Chapter 6

Sweet and sour after renal transplantation

‘Being disappointed = the expectations minus the actual situation’

(quote of a patient, participating in the study as described in this chapter)

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Abstract

This qualitative study about the experiences of renal patients following transplantation leads to three important insights. Firstly, patients may experience a wide range of positive and negative emotions, in particular guilt, gratefulness and fear, partly as a result of normative persuasions. A second interesting finding is that even physical improvements may give rise to challenging emotions and problems. Thirdly, patients report using different, mainly adaptive coping strategies to adjust to life after transplantation. Patients use strategies such as looking for opportunities rather than focusing on problems and barriers, setting different priorities, making their own choices, trying to maintain control and taking good care of oneself and appreciating other things in life. Health professionals are invited to pay more attention to the full range of positive and negative experiences following transplantation, including the existence of normative persuasions which may transform inherent positive emotions into negative ones and subsequent maladaptive behaviour. Health professionals may assist renal patients by helping them recognize and acknowledge their emotions, with a nonjudgmental attitude and by encouraging the use of more beneficial coping strategies.
1. **Introduction**

Across Europe, approximately 50-80 people per million develop end-stage renal disease (ESRD) (USRDS Annual Data Report, 2009). The number of patients with ESRD has steadily increased worldwide in recent decades (K Landreneau, Lee & D. Landreneau, 2010; A. Orr, Willis, Homes, Britton & D. Orr, 2007) with much higher incidence rates of ESRD in the USA than in Europe (USRDS, Annual Data Report, 2009). ESRD is chronic kidney failure that reduces kidney function to 10 percent or less of normal function, requiring the patient to have renal replacement therapy such as dialysis or a transplantation in order to stay alive. Although dialysis is more common, kidney transplants have also become widely available and doctors consider transplantation as the treatment of choice for many people with ESRD (Ouellette, Achille & Pâquet, 2009) as it is associated with better survival rates and fewer risks compared with people on dialysis (Landreneau et al., 2010; Orr et al., 2007). As a result of these better survival rates, a large group of people have to live with the illness and consequences of the illness and transplantation. It is therefore important to know more about the Quality of Life (QoL) of renal patients after transplantation.

Research into QoL in renal patients has grown in the past 20 years (Landreneau et al., 2010). A review article (Dobbels, De Bleser, De Geest & Fine, 2007) shows that there is almost 100 percent agreement that QoL, especially physical functioning, improves from pre-transplant to post-transplant, with the overall QoL of patients who received a donor kidney comparable with that of other chronic illness populations. Yet it was also indicated that post-transplant QoL is not restored to the level of a healthy population. In particular, lower scores on physical functioning, compared with healthy controls, have been consistently found (Dobbels et al., 2007). A recent meta-analytic review showed similar results. QoL is distinctly better for renal patients with a transplant than for haemodialysis patients, although the QoL may not be the same after transplantation as before renal failure (Landreau et al., 2010).

Most studies into the QoL of renal transplantation patients used a quantitative study approach. These studies have provided important empirical evidence and insights into the effects of renal transplantation on QoL of patients with ESRD,
mainly regarding pre-post transplant comparisons of QoL and comparisons with healthy controls. However, a number of methodological problems should also be mentioned. An initial methodological drawback in this type of research is the lack of a conceptual framework to define and measure QoL with QoL being operationalized and measured in multiple ways in the kidney transplant literature (Dobbels et al., 2007). There is continued disagreement about what to measure and how and when it should be measured (Landreau et al., 2010). This frustrates comparisons between different studies and makes it almost impossible to draw firm conclusions about the QoL after renal transplantation. Secondly, and related to this, it has been suggested that quantitative studies are less suitable for exploring the individual meaning of living with a donor kidney (Dobbels et al., 2007). Qualitative studies seem to be better suited since these studies may and have contributed to the understanding of clinical issues, and patients’ needs and wishes (Kuper, Reeves & Levinson, 2008). Using qualitative methods to study the perspectives of patients may bring in new themes that are overlooked by questionnaires in quantitative research. Previous studies on the personal and life experiences and wellbeing among other patient populations have clearly demonstrated that patients may have their own perspective on what constitutes and determines their quality of life and wellbeing. For instance, a study among burn survivors showed that itching and oedema on scars are considered by patients as the main problems. Clinical quantitative research in this area is, however, still rare (Broerse, Zweekhorst, Van Rensen & De Haan, 2010).

