

Reclaiming their lives: The decision-making process in living liver donation – An interpretative phenomenological case study analysis of one couple

Lesley M. McGregor^{a,c*}, Adele Dickson^b, Paul Flowers^c, Peter C. Hayes^d and Ronan E. O’Carroll^a

^aDepartment of Psychology, University of Stirling, Stirling, UK; ^bSchool of Life, Sport and Social Sciences, Edinburgh Napier University, Edinburgh, UK; ^cSchool of Health and Life Sciences, Glasgow Caledonian University, Glasgow, UK; ^dDepartment of Gastroenterology, Royal Infirmary of Edinburgh, Edinburgh, UK; ^eDepartment of Epidemiology and Public Health, Health Behaviour Research Centre, University College London, London, UK

(Received 21 October 2013; accepted 28 June 2014)

Objectives: Adult-to-adult living liver donation (LLD) is a controversial procedure due to the risk to the healthy donor. The decision to proceed with LLD is an important, yet under-researched area. This study aims to explore the decision-making process of the donor and recipient independently, and within the donor–recipient dyad.

Design: A longitudinal, qualitative analysis of the LLD decision from the perspective of a LLD donor–recipient dyad.

Methods: In-depth interviews were conducted with the donor and recipient separately on three occasions: pre LLD, six weeks post and six months post LLD. Transcripts were subject to interpretative phenomenological analysis.

Results: During the pre-LLD interviews, a series of intra- and interpersonal negotiations were reported as both the donor and recipient grappled to make a decision about LLD. Following the decision, the focus then centred on the consequences of the decision and making sense of unanticipated outcomes. By six months post LLD, both were able to reflect on adapting to the changes their decision had ultimately caused.

Conclusions: This case study offers a unique insight into the risk assessment and decision-making demands of LLD and the results can help support future LLD candidates.

Keywords: UK; living liver donation; interpretative phenomenological analysis; decision-making; case study

Introduction

The shortage of deceased organ donations for transplant is a well-documented public health concern and finding ways to increase the supply of suitable organs is a continuing challenge. Adult-to-adult living liver donation (LLD) allows a healthy individual to donate up to 60% of their liver to someone with liver failure. It is one of many surgical advances introduced in an attempt to increase the supply of transplantable organs and

*Corresponding author. Email: l.mcgregor@ucl.ac.uk

reduce the number of patient deaths while on the transplant waiting list (Abouna, 2008). However, the procedure is also controversial as it involves a substantial degree of risk to a healthy donor, who is not set to physically gain from the operation (Cronin, Millis, & Siegler, 2001; Neuberger & Price, 2003). A systematic review of the literature previously reported donor mortality to be .5% (Middleton et al., 2006) but a recent review of LLD procedures conducted in the USA suggests the long-term risk of death for the donor is now 1.2%, and .17% if considered within the first 90 days post procedure (Muzaale et al., 2012). A lack of consistency in the reporting of donor outcomes across all transplant centres means that mortality data may be underestimated and the long-term health implications for the donor remain uncertain to this day (Gordon, 2013).

A number of studies have addressed the issue of decision-making in donors and results regularly suggest that the decision is predominantly made without consideration for personal risk (Gordon et al., 2011). At the heart of this decision-making process is a moral obligation to save the patient and thus, the decision to donate is often made as an immediate reaction to the situation. Only after this response does attention turn to the procedural risks and potential consequences of the surgery. This period of reflection then serves to either render the option of donating as not personally feasible at that time (e.g. McGregor, Swanson, Hayes, Forsythe, & O'Carroll, 2009) or provides a context within which the decision is strengthened (e.g. Papachristou, Walter, Frommer, & Klapp, 2009).

The decision and motivation to donate is thought to be dependent on a number of factors including the quality of the relationship with the recipient, family dynamics, personal history, trust in the medical team and psychological traits such as levels of anxiety and alexithymia (Papachristou, Marc, Frommer, & Klapp, 2010; Papachristou et al., 2004; Uehara, Hayashi, Murai, & Noma, 2011). However, the donor's decision to proceed with LLD is futile without the support and agreement of the recipient. For the option of LLD to be realised both the donor and the recipient must agree and yet there is a dearth of literature exploring decision-making processes from either the recipient's perspective or from within the context of the partner dyad itself.

Research with LLD recipients has predominantly focused on quantitative measures of the physical and psychosocial outcomes of the procedure (e.g. Jin et al., 2013; Olthoff et al., 2005). However, the decision to consent to LLD is an important ethical consideration that, thus far, has not been well researched and deserves further investigation (Fournier, Foureur, & Rari, 2013).

A retrospective qualitative interview study in Japan was one of the first to address the experience of LLD recipients, from decision-making to recovery (Watanabe & Inoue, 2010) but, to our knowledge, no research has focused on the recipient's pre- and post-transplant experience within a UK context, and no research has closely considered the dynamics of the donor-recipient decision-making process. Moreover, we are also unaware of any study that has employed phenomenologically oriented approaches to illuminate the lived experience of LLD. This might be explained, in part, by the fact that few LLD procedures are carried out on the UK NHS. Recent statistics show that since its inception as an NHS procedure in 2006 only 31 LLD procedures, between adults, have been performed (UK Transplant Registry 2013, unpublished) and, therefore, opportunities for researchers to explore such processes are limited.

In response, the current article presents an in-depth case study analysis of one partner dyad and the intra- and interpersonal decision-making processes involved in the

decision to proceed with LLD. This article is the first of its kind and presents a chronological trajectory mapping the ongoing costs/benefits analysis of LLD both pre- and post procedure, both from the perspective of each separate individual but also within the context of the partner dyad. In adopting an inductive and phenomenological approach, our aim is to provide an opportunity for the partner dyad's experiential narratives to act as a resource for future donors and recipients and to guide medical staff involved in the future care and support of LLD dyads.

Methodology

Participants

The donor was a healthy 25-year-old female who donated the right lobe of her liver (approximately 60% of the entire liver mass) to her 28-year-old husband, the recipient. As a teenager, the recipient was diagnosed with primary sclerosing cholangitis, a disease affecting the bile ducts in and around the liver, which is thought to be the result of an autoimmune disturbance (Karlