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**Exploring the potential of self-monitoring kidney function after transplantation : from patient acceptance to replacing outpatient care**  
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## CHAPTER 2

Patient experiences with self-monitoring renal function after renal transplantation: results from a single center prospective pilot study.

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**ABSTRACT**

After a kidney transplantation, patients have to visit the hospital very often to monitor early signs of graft rejection. Self-monitoring of creatinine in addition to blood pressure at home could alleviate the burden of frequent outpatient visits, but only if patients are willing to self-monitor and if they adhere to the self-monitoring measurement regimen. A prospective pilot study was conducted to assess patients' experiences and satisfaction.

During three months after transplantation 30 patients registered self-measured creatinine and blood pressure values in an online record to which their physician had access too. Patients completed a questionnaire at baseline and follow-up to assess satisfaction, attitude, self-efficacy regarding self-monitoring, worries, and physician support. Adherence was studied by comparing number of registered with number of requested measurements.

Patients were highly motivated to self-monitor kidney function and reported high levels of general satisfaction. Level of satisfaction was positively related to perceived support from physicians ( $p < .01$ ), level of self-efficacy ( $p < .01$ ) and amount of trust in the accuracy of the creatinine meter ( $p < .01$ ). The use of both the creatinine and blood pressure meter was considered pleasant and useful, despite level of trust in the accuracy of the creatinine device being relatively low. Trust in the accuracy of the creatinine device appeared to be related to level of variation in subsequent measurement results, with more variation being related to lower levels of trust. Protocol adherence was generally very high, although the range of adherence levels was large and increased over time.

Patients' high levels of satisfaction suggest that at home monitoring of creatinine and blood pressure after transplantation offers a promising strategy. Important prerequisites for a safe implementation in transplant care seem to be support from physicians and patients' confidence in both their own self-monitoring skills and the accuracy of the devices used.

## BACKGROUND

Kidney transplantation is the treatment of choice for end stage renal disease (ESRD) patients. It is associated with a reduced risk of mortality and cardiovascular events as well as better quality of life than treatment with chronic dialysis.<sup>1</sup> However, patients are at risk for acute rejection, predominantly in the first 6 months after transplantation.<sup>2</sup> Most patients who develop acute rejection are asymptomatic and present only with an increased serum creatinine. Consequently, frequent laboratory monitoring is essential in order to detect a creatinine increase as early as possible. Further, as hypertension is both a potential indicator of decreased kidney function and an important risk factor for kidney transplant failure<sup>3-6</sup>, blood pressure needs to be closely monitored too. Besides being burdensome to healthcare capacity, the high frequent monitoring visits are a burden to patients. First, because many patients need to travel a considerable distance to get to the hospital. Second, because fear of rejection, the most common stressor among kidney transplant patients<sup>7-10</sup>, is more intense prior to clinical visits.<sup>10</sup> The latter is conceivable, as the visits focus on discussing laboratory results that indicate how patients' graft is functioning.

Being able to monitor creatinine and blood pressure at home could alleviate the burden of frequent outpatient visits and high levels of stress prior to consultations. With the development of a handheld point of care creatinine device, patients are now enabled to self-monitor creatinine. In contrast to self-monitoring creatinine, patients self-monitoring blood pressure is more common practice yet and the clinical benefits of home-based blood pressure measurements in kidney transplant patients have already been shown.<sup>11;12</sup> However, experiences and satisfaction with self-monitoring of transplanted patients have never been taken into account. Research in other chronic disease populations shows that self-monitoring is generally highly valued by patients.<sup>13-17</sup> However, this does not pertain to every patient. A factor that seems to influence patients motivation for and satisfaction with self-monitoring is level of trust. Patients have to trust the accuracy and reliability of the monitoring device(s)<sup>18;19</sup> and their own self-monitoring skills<sup>20;21</sup>, and they have to experience support and trust from their clinician as well.<sup>22;23</sup> Further, previous studies showed that self-monitoring increased patients' feelings of security, reassurance and control over their own medical condition<sup>13;14;16;24;25</sup>, suggesting that worrisome patients have more to gain from self-monitoring than those worrying less. On the contrary, self-monitoring bodily symptoms can also rouse intrusive feelings of fear and doubt, especially when frequent self-monitoring picks up even small fluctuations.<sup>13;26</sup>