To date, the literature on QoL after renal transplantation covers only a few qualitative studies. Some recent studies investigate (non)adherence to medication regimens (e.g. Ruppar & Russell, 2009; Tong et al., 2010) or self-care after transplantation (Gordon, Prohaska, Gallant & Siminoff, 2009). Other qualitative studies describe how patients experience living related kidney transplantations (Gill & Lowes, 2008) or how patients experience rejection of their transplant kidney (Ouellette et al., 2009). Only a few systematic qualitative studies have been performed that focused on the full range of issues and experiences that may be relevant for patients living with a transplant kidney. For instance, Sanner (2003) conducted a qualitative study in which 23 kidney transplant patients were interviewed during the first two years after transplantation. The focus was on how the recipients viewed the organ donation, the organ donor, and the incorporation
of the transplant into their bodies. Themes that emerged included feelings of joy and sorrow, gratefulness, guilt, and dishonesty. Moreover, they revealed that recognition of and identification with the donor and the relationship with the living donor play a role. The theme of gratitude was also found in a phenomenological study by Buldukoglu and colleagues (2005). This study examined the perceptions of adult Turkish recipients with respect to their transplant kidney, using three open-ended questions (Buldukoglu et al., 2005). This study also identified feelings of responsibility as an important issue for patients. More recently, Orr and colleagues (2007) used focus groups to explore the experience of living with a transplant kidney. Again, gratitude appeared to be a main theme, but also medicalization and fear. These themes that are introduced by patients are often overlooked in quantitative studies which focus mainly on generic QoL measures and indicators, and on the incidence of depressive symptoms (Christensen, Ehlers, Raichle, Bertolatus & Lawton, 2000; Taskintuna, Ozcurumez, Duru, Colak & Haberal, 2009) and guilt (Griva et al., 2002). All together, these qualitative studies revealed some overlapping and some unique issues that seem to play an important role in patients’ life after transplantation. However, as a result of the narrow focus of these previous studies on a particular aspect of renal transplantation, it is difficult to get a full picture of the wide range of feelings and experiences that patients may possibly have. Even less is known about how patients cope or deal with their disease and its consequences and which coping strategies are beneficial for their QoL. Only a handful of, mainly quantitative, studies show that patients on dialysis and those who have received a donor kidney tend to use mainly emotion-focused coping strategies such as ‘having a positive attitude and staying positive’ (Visser, van de Griendt, Tuinstra & Ranchor, 2008).

In order to verify and expand these previous findings, the aim of the present qualitative study was to systematically investigate a wide range of positive and negative issues that patients may feel and experience after transplantation, as well as the strategies they use to adapt to the transplantation. Focusing on such a wide range of issues and emotions may not only provide more insight into the distinct experiences of patients, but may also shed light on possible interconnections between these distinct issues. Such a broader understanding of patients’ experiences of renal transplantation and how they adapt to their new situation may help healthcare professionals recognize and understand the kidney recipients’
postoperative feelings and experiences, and enable them to provide the appropriate medical and psychological care (Orr et al., 2007).

2. **Materials and Methods**

2.1. **Participant selection**

The data were collected in 2009 and 2010 through 18 semi-structured interviews with transplant patients. Patients were eligible to participate if they were able to speak Dutch, between 18 and 80 years of age, and able to give informed consent. Participants were recruited by internet, the patient organization and by 5 university teaching hospitals. Patients were selected, based on age, gender, time since transplantation and transplantation method, in order to get as many perspectives as possible (Meadows & Morse, 2001). The interviews involved 18 participants who had received a donor kidney between 2 and 9 years previously. The male-female division was equal. The participants’ age ranged from 27 through 70 and the division of post mortal donations (n=8) and living related donations (n=10) was about equal. 5 patients had a history of earlier transplant rejection. The data from the interviews were validated in 2 sessions in a focus group consisting of 6 other patients (2 females and 4 males). All of them had received a donor kidney between 2 and 7 years previously. The participants’ age ranged from 37 through 65 and the division of post mortal donations (n=3) and living related donations (n=3) was equal. Table 1 presents the characteristics of the participants in the interviews and focus group.
Table 1 The characteristics of those participating in the interviews (A-R) and focus group (S-X)

