For patients with end-stage renal disease, kidney transplant is the treatment of choice. In spite of increased quality of life in most cases, kidney transplant recipients continue to live with a chronic condition. They must manage lifelong treatment and medical follow-up while having higher risk of infection, cardiovascular disease, and certain types of cancers than the general population.

The importance of supporting chronically ill patients’ self-management in their health care provision is well known. Corbin and Strauss have proposed 3 sets of self-management tasks: managing the medical regimen, new life roles, and emotions. Based on their work, Lorig defined self-management tasks as problems or challenges caused by the condition or its impact that patients have to manage in daily life.

In caring for kidney transplant recipients, the focus has been primarily on managing the medical regimen. Although some reports have been published on adherence to medical recommendations, less has been reported about effective interventions that support self-management in categories other than managing the medical regimen. Redman suggested a paradigm shift.

A mixed-method study to explore patients’ perspective of self-management tasks in the early phase after kidney transplant

**Context**—Patients’ perspectives of posttransplant self-management tasks have not been explored.

**Objective**—To explore the concept and the presence of self-management tasks mastered by patients in the early phase after kidney transplant.

**Design**—Mixed-method study using semistructured interviews and a structured questionnaire.

**Setting**—Outpatient Division of Nephrology at University Hospital Zurich, Switzerland

**Patients**—Twelve patients (median age, 52 years, interquartile range, 42.25-65.25 years; median time after kidney transplant, 6.5 months; interquartile range, 2.25-15.75 months) were included.

**Analysis**—Qualitative data were analyzed according to Corbin and Strauss’ 3 self-management tasks with content analysis procedures. In the quantitative analysis, the presence of each self-management task is expressed as a frequency.

**Results**—The qualitative findings showed that patients were greatly challenged by the effort to manage the upcoming instability, which has a persistent broad impact on their lives. Managing emotions comprised dealing with uncertainty, disappointment, and frustration. Additionally, patients had to manage changes in self-perception. Managing life roles mainly involved an adaptation of relationships, occupational changes, and interactions with health care providers. Taking medications, managing symptoms, integrating new behaviors, and understanding one’s course of disease were further tasks. Quantitatively, self-management tasks that were perceived as a challenge by at least half of the patients were primarily tasks from the questionnaire section “managing stressful emotions and self-perception.” The synthesis of qualitative and quantitative findings indicates that self-management programs for kidney transplant recipients should focus on strengthening patients’ self-management of emotional tasks and on regaining stability in daily life. (Progress in Transplantation. 2014;24:8-18)
Self-management tasks in the early phase after kidney transplant

from adherence to self-management in transplant recipients, but the conceptualization of self-management in kidney transplant recipients is still evolving. For example, Schäfer-Keller and colleagues identified infection control, monitoring vital signs, medication intake, symptom management, sun protection, physical exercise, healthy eating, and smoking cessation as essential medical tasks after kidney transplant. However, their work did not specifically explore managing emotions and new life roles. Furthermore, the conceptualization that was derived from the literature excludes the patient’s perceptions. Some studies have examined patients’ perspectives on life or quality of life after kidney transplant, but none has been focused on post-transplant self-management tasks. Consequently, further research is needed to advance knowledge in this field. The objective of this study was to explore patients’ perspectives on self-management tasks in the first 2 years after kidney transplant.

Methods

Design, Sample, and Setting

This mixed-method study was conducted at the Outpatient Division of Nephrology at University Hospital Zurich (UHZ) Switzerland between August 2009 and January 2010. The UHZ transplant center performs about 80 kidney transplants annually. We applied a concurrent nested approach, which means that we collected the qualitative and the quantitative data at the same time in the same patients. The predominant method was qualitative, whereas the quantitative approach was nested in the qualitative approach.

Qualitative methods were used to explore the concept of self-management tasks in kidney transplant recipients. Quantitative methods were used to assess the presence or absence of 44 self-management tasks that had been identified in published reports. We analyzed each source of data separately. Thus, the quantitative data did not influence the interpretation of the qualitative data—or vice versa.