To the best of our knowledge, there is a lack of data about the attitude of kidney transplant patients towards self-monitoring. This poses a problem, as the feasibility of self-monitoring is highly dependent on the willingness and ability of patients to monitor at home.<sup>19;27</sup> The aim of the current study was as

follows. Firstly, to study kidney transplant patients' willingness to self-monitor after kidney transplantation and their experiences with self-monitoring. Secondly, to assess how worries and trust regarding devices, personal skills and the doctor-patient interaction are related to experienced level of satisfaction. Thirdly, to study patients' adherence to the measurement protocol, as a good adherence to the protocol is a prerequisite for safety from a clinical point of view.

## **MATERIALS AND METHODS**

### **Subject and methods**

This prospective pilot study was performed at the Leiden University Medical Centre in advance of a randomized control trial on the applicability of self-monitoring after kidney transplantation. The study protocol was reviewed and approved by the Medical Ethics Committee. Patients were recruited from June 2010 to January 2011, at 2-4 weeks prior to a living donor transplantation. Inclusion criteria were being  $\geq 18$  years of age, mastering the Dutch language and having access to the Internet. All participants provided written informed consent.

All patients received transplant care as usual. Immunosuppressive regimens comprised of basiliximab for induction (except for one patient receiving Alemtuzumab) and glucocorticoids, tacrolimus and mycophenolate mofetil for maintenance therapy. To optimize levels of the immunosuppressive agents regular monitoring of trough levels was combined with monitoring systemic exposure (as measured by areas under the curve) at 6 weeks and 6 months post-transplantation and yearly afterwards.

In addition to regular outpatient care, participants monitored level of whole blood creatinine and blood pressure at home during the first 12 weeks after kidney transplantation. They received a planning starting from the day after discharge. Measurement frequency was decreased stepwise, ranging from daily in the first weeks to once a week in weeks 9-12. Patients registered their measurement results in an online disease management system (DMS) to which their physician had access too.

Patients completed a questionnaire at discharge from hospital after kidney transplantation (i.e. baseline) and at the end of the study period after twelve weeks (i.e. follow up). Baseline questionnaires and return envelopes were supplied one day in advance of discharge from the hospital. Follow-up questionnaires were sent out after completing the study period, that is after 12 weeks.

The first 10 patients who finished participation were interviewed about their experiences. A semi-structured protocol was applied with open-ended questions that reflected topics from the questionnaire (see Supplemental table 1). Interviews were recorded and transcribed in full. As

interview data were only used to facilitate interpretation of quantitative results, no further formal coding and analysis was conducted.

### **Self-monitoring procedure**

Prior or immediately following transplantation, patients received instructions about how to perform, interpret and record the creatinine and blood pressure measures.

For self-monitoring creatinine, each participant received a StatSensor® Xpress-i™ Creatinine Hospital Meter (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). Although the devices' accuracy for detecting current kidney function with a single creatinine measurement is debated<sup>28-31</sup>, it seems suitable for monitoring creatinine trends with serial creatinine measurements in kidney transplant patients.<sup>31</sup> It is important to distinguish between these applications, as this determines the analytical performance requirements of the device.<sup>32</sup> In case of trend monitoring, the accuracy of a single creatinine test result is less critical as test results are used to detect changes between sequential measurements. Patients received specific instructions about how to interpret sequential results, rather than single measurements. Further, values registered in the online DMS were depicted in a graph to support trend-wise interpretation of test results.

For self-monitoring blood pressure, each participant received a Microlife WatchBP® Home (Microlife, Heerbrugg, Switzerland), an oscillometric device for blood pressure self-measurement on the upper arm. The Microlife WatchBP® Home fulfils the validation requirements of the ESH International Protocol for self-monitoring blood pressure at home.<sup>33</sup>

### **Questionnaires**

Both validated and questionnaires that were specifically developed for the study were used. We measured level of general and more specific satisfaction, experience with self-monitoring, amount of transplant related worries (Worry scale, Transplant Effects Questionnaire<sup>34</sup>, trust in own monitoring skills (self-efficacy) and patients' perception of the level of autonomy support from their physician (Health Care Climate Questionnaire<sup>35</sup>). Item examples, answering scales and time of application are listed in table 1.