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Gender</th>
<th>Transplantation</th>
<th>Years since transplantation</th>
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<tr>
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<td>M</td>
<td>LRT</td>
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<tr>
<td>B</td>
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2.2. **Data collection and analysis**

The aim of the interviews was to obtain information about how patients experience their lives after transplantation. The focus was on positive and negative changes and on how patients experienced these changes. The stories of the participants were leading and a list with topics was used in order to check whether all relevant topics were discussed. The topic list, as shown in Table 2, was based on a literature review.

**Table 2 Topic list**

<table>
<thead>
<tr>
<th>Experienced positive and negative changes after transplantation.</th>
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<tbody>
<tr>
<td>Coping with changes.</td>
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<tr>
<td>Helping and hampering factors (in dealing with changes).</td>
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<tr>
<td>Extent to which respondents wanted/needed psychological/psychosocial support (also in which period and which type of support and which professional).</td>
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<td>What kind of psychosocial/psychological support did respondents receive?</td>
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<td>How did the actual support meet with the support needed?</td>
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<td>Any shortcomings or suggestions for improving psychological/psychosocial support?</td>
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Patients could choose the location of the interview and most interviews were held at home. The interviews took about one and a half hour and were audio recorded and transcribed following patient consent. All transcripts were analysed with inductive content analysis in line with the Grounded Theory approach (Charmaz, 2005) by an expert in this method of interview analysis. The Grounded Theory approach focuses on trajectories: the course of disease, and adaptation processes. The entire interviews were first read to identify emerging themes and sub themes (open coding). Labels were given to the text parts related to a specific (sub) theme. Each interview was first analysed separately. Any new emerging themes were added to the process of labelling and analysis and also adopted to the interviews analysed previously (axial coding). All themes were related and clustered, and this iterative process between the interview data and the clusters of themes continued until a robust framework was developed. To check validity, participants received an interpretation of the interview and asked whether they recognized the analysis (Meadows & Morse, 2001). All patients agreed and some extended their account. The
analyses and results of the interviews were compared and discussed in the different project-team meetings in order to increase reliability. In a subsequent step, the data from the different interviews were grouped into clusters based on the main (sub) themes that emerged in the interviews. The quotes from the different interviews were compared and sample citations were identified per cluster and theme. The analyses resulted in some repeated, interrelated issues.

These issues from the individual patient interviews were discussed in a focus group of kidney patients. The focus group met twice and was led by an experienced focus group facilitator which meant that each person had a voice and it was possible to validate and explore the data in more depth. A protocol was developed and used for both focus group meetings. Attention was given to the equal participation of all members and on giving each participant a voice. The meetings were aimed at the discussion and validation of the data as found in the interviews. Participants were asked to react to these themes. They were asked whether they recognized these themes or not and if they thought some themes were missing. The focus groups led to further validation of the themes since participants recognized the themes mentioned and even expanded on them.

2.3. **Quality procedures**

To assess the validity of our study we used the checklist published in the BMJ in 2008 (Kuper, Lingard & Lewinson, 2008). The ‘rock bottom’ of the internal validity in qualitative research is considered to be the ‘member check’ as this procedure helps eliminate bias (Meadows & Morse, 2001). Individual respondents received an interpretation of their interview and asked whether they recognized the analysis. Any additional comments were incorporated. During the focus group meetings the input of participants was repeated in order to verify understanding. A member check was conducted with all participants at the end of the focus group to clarify and synthesize findings and to ensure trustworthiness in representing perspectives (Huberman & Miles, 1994). The findings were furthermore checked by sending a report, based on audio tapes of the meeting, to all participants. This second member check made it possible to check the content of the conversation and interpretations. Any additional comments made by participants were incorporated.
In qualitative research the process of data collection and analysis ends when ‘saturation’ is reached (Meadows & Morse, 2001). This is the point where no information is added and data replication occurs. The saturation point cannot be predicted in advance and depends on the scope of the study, the quality of the interviews and the appropriateness of participant selection. Saturation was reached in this study after the interviews and focus group meetings. Another procedure involved ‘triangulation’ as we combined various data collection methods. Whereas the interviews gave an insight into personal experiences, the focus group helped expand the set of themes and their connections. This provided us with a wider range of information. The analyses of the data were done separately and discussed in the different team meetings (check coding) in order to increase the reliability of the findings.