Inclusion criteria were kidney transplant, time after transplant (0-2 years), age (>18 years), language (German speaking), and outpatient follow-up. Exclusion criteria were multiorgan transplant, current hospitalization, lack of mental acuity, and illiteracy.

To obtain a broad spectrum of self-management tasks, we used a purposive sampling. We selected patients according to the following characteristics: age (broad spectrum from younger to older, approximately 50% were >54 years old), time since kidney transplant (broad spectrum from 0 to 24 months, approximately 50% in the first year since transplant), and health status as perceived by professionals (broad spectrum from good to poor, approximately one-third good, one-third intermediate, one-third poor). The professionals were either nurses or physicians who were very familiar with the patient. They were asked an open-ended question about how they assessed the patient’s general health status.

Eligible patients who came to follow-up visits were checked for the criteria just mentioned. Certain patients who had criteria that were underrepresented in the sample at that point in time were invited to participate, for example, a person of younger age and longer time since kidney transplant whose health status was perceived by professionals to be good.

Demographic and clinical data were retrieved from medical files. These data were used to describe sample characteristics. We recruited patients until no substantially new topics arose.

Instruments: Interview Guide and Questionnaire

An interview guide based on Lorig’s evidence and self-management conceptualization was developed. As self-management is based on a patient’s perspective, our intent was to identify tasks confronting patients. We used the following questions to explore the impact of kidney transplant on everyday life and self-management: What consequence(s) (effect/impact) did the transplant have on your everyday life? What consequence(s) did the transplant have on your emotions? What consequence(s) did the transplant have on your family/friends/work? What are your greatest challenges or problems living with your kidney transplant? What do you worry about most regarding the future?

In addition, a structured questionnaire was developed and used to identify the presence of 44 self-management tasks that covered the 3 sets of self-management tasks described by Corbin and Strauss and Lorig: managing the medical regimen, new life roles, and emotions. These potential self-management tasks were identified from published reports about patients’ experience of living with a kidney transplant or potential education needs after a kidney transplant. The reports were focused on the patients’ perspectives as well as on the views of the health professionals. In a structured interview, patients were asked which of the 44 tasks were challenging to manage at that moment. A yes/no response format was applied.

Data Collection

Eligible patients were informed about the study by letter and phone call before their outpatient visits. During their visits, they were provided with further written information. Those willing to participate gave written informed consent.

The interview was conducted by the first author, who used the semistructured interview guide followed by the structured questionnaire. All interviews were audio taped and transcribed.
Ethical approval was received from the Cantonal Ethics Committee of Zürich.

Data Analysis

**Qualitative Data Analysis.** Content analysis methods were used according to Mayring.\textsuperscript{20} For data management, MAXQDA 2007 was used (Verbis Software).

We used a combination of deductive and inductive strategies of category development.

Deductive category development: The definition of self-management\textsuperscript{13,15} formed the framework for the analysis and the 3 sets of self-management tasks (managing the medical regimen, new life roles, and emotions) built the main categories.

Inductive category development: In the first step, the text-bearing tracts regarding self-management were condensed into paraphrases. The paraphrases were generalized based on a previously defined level of abstraction, summarized, and grouped into inductively emerging themes. The themes were further summarized and grouped in subcategories.

The inductively identified subcategories were integrated in the 3 deductive categories. This resulted in additional and rich information for specific self-management tasks, for example, self-management strategies reported as being used by patients to manage tasks. The topic “Managing instability” was reflected in all categories and subcategories and was therefore set as superordinate topic.

The analysis was conducted by the first author and validated according to the following steps:

1. The category system was discussed with 2 participating patients in 2 different settings. Patients were asked to what extent the identified self-management tasks represented their own experience. Both patients reported recognizing their personal situation in the given categories.