Demographics that could not easily be extracted from the hospital system (marital status, nationality, educational level and Internet use) were self-reported at baseline. Education level was based on the highest level of education accomplished, and categorized in three categories according to the International Standard Classification of Education (ISCED) (i.e. low, middle and high level).<sup>36</sup>

**Clinical data**

Creatinine and blood pressure values that were recorded by the patients were exported from the DMS database. Number of registered measurements was counted per 3-week study period (week 1-3, week 4-6, etc.). Laboratory creatinine and eGFR (according to the Modification of Diet in Renal Disease (MDRD) Study equation) were exported from the hospital system. Average eGFR was calculated per 3-week study period for each individual patient.

**Statistical analyses**

Descriptive statistics were calculated for patients' creatinine, kidney function, blood pressure (Mean Arterial Pressure, MAP) and anti-hypertensive treatment, as well as for level of general satisfaction, experience with using the devices, self-monitoring skills and experienced autonomy support. When applicable, scores on the five-point Likert scales were grouped into three categories to describe patients' views: don't agree (score  $\leq 2$ ), agree (score  $\geq 4$ ) or neutral (score 3). T-tests were used to assess whether patients' self-monitoring experiences differed between the creatinine and blood pressure device. Paired samples t-tests were used to compare baseline and follow-up scores regarding satisfaction and self-monitoring skills. To investigate whether specific patient characteristics were related to experiences and attitudes, Pearson's correlations were computed with a pre-set subset of patient characteristics that was derived from the literature, being age, gender, level of trust in accuracy of the devices (creatinine and blood pressure), support from the physician to be autonomous, self-efficacy regarding self-monitoring and transplant related worries.

Adherence to measurement frequency according to protocol was calculated by dividing the number of online registered measurements per week by the number of requested measurements per week. This procedure has been used before to calculate adherence to self-monitoring blood glucose.<sup>37</sup>

All statistical analyses were performed with SPSS version 20.0. P-values of  $<.05$  were considered significant.



**Table 1.** Characteristics of the questionnaires.

Questionnaire (reliability, if applicable)	No. of items	Time point <sup>1</sup>	Example	Scale
Overall satisfaction	1	B, FU	<i>On a scale of 1-10, how satisfied are you with the offered self-monitoring facilities?</i>	1-10
Specific aspects of satisfaction	15	FU	<i>Number of outpatient appointments.</i>	1. Want it to be diminished - 5. Want it to be increased
Advantages of self-monitoring	12	B, FU	<i>It is an advantage to check creatinine as often as wanted.</i>	1. Disagree – 5. Agree
Disadvantages of self-monitoring	13	B, FU	<i>It is a disadvantage that I have to puncture my finger.</i>	1. Disagree – 5. Agree
Experiences with using the creatinine and blood pressure device	10	B, FU	<i>Having a creatinine/blood pressure device is...</i>	1. Annoying – 5. Pleasant 1. Not reassuring – 5. Reassuring 1. Frightening – 5. Not frightening 1. Useless – 5. Useful 1. Frustrating – 5. Not frustrating
Trust in accuracy	2	B, FU	<i>I have confidence in the accuracy of the blood pressure device.</i>	1. Totally disagree – 5. Totally agree
Self-efficacy ( $\alpha$ .97)	6	B, FU	<i>I am able to correctly interpret measurement results.</i>	1. Totally disagree – 5. Totally agree
Autonomy supportiveness ( $\alpha$ .96)	15	FU	<i>My physician encourages me to ask questions.</i>	1. Strongly disagree – 5. Strongly agree
Transplant related worries ( $\alpha$ .66)	4	B, FU	<i>I am worried about damaging my transplant.</i>	1. Strongly disagree – 5. Strongly agree

<sup>1</sup> B = baseline, FU = follow-up.

## RESULTS

### Study population

During period of inclusion, 42 patients received a kidney from a living donor. Of the 34 eligible patients, 32 gave informed consent. Two patients dropped out because of serious medical complications following surgery. Thirty patients received the self-monitoring equipment and started performing self-measurements after a mean of 8 (SD=3) days after transplantation. One patient was lost to follow-up (see supplementary data figure 1 for the study flow chart). Characteristics of the study population are shown in table 2. The majority of patients were female, married or living together and of Dutch origin. Just over half was transplanted prior to initiation of dialysis (preemptive).