2.4. Ethical considerations

All patients who participated in our study did so voluntarily after they had given consent. Names and other patient details were removed. Their transcripts were not shared with their therapists or other external parties and the transcripts and tapes were destroyed once the study ended.

3. Results

The analyses of the data resulted in 4 themes: 1) Physical impairment and related emotions before transplantation; 2) Physical improvement and related emotions after transplantation; 3) Physical restrictions and related emotions after transplantation; 4) Adaptation and resilience.

These themes were validated and explored in depth in the focus group and are examined in the sections below. The quotations are marked: the first letter corresponds to a specific respondent. This is followed by the respondent’s age, gender, type of transplantation and time (in years) since transplantation.
3.1. Physical impairment and related emotions before transplantation

The period of dialysis is characterized by physical problems, limitations and a lack of freedom. Dialysis meant that the lives of renal patients underwent dramatic change, though patients try to adapt as best they can: “The treatment influences your life enormously. You have to go to hospital 3 times a week and the other things just fade away. People were surprised at how I was able to keep going. Yes it really is hard to keep going, but you have to. But later on, if you’ve received a kidney, you wonder again how you coped with it all. But you’re not preoccupied with the answer to this question during the dialysis period simply because you just have to get on with it.” (M, 65, f, PM: 5 years.)

Patients do, generally speaking, look forward to receiving a donor kidney. The respondents admit that the dialysis period is a matter of survival and waiting, day in, day out, for a donor kidney. This waiting period is often experienced as difficult with various emotions, such as hope, emerging: “The doctors often gave us hope by saying that a kidney would probably become available in the near future. What they said gave us hope, but it wasn’t really worth much…..their words were empty……” (J, 66, m, PM: 2 years.) Feelings of anger may also arise: “The long waiting period made me feel rebellious. I was angry and rebellious.” (N, 69, f, PM: 2 years.) Patients also mentioned fear: “The time before the transplantation was exciting and stressful: Will I be a possible candidate for a donor kidney, will the kidney be in time and what if I miss “the” call when they offer me a kidney?” (J, 66, m, PM: 2 years.) Feelings of jealousy may also arise during the waiting period: “Sometimes people suddenly didn’t arrive at the dialysis unit anymore because they had had a transplant. I had mixed feelings about these situations. I was, of course happy for them, but it also made me feel a little bit jealous. They had a kidney and I was still waiting……” (U, 59, f, PM; 2 years.) Some patients also reported doubts about a transplantation: “I started having doubts when it became clear that my dad was able to offer me his kidney. I knew how I experienced and lived my life right now but I didn’t know what it would be like after the transplantation.” (L, 35, f, LRT: 8 years.) However, most of them were looking forward to receiving a donor kidney and to having a better life afterwards: “A dream came true. You are about to start a new life.” (D, 68, m, PM: 2 years.) This was even more so if people had already experienced a previous transplant. They
knew how a renal transplantation could lead to a better life: “I was really disappointed when my kidney was rejected but you can’t stop it. I had to start dialysis again and I had to wait again for a kidney. This was even more difficult since I knew what I was missing. I was able to compare both situations which made my desire for a donor kidney even stronger.” (S, 64, m, LRT; 2 years.)

3.2. Physical improvement and related emotions after transplantation

Patients reported at length on the positive changes experienced after transplantation: “I felt like I used to feel before. It was perhaps less, but I was able to do everything!” (J, 66, m, PM: 2 years.) They reported, in the first place, that their physical condition improved: “I’ve entered a new, more positive phase of life. I can do anything! Years ago I felt about 80, but now, I feel sometimes far from my 70 years!” (A, 69, m, LRT: 5 years.) Experiencing a better physical condition is related to a regained sense of freedom: “I no longer depend on a machine. You’re never stuck to the dialysis. You’re freer, you don’t need to go to hospital anymore.” (F, 70, m, PM; 6 years.) It also leads to a sense of control: “It’s nice to be the boss of your own time and your own life again and you want to shout it from the rooftops: I’m in control again!” (A, 69, m, LRT: 5 years.)