2. Interviews and the category system were discussed with 3 health professionals, 1 psychologist (third author), and 2 nurse researchers (second and last author). They checked whether all self-management tasks were identified, whether they were interpreted appropriately, and whether the semantic differentiation between categories was established.

Four of the 5 researchers have training and experience in qualitative methods and analysis. The interviewer has experience in interviewing patients. The last author has wide-ranging training and experience in qualitative and mixed methods, as well as in instrument development.

**Quantitative Data Analysis.** Quantitative data from the sample characteristics and the structured interview were entered into SPSS 20 (PASW Statistics, Rel. 18.0.0, IBM Corporation). Data were analyzed descriptively. Because of the small sample size, only frequencies, interquartile ranges (IQRs), and medians were calculated. In the structured interviews, all yes answers were summarized for each task.

Results

Sample Characteristics

We asked 16 patients to participate. Four declined. The purposive 12-patient sample (7 men, 5 women) had a median age of 52 (IQR, 42.25-65.25) years and a median time since transplant of 6.5 (IQR, 2.25-15.75) months. It was the first kidney transplant for 11 of the patients and the second transplant for 1. Eight received their graft from a deceased donor and 4 from a living donor. Median creatinine level was 198 (IQR, 99.5-244.25) µmol/L and median hemoglobin level was 11.85 (IQR, 10.6-12.68) g/dL. Two patients worked part-time, 2 others were unemployed, 3 were retired, 1 was a stay-at-home father, and 4 were on full medical disability. Treatment techniques used before transplant were hemodialysis in 10 patients, peritoneal dialysis in 1 patient, and no treatment in 1 patient. The nationalities of the patients were Swiss (n=6), Italian (n=2), English (n=2), Albanian (n=1), and German (n=1).

Eight patients (patients 1, 5, 6, 7, 8, 10, 11, and 12) reported that their physical and psychological health status improved significantly after transplant. Two patients (patients 2 and 9) described their health status as more or less the same and 2 patients (patients 3 and 4) thought that their health status had worsened from the time before transplant.

Qualitative Analysis

Based on the findings from the qualitative interviews, the category system consists of the main task, “managing instability,” and 3 categories of self-management tasks according to Lorig’s conceptualization\textsuperscript{4}: managing the medical regimen, managing emotions and changes in self-perception, and managing social interactions and new life roles. Each of the 3 categories includes subcategories that are presented in the Figure.

**Managing Instability.** The main task was to manage instability in 1 or more areas of life. Based on the work of Corbin and Strauss,\textsuperscript{4} we define instability as the absence of perceived stability in daily life combined with an increased inability to predict the upcoming course of events owing to changes in 1 or several areas of life. Most participants experienced their circumstances as stable before transplant. Kidney transplant brought change and led to instability; for example, changes in physical condition or appearance, occupational changes, or changes in the medical regimen. Dealing with instability was shaped by 2 context factors. The first is that, despite new instability, most patients reported that kidney transplant had resulted in a new freedom. They were free of dialysis and could...
eat what they wanted. Traveling and spontaneous undertakings were once again possible. Additionally, patients reported that their individual living conditions had an enormous impact on how they experienced life in general. The living conditions of participants varied greatly, in age, family, and finances. One patient in particular mentioned high stress due to her living conditions (single mother, financial constraints), which may have added to instability.

**Managing Emotions and Changes in Self-Perception.**

This category involved managing changes in self-perception as well as stressful emotions arising from uncertainty regarding the future, complications, and unrealistic expectations.

**Managing uncertainty regarding the future.**

Patients reported a fear of deterioration as their most pressing concern. They feared that their health status could remain unstable, not improve, or even worsen. Most patients worried about a decline in kidney function due to rejection or through a relapse of their underlying disease, resulting in the loss of the kidney.

One patient reported that he often thought of losing his life. Another patient said that this thought occurred frequently at the time of dialysis, but after her transplant, she no longer thinks of death. A father
with young children said that he hopes to live until his children are grown up. Some patients expected to live shorter lives, but they did not have a concrete idea of what this might mean.

