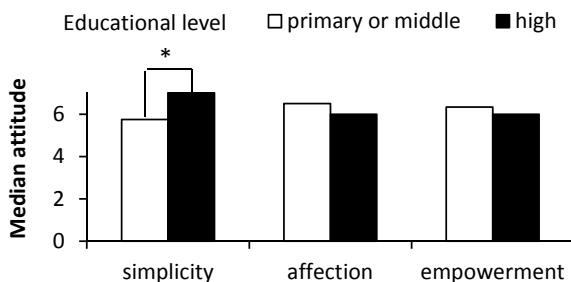
Figure 2.11: Median attitude by prototype and participant's education
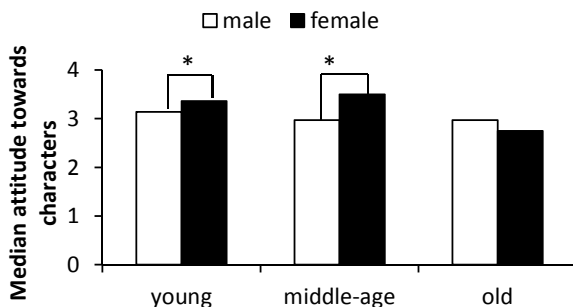
Figure 2.12: Median attitude by virtual character's gender and age

der, their age, and their clothing style. It revealed a significant main effect for the character's age ($F(2,30) = 4.51, p = 0.019$). Attitudes towards young characters ($Mdn = 3.21$, $IQR = 2.64, z = 2.47, p = 0.011$) and middle-age characters ($Mdn = 3.31, IQR = 2.13, z = 2.56, p = 0.008$) were significantly more positive than towards old characters ($Mdn = 2.90, IQR = 1.89$). Furthermore, a significant main effect for clothing style was found ($F(1.41, 21.11) = 17.03, p < 0.001$). Characters dressed in white doctor coats ($Mdn = 4.53, IQR = 2.75$) were rated significantly higher than both those dressed in formal ($Mdn = 2.54, IQR = 2.72, z = 3.30, p < 0.001$) and informal clothes ($Mdn = 1.94, IQR = 1.88, z = 3.32, p < 0.001$), while ratings of characters in formal clothes were significantly higher than of those in informal clothes ($z = 3.30, p < 0.001$).

Although the ANOVA did not find significant main effect for characters' gender ($F(1, 15) = 2.43, p = 0.14$), it did reveal a significant interaction effect between character's gender and their age ($F(2,30) = 3.55, p = 0.041$). Examining the medians (Figure 2.12) suggests that character's gender had different effects on people's ratings depending on the age of the character. To understand this interaction effect, two separate Wilcoxon signed ranks tests were conducted which revealed that young and middle-aged female characters ($Mdn = 3.43, IQR = 2.78$) received significantly higher ($z = 2.84, p = 0.005$) ratings than young and middle-aged male characters ($Mdn = 3.10, IQR = 2.01$) whereas no significant difference ($z = 0.39, p = 0.69$) was found between the rating of the old male and female characters.
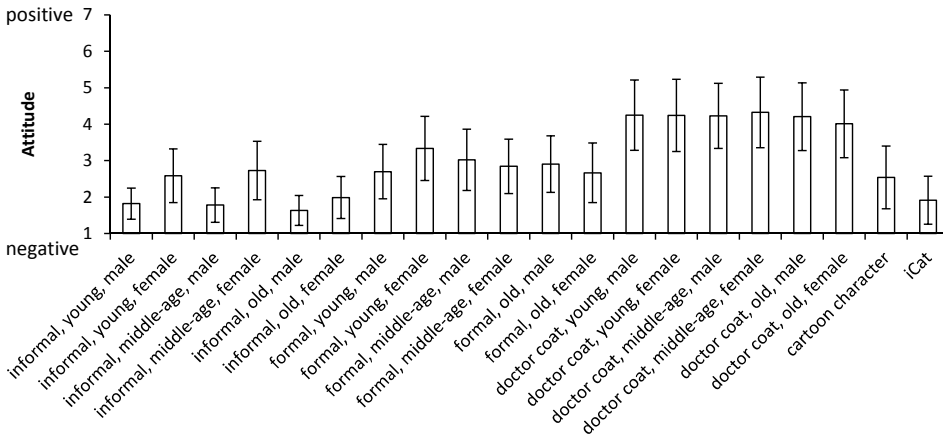
Figure 2.13: Mean attitude towards each character with 95% confidence interface

Figure 2.13 shows the mean attitude score towards all characters, both humanoid and cartoon characters. A Friedman test on the average attitude towards all eighteen humanoid agents, the attitude towards the iCat, and the attitude towards the cartoon character found no significant difference ($\chi^2(2, n = 16) = 4.10, p = 0.13$). However, a Friedman test among the average rating of the six characters in a white doctor coat, the iCat, and the cartoon figure showed a significant difference ($\chi^2(2, n = 16) = 7.86, p = 0.02$). Wilcoxon signed pair tests revealed that the ratings of humanoid characters in white doctor coat ($Mdn = 4.53, IQR = 2.75$) was significantly higher than the rating for cartoon character ($Mdn = 1.50, IQR = 3.08, z = 2.25, p = 0.02$) and the rating for the iCat ($Mdn = 1.25, IQR = 1.17, z = 2.79, p = 0.003$).

ATTITUDE TOWARDS TEXT STYLES

The first step in the analysis of the texts was to compare the formal and informal text style for affection text. A repeated-measures ANOVA was conducted on ART attitude with formality and renal condition as within-subjects variables. No significant difference was found between formality text styles ($F(1, 15) = 0.14, p = 0.71$). Hence, for the next analyses the average rating for formal and informal texts style was taken as attitude score towards the affection texts. To compare attitudes towards the three text styles, a repeated-measures ANOVA was conducted on ART attitude taking as within-subjects variables the text style and renal condition. Although the analysis found no significant effect for renal condition ($F(2, 30) = 2.31, p = 0.12$), it revealed a significant main effect for the text style ($F(2, 30) = 5.05, p = 0.013$). Wilcoxon signed rank pair tests showed that both simplicity ($Mdn = 6.58, IQR = 0.83$) and empowerment texts ($Mdn = 6.58, IQR = 0.92$) had significantly higher ($z = 2.61, p = 0.007$ and $z = 2.52, p = 0.008$, respectively) ratings than affection texts had ($Mdn = 6.17, IQR = 1.38$). One reason might be that the affection texts lead to some negative emotions, such as irritation or fear, as four participants commented.

2.4.4. Discussion

The patient group more often deviated from the system recommendations than the non-patient group in the previous experiment. Although both groups are not fully comparable, for example the educational level of the non-patients was higher, recommended actions were presented explicitly. This makes it unlikely that educational level is the only explanation for the difference between groups. A possible additional explanation might have been that although patients cognitively understood the system's recommendation, they were more aware of the potential risk involved and therefore applied a safer strategy by contacting the hospital. Indeed, most deviations were found if the renal status indicated that there was some level for concern, which could have induced a feeling of insecurity. Because of this insecurity, patients might have desired more information than non-patients and therefore suggested to contact the hospital more often. Likewise, additional information provided by the system seems to have prevented this feeling of insecurity. The higher level of adherence in the empowerment design compared to the simplicity and affection design seems to support this. If patients followed up on the initial recommendation to conduct a re-measurement, the lack of information seems to have again influenced the adherence level towards the second recommendation as well. The adherence level was significantly lower for the simplicity design, with its limited information, than for the two other designs.

The adherence analyses in this iteration also have their limitations. Using mean values to replace one third of the data that was missing in the situation causing some level of concern made it possible to study the effect of the designs, but the interpretation of these results should be done with some reservation. Besides the adherence to system recommendations, the errors made during entering monitoring data should also be noticed. Three cases were observed where participants had entered wrong data or no data. This might suggest that when using such an application at home, patients might also make such errors which, when left unnoticed, lead to wrong recommendations.

The second conclusion that can be drawn from this experiment is that on average, attitude towards the three prototypes was positive. All three prototypes received a median attitude score of above six on a seven-point scale. Although on average, patients did not seem to prefer one specific prototype, the distribution of preference did differ. The preference for the simplicity prototypes was polarized. For some patients the simplicity prototype was their first choice, while for some others it was their last choice. The preference for affection prototype was equally distributed, more or less an equal number of patients show it as their first, second or third choice. The empowerment prototype on the other hand was more often seen as a second choice option. These findings argue against a single 'one size fits all' design for all patients. Instead different patients might prefer different designs. One potential explaining factor is patients' educational level. The higher educated participants were more in favour of the simplicity prototype compared to lower educated participants. With regard to text style, the findings suggest that the affection text style was less preferred than other text styles. The third conclusion that can be drawn relates to the appearance of the virtual character. The characters' age and clothing style had a significant effect on patients' attitude. Although these patients were on average 51 years old, they preferred a character with a perceived age of 30.5 years. They also preferred virtual characters dressed as doctors. This experiment has some lim-

itations that should be considered. The number of participants included was relatively small. Participants had some experience with a SMSS already, and had probably become accustomed to a post-transplant life style, the results therefore might not be generalized to newly transplant patients. For the comparison between different ages and genders of humanoid virtual characters, different characters were used instead of presenting the same character at difference ages or morphing face for different genders. The different faces might therefore have been a confounding variable.

2.5. ITERATION 4: ADJUSTABLE PROTOTYPE AND RENAL TRANSPLANT PATIENT FOCUS GROUP

THE main insights obtained from the previous iteration were that (1) adherence could vary between prototypes and situation, and that (2) variation existed between patients when it came to their attitude towards the designs. The emphasis in the fourth iteration was therefore to establish a single adjustable design that could cope with these various demands, and to study patients' values and concerns underlying their attitude and behaviour.

2.5.1. PROTOTYPE MODIFICATIONS

The results of the previous iteration showed no overall preference dominance for one of the three design concepts. Patients seemed to vary in their preferences. Their adherence to the system recommendations also varied across the renal status. An adjustable prototype was therefore explored as this could potential accommodate these issues. For example, patients could choose whether or not to include colour-coded dots to indicate the status of the renal function, and the thresholds between three zones in the creatinine level graph. In addition to a text message about the status of the renal function, patients could also choose to have a traffic light indicator, a virtual character, or nothing at all. Figure 2.14 shows some possible user interface configurations.

2.5.2. METHOD

PARTICIPANTS

Participants were recruited from the same pool as the previous experiment with renal transplant patients. The 7 participants, 6 male and 1 female, were between 28 to 68 years old. All except one had participated in the previous experiment.

SETTING

The participants were divided into two groups based on their availability. One of the co-authors chaired the discussion; two other co-authors observed and took notes in the same room. The two observing co-authors also asked questions when they thought it was needed. A voice recorder was used to record the discussion.

PROCEDURE

Participants were first sent a short introduction text about the focus group study and an informed consent form, which they signed and returned at the start of the focus group. During the focus group, pictures of the prototype were projected on a screen, with the
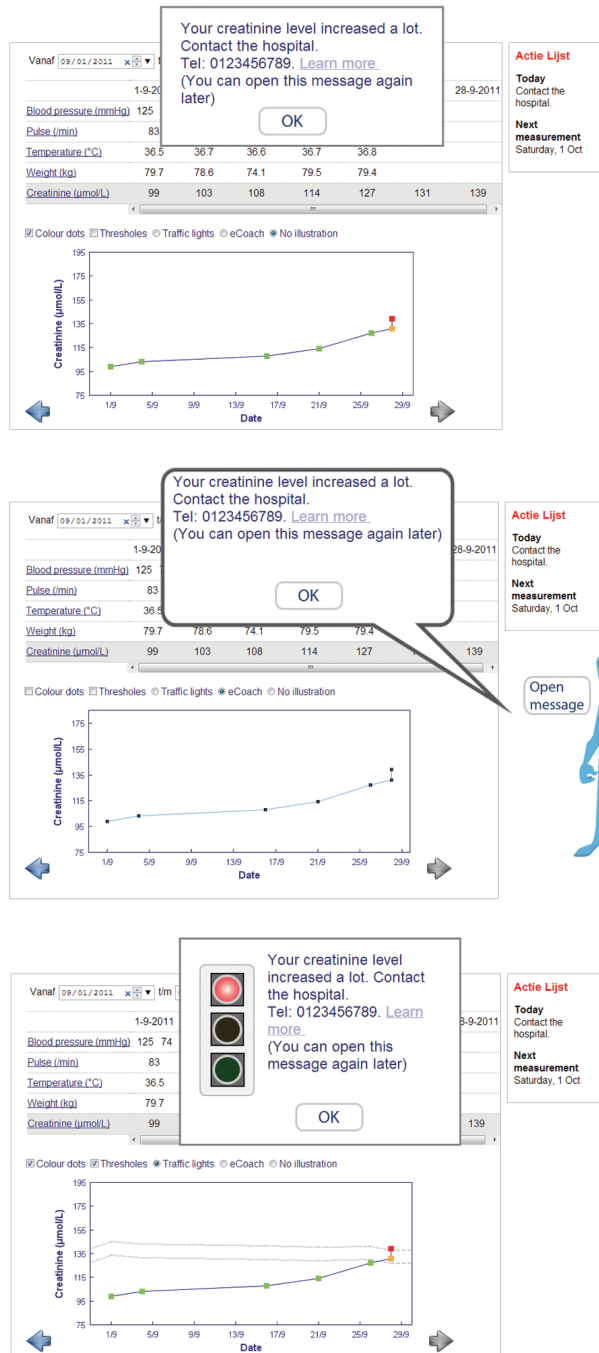
Figure 2.14: Possible user interface configurations. Top: with only colour-coded dots, middle: with only the virtual agent, bottom: with colour-coded dots, thresholds, and traffic lights.

researcher emphasizing the personalized features. Participants were asked to comment on the prototypes and explain their preference. They were asked which features they expected to be more suitable in what situations, for what kind of patients, and why they thought so.

2.5.3. RESULTS

The notes made during the focus groups were analysed bottom-up. Firstly, the underlying rationales, concerns, or emotions of the participants' comments were determined. Then recurring ideas or feelings were clustered together and different themes emerged. These themes were compared and converged to final themes. The themes that emerged were transition, status of the renal function, effort, fear, and self-esteem. As Table 2.5 shows these themes interweaved with each other. An important insight that patients shared was that their concern and behaviour changed when they became more adapted to their post-transplant lifestyle. Just after their operation, they had been anxious about possible rejection of their new kidney. Interpreting information about the status of the renal function by a system could generate stress in this starting period, as patients worry about taking the wrong action, as they have no experience yet to rely on. Patients saw the benefit of a virtual character in this situation as it might provide a sense of reassurance to new patients. On the other hand, the patients might perceive themselves already as experts and therefore would consider it unprofessional to use a virtual character. From the comments made by the patients, it emerged that when they become more used to their post-transplant lifestyle, they preferred a SMSS that does not require too much effort. They preferred simple feedback if there are no reasons for concern. Interestingly, they became more confident and more critical towards the reliability of the measuring device and recommendations of the SMSS as their experience and trust in their own judgement increased. Put differently, with increasing levels of self-esteem patients became less inclined to follow blindly their doctor's instructions, not to mention a SMSS or a virtual character. Another important insight was the relationship between status of the renal function and experienced (un)certainty. As mentioned before, if the renal function did not give cause for concern, patients wanted to focus their attention on other things in life than the SMSS, and therefore liked to get a quick and simple update about their renal function. Interesting was the parallel with the situation where the renal function was alarming. Again this situation characterised itself by desire for clearness of the appropriate actions. Here patients want to be able to focus their attention fully at things that matter. They do not want to be side-tracked or overloaded by information as they worry about missing key information or instructions at this critical situation. They also seemed to be more sensitive about being unnecessary scared or being judged. The desire for more information was, however, more prominent when the situation was less certain, specifically when the status of the renal function gave cause for some level of concern and the SMSS instructed to measure again. This uncertainty could lead to some anxiety and patients also became more willing to spend effort in understanding their current situation and the SMSS rational for its recommendations. In this situation, more relevant information was appreciated.

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Table 2.5: Themes gathered from focus group

	Transition		Status of renal function		
	Just after transplant	Habituation to post-transplant lifestyle	All right	Some concern	Alarming
Effort	Unsure about own ability; Might be physically or mentally less capable	Do not want to spend much effort; physically and mentally capable	Do not want to spend much effort	Want to understand the reasoning and be informed	Do not want to be distracted from primary action (contact hospital)
Fear	Want medical staff to confirm; Unsure about own ability; Want to be informed; A virtual character may comfort patients	Afraid of missing the urgent message; Want to understand the reasoning and be informed; Some distrust of the system		Want to understand the reasoning and be informed; Do not want frightening elements; Want to know what is relevant information (and what can be ignored)	Afraid of missing the message; Do not want frightening elements; Want to know what is relevant information (and what can be ignored)
Self-esteem	Newly transplant patients are also experienced, so do not want to be treated as novices	Be taken seriously and seen as a professional; Some distrust of the system; Do not want to be judged; Not necessarily follow doctor instructions, not to mention a virtual character			Do not want to be judged

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2.5.4. DISCUSSION

Although caution should be taken when generalising findings from a focus group, the results of these focus groups revealed that patients' attention, emotions, and self-esteem needs vary depending on their lifestyle adaption stage and status of their renal function. The observation that these patients do have different needs depending on the stage of lifestyle adaption corresponds to what Sen and Spring found for young people with long term illnesses[73]. As their group of patients became more informed, their confidence and capacity increased and they often wanted to share their knowledge. Together this seems to support the idea of an adaptable SMSS to accommodate these varying aspects in several stages of illness.

2.6. GENERAL DISCUSSION AND CONCLUSIONS

WHEN it comes to supporting patients in their ability to self-monitor their creatinine level and to take appropriate action, this study shows that experienced patients tend to deviate from the systems recommendations more than highly-educated non-patients. Regarding the performed tasks as purely cognitive problem-solving activities, the highly-educated non-patients might have been favoured. For patients, their experience and knowledge might have been both an advantage and disadvantage. They can be expected to have a far better understanding of the monitoring data, and also a higher tendency to rely on their own and less on the SMSS to decide on the course of action. Key of course in this context is what constituted an appropriate action? Here this was defined as the action suggested by the system. Still to put the found 60.4% - 68.8% level of adherence into context, it seems to be similar to or slightly higher than reports about patient adherence to physicians' medicine prescription for chronic deceases (approximately 50%)[42], to treatment for chronic diseases (50% in developed countries)[74, 75], or to physicians' recommendations in case of colorectal cancer screening (25% - 59%, varied between studies and timing)[76, 77], in smoking cessation (19% - 96%, varied between studies)[78], and in self-monitoring blood glucose for diabetes (25% - 40%, varied between studies and the types of diabetes)[79, 80]. In this study, patients overwhelmingly adhere to system recommendations when the status of their renal function was either stable or alarming. Common ground in both situations is that there was little uncertainty on how to respond. Deviations were especially observed in situations with uncertainty, i.e. the system indicated some level of concern, but not so alarming to warrant a visit to the hospital. Having an external or a more objective justification available, for example self-monitoring data, has been reported by patients as a more convenient argument for visiting a care provider[81]. In this study, the uncertainty was probably not caused by a lack of clarity about the SMSS' instruction, as the non-patient group had no problem adhering to the system recommendations. Instead, it might be more related to patients' recollections about such situations in the past, their emotional reaction towards the situation, or their confidence in questioning the reliability of the measuring device. As focus group results indicated, the uncertain situation might cause anxiety, which the patients try to overcome by obtaining additional information. As the high-

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Ignoring the not available 16 cases in Table 2.3, the adherence level of re-measuring task is $22/(48-16) \times 100\% = 68.8\%$

est level of adherence was found with the empowerment prototype, its' design concept might have fulfilled the informational needs. However, patients did not prefer the empowerment design to the other two designs or vice versa. Instead, the different stages of lifestyle adaptation and possible renal function statuses seem to change patients' needs. This has been shown before in adolescents with cancer[82] and young people with long term illnesses [73]. Future research into a SMSS that can address these different needs seems therefore appropriate.

To conclude, the scientific contribution of the work presented here can be summarised in two ways. First, it provides insight into renal transplant patients' adherence behaviour, attitude, values, and concerns when responding to monitoring feedback and recommendations provided by a SMSS. Second, it formulates and evaluates three distinct mechanisms in providing renal monitoring feedback and subsequent recommendations.

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GUIDED OR FACTUAL COMPUTER SUPPORT FOR KIDNEY PATIENTS WITH DIFFERENT EXPERIENCE LEVELS AND MEDICAL HEALTH SITUATIONS: PREFERENCES AND USAGE

The finding of chapter 2 suggests the need for a personalized SMSS that presents monitoring feedback to renal transplant patients, based on their renal function states and their post-transplant lifestyle adaptation stages. On the other hand, how to personalize such systems was not clear. Therefore, this chapter aims to propose and evaluated the principle of such personalization. Section 3.2 formulates the hypothesis by examining the design rationale and principle from literature and proposes a corresponding prototype. Section 3.3 describes the experiment with different types of renal transplant patients to evaluate the prototype. Section 3.4 presents the results that not recently transplanted patients were relatively more positive towards one communication style than another, and section 3.5 concludes the chapter and provides suggestions for future research.

ABSTRACT

Motivation Key for the success of a self-management support system (SMSS) is the patients' motivation and ability to understand and to adhere to its recommendations.