The baseline questionnaire was completed by 30 (100%) and the follow-up measure by 25 (83%) patients. Although the number of patients who did not complete the follow-up questionnaire was too low to conduct formal analyses, non-responders to the follow-up questionnaire seemed to perceive more disadvantages of performing and interpreting self-measurements at baseline than responders. The ten patients that were interviewed seemed representative of the total study population (i.e., no differences were observed regarding sociodemographics, internet experience, satisfaction and opinions about self-monitoring (data not shown). Patient quotes that reflect questionnaire results are given in table 3.

### Clinical data

Mean level of creatinine and mean eGFR measured at baseline was 132 (SD 35) and 51 (SD 19), respectively. Mean level of creatinine and mean eGFR at follow-up was 134 (SD 37) and 49 (SD 11), respectively. Mean arterial pressure (MAP) was 101 (SD 7) at baseline and improved over time (see table 2). Twenty-one out of 30 patients (70%) were prescribed antihypertensive treatment at discharge after transplantation. For one patient, baseline antihypertensive treatment could not be traced. The remaining patients (n=8) did not use any antihypertensive medication at baseline. Mean number of antihypertensive prescriptions was 1.28 per patient (ranging from 0 to 3).

During period of inclusion, three patients experienced an episode of acute rejection (at 26, 84 and 90 days post-transplantation, respectively). For two of these patients, a steep increase in blood level creatinine was visible in the self-measured creatinine values preceding hospital admittance for rejection treatment. The third patient did not self-monitor creatinine in the week preceding diagnosis of acute rejection. It therefore remains unclear whether this specific rejection could have been detected at home.

**Table 2.** Characteristics of study population.

Characteristics	Study population (N=30)
<b>Sociodemographic</b>	
Age (years)	
Mean $\pm$ SD	49.5 $\pm$ 13.01
Min - max	25 - 70
Male, no. (%)	10 (33.3)
Marital status, no. (%)	
Single	4 (13.3)
Married or living together	26 (86.7)
Nationality, no. (%)	
Dutch	27 (90)
Other	3 (10)
Educational level, no (%)	
Low	9 (30)
Middle	9 (30)
High	12 (40)
<b>Clinical</b>	
Renal status prior to transplantation, no (%)	
Pre-emptive	17 (57)
Dialysis dependent	13 (43)
Hemodialysis	8 (27)
Peritoneal dialysis	5 (16)
Creatinine ( $\mu\text{mol/l}$ ) mean $\pm$ SD	
Baseline <sup>2</sup>	132 (35)
Follow-up <sup>2</sup>	134 (37)
eGFR <sup>1</sup> mean $\pm$ SD	
Baseline <sup>2</sup>	51 (19)
Follow-up <sup>2</sup>	49 (11)
MAP <sup>3</sup> (mmHg) mean $\pm$ SD mean	
Baseline <sup>4</sup>	101 (7)
Follow-up <sup>4</sup>	97 (13)

<sup>1</sup> Laboratory based assessment; <sup>2</sup> Baseline = measured at first outpatient consult (mean 13 days since transplantation); follow-up = measured at first outpatient consult after finishing study participation (mean 101 days since transplantation); <sup>3</sup> Home-based assessment; <sup>4</sup> Baseline = first value measured at home (mean 8 days since transplantation); follow-up = last value measured at home (mean 88 days since transplantation).