Individual participants dealt differently with instability and uncertainty. They perceived certain strategies as helpful, such as actively seeking knowledge, focusing on and living in the moment, setting goals for the future, accepting unchangeable situations, and having positive thoughts. Emotional support, as well as adjusting one’s thoughts by speaking with others was helpful. The exchange with peers helped patients not to feel alone or marginalized.

**Dealing with complications and unrealistic expectations.** Several patients reported frequent follow-ups, emergency consultations, or rehospitalizations since their kidney transplant. Patients found this frustrating, tiresome, and depressing. Participants experiencing several complications reported high levels of stress. As a consequence, follow-up dates were dreaded because patients feared further bad news.

Last year I had to be hospitalized 9 times. They saw that my kidney had worsened and I had to come to the hospital, had to receive an infusion . . . It exhausts me to come to the hospital again and again. (Patient 2)

Another issue that needed to be dealt with was disappointment. Some participants expected that life after transplant would return to the way it was before the first symptoms of renal insufficiency and that they would be healthy. Patients had to adjust these beliefs and adopt realistic expectations. They wished they had received more information about the posttransplant period and had been better informed of what to expect.

On that day when the coordinator called me, I said: “Yippee! Great! Cool! Christmas! One operation and everything will be fine. No more medication, no hospital, no injections, finished, it is all over, a new life.” And needless to say, it was not at all like this... My expectations were too high. Fine, I have had to lower them. (Patient 4)

**Managing changes in self-perception.** Participants, females in particular, suffered from changes in appearance such as hair growth on their body or face, weight gain, tremors, and an abdominal bulge because of the transplanted graft.

Participants talked about changes in their level of energy. Whereas some felt more energetic, a substantial number still felt reduced in their overall condition. Some participants reported less physical energy and a reduction of muscular strength. For some of the participants, this was a new problem. Others were already familiar with this from their experience with dialysis. Three participants mentioned sleep disturbances. They attributed this to medication side effects or increased urine production, which forced them to get up and use the toilet at night.

Two participants noted that they lacked a sense of their kidney, even when rejection was beginning. Their perception of their kidney was influenced by medical information they received such as “my kidney works only 25%.” One man had a liquid collection (lymphocele) around the kidney and felt it moving. He concluded that the graft could not be his own if he could feel it. He had several rejections and described difficulties with defining whether the kidney was his or was alien. This ambivalence was very distressing to him. In the discussion for validation, he said that the task is “to form a bond (‘we’) with the transplanted kidney.”

Off the top of my head, I have to say the most difficult [adaptation] is the dialogue between my kidney and myself. My thoughts are often: “Is it alien, is it not alien? Is it mine? Is it not mine? Will it remain? Will it not?” (Patient 4)

**Managing Social Interactions and New Life Roles.** This category includes social tasks that participants have to deal with: adapting to changes in relationships, managing occupational and financial changes, and interactions with health care providers.

**Maintaining and adapting relationships.** Participants described their circumstances after the transplant variously, from more freedom for the whole family to more stress and uncertainty. Most described close family members and friends supporting them and encouraging them to adhere to recommendations. These patients valued the emotional support and empathy they received.

A few participants reported encountering a lack of empathy. One reason was a discrepancy between a patient’s health perception (I’m ill) and that of others (she/he is healthy). As a consequence, patients felt misunderstood. A lack of empathy was perceived as very stressful and painful. Some participants withdrew from or reduced their social contacts, particularly if they did not feel well or had changes in their physical appearance. One man speculated that people were uncertain how to interact with him in his difficult circumstances.

Most people don’t understand when I tell them what I have. It is because they haven’t experienced it. . . . Sometimes, I feel misunderstood. (Patient 2)

Participants mentioned changes in their roles and role performance due to the illness and subsequent transplant. Two men said that they had been the principal
wage earner, but now they stayed home while their wives had reentered the workforce. Participants talked about restrictions in role performance as mother, father, or partner because of frequent hospitalizations or because of poor health. Parents reported trying to shield their children from stressful news.