The improved physical condition and regained freedom positively influence work fulfilment, the ability to go on holiday and perform daily tasks. Patients reported, for example, that going on holiday is easier than it used to be during dialysis: “Since I got my new kidney I go to exotic, far-away places. Trips like this weren’t possible when I was on dialysis.” (L, 35, f, LRT: 8 years.) It is also easier to work. Patients are no longer restricted by their dialysis and they are often able to work more than during dialysis. However, not every patient gives work priority: “I work 24 hours a week. I’m actually able to work 40 hours, but I want to enjoy life.” (B, 27, f PM: 5 years.) Doing nice things is also easier as a result of the transplantation and the new-found freedom: “I’m able to walk, I do odd jobs, I travel around with my caravan and I love gardening. I even bought a little boat.” (A, 69, m, LRT: 5 years.)

Patients and their relatives also mentioned, even in the context of physical improvement, that they needed to adapt to the new situation after
transplantation. They remembered this as a pleasant yet challenging time. Firstly, patients mentioned difficulty with changes in daily activities and role functioning: “Feeling better is sometimes scary. You suddenly lose your daily routine. It was hard to find new fulfillment in your days. You have to learn to do different things with your time.” (X, 54, m, PM: 2 years.) Patients had to learn how to live a new and more normal life, to abandon their role as patient and to adopt new roles and identities: “Some while ago, a friend of mine told me not to let the disease rule my life and that I didn’t have to be a ‘victim’. At first I denied that that was happening. But when I thought about it later, I realized that she might be right to a certain extent! I’d like to improve that about myself.” (H, 30, m, LRT: 3 years.)

Secondly, the transplantation may also lead to changes in the social aspects of functioning with family and friends. After transplantation, the illness is no longer the leading factor, which leads to fresh opportunities. It may, however, also lead to patients and their relatives having to find a new balance. They have to adapt to new roles that fit the current situation. The spouse is no longer the one with the caring role and the patient is no longer the one who needs help and care. These changes can give rise to role confusion: “Our relationship changed after the transplantation. My husband saw me changing - from being dependent to becoming independent. And this made him insecure and we had to find a new balance. I wasn’t the woman I was before.” (G, 69, f, PM: 9 years.)

Improvement after transplantation may be accompanied by various moods and emotions. The first emotion mentioned by patients is gratefulness. Patients are, above all, grateful after transplantation. They are grateful that they have received a kidney, that somebody was willing to donate his or her kidney and that they now have the opportunity to live a new life: “It’s a nice feeling that someone was willing to donate his organs. I have a better life because of that decision!” (W, 61, m, PM: 4 years.) Patients demonstrate gratitude in many different ways. Some may write to the family of the deceased donor; some celebrate the ‘donation day’ every year; some buy presents for the living donor, or take good care of themselves.

Patients also mentioned feelings of trust and fear. Some patients reported considerable trust in their donor kidney: “We’ve always put a lot of trust in this
kidney.” (O, 30, f, LRT: 4 years.) Others said they were afraid their donor kidney would be rejected: “I’ve really trusted my donor kidney from the very start, but the fear is always there. It doesn’t influence my whole life, day after day, but you’re always aware that it may all come to an end tomorrow.” (C, 38, f, LRT: 3 years.) Patients experienced the period after transplantation as much better and are, as a result, afraid of losing these improvements. Some patients admitted they would rather die than return to dialysis: ‘If I’m honest I have to admit my moody feelings about my future. My worries are my biggest problem: how long do I have? How long will my kidney keep functioning?’ (R, 45, m, PM; 7 years.)

Patients also mentioned feelings of guilt. Some patients found it, first of all, difficult to accept that someone had to die or that a living donor had to suffer: “Of course...you’re happy! But it’s also strange. Someone has died and while you’re happy, other people are, at the same time, sad because they’ve just lost a loved one.” (U, 59, f, PM; 2 years.) Feelings of guilt towards other kidney patients still undergoing dialysis or who have experienced rejection are also reported: “I felt a little bit guilty when I received a kidney after having waited for only two years. Other patients had already been waiting much longer but I received a post-mortem kidney and they didn’t.” (X, 54, m, PM; 2 years.) Guilt can, at last, be related to the experienced gratefulness since patients do not always know how to show their gratitude: “It’s such a magnificent gift...I felt I had to do something in return, but what and how? Nothing can be compared to a gift like this.” (T, 55, m, LRT: 7 years.) Feelings of not being able to sufficiently express gratefulness may be associated with feelings of guilt: “I felt guilty since she offered me her kidney, but I can’t be grateful for the rest of my life and I can’t show it enough... it makes me feel even more guilty.” (C, 38, f, LRT: 3 years.)