Methods Layering, nudging, emphaticizing, and focusing principles were applied for the development of a web-based SMSS prototype with two communication styles: (1) a guided style that provided more interpretation support and addressed emotional needs; and (2) a factual style that showed only measurement history, medical information, and recommendations. Forty-nine renal transplant patients with three different experience levels participated in a lab study, in which they used the system in imaginary scenarios to deal with three medical health situations (alright, mild concern, and concern).

Results On average, a 96% understanding and 88% adherence rate was observed, which was not found to differ across communication style, patient group, or medical health situation. Still, compared to recently transplanted patients, not recently transplanted patients were relatively more positive towards the factual than the guided communication style. This difference was less noticeable in the "concern" condition. Furthermore, in this condition, or with the factual style, patients proved to search less for information and a majority did not change the communication style to their preferred styles.

Contribution By attuning the communication style to patient's experience and medical health situation according to the applied principles and acquired insights, SMSSs are expected to be better used.

KEYWORDS

Self-management support system, user interface, renal transplant patient, adherence, preference, attitude

3.1. INTRODUCTION

SUPPORTING chronic patients conducting self-management effectively is a key issue when designing and implementing a self-management support system. Self-management has been proposed for chronic patients to increase compliance with medical standards, stimulate awareness of early physical changes, and facilitate patients' autonomy [1, 2]. It means that the chronic patients should perform a cluster of daily behaviours to manage their diseases, including treatment management, lifestyle management, and emotion management[2, 3]. For example, patients should overcome barriers to adherence to medicine, adapt to healthy diet, and accept their diseases[4].

To support such self-management, computer systems have been suggested[5]. These computer systems, referred to as self-management support systems (SMSSs), can help to empower patients by giving them more control of their care process and daily activities, thereby increasing their autonomy[5]. Existing SMSSs provide various types of support. Some provide knowledge on how to conduct self-management, such as knowledge of self-monitoring or problem solving skills. Other systems guide users for making plans, such as taking exercises, eating a healthy diet, and self-monitoring, and coach them to implement these plans into daily life[6]. Alternative systems provide platforms for communicating with care-givers or fellow patients, or a combination of such support[5, 7].

Beneficial effects of SMSSs have been shown for chronic diseases, such as heart dis-

eases, chronic lung diseases, diabetes, and cardiovascular care[5, 8, 9]. In principle, self-management could also be beneficial to renal transplant patients, who had a kidney transplant as a treatment for End Stage Renal Disease (ESRD). Another treatment for ESRD is dialysis, but this is not the preferred treatment option, as the risk of death of dialysis patients is more than twice of that of kidney transplant patients[10]. In addition, patients gain more freedom and energy from a successful kidney transplant than from dialysis[11]. After the transplantation, however, complications may occur, such as rejection of the transplanted kidney[12, 13]. Therefore, renal transplant patients need lifelong care and are treated as chronically ill. Usually, patients visit the hospital regularly to monitor their kidney function by measuring the creatinine level in their blood. Further, as hypertension is both a potential indicator of decreased kidney function and an important risk factor for kidney graft failure[14–17], blood pressure needs extensive monitoring too. By using a SMSS for renal transplant patients, it is expected that these patients can conduct daily self-management at home, and visit the hospital less frequently. In addition, they are better informed about their current health status and may be more alert to detect early symptoms of graft failure.

Unlike most of other chronic patients, however, the risk of possible acute rejection and the tremendous consequences of losing their kidney may let renal transplant patients have more reservations towards using a SMSS and relying on its advice. To improve the acceptance of its advice, the system could have an adaptable way to present feedback more personalised. This paper, therefore, aims to identify the principles of adapting the system's communication style towards renal transplant patients so that they would accept the SMSS and its advice.

3.2. COMMUNICATION STYLE AND HYPOTHESES

3.2.1. DESIGN RATIONALE AND PRINCIPLE OF THE SYSTEM

PATIENTS in different situations could have different needs, e.g., need for information, need for information presentation, and affective needs. As the model of self-regulation processes in disease prevention and management indicates, over time chronic patients learn strategies to manage their disease[18]. Their needs therefore may vary according to the patients' experience, i.e. their experience of being a renal transplant patient, their experience in using a SMSS, and their experience in coping with specific medical health situations, e.g. the SMSS warning about a medical concern and the recommendation to contact the hospital. This suggests that to accommodate these needs, the interaction design, i.e. the way in which information is presented to patients, needs to be personalised according to patients' needs. The proposed design here focuses on personalisation based on patients' experience and the medical health situation (i.e., the progress of renal function over time). To design a SMSS for renal transplant patients, the following four design principles were established based on literature: layering, nudging, emphaticizing, and focusing. First, for layering, a key assumption is that, although the system is personalised, essential medical information should not be withhold from patients. However, medical information can initially (i.e. just after transplantation) be too complex for patients to understand. Reducing the complexity by simplifying the medical information could however lead to withholding information, which should be

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avoided. Instead, we propose a stepped approach, in which an additional interpretation layer is offered to less-experienced patients to support them to develop appropriate cognitive schemas to understand complex medical information provided by the system. The schema theory assumes that when people encounter new information, they tend to interpret it with their pre-existing knowledge patterns (called schemata), and use the interpretation to modify their beliefs[19]. According to this theory, when patients become more experienced, they will have internalised these cognitive schemas making the interpretation layer no longer desirable to present. Instead they might be directly presented with the factual medical information, such analysis results from self-measurement data.

The second design principle, nudging, is based on the Nudge theory, which argues in favour of indirect suggestions instead of forced compliance as this could create resistance [20]. Nudging means offering a desirable default while leaving it still possible with some effort to deviate from this default. As people are likely to avoid making additional effort, most people will follow the default offering. For the design this means that patients can select another communication style, e.g. for recently transplanted patient the style with the interpretation layer would be offered by default, but the patient could deselect this and use the style without the interpretation layer but only factual medical information.

The third design principle, emphaticizing, is to satisfy needs of different patients: for empathy or for conciseness. Empathy of physicians has positive effects on patients' health, satisfaction, ability, and anxiety and distress reduction[21]. As people have shown to respond to computers in a similar manner as to other humans, Fogg hypothesizes that computer systems can use social cues to express empathy and achieve higher adherence [22, 23]. Computer applications that include emotional responses are reported to result in better health outcomes, better adherence to self-management, and less decline in motivation[7]. Therefore, to satisfy patients' need for empathy or social communication, the system could use social cues, such as a virtual health agents (i.e. virtual coaches), with different facial expressions to express empathy. However, some patients would prefer a more straightforward instruction or explanation, instead of empathy, especially if they are already familiar with their medical situation[24]. As newly transplant patients are probably more anxious or worried[25], we assume therefore that less experienced patients will prefer more empathy, while more experienced patients prefer more conciseness.

The last design principle, focusing, centres on the severity of the medical condition (i.e. progress of renal function). The information about the medical health situation provided by the system determines patients' focus of attention and the amount of effort that they are willing to invest. According to the arousal theory, different levels of arousal are required for different tasks to achieve optimal performance[26]. For example, in an alarming situation, people's arousal levels are often high and therefore they lack the cognitive capability to process and obtain new information[26]. In addition, when there is reason for medical concern, it is important that patients take appropriate action immediately. They would probably not want to spend much effort on gaining new knowledge (e.g. why they need to take the action), but focus their attention on the actions they have to take instead. Therefore, information presented by the system aims at drawing patients' attention towards the current situation and providing information about

appropriate patient actions. When there is no reason for alarm, a heightened arousal level is unlikely, and it can be an appropriate moment to gain knowledge. Therefore, the system should draw patients' attention towards consolidating procedural knowledge in case of less experienced patients, or extending existing knowledge in case of more experienced patients. When there is only reason for some medical concern without need for direct intervention, patients would probably be worried and eager to know the rationale of being provided with such feedback. The information presented here should focus on addressing patients' need for understanding the current situation.

3.2.2. Implementation of Principles into Prototype

Based on the four design principles, the proposed user interface design had two communication styles: a guided style especially for less experienced patients that provided the additional interpretation layer, and a factual style especially for more experienced patients that only showed factual medical information about the current renal status and corresponding recommendation of the patient. The guided style also included a virtual coach, which was a graphical presentation of a female dressed in a white doctor coat. This virtual coach addressed potential affective needs of less experienced patients, i.e. acknowledging patients emotional state aiming for affective empathy. The virtual coach did this by expressing emotion with its face. Next, in verbal communication the coach made statements to reassure people. For example in a situation that indicated concern it stated "It does not necessarily mean that there is something wrong. However to be on the safe side, you are strongly advised to contact the hospital to discuss this with your doctor".

The prototype presentation was also different for three medical health situations and corresponding recommendation categories: (1) alright, i.e., creatinine level was stable or decreased, and therefore patients did not have to take extra action; (2) mild concern, i.e., creatinine level had increased a little, and therefore patients were requested to measure again the next day; and (3) concern, i.e., creatinine level had increased substantially, and therefore patients were advised to contact the hospital. The main presentation differences are listed in Table 3.1 and the screenshots are in Appendix C. The screenshots show the situation where a user has clicked on a link for additional information. Appendix D shows four screenshots that demonstrate the progression of providing more additional information in the guided style.

When patients were in the alright situation, the system invited patients to read more about the procedure about conducting self-management at home in the guided style, whereas the factual style invited patients to read more about daily life after renal transplantation.

When patients were in the mild concern situation, interpretation layers with simplified information and links to factual explanation were added to help patients understand complex medical information easier in the guided style, or all the factual explanation of medical factors in the factual style. Figure 3.1 shows how the information was presented with and without the interpretation layer.

When patients were in the concern situation, the system addressed patients' current renal situation, with information about appropriate actions. In this situation the interpretation layer conveyed a comforting message to patients in guided style, but not in

Table 3.1: Characteristic of guided and factual communication style in three different medical health situations

| | | Action deviation | |
		Guided	Factual
Medical health situation	Alright	'Did you know' message to provide basic procedural self-management knowledge; a virtual coach to build an emotional connection with users; factual explanation with a link to detailed explanation	'Did you know' message to provide broader, lifestyle knowledge; factual explanation with a link to detailed explanation
	Mild concern	A pop-up with an action instruction; an interpretation layer and a virtual coach to offer empathic support; links to factual explanation	A pop-up with an action instruction; factual explanation with links to detailed explanation
	Concern	A pop-up with an action instruction; an interpretation layer and a virtual coach to offer empathic support; a link to factual explanation	A pop-up with an action instruction; factual explanation with a link to detailed explanation
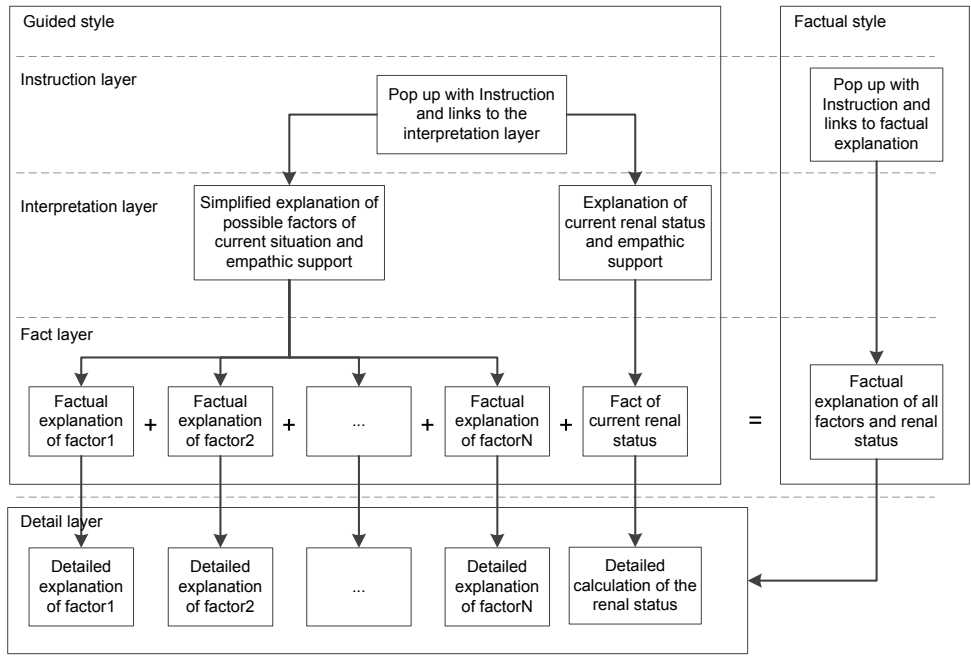
Figure 3.1: The information presentation with (left) and without (right) the interpretation layer

factual style.

3.2.3. HYPOTHESES

The previous section presented the two communication styles in which the layering, nudging, emphaticizing, and focusing principles were instantiated. The general assumption is that this style should be attuned to patients' experience and medical health situation. Layered and empathic support is fitted for less experienced patients, focusing is important in more indefinite situations, and nudging leaves patients free in their style usage while expecting most people to stick to the default style. To investigate these three aspects of the general assumption, the following hypotheses were formulated:

H1. Less-experienced patients understand, prefer, and adhere to a guided communication style better than to a factual communication style, while this is the opposite for well-experienced patients.

H2. Patients try to obtain more information about their medial health situation in a mild concern situation than in an alright or concern situation.

H3. Instead of selecting their preferred communication style, a majority of patients do not change the default communication style.

3.3. METHOD

3.3.1. EXPERIMENT DESIGN

THE experiment had both a within- and between-subjects design. The within-subject factors were 1) the two communication styles (guided versus factual style), 2) the three medical health situation based on the progress of the renal function over time (alright, mild concern, and concern), and 3) default communication style (default guided or default factual style in which the system starts). The between-subject factor examined in the study was patients' experience.

To reduce the complexity of the design, the three within-subject factors were compared in two separated phases. The first phase had six conditions in a two by three design, to study the effect for the two communication styles set within the three medical health situations, and the interaction effect of these two factors. The next phase only had two conditions to examine the effect for the default communication style set within mild concern situation. Both phases allowed studying potential interaction effects with the between-subject factor patients' experience. Ethical approvals for the study were obtained both from the Human Research Ethics Committee of Delft University of Technology, and from the Medical Ethics Committee of Leiden University Medical Centre (addendum to P11.188), where the study was conducted and the participants were recruited following an opportunity sampling strategy.

3.3.2. PARTICIPANTS

Although 51 renal transplant patients participated in the experiment, two were excluded from the analyses. One quitted half way because she found the experiment too complex to finish, and another patient did not bring his reading glasses and could hardly

Table 3.2: Participants profile

Participants	Less experienced	Intermediate experienced	Full experienced	Total
Number, n	16	15	18	49
Male, n (%)	11 (68.8)	5 (33.3)	10 (55.6)	26 (53.1)
Age				
Mean (SD)	52.8 (13.1)	55.6 (12.0)	58.1 (13.2)	55.6 (12.7)
Range	24 – 69	32 – 72	27 – 79	24 – 79
Educational level				
Median	Secondary	Secondary	Secondary	Secondary
Months since transplantation				
Mean (SD)	5.3 (1.1)	121.9 (154.7)	37.0 (55.0)	52.6 (101.9)
Range	3 – 7	16 – 444	14 – 255	3 – 444

see the content in the monitors. Patients were recruited for three roughly equally sized groups based on their level of experience, namely: 1) less experienced patients ($n = 16$), patients who had their first renal transplant surgery more than 2 months but no more than 7 months before participating the experiment, and had not used a SMSS for renal transplant patients; 2) full experienced patients ($n = 18$), patients that had their first renal transplant surgery more than 12 months ago, and who had used a SMSS for renal transplant patients for one year; and 3) the patient group labelled as intermediate experienced patients ($n = 15$), patients that had their first renal transplant surgery more than 12 month ago, and who had not used a SMSS for renal transplant patients. This classification is only a rough indication of patients' experiences, which was used to test the hypotheses. The profile of these participants is presented in Table 3.2.

3.3.3. Procedure

Each participant went through the following steps. First participants were told that the purpose of the study was to evaluate the user interface of a SMSS. They were introduced to the procedure of the experiment, after which they filled out a questionnaire about their personal information. This was followed by an introduction video on how to use the system. Next, participants had the opportunity to explore the system for 10 minutes. The default style setting (guided or factual) of the user interface was set randomly. During this step participants were allowed to change the communication style and experience both styles. In this step, participants were confronted with a recommendation by the system to do nothing extra.

In the main part of the experiment, participants were exposed to eight imaginary conditions. The first six conditions were the two different communication styles by three medical health situations. It was not possible for participants to change the communication style. The order of the six conditions was random and different for each participant. In condition seven and eight, participants could switch between the two styles, while the default style was different between the two conditions and the order was randomly assigned. Instructions given during these two conditions reminded the patients of the possibility to change the style. The medical health situation was mild concern in both

conditions. To avoid potential learning effects, nine datasets with creatinine measurements were used, one for practise, two for alright, four for mild concern, and two for concern. Within each medical health situation, the datasets were randomly assigned to each participant.

In every condition, participants were asked to enter a pre-defined creatinine level in the SMSS, and receive the corresponding feedback. They could interact with the system for as long as they wanted to. Next to the SMSS, there was another monitor for them to indicate their understanding of the system instructions, their planned actions, and their attitude towards the system.

After interacting with the system, the participants were asked which communication style they preferred for each of the medical health situation. They were also asked to discuss their opinions about the system at the end of the experiment in the debriefing. To standardize the information procedure, video clips were used to instruct participants during the various steps.

3.3.4. MEASUREMENTS

Before the interaction with the prototypes, participants completed a questionnaire about personal information such as gender, age, and educational level. In the main part of each condition, they were asked to answer seven questions: 1) what the system asked them to do, 2) what they would do, 3) why they would do that, 4) how much they liked the way that the system had supported them, 5) how effectively or ineffectively the information was presented, 6) how worried or relaxed the information made them feel, and 7) with how much dignity they were treated by the system. All the questions were closed questions, except question 3. Questions 1 and 2 had the choices of a) to do nothing extra, b) to re-measure tomorrow, c) to contact the hospital, and d) other, with stating what that was. Question 4 was answered with a 7-point Likert scale ranging from 1 'not at all' to 7 'very much'. Patients were asked to respond to questions 5 to 7 by setting a slider from -10 for 'extremely negative' to 10 for 'extremely positive'. After the main part, participants were asked which communication style they preferred for each of the medial health situation with a slider, with -10 for extremely preferring the guided style to 10 for extremely preferring the factual style, or the other way around, as the direction was random for each participant. Self-report about experience and opinion was collected in the debriefing. Besides subjective data, behavioural data was also collected on whether or not patients clicked on the 'learn more' link, on the 'did you know' link, and on the button to switch communication styles.

3.3.5. DATA PREPARATION AND DATA ANALYSES

SPSS version 22 and R version 3.3.2 were used to conduct several statistical analyses. The first step was a reliability analysis on question 4 - 7. A Cronbach's alpha with a value of 0.73, showed an acceptable level of consistency between the questions. Therefore, the mean of these four questions was taken as an index for participants' attitude towards the system. For this question 4 was rescaled to a 21-point scale so that it had the same range as the other questions. One-sample t-tests were conducted to examine whether attitude and preference data deviated from zero, the neutral value. A relative attitude scale was calculated by subtracting a participant's attitude score towards the system in

the guided style from the factual style. A negative score on this relative attitude scale indicated a more positive attitude towards guided mode, while a positive score more positive attitude towards factual mode. To test whether patients had a more positive attitude towards one of the communication styles, one-sample t-tests were conducted on the relative attitude value of zero, a neutral attitude. This was also done for a single experienced patient group in which both intermediate and full experienced patients group were combined. Next, a multilevel analysis was conducted across the patients groups, taking participants as random intercept and medical health situations and patient experience, and two-way interaction between them as fixed factors. In addition, this analysis was repeated with the patient experience reduced to a two levels factor by combining the two experienced groups into a single group.

Exploration of the preference data revealed a W-shape distribution, with 19%, 17% and 40% of the measurements for -10, 0, and 10 score respectively. After removing the zero score from the data set, the preference variable was recoded in a dichotomous variable taking zero as the cut of point to split the data set into a 0 for a preference for guided style, and a 1 for factual communication style. A multilevel generalized linear model analysis for dichotomous outcome was conducted taking the same factors used in the analysis of relative attitude.

The question about what the system asked the patient to do was recoded into a dichotomous variable, i.e., whether the patient understood it correct or not. Similarly, the question about what patients would do was recoded into whether patient would adhere to the desired action or not. Both variables and the data, whether or not a patient clicked on the 'learn more' link or the 'did you know' link, were analysed with a generalized linear mixed model with a binomial distribution and a logit link function. The analyses used communication style, medical health situation, patients' experience level, and their interactions as fixed factors, and participants' number as random intercept with as Scaled Identity as covariance type. Pairwise contrasts analyses were used to examine interaction effects in more details. Finally, a binominal test was used to analyse if the majority of patients did not change the default communication styles to their preferred styles.

Potential confounding variable were examined by comparing age, education level, and gender ratio difference between the three patient groups. No significant (all $ps > .05$) difference was found by Kruskal-Wallis H tests. Furthermore, participants' age, gender, work hours, and internet using were considered as possible covariates. However, none of variables correlated consistently across the patient groups.

