

# EXPERIENCES OF RECIPIENTS AND LIVING DONORS THE FIRST THREE DAYS AFTER KIDNEY TRANSPLANTATION

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## SUMMARY

**Background:** Living donor transplantation is described as a stressful and complex process for both recipients and donors. Few studies have described the experiences of recipients and donors in the first three post-operative days after living kidney transplantation.

**Objectives:** To explore how recipients and living donors experienced the first three post-operative days after kidney transplantation.

**Design:** A qualitative phenomenological-hermeneutic framework was used to uncover the meaning of lived experiences through interpretation of transcribed interviews.

**Participants:** Seven dyads of kidney recipients and donors admitted at a Danish university hospital were included from September 2013 to November 2013.

**Approach:** Fourteen semi-structured qualitative interviews were analysed using Malterud's principles of systematic text condensation.

**Findings:** Recipients and donors both experienced post-operative discomfort, though not the same. Both recipients and donors expressed that it gave them peace of mind to be able to follow each other at close hand sharing the same room during the post-operative period. All recipients saw receiving a kidney as a huge gift; donating a kidney gave donors a feeling of satisfaction.

**Conclusion:** The first three post-operative days were characterised by different types of post-operative discomfort and caring needs. Recipients and donors all experienced benefits from staying in the same room during hospitalisation. All patients in this study were related; this may have influenced their experiences, choices and opinions.

**KEY WORDS** Renal transplantation • Living donor • Recipients • Lived experience

## INTRODUCTION

Recipients and living donors are usually hospitalised for four to eight days after kidney transplantation. In Denmark, there are

different practises concerning where recipients and donors are cared for in the post-operative period. In our hospital, recipients and donors are generally placed in the same room in the immediate post-operative recovery phase. We are aware of different practices nationally and internationally. These different practices may be accidental or be rooted in organisational issues rather than reflecting the needs for care of the donors and recipients. Existing evidence, though limited, reports both advantages and disadvantages of recipients and donors sharing the same room post-operatively while still hospitalised (Andersen *et al.* 2005 & Froejk 2006). In connection with an organisational process of optimising continuity of care in our transplantation services, we wanted to investigate experiences of recipients and donors in the first three post-operative days after living kidney transplantation.

## BIO DATA

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## BACKGROUND

Kidney transplantation in patients with chronic kidney disease results in improved biochemical control and quality of life. All transplanted kidneys come from three sources: deceased donors, living related donors or living unrelated donors. In

2012, 214 kidney transplantations were performed in Denmark; 40% of these involved living donors. The majority of transplants with living donors involved related donors: siblings 33.3%, parents 24% and 9.3% other family relations; 33.3% were non-related donors (e.g. spouse or friend) (Danish Nephrology Registry 2012). Living donor transplantation results in a higher 5-year graft survival compared with transplantation involving deceased donors (Danish Nephrology Registry 2012).

A systematic literature search in the databases CINAHL, Pub Med, Bibliotek.dk and Scopus resulted in few studies describing the experiences of recipients and donors in the immediate post-operative period (up to three days). Existing studies on living kidney transplantation have varying aims and research data have been collected between one week and 12 months after transplantation (Andersen *et al.* 2005, Crombie & Franklin 2006; Gill & Lowes 2008; Gill 2012). However many studies did not report on experiences of donor or recipient in the early post-operative period.

The few available studies covering the first three post-operative days describe living donor transplantations as a stressful and complex process for both the recipient and the donor (Kamper *et al.* 2003, Andersen *et al.* 2005, Gill & Lowes 2008, Gill 2012). Stress can occur at the time of the first decision-making process and continues during the peri-operative period and post-operative recovery (Gill 2012). The concern recipients and donors have for each other is highlighted as a major stressor (Andersen *et al.* 2005, Gill 2012, Mazaris *et al.* 2012), and recipients are often worried about causing the donor pain. However, some recipients experience it as a special and emotional situation to be close to the donor in the post-operative recovery phase (Froejk 2006, Gill 2012).

