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

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CHAPTER 1

GENERAL INTRODUCTION

From acute to chronic illness

In the traditional care delivery model, a doctors' main job was to respond rapidly and efficiently to situations requiring immediate medical care. The focus was on the definition of the problem and the initiation of treatment. Since the full clinical course usually took only a short amount of time, there was little need for the patient to develop any disease-related skills and the patient's role was largely passive [1]. Nowadays, however, the majority of patients suffer from chronic disease(s), requiring a completely different relationship between patient and healthcare professional. The patient needs to be the manager of his own healthcare and the healthcare professional fulfils a coaching role [2]. The following metaphor nicely illustrates the position of chronically ill patients and their healthcare professionals:

'Living with chronic illness is like flying a plane. If the plane is flown well, one gets where one wants to go. If it is flown badly, one either crashes or lands shakily in the wrong airport, reluctant to ever leave the ground again. The patient must be the pilot, because the other possible pilot, the health care professional, is only in the plane a few hours every year, and this plane rarely touches ground [1].'

Patients have to become more independent and perform certain care tasks themselves. However, this does not mean that patients should be left to fend for themselves. A new task for healthcare professionals is to assure that their patients are 'skilled pilots', by giving them the confidence and skills to manage their condition[1]. Patients managing their own condition is often referred to as self-management.

Self-management and self-monitoring

There are several definitions of self-management, but the one most often cited comes from Barlow and colleagues: S*elf-management refers to the individual's ability to manage symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life[3]*. In this definition, monitoring one's condition is considered an essential element of self-management. Self-monitoring in the context of chronic illness has been defined as a patient undertaking one or more of the following activities (i) self-measurement of vital signs, symptoms, behaviour or psychological well-being, (ii) self-interpretation of self-measured data; or (iii) self-adjustment of medication, treatment, lifestyle or help-seeking behaviour as a result of self-awareness or self-interpretation[4, 5]. Patients can self-monitor by using highly advanced measurement devices that can sometimes even replace laboratory analysis, but one can also self-monitor by keeping a diary (either digitally or with paper and pencil) to track symptoms. It is important that patients closely monitor their condition themselves, as chances are very small that the onset or worsening of symptoms happens just prior to the few moments that 'the other pilot is on board'. If patients keep track of their own condition, exacerbations, complications and potentially even death can be prevented[6].

The (potential) merits of self-monitoring in chronic conditions

The concept of self-monitoring has been mainly studied and applied in conditions that need frequent monitoring to achieve optimal medication management. For example, diabetic type 1 patients need to monitor their glucose level several times a day to adjust their insulin doses. It would be extremely burdensome for both patients and healthcare capacity if these measurements could solely be performed by healthcare staff. It is therefore not surprising that the idea of diabetics self-testing goes back to the mid-1970s[7]. The first study in which self-monitoring blood glucose (SMBG) was successfully applied was performed in 1978[8]. Since then, many studies have followed showing that self-monitoring can lead to reductions in HbA1c[9-12] in patients with diabetes. This has resulted in the universal recognition of SMBG to be an essential element of optimal type 1 diabetes management[13]. Much experience with self-monitoring has further been gained on the usability of self-monitoring International Normalized Ration(INR) [14-19]. INR is an assay to determine the clotting tendency of blood, which is important information for patients with thrombosis who receive oral anticoagulant therapy. Due to the narrow target ranges, INR needs to be frequently monitored in order for anticoagulant medication to be appropriately dosed[16]. Studies have shown that with self-monitoring INR, the number of thromboembolic events in this population can be reduced [15, 16]. In other disease populations, self-monitoring has also been shown to be beneficial: patient self-monitoring blood pressure has a positive impact on the management of hypertension [20-24] and self-monitoring asthma symptoms can lead to improved asthma control [25]. Further, several studies in different disease populations have shown that patients who self-monitor experience higher levels of quality of life[26-29] and more empowerment[14, 18, 29-31] than patients who do not. In addition, patients seem to prefer self-monitoring above regular care in a variety of chronic conditions[14, 18, 23, 26, 27, 29].

Besides being beneficial for the individual patient, self-monitoring has also been shown to offer a way to control volume and costs of chronic care[32-34]). There are great concerns that the increasing numbers of chronically ill will outgrow the capacity of the working-age population to both finance the public health spending and fulfil the healthcare capacity needs. In the last decennium, 10% of the gross domestic product (GDP) in the European Union is spend on health care. Moreover, the health care costs have been increasing more than the GDP[35] and are expected to increase further posing a risk for the sustainability of health care financing [36]. With more than 70% of the total healthcare expenditure being spent on chronic diseases[37], it is not surprising that efforts to decrease healthcare costs are mainly targeted at the management of chronically ill patients. Due to the positive effect of self-monitoring on healthcare spending [32-34], improving the self-monitoring skills of people with chronic conditions has become an important objective in chronic care management[5]. With the widespread availability of the Internet, self-monitored data can be easily shared and discussed with healthcare providers enabling the provision of care while patient and doctor are remote in place and even in time. This has made self-monitoring an attractive addition or alternative to regular care for many chronic conditions. Using the Internet to provide care at a distance is often referred to as eHealth. EHealth can bring efficiency to healthcare delivery, for example by reducing routine healthcare visits[38], and is therefore seen as a key solution to the challenge of rapidly increasing numbers of patients requiring chronic care.