3.4. Results

3.4.1. Understanding and Adherence

Table 3.3 shows the number of patients that understood the action suggested by the system and that adhered to the advised action. With a 96% average for understanding and 88% adherence, a large majority of patients understood the suggested actions and indicated to also adhere to the actions. In the cell with the relative lowest understanding rate of 83%, the three full experienced patients thought the system instructed them to do nothing extra in the mild concern situation. In the cell with the relative lowest adherence rate 69%, the five less experienced patients wanted to take some action,

Table 3.3: Number of patients that understood and adhered to the requested action

Medical health situation / Style	Understand (%)			Adhere (%)		
	Less ($n = 16$)	Inter-mediate ($n = 15$)	Full ($n = 18$)	Less ($n = 16$)	Inter-mediate ($n = 15$)	Full ($n = 18$)
Alright						
Guided	15 (94)	14 (93)	17 (94)	11 (69)	12 (80)	17 (94)
Factual	16 (100)	15 (100)	17 (94)	14 (88)	13 (87)	15 (83)
Mild concern						
Guided	16 (100)	15 (100)	15 (83)	16 (100)	14 (93)	15 (83)
Factual	15 (94)	14 (93)	17 (94)	13 (81)	14 (93)	16 (89)
Concern						
Guided	16 (100)	15 (100)	17 (94)	15 (94)	15 (100)	14 (78)
Factual	16 (100)	14 (93)	17 (94)	15 (94)	14 (93)	14 (78)

re-measure or contact the hospital, while not instructed by the system to do so. In total there were 37 non-adherent cases made by 22 different patients, ranging from 12 patients that showed non-adherence only once to one full experienced patient that showed non-adherence in 4 cases. Twenty-two percent of these non-adherence cases could be attributed to not correctly understanding the system's suggestion. For the remaining 78% of non-adherence, in 17 cases (59%) the 12 patients wanted to do more than advised by the system, in 7 cases (24%) the 7 patients wanted to do less than the system advised (e.g. re-measure instead of contacting hospital), while in 5 cases (17%) the 3 patients wanted to do something else, for example re-measure directly instead of re-measure the next day or contact the hospital. The generalized linear mixed model analyses found no significant effect for the patient group, medical health situation, or the communication style on the understanding or the adherence results (all $ps > .05$).

3.4.2. Preference and Attitude

Table 3.4 shows the mean preference and attitude rating. Although the analysis on dichotomous preference variable did not find a significant effect for patient group ($\chi^2(2) = 0.82, p. = 0.66$) or medical health situation ($\chi^2(2) = 5.34, p. = 0.069$) separately, it did find a significant two-way interaction effect these two factors ($\chi^2(4) = 21.91, p. < 0.001$). Detailed examination did not revealed that the less experienced group had a preference for one of the two communication styles, $B_{intercept} = -0.12, t(70) = -0.08, p. = 0.934$. However, the analysis did find that the factual style was significantly ($B = 4.76, t(43) = 2.31, p. = 0.026$) more often preferred by the intermediate-experienced groups than by the less experienced group in the medical health situation that gave no cause for concern. However, this preference of intermediate group swayed more towards the guided style in a health condition that gave cause for concern, $B = -6.30, t(70) = 2.31, p. < 0.001$.

Table 3.4 shows that on average all three patient groups in all medical health situations, had a significant positive attitude towards the user interface with both communication styles. Overall, the experienced patients held a more positive attitude ($M = 1.0395\% CI[0.33, 1.73]$) towards the factual than towards the guided communication style

Table 3.4: Mean (SD) preference and attitude of 3 patient groups for guided and factual communication style

Medical health situation	Style	Attitude / Preference, M (SD)		
		Less	Intermediate	Full
Alright	Absolute Attitude			
	Guided	6.5** (3.3)	5.2** (3.8)	5.4** (3.3)
	Factual	5.7** (3.9)	6.3** (3.0)	6.4** (3.0)
	Relative attitude	-0.7 (2.0)	1.1 (2.2)	1.0* (1.8)
	Preference	0.5 (8.5)	2.5 (6.7)	1.4 (7.8)
Mild concern	Absolute Attitude			
	Guided	5.4** (3.3)	4.7** (3.6)	4.9** (2.6)
	Factual	5.0** (3.4)	5.3** (2.7)	4.5** (2.7)
	Relative attitude	-0.4 (3.2)	0.6 (1.6)	-0.3 (1.7)
	Preference	-0.9 (8.3)	1.5 (7.2)	2.7 (7.4)
Concern	Absolute Attitude			
	Guided	4.7** (3.4)	4.7** (2.7)	3.7** (1.9)
	Factual	5.0** (3.8)	4.3** (2.7)	3.9** (2.6)
	Relative attitude	0.27 (1.4)	-0.4 (1.4)	0.1 (1.5)
	Preference	0.3 (8.5)	-0.1 (8.0)	0.9 (7.7)

Note: t-test, $H_0 : \mu = 0$; $p < .05$,** $p < .01$. The higher the preference or relative attitude was, the more they preferred (or hold a positive attitude towards) the factual style, and the lower it was, the more they preferred the guided style.*

as was found in medical health situation that gave no cause for concern, $t(32) = 3.01, p = 0.005$. This was also found back for the full experienced patients group separately, $t(17) = 2.25, p = 0.038$. The multilevel analyses on the relative attitude variable again found no significant effects for patient group ($\chi^2(2) = 3.84, p. = 0.146$) and medical health situation ($\chi^2(2) = 2.14, p. = 0.343$) separately, but a two-way interaction effect between these factors that approaches the significant threshold of 0.05 ($\chi^2(4) = 9.33, p. = 0.053$), and reaches a significant ($\chi^2(2) = 6.83, p. = 0.033$) level when the intermediate and full experience patients group were combined into a single group. Detail examination revealed that the intermediate ($B = 1.86, t(138) = 2.68, p = 0.008$) and full ($B = 1.71, t(138) = 2.58, p = 0.011$) experienced group had a more positive attitude towards that factual communication style than the less experienced patient group in the medical health situation that gave no cause for concern (Figure 3.2). Again in the health condition that gave cause for concern, the relative attitude of the intermediate group attitude swayed more towards the guided communication style, $B = -2.54, t(138) = -2.59, p = 0.011$. A similar, but not significant, trend was also observed for the full experienced group, $B = -1.85, t(138) = -1.94, p = 0.051$.

3.4.3. Behaviour
During the two alright conditions, on average 27% of the patients clicked on the 'did you know' link to broaden or to consolidate their knowledge, while on average 30% clicked on the 'learn more' link during all eight conditions. While generalized linear mixed model analyses found no significant effect (all $ps > .05$) for factors on 'did you know'
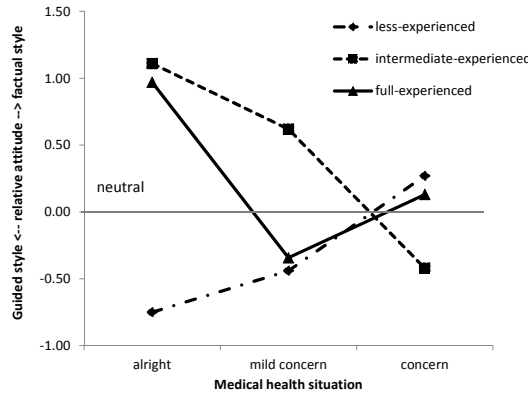
Figure 3.2: Mean relative attitude for the guided and factual communication style by medical health situations and participants' experience group
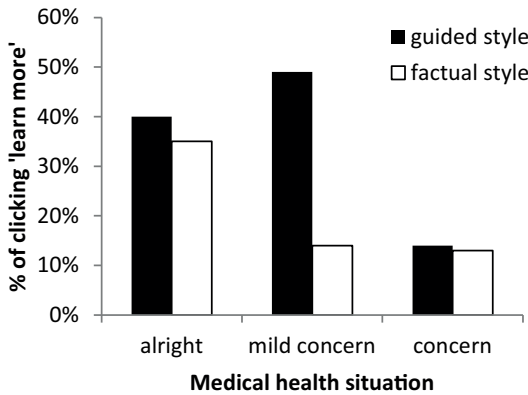

Figure 3.3: Percentage of patients that clicked on the 'learn more' link by medical health situations and communication styles

clicking behaviour, on the clicking 'learn more' behaviour a significant main effect was observed for communication style ($F(1, 276) = 5.00, p = 0.03$), and for medical health situation ($F(2, 276) = 5.83, p = 0.003$, Figure 3.3). Furthermore, it revealed a two-way interaction effect ($F(2, 276) = 3.33, p = 0.04$) between communication style and medical health situations. Pairwise contrasts revealed that patients clicked significantly less on the 'learn more' link when confronted with a medical health situation that caused concern ($M = 0.13, SD = 0.04$) than when confronted with an alright state ($M = 0.38, SD = 0.06, t(276) = 3.60, p < 0.001$) or with a mild concern state ($M = 0.28, SD = 0.06, t(276) = 2.27, p = 0.02$). Furthermore, when the medical health situation caused mild concern, they also clicked significantly more on this link in the guided style ($M = 0.49, SD = 0.09$) than in the factual style ($M = 0.14, SD = 0.05, t(276) = 3.82, p < 0.001$, Figure 3.3).

In the last two experimental conditions, patients could change the systems communication style when confronted with the medical health situation that caused some mild

concern. Of the 42 patients who indicated to have a preference for one of the two communication styles in this specific medical health situation, only 36% changed the default style to the style they preferred when the styles did not match their preference. This was significantly less than 50% of the patients ($p = 0.04$, 1-sided). For comparison, 29% of these patients changed the default style when it was already in their preferred style. No significant ($p > .05$) point-biserial correlation was found between the strength of the preference, i.e. the absolute preference value, and whether or not the patient had shifted to their preferred style.

3.5. Discussion and Conclusions

To improve patients' understanding and adherence to a SMSS, a design rationale for developing of a web-based SMSS prototype was proposed. This included the principles of layering, nudging, emphaticizing, and focusing. It resulted into two communication styles: guided and factual. When interacting with the prototype, the patients showed on average a 96% understanding and a 88% adherence rate, which was not found to differ across communication style, patient experience level, or medical health situation.

Overall both communication styles were positively received, and findings provided partly support for the first hypothesis, i.e. the difference between patient groups across the communication styles. Though the results showed no understanding and adherence differences, the results showed preference and attitude differences between patient groups. Considering the groups in isolation, it was shown that experienced patients, specifically the fully experienced ones, had a more positive attitude towards the factual communication style than the guided style in a medical health situation that gave no cause for concern. It was further shown that medical health situation had an impact on preferences and attitude, as preference and attitude differences between patients groups decreased in case of concern. A potential ceiling effect might explain why no effect on adherence or understanding was found. The overall 88% adherence rate observed was relative high when comparing this to other adherence rates reported in the literature, for example 50% to physicians' medicine prescription for chronic deceases[27], 50% to treatment for chronic diseases in developed countries[28, 29] , 25% - 59% to physicians' recommendations for colorectal cancer screening[30, 31], 19% - 96% in smoking cessation[32], 25% - 40% in self-monitoring blood glucose for diabetes[24, 33], and 52% for technology-mediated insomnia treatments[34]. However, the level of adherence studied in this experiment was just a snapshot in a lab setting, and did not look at adherence over time or considering other factors that influence adherence. Given the relative small sample size, the analysis might have lacked enough statistical power to examine factors that could explain the limited variance observed in the level of adherence. Although an average 96% understanding rate was found, 22% of non-adherence could be explained by a misunderstanding of the system's instructions. This suggests that improving understanding could still have a small effect on non-adherence observed in this experiment.

The second hypothesis, stating that medical health situation has an effect on patients search behaviour for additional information, was partly supported. We hypothesized that an increase in search behaviour would occur in case of a mild concern situa-

tion, but we found that patients looked for additional information less when confronted with a situation that caused concern compared to situations that caused no or only mild concern. For the alright situation, the system was designed to draw patients' attention towards accessing more information by using the "did you know" link, either to consolidate or to extent their knowledge. Patients, however, seemed to have mainly ignored that link and instead were more interested to learn about their current medical health situation. It was further observed that the guided style had an effect on additional search behaviour. It seemed that patients wanted to go beyond information initially offered in the interpretation layer and looked for more background information in case of no or mild concern situations. When given the advice to contact the hospital, patients' priority might have shifted from information seeking to going to hospital. Also they might expect getting information at hospital any way. For example, Medlock et al. found that senior patients searched for health information more frequently after than before an appointment with doctors[35]. The findings support the third hypothesis, which stated that a majority of patients do not change the default communication style to their preferred one. These results showed the importance of the default communication style setting. Only a minority of patients changed the default if it did not match their preference (support H3). Hence, future designers should consider this behaviour and not expect that patients will select an appropriate communication style spontaneously. Interesting was also the finding that whether patients switched to their preferred styles was not correlated with the strength of their preference. Besides, about 30% patients switched to their non-preferred styles. A possible explanation is that patients might not know what they really preferred: what they rationally thought and what they actually selected could be different[36]. Still, these patients might simply switched between the styles to explore them more in this experiment.

To the best of our knowledge, this is the first study that examines how patient experience and communication style of a SMSS could affect renal patients' preference, attitude, and behaviour. However, like in any empirical study, the results should be interpreted within the study's limits. The first limitation is the relative small sample size, especially to study the between-subjects factor patient group. This has limited the statistical power of the analyses, and the confidence by which conclusions could be drawn. A second limitation is the controlled setting under which patients had to operate. The experiment only took one hour and patients were asked to react to fictitious situations in the presence of an experimenter. All factors that would be different in a real life situation. Still the setting allowed for systematic comparison between different medical health situations and provided insight into patients' understanding and adherence. The third related limitation is that this study did not consider other potential important factors such as attitude of health providers towards the SMSS, as this was found associated with patients' intentions to use a personal health tool[37]. The fourth limitation is the lack of experimental control on the assignment of a patient to one of the three patient groups. This means that variations between the groups could in theory be attributed to other factors besides the patients' experience. Still, examination of potential confounding factors ruled out factors such as age, education level, and gender ratio.

The work can be extended in several directions. First, it would be interesting to see if these findings can be generalized to SMSSs that target other chronic diseases such

as diabetes or hypertension. Second, future research could explore the possibility for adapting communication style based on patients beliefs such as perceived susceptibility, severity, benefits, and barriers[38].

The main scientific contribution of the work presented in this paper is the insight of (1) the potential association between renal patients' experience and their preference and attitude towards a guided or factual communication style; (2) the reduced need for additional medical information when patients are confronted with a situation that gives cause for concern and a SMSS instructing them to seek medical assistance; and (3) patients' reluctance or ignorance to change the default communication style to their preferred style. Together this information suggests that when designing a SMSS, the communication style should be attuned to patient's experience and medical health situation.

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3

4

RENAL TRANSPLANT PATIENT ACCEPTANCE OF A SELF-MANAGEMENT SUPPORT SYSTEM

Chapter 2 and 3 focused on the user interface design of a SMSS. This chapter aims to understand the influencing factors of renal transplant patients' acceptance of a SMSS in their daily life. Section 4.2 proposes the potential influencing factors and the research model. It also describes the questionnaire survey procedure, its participants, and the analysis. Section 4.3 presents the results that patients' affect towards the system accounts for 26% of the variance in behavioural intention of using the SMSS. In section 4.4, the factor Affect were discussed by comparing with traditional factors, and recommendations for designers were provided. Conclusions are in section 4.5.

ABSTRACT

Background: Self-management support systems (SMSS) have been proposed for renal transplant patients to increase their autonomy and reduce the number of hospital visits. For the design and implementation of such systems, it is important to understand factors influencing patients' acceptance of a SMSS. This paper aims to identify these key factors.

Methods: From literature, possible factors and related questionnaire items were identified. Afterwards, focus groups with experts and patients were conducted to adapt the items to the application domain. To investigate acceptance of a SMSS and the influencing factors, fifty renal transplant patients answered the questionnaire before and after using the SMSS for four months.

Results: All the questionnaire constructs had a satisfactory or higher level of reliability. After using the SMSS for four months, trust and performance expectancy could explain part of the variation in behavioural intention of using the SMSS, but not beyond the explanation given by patients' affect towards the system, which accounted for 26% of the variance.

Conclusions: We anticipate that in future caregivers implementing a SMSS will benefit from taking steps to improve patients' affect as this was found to correlate with patients use intention.

4.1. BACKGROUND

CHRONIC kidney disease (CKD) is regarded as a major public health problem[2]. In the last stage of this disease, referred to as end-stage renal disease (ESRD), the preferred treatment is renal transplantation. Mortality rates for these patients are less than half compared to patients receiving dialysis treatment[3]. In addition, patients gain more freedom and energy from a successful kidney transplantation than from dialysis[4]. After kidney transplantation, however, patients need to adhere to a strict medication regimen and are followed-up frequently to monitor for signs of graft dysfunction or comorbidities. Kidney transplant patients are therefore still considered to have a chronic disease.

Self-management, the process of managing symptoms, treatment, physical and psychosocial consequences by patients themselves in daily life, has been proposed to be useful when dealing with chronic illness[5]. Self-management support systems (SMSSs) can help to increase the level of self-management[6]. These systems aim at empowering patients by giving them more control of their care process and daily activities, and thereby increasing their autonomy[6].

SMSSs have already been successfully used in the health domain to support healthy behaviours, and reports indicate that people are capable of using them. Examples include an internet-based diabetes self-management and support system[7], and systems to manage physical activities[8–10], fruit and vegetables consumption[9], and medication intake[8].

4.1.1. NEED FOR A SPECIFIC MODEL

Besides users' capability, their willingness, i.e. acceptance of using a SMSS, is also important. Several theories and models have been proposed to explain users' acceptance of information technology (IT) or information systems. These theories explore the underlying factors of users' acceptance, so that designers and organisations can anticipate on them to improve system acceptance. Both generic and specific models have been developed. The theory of reasoned action (TRA)[11], the theory of planned behaviour (TPB)[12], and the technology acceptance model (TAM)[13] are generic models formulated to apply across domains. Specific models, which are often derived from generic models, have been formulated for specific domains, such as models for Internet commerce[14, 15], online gaming[16], and mobile commerce[17].

In the area of health informatics and chronic diseases, understanding the acceptance of a SMSS could benefit from a specific model with its own unique set of factors and values, as the use of the technology may influence patients' health and lives: people may be more concerned and reserved to use a SMSS. For example, interviews with diabetic patients about a SMSS for their insulin therapy showed that emotional aspects were important, such as being embarrassed to inject insulin in public or fear of hypoglycaemia when increasing insulin dose[18]. For patients with depression or with an increased risk of cardiovascular problems, the level of interest in using a tele-health application was found to be related to confidence and perceived advantages and disadvantages of the application[19]. Furthermore, studies of internet-based testing for sexually transmitted diseases[20] and the use of personal electronic health records and secure messaging[21] put forward internet and technology usage, health care access, provider satisfaction, interactions between environmental factors, and interactions between patient activation and tool empowerment potential as key factors determining people's use of SMSSs. Arning and Karsh have also noticed that the current IT acceptance models were insufficient to understand patients[22, 23], and various researchers have worked on determining relevant factors that explain patients' behavioural intention to use eHealth technology[23–26].

Renal transplant patients, however, might be at more risk than the previous examples of chronic patients, as rejection can occur acutely with the risk of losing the transplanted kidney. Although other domains such as office applications or e-commerce, even the eHealth domain in general, have received substantial research attention, less is known about patient acceptance of a SMSS in general and more specifically, the acceptance of a SMSS by renal transplant patients.

4.1.2. OBJECTIVE

To better understand the renal transplant patients and their acceptance of using a SMSS, this paper studies their intention of using a SMSS and the underlying factors that explain this use intention. This understanding would allow system designers and health program managers to direct their attention and effort effectively and efficiently.
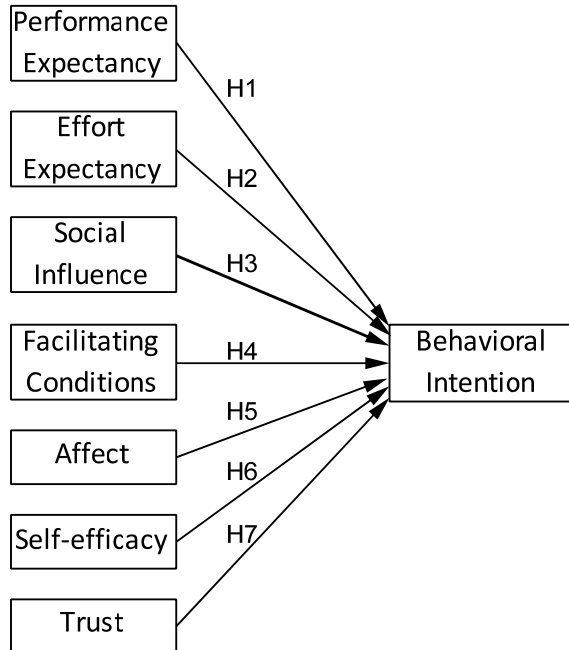
Figure 4.1: Renal transplant patient technology acceptance model

4.2. LITERATURE REVIEW

THE most well-known models or theories that have been used to explain peoples' acceptance of technology are the theory of reasoned action (TRA)[11], the theory of planned behaviour (TPB)[12], the technology acceptance model (TAM)[13], and their extensions, such as TAM2[27], the unified theory of acceptance and use of technology (UTAUT)[28], and TAM3[29]. These models are used widely and their coefficient of determination (R^2) ranged from 17% to 70%. In other words, the factors in these models can explain this amount of variation between people's intentions to use information technology[28]. R^2 is calculated by the squaring the correlation between the predicted behavioural intention by the model and the actual behavioural intention reported by the individuals. Further meta-analysis and review showed that TAM and its extensions are valid and robust, but more variables should be integrated to enhance the explained variance regarding the acceptance and use of technology[30, 31]. These models are generic as they were aimed to apply across domains, and did not consider different context in specific domains, such as eHealth or eCommerce. These generic theories and models have been used to formulate a renal transplant patient technology acceptance (RTPTA) model for a SMSS (Figure 4.1). In the remainder of this section, each determinant in the model is defined and provided with the theoretical justification.

