



BIROn - Birkbeck Institutional Research Online

Spiers, Johanna and Smith, Jonathan A. and Drage, M. (2015) A longitudinal interpretative phenomenological analysis of the process of kidney recipients' resolution of complex ambiguities within relationships with their living donors. *Journal of Health Psychology* 21 (11), pp. 2600-2611. ISSN 1359-1053.

Downloaded from: <https://eprints.bbk.ac.uk/id/eprint/12022/>

Usage Guidelines:

Please refer to usage guidelines at <https://eprints.bbk.ac.uk/policies.html> or alternatively contact lib-eprints@bbk.ac.uk.

A longitudinal interpretative phenomenological analysis of the process of kidney recipients' resolution of complex ambiguities within relationships with their living donors

Accepted version

Corresponding author: Johanna Spiers

(Department of Psychology) Birkbeck University, Malet Street, London, WC1E 7HX, UK.

Email: Johanna.spiers@gmail.com

Jonathan A Smith

(Department of Psychology) Birkbeck University, UK

Martin Drage

Guy's Hospital, UK

A longitudinal interpretative phenomenological analysis of the process of kidney recipients' resolution of complex ambiguities within relationships with their living donors

Abstract

Much previous research into living kidney donation has focused on the decision making of the donor, despite evidence suggesting this may be a more psychologically challenging time for the recipient. This longitudinal study explores the experiences of four recipients of kidneys from living donors throughout the transplant process. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA). Three themes arose from the data, which were: Changing perceptions of relationships with kidney donors; Upbeat, temporal strategies for remaining positive; and Journey of the self. Findings from the first theme are presented in detail here. It was found that each participants' relationship with their donor grew and developed in different ways, presenting their own complex challenges in terms of developing relationships and ambiguity around the decision to use the chosen donor.

Keywords

Kidney, Interpretative Phenomenological Analysis, Illness, Organ Transplant, Qualitative Methods

Introduction

It is estimated that 100,000 people in the UK have chronic kidney disease (CKD) (NHS, 2014). There are five stages of kidney function, with stage one being normal functioning and stage five being End-Stage Renal Disease (ESRD) (Renal Association, 2014). A minority of CKD patients will progress to stage five, at which point treatments such as dialysis and transplantation generally occur. In the UK, more than 20,000 people are on dialysis, and 6,000 people are waiting for a transplant. Despite this, only 3,000 transplants are performed per year. In the year 2013-2014, 1106 of these come from living donors (NHS Blood and Transplant, 2015). Sadly, 350 people die every year waiting for a kidney transplant (Kidney Research UK, 2015).

Transplantation, which is generally performed laparoscopically and has a three month recovery period, is the treatment goal for most patients with ESRD. It has been consistently found that kidneys from living donors lead to longer, healthier post-transplant lives (Olbrisch et al., 2001, Leo et al., 2003, Gill and Lowes, 2008). Figures show that 77% of kidneys from living donors will still be working 10 years after transplantation, whereas 72% of kidneys from deceased donors will still be functional at this point (NHS, 2015). Therefore, living kidney donation is seen as the optimal treatment for ESRD patients.

A literature review was undertaken as part of the first author's PhD, searching for the terms 'living donor,' 'kidney,' 'renal' and 'qualitative' on Google Scholar, PsychInfo and Web of Science. Citations of note within the initially found papers were followed up, and it was found that existing qualitative literature on living kidney donation tends to focus on donors (see eg. Olbrisch et al., 2001, Lennerling et al., 2003, Brown et al., 2008, Challenor and Watts, 2013) or on dyads of recipients and donors (Gill and Lowes, 2008, Gill and Lowes, 2009) despite various researchers (Gill and Lowes, 2008, de Groot et al., 2012) stating that living donor transplantation may be more psychologically complex for recipients than donors. One area in which there is more qualitative research on receiving organs is for adolescents, as detailed in Tong et al. (2009).

Whilst donors sometimes make a spontaneous decision to give a kidney (Gill and Lowes, 2008), recipients must be comfortable with donors undergoing painful elective surgery, and must negotiate feelings of indebtedness towards them (de Groot et al., 2012, Tong et al., 2009). In addition to this, the ability of recipients to be open about their feelings, to their donors or others, can vary.

The issue of relationships between recipient and donor dyads is one that has been touched on by the existing literature, although once again, the focus has tended to be on donors rather than recipients. One questionnaire study (Burroughs et al., 2003) spoke to triads of donors, recipients and one third party involved in the process. Perceptions of donor pre-op concerns and post-op experiences were explored, hence

revealing a privileging of donor experience over recipient experience. It was suggested that donor/recipient relationships improved following donation.