3.3. Physical restrictions and related emotions after transplantation

The previous section shows that the post-transplant lives of patients are characterized mainly by improvements and positive changes. These improvements may, paradoxically, lead to challenging emotions and require patients and their relatives to adapt. This is also the case for the negative changes that patients reported. They also mentioned the other side of the coin: the lasting restrictions
imposed by the transplantation and the side effects of medication, such as fatigue: “I’m still tired, so I’ve had to change my dreams.” (H, 30, m, LRT: 3 years.) Other restrictions include sexual problems: “It was over. Nobody ever speaks about sexual problems. It’s taboo. But it’s still a problem after transplantation.” (F, 70, m, PM: 6 years.) Weight gain or hair growth were also mentioned: “I started putting on weight and I got an awful lot of hair on my face. I wanted to go out and look pretty but I couldn’t look pretty.” (Q, 33, f, LRT: 3 years.) These restrictions or side effects were not experienced by all respondents and they differed as to how they experienced these side effects and restrictions. Some expected more side effects than actually turned out to be the case: “They weren’t as bad as I thought….” (L, 35, f, LRT: 8 years.) Others said that they had not anticipated this other side of the coin. They attribute this to the positive images presented in the media and the information given by professionals. Patients might see this information as incomplete or too positive: “It’s all been talked about too positively by the doctors.” (E, 53, f, LRT: 2 years.) Patients admitted that, as a result, they also had too positive a picture of their life after transplantation which, in turn, may give rise to disillusion.

Patients have to deal with disillusion, which can be difficult. Those patients, who were disappointed about their situation after transplantation, were those who acknowledged that their expectations had been different. They had hopes and dreams that did not come true: “In the long term it all disappoints me a little. I thought I’d be able to do anything with my new kidney but that isn’t true. My expectations were too high. Of course you want a new kidney and you know about the side effects of the medication, that’s part of the deal, but nevertheless.” (G, 67, f, PM; 9 years.) Patients also reported how their disillusion may lead to feelings of guilt or problems even admitting they were disillusioned. Patients may find it difficult to admit their disillusion to themselves and their surroundings since they may have the normative feeling that they have to be grateful and that they are not allowed to be disappointed: “I thought I’d be able to do more after the transplantation, but it isn’t true. But you don’t want to be ungrateful, so I don’t talk about it in the open. You think you’re the only one because nobody talks about it.” (E, 53, f, LRT: 2 years.) Patients do not want to be ungrateful and they may feel guilty about their negative feelings. Consequently they may not admit their feelings and limitations and may cross their own borders: “I don’t give up.
You shouldn’t complain, you don’t want to be unthankful.” (G 67, f, PM; 9 years.) Disillusion may be even greater if patients receive a pre-emptive kidney i.e. they receive a kidney before they have to start dialysis: “It felt as though my situation was even worse than it used to be before. The social worker explained to me that I should realize what had been avoided by getting a kidney.”(Q, 33, f, LRT: 3 years.)

Patients without any high expectations seem to be more able to enjoy the progress they make, or may even be surprised at the progress after transplantation: “When I was on dialysis I used to think: if this is it, I don’t want to live any longer. I saw transplantation just like dialysis, as a way to stay alive and now, after my transplantation, it’s much more positive than I thought!” (A, 69, m, LRT: 5 years.)

Patients’ immediate surroundings may also have high expectations, which may lead to tension in a relationship: “My husband also said: I expected you to be able to do more things. This led to an awful lot of tension in our relationship.”(E, 53, f, LRT: 2 years.) It may also lead to an unforgiving environment and incomprehension: “People in your surroundings think it’s all done and dusted now you’ve got a new kidney. And since then I’ve lost all the support from my surroundings. They think it’s over, I can do it by myself.”(C, 38, f, LRT: 3 years.)