4.2.1. PERFORMANCE EXPECTANCY

Performance expectancy (PE) is adapted from UTAUT[28] and is defined here as the degree to which renal patients believe that using the system will help them attain gains or make losses with the performance of their health management. It investigates if participants expect that the system can help them with monitoring their health. PE is strongly related to the perceived usefulness construct in TAM[32]. In many studies, PE has been shown to be one of the strongest predictors of behavioural intention[24, 25, 28] and it has been used in the health informatics domain before, for example by Ahadzadeh[24] and Beenkens[25].

4.2.2. EFFORT EXPECTANCY

Effort expectancy (EE) is defined as the degree of ease associated with the use of the system[28], e.g., whether patients experience any difficulties using the system. Perceived ease of use (PEOU) in TAM is a theoretically similar construct and is mainly found an effective predictor for peoples' use intention when they are new to a technology[28]. EE has been shown to have a significant effect on patients' intention of using an e-health service[25].

4.2.3. SOCIAL INFLUENCE

Social influence (SI) is also adapted from UTAUT[28] and is defined here as the degree to which renal patients perceive that important others believe they should use the system. It refers to what people in the patients' environment think of using the system. TRA, TPB, TAM2, and TAM3 refer to this construct as subjective norm[12, 27, 29, 33]. Venkatesh et al. were unable to find SI as an effective predictor for voluntary technology use[28]. However, they did find it to be an effective predictor in a compulsory use context, for example when the working environment requires using that specific software application; but only at a stage where people had limited use experience. In the context of health-management, patients' usage of a technology is often voluntary, the decision on whether or not using a system might be influenced by health-providers, family members, or fellow patients. Kim and Park have reported subjective norm to have a strong indirect association with patients' behavioural intention of using health information technology via perceived usefulness[26].

4.2.4. FACILITATING CONDITIONS

The factor referred to as facilitating conditions (FC) is often put forward as an effective predictor[28, 34]. In the current model, FC is defined as the degree to which renal patients believe that there are objective factors available in their environment to support their use of the system[28]. Examples of these objective factors include a computer that is appropriate for use of the system, and the availability of supporting others who can help to use the system if needed. Studies have reported mixed outcomes concerning the relevance of facilitating conditions for behavioural intention[28, 35, 36]. In the eHealth domain, however, facilitating conditions are considered an important predictor of patients' acceptance[23].

4.2.5. Affect

Affect (AF) is defined as the renal patients' overall affective reaction towards using the system. It addresses whether individuals find it pleasant to use the system. TRA, TBP, TAM nor UTAUT include the emotional reaction in performing the intended behaviour directly in their model. Instead, emotional outcomes are only indirectly included in the models as attitude towards the intended behaviour[13, 33, 37, 38]. Others have argued for the inclusion of affect as a separate construct, because one's liking of a technology could influence his or her actual usage of this technology[39]. For example, computer games are used in healthcare domain because they have the advantage of entertaining people in otherwise painful or boring health promoting processes[40]. Anxiety, as the opposite of liking, is expected to negatively influence system use[39]. In fact, affect has been found to be a predicting factor for general IT usage[39].

4.2.6. Self-efficacy

Self-efficacy (SE) is a key factor in predicting people's behaviour as it determines if they will initiate certain behaviour, how much effort they will spend on it, and how they will cope with potential obstacles[41]. In the current model, SE is defined as the degree to which renal patients judge themselves capable in using the system to manage their health, which is in line with Compeau and Higgins[39]. The concerning items address if patients think they can handle the system. So far, results concerning the role of self-efficacy in technology acceptance have been mixed. Venkatesh et al., for example, left out self-efficacy in the UTAUT model because they failed to find a stable association over time between self-efficacy and behavioural intention[28]. Others, however, do report self-efficacy beliefs as a significant precursor to information technology use[42, 43]. In the health informatics domain, however, self-efficacy was found to be indirectly linked with behavioural intention by influencing perceived usefulness and perceived ease of use[26].

4.2.7. Trust

Trust (TR) is defined as the degree to which patients believe that using the system will occur in a safe and reliable manner, consistent with their expectations of the health management task[15]. The latter is important because using any system does not mean that the patients themselves will always be safe, but that the system will run in a safe and reliable way. Participants are therefore asked how trustworthy they find the system. Although trust is not included in the generic models, it has been included in extensions of these models, for example as an extension of TAM regarding Internet shopping[44, 45]. In this case people are concerned about losing their money, which might stop them from making online purchases. Similarly in the health informatics domain, various trust aspects have been identified, including personal technical insecurity, perceived threat, and perceived health risk[24–26]. Renal patients' trust in a SMSS is therefore suggested to influence their willingness to use such a system.

4.2.8. Behavioural Intention

Behavioural intention (BI) is defined as the degree to which an individual intends to perform a certain behaviour[13]. People's behavioural intention determines their perfor-

mance of the behaviour and it is widely used to evaluate user acceptance of technology[13, 16, 24, 25, 28]. In the case of a SMSS for renal patients, the intended behaviour is the patients' use of this system for managing their health. In this paper it is hypothesised and tested that all the factors introduced earlier on, i.e. PE, EE, SI, FC, AF, SE, and TR, positively correlate with patients' intention to use and therefore acceptance of the SMSS (Figure 4.1).

4.3. METHODS

4.3.1. CLINICAL SETTING

The data used in this study were collected in the context of a randomized controlled trial, which included an intervention group that used a SMSS during the first year post-transplantation and a control group that received usual care, which did not include self-management. The general aim of the randomized controlled trial was to investigate whether part of the post-transplantation care can be transferred to a home setting using a SMSS without compromising on quality of care.

The study presented in this paper focuses on a survey completed by the intervention group only. The survey included a questionnaire that participants completed at the start and after four months into the trial.

4.3.2. SYSTEM DESCRIPTION

Patients used a blood pressure meter and a creatinine device at home to measure their blood pressure and kidney function according to a fixed schedule. They were instructed to enter the measured values into a specially designed website called MijnNierInzicht (MNI), which was designed by the LUMC with help from the Dutch Organization for Applied Scientific Research (TNO) and maintained by company Bonstato. After entering their measured values, the website provided patients with an overview of their measurement history, an evaluation of their current renal function, and an instructions for further actions, which could be: to continue their regular schedule, to conduct an additional measurement, or to contact the hospital. Besides the advice and monitoring function, the system included online learning modules (eLearning) providing relevant information, such as bodily functions, renal transplantation, and self-management. The system further allowed patients to record their weight, body temperature, and scheduled face-to-face and phone appointments with their doctors. The measuring devices, MNI website, and eLearning formed together the SMSS and in the survey it was referred to as the ADMIRE (Assessment a of a Disease management system with Medical devices In REnal disease) system to patients.

4.3.3. MEASURES

A tailored renal transplant patient technology acceptance questionnaire was developed for this study. This questionnaire included several items to measure each construct included in the renal transplant patient technology acceptance model. Initial questionnaire items were based on the questionnaires reported in the literature[13, 15, 32–34, 37–39, 46–49]. These initial items were discussed in workshops with a doctor, experienced patients, and researchers in the self-management domain. This resulted in an adjusted

set of items that was adapted to 1) the content of the SMSS and 2) patients' language and knowledge. The items were all statements that had to be rated on a 7-point Likert scale with 1 for totally disagree to 7 for totally agree with the statement and a 'not applicable' option. Participants were asked to complete the questionnaire at the start of the study (T0) and after four months of using the SMSS (T1). In most cases, at T0, the questionnaire items formulation prompted for future use, while at T1 the items formulation prompted for current use. For example, the performance expectancy item PE1 at T0 was formulated as "with the ADMIRE system, I will be able to monitor my health very well myself", while at T1 it was formulated as "with the ADMIRE system, I can monitor my health very well myself". Still, both in T0 and T1 items related to the behavioural intention always prompted for future usage. The items were in Dutch. An English translation of the T1 questionnaire items can be found in Additional file 1. At T0, patients' demographic data was collected, including the knowledge dimension items of the Partners in Health (PIH) scale that assesses patients' perceived chronic condition self-management knowledge[50]. The PIH items were rated on a 9-point Likert scale from 1, for very poor, to 9 for very good. In addition, health-related information was obtained from the hospital record.

Besides collecting data related to the RTPTA model, additional data was collected related to the specific implementation of this SMSS. The additional questions focussed on satisfaction with the training given in using the system (training), patients' options on conducting self-management through the system (self-management), contact with doctors (doctor), the time needed to use the system (time), the use of the creatinine device measuring kidney function (creatinine), the use of the blood pressure meter (blood pressure), and their feeling of conducting self-management at home (feeling, only asked at T1 as patients had to have experience with using the SMSS before being able to respond to these items, see Appendix E). All items were rated on a 7-point Likert scale with 1 for totally disagree to 7 for totally agree with the statement.

4.3.4. PROCEDURE

Intake and training procedure differed between patients receiving a kidney from a living donor and those receiving a kidney from a deceased donor. For recipients of a living donor kidney, the transplantation procedure could be well prepared, so they received an explanation about the experiment, signed the consent form, and got access to MNI website and eLearning before the transplantation. They were explained how to use the system and were encouraged to try it themselves before transplantation. For patients who received a kidney from a deceased donor, the whole procedure was postponed to after transplantation, but was preferably arranged before discharge from the hospital. Around the day of discharge (T0), all patients were asked to complete the T0 questionnaire. At home patients were asked to use the system regularly, according to a predefined schema for one year: measure and log the data daily during the first four weeks, every other day for week 5-9, twice a week for week 10-15, and weekly from week 16 onwards. After four months of using the system (T1), patients were again asked to complete the questionnaire. Both the baseline and the follow-up questionnaires were distributed in paper form.

Table 4.1: Participant profile

Participants	T0	T1
Number	46	46
Male (%)	30 (65.22%)	29 (63.04%)
Living donor recipients (%)	40 (86.96%)	39 (84.78%)
Dialysis before transplant (%)	24 (53.17%)	23 (50.00%)
Age at transplant (sd)	51.43 (14.09)	51.87 (14.33)
Educational level		
Median (number, %)	Middle (24, 53.17%)	Middle (22, 47.82%)
Mode (number, %)	Middle (24, 53.17%)	Middle (22, 47.82%)
Number of kidney transplants		
1	43 (93.48%)	42 (91.30%)
2	3 (6.52%)	4 (8.70%)
PIH - knowledge score (sd)	7.88 (1.31)	7.96 (1.33)

4.3.5. PARTICIPANTS

The intervention group consisted of renal transplantation patients who had their most recent transplantation in the LUMC. Sixty-five patients were enrolled into the trial, fifty of them responded to the questionnaire at least once, and 47 completed the one-year trial. Eighteen patients dropped out: one patient's transplantation was cancelled, four patients cancelled participation before start, one patient was excluded due to high level of creatinine after transplantation, two patients died before start, one patient died after start, four patients never used the system, and five patients quitted after using the system for a while. These five patients indicated a variety of reasons for this: variety in self-measured creatinine values ($n = 3$), stress caused by self-monitoring ($n = 1$), and too little benefit ($n = 1$). The profile of the participants who responded to T0 and T1 questionnaire is shown in Table 4.1. In both cases 46 patients completed the questionnaires. Although these populations were not made up of the exact same responding patients, no significant differences in profile were found between the populations who responded at T0 and T1.

4.3.6. DATA PREPARATION

NOT APPLICABLE AND MISSING DATA

A distinction was made between situations where participant specifically indicated that a question was not applicable (NA) for them, or when they had left the question unanswered, i.e. missing values. The relative NA percentage, i.e., the number of NA/(the number of participants - the number of missing values) × 100% for each item was calculated. The majority of questionnaire items (77.03%) had less than 5% of the participants rated the question as NA. However, items with a relative NA percentage above 1.5 × interquartile range (4.88%) + 3rd quartile (4.88%) = 12.20% were regarded as outliers[51] as apparently an unusual number of patients considered them as not applicable to their situation and were therefore not appropriate items to capture the underlying constructs across the patient sample. Twelve items (18%) turned out to be outliers and were there-
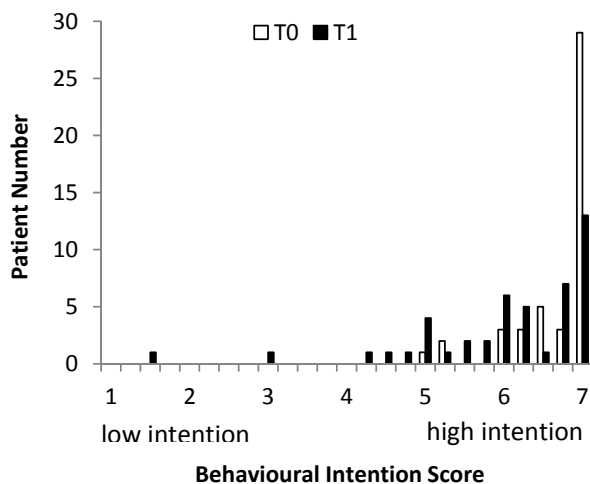
Figure 4.2: Histogram of behavioural intention measured around the discharge day (T0) and four months after (T1)

fore removed from the analysis, leading to the removal of the social influence construct all together and facilitating condition item 3 and 4 (all at T0 and T1, Appendix E. For the remaining items, 'not applicable' was treated as missing.

There were 394 (12.71%) values missing in total. Fifteen out of fifty (30%) participants answered all the questionnaire items, and none of the items were answered by all participants. To avoid exclusion of participants and thereby biasing the analysis[52], Maximum Likelihood methods using the expectation–maximization (EM) algorithm was applied to substitute missing data of the RTPTA questionnaire items. This methods produces unbiased parameter estimates with missing (completely) at random data[53]. Patients' age, gender, type of donor, and pre-transplant status were used as predictors.

BEHAVIOURAL INTENTION AT T0
Behavioural intention at T0 and T1 was computed by taking the mean score of the five questionnaire items, as their Cronbach's αs were 0.66 and 0.79, respectively. Figure 4.2 shows the histogram for the score at both T0 and T1. At T0 almost half (45.7%) of the patients had given the maximum score, and data showed limited variation. Variation at T1 was larger, therefore further analyses predominantly focus on data collected at T1.

4.3.7. DATA ANALYSIS
The data were analysed using SPSS version 22. The analyses included: Pearson correlation analyses to examine the constructs' correlation coefficients, controlled correlation analyses to examine factors' association with behavioural intention, t-tests to analyse the factors' change between T0 and T1, and hierarchical multiple linear regression

Table 4.2: Construct reliability

Constructs	Cronbach's α	Items to delete	Cronbach's α if items deleted
Performance expectancy	.56	-	-
Insight (PE1, PE2, PE3)	.73		
Health improvement (PE4, PE5, PE6)	.15	PE6	.54
Time (PE7, PE8)	.93		
Effort expectancy	.67	EE3	.73
Facilitating conditions	.99		
Affect	.75		
Self-efficacy	.21	SE3, SE4	.85
Trust	.77		
Behavioural intention	.79		

to understand how much each factor explains the observed variation between patients' behavioural intention. To understand the possible underlying factors, correlations between patients' characteristics, factors from RTPTA model, and behavioural intention were analysed, for which Pearson correlation, Kendall rank correlation, or point-biserial correlation were used depending on the data level. Bootstrapping procedure with 1000-sample was applied to the above analyses. This procedure is less biased by deviation from normality assumptions and by extreme values in a small sample[54, 55]. Furthermore, analysis included Cronbach's α and principal component analysis to examine the constructs' reliability. As there are currently limited reports available that directly support the proposed model, the principal component analysis helped to explore how well questionnaire items of the same construct correlated with each other, and how they related with items from other constructs. Note that at later stage when the model is more mature, the application of statistical techniques such as confirmatory factor analysis would be desirable[56].To examine the position of the rating on a 1-7 Likert scale, scores were compared with 4, which was regarded as the middle point of the scale.

4.4. Results

4.4.1. Reliability and Principal Component Analysis

Table 4.2 shows the results of the reliability analysis for each construct at T1. The table also shows Cronbach's α after items deletion for those constructs with initially low reliability level. The construct performance expectancy was split into three dimensions: 1) insight, meaning gaining insight in one's renal condition; 2) health improvement, meaning gaining a better health status; and 3) time, meaning spending less time on outpatient appointments. As the dimension health improvement had a low reliability level, these items were excluded in further analyses.

A principal component analysis (PCA) was conducted on the remaining 20 independent items with orthogonal rotation (varimax). The Kaiser–Meyer–Olkin (KMO) measure verified the sampling adequacy for the analysis, KMO = 0.64, respectably above the 0.5 criterion. Two individual items had a KMO value clearly below the acceptable limit of

Table 4.3: Descriptive statistics

	Constructs	T0 Mean	SD	T1 Mean	SD	Correlation T0 and T1	Difference T0 and T1, $t(41)$
Acceptance factors	Performance expectancy - insight	6.22**	0.80	6.04**	0.98	0.29	-1.47
	Performance expectancy - time	6.32**	0.80	6.22**	1.00	0.44*	-0.04
	Effort expectancy	6.04**	0.87	6.57**	0.68	0.25	3.36**
	Facilitating conditions	6.72**	0.54	6.75**	0.92	-0.03	0.25
	Affect	5.87**	1.00	5.90**	1.21	0.61*	-0.13
	Self-efficacy	6.06**	0.89	6.22**	1.43	0.43*	0.68
	Trust	6.10**	0.82	6.21**	0.95	0.49*	1.06
	Behavioural intention	6.63**	0.54	5.93**	1.15	0.49*	-4.50**
Different aspects	Training	6.29**	0.63	6.24**	1.06	0.29	-0.50
	Self-management	6.27**	0.85	6.35**	0.80	0.47*	0.64
	Doctor	5.80**	0.72	6.20**	0.67	0.33*	3.68**
	Time	6.38**	2.48	6.41**	0.87	0.16	2.69**
	Creatinine	6.26**	0.46	6.18**	0.77	0.29*	-0.66
	Blood pressure	6.69**	0.42	6.76**	0.35	0.34	0.85
	Feeling	-	-	4.43**	0.63	-	-

Note: $H_0 : \mu = 4,$ * $p < 0.05,$ ** $p < 0.01$ for bootstrapping of t-test, or *the 95% CI does not include 0 for bootstrapping of correlation.

0.5[57], indicating that these items share limited variance with other items. Bartlett's test of sphericity $\chi^2(153) = 662.24, p < .001$, indicated that correlations between items were sufficiently large for PCA. The analysis resulted in five components with an eigenvalue over Kaiser's criterion of 1. Combined they explained 73.26% of the variance. The factor loading after rotation, sampling adequacy, eigenvalue, percentage of variance, and communality scores can be found in Appendix F.

Although some components were mainly associated with the items from a single construct, such as performance expectancy - time dimension and effort expectancy, other components were associated with multiple constructs. The items for the constructs trust, affect, and the insight dimension of performance expectancy loaded almost together on a single component, and the same was observed for the constructs self-efficacy and facilitating conditions. This therefore suggested dependency between some of the constructs.

4.4.2. T0 versus T1 Measurement

Table 4.3 presents mean and standard deviation for variables of the renal transplant patient technology acceptance (RTPTA) model. Overall patients seemed positive towards using this SMSS. Paired t-tests comparison between T0 and T1 showed that ratings on effort expectancy, doctor, and time increased over time, while behavioural intention decreased over time. Behavioural intention had an exceptional high score at T0, leaving mainly room for a decrease at T1.

Table 4.4: Correlations between each construct pair

	PE-insight	PE-time	EE	FC	AF	SE	TR	BI
Performance expectancy-insight	1.00	-0.02	0.19	-0.13	0.69*	-0.02	0.64*	0.32*
Performance expectancy-time	-0.02	1.00	0.13	0.47	0.20*	0.18	0.13	0.40*
Effort expectancy	0.19	0.13	1.00	0.01	0.30*	-0.02	0.27	0.13
Facilitating conditions	-0.13	0.47	0.01	1.00	0.12	0.57*	-0.02	0.57
Affect	0.69*	0.20*	0.30*	0.12	1.00	0.35*	0.79*	0.51*
Self-efficacy	-0.02	0.18	-0.02	0.57*	0.35*	1.00	0.15	0.37
Trust	0.64*	0.03	0.27	-0.02	0.79*	0.15	1.00	0.31*

Note: *the 95% CI does not include 0.

Table 4.5: Controlled correlation between independent factors and behavioural intention (BI)

Factors	Control factors	Correlation
Performance expectancy-insight	Performance expectancy-time, trust, and affect	0.07
Performance expectancy-time	Performance expectancy-insight, trust, and affect	0.36
Affect	Performance expectancy-insight, performance expectancy-time, and trust	0.39*
Trust	performance expectancy-insight, performance expectancy-time, and affect	-0.19

Note: *the 95% CI does not include 0.

4.4.3. CORRELATIONS

Table 4.4 shows correlations between the factors of RTPTA model at T1. Performance expectancy (both insight and time dimension), affect, and trust correlated significantly with behavioural intention. These factors also correlated with each other. Table 4.5 shows the results of controlled correlations between behavioural intention and the four (sub-)factors when controlled for the other (sub-)factors that correlated with behavioural intention. Only affect had a significant correlation with behavioural intention when controlled for other (sub-)factors.

4.4.4. REGRESSION ANALYSIS

Hierarchical multiple linear regression was conducted on behavioural intention. Bootstrapping with 1000 samples was again applied. First, affect, the factor that partially correlated with behavioural intention, was entered as a predictor (model 1). After this, all remaining factors that correlated with behavioural intention were entered into the model (model 2). Model 1 resulted in a significant ($F(1, 44) = 15.80, p < .001$) model with R^2 of 0.26, meaning that affect could account for 26% of the variance between patients' usage

Table 4.6: Model coefficients

Model 1	B	Std. Err	Beta	t	p	Bias	Std. Err	p	95% CI Lower	Upper
			Coefficients				**Bootstrap Coefficients**			
(Constant)	3.05	0.74		4.12	<.001	-0.21	0.96	0.002	0.50	4.26
Affect	0.49	0.12	0.51	3.98	<.001	0.03	0.15	0.001	0.31	0.90

intention, and the p value suggests it was a significant predictor (table 4.6). Although Model 2 has its R^2 improved (0.38), it was not found significantly better in explaining behavioural intention ($R^2_{change} = 0.12, sig.F_{change} = 0.06$) than Model 1. In other words neither performance expectancy nor trust could explain patients' behavioural intention beyond affect, which was again the only significant predictor.

The model was examined for possible biases caused by outliers or influential cases. First, the model fit did improve ($F(1, 42) = 23.55, p < .001, R^2 = 0.36$) after removing two outliers with standardized residuals larger than 2.58, which is more than 1% of the sample cases[57]. Secondly, influential cases were examined by calculating Cook's distance, leverage, and DFBeta. No cases were found having Cook's distance or standardized DF-Beta larger than the recommended upper value of 1[57]. Still two patients had their leverage value larger than the recommend upper value of 0.13, i.e. $3 \times$ (the number of predictors+1)$/n$[56]. Excluding these two patients resulted in a model with $F(1, 42) = 16.13, p < .001, R^2 = 0.28$. The original model therefore seems stable and not influenced by possible outliers or influential cases.

4.4.5. CORRELATION WITH EXOGENOUS VARIABLES
The constructs affect and behavioural intention were future explore by examining correlations with patient characteristics, i.e. age, gender, donor type, educational level, the number of kidney transplants, being dialyses before transplant, and PIH - knowledge dimension. The analyses were done on paired complete cases. The analyses revealed that deceased, compared to living donor recipients, were associated with a higher Affect level, $r_{pb} = .29$, 95% CI[.16, .47], $n = 42$. Furthermore compared to patients that did not receive dialyses before transplant, patients that did were associated with a higher Affect level, $r_{pb} = .34$, 95% CI[.07, .55], $n = 42$. The analysis also revealed that female, compared to male patients, were associated with a stronger behavioural intention at T1, $r_{pb} = .33$, 95% CI[.16, .51], $n = 45$. No other significant correlations were found.

4.5. DISCUSSION
KIDNEY transplantation is the treatment of choice for patients with end stage renal disease, but does not free patients from needing medical care. As kidney transplant patients have to adhere to a strict medication regimen and need to be frequently monitored for signs of graft dysfunction, they are still considered chronically ill. Self-management, the process of managing symptoms, treatment, physical and psychosocial consequences by patients themselves in daily life, has been proposed to be useful when dealing with chronic illness[5]. A self-management support system (SMSS) aimed at em-

powering patients by giving them more control of their care process and daily activities, can help to implement self-management in daily life[6]. The current study investigated kidney transplant patients' intention to use a SMSS and potential explaining factors.

Results show that patients were on average positive towards using the SMSS, both in advance of use and after having used the SMSS for four months. The behavioural intention to start or continue using the SMSS could mostly be explained by patients' affect towards the SMSS (26% explained variance, supporting H5). The analysis also found performance expectancy on insight and on time, and trust to be correlated with behavioural intention, supporting H1 and H7 respectively. Still, these factors were not able to explain variation in behavioural intention beyond the affect factor. No support was found for the other hypotheses (H2, H3, H4, and H6). This result is different than what is usually found when using TAM or UTAUT[28], with effort expectancy being traditionally one of the most important factors explaining behavioural intention. Although 26% of explained variance is at the lower end of the range of 17% to 70% reported by other studies[28], the regression model included only one factor, which might be a reason for the relatively small R^2.

Although affect overlapped with performance expectancy to some extent, affect was the only remaining factor in the regression analysis being significantly associated with patients' behavioural intention to continue using the system after four months of use. In the first few months post-transplantation, only a limited number of outpatient visits was replaced by a telephonic consult. Many patients therefore visited their doctors in the usual frequency, putting less need on using the system to be informed on their kidney function. The fact that there was no absolute need to use the system, contrary to what happens when an entire organization implements a new technology and replaces the old one, might explain why affect was found to be the most important factor related to behavioural intention. When patients are 'free' to choose, it seems logic that emotions are crucial. Comments made by patients at the end of study participation confirm the emotional aspect. Some patients mentioned that if possible they would like to continue using the SMSS after one year, as it gave them a feeling of safety. Others indicated that the first year after transplantation is of most risk and as they had safely reached this milestone, they no longer felt the need to use the SMSS.

It was further found that some questionnaire items, especially the social ones such as social influence and facilitation related to the social environment, were rated as not applicable by a substantial part of the group. These participants might not have understood these questions or had not discussed the use of system with their social environment and felt therefore unable to give answer. Reformulation of these items or informing people that holding social related beliefs does not require actual discussion with the social environment might therefore be advisable in the future.

The main scientific contribution of the current study is that it introduced affect as a new factor explaining kidney transplant patients' behavioural intention to use or continue using a SMSS. In practice, the finding suggests that the emotional experience of using a SMSS should be taken into account when designing and implementing a system to be used in healthcare. Several strategies have been put forward for this, for example by empowering patients to interpret their measurements, instead of providing automatic interpretation from the system as a method to decrease patients' stress of using

the technology[58]. Furthermore, using warm colours rather than bright colours to get a calming effect, and cold colours for a more relaxing effect[59–61].

4.5.1. LIMITATIONS AND FUTURE RESEARCH

To appreciate the study, awareness of its limitation is necessary. First, the study has a relatively small sample size considering the number of factors included in the study. Another limitation is the way of dealing with the 'not applicable' ratings. Although items indicated as not applicable by a substantial sub group were excluded in the analyses, others were treated as missing values, but they could have had a different meaning. A third limitation is pre-selection, as the data used in this study were derived from a group of patients that had already agreed to use the SMSS. The high intention at the beginning of the trial to use the system confirms this bias. Besides, among all 36 patients who declined to participate in the randomized controlled trial at first place, 17 patients declined because they expected additional burden and 2 because they expected no gain of using it, which belonged to the performance expectancy factor. Fourth, the SMSS has different components, such as the medical devices, MNI, and the eLearning modules, and the patients might have held different attitudes towards them. However, their intention to use each of these components and the corresponding influencing factors were not investigated in the questionnaire.

This work can be extended in several directions. First, enlarging the sample size would increase the statistical power, and additional research would also help to mature the model, justifying the use of more sophisticated statistical techniques such as confirmatory factor analysis, or, when including other dependent variables such as observed usage and health indicators, structural equation modelling. Second, interviewing some respondents would provide essential insights in, for example how they interpreted the items, especially the affect items, and the rational for considering items as not applicable. This could help in the re-formulation of some items. Third, it would be interest to include patients who would not use the SMSS to understand them as well. Another direction could be to investigate patients' acceptance of the different components of a SMSS.

4.6. CONCLUSIONS

THIS study builds a model to investigate the influencing factors for renal transplant patients to accept a self-management support system. Trust and performance expectancy could explain variation in behavioural intention of using the SMSS, but not beyond the explanation given by patients' affect towards the system. As behavioural intention is considered an indication for system acceptance, paying attention to the emotional experience of kidney transplant patients when using a SMSS seems important for successful implementation of this kind of systems into chronic care.

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5

ADHERENCE TO AND RELIABILITY OF SELF-MONITORING KIDNEY FUNCTION AFTER RENAL TRANSPLANTATION WITH THE SUPPORT OF A SELF-MANAGEMENT SUPPORT SYSTEM

In Chapter 4 the patients' behavioural intention of using the ADMIRE system was investigated, but their real behaviour towards it was not clear yet. Therefore this chapter will examine their actual usage of the system and identify their behavioural patterns, so that designers and hospitals could understand these patients better and provide them the needed system. Section 5.2 describes the system, the material to analyse, and the method to identify potential behavioural patterns. Section 5.3 presents participants' actual patterns of using the system. The conclusion and recommendation for future system design and implementation are in section 5.4.

ABSTRACT

Motivation: To reduce the burden caused by renal transplant patients' frequent hospital visits, self-management has been suggested. For self-monitoring to be useful, self-monitored data must be accurate and reliable.

Method: For a year after transplant, a group of patients (n = 49) used a StatSensor creatinine hospital meter to measure their creatinine level and enter this into an online website that provided them with advice. Registered measurements in the device, recorded measures entered online, and hospital records of outpatient visit and telephone consultations were compared.

Results: 83.6% of online entries could be directly linked to single measurement, from which 9.4% deviated from measured data. 12.9% of the online entries were derived from a series of measurement. Here participants often selected a measure for entry that was closest to previously entered measurement. Overall participants showed high adherence level (100% or more) to the measure and entry frequency set by the measurement protocol. To obtain updated online advice, participants required entering creatinine values on the day of measurement. 37.5% of the first online entries made on a day were however measured on previous days. When considering the timely entered online measurements, a 50% compliance rate was observed in cases where the online system instructed the patient to take actions.

Conclusion: The high measurement adherence, but relative low rate of timely online entry implies the need for strategies that could avoid or reduce delayed manual online entry.

5.1. INTRODUCTION

KIDNEY transplantation is the treatment of choice for end stage renal disease (ESRD) as it is associated with a reduced risk of mortality and cardiovascular events as well as better quality of life than treatment with chronic dialysis[2]. Although clearly beneficial, transplantation holds its own risks necessitating frequent follow-up of transplant patients. Many of these visits consist of routine checks of blood level creatinine, blood pressure, and current medication. The high frequency of these visits puts high pressure on healthcare capacity and is a burden to patients, as many of them need to travel a considerable distance to get to the hospital. Previous studies have shown the possibilities of patients who self-monitor important disease parameters at home[3–6]. Besides the convenience of not having to travel, patients have access to the results immediately. Further, most self-test devices use finger-stick testing, which is shown to be preferred by patients over venepuncture[7, 8].

However, for self-monitoring to be useful, the self-monitored data must be accurate and reliable. Previous studies have shown different levels of accuracy and reliability of self-monitored data. Most studies have been performed for self-monitoring blood glucose, with percentage of reliable logbook entries ranging from 46-93%[9–14]. Level of reliability increased considerably when patients knew logbook data would be compared

to device memory[15]. For self-monitoring blood pressure, higher mean levels of reliability were found[16–18]. However, deviations seemed serious with one study showing a difference of >10 mmHg between logbook entries and actual values in 20% of all logbook content[17]. The highest level of reliability was found for self-monitoring International Normalized Ratio (INR); the majority of patients was 100% accurate in reporting their results[19].

In addition to reliability of measured data, adherence to measurement protocol is mandatory in order for self-monitoring to be safe. One pilot study showed that adherence to self-monitoring creatinine in the first months after transplantation was high, with the majority of patients reporting more measurements than required. However, differences between patients were large and seemed to increase over time[20]. In other disease populations, level of adherence ranged between 52- 92%[18, 21–26] and decreased over time[27].

To the best of our knowledge, however, no study has been performed on the adherence to measurement protocol and reliability of kidney transplant patients' generated data. Our research goals were to determine 1) patients' reliability of entering the self-monitored creatinine data online, 2) level of adherence to monitoring plan, and 3) level of adherence to automatically generated instructions.

5.2. METHODS

5.2.1. INTERVENTION

THE data was obtained from the intervention group of the ADMIRE study (Assessment of a Disease management system with Medical devices In RENal disease). The ADMIRE study included a randomized controlled trial among kidney transplant patients performed at the University Medical Center of Leiden (LUMC), the Netherlands. The study protocol was reviewed and approved by the Medical Ethics Committee of the LUMC.

For self-monitoring creatinine, each participant received a StatSensor® Xpress-i™ Creatinine Hospital Meter (StatSensor, Nova Biomedical, Waltham, USA; certified according to ISO 13485:2003, IVDD, meets IEC 61010, UL and FDA labelled for in-vitro diagnostic use) and measurement accessories (i.e. test strips, control solution to test the quality of the strips, and safety lancets for capillary blood sampling). When started to use a new bottle of test strips, patients were instructed to test one strip from the bottle of its quality. They could indicate in StatSensor that it was a test measurement of the strip, instead of themselves.

Measurements were performed according to a fixed schedule in four phases: phase 1, daily during the first four weeks; phase 2, every other day for week 5-9; phase 3, twice a week for week 10-15; and phase 4, weekly from week 16 onwards. Participants were asked to enter the measurement results in the website admire.mijnnierinzicht.nl (Mijn-NierInzicht, MNI, meaning "my renal insight", not available any more). Furthermore, they also had to enter the date when they conducted the measurement, the so-called announced measuring date. MNI also provides links to eLearning modules including instructions on how to perform the measurements and use MNI, information on kidney anatomy, kidney transplantation procedure, medication, and life with a kidney transplant and corresponding tests.

Feedback was given to support patients' interpretation of creatinine trends. It appeared directly after entering a new creatinine value. Depending on patients' creatinine level, the advice could be either to do nothing extra but continue regular measurement schedule, or to re-measure on the day to confirm the current renal status. If the patient followed the re-measure instruction, the system would again provide advice, which could be 1) to do nothing extra but continue regular measurement, 2) to re-measure on the next day to confirm the renal status, or 3) to contact the hospital and consult a health provider directly.

All nephrologists related to the nephrology department of the LUMC with kidney transplant consulting hours ($n = 10$) had access to patients' home-measured values. After the first eight weeks post-transplantation, the protocol prescribed every other face-to-face outpatient visit with regular laboratory analysis to be replaced by a telephonic consult to discuss the values measured at home. It was, however, up to the treating nephrologist to judge whether a patients' condition allowed for the visits to be replaced.

5.2.2. Participants

Patients were eligible for participation if they were scheduled to have kidney transplantation within 3 months (living donor program) or if they recently received a kidney from a deceased donor for which they were still hospitalized, were ≥ 18 years of age, mastered the Dutch language sufficiently, had access to Internet, could perform the required actions independently, and had a creatinine level of ≤ 300 µmol/l within 4 weeks post-transplantation. Patients were excluded if they had received a combined transplantation (e.g. kidney-pancreas), had insufficient understanding of the treatment, had a history of incompliance, or were mentally retarded.

Recruitment of living donor recipients took place during a pre-transplant appointment with a nurse-practitioner aimed at informing patients on the transplant procedure. Recipients of a post mortem kidney were recruited during their post-transplantation stay in the hospital. Patients received a short introductory talk and were supplied with a detailed description of the study design. The nurse practitioner informed the clinical researcher on potential participants. If a signed informed consent was not returned within 2 weeks from the appointment, patients were contacted to ask whether they were (still) interested in participating. Reasons for exclusion or declined participation were registered.

After signing informed consent, each participant was assigned a study number. Incoming informed consents were treated in consecutive order. Study numbers were allocated to either the intervention or control group.

During the period of inclusion, 227 patients received a kidney transplant of which 155 were considered eligible for participation. The main reason for ineligibility was insufficient mastery of the Dutch language (32%). 119 patients (77%) signed an informed consent of which 65 were randomized to the intervention group, the group that is studied in this paper. After randomization, 3 patients were excluded from further analysis because of graft dysfunction, death, and cancellation of transplantation (none was study related). Another 4 patients cancelled their participation before starting to self-monitor kidney function at home, because of little trust in the creatinine device, experienced difficulties when logging into MNI, business rush, and worsened condition

Table 5.1: Characteristics of participants

Characteristics	Adherence to plan	Entering data & adherence to system
Number	49	43
Female	17 (34.7%)	16 (37.2)
Age at transplant (sd)	51.6 (14.6)	52.4 (14.5)
Former transplant	4 (8.2%)	3 (7.0%)
Living donor transplant	43 (87.8%)	38 (88.4%)
Dialysis before transplant	22 (44.9%)	22 (51.2%)

post-transplantation. Fifty-eight patients were supplied with a creatinine device.

To study level of adherence to measurement plan, patients of whom measured values were available for at least one complete study phase were included ($n = 49$). To study the behaviour of entering data and adherence to system instruction, patients who performed measurements during all phases and had an analysable amount of online enter data available were included ($n = 43$). The characteristics of these patients are shown in Table 5.1.

5.2.3. PROCEDURE

Two weeks prior to scheduled living donor transplantation, patients were informed on the study group that they were allocated to. Intervention patients received account details to log in to MNI and the eLearning modules for instructions of self-monitoring. Live instruction was given during hospitalization prior to transplantation. Patients were supplied with the measurement devices and related test materials to practice using them during hospitalization. On the day of discharge, a personalized self-monitoring scheme was created online starting from the first day at home. Paper instructions of how to use the device and solve problems were supplied to enable patients to continue monitoring in case of a shutdown of MNI. Recipient from a deceased donor kidney received all information and training during hospitalization after transplantation, for which a laptop was available.

At home, patients performed measurements of creatinine combined with blood pressure, body temperature, and weight according to the fixed schedule during the first year post-transplantation. After the first 8 weeks post-transplantation, patients were contacted to announce the start of alternating face-to-face visits and telephonic consults. A note with words of the same effect was put in the electronic file of all intervention patients to inform the nephrologists that the concerning patient was a participant of the current study. This note was shown repeatedly during study participation to remind the doctor of alternating face-to-face visits and telephonic consults, taking a patients' clinical condition into account.

After one year of participation, patients were invited for a semi-structured interview ($n = 20$) or for a short evaluation with the clinical researcher. Patients handed in their creatinine device to download stored measurement values to an Excel file. During participation, patients were not informed about the comparison of the MNI entries and device memory.

5.2.4. Measures

Measurements of the study consist of three parts: 1) the logged data in the device, including the measured value, the measuring date and time, and if it was indicated as a test measurement; 2) the logged data in MNI, including the entered value, the entering date and time, the announced measuring date, and the corresponding advice given by MNI; and 3) hospital records of outpatient visit, telephone consultation, patients' laboratory test results, and patients' characteristics. In addition, the logged data of the eLearning modules usage was analysed.

5.2.5. Data Preparation

Before analysing the data, the device logged data and MNI logged data was combined to be compared. The combination was mainly based on the measuring date in the devices and patients' announced measuring date in MNI. The measured value and entered value was another reference. For example, if the two values were the same but the measuring date and announced measuring date had a constant difference since a certain point, then the time on the device was checked with the current time. Six patients' devices were found with incorrect time, ranging from 8 days to 3 years and 361 days. However, some patients' devices were missing after exporting the data, or the data was erased from the devices. In those cases, the dates were corrected by comparing the announced measuring day and the logged measuring day. This happened to data of five patients, and the correction ranged from 1 day to 2 years.

One participant's 66 continuous entered measurements were missed in his device. These records were, therefore, excluded in further analyses.

Many patients either did not perform test measurements or did not indicate them as such. To prevent test values to be mistakenly considered as actual creatinine measurements, all values were manually checked by a clinical researcher who used the following criteria: 1) the value was not registered in MNI, 2) the value felt within test value range (133-239 μmol/l), 3) the value followed or was followed by at least one entered value measured on that same day, and 4) the clinical researcher found the value clearly different from the values preceding and following. After having thoroughly checked and discussed all potential test values, for 24 values it remained unclear whether they were test values or not. To control for the potential bias of regarding them as test measurements or not, an analysis was conducted to compare the results of regarding them as or not as test measurements.

When a difference between measured and entered values was found, the possible reason of the difference was classified as:

- Typo: switch between digits (such as 137 and 173, and 217 and 271) or type an adjunct digit on the keyboard (such as 137 and 138, and 137 and 167)
- Round off: round up to 0 or 5, and not a typo
- Other: neither typo nor round off, no clear reason

Adherence to the measuring protocol was calculated based on the number of distinct days on which a measurement or an online entry was made. This was divided by the number of days scheduled in a week. Phase 2, with its schedule of a measurement every

other day, was simply interpreted as a measurement and online entry on 3.5 distinct days during the week.

5.2.6. DATA ANALYSES

The measured and entered data were compared with each other, including the existence, the value, and the date. Patients' adherence to both the schedule and the system feedback were also examined. SPSS 22 was used to conduct Spearman's correlation between on one hand patients' characteristics, i.e., gender, age at transplantation, the times of renal transplantation, renal function before transplantation, and the transplantation type, and on the other hand their adherent behaviour. Bootstrapping procedure with 1000 samples was applied.

5.3. RESULTS

5.3.1. ENTERING DATA

TABLE 5.2 shows that on average patients measured their creatinine 139.6 times in a year (measured). Seventy-five percent of these measurements were entered into MNI (measured-entered), leaving 11.1% not being entered (not entered) excluding the 4.0% possible test measurements of strips (test) and 9.7% parts of a series of measurements. Interesting, 2.7% of 107.3 mean data entries in MNI (entered) could not be directly be related to a corresponding measurement logged in the devices (not measured), and another 0.3% could however be related to a corresponding laboratory results from the hospital (lab). Besides the mean frequency values, the table also shows the median. Comparing the median with mean shows relative small differences, which support the mean as a representation the central tendency of the data. One exception is the not entered data. This is positively skewed as one patient was observed not to have entered their measurements in more than 100 occasions.

Table 5.2 also shows that 86.4% of the entered data resulted from a single measurement (single-measurement-single-entry, SMSE) and that 10.7% of entered data was the result of multiple measurements performed on a single day (multi-measurements-single-entry, MMSE) excluding the multiple measurement that simply included test measurements. For all the SMSE data, the measured and entered values were compared. In 8.9% a difference was found (value different). These differences were not caused by a minority of the patients, as 75% of the patients entered at least one value that was different to what was actually measured. Among the values with differences, 20.7% seemed to be due to type errors, and 11.4% were rounding off differences, while for the remaining 67.8% no cause or strategy could be determined. Including the 24 unclear measurements as test measurements changed 0.1% to 7.5% of the mean frequencies of not entered, test, not entered multi-measurement, MMSE, and SMSE categories. Since the change is very limited, the following analyses remain exclude them as test measurements.

The 11.1 entries into the MNI patients made on average that were derived from multiple measurements, resulted in a total of 479 entries. Table 5.3 shows a breakup of the percentages for the various strategies observed in deriving a value from multiple measurements per patient. First, it shows that on average 13.6% of these entries were different than any value measured that day. In over half of these entries (8.6%), patients en-

Table 5.2: The average number and percentage per participant of measuring and entering behaviour

| | Mean% | Frequency | | | | |
		M	SD	Mdn	Min	Max
Measured	100.0	139.6	46.0	132	65	301
Measured-entered	75.3	104.2	41.5	96	36	281
Not entered	11.1	16.3	25.9	8	0	147
Test	4.0	5.3	4.6	4	0	18
Not entered multi-measurement	9.7	13.6	9.3	12	1	41
Entered	100.0	107.3	43.5	100	42	306
Not measured	2.7	2.8	5.3	0	0	25
Lab	0.3	0.3	0.7	0	0	3
Multi-measurements-single-entry	10.7	11.1	6.8	11	1	29
Single-measurement-single-entry	86.4	93.1	40.2	87	35	270
Value different	8.9	8.9	16.3	3	0	92
Typo	20.7	1.7	2.7	0	0	10
Round off	11.4	0.8	1.8	0	0	11
Other	67.8	6.4	13.6	2	0	80

Note: indention indicates to what the percentages relate to, e.g. for Typo, 20.7% of the 8.9 entries observed on average with a value different were identified as a typo.

tered a value that was lower than all of the actual measured values. The table also shows that a majority of entries (86.4%) was based on a value that was actually measured. Most of these entered values seemed to be chosen because of their similarity to the last entered values (68.6%). Other frequent strategy was to enter the lowest of all measured values (55.1%) or interestingly, the last measured values (39.0% + 8.1% = 47.1%).

5.3.2. ADHERENCE TO PLAN

The adherence over the year calculated by averaging the week adherence, showed a median measuring adherence of 100.0% ($M = 119.9\%$, $SD = 116.5\%$), and entering adherence of 100.0% ($M = 106.5\%$, $SD = 108.7\%$). Figure 5.1 shows the mean, the 10th, the 50th, and 90th percentile of patients' measurement adherence to the scheduled measurement frequency per week. For example, in phase 3 patients were scheduled to measure twice in a week. Therefore, 100% adherence was obtained when during the week a patient measured his or her creatinine level on two distinct days, while 150% adherence was obtained when a patient measured on three distinct days in phase 3. Figure 5.2 shows the same, but then for the MNI entries with a corresponding measurement. The overall observation is that at least half of the patients followed or did more than schedule in most weeks. At the start of phase 1, where 100% was the maximum achievable adherence, mean adherence felt below 100%, as patients were probably too weak or too busy to follow the schedule. Both figures also show peaks in mean adherence at the start of phase 2, 3 and 4. Probability patients continued for a while the more frequent measuring and entering routine of the previous phase before adapting to new lower frequency schedule.

The figures also shows patients adhered to the schedule very differently. For exam-

Table 5.3: Strategies observed when determining the value to enter from multiple measurements in percentage of the mean total number of entries made by a patient that resulted from multi-measurements

		Closest to last entered value				Not closest to last entered value				Total
		First	Last	Other	**Total**	First	Last	Other	**Total**	
One of	Lowest	16.3	29.5	0.4	**46.1**	3.9	5.0	0.1	**8.9**	**55.1**
mea-	Highest	7.6	8.8	0.0	**16.5**	4.5	2.2	0.1	**6.9**	**23.4**
sured	Median	0.6	0.3	0.4	**1.3**	0.2	0.8	0.5	**1.4**	**2.7**
values	Mode	-	-	-	**4.2**	-	-	-	**0.0**	**4.2**
	Other	0.2	0.4	0.0	**0.6**	0.0	0.2	0.3	**0.5**	**1.1**
	Total	**24.7**	**39.0**	**0.8**	**68.6**	**8.6**	**8.1**	**1.1**	**17.8**	**86.4**
Not one	Mean									**0.7**
of	Higher than highest									**1.1**
mea-	Lower than lowest									**8.6**
sured	Between highest and lowest									**3.1**
values	**Total**									**13.6**
									Grant total	**100.0**
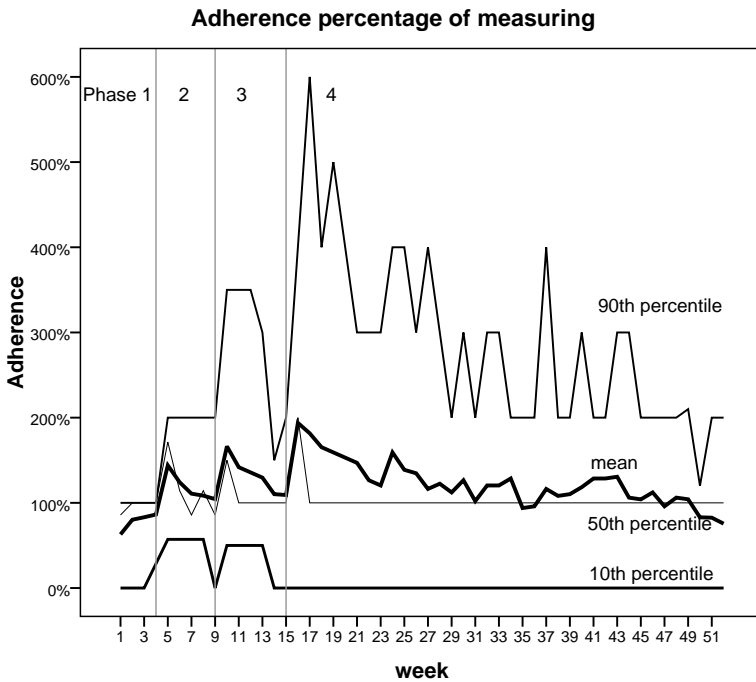
Figure 5.1: Mean, 10th, 50th, and 90th percentile of patient measuring frequency compared to the weekly schedule frequency
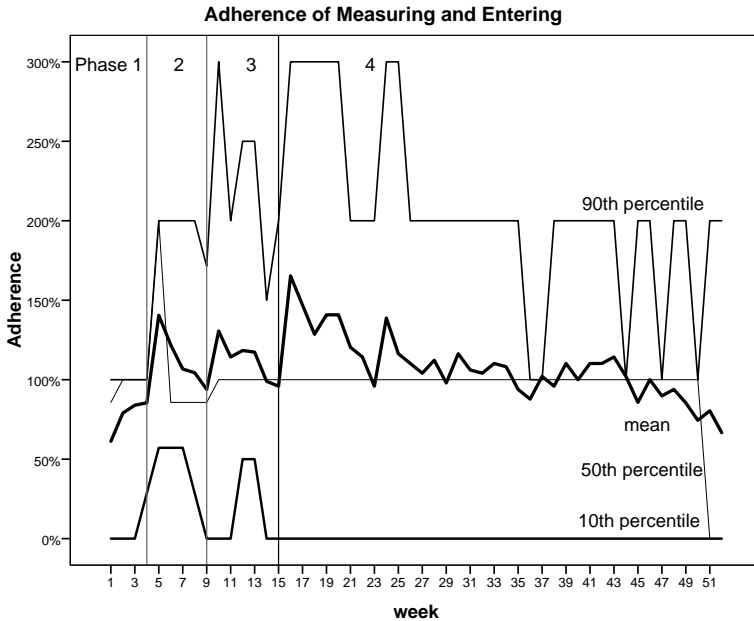
Figure 5.2: Mean, 10th, 50th, and 90th percentile of patient measuring and entering frequency compared to the weekly schedule frequency

ple, in the lower 10th percentile adherence, this patient rarely reached 100% adherence, stopped entering measurement after 14 weeks, and completely stopped measuring after 35 weeks. Contrary in 90th percentile adherence, here the patient made more measurements and entries than scheduled. Variations in patients' adherence could not be explained by the patients' characteristics of Table 5.1 as no significant (all $p > .05$) correlation where found with the average adherence.

Besides patients' adherence to the scheduled measure and entry frequency, adherence to timely entering the measured creatinine value was also examined. Entering the measure value on the same day was essential for the effectiveness of the advices given by MNI. Since one patient has never entered his value online, he was excluded from this analysis. Measuring dates, entering dates, and announced measuring dates of the 98.9 measurements patients made and entered on average were compared. Table 5.4 shows that a large majority of the patients (89.6%) did not always enter their data on the measuring day, and on average 37.5% of entries a patient made were from another day. As Figure 5.3 shows, two patients each entered more than 200 values measured on another day. This skewed the mean positively. The median of 27.1% is therefore considerable lower. Still as Figure 5.4 shows, extensive variation between patients was observed. The histogram actually shows a V-shape, with a single patient in the turning point interval of 40-50% entries made on another day. 62.5% of the patients entered more often their measures on the same day, and 37.5% of patients entered more often their measurement on later days. The median time between measuring and entering was 1.3 days ($M = 4.3, SD = 6.4$). In cases where measured values where not entered on the same day,

Table 5.4: Different in dates of measuring and entering

Different days	Mean%	M	SD	Median%	Mdn	Min	Max
Measuring and entering							
Patient number: 43 (89.6%)							
Frequency	37.5	36.5	49.1	27.1	26	0	263
Entry delay (in days)	-	4.3	6.4	-	1.3	0.0	29.2
Entry delay ≥ 1 day	-	7.7	7.0	-	5.9	1.0	29.2
Measuring and announced measuring							
Patient number: 35 (72.9%)							
Frequency	5.7	4.7	6.3	3.0	3	0	26
Entry delay (in days)	-	0.0	0.2	-	0.0	-1.4	0.3
Entry delay <> 0 day	-	-0.6	1.9	-	-0.5	-7.0	4.3
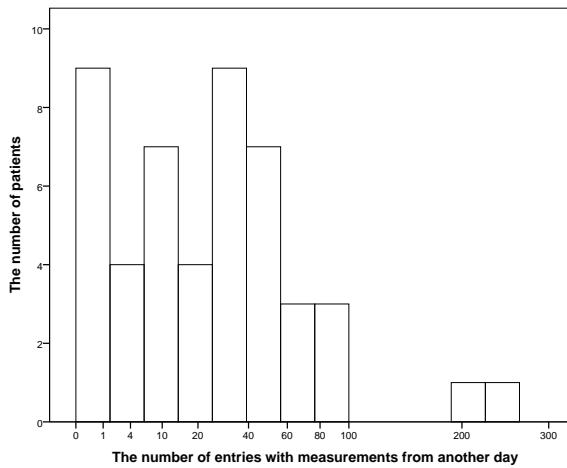
Figure 5.3: Histogram of entries with a measurement conducted on another day

the median delay was 5.9 days (M = 7.7, SD = 7.0). Table 5.4 also shows that on average a patient announced 4.7 times the wrong measurement day, and 72.9% of the patients entered the wrong date at least once during the year.

The patients' age was found to be associated with the adherence to timely entering the measurements. A significant negative correlation was found between on one hand the patients' age and on the other hand: the relative frequency of values entered on another day ($r = -0.35, n = 48, p = 0.02, 95\%$ CI $[-0.58, -0.08]$), and the number and percentage of wrong announced measuring days ($r = -0.35, n = 48, p = 0.01, 95\%$ CI $[-0.60, 0.07]$; and $r = -0.36, n = 48, p = 0.009, 95\%$ CI $[-0.60, -0.06]$).

5.3.3. ADHERENCE TO SYSTEM INSTRUCTION
The final analysis of the patients' adherence focused on their adherence towards the advice given by the MNI after entering their creatinine. For this, the first entries made on a
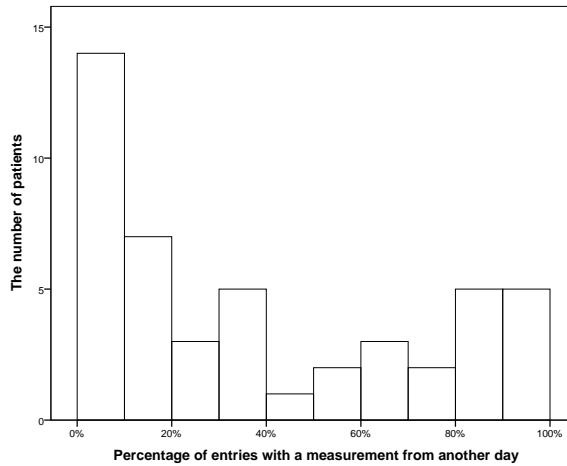
Figure 5.4: Histogram of the percentage entries with a measurement from another day set against total number of entries made by a person

day were examined. The top node of Figure 5.5 shows a mean value of 99.4 entries made in a year by a patient. Only 64.5% were made on the day of measured, and 35.5% were out dated entries as measurements were conducted in previous days thereby making the MNI advice out dated. The possibility that patients delayed entering because they somehow rightly estimated that these values would less likely cause concern for medical complication was unlikely. The odds of being instructed to do nothing extra or to re-measure were 13.9 to 1 and 14.0 to 1, for an entry made on the same day of measurement and on previous days respectively.

In Figure 5.5, each end-node of a patient respond is classify either doing less, more or did as instructed. Adding up these end-nodes shows that on average for 37.6% of the entries a patient did less than instructed, which was made up almost completely by 35.5% of delayed entries. Looking only at the 64.5% timely entered measurement, gives an insight into the adherence towards the advice given by MNI. In 62.4% of these entries patients did at least as instructed. 60.1% of the times patients however were instructed not to do anything extra. In the case they were instructed to do something, 50% complied or did even something more. In 50% of these situations did a patient not follow up the advice for action.
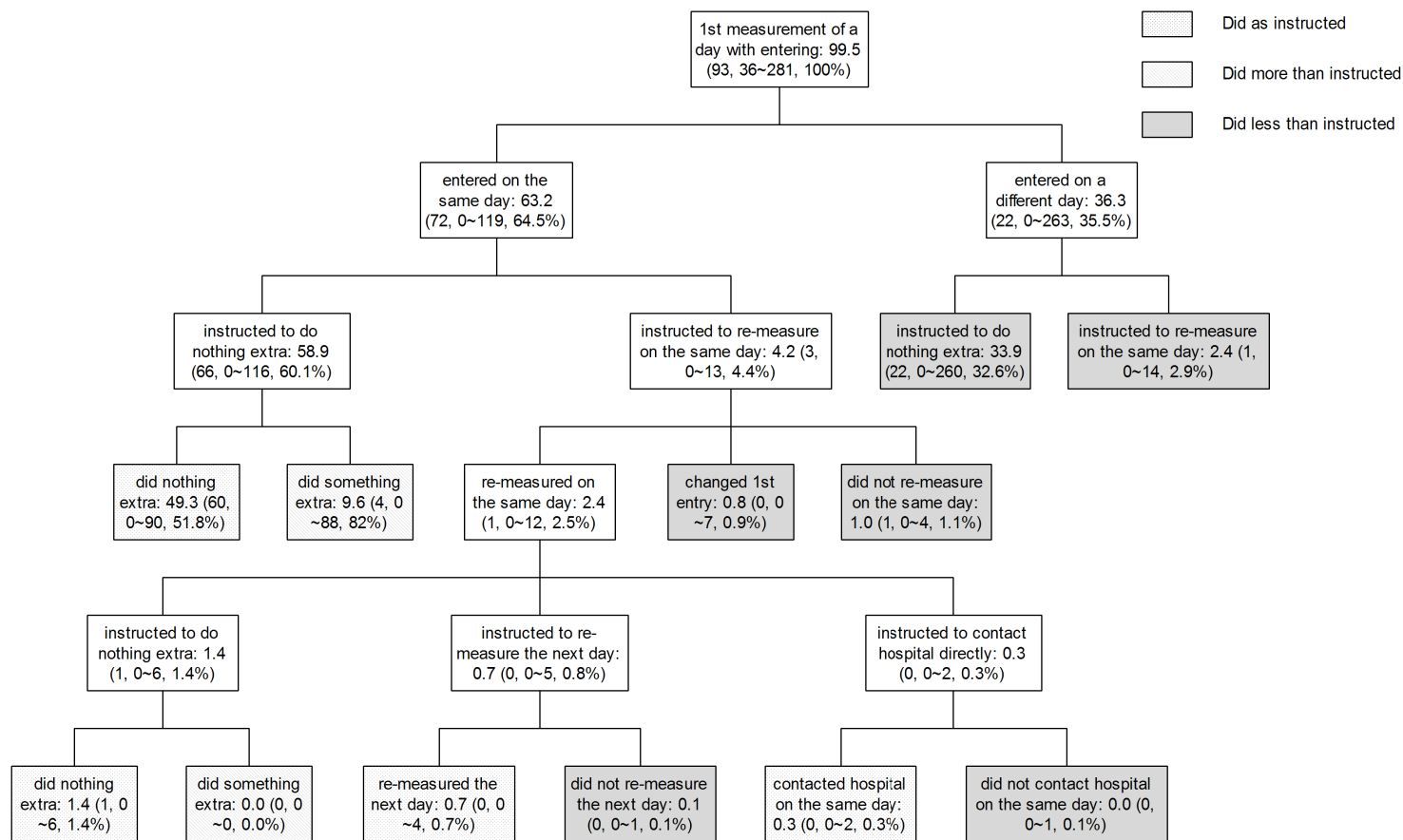
Figure 5.5: Patients' adherence to system instruction, mean number of entries made by a patient (median, min max, mean percentage of the total number of first entries made by a patient)

Interesting, when asked to re-measure on the same day (4.4%), for 0.9% of the total entries, i.e. 18.3% of the asked re-measure cases, patients changed their original first entries in such a way that it led to a modified system instruction that did not require a second measurement. In total, across all patients, this behaviour was observed 36 times, and was done by almost half of the patients ($n = 20$). Twenty-one of these cases were the results of a MMSE situation. It should be noted that patients might simply have done a second measurement as instructed but entered it by overwriting the original first entry. The remaining 15 cases were the result of a SMSE situation, whereby in 11 cases the entered values were the same as originally measured value. This might suggest that patients might have tried to correct an initial typing error. Still, in 4 cases the values were different than measured. Patients might have been experimenting with the system to see the kind of advice the system would offer.

Patients' reactions toward being instructed to contact the hospital were also examined in more details. In total, this instruction was issued 14 times. Eleven patients received this instruction, three of them twice. In 12 cases (85.7%) patients called or visited hospital on the same day as instructed. One patient, who did not contact the hospital at the same day, already had an outpatient appointment within two days. The other patient also had a scheduled telephonic appointment with her doctor, this time within four days. Three days after the phone call, the system instructed this patient again to contact the hospital that coincided already with a scheduled laboratory analysis in the hospital. Here a significant increase in creatinine was found.

5.3.4. USAGE OF ELEARNING MODULES

As Figure 5.6 shows, patients' use of eLearning modules was mainly centered before the start day. The mean time spent on eLearning modules was 16.9 minutes ($Mdn = 0.0, SD = 42.7$). Note, it was estimated that at least 2 to 3 hours were needed in total to read and watch the videos of all required modules. The mean score on the online tests that accompanied the learning modules was 17.7% ($Mdn = 0.0\%, SD = 28.9\%$). A large deviation between mean and median was observed as a large group of patients (53.1%) did never use the eLearning modules or spent less than one minute on it. Still most patients had accessed the learning environment (95.9%). Furthermore, a majority (65.3%) got the score of 0 for the online tests, which probably because they did not take the tests at all.

5.4. CONCLUSION AND DISCUSSION

THE study was set out to address three key questions. The first question focused on patients' reliability of entering self-monitored data online. From the 86.4% of online entries that could be mapped directly to a single measurement, 8.9% of the entered data deviated from the measured data. On the other hand, 10.7% of online entries were derived from a series of measurements. Here patients seem to have a tendency to look for a measure that was close to the previously entered measurement online. This selective data entry strategy seems to suffer from a confirmation bias[28].