A significant issue for participants was their relationship to the donor. Those who had received their graft from a living donor reported having a guilty conscience before and immediately after the transplant. It was helpful to see that the donors felt well after transplant and to know that the donor did not regret the donation. Participants said they had to find a new balance between closeness and distance in the relationship to the donor after transplant. They made an effort to keep in touch with the donor.

Participants who had received a donation from a deceased person shared that they often thought of the dead donor. Some wanted to know more about this person; one woman wished she could connect with the donor’s family. They reported not being burdened by these thoughts, except for one man who avoided thinking of the donor because these thoughts were very stressful for him. Achieving a peaceful mental attitude toward the deceased donor is a self-management task for these patients.

Managing occupational and financial changes. Participants had to manage daily tasks despite inhibiting factors such as a reduced level of energy or frequent follow-up visits. For example, one man gave up a caretaker job because he could not manage it any more because of leg pain. Participants who could perform activities such as household chores reported needing to rest more often.

Always step-by-step. I can’t do it all at once . . . I lie down again for an hour and then it is fine again for a certain period of time. (Patient 9)

Nonretired participants planned reentry into their profession. They described their working capacity being affected by a reduced ability to concentrate, making reentry more difficult. They held a gradual reentry to be realistic, but difficult to implement. During this period, they had to maintain their professional expertise.

Participants stated that dealing with their disability insurance was troublesome and time-consuming. One woman said that the insurance company often delayed accepting her claims because of the instability of her health status. This imposed severe financial constraints on her. Others also talked about financial constraints due to reduced income. Some participants feared that their disability insurance might be terminated before they were able to reenter the workforce.

It all depends on me. One must bring home a paycheck month-per-month. I’m obliged to do it because the money from the social benefits doesn’t cover a lot. (Patient 1)

Interacting with health care providers. Patients reported various expectations; they wished that their health care providers took their need for information and participation in care into account. Participants did not voice their needs to their health care providers.

I don’t believe in positive thinking. I want facts . . . so that I can prepare myself mentally. And health professionals should assess at the beginning what kind of patient the person in question is: Does the patient want to know anything at all? Or will he ask questions and expect answers? . . . Not all patients can be treated the same. (Patient 3)

Participants said that they wished to trust the medical doctor. One mentioned that the doctor’s honesty was important for building trust. Patients reported 2 factors hindering this process: receiving contradictory information from different physicians and not having a consistent physician provider.

Managing the Medical Regimen. This category involves patients’ daily medical tasks such as their medication regimen, managing symptoms, performing health-promoting behaviors, and becoming knowledgeable about the key elements of their therapy.

Taking medication. Participants reported having to take their medication correctly and punctually. Some said they got used to the medication routine. Others reported barriers such as forgetfulness, unexpected changes in daily routine, nausea, or a complex medication regimen with several doses per day. One task was overcoming these barriers and integrating medication intake into daily life.

Managing symptoms. Participants reported that they were more aware of their body after transplant than before.

You are more aware of your body and listen more to it. I never did that before . . . but now I’m more aware. (Patient 5)

They said that posttransplant education and the action plan helped them interpret the symptoms and react accordingly. One woman was told that she should call the transplant center for each “bagatelle” (trifle) such as pain medication for headache. She wished she had more freedom in decision making and wanted to know which medications she could take on her own.
Participants mentioned many symptoms and adverse effects of medications such as pain, gastrointestinal problems, visual disturbances, or tinnitus. Symptom distress varied greatly: one person described the tinnitus as barely noticeable; another suffered to the point that he was unable to listen to music, his favorite hobby. Participants tried to reduce symptom distress by seeking medical help. If this was not helpful, they sought other ways to deal with the symptoms.

Six of the participants suffered from back, joint, or foot and leg pain. They had received analgesics that were not totally effective. Others said they had not taken them because they did not want additional medication. None of the participants interviewed took pain medication on a regular basis. Some went to the chiropractor or to the physiotherapist.