3.4. Adaptation and resilience after transplantation

As demonstrated above, patients, both before and after transplantation, are forced to deal with physical improvement on the one hand and physical restrictions on the other, and all the concomitant emotions. Renal patients reported several things that actually helped them live a good life despite the circumstances.

One of these strategies is to look for opportunities rather than focusing on problems and barriers: “I’ve taught myself to deal with my tiredness but I still wonder exactly what’s normal and what’s not normal. Are normal people without a donor kidney just as tired as I am or am I much more tired than them? But now I can do much more than when I was on dialysis. My tiredness now is nothing compared with how tired I was during dialysis...so why should I complain or grumble?” (L, 35, f, LRT: 8 years.)
A second strategy is an ability to appreciate different things or in different ways: “I appreciate different things right now and my ideas and wishes have changed but I needed time to do this and it wasn’t easy to get this far.” (T, 55, m, LRT: 7 years.)

Thirdly, making your own choices and making choices that fit in with your actual wishes and values is another quality that influences the level of resilience, as mentioned by kidney patients: “I’m making different choices now and other people aren’t always able to understand my choices and decisions. My decisions are different from what they used to be. But I don’t care any more about what other people think. It’s ok if I lose people who don’t understand or accept me.” (L, 35, f, LRT: 8 years.) This does require a certain amount of willpower and taking responsibility for your own life and behaviour: “You should not be a victim. ………It’s not a good thing to give in too much to your illness. Sometimes it’s necessary to be strong and to hold on.” (U, 59, f, PM: 2 years.)

Another way of dealing with the situation is to attempt to retain control. This was mentioned particularly in relation to rejection or signs of rejection. Rejection may lead to diminished trust in one’s own body and may, consequently, lead to feelings of insecurity and the wish to regain control, for instance by controlling the situation: “I wanted to arrange everything myself, like taking my own blood off to the lab. I tried to maintain control by doing this, but I realized later that my body would do what it wanted anyway, regardless of my attempts to control it.” (L, 35, f, LRT: 8 years.) Patients also try to maintain control by focusing on their blood results: “You really look forward to the results of the blood tests. They tell you if things are going well or not. Your feelings tell you one thing, but the test results actually tell the truth.” (N, 69, m, PM: 2 years.) Another way of dealing with fear and staying in control is to take good care of oneself. Patients attempt to prevent rejection by taking their medication regularly: “I’ll never ever put off taking my medication or skip it.” (O, 30, f, LRT: 4 years.) Patients also try to live a healthy life in order to keep their new kidney as long as possible: “I’m really taking good care of myself and my donor kidney since I couldn’t forgive myself if anything went wrong! I’d feel awfully guilty!” (K, 31, m, LRT: 9 years.) This may also lead post-transplant patients to being permanently alert to recognizing and understanding signs in their body which may indicate potential rejection or other
complications: “I was nasty and had a bit of a headache one morning and I thought ‘here we go again...this isn’t a good sign.’” (O, 30, f, LRT: 4 years.)

Finally, expressing emotions towards others was mentioned as beneficial. Resilience may improve if people are clear and honest about their options and restrictions: “You have to be honest with yourself and those around you. Things don’t go well every single day. .....I’ve learnt to be honest with my relatives but I wasn’t able to do that before. It’s just a new skill.” (C, 38, f, LRT: 3 years.)

4. Discussion

This qualitative study aimed to investigate both the positive and negative issues that patients may experience before and after transplantation and how they adapt to their changed lives. It gives three important insights, starting with the finding that patients may experience a wide range of positive and negative emotions and the important role of normative persuasions in the origin of some of these emotions. A second and related insight is the finding that even physical improvements may give rise to challenging, difficult emotions. Patients reported employing several distinct successful strategies to adapt to the new situation, which can be seen as the third insight emanating from this study.