A small number of studies have examined donor and recipient relationships. For example de Groot et al., 2012 used focus groups to talk to donors and recipients, and found that fears around an imbalance developing in the relationship, an inability to say no and increased feelings of guilt had materialised for some recipients. However, these negative changes were balanced out with positive changes also.

One study focused on recipient experience alone, and touched on relational dynamics (Schipper et al., 2013). This paper notes that improved health following donation can lead to a shift in roles for recipient and donor, which can be challenging to negotiate, plus highlights that recipients may feel a mixture of gratitude and guilt towards living donors which can complicate relationships. However, although these findings are interesting, they are not explored in great detail. Therefore, it can be seen that more work is needed into the relational experiences of recipients as they go through the process of kidney donation.

The need for more longitudinal work within living kidney donation has been highlighted (see eg. Gill and Lowes, 2008, Harwood et al., 2011). Receiving a kidney from a living donor is a lengthy process, during which emotions are open to complex change. Therefore, a longitudinal design seems most suitable for capturing the nuances of the transplant process.

We conducted this longitudinal study in order to explore recipient experiences within living donor kidney transplantation. Although we set out to conduct an inductive study exploring all aspects of recipient experience, this paper focuses on relational dynamics which was one of our research interests and which emerged as a key issue in the study.

Qualitative methods were selected as they are useful for researching experiential processes about which little is currently known; these methods ask about meaning rather than measurements (Tong and Craig, 2014). Phenomenological methods within psychology deal with a detailed examination of life as it really is for small groups of

individuals (Smith et al., 2009), and so are relevant to this research, which is interested in individual experience. Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was selected as the most suitable method. IPA takes an idiographic, phenomenological stance that allows for a nuanced, detailed explication of participants' experiences, and is well suited to topics that are complex and equivocal (Smith et al., 2009). Further to this, the methodology is ideally suited to exploring both health psychology (Brocki and Wearden, 2005) and with lived experience that has existential import to the participant (Smith, 2011), suggesting that the method is the best fit for this topic.

Method

Design

Participants took part in three in depth semi structured interviews during the transplantation process. Interviews were transcribed verbatim and subjected to IPA first within case, then cross case.

Ethics

This study received ethical clearance from North West London Research Ethics Committee as well as Birkbeck University of London. Informed consent was taken by the first author at the time of the first interview. Names and some other details of participants' stories were changed, and participants were assured of confidentiality. Care was taken to ensure that while these changes made it harder to identify participants, they didn't alter the meaning or key issues around participants' stories (Lipson, 1997). Some data was felt too be too recognisable, and so was excluded from the analysis.

Participants

Participants were purposively recruited via a kidney clinic at a London (UK) hospital. Potential participants were approached if they were native English speakers who were due to receive a kidney from a living donor within the next few weeks.

Two hospital workers (a living donor matron and an administrative worker) identified potential participants and sent recruitment letters. Those who wanted to take part in the study contacted the first author, who explained what taking part would entail and then took informed consent. Four participants were recruited.

Demographics are recorded in table one, below.

^^

Table 1 about here

^^

Although it had initially been hoped to recruit six participants, it took around 18 months to recruit four. In reality, participants had only a couple of weeks' notice before the transplant. Given the preparation required for the procedure, it is not surprising that some potential participants felt unable to take the time for an interview in this small busy window. Also, kidney recipients are heavily researched by biomedical practitioners. Therefore, the healthcare team rightly used their discretion about which patients to contact for which study and were guided by ethics in terms of not overloading patients with requests from researchers.

Although four may be considered a fairly small sample size, the principles of IPA involve working with small, homogeneous groups, so that idiographic similarities and differences between participants can be teased out (Smith et al., 2009). A huge wealth of data arose from this small sample, and was analysed in great detail, so it is felt that what this study sacrifices in width, it makes up for in depth.

Data collection

Interview schedules were constructed based on a literature review and consultation with a recipient of a living donor kidney. The schedules contained open questions on biography, time in hospital, donor and the future. Of particular relevance to this paper, participants were asked about how the decision to use that donor was reached, if they felt that the relationship had changed at all following donation and how they felt about using that donor once the transplant had taken place.

Participants took part in three semi-structured interviews:

- (T1) shortly before transplant
- (T2) two months post transplant
- (T3) nine months post transplant

Given that dyads are usually only given a green light for surgery in the two or three weeks before transplantation takes place, interview one needed to be close to surgery. The second interview was timed so as to allow participants recovery time, yet also gather first impressions of life with a new kidney. The third interview aimed to give a perspective of life once things had hopefully settled down a little for participants.