I took paracetamol [acetaminophen]. But that stuff did not help at all. And then I decided to go to the chiropractor. And so far this has helped me quite a lot, but I’m not completely without pain. (Patient 11)

Making health promoting behaviors a part of daily life. Participants mentioned receiving recommendations from health professionals regarding prevention of infections, adequate fluid intake, smoking cessation, careful lifting, sun protection, traveling, avoiding grapefruit, and healthy eating and exercising. The extent to which these recommendations were incorporated into their daily lives varied greatly among patients. Some participants found particular recommendations impossible to adopt in their daily lives, for example, if they could not exercise because of pain or fatigue.

Becoming familiar with key elements of therapy. Several patients reported information that they had obviously misunderstood, as the following quotation illustrates.

In the case of a rejection, the professionals say . . . that one cannot go back to dialysis again. And you will have a lot of other problems, you will get another disease—I don’t know, skin cancer—and you can’t go back to dialysis and then you will die. (Patient 6)

Some said they did not understand the meaning of some recommendations given to them. Others reported having questions regarding beneficial and adverse effects of medications, rationale and plan for follow-up care, therapy and diagnostics, and renal function testing. Consequently, 1 self-management task for kidney transplant recipients is to become familiar with and understand key recommendations and their disease trajectory.

At the same time, finding trustworthy sources of information was a challenge. Most participants received information from their physician or nurses in one-on-one contact, informational evenings or posttransplant education. But some reported receiving outdated or incorrect recommendations even from health care professionals. Most participants used books, brochures, and the Internet as supplemental information. One woman reported being scared of the information she read on the Internet. Participants shared that they discussed information with peers they knew from dialysis or patient organizations. Some wished to meet peers in the future as an additional source of information.

We belong to an association for transplant patients. If we need help, we can contact them and get advice. (Patient 8)

Quantitative Data

The 11 participants reported a median of 13 (IQR, 5-18 challenges) out of a total of 44 tasks. The range of self-management tasks was 1 to 24. Data from the twelfth participant (patient 8) are missing because he declined to complete the questionnaire. Self-management tasks that were perceived as a challenge by at least half of the patients are highlighted in gray in the Table. These were managing side effects of medication (6 of 11), finding the balance between normality and abnormality (6 of 11), the fear of complications (7 of 11), uncertainty about how long the kidney would function well (8 of 11), changes in appearance (7 of 11), the fear of rejection (6 of 11), and the fear of harming the kidney (6 of 11). Six of the 7 tasks were in the domain of emotional tasks. One of the 7 tasks (managing side effects of medication) was in the category of managing the medical regimen.

Discussion

This study is the first to explore self-management tasks in the first 2 years after kidney transplant from the patients’ perspective. Based on the qualitative data, we developed the conceptualization of self-management in kidney transplant recipients further, especially in the field of social and emotional tasks. The category system describes the self-management tasks that patients had to master in the early phase after kidney transplant. The quantitative data provide insights on the prevalence of certain tasks in this population.

One important finding is that study participants reported that kidney transplant brought changes and instability to most areas of their lives. Managing instability was reflected in all categories and subcategories. Under the illness trajectory theory, kidney transplant can be seen as an event that initiated an unstable phase...
after an often longer phase of illness and ongoing health deterioration. Therefore, posttransplant care should be focused on supporting patients in regaining stability in daily life.

In the qualitative findings, 6 patients reported the challenge of managing pain but did not take analgesics on a regular basis. Masajtis-Zagajewska and colleagues examined the prevalence of pain in 114 kidney transplant recipients who had undergone hemodialysis therapy for at least 12 months before transplant. The prevalence was 62%, whereas 7% reported mild pain, 52% reported moderate pain, and 41% reported severe pain. The prevalence of pain is higher in transplant recipients than in the healthy population, probably owing to comorbid conditions of renal or nonrenal origin such as diabetes (neuropathy), osteoporosis (fractures), and cardiovascular diseases. Strikingly, 37% did not take any analgesics. The reasons for underuse of pain medications in this population may vary: first, the range of analgesics is limited in this population because nonsteroidal anti-inflammatory drugs including COX-2 inhibitors are contraindicated in kidney
Second, the attitude of patients toward analgesics could be a further factor, as patients indicated in this research that they do not want to take additional medication. Third, the attitude of health professionals regarding pain management may have an effect, but this phenomenon has not yet been studied in this population.