Generally, kidney donation affects donors psychologically, and this can be manifested as depression and/or obsession (Taghavi *et al.* 2001, Tong *et al.* 2012). Donors experience difficulties being both a patient and a relative. They are also worried and concerned about the recipient and potential transplant failure (Tong *et al.* 2012). Donors put themselves and their needs after the needs of the recipient (Andersen *et al.* 2005, Mazaris *et al.* 2012). One study showed that the donor's well-being depended on the well-being of the recipient if the donor and recipient were close (Tong *et al.* 2012).

Nevertheless studies report that recipients and donors benefit from support each other during hospitalisation (Crombie & Franklin 2006, Mazaris *et al.* 2012). A study showed that 58% donors believed it was important that they were placed in the same room in the post-operative recovery period (Mazaris *et al.* 2012)

One study found that recipients and living donors do not have the same needs in the post-operative period. The living donor is a healthy individual voluntarily undergoing major surgery to help another human being, while the recipient is a patient with a chronic kidney disease, who is familiar to hospital routines (Kamper *et al.* 2003). One study highlights the importance for the recipients and donors to establish their relationship before the transplantation to avoid future conflicts (Buer & Hoffmann 2012). The different needs of recipients and donors can also be a challenge for nurses in the immediate post-operative period (Crombie & Franklin 2006). The recipient and especially the donor compare the attention they get from the health professionals (Crombie & Franklin 2006, Gill 2012). The donor can feel overlooked and neglected in the post-operative period (Gill 2012). However, studies showed that donors are generally proud to donate and help another human being; they see the donation as a meaningful action adding to their personal growth and development (Andersen *et al.* 2005, Gill 2012)

## OBJECTIVES

To explore how recipients and living donors experienced the first three post-operative days after kidney transplantation.

## METHODS

We used a qualitative, phenomenological-hermeneutic framework to gain an understanding of experiences of recipients and donors in the post-operative period (Andersen *et al.* 2005, Birkler 2005). The purpose of this approach was to uncover the meaning of lived experiences through interpretation of transcribed interviews.

The setting was a transplant unit at a Danish university hospital. Donors and recipients are normally admitted to the renal care unit one day before the transplantation. After the operation the recipients go directly to a recovery room before they are transferred to the renal care unit. The donor will also go directly to the recovery room after the operation and will be transferred to the same unit for post-operative recovery. Normally, recipients are ready to go home three to seven days after

surgery. In this period donor and recipient is routinely placed in the same room.

Male and female kidney transplanted recipients and donors above 18 years of age treated at the Danish university hospital who could speak and understand Danish were eligible for inclusion into this study. Due to the physical and mental burden of experiencing complications at a high risk phase of the transplantation process, donors and recipients experiencing complications in the peri- or post-operative period were excluded. The participants were consecutively enrolled from September 2013 to November 2013. In this period seven dyads of recipients and donors were eligible for inclusion and were asked to participate. A total of seven dyads equal to 14 participants accepted to participate; four related and three unrelated dyads, two females and five male recipients and six females and one male donor with an average age of 36 years (range 22–63) among recipients and 57 years among donors (range 36–67), constituted the study population. See Table 1 for characteristics of participants.

**ETHICAL CONSIDERATIONS**

All participants were informed about anonymity, confidentiality, publication, and their right to withdraw from the study at any time without any consequences. Oral and written consent was obtained before participation. According to Danish law, approval from an ethics committee was not required for this type of study. The study was reported to the Danish Data Protection Agency.

**DATA COLLECTION**

The interview was undertaken on the third post-operative day because this is normally the last day donors and recipients are hospitalised together. The individual semi-structured interviews were based on an interview-guide inspired by Kvale and Brinkmann (Kvale & Brinkmann 2009). The guide covered four main topics consisting of a broad opening question: ‘Please, tell

me about yourself’. This was then elaborated on and followed up with three focused questions: ‘How did you experience the post-operative period?’, ‘How did you experience being hospitalised in the same room as recipient/donor?’ and ‘How is it to receive or donate a kidney?’ The interview guide was developed and tested on one recipient and one donor. All interviews lasted between 20 and 30 minutes, they took place in a separate room at the hospital, were audio-recorded and transcribed verbatim by the two investigators. Transcripts were not returned to participants for comment.