The potential of self-monitoring and eHealth in (kidney) transplant follow-up

Recipients of solid organ transplantations have to pay frequent and usually routinely scheduled visits to the hospital to monitor graft function. As the onset of complications like acute rejection usually does not run synchronously with the monitoring appointment interval, it would be highly beneficial and efficient if patients could monitor graft function themselves. Studies regarding the potential of transplant patients self-monitoring health parameters at home have been mainly performed in a population of lung-transplant recipients. As these patients have an even higher risk for acute rejection and infection than recipients of other solid organs[39, 40], they need to frequently self-monitor vital signs to enable early detection of changes in their condition. Self-monitoring with electronic devices and the support of technology systems has been shown to be a valid and reliable way to detect complications after lung-transplantation early[41, 42] and to lead to better survival[43] and a higher quality of life for lung-transplant patients[44].

Self-monitoring may also be a promising approach for kidney transplant follow-up, with the frequent and usually routinely scheduled appointments to monitor kidney function being highly burdensome to the recovering patient and to healthcare resources. Although significant improvements in kidney transplant outcome have been achieved in the last decade [45], patients continue to be at risk for acute rejection of their kidney graft, mainly in the first year after transplantation. As early detection of a rejection episode is mandatory to minimize permanent damage to the kidney graft[46-51], kidney transplant patients in the Netherlands visit the outpatient clinic about 20 times during the first year post-transplantation. Despite the high frequency of outpatient visits, the potential of self-monitoring after kidney transplantation has not yet received a great deal of attention. Studies that did cover this subject focused on the viability of self-monitoring blood pressure after kidney transplantation, showing that self-monitoring blood pressure is an effective way to detect poor control of hypertension[52-54]. Although blood pressure is an important parameter to be monitored after transplantation, healthcare professionals and patients are especially interested in serum level of creatinine. Creatinine is a waste product of the muscles that is filtered from the blood by the kidneys. In case of a deteriorating kidney function, for example due to rejection, the level of creatinine and other waste products in the blood will increase. Besides the accumulation of waste products in the body, which eventually becomes toxic, a decreased kidney function leads to increased blood pressure via two routes. First, as kidneys filter and excrete excess fluid, suboptimal kidney function leads to the accumulation of fluid in the body resulting in an increased pressure that is put on the blood vessels. Second, the kidneys play an important role in keeping blood pressure in a healthy range by the excretion of blood pressure regulating hormones. Decreased renal function will therefore result in suboptimal blood pressure regulation. The relationship between kidney function and blood pressure is bi-directional: through the increased pressure that is put on the vessels, the dense network of blood vessels present in the kidneys can become damaged, reducing the ability to remove waste and excess fluid from the body. This will again lead to increased pressure that is put on the blood vessels, resulting in a downwards spiral. The narrow relationship between kidney function and blood pressure makes the frequent monitoring of both parameters necessary.

Aim and outline of this thesis

Based on the experiences in other conditions requiring chronic care, self-monitoring kidney function after transplantation has the potential to increase patient independency and satisfaction and accelerate the detection of complications while reducing healthcare consumption at the same time. The general objective of this thesis was to investigate whether self-monitoring kidney function after transplantation supported by an online self-management support system is well accepted by patients, and can replace part of regular care safely and without loss of quality of care. The different studies that have been performed to answer this question are outlined below.

Chapter 2. Enabling patients to monitor kidney function at home could decrease the high frequency of outpatients visits and improve speed of rejection detection. For this to be possible, however, patients have to be willing to self-monitor. In this chapter, the results of a prospective pilot study investigating patients' experiences and satisfaction with self-monitoring kidney function after transplantation are described.

Chapter 3. For the design and implementation of self-management support systems (SMSS), it is important to understand the factors that influence patients' acceptance of a SMSS. In the questionnaire study described in this chapter, we identified key factors influencing renal transplant patients' acceptance of the SMSS. The questionnaire items were developed based on literature describing factors that influence patients' acceptance of a new system.

Chapter 4. The StatSensor® Xpress-i ™, a point-of-care system for blood creatinine measurement, offers patients the possibility to self-monitor kidney function. As this device has never been used in a kidney transplant population before, we investigated whether the StatSensor® can be applied safely for kidney transplant follow-up by examining its' analytical performance for both detecting current renal function and monitoring renal (dys)function over time.

Chapter 5. This chapter describes the results of a randomized controlled trial (RCT) in which the safety and usability of self-monitoring creatinine and blood pressure with the support of an online SMSS during the first year post-transplantation was investigated. Self-monitoring kidney function after transplantation was compared to usual care with regard to healthcare consumption, kidney function (eGFR), blood pressure, quality of life, satisfaction and self-efficacy regarding self-management behaviour.

Chapter 6. For self-monitoring to be a safe alternative to regular face-to-face follow-up, patients have to adhere to a monitoring schedule, report test results accurately and act upon test results if these suggest graft failure may occur. We used data that was collected in the RCT to investigate level of adherence to both the self-measurement regimen and to the automatic advice patients received upon registering their creatinine measurements in the online SMSS (e.g. repeat measurement, contact the hospital) and to assess the reliability of the measurements that were registered in the SMSS.

Chapter 7. The results presented in the previous chapters and their implications are discussed in a broader context. Recommendations for future research are provided.

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