Regarding the wide range of emotions - patients generally mentioned emotions of gratefulness, fear, and guilt. These emotions are interrelated and may influence one another. These findings validate the results from other studies (Baines, Joseph & Jindal, 2002; Buldukoglu et al., 2005; Goetzmann et al., 2008; Griva et al., 2002; Orr et al., 2007; Sanner, 2003). Altogether, this and previous studies suggest that gratitude and joy may be tempered by guilt and sadness since someone had to die to make the kidney available (Orr 2007; Sanner 2003). The present study is the first to demonstrate the role played by normative persuasions. It shows, how, for instance, gratefulness may change into feelings of guilt as a result of normative persuasions such as ‘I have to be grateful’ or ‘I’m not allowed to complain’. These emotions of fear and gratefulness can be regarded as more or less natural, whereas guilt seems to overshadow these natural emotions. Another novel finding is that these normative persuasions may lead to un-adaptive behaviour, e.g. not expressing emotions or transcending one’s borders. Health-care professionals may
help renal patients adapt by teaching them to be more aware of the presence and effects of normative persuasions.

The second result concerns the unexpected finding that even physical improvements may give rise to challenging emotions and problems, such as changes in roles, identity, daily functioning, and relationships. Earlier studies have shown that, in addition to the many physical improvements such as increased energy and a less restricted lifestyle (Orr et al., 2007), living with a donor kidney may also be accompanied by limitations such as fatigue (e.g. Rodrigue et al., 2010) and potential side effects of the immunosuppressive medication (e.g. Brasile, Glowacki, Castracane & Stubenitsky, 2010). Our finding that these restrictions may lead to disillusion validates the study by Cleemput and colleagues (2003). However, this study is the first to suggest that even physical improvements may give rise to challenging emotions and problems. Patients and often also relatives have to find new roles and fulfilment in their lives and to find a new balance. Studies on this issue are scarce. Hutchinson (2005) describes that renal patients also have to deal with difficult human transitions that accompany dialysis and transplantation (Hutchinson, 2005). Health professionals could be aware of these possible negative or challenging emotions and the environment could have more understanding for these feelings.

The third finding - the capacities of patients - showed that patients use several cognitive and behavioural coping and goal adjustment strategies such as looking for opportunities rather than focusing on problems and barriers, setting different priorities, making their own choices, trying to maintain control and taking good care of oneself and appreciating other things in life. More insight into these strategies would be very helpful since very few studies have considered the adaptation and coping processes in people who have undergone a kidney transplantation (White & Gallangher, 2010). There has been little research into coping processes following renal transplantation. Our findings give a closer and more detailed insight into the specific strategies that renal patients use, and add to the paucity of knowledge on this theme. Our findings advocate more attention in clinical practice for the coping strategies used by patients after transplantation. Health professionals could be more aware of the coping strategies of each individual patient and they should encourage patients to adopt the more advan-
tageous strategies instead of those with possible negative effects (White & Gallangher, 2010).

To conclude, it can be said that this qualitative study adds some important insights about living with a donor kidney, as experienced by patients. However, this study also has, nevertheless, a number of limitations. A relatively small number of patients were interviewed and we do not know whether those who participated reflected a representative group of patients. However, qualitative research never pretends that the results can be unthinkingly generalized to other situations. Readers may, at best, assign the information to their own context and by doing so they can co-operate by developing better psychosocial support for patients following kidney transplantation.

This study offers essential insights into an understanding of the life of post-transplant renal patients and this knowledge can improve professionals' ability to understand, communicate and work with these patients. We conclude, as other authors have done, that the overwhelming majority of organ transplant patients experience life after transplantation as an improvement. However, our findings refine the tendency to make a clear distinction between positive experiences on the one hand and negative experiences on the other, as our results suggest that patients may experience challenging emotions, even when things go well or perhaps precisely because things go well. Sweet and sour go hand in hand after transplantation. Despite the fact that only a small minority of patients report specific problems in handling the new situation, health professionals should be more aware of the possible feelings and issues mentioned above. More attention needs to be given to the ambiguous situation in which even improvements can lead to tough emotions, as well as to the role of normative persuasions and expectations. This is particularly important since patients may have difficulty expressing or admitting feelings of fear or guilt. Patients should be actively questioned about any worries they may have about the transplant organ, and about their family. It is furthermore important that during communication health professionals are aware of the fact that patients might have unrealistic expectations about the consequences of transplantation. Psychological support should, at last, focus on strengthening patient resilience. This may help patients who have undergone a transplantation to balance the sweet and the sour.
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6. References