**ANALYSIS**

Data were recorded, transcribed and analysed in accordance with the hermeneutic tradition using Malterud’s principles of systematic condensation: overall impression, meaningful units, condensing and summarising. This method is well-suited for novice researchers and is similar to method described by Miller and Crabtree (Malterud 2012). Table 2 shows the systematic condensation. First, all interviews were read to gain an overall impression of the content. Then meaningful units were identified in each interview, and subgroups were created. Next, a quotation was identified which paraphrased and summed up on the subject matter. At last, the sub-groups were condensed and summarised into themes.

**FINDINGS**

From the 14 interview transcripts, five themes were identified: ‘Experiences comparing receiving and donating a kidney’, ‘Post-operative discomfort’, ‘Peace of mind to be in the same room’, ‘Being together is natural and useful’ and ‘Respecting habits and borders of each other’. The themes are now explored (R = Recipient, D = Donor).

**THEME 1: EXPERIENCES COMPARING RECEIVING AND DONATING A KIDNEY**

For the recipients it was hard to describe receiving a kidney without using the word gift. They had received something very

Number	Recipient	Donor	Related	Un-related
1	23 years, male	56 years, female	Son and mother	
2	40 years, female	42 years, male		Wife and husband
3	29 years, male	36 years, female	Brother and sister	
4	26 years male	46 years, female	Son and mother	
5	63 years, male	59 years, female		Husband and wife
6	48 years, male	48 years, female		Husband and wife
7	22 years, female	67 years, female	Granddaughter and grandmother	
Total			4	3

Table 1: Characteristics of participants.

Meaningful units	Subgroups	Condensing	Themes
Donor: "I'm very very tired"	Tiredness	The donors experienced the post-operative discomfort in different ways. Several of the donors experienced being very tired in the post-operative recovery period	Post-operative discomfort
Recipient: "...I have been in pain and I haven't slept very well. Also, I don't think I have been sufficiently relieved for pain, and to be honest, that has been pretty tiring" (R3)	Pain		
Recipient: "I don't think I am in pain. I get pain relievers"		Some recipients have pain in the post-operative recovery period, others do not	

Table 2: Example of systematic condensation.

special, and it was the biggest gift they could imagine. It gave them back their life and they were extremely grateful:

'It's a huge gift to get a kidney. You will be completely free again from being bound. I might compare it to someone who has been in prison and, then was released again' (R5).

For all the donors it was an easy decision to donate a kidney because it would help a close relative to get their life back. Donating a kidney gave the donors a feeling of satisfaction:

'I have experienced some pain afterwards, but to give (name of recipient) a kidney has really just been associated with feeling satisfied that I could help. It's been really nice' (D3).

**THEME 2: POST-OPERATIVE DISCOMFORT**

On the third post-operative day both recipients and donors experienced post-operative discomfort. The recipients had more pain and nausea which influenced their sleep, appetite and level of activity:

'...I have been in pain and I haven't slept very well. Also, I don't think I have been sufficiently relieved for pain, and to be honest, that has been pretty tiring' (R3).

Few donors expressed that the post-operative discomfort was worse than expected. The most pronounced post-operative discomfort for the donors was tiredness. They experienced difficulties sleeping at night because of the nurse monitoring the recipient every hour:

'It hasn't been as bad as I thought it would be, not even close. I'm sore, but now I have learned how to get out of the bed

without pain, which the physiotherapist has taught me, but I would not complain about pain' (D7).

Overall, the donors did not worry about their own health, but they were concerned for the recipients and feared transplant failure:

'Oh, I'm hoping it's working [the kidney]. That everything is alright and that it's working without problems. All those thoughts are just overwhelming to you, but we were told that it would happen, so we are prepared. You are just nervous about everything working out' (D4).