### **Patients' experiences with using the measurement devices**

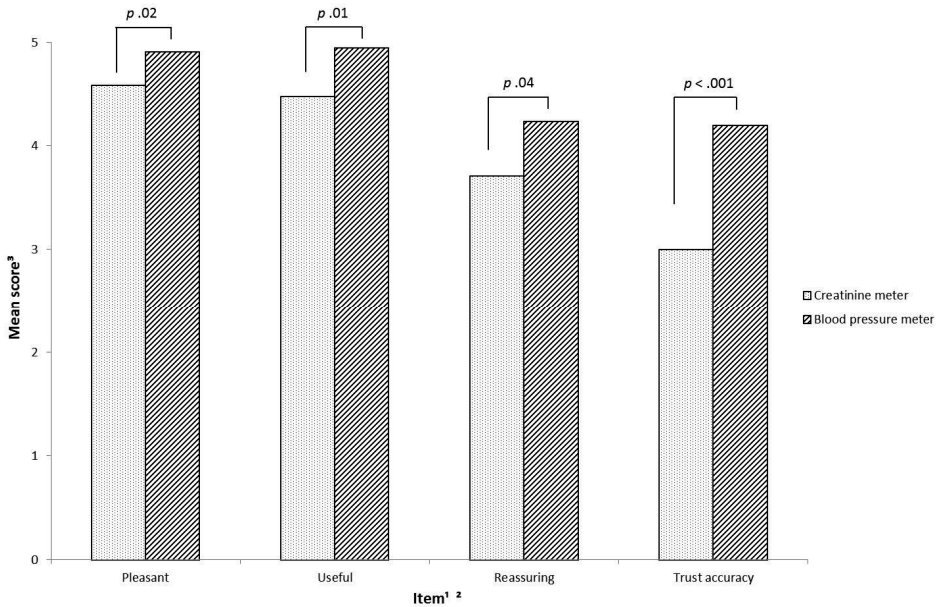
The majority of patients considered using the creatinine and blood pressure devices to be pleasant (95% and 100%, respectively), useful (91% and 100%, respectively) and reassuring (63% and 76%, respectively). Trust in accuracy of the creatinine meter was significantly lower than trust in accuracy of the blood pressure meter ( $p < .001$ ) (see figure 1). Based on the remarks patients made during the interviews (table 3, quote 1), we hypothesized that levels of unexplained variation in successive creatinine measurements might have resulted in lower levels of trust in the accuracy of the creatinine meter. To verify this, we calculated variation in creatinine measurements designated as the mean percentage change from successive measurements (i.e. difference between two measurements divided by their average). In line with the hypothesis a higher level of mean variation was related to a lower level of trust in the creatinine meter ( $p = .03$ ). However, no associations were found between the amount of mean variation in creatinine results and whether using the creatinine meter was considered pleasant, reassuring or useful ( $p = .78, .71$  and  $.57$ , respectively). The same analyses were conducted with regard to variations in successive measurements of Mean Arterial Pressure (MAP). Mean variation in MAP was neither related to trust in accuracy of the blood pressure meter ( $p = .86$ ), nor to whether use of the blood pressure meter was considered pleasant, reassuring or useful ( $p = .88, .43$  and  $.99$ , respectively).

### **Psychological measures: self-efficacy, perceived autonomy support and worries**

Patients reported a high amount of trust in their own monitoring skills at baseline ( $M = 4.37, SD = .49$ ) already and this did not change over time ( $p = .69$ ; follow-up  $M = 4.31, SD = .78$ ). In line with this, interview data suggest that self-monitoring was perceived as very easy, with half of the patients ( $n = 5$ ) spontaneously mentioning the simplicity of the required actions, while none reported any difficulties (table 3, quote 2).

Although patients were generally satisfied with the level of autonomy support they received, ( $M = 3.87, SD = .70$ ) half of the interviewed patients ( $n = 5$ ) stated that their physicians had only limited interest in patients' self-measured creatinine data. Despite the seemingly limited attention some physicians paid to the creatinine values measured at home, patients considered self-monitoring creatinine to be beneficial anyway (table 3, quote 3).

Physicians did, however, pay attention to patients' self-measured blood pressure results (table 3 quote 4). In line with this, analysis of hospital records revealed that for 80% of our patients home-based blood pressure measurements were registered in the hospital system. On average, patients seemed to be somewhat worried about their transplantation, but these worries declined over time (baseline ( $M = 2.98, SD = .88$ , follow-up  $M = 2.38, SD = .82, p = .01$ ).



**Figure 1.** Patients' experiences with using the creatinine and blood pressure device at follow-up.

<sup>1</sup> Having access to a creatinine device is pleasant / reassuring / useful; <sup>2</sup> I have trust in the accuracy of the creatinine / blood pressure meter; <sup>3</sup> On a scale of 1 to 5.

**Table 3.** Patient quotes from the interviews (N=10).

Quote 1	<i>"The accuracy [of the creatinine device] is not optimal. That's why you start to take everything with a pinch of salt after a while."</i> Male, age 38.
Quote 2	<i>"When you've seen it once, you can start doing it yourself right away."</i> Male, age 38.
Quote 3	<i>"That you're on top of it yourself is the most important to me."</i> Male, age 51.
Quote 4	<i>When I took the list with all my measures with me, the doctor only looked at my blood pressure."</i> Male, age 65.
Quote 5	<i>"It gives a sense of security that if something happens, you notice it right away."</i> Male, age 65.
Quote 6	<i>"I sometimes get the idea that the outpatient appointments are only there to remind a physician to check his patients' values."</i> Male, age 57.

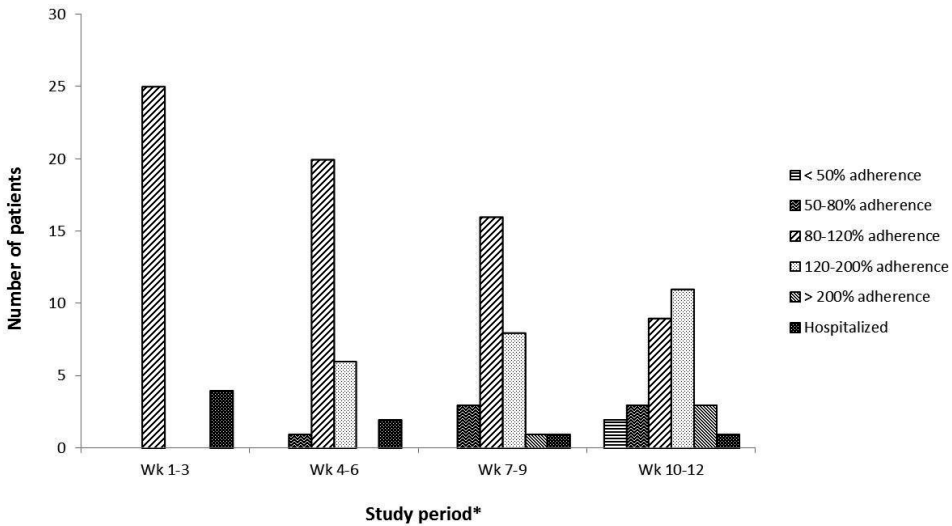
**Patients' satisfaction**

Patients reported high levels of satisfaction with the self-monitoring facilities of the DMS (baseline  $M=7.25$ ,  $SD=1.23$ ) which significantly increased over time (follow-up  $M=7.78$ ,  $SD=1.19$ ,  $p=.01$ ). A high level of satisfaction at follow-up was related to higher levels of trust in the accuracy of the creatinine meter ( $p<.01$ ), perceived autonomy supportiveness of physicians ( $p<.01$ ) and self-efficacy concerning self-monitoring skills ( $p<.01$ ).

The most important perceived advantage of self-monitoring at follow-up was the receipt of an automatic warning in case creatinine level was increased (table 4 and table 3, quote 5). In general, patients tended to agree with the list of suggested advantages, whereas they tended to disagree with the list of suggested disadvantages (table 4). Slight changes were observed in the ratings of advantages and disadvantages over time (table 4). For example, the advantage that physicians had access to the values measured at home was rated as less advantageous at follow-up than at baseline ( $p=.01$ ).

**Patients' adherence to measurement protocol**

Level of adherence to measurement protocol is depicted in figure 2. As number of registered creatinine and blood pressure values was similar within patients, adherence rates pertain to both creatinine and blood pressure measurements. Mean adherence was consistently close to or greater than 100% (i.e. more measurements than requested were registered). However, there were large differences between patients that increased over time. Adherence ranged from 0 to 367% during the follow-up period in week 10-12, with 4 patients recording less than 80% and 14 patients recording more than 120% of the required measurements. None of the patient characteristics was related to measurement adherence. We hypothesized that either patients' kidney function (i.e. eGFR according to the MDRD formula using laboratory serum creatinine) or the amount of variation in successive measurements might be related to how frequent patients measured their creatinine and blood pressure. Additional analyses showed that kidney function was not related to measurement frequency ( $p .33$ ). However, between measurement frequency and mean variation in successive measurements a trend was observed ( $p .08$ ), suggesting a higher amount of variation to be related to lower measurement frequency and vice versa.



**Figure 2.** Percentage adherence to measurement frequency per protocol.

\* Measurement frequency: week 1-3 daily; week 4-6 every other day; week 7-9 twice a week; week 10-12 weekly.

## DISCUSSION

Patient self-monitoring after kidney transplantation could possibly alleviate the burden of frequent outpatient visits and high levels of stress prior to consultations. The feasibility of self-monitoring, however, is highly dependent on the willingness and ability of kidney transplant patients to monitor at home. The current results showed that patients were highly motivated to self-monitor kidney function and reported high levels of general satisfaction. The use of both the creatinine and blood pressure meter was considered pleasant and useful, despite level of trust in the accuracy of the creatinine device being relatively low. Trust in the accuracy of the creatinine device appeared to be related to level of variation in subsequent measurement results, with more variation accompanying lower levels of trust. Average adherence to the monitoring protocol was good, but large individual differences between patients were found that increased over time.

Our results indicate that self-monitoring may be highly attractive to transplanted patients. Especially in the first six months after transplantation, when a relative high risk of rejection<sup>2</sup> necessitates high frequent monitoring, self-monitoring may provide both additional reassurance to patients about how their graft is functioning and a potential measure to diminish number of outpatient appointments. The experience of an extra sense of security, reassurance and control has been reported in other self-monitoring studies.<sup>14-17</sup> Our high response rate (32 out of 34 willing to participate) further suggests

**Table 4.** Experience of advantages and disadvantages of self-monitoring at baseline and follow-up.

	Baseline		Follow-up		Dependent t-test
<b>It is an advantage that...</b>	Mean*	SD	Mean*	SD	<i>p</i>
- I can control creatinine regularly	4.20	.91	3.84	1.38	.15
- I can control blood pressure regularly	4.20	.91	4.08	1.15	.60
- Physicians have direct access to results	4.72	.46	3.96	1.31	.01
- Changes in my condition are noticed quickly	4.76	.52	4.08	1.19	.02
- I have to take up a more active role in my own care	4.68	.56	4.04	1.06	.01
- I receive a warning in case of raised creatinine levels	4.76	.44	4.20	1.04	.01
<b>It is a disadvantage that...</b>					
- I have to perform measurements myself	1.60	1.00	1.36	.91	.16
- Performing the measurements takes time	2.00	1.32	1.48	.92	.05
- I have to interpret results myself	1.72	1.17	1.16	.47	.03
- I can keep track of values digitally	1.88	1.13	1.12	.44	.00
- I have to take up a more active role in my own care	1.68	1.18	1.36	.91	.12

\* On a scale of 1-5.

that self-monitoring is not just an attractive option for a small selection of patients, which has been observed in other chronic disease populations<sup>27;38-40</sup>, but may be appealing to the majority of recipients of a living donor kidney.

However, for a successful implementation of self-monitoring into post-transplantational care some barriers should be considered. Several factors were related to patients' satisfaction with self-monitoring. Firstly, although patients' relatively low levels of trust in the accuracy of the creatinine meter did not seem to discourage them from measuring, patients were more satisfied if they perceived the self-monitoring devices as being reliable. This corresponds with existing literature, showing that patients' confidence in the accuracy and perceived reliability of devices is an important prerequisite to the acceptance of these devices.<sup>18;19</sup> Although patients received instructions for trend monitoring, their unfamiliarity with interpreting successive rather than single measurement values may have hampered their trust in the creatinine device. Indeed, trend monitoring may be more



demanding than interpreting a single measurement value, as trend monitoring requires a careful consideration of the combination of several measurements.