In line with NHS guidelines, all interviews except one took place in private areas of the participants' hospital. Harriet's third interview took place in a cafe. A proportion of the recording was not audible. However, the section that was audible was sufficient to be transcribed and included in the analysis presented here.

It is accepted that using hospital rooms to conduct the interviews may have influenced participants' answers (Challenor and Watts, 2013, Tong et al., 2007). Participants may not feel fully at ease, may have unpleasant associations with the hospital and may also have more strongly associated the interviewer (the first author) with their healthcare teams. It may have been preferable to speak to participants in their homes (King and Horrocks, 2010). However, these participants had to come in and out of hospital very frequently, so meeting them at the hospital hopefully cut down on inconvenience to them. On balance, it is felt that enough rapport was created that participants were able to be open and honest with the interviewers.

The interviews were carried out by the first author who made field notes after each interview. The interviews followed a semi-structured format, meaning that the schedule was used as a guide, and any interesting or unusual points followed up. The first author is a living kidney donor. She made a decision not to disclose this to participants in case this influenced responses. There is evidence to suggest that transplant recipients can be keen to prove their 'deservedness' and gratitude, perhaps as a way of re-paying the second chance of life they have been given

(Fisher et al., 1998). Consequently, transplant recipients may feel under pressure to present themselves a certain way when speaking to donors, so it was felt that this would not be helpful information. Interviews were audio recorded and lasted between 45 minutes and three hours. Interviews were transcribed verbatim.

Analysis

Data were analysed according to the principles of IPA (Smith et al., 2009). Transcripts were read and analysed by searching for points of descriptive, linguistic and conceptual note. Emergent themes were clustered into tables and compared within and between time points for each participant, and then across participants. Analysis continued into the writing up process, when patterns of convergence and divergence continued to emerge. Analysis was undertaken by the first author, who took steps to acknowledge and set aside any bias as a result of her experience as a donor, by keeping a reflexive journal about any feelings that arose for her as she undertook the work. Analysis was audited by the second author, who read over transcripts and tables of themes, and suggested alternative interpretations. Where the authors disagreed, further discussion and analysis of the data was undertaken until agreement was reached.

Results

Three themes emerged from the data: changing perceptions of relationships with kidney donors; upbeat, temporal strategies for surviving ill health; and journey of the self. For reasons of both brevity, and not wishing to sacrifice depth for width, this paper will explore the first theme in detail.

Note that within verbatim quotations ... indicates a short pause and (pause)... a longer pause. [...] indicates that a small portion of irrelevant text (often interjections by the interviewer) have been deleted.

Changing perceptions of relationships with kidney donors

This was an important issue for all participants. All but one of them expressed some trepidation or uncertainty about receiving the kidney from the selected donor. In effect we see the working through of these issues during the course of the interviews so that by the third interview at 9 months after the transplant there is some resolution. For the fourth participant, Elizabeth, a comfort with receiving the organ from her donor is already there from the beginning so less cognitive and affective effort is noticeable and there is less change during the process.

The stories are presented as discrete, idiographic case studies, so that the reader can clearly follow complexities facing each recipient, which are diverse despite their similar overall arc. In this way, we can see that the experiences of different kidney recipients are complex and unique, and therefore are worthy of both researcher and clinician attention.

When Mark first talks about receiving a kidney from his sister, he presents a ‘press release’ version of the gratitude he senses he has to feel:

I would feel duty bound to be more like... appreciative and loving of her... But it sounds, I suppose it sounds a little bit wrong to think that I would be duty bound cos she is my sister... and so I should do that anyway, but... cos she's, what she's doing for me, she's, yeah, she is transforming my life, really, so that will... make me feel... like I should (pause)... feel like I should do the same thing for her... and do whatever I can to help her... I suppose. (T1).

Mark repeats words like ‘duty bound’ and ‘should’ throughout this awkward, hesitant extract; these are obligated rather than genuine feelings, further complicated by the fact that he also feels an obligation to not be obligated: ‘I should do that anyway’. Mark is driven by a need to reciprocate – but how can a person do ‘the same thing’ for someone who has given them an organ? It can’t be done, and Mark seems to realise this, ending the extract on a note of uncertainty.

By T2, while still concerned with a feeling of needing to pay his sister back, Mark feels less obligated to fulfil the demand of quid pro quo reciprocation. He talks here about their shared convalescence at their parents' house:

I kind of was able to look after her a bit, like bring her drinks and things. And so that was quite nice, it kind of, it wasn't (laughs) re-paying her, but it was kind of... able to say thank you. (T2)

Whilst Mark again recognises the difficulty of repaying his sister, he now sees the use of a gesture to say thank you as enough to help him make his peace with her donation. His easy laughter here suggests he feels comfortable with this situation, and his emotion towards his sister appears warm and real.