One donor felt overlooked in the post-operative period because the focus from the healthcare professionals was on the recipient. This resulted in a mounting concern for own health:

'Everything is about [name of recipient] now, and of course it's supposed to be like that, but I think, as a donor, you can feel a bit forgotten' (D4).

**THEME 3: PEACE OF MIND TO BE IN THE SAME ROOM**

All recipients and donors in this study had been placed in the same room in the post-operative recovery period. They saw the transplantation as a common experience and it gave them peace of mind to follow each other at close hand:

'I think it give's a sense of security. We are in a relationship and therefore used to be together. I think it's really nice that I can see how he is and what he can do and see all the progress' (D6).

Recipients and donors also experienced that their knowledge about each others' habits and borders gave them peace of mind. It was not an unknown person in the room, which meant that

they could easily support each other through the recovery and talk about worries and feelings:

'... it's nice since we're siblings, being able to follow each other's progress and talk and if there's been any concern about anything, we can talk about it right away. It's also been a lot easier when our family has been visiting' (R3).

Some recipients and donors also felt safer being hospitalised in the same room to minimise the risk of infection. This reduced their worries about complications during the post-operative recovery period.

None of the recipients and donors regretted being hospitalised in the same room. On the contrary, they all experienced that it was the right way to spend the post-operative recovery period after living kidney transplantation:

'It's definitely been the right way to do it for us, because it's created peace around us. I have been able to be sick, because grandma knew I had a bad day. We have been able to talk, and yeah, I just think it's been really nice that we could stay together' (R7).

#### **THEME 4: BEING TOGETHER IS NATURAL AND USEFUL**

Several of the recipients and donors stated that being separated would make the recovery period in hospital difficult.

'It would be hugely frustrating not being able to follow what was happening to [name of recipient] and also quite difficult in relation to visits from the family' (D1).

They imagined that being separated would prevent them from seeing each other freely, follow each others' development and be together with their relatives. All the interviewed recipients and donors found it natural to be together with their relatives in the same room. They were afraid that one of them would be excluded and lonely if they were in different rooms. One donor even stated that being placed apart in the ward would cause insecurity:

'I would feel insecure if we were not allowed to [stay in the same room]' (D 5).

It was natural and a big support for both the recipients and the donors being hospitalised in the same room in the post-operative recovery period.

#### **THEME 5: RESPECTING HABITS AND BORDERS OF EACH OTHER**

Recipients and donors used a variety of coping strategies to manage being hospitalised in the same room during post-operative recovery without too many conflicts. The recipients and donors were aware that they needed to respect their differences. This is illustrated in the quotation below:

'Of course you use the headphones or turn off the TV if the other person is sleeping. It's all about being thoughtful and respecting others and that's very important if you're staying in the same room. When you do that, it's hard to run away' (R1).

Recipients and donors also experienced that they advised and motivated each other. Sometimes humour was used during recovery:

'.. It's all about the disease, so it's a question about respecting each other's limits and humour and make some room for the fun times, too. That's actually what we've been doing in this long period. We have to make some fun out of it' (D4).

#### **DISCUSSION**

This study explored experiences of living kidney donors and recipients during post-operative recovery. Receiving and donating a kidney was a significant experience for both recipients and donors. Already at the third post-operative day, all recipients told that receiving a kidney was the biggest gift they could ever imagine; all donors experienced a feeling of satisfaction helping another human being. This is consistent with findings by Andersen *et al.* (2005) and Gill *et al.* (2008). However, in these studies, satisfaction was reported ten months after transplantation.

Both recipients and donors experienced being concerned for each other. Some donors were concerned that the recipient might be at risk of acute kidney injury; this affected their entire post-operative recovery. Being concerned for each other is the biggest stressor according to Gill (2012). Despite this, all recipients and donors felt that it caused less concern to be hospitalised in the same room. It gave both recipients and donors peace of mind to be in the same room and gave them an opportunity to support each other through the post-operative recovery. Despite this, one donor felt overlooked by the health care professionals; this is consistent with Froejk (2006).