In the qualitative findings, patients mentioned interacting with health care providers as another important topic. They stressed the importance and challenge of building a trustful interaction with their health care providers and voicing their needs. In chronic disease, the delivery of care needs a different approach than in the case of acute illness, with continuity and coordination of care being a main principle. Yet, promoting continuity often runs counter to the hospital’s responsibility to train health care professionals. The reality is that Swiss physicians often rotate every 6 months. The question then becomes, how establishing a relationship based on trust between health professionals and patients can be supported despite these limitations? One strategy may be empowering patients to voice their needs and to take an active role in their follow-up visits. Another approach would be to focus on the training and supervision of health professionals in communicating effectively with patients, sharing decisions, and supporting self-care.

Other identified self-management tasks have also been reported in other transplant populations: In a study of lung transplant patients, participants mentioned changes in physical appearance, fear of graft loss, the issue of their own mortality, the question of being ill or healthy, and financial constraints as relevant topics. The relationship to both the organ and the donor is specific to the transplant population. Participants reported thinking frequently of the donor, but also reported that they were not burdened by these thoughts. In lung transplant recipients, it has been reported that patients see the donor as a living omnipresent person with specific qualities. This is probably true for kidney transplant patients as well, but was not explicitly studied in this investigation. This area is in need of further research.

Managing uncertainty is another task described in other chronic illness populations, for example, patients with cardiac disease. Issues that are common to other chronically ill populations should be kept in mind when developing self-management programs for transplant patients. The suitability of existing programs and their transferability to the transplant population should be considered.

<table>
<thead>
<tr>
<th>List of possible challenges</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance between normality/feeling healthy and abnormality/feeling ill</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Fear of getting an infection</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Fear of complications</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Feeling tired</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Uncertainty about how long the kidney will function well</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Feeling frustrated if complications occur</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Feelings of powerlessness</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Feeling at the mercy of the transplant center/the doctors</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Feeling under pressure</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sleeplessness/not able to relax</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Feeling depressed or hopeless</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Changes in mood</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Changes in appearance</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Sorrows or fear of rejection</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Fears of harming the kidney</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Living with someone else’s organ</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total number of challenges</td>
<td>1</td>
<td>13</td>
<td>22</td>
<td>15</td>
<td>5</td>
<td>9</td>
<td>4</td>
<td>18</td>
<td>11</td>
<td>15</td>
<td>24</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In our sample, patients’ expectations of life and of regaining normal health after transplant were very high. They spoke of their disappointment regarding their current perceived health status or working capacity. This could be a key issue as Cleemput and colleagues have also described patients having high expectations regarding health status after kidney transplant. Future program development should support patients in developing a more realistic conception of life after transplant, beginning before transplant. A challenge for delivering structured self-management support before transplant is the decentralized organization of nephrological care delivery. Normally, patients have only 1 consultation in the transplant center before their transplant surgery. All other visits are undertaken by their nephrologist outside the transplant center.

After transplant, patients’ self-management is promoted systematically. During the inpatient hospitalization, every patient receives training in taking medication and in observing and interpreting symptoms. Patients practice these skills, for example, resolving at least 2 hypothetical situations with the use of a written action plan. Based on this research, we broadened the action plan with a list of medications that patients can take on their own in a clearly described situation. Psychologists, nutritionists, and social workers are involved as the need arises. Additionally, each patient receives a short instruction annually by the dermatologist regarding sun protection. The structured in-patient education introduced in 2007 could explain why patients reported few challenges in the medical regimen and none reported a need in symptom management in the quantitative results.