The second question of the study focused on patients' adherence to the monitoring plan. When it came to measurement and data entry frequency, the results shows
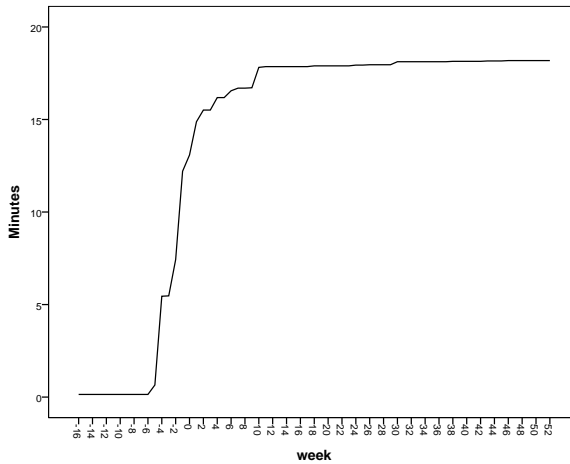
Figure 5.6: Mean of cumulative time patient spent on the eLearning modules

a high level of adherence with about 100% adherence for a majority of patients. Still, patients with lower adherence were also observed, some stopping measuring and entering data all together halfway into the year. Adherence to monitoring plan also included entering data on the day of measurement. Only then could the online system provide update advice. For this issue the results indicated a clear problem, as on average 35.5% of the first online entries a patient made on a day were out of date measurements. The average delay was 7.7 days. The results showed a wide variety in patients' behaviour of timely entering online data. With a considerable group of patients (35.4%) entering their measurement more often on later days. The results also revealed a negative association between patients' age and adherence of timely entering measurement, whereby older patients had higher adherence rate. Age can, however point to a multitude of underlying factors. For example, the association might point to generation difference into compliance to authority[29]. It could also point to variation in cognitive ability, such as memory[30]. As a coping strategy for declining memory, elderly patients might avoid delaying entering data. Finally, it could also point to a difference in lifestyle that allow for more opportunities to enter data at the day of measurement.

The patient's adherence towards automatically generated online advice was the focus of the third and final question. When considering the timely entered online measurement, a 50% compliance rate was observed in cases where the online system instructed the patient to take actions. Still, in the few cases where the system instructed patients to contact the hospital compliance rate were much higher (85.7%).

The study also had a number of limitations to consider. First, some measured values, which were not entered online, were much lower than other values, which suggest they might not have been from the patients but maybe from the patients' family members or friends. Second, participation in the study was optional, which could cause a pre-selection bias when it comes to patients' motivation. Third, hospital records were only analysed to confirm if patients had follow up the system advice to contact the hospi-

tal. Records were, however, not examined whether patients did contact hospital without advice from the online system.

The implication of the study is the need to address the identified problem of timely online entering. This behaviour change can be support in several ways: (1) considering the need for the behaviour to occur, (2) supporting habit creation, or (3) improving the motivation, ability, and awareness of urgency to exhibit this behaviour[31]. Considering the first strategy, if the measurement could be automatically uploaded to the online server, this would remove the need for this behavioural altogether, thereby avoiding potential typing errors, patients' selectiveness, and entering delays. Still, this solution should make it also easy for patients to receive system's feedback, as patients might still show reluctance into going online to access system feedback. Sending automatically a text to their mobile device or integrating the feedback into the measuring device might be preferable therefore. If this is not possible, and manual online data entry is required, a second strategy would be to support habit creation of entering data on the same day. This requires a clear, unambiguous cue for a patient that triggers the data entering behaviour, e.g. a reminder given by the measuring device; and a reward given immediately after entering the data, e.g. a complement by a virtual agent[32]. The third strategy focuses on supporting conscious decision making in executing the behaviour, specifically enhancing motivation, ability and opportunity[33, 34]. For example, this could mean educating and reminding patients about the need for timely entries; cueing for entering data at a moment a patient does have time, e.g. self-set reminders on mobile phone; and making it easier for a patient to enter the data, e.g. providing a tablet at the place where a patient conduct the measurement. Strategy 2 and 3 might also benefit from active adherence monitoring, an activity also suggested for other health conditions such as asthma[35, 36] , and chronic pain[37].

To conclude, the main contribution of the presented study can be summarised as providing an insight into actual adherence and usage of a self-management support system by renal transplant patients. It showed relative high adherence in measurement and data entry frequency. But it also identified as a key problem the delayed online data entry, and patients' strategies of selective measurement entry. Although the study focussed on self-monitoring kidney function, conclusions are likely also generalizable to self-managing system for other chronic deceases.

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6

CONCLUSION AND DISCUSSION

6.1. RESEARCH QUESTIONS

SELF-MANAGEMENT support of renal transplant patients is needed. Currently, they have to visit the hospital regularly for monitoring their renal function. In this way, they remain depend on health care professionals' support. For their well-being, a higher level of autonomy is beneficial[1]. Furthermore, self-management support would reduce the healthcare costs as well. This thesis focused on designing and evaluating a self-management system for renal transplant patients. Various design concepts were developed and evaluated for providing feedback and advice. In addition, acceptance and adherence to the SMSS was studied in a clinical trial. The study was set out to answer the following main research question:

> *What are influencing factors, concerning the patient or the design characteristics, for renal transplant patients to adhere to and accept a self-management support system?*

The results presented in this thesis demonstrate that the medical health condition of the renal function indeed affects patients' adherence and preference, that the interaction between communication style of a system, patients' experience level, and medical health condition affects patients' preference, and that a patient technology acceptance model can partly explain patients' acceptance. Patients' reliability and adherence to the system was also identified. More in detail, three hypotheses and one sub research question were formulated to answer the main research question. The first hypothesis is

H1. Renal transplant patients' adherence to and preference for a specific type of the user interface design- depend on the state of their renal function they are confronted with.

Support for the first hypothesis was established through an iterative approach of empirical studies that investigated the effect on patients when confronted with different medical health conditions of their renal function. Three design concepts and corresponding prototypes were developed: (1) *empowering* the patients by providing more insight into their renal function, (2) *simplifying* information presentation to reduce patients' effort to manage their health, and (3) establishing *affective* connection to address patients' emotional needs. The study was first done with a group of 12 non-patients, and later with a group of 16 patients. They interacted with the prototypes and indicated their preferences and planned actions after each interaction. The results showed that the patient group more often deviated from the system recommendations than the non-patient group. These deviations were specifically apparent when the renal status indicated that there was some level for concern compared to situations with no or, just opposite, with clear reasons for concern. When confronted with a situation that gave course for some level of concern, the level of adherence was higher when using an empowering user interface compared to a simplicity or an affection design that. When confronted with other situations, no such difference was found. These findings therefore support that the medical condition of the renal function can affect patients adherence to a specific type of user interface. The study also found that patients' preference differs among the three interface designs. Their preference showed polarization between patients who rated the simplicity design as their first or, oppositely, as their last choice of

preference, while an equal choice distribution was found for the affection design. The empowerment design was consistently rated as their second choice of preference. The focus group discussion with patients provided some insight into the preference variation. It revealed that patients' attention, emotion, and self-esteem needs vary depending on the medical condition of the renal function, which is again in line with the first hypothesis.

H2. Renal transplant patients' preference for a specific communication style depends on their level of experience (of being a renal transplant patient, using a SMSS, and coping with specific medical health situations).

To answer this research question, we developed two design communication styles:(1) a *guided* style that provided more interpretation support and a virtual health agent showing empathy to address emotional needs, and (2) a *factual* style that showed only measurement history, medical information, and recommendations. A prototype with these two communication styles was tested in an empirical experiment with renal transplant patients of different experience levels, i.e. how recently patients received a transplant. Participants were again asked to interact with the prototype and indicate their preference. The results showed a difference in preference and attitude between patient groups. For example, compared to recently transplanted patients, not recently transplanted patients were relatively more positive towards the factual than the guided communication style. When there was no cause for concern, the less recently transplanted were in absolute terms even significantly more positive towards the factual communication style than the guided style.

H3. A domain specific patient technology acceptance model can partly explain renal transplant patients' acceptance of a self-management support system.

The third hypothesis was examined by formulating a domain specific acceptance model and testing it in the form of a survey. The model included possible factors that could affect renal transplant patients' intention to use a SMSS. Fifty patients, who were recruited to use a SMSS for one year, answered the questionnaire at the beginning and/or four months after start. In the four-month questionnaire response, it was found that the domain specific acceptance model could explain 26% of the variance of patients' intention to use the SMSS. When looking at the predicting factors in the model, it was found that trust and performance expectancy could explain part of the variation, but not beyond the explanation given by patients' affect towards the system.

Q1. How do renal transplant patients use and adhere to a self-management support system?

This sub research question was answered by examining the behaviour of 49 renal transplant patients during their one year usage of a SMSS. Their measurements logged in the self-monitoring devices, measurements entered online, and hospital records of outpatient visits and telephone consultations were compared. It revealed that from the online entries that could be directly linked to single measurements (86.4%), 8.9% deviated from measured values. Eleven percent of the online entries were derived from a series of measurements, where the most similar to previously entered measurement were

often entered. It was also observed that the patients highly adhered to the measuring frequency set by the protocol, but adhered less when it came to entering the measurements online on time. When considering the cases that patients did enter the measure data on time, a 50% adherence rate was observed when the online system instructed patients to take an action, i.e. to measure again or to contact the hospital.

6.2. LIMITATIONS

As in any research, this thesis also has its limitations that need to be considered. First, only renal transplant patients were recruited to participate in the study. This means that findings cannot directly be generalised to other patient groups with other illnesses. For example, renal patients always live with a chance of a rejection of the transplant, other chronic conditions might not have a similar risk, and consequently these patients might have a different mindset towards their disease, self-management, and SMSS. On the other hand, the findings might be generalized to those chronic diseases that could be (life-)threatening, such as asthma, cancer, and HIV. Nevertheless, additional research is needed before making any firm claim about such generalization.

Second, in the lab experiments, patients were only asked what they would do after interacting with the prototypes, instead of being observed what they really would do in their daily life. Actual behaviour is not always intentional and based on a rational thinking process[2], and therefore the answers patients gave in the lab might not always be similar to decisions they would make in real life. However, the study also collected data of actual patients behaviour, and similar patterns in patients' compliance towards the system advice were observed. Patients' adherence was higher in situations with certainty (i.e. requiring no additional action or contacting the hospital), than situations with uncertainty (i.e. advising additional measuring).

Third, not all problems identified in the clinical trial were addressed in the lab experiments. This was a consequent of the work scheduling that was conducted into two parallel branches. More specifically, the clinical trial revealed that a considerable number of online entries were out of date and some entries were based on multiple measurements. These were not anticipated, and therefore potential solutions were not empirically studied in the lab.

Fourth, not all potential moderating factors on patients' adherence were studied. One such potential factor is the involvement of the nephrologists. In the clinical trial, it was up to them whether or not to look at the patients' self-monitoring data, and patients might have been aware of this. Being informed that caregivers could review data collected by patients can improve adherence rate as has been observed for self-monitored blood glucose[3, 4]. Therefore, the observed adherence rates in the clinical trial cannot directly be generalized to situations with another protocol for the involvement of the caregivers.

Fifth, the user interface design of the prototypes was constrained with a three levels advice protocol for the status of renal function. Furthermore, the solution was also constrained by requirement to fit the solution within an online website. Without such constrains, a larger solution space could have been considered. Still, these constrains are not exceptional as a three level risk classification are often used[5, 6], as are online websites for self-monitor, for example for weight loss[7], chronic widespread pain[8],

and congestive heart failure[9].

6.3. CONTRIBUTIONS

IN this section we establish suggestions to improve a SMSS including both designing and implementing aspects. Although the study was conducted in the context of renal transplant patients, the insights obtained should also be considered for self-management of other chronic diseases, such as asthma, cancer, or HIV.

6.3.1. SCIENTIFIC CONTRIBUTIONS

UNDERSTANDING OF ADHERENCE AND ACCEPTANCE

There is a relatively large amount of research on support of chronic diseases, such as diabetes, obesities and cardiovascular diseases[10, 11]. For self-management to be safe, patients' adherence to the protocol is mandatory. Research in other diseases shows large variance in patients' adherence to schedule, ranging from 52% to 92%[12–17]. To our knowledge, this thesis is the first to examine renal transplant patients' adherence to a measurement protocol. It provides insight into adherence, which was relative high for measurement frequency, and relative low for timely online data entry. Furthermore, the thesis also provides insight into patients' adherence when a system advises them to take actions. As mentioned before, both lab and clinical trial showed a similar pattern. Adherence was higher in medical health conditions that provided certainty than those that provided uncertainty.

In addition to adherence, patients' acceptance of using a SMSS is also important. This thesis provided a model to explain renal transplant patient technology acceptance. Although the model included several factors from the literature[18–29], the analysis only found that the patients' affect towards the SMSS was able to explain variations between patients' intention of using the SMSS.

DESIGN ELEMENTS TO CONSIDER

This thesis showed that the style of information communication in a SMSS affects patients' adherence (i.e., how the information is presented and expressed), and that this adherence is affected by the context. When patients are confronted with uncertainty in their medical health condition, a user interface that provides cognitive support for understanding self-monitoring data, i.e. empowering the patient, evokes a higher adherence than a user interface that focusses on effort reduction or empathic support. When considering the patient preferences, much diversity was observed. This argues for an adaptable way in which monitoring data and advice is presented. Factors to consider are the medical health situation and the patients' experience level , as they affect patients' preference for cognitive support and empathy elements.

6.3.2. PRACTICAL CONTRIBUTIONS

The increasing costs and shortage of medical resources requires chronic patients to manage their medicine and daily life more actively. By evaluating a SMSS and its usage by renal transplant patients, it is expected that future SMSSs could be better designed and implemented, and therefore both patients and healthcare organizations could benefit

from that.

FOR DESIGNING A SMSS

This research provided design solutions for some generic self-management support needs. Several features that can help the design a SMSS for these chronic patients have been identified. First, a SMSS can be personalized according to patients' experience level. Less experienced patients, compared to more experienced patients, are more inclined to prefer empathic and cognitive support for understanding self-monitoring data and related system advice. More experienced patients prefer a more sober user interface, communicating mainly the facts. When providing two or more communication styles, although patients should be able to switch between communications style, it should not be expected that a majority of patients would do this actually. It is therefore important to provide patients with an appropriate default setting for the communication style, which should automatically change when patients are experienced. When designing a SMSS designers should not underestimate the emotional components as this was found to be associated with patients' intention of using the SMSS. Likewise the presentation of empathic elements, such as virtual characters, does elicit specific preferences. For example, patients less preferred an old looking character and instead preferred characters dressed in white doctor coat.

Designers should also give attention to problems of out of date online measurement entries. One solution could be an integrated physical system that includes measuring functionality, automatic uploading functionality, access to self-monitoring overviews, and medical health advice. In this way, if patients measure themselves they receive directly up to date advice. If such integration is not possible, designers should focus on supporting habit creation of timely online data entry. For this motivation, ability, opportunity, triggering, and rewarding should be considered[30–33]. First of all, patients need to be aware of the importance of timely data entry to motivate them to do this. Secondly, it should be very easy for them to enter the data. For example, having a tablet to enter data in the same room were a patient conduct the measurement. Third, patients need to be supported to fit this routine into their daily life, so they have enough time scheduled to enter the data online. Fourth, the completion of the measurement should act as a trigger to enter the data online. Finally, data entry should immediate result in a reward, preferable with variation, for example, everyday another life style tip, a compliment, or progress report on goal completion.

Like people's tendency of often not reading manuals[34, 35] and the leaflet accompanying drugs[36, 37], designers should not expect high usage of the online eLearning modules by patients. Usage was mainly observed when patients started with self-management. To continuously enhance patients' knowledge or consolidate existing one, designers should consider an information dripping approach by including a single "Did you know" information statement with a link for more background information in the interface displayed after the patients has entered their measuring data, and there is no reason for medical concern.

FOR CAREGIVING ORGANISATION

Reviewing by caregivers of self-monitoring data, monitoring patients' adherence to the measuring and data entry protocol, as well as to the advice given by the system is some-

thing caregivers should consider for three reasons: (1) to monitor trends data of renal function; (2) to improve adherence rate; and (3) identify patients that are unable to use the system adequately for self-management. Although self-monitoring data might be less accurate than measurements obtain in the hospital, it provides more samples stretched over time and therefore gives insights to trends[38]. Next, the classical Hawthorne effect[39] shows that people awareness of being observed improves their behaviour. Similar effects have been found for patients' adherence for self-monitoring[3, 4]. Patients' adherence can also be discussed during consultation meetings. Having objective (self-)monitoring data instead of patients' verbal assessment of their adherence or clinical judgment to rate adherence is more reliable[40, 41]. During such meetings barriers patients facing to adherence can be discussed, and interventions to improve adherence can be considered with the patient[40, 42, 43]. As a safety check, caregivers should also consider monitor adherence when measurements done in hospital are replaced by self-management.

FOR RENAL TRANSPLANT PATIENTS

The mean Chronic Kidney Disease prevalence Stages 1 to 5 was found 13·4% globally, or 6.7% in the Dutch adult population[44, 45], and the Dutch transplant rate was 59.2 per million population[46]. By conducting self-management and using a SMSS, it is expected that renal transplant patients might visits hospital less frequently, have more autonomy, and aware disease changes earlier. Improving the existing system would help patients use the system more properly and willingly, and conduct self-management more safely.

6.4. FUTURE WORK

THE work presented in the thesis can be extended in several ways. First, research on SMSS usage can be extended by considering the caregivers' side. As was already possible in the studied SMSS, caregivers could use the system to look at patients' self-monitoring data and communicate with them through messages. It is important to understand the design factors that influence the SMSS usage and acceptance by for caregiver, especially if they have roles in monitoring patients' adherence. The system can support caregivers in helping patients use the system. For example, patients might not understand the importance and necessity to adhere to the self-management protocol, or sometimes other barriers are at play. It would be helpful if the SMSS could detect such cases, report it to the caregivers, suggest them to react on it, and provide the platform to do so.

Second, as patients' adherence is important and as online data entry was not always done on time, a SMSS could monitor not only patients' renal functions, but also their adherence level, including timely entering, monitoring frequency, and adherence to system instructions. Research could focus on exploring effective strategies that can be implemented in the SMSS that use adherence data to improve adherence. Personalize adherence strategies could be considered. Fogg has proposed the idea of persuasive technology that uses computer systems to influence user behaviour[47]. Although most persuasive strategies are effective on average, Kaptein also found large individual differences and proposed to personalize the strategies according to individuals' persuasion

profiles[48]. Studying the personalization needs and effective design approaches might be interesting in this context as well.

Third, research could explore ways in which a SMSS can facilitate patients' lifelong learning when it comes to their health conditions and lifestyle. The implemented eLearning modules in this study did not provide this function, and the idea of providing "Did you know" information was only tested in the lab, in the setting of a single hour. Research on long-term effect of these facilities is therefore desirable. One possible method suggested to encourage long-term effectiveness is to employ relational agents. Virtual agents have already been used to maintain long-term engagement for health behaviour change[49, 50]. It might be possible to build a long-term relationship between a virtual agent and patients thereby keeping patients overtime responsive to new suggestions of a SMSS.

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ACKNOWLEDGEMENTS

First and foremost I would like to thank my promoter Mark Neerincx and co-promotor Willem-Paul Brinkman, for supporting and encouraging me throughout my PhD study. Special thanks to Willem-Paul, for all the inspiring ideas, interesting discussions, helping me when I was stuck, and always being available.

I would also like to thank the rest of the ADMIRE project members: Céline van Lint, Ton Rovekamp, Laurance Alpay, Sandra van Dijk, and Paul van der Boog. Thank you for the co-authering papers and helpful discussions that we had. Thanks also to Mirjam Meys, Willem-Sander Markerink, Chiara Jongerius, and Rik Stoevelaar. I enjoyed the cooperation with you, thanks for the help that I got for my experiments.

I am also thank the current and former VRET/eHealth members: Yun Ling, Chao Qu, Vanessa Vakili, Ni Kang, Dwi Hartanto, Iris Cohen, Corine Horsch, Alex Kayal, Dylan Schouten, Myrthe Tielman, Siska Fitrianie, Ursula Beer, and Ding Ding. It was inspiring and fun to discuss with you together, and I also appreciate all the help I received from you every now and then.

I also thank the rest of the II group in TU Delft and Life style group in TNO, for all the time we spent together in the groups. I am grateful for the technical support I received from Ruud de Jong, Bart Vastenhouw, and Joris van Benten, and the support with paperwork from Anita Hoogmoed, Lia Hinne-Pluimgraaff, Mariëtte Verdonk, and Helga Cebol. I also thank Martin Laverman, for the interesting chats and discussions that we had.

Finally, I would like to thank all my friends and family, who have supported me during all my life. I give great thanks to my mother-in-law, Jimei Xu, for helping and supporting me. I especially want to thank my parents, Zhiyuan Wang and Min Yang, for bringing me up and supporting me with your love. The very special thanks are for my beloved husband Bin Shi, for accompanying me and for loving me. To our dearest boys Mingzhong and Mingyi, I have special thanks as you bring me so much joy and share a fantastic point of view with me.