By T3, Mark's feelings have developed further, as his complex explanation of gratitude demonstrates a genuinely increased sibling bond:

I'm glad that she did what she did and I'm really thankful. I think it means I do love her more than I did. I mean obviously I loved her before as my sister, but now I mean, I love her more as my sister for what she did for me because (pause)... I mean giving up an organ for someone is no small thing. So I mean, I'd have to feel, I have to feel something. But it's not that I have to. It's actually that I do. (T3)

Mark is still aware of a obligation to show gratitude towards his sister. However, he has now transcended these feelings of being duty bound and genuinely feels a new closeness and love for her. He twice talks about loving her 'as my sister,' giving the phrase two meanings. One senses he had previously loved her 'as a sister' in the grudging way that some young siblings sometimes do; love that is buried beneath bickering. However, Mark goes on to use the word 'sister' to imply warm, deep love, as one might talk about a friend being part of one's chosen family. Mark speaks about the transition in this relationship in a heartfelt yet confident manner, again seeming to demonstrate that he feels at peace with the transplant and his new relationship with his sister donor.

While Mark's feelings towards his sister grow and develop from awkwardness to a resolution of genuine love, the process of Andy's changing feelings towards his son-in-law donor is more complicated and unpredictable. Andy was extremely forthcoming during his interviews, yet talked about how difficult he found it to share his feelings with people he loves. This included Bruce, his son-in-law donor. Andy wanted to find the words to thank Bruce properly before the transplant went ahead, but found this impossible:

I still didn't know how to actually... talk to him about it. And I, so I didn't.

(T1)

Even when Bruce takes the matter into his own hands and calls Andy to have this difficult conversation, Andy seems to have subconscious difficulty relaying it:

He said, you don't have to thank – now whether my daughter had said something to him that I was finding it hard, whether my wife had said something, my daughter, to him, I don't, I don't think so, but you don't, you haven't got to thank me, I know you probably want to, but you haven't got to.

(T1)

Andy stops himself before completing the sentence he found so hard to say ('you don't have to thank – '). Note that he 'plays' Bruce as he relays the discussion, further removing himself from the story. However, Andy later states, '*After our phone call last night I feel a lot closer towards him*' (T1). Even before the operation, Andy's relationship with his donor has changed and strengthened.

However, at T2, Andy starts to talk about Bruce in a more ambiguous manner, saying:

I would defend him now, whereas before, if someone said something about Bruce... I might have thought the same myself, so I would go along with the joke. Whereas now, I would defend him. [...] I suppose he's got under my skin a lot more now... (T2)

The first section of this extract presents a position of being closer to Bruce than in previous times. However, note the somewhat indirect way in which this is done, suggesting that although there might be a reason to joke about Bruce, Andy now feels honour-bound not to join in.

The extract ends with a beautiful encapsulation of the living donor process, which suggests a multi-layered merging of the two men. Andy acknowledges that he and Bruce are closer in both a relational and a literal sense. There is now a part of Bruce inside Andy and the phrase 'under my skin' illustrates the embodied aspect of the transplant. However, there are two more possible readings of this phrase. It can mean that you cannot stop thinking about someone in a positive sense. However, it can also mean that someone is an irritant to you, niggling beneath your skin. Andy's statement is ambiguous and can be read in multiple ways. The preceding text in the extract seems to suggest that Bruce is closer to Andy now, perhaps has even become part of his flesh and blood family, rather than being an external family member, only there because he married in. It remains unclear whether Andy sees Bruce favourably or not, but it seems that the bond is strengthened between them.

He goes on to say:

It sounds bad, but before, I always thought Bruce is a bit of a... I don't know what the phrase is I'm looking for. (T2)

Although Andy is very reluctant to fully articulate this thought, it clearly isn't completely positive. Just as he initially found it impossible to express thanks to Bruce, he now finds it impossible to express that he ever had difficulty with Bruce, even though the narrative is that those difficulties are now over. Maybe Andy feels he has to look grateful at all times, and so cannot speak his mind. This interpretation is given further weight here:

I'm not saying I did what I wanted, I didn't want to say no, I wanted to say no... or I didn't want to say no, whichever. (T3)

The confused, hesitant language here suggests it is impossible for Andy to express, or

even perhaps fully come to terms with, what it is that he truly wanted to do as he made a decision about receiving a kidney. Perhaps a sense that he had to fall in line with others robbed him of his ability to decide if he wanted his son-in-law to donate.

Despite these complications, by T3 Andy's relationship with Bruce is stronger than ever and free from ambiguity, '*I could never do better than Bruce, he give me a kidney*' (T3). Hence we can see that, like Mark, Andy has moved from a place of ambiguity and uncertainty in his relationship with his donor through to a resolution, in which the relationship is stronger than it was before.

Harriet was receiving a kidney from her daughter Suzanne. Unlike Mark and Andy, Harriet's relationship with her donor didn't seem to change. However, the narratives around parent/child relationships impacted on Harriet in a dynamic fashion throughout the transplant process, leading to feelings of uncertainty within herself, which she then goes on to resolve.

Harriet starts from a position of feeling very unsure about receiving a kidney from her daughter:

I feel very conflicted... Cos, you know, it feels the wrong way round... that, ah... child... should be donating to a parent... sorry (starts to cry). (T1)

The crux of Harriet's distress revolves around a deep sense that this transplant is in the wrong direction. She sees her young, yet grown up daughter in the role of child and herself (naturally enough) in the role of parent. One can interpret that she feels she should be sustaining Suzanne, giving her life. That it is Suzanne who is doing these things for her feels unacceptable for Harriet.

Like Andy, Harriet also has difficulty expressing her true feelings:

So I have agreed to it (long pause). But... you know, I still don't feel (long pause)... um (long pause)... it's not what I'd wish, let's put it that way. (T1)

Harriet's hesitant speech mirrors her hesitation to proceed with what feels so wrong. Although she is able to communicate that this isn't what she wants, one senses that she is holding back from expressing the depth of her emotion. It appears that her family want to go ahead, and so Harriet feels she must agree and keep her true feelings unexpressed.

At T2, Harriet is brutally honest when relaying the highly anxious moment when Suzanne has gone into surgery and Harriet is waiting to go in herself:

There was a moment, after she'd gone... where I thought (starts to cry) I don't want to do this. (T2)

Harriet speaks in the present tense and is still deeply distressed, two months later. This unhappiness over the 'wrong direction' transplant which subverts the typical narrative of the mother daughter relationship is still ongoing for her, even though the operation is now in the past.

Conversely, Harriet presents a position of having made her peace with the transplant:

I guess I feel a lot better about it now. You know, err, err (long pause)... you know, Suzanne's clearly fine, perky [...] Everything's... easier and happier for our whole family. You know? So, erm... it's not just me it's helped. I've kind of freed, everyone up. Including Suzanne, too. You know, cos... erm, cos I was a worry, you know, to her. Erm... as well as my husband and my son, you know? So (pause)... erm, so, yeah I feel... it was definitely the right thing to do for all of us, really. (T2)

At initial reading, this extract seems upbeat and positive. However, a closer reading suggests that multiple emotions are at play here. Note Harriet's uncertain language at the beginning when she 'guesses' she feels better. She hesitates before listing her reasons why she is now ok; these reasons all revolve around Harriet's family, not herself. She characterises herself as being a burden to her family, stating the transplant has 'freed them up' from worry about her. Harriet's language is hesitant and uncertain, suggesting she may not feel that confident in the positive image she is

presenting. When she sums up by saying this is better for herself as well as them, this no longer feels convincing.

By T3, Harriet seems to have made a choice to focus on the positive by looking at the health aspects of the transplant and putting aside the challenge to her perceptions of a parenting relationship:

Well I think it turned out rather well. Erm... you know I don't have any regrets [inaudible] you know on the health side. (T3)

Her language is much calmer than at previous times; this feels like a pragmatic decision to focus on physical health and leave emotions behind. Like Mark and Andy, she appears to have reached a place of resolution, following challenging uncertainty.

Finally, Elizabeth was receiving a kidney from David, her husband of several decades. Her story differs from those of the other three recipients. Elizabeth and David have a strong relationship and are supportive of one another. At time one, she expressed delighted surprise that David was able to be a match for her:

I didn't believe it to start with, I just thought oh, well, a 2/6 match, you know, that's obviously not enough, and they were no, no, that's, it's great! I was a bit stunned to start with, I was oh no, I can't believe this, I can't believe it! (T1).

Elizabeth is stunned that her husband was able to donate, adding a sense of magic to their story. Elizabeth's feelings towards David and his role as her donor remain unambiguously positive as time goes on, as her language here ('brilliant', 'lovely') illustrates:

Oh, brilliant [...]. I just thought it was such a lovely thing that he was able to do that. (T2).

Elizabeth has a gracious approach to the donation; her use of the phrase 'he was able to do that' could be interpreted to mean she is able to see that the transplant is a gift

for him as well as her. She doesn't show any sign of feeling beholden to him; instead, the transplant was easy for both parties.

When you're sort of husband and wife, you sort of give each other anything, but... if it, if you're donating to a stranger or something, then that must be... amazing. (T3)

Elizabeth sees donation between spouses as universally acceptable, and as set apart from other donation relationships. She admires other donation dyads, but sees them as unusual. However, within a positive spousal relationship, giving each other anything (including an organ) seems to be normalised for her.

Whilst these portraits of recipients receiving kidneys from living donors have shown four different experiences of the transplant process, we can see that a pattern emerged. Three of the four recipients faced ambiguity, either in terms of their relationships with the donors themselves, or internally, as a result of that relationship. However, each of these three stories ended in resolution. The fourth recipient, Elizabeth, felt comfortable with using her spousal donor from the outset, and so showed no such process. Thus we hope we have presented a nuanced account which demonstrates individual complexity along with convergent sharedness.

Discussion

All four participants received a kidney from a living donor, with differing reactions. Despite the similarity, each recipient's story is diverse and complicated. Indeed, it might be expected that the experience of receiving a kidney from such different sources (sister, son-in-law, daughter and husband) would result in very different emotions. However, what the current findings do is show us how worthy of attention recipient relational dynamics are by both researchers and clinicians alike.

Several studies have begun to find evidence for the notion that negotiating relationships with potential donors can be problematic due to worries about ill effects on the relationship or fears around guilt if the kidney were to fail (de Groot et al.,

2012, Gill and Lowes, 2014). Recipients have also reported changes in their relationships with donors that are both positive, such as growing closer, and negative, such as no longer feeling they can speak their minds (Schipper et al., 2013, de Groot et al., 2012). Another study used content analysis to examine consultation procedures and interviews with donors, recipients and family members (Schweitzer et al., 2003). The results favoured donor experience, although here, it was found that some donors developed hostile feelings towards their recipients as time passed.

Gill and Lowes (2008, 2009) have used content analysis to explore donor/recipient experience in more detail. The first study (2008) found that there were no detrimental changes to the relationships, although no positive changes were reported either. The second (2009) presented the longitudinal case study of a dyad for whom the kidney graft failed. The relationship between the husband donor and wife recipient, which was strained by the loss of the new kidney, is described in detail as part of the findings. By the final interview, the couple felt determined to enjoy life together. These two papers signpost how complex donor/recipient relationships can be, and do move away from privileging the donor, but focus instead of both partners in the dyad.

Despite these findings, there is a dearth of work that uses an in-depth, longitudinal design to explore the experiences of kidney recipients. The current study adds to the existing picture by detailing, in a nuanced fashion, the ongoing challenges faced by four kidney recipients. In particular, the stories of Andy and Harriet demonstrate ways in which it can be hard for recipients to speak their minds about the donation process.

Andy was unable to vocalise his thoughts about various aspects of his relationship with his son-in-law and his wishes for the transplant. This demonstrates that those deceased donor recipients in de Groot et al.'s study (2012) who feared that they would be unable to speak their minds to potential living donors in the future may have been right to be concerned. It is conceivable that the nature of Andy's relationship with Bruce – that of father-in-law – added to his difficulty in speaking his mind to Bruce. Here is a relationship type which doesn't have the history of blood relatives. Plus, like Harriet, Andy is receiving a kidney from a generation below him. Perhaps this added to any feelings of awkwardness around the donation. The longitudinal design of the study allows us to follow Andy's complex relational journey.

It seems reasonable to posit that Harriet's distress over accepting a kidney from her daughter was a result of guilt. Schipper et al.'s kidney recipients (2013) also talked about experiencing guilt, although their guilt tended to be a result of feeling unable to continually express gratitude. The authors of another case study of a woman experiencing severe guilt following a living liver donation from her son (Fukunishi et al., 2002) suggested that organ recipients receiving organs from grown up children may find it difficult to adjust without guilt, but called for more evidence to support this claim. Harriet's case provides this, and adds emphasis to the notion that the relational journey of receiving a kidney will differ depending on the status of the donor/recipient relationship.

Findings like these add detail to the foundation laid by existing research (de Groot et al., 2012, Gill and Lowes, 2008) and show that more longitudinal, qualitative research needs to be done with kidney recipients, to illuminate the various ways in which their voices may be silenced.

Mark felt a pressure to show gratitude to his sister. Although this gratitude grew to become genuine, it initially felt forced. It is arguable that siblings in young adulthood may feel an extra burden to reciprocate to one another, having been taught to share and exchange gifts throughout their lives. The literature has long suggested that gifts must be reciprocated, either with commodity or affection and regard (Mauss, 1990, Ashworth, 2013), and this social rule may be felt very keenly between siblings, emphasising again how different donor/recipient relationships may have a bearing on the experience of receiving a kidney. It can be hard to know how to reciprocate the so-called 'gift of life' (Gill and Lowes, 2008). One study on the relationships between living liver donors and recipients (Papachristou et al., 2009) suggests that doctors should discuss 'gratitude rituals' with donors and recipients.

Elizabeth stands alone as not having experienced any changes or difficulties with her donor husband. She herself posits that this is because spouses expect to give each other 'anything'. Of course, this will not go for all spouses, as further qualitative research may reveal.

Reflections

Numerous studies have suggested that more longitudinal work is needed for exploring recipient's experiences of living donor kidney transplantation (Decker et al., 2008, Gill and Lowes, 2008, Harwood et al., 2011, Joralemon and Fujinaga, 1996). The current research begins to address this gap. However, while it is hoped that the study addresses some previously unexplored questions, it does have limitations. Due to a slow recruitment period, only four participants were recruited. Perhaps future studies could include more participants; however, the stories of living donor kidney recipients are so complex and nuanced that a larger study may lose some idiographic detail.

Reflexivity

Throughout the process of analysis, the first author (JSp) kept a reflexive journal, recording the thoughts and feelings that arose during both interviews and analysis. It was found that the further away she moved from her own experiences as a donor, the easier it was to set those experiences aside and immerse herself in the participants' data. The first author initially found herself comparing the participants' stories with that of her experience and being troubled by disparity between her story and those of her participants. However, given that each participant's story was fascinating, and different from the story of the first author and her recipient, she became more immersed in the data and found it easier to bracket her own experiences as time passed.

Recommendations

This study provides evidence for the previous supposition that the experience of receiving a kidney from a living donor can be emotionally complex and challenging (Gill and Lowes, 2008, de Groot et al., 2012). As such, it would be recommended that transplant centres think about offering pairs of recipients and donors, or recipients alone, therapeutic support through this period. Further to this, we support the recommendation of Papachristou et al. (2009) that recipients and donors are encouraged to think about 'gratitude rituals,' as these may ease difficult emotions and make it easier for both parties to relate to one another successfully at this time.

However, recommendations must of course be viewed with caution and seen as a starting point that should lead to further research, since this piece of qualitative research has a small sample size.

It is hoped that this longitudinal study has demonstrated the benefit of using health psychology to provide nuanced, idiographic detail in order to complement the wider-ranging, less in-depth existing research in the field. However, it also suggests spaces that might be filled by future research. For example, it might be beneficial for some qualitative research to compare more people receiving kidneys from the same donor source; so several recipients of kidneys from parents, from siblings and so on. In this way, convergences and divergences within these more homogeneous groups can be teased out. Secondly, it would be fruitful to look at recipients of kidneys from living donors at a later stage in their lives; perhaps five years after transplantation, in order to see if further relational changes may take place.

References

- ASHWORTH, P. 2013. The gift relationship. *Journal of Phenomenological Psychology*, 44, 1-36.
- ASSOCIATION, R. 2014. *CKD Stages* [Online]. Available: <http://www.renal.org/information-resources/the-uk-ekkd-guide/ckd-stages> - sthash.tFUCjiDo.dpbs.
- BROCKI, J. & WEARDEN, A. 2005. A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21, 87-108.
- BROWN, J. B., KARLEY, M., BOUDVILLE, N., BULLAS, R., GARG, A. & MUIRHEAD, N. 2008. The experience of living kidney donors. *Health & Social Work*, 33, 93-106.
- BURROUGHS, T., WATERMAN, A. & HONG, B. 2003. One organ donation, three perspectives: experiences of donors, recipients, and third parties with living kidney donation. *Progress in Transplantation*, 13, 142-150.
- CHALLENGER, J. & WATTS, J. 2013. 'It seemed churlish not to': how living non-directed kidney donors construct their altruism. *Health*, 1363459313501358.
- DE GROOT, I., SCHIPPER, K., VAN DIJK, S., VAN DER BOOG, P., STIGGELBOUT, A., BARANSKI, A. & MARANG-VAN DE MHEEN, P. 2012. Decision making around living and deceased donor kidney transplantation: a qualitative study exploring the importance of expected relationship changes. *BMC nephrology*, 13, 103.
- DECKER, O., LEHMANN, A., FANGMANN, J., BROSIG, B. & WINTER, M. 2008. Phases of organ integration and conflict in a transplant recipient: A