Based on this research and scientific literature, we developed a self-management program: since 2012, each patient receives a further 1-hour instruction 1 to 2 months after transplant, provided in the outpatient clinic. The session focuses on evaluating and strengthening the patient’s self-management in relevant topics such as medication taking, engaging in regular physical exercise, prevention of weight gain, smoking cessation, sun protection, and others.

In the quantitative data, 6 of 7 tasks that were seen as an important challenge by at least half of the patients were in the domain of managing stressful emotions. In this regard, the quantitative data support the qualitative findings, which identified managing emotions tasks, for example, uncertainty or fear, as a major topic from patients’ perspective. The seventh task, which was seen as a challenge by at least half of the patients was “managing side-effects of medication.” This item was in the questionnaire section “managing the medical regimen.” Interestingly, in the qualitative data, symptom management was addressed by patients from a more emotional rather than from a medical perspective. Consequently, interventions regarding symptom management should target coping with this situation rather than just giving information to these patients that may not adequately address their needs. Patients apparently viewed self-management tasks differently than health care professionals normally view such tasks. A health care professional’s main focus is often on medication, symptom management, and health-promoting behavior, whereas a patient’s main focus is on managing life, including stress and coping; their illness is only 1 component.

Future program development should take this difference in focus into account and include medical, social, and emotional support, keeping in mind that the main challenge of patients is to manage the stressful emotions. A multiprofessional approach is needed to encompass this wide range of support.

Apparently, the number of overall self-management tasks and patients’ perceived health status do not always follow the expected order: One participant with 24 challenges (patient 12) felt better after transplant, whereas one with 15 challenges (patient 4) felt worse after transplant. Patients were asked how they perceive their actual health status in comparison to their health status at dialysis. Therefore, it depends largely how patients had perceived their time before transplant. For example, the person with 24 tasks had a lot of things to manage but said “it’s much better now, because dialysis was dreadful for me.” The patient with 15 tasks said that he had “more energy at the dialysis.” A connection between perceived health status and number of self-management tasks cannot be concluded from this research. To investigate this topic, further research is needed. Additionally, more data on patients are needed to do the validity and reliability testing of the developed instrument.

Limitations

The first limitation of this study is that the principal investigator worked at the same hospital where the study was conducted, possibly influencing the objectivity of data interpretation. To address this limitation critically, findings were validated with patients and other health professionals who were not familiar with our specific clinical practice.

We applied purposive sampling with the aim of having a broad view on self-management in kidney transplant recipients. Therefore, our study did not include a representative sample for general kidney transplant recipients. Our study participants had higher creatinine levels and lower glomerular filtration rates than other kidney transplant populations in the early phase. Poorer renal function could be associated with more health problems in general and more emotional and social stress. This possibility means that in the quantitative questionnaire the number of self-management tasks that are seen as a challenge are most likely
higher than the number would be in patients with better renal function.

Conclusions
The implications of this study are that kidney transplant leads to changes and instability in most areas of the kidney recipients’ lives. They are confronted not only with challenges in medical management, but also in managing stressful emotions, changes in self-perception, social interactions, and adapting to new life roles.

The synthesis of qualitative and quantitative results indicates that self-management programs for kidney transplant recipients should focus on strengthening patients’ self-management of emotional tasks and on regaining stability in daily life. The development of self-management programs for kidney transplant recipients should address and include patients’ perspectives on relevant topics and deliver support in regaining stability in daily life.

Acknowledgments
We are grateful to the patients for sharing details of living with their kidney transplant with us. Our sincere thanks to Novartis Pharma AG Switzerland for financial support. We also thank Dr Leslie Nicoll and Jane White for editing support.

Financial Disclosures
This project was partly funded by an unrestricted grant from Novartis Pharma AG Switzerland. Novartis Pharma AG had no influence on the design, conduct, analysis or review of this study.

References