Secondly, satisfaction about self-monitoring was related to patients' perceived support from their physicians to be autonomous. This is in line with self-determination theory<sup>41</sup>, which emphasizes the need of autonomy supportive social contexts. It also emphasizes that patients do consider self-monitoring as a care system in which their physicians keep playing an important role. Indeed, several studies show that patients consider self-monitoring as a less attractive option if this automatically implies a loss of human interaction with the clinical staff.<sup>19;42</sup>

Although patients were satisfied with the general amount of autonomy support from their physicians, interview data revealed that several physicians paid little attention to the self-measured creatinine data. Previous studies have also shown that physicians may be somewhat hesitant towards patient self-monitoring.<sup>43;44</sup> It has been suggested that physicians consider it difficult to determine whether patients are capable of self-monitoring and interpreting the measurements<sup>45;46</sup>, are afraid that self-monitoring will lead to a loss of control over therapy, and think that allowing patients to self-monitor will be more time-consuming.<sup>45;47;48</sup> However, in the current study physicians did pay attention to self-measured blood pressures. The difference in attention for creatinine and blood pressure measurements might be due to a relatively low level of trust in the accuracy of the creatinine device. Although they were also informed on the suitability of the device for monitoring creatinine trends, physicians expressed doubts about the accuracy of the meter due to a variation in successive measurements. The greater familiarity with home-based blood pressure monitoring might have also played a role. The positive effects of self-monitoring blood pressure on therapy outcomes have been clearly demonstrated<sup>27;49</sup>, whereas for self-monitoring creatinine this has yet to be established.

Thirdly, patients were more satisfied if they had a high self-efficacy regarding their own monitoring skills. The importance of self-efficacy for experienced satisfaction has been shown before<sup>20;21</sup>, suggesting that thoroughly instructing and supporting patients are important prerequisites for successful and satisfactory self-monitoring.

Our data did not support the suggestion that self-monitoring bodily symptoms could cause (unnecessary) worry and doubts<sup>13;26</sup>, or would be more or less beneficial for worried patients.

Finally, to enhance a safe implementation of self-monitoring in which self-measured values are an important source of information, patients should adhere to the self-monitoring protocol. Non-adherence to the protocol may leave serious complications unnoticed, which could ultimately lead to permanent loss of kidney function. Protocol adherence in the current study was generally good with the majority of patients measuring more often than requested. Considering that fear of rejection is common in patients after a (recent) transplantation<sup>7-10</sup>, it is tempting to assume that conducting extra

measurements indicates a high need for reassurance. In the current study, however, no relation was found between measurement frequency and level of transplant related worries. Besides patients performing more measurements than required, some patients did not adhere to the protocol and their number increased over time. The current dataset did not offer a clear-cut explanation for this finding, although a trend for a negative relation between measurement frequency and amount of variation in subsequent creatinine test results was observed. This suggests the existence of a relation between higher amount of variation and lower measurement frequency and vice versa. In addition to the suggested role of level of variation, two features of this study could have contributed to a lower level of adherence over time. First, the limited attention some physicians paid to measurement results might have reduced the perceived need to perform the measurements. Second, as self-monitoring creatinine and blood pressure was an add-on service to regular outpatient care, patients were not dependent upon their own measurements for information on their kidney function. This could have diminished patients' perceived need to self-monitor. Adherence might therefore improve when monitoring at home has a more prominent role in post-transplantational care instead of being just an add-on service. Nevertheless, protocol non-adherence remains a serious issue to consider in future studies to ensure safety of self-monitoring.

## CONCLUSION

To the best of our knowledge, this is the first study to investigate the possibility of self-monitoring kidney function after kidney transplantation and the first study on kidney transplant patients' attitude towards self-monitoring. The results show that self-monitoring creatinine and blood pressure after kidney transplantation is well received by kidney transplant patients. However, the relatively small number of participants and the selection of recipients of living donor kidneys prevents us from drawing strong conclusions that can be generalized to the entire kidney transplant population. Further, as non-responders to the follow-up questionnaire seemed to be somewhat less positive about self-monitoring at baseline, the absence of their follow-up experiences could have introduced a small bias towards a positive evaluation.

Overall, our results suggest that a self-monitoring care system has the potential to improve post-transplantational care in several ways. Firstly, by increasing patient satisfaction.<sup>14;17;24;27;37;38;50-52</sup> Secondly, by decreasing the high number of outpatient visits, as important parameters can be monitored at home. Finally, by advancing the detection of acute rejection and hypertension due to higher frequent monitoring, which may improve kidney graft survival.<sup>5;53-59</sup> Future studies should

determine whether it is feasible and safe to implement patient monitoring kidney function and blood pressure into transplantational care.

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