A

VIRTUAL CHARACTERS

A

Figure A.1: Humanoid characters differing by gender, age, and clothes. Mean and SD of estimation age. The formal and informal ones were obtained from Vizard (WorldViz, 2012), while those in white doctor coat were photoshopped the coat on

Figure A.2: Iconic characters. Left: iCat, right: a cartoon

B

Questionnaires Used in the Experiment with Renal Transplant Patients

Preference in design

Design

- How much do you like this design? (7-point Likert scale, from definitely dislike to definitely like)
- How much do you trust this design? (7-point Likert scale, from definitely distrust to definitely trust)
- How difficult or easy do you find to use this design? (7-point Likert scale, from very difficult to very easy)
- How much would you like to use this design? (7-point Likert scale, from not at all to very much)

Design usage over time

- How much would you like to use this design **in the first 6 months** after the renal transplantation? (7-point Likert scale, from not at all to very much)
- How much would you like to use this design **after 6 months** of the renal transplantation? (7-point Likert scale, from not at all to very much)

Virtual character

- How much do you like this virtual character? (7-point Likert scale, from definitely dislike to definitely like)
- How much do you find this virtual character knowledgeable? (7-point Likert scale, from not knowledgeable at all to very knowledgeable)

B

- How much do you trust this virtual character? (7-point Likert scale, from definitely distrust to definitely trust)
- How much personality do you find that this virtual character has? (7-point Likert scale, from very little to very much)
- How much would you accept the advice given by this virtual character? (7-point Likert scale, from not at all to completely)
- How much would you like to use this virtual character? (7-point Likert scale, from not at all to very much)

Text

- How much do you like this text? (7-point Likert scale, from definitely dislike to definitely like) •
- How much do you trust this text? (7-point Likert scale, from definitely distrust to definitely trust)
- How difficult or easy do you find to understand this text? (7-point Likert scale, from very difficult to very easy)
- How likely would you follow this advice? (7-point Likert scale, from very unlike to very likely)

C

THE SCREENSHOTS OF THE TWO COMMUNICATION STYLES AND THE THREE MEDICAL HEALTH SITUATIONS
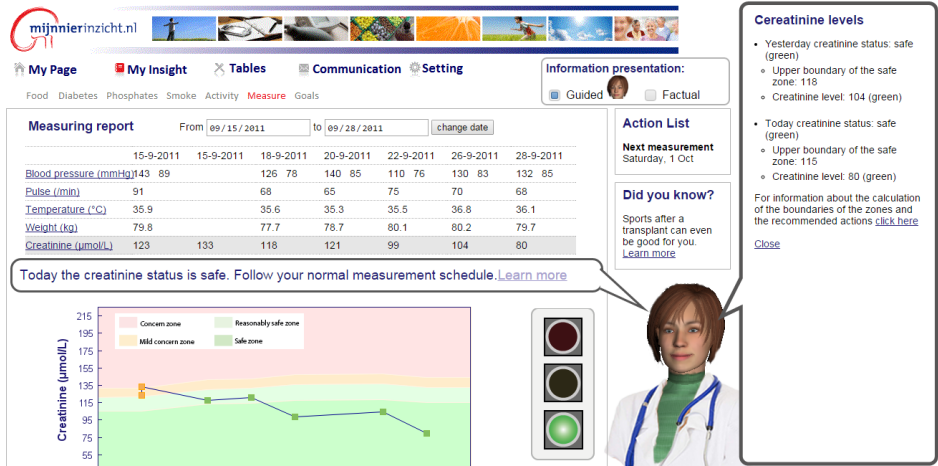
C

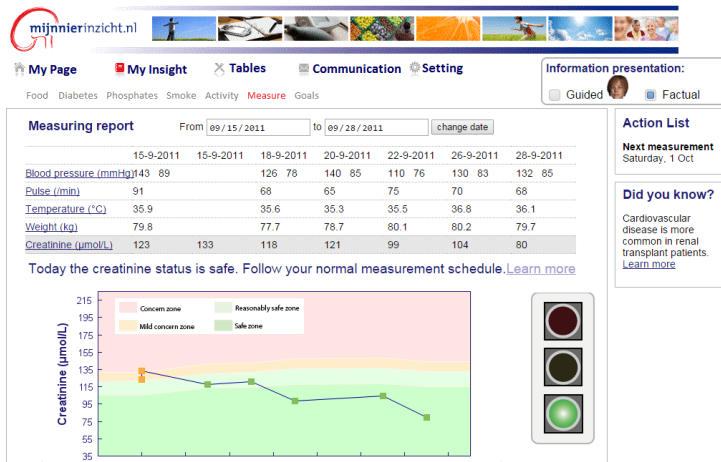Figure C.1: Guided style of alright state

Figure C.2: Factual style of alright state

Figure C.3: Guided style of mild concern state
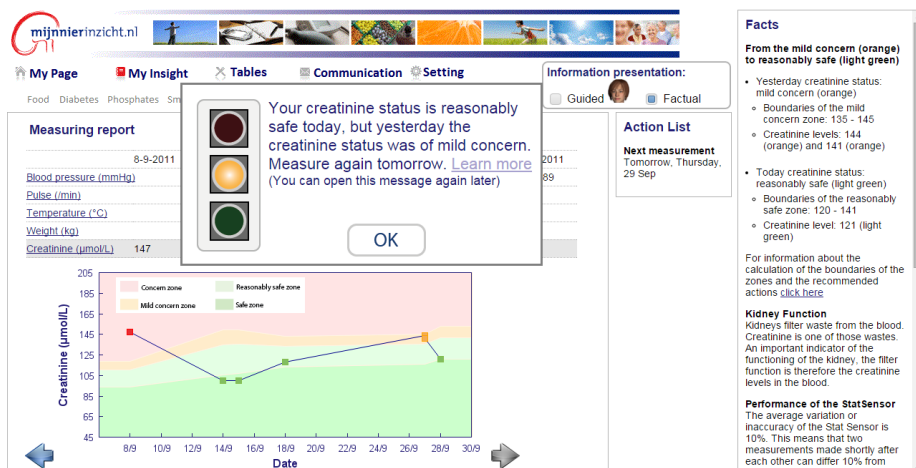

Figure C.4: Factual style of mild concern state

C

Figure C.5: Guided style of concern state
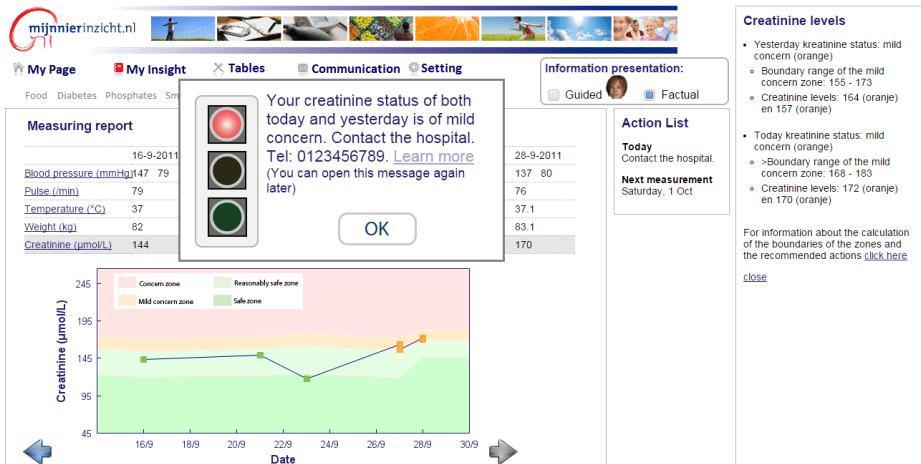

Figure C.6: Factual style of concern state

D

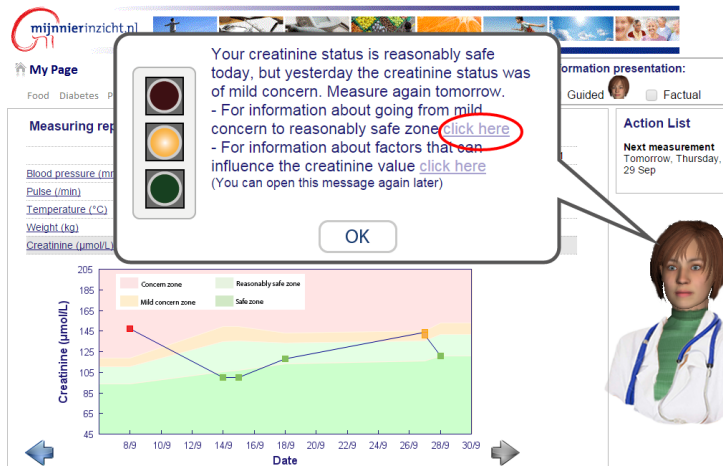## THE PROGRESSION OF PROVIDING MORE INFORMATION IN GUIDED STYLE OF MILD CONCERN SITUATION
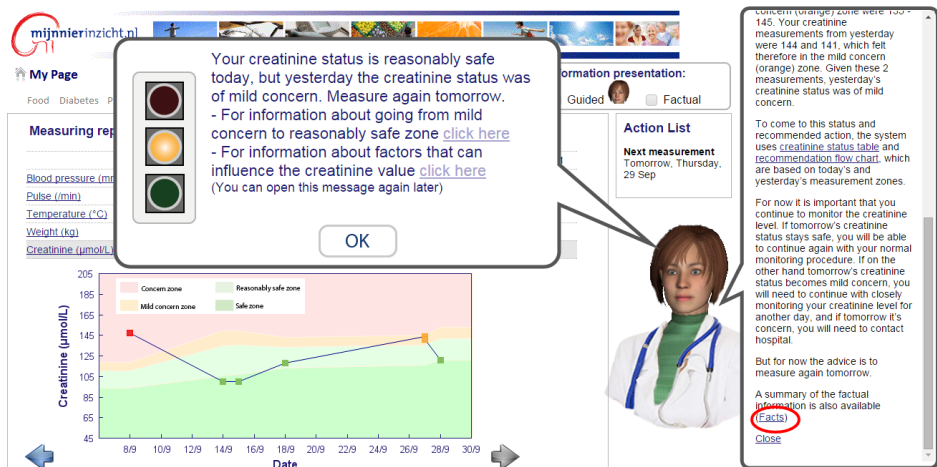
Figure D.1: Start point of action instruction

Figure D.2: An interpretation layer that explains current renal function course
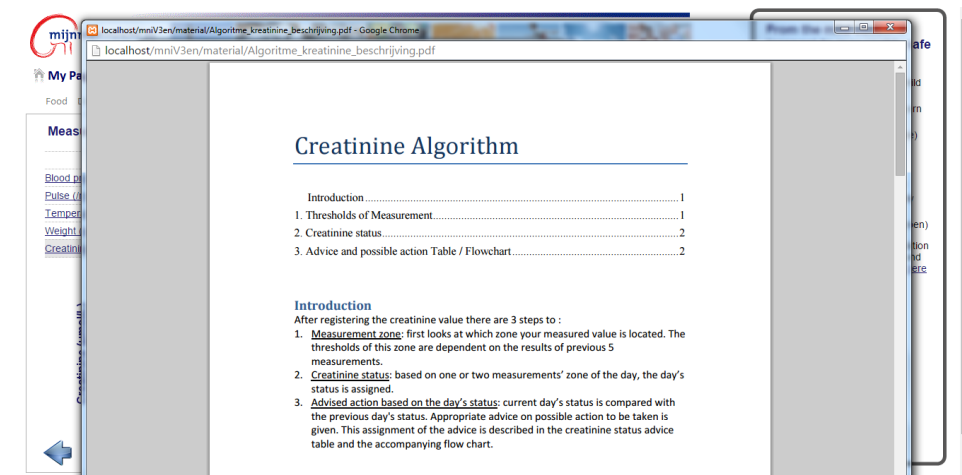
Figure D.3: Facts of current renal function course

Figure D.4: Detailed algorithm that explains renal function course

E

RENAL TRANSPLANT PATIENT TECHNOLOGY ACCEPTANCE QUESTIONNAIRE ITEMS

ACCEPTANCE FACTORS AS FORMULATED AT T1

PERFORMANCE EXPECTANCY

PE1 With the ADMIRE system, I can monitor my health very well myself.
PE2 Through the ADMIRE system I understand my condition and treatment better.
PE3 The ADMIRE system gives me clear insight into my current health.
PE4 With the ADMIRE system, I can detect problems with my renal function earlier.
PE5 I think using the ADMIRE system puts my health at lower risk.
PE6 With the help of the ADMIRE system, I can play a greater role in my own medical care.
PE7 I think an advantage of ADMIRE is that I can travel to the hospital less often.
PE8 I think an advantage of ADMIRE is that I have more time for other activities, since I have fewer outpatient appointments.

EFFORT EXPECTANCY

EE1 Working with the ADMIRE system gives me little trouble.
EE2 The ADMIRE system is easy to use in my daily life.
EE3 I think the use of the ADMIRE system gives no ambiguities.
EE4 Learning to work with the ADMIRE system is easy for me.

SOCIAL INFLUENCE

SI1 I think my family think that I should use the ADMIRE system.
SI2 I think my friends think that I should use the ADMIRE system.
SI3 I think my care-givers think that I should use the ADMIRE system.

SI4   I think my peer patients think that I should use the ADMIRE system.

Facilitating conditions
FC1   My computer is good enough to use the ADMIRE system.
FC2   My internet connection works perfectly.
FC3   Where necessary, my family helps me to use the ADMIRE system.
FC4   Where necessary, my friends help me to use the ADMIRE system.

Affect
AF1   I find using the ADMIRE system interesting.
AF2-R* I experience using the ADMIRE system as annoying.
AF3   I find using the ADMIRE system pleasant.
AF4-R* Using the ADMIRE system makes me feel restless.
*R: reversed.

Self-efficacy
SE1   I can use the ADMIRE system without the help of others.
SE2   I can use the ADMIRE system without the help of the ADMIRE-team.
SE3   I can use the ADMIRE system as long as there is someone available to help me.
SE4   I can use the ADMIRE system as long as nothing abnormal happens.

Trust
Tr1-R* I think using the ADMIRE system puts my privacy at risk.
Tr2   I am confident that the ADMIRE system works well.
Tr3   I trust the information that the ADMIRE system provides me with.
Tr4   I am confident that data I registered myself provides a sufficient basis for good health advice.
*R: reversed.

Behavioural intention
BI1   I will certainly measure at the specified time points and enter the data into the ADMIRE system.
BI2   I will certainly look at the overview of my measurements carefully.
BI3   I will certainly follow the instructions of the ADMIRE system after entering my measurements.
BI4   I will certainly first consult the eLearning module if I have medical questions.
BI5   I will certainly use the planning function within the ADMIRE system to keep track of my measurement time points and my appointments with my healthcare provider.

Different Aspects

Training
- The ADMIRE training teaches me useful things.
- I am very pleased about the introduction given by a member of the ADMIRE-team.

- I find the online learning module very informative.
- I got sufficient knowledge and skills to work with the ADMIRE system through the online learning module.

SELF-MANAGEMENT

- With the help of the ADMIRE system, I will be able to play a greater role in my own medical care.
- The ADMIRE system contains lots of interesting information.
- I find it an advantage that changes in my condition will be quickly noticed due to the frequent home measurements.
- I find it a disadvantage that through self-measuring I will be more occupied with my kidney disease.

DOCTOR

- I think that telephone contact with my doctor will be a full replacement for an outpatient appointment.
- I find it a disadvantage that when my creatinine rises I will receive an automatic notification instead of a personal message from my doctor.
- I find it an advantage that my doctor will have direct access to my measured values.
- I find it a disadvantage that I will see a doctor less often due to my participation in ADMIRE.

TIME

- I think that a disadvantage of ADMIRE is that I have to spend time on performing self-measurements.
- I think that a disadvantage of ADMIRE is that I have to be telephonically available at agreed time.
- I think that a disadvantage of ADMIRE is that by self-measuring
- I have less time for other activities.
- I think that an advantage of using the ADMIRE system is that I need to travel to the hospital less often.
- I think an advantage of using the ADMIRE system is that I have more time for other activities, because I have fewer outpatient appointments.
- I think an advantage of using the ADMIRE system is that blood samples can be taken less frequently in the hospital.

CREATININE

- I am well able to use the creatinine meter.
- I find it an advantage that I can measure my creatinine value.
- I find it a disadvantage that I have to prick in my finger myself.
- I think I will find it pleasant to use the creatinine meter.
- I will find using the creatinine meter reassuring.
- I will find using the creatinine meter frightening.
- I will find using the creatinine meter useful.
- I will find using the creatinine meter frustrating.

- I have confidence in the accuracy of the creatinine meters.
- I will be able to carry out the self-measuring at the agreed time.
- I will be able to assess the self-measured results.
- I will be able to judge at what time it is important to contact the hospital.
- I find it a disadvantage that I myself will have to react as my creatinine value increases.
- A good self-measuring result will reassure me as much as a good outcome from the hospital laboratory.
- I find the self-measured values match the values measured in LUMC (T1 only).

Blood pressure
- I am able to use the blood pressure meter.
- I find it an advantage that I can measure my blood pressure.
- I think I will find it pleasant to use the blood pressure meter.
- I will find using the blood pressure meter reassuring.
- I will find using the blood pressure meter frightening.
- I will find using the blood pressure meter useful.
- I will find using the blood pressure meter frustrating
- I have confidence in the accuracy of the blood pressure meter.

Feeling
- I am often worried about whether I have carried out the measurements correctly.
- After a good result of the self-measuring I am sufficiently reassured.
- I am afraid of rejection when I measure my creatinine.
- I regularly conduct an additional measurement to reassure myself.
- I am not worried if I get a notification from the ADMIRE system that my creatinine has increased.
- I am afraid of rejection when I await the results of the laboratory.

F

SUMMARY OF RENAL TRANSPLANT PATIENT TECHNOLOGY ACCEPTANCE QUESTIONNAIRE PRINCIPAL COMPONENT ANALYSIS RESULTS

Table F.1: Summary of Principal Component Analysis Results

Items	Component					Sampling adequacy	Communality scores
	1	2	3	4	5		
Affect (AF3)	**.83**	.08	-.04	.25	-.11	.72	.76
Trust (TR4)	**.79**	.15	-.09	-.07	.18	.74	.69
Performance expectancy - insight (PE3)	**.77**	-.20	.04	.20	.10	.86	.69
Trust (TR2)	**.77**	.13	.21	.11	.15	.57	.69
Affect (AF2)	**.75**	.06	.22	.17	.23	.61	.69
Trust (TR3)	**.72**	.02	-.12	.04	.35	.75	.66
Affect (AF1)	**.72**	.16	-.15	-.11	-.24	.79	.64
Performance expectancy - insight (PE2)	**.69**	-.11	.01	-.02	-.15	.70	.51
Performance expectancy - insight (PE1)	**.69**	.02	-.06	.04	.37	.57	.61
Self-efficacy (SE1)	.06	**.92**	.09	.03	-.01	.73	.85
Self-efficacy (SE2)	.15	**.84**	.01	-.07	-.02	.58	.73
Facilitating conditions (FC2)	-.14	**.72**	**.51**	.01	.05	.49	.79
Facilitating conditions (FC1)	-.12	**.71**	**.56**	.03	.00	.52	.84
Affect (AF4)	**.48**	**.52**	.16	.30	.04	.79	.62
Performance expectancy - time (PE8)	.01	.16	**.92**	-.03	-.05	.47	.87
Performance expectancy - time (PE7)	.06	.21	**.92**	.00	.07	.55	.89
Effort expectancy (EE1)	.16	-.06	.04	**.86**	.20	.51	.81
Effort expectancy (EE4)	-.04	.15	-.15	**.85**	-.14	.29	.79
Effort expectancy (EE2)	.26	-.12	.15	**.59**	**.41**	.85	.62
Trust (TR1)	.14	.06	.01	.12	**.91**	.33	.86
Eigenvalues	**5.48**	**3.08**	**2.48**	**2.08**	**1.54**		
% of variance	**27.38**	**15.40**	**12.39**	**10.41**	**7.68**		

Note: Factor loadings over .40 appear in bold.

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LIST OF PUBLICATIONS

6 **W. Wang**, W-P. Brinkman, T.J.M. Rövekamp, W-S. Markerink, L. Alpay, C.L. van Lint, S. van Dijk, P.J.M. van der Boog, M.A. Neerincx, *How to Support Renal Transplant Patients with Self-Monitoring and Taking Appropriate Actions*, Interacting with Computers (submitted).

5 **W. Wang**, C.L. van Lint, W-P. Brinkman, T.J.M. Rövekamp, S. van Dijk, P.J.M van der Boog, M.A. Neerincx, *Guided or Factual Computer Support for Kidney Patients with Different Experience Levels and Medical Health Situations: Preferences and Usage*, Healthcare and Technology (submitted).

4 C.L. van Lint*, **W. Wang***, S. van Dijk, W-P. Brinkman, T.J.M. Rövekamp, M.A. Neerincx, A.J. Rabelink, P.J.M. van der Boog, *Self-Monitoring Kidney Function After Transplantation: the Reliability of Patient-Reported Data*, Journal of Medical Internet Research (in press).

3 **W. Wang**, C.L. van Lint, W-P. Brinkman, T.J.M. Rövekamp, S. van Dijk, P.J.M. van der Boog, M.A. Neerincx, *Renal Transplant Patient Acceptance of a Self-management Support System*, BMC Medical Informatics and Decision Making, 17(1): 58 (2017).

2 **W. Wang**, W. P. Brinkman, T. J. M. Rövekamp, P. J. M. van der Boog, L. Alpay, M. A. Neerincx, *Feedback to Renal Transplant Patients in a Self-management Support System*, European Conference on Cognitive Ergonomics 2012: 147-150 (2012).

1 **W. Wang**, T. J. M. Rövekamp, W. P. Brinkman, L. Alpay, P. J. M. van der Boog, M. A. Neerincx, *Designing and Evaluating a Self-Management Support System for Renal Transplant Patients: the First Step*, European Conference on Cognitive Ergonomics 2012: D15-D19 (2012).

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