- longitudinal study using a diary. *The American Journal of Psychoanalysis*, 68, 237-256.
- FISHER, R., GOULD, D., WAINWRIGHT, S. & FALLON, M. 1998. Quality of life after renal transplantation. *Journal of Clinical Nursing*, 7, 553-563.
- FUKUNISHI, I., SUGAWARA, Y., TAKAYAMA, T., MAKUUCHI, M., KAWARASAKI, H. & SURMAN, O. 2002. Association Between Pretransplant Psychological Assessments and Posttransplant Psychiatric Disorders in Living-Related Transplantation. *Psychosomatics*, 43, 49-54.
- GILL, P. & LOWES, L. 2008. Gift exchange and organ donation: Donor and recipient experiences of live related kidney transplantation. *International Journal of Nursing Studies*, 45, 1607-1617.
- GILL, P. & LOWES, L. 2009. The Kidney Transplant Failure experience: A longitudinal case study. *Progress in Transplantation*, 19, 114-121.
- GILL, P. & LOWES, L. 2014. Renal transplant failure and disenfranchised grief: participants' experiences in the first year post graft failure. *International Journal of Nursing Studies*.
- HARWOOD, L., WILSON, B. & SONTROP, J. 2011. Sociodemographic differences in stressful experience and coping amongst adults with chronic kidney disease. *Journal of Advanced Nursing*, 67, 1779-1789.
- JORALEMON, D. & FUJINAGA, K. 1996. Studying the quality of life after organ transplantation: research problems and solutions. *Social Science and Medicine*, 44, 1259-1269.
- KING, N. & HORROCKS, C. 2010. *Interviews in Qualitative Research*, London, Sage.
- LENNERLING, A., FORSBERG, A. & NYBERG, G. 2003. Becoming a Living Kidney Donor. *Transplantation*, 76, 1243-1247.
- LEO, R., SMITH, B. & MORI, D. 2003. Guidelines for Conducting a Psychiatric Evaluation of the Unrelated Kidney Donor. *Psychosomatics*, 44, 452-460.
- LIPSON, J. 1997. The politics of publishing: protecting participants' confidentiality. In: MORSE, J. (ed.) *Completing a Qualitative Project*. London: Sage.
- MAUSS, M. 1990. *The Gift: The Form and Reason for Exchange in Archaic Societies*, London, Routledge.
- NHS. 2014. *Setting standards in kidney care* [Online]. Available: <http://www.nhs.uk/nhsengland/NSF/pages/Renalservices.aspx>.
- NHS. 2015. *NHS choices - Organ donation: Living donation* [Online]. Available: <http://www.nhs.uk/Conditions/Organ-donation/Pages/Recommendations.aspx>.
- OLBRISCH, M., BENEDICT, S., HALLER, D. & LEVENSON, J. 2001. Psychosocial Assessment of Living Organ Donors: Clinical and Ethical Considerations. *Progress in Transplantation*, 11, 40-49.
- PAPACHRISTOU, C., WALTER, M., FROMMER, J. & KLAPP, B. 2009. Living donor liver transplantation and its effect on the donor-recipient relationship - a qualitative interview study with donors. *Clinical Transplantation*, 23, 382-391.
- SCHIPPER, K., ABMA, T., KOOPS, C., BAKKER, I., SANDERMAN, R. & SCHROEVERS, M. 2013. Sweet and sour after renal transplantation: a qualitative study about the positive and negative consequences of renal transplantation. *British Journal of Health Psychology*.

- SCHWEITZER, J., SEIDEL-WIESEL, M., VERRES, R. & WIESEL, M. 2003. Psychological consultation before living kidney donation: Finding out and handling problem cases. *Transplantation*, 76, 1464-1470.
- SMITH, J. 2011. Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, 5, 9-27.
- SMITH, J., FLOWERS, P. & LARKIN, M. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*, London, Sage.
- TONG, A. & CRAIG, J. 2014. Horses for courses: promoting transparent reporting of qualitative research in AKJD. *American Journal of Kidney Disease*, 63, 1-3.
- TONG, A., MORTON, R., HOWARD, K. & CRAIG, J. 2009. Adolescent experiences following organ transplantation: a systematic review of qualitative studies. *The Journal of Pediatrics*, 155, 542-549.
- TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349-357.
- TRANSPLANT, N. B. A. 2015. *Organ Donation and Transplantation - Activity figures for the UK as at 11 April 2014* [Online]. Available: http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/annual_stats.pdf.
- UK, K. R. 2015. Available: <https://www.kidneyresearchuk.org/about-us>.

Table one: Participant demographics.

Name	Age	Donor	Dialysis?	Previous transplant?	Condition
Mark	Early 20s	Sister	Haemodialysis (hospital)	No	Vasculitis
Harriet	50s	Daughter	Haemodialysis (home)	Yes (father)	Acute failure, cause unknown
Andy	Late 50s	Son-in-law	None, though previously CAPD	Yes (deceased)	Glomerulonephritis
Elizabeth	60s	Husband	Haemodialysis (hospital)	No	Vasculitis