Neither recipients nor donors could imagine what it would be like to be hospitalised in two different rooms. This was also reported in the study of Mazaris *et al.* (2012) where 58% of recipients and donors believed they should stay in the same room. All recipients and donors could only think of disadvantages about being separated and had difficulties mentioning any benefits in being placed in separate rooms. This shows that they only could relate to the specific situation of being in the same room. Donors' well-being depended on the recipients' well-being; the donors' recovery is thus debatable if donors are hospitalised in the same room as recipients. This is consistent with Tong *et al.* (2012). Also the different post-operative needs challenge the post-operative recovery. Donors in particular experienced difficulties sleeping at night because nurse monitoring of the recipients every hour. Recipients and donors have different post-operative discomforts and therefore different post-operative needs; in some cases the donor felt overlooked. This is consistent with Gill (2012).

Recipients and donors used different coping strategies to deal with being in the same room in post-operative recovery period. They respecting each other's habits and borders and they supported each other by motivating and advising. One of the interviewed dyads even used humour to get a respite from the worries associated with kidney transplantation. Recipients and donors also used compromising to avoid conflicts. Using different coping strategies in the post-operative recovery is supported by two studies (Andersen *et al.* 2005, Gill 2012). There are both advantages and disadvantages to placing recipients and donors in the same room. It takes a lot of energy from both recipients and donors to compromise and use different strategies to avoid conflicts.

### **LIMITATIONS**

Interviews were performed on the third post-operative day. None of the recipients had at that time rejected their kidney and none of the donors had complications. It is impossible to know how the above events might have influenced the experiences of recipients and donors. In this study we have included both related and nonrelated donors, and there seemed not to be any significant differences in their experiences. Therefore, further research including donor-recipient dyads placed in different rooms or departments may contrast and deepen our knowledge. Furthermore, studies including nonrelated donors other than spouses, such as friends or other more distant donors,

could contribute to our knowledge. In addition, we need to study if recipients and donors experiencing complications during the post-operative recovery phase report different experiences.

### **IMPLICATIONS FOR PRACTICE**

The findings of this study provide health care professionals with insight into recipients' and donors' opinions and thoughts, which can optimise the post-operative recovery after kidney transplantation/donation. Different post-operative needs challenge nursing to recipients and donors, especially, when they are in the same room. Recipients and donors compared the attention they got from health care professionals. To avoid donors are feeling overlooked by the health care professionals, it is important that health care professionals make ongoing evaluations of the needs of recipients and donors, respectively to ensure that they are both in focus in the post-operative recovery period.

Another important initiative could be to let the recipients and donors be together in the daytime and sleep in two different rooms at night. In that way the donors would not be disturbed at night by the health care professionals monitoring on the recipient. This would reduce tiredness and give the donors more energy to eat, walk and take care of themselves and thus improve their recovery. In the future organisation of transplant care for both donor and recipient it should be considered to place donor and recipient in separate rooms to meet their individual needs for post operative care. However, this challenges nurses to enable donor and recipient to be together, and thus to maintain the positive elements of being hospitalised together and at the same time.

### **CONCLUSIONS**

From a donor-recipient perspective there are both advantages and disadvantages in being cared for in the same room. Both recipients and donors experienced post-operative discomfort. Recipients and donors do not have the same needs for care during post-operative recovery. Despite this, all recipients and donors in this study found that staying in the same room during hospitalisation was a benefit. Both recipients and donors expressed worries and concerns about each other. Some donors put themselves and their needs after the needs of the recipient. The overall conclusion to this study indicates that it is important for both recipients and donors to be at close hand in the immediate post-operative recovery phase.

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**CONFLICT OF INTEREST**

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**AUTHOR CONTRIBUTIONS**

KHB: Participated in design and coordination of the study, performed interviews, analysed the data, drafted the manuscript, read and approved the final manuscript. KR: Participated in design and coordination of the study, performed interviews, analysed the data, read and approved the final manuscript. MSL: Conceived the study, helped to draft manuscript, read and approved the final manuscript. JF: Principal Project Leader, Participated in design and coordination of the study, analysed the data, helped to draft manuscript, read and approved the final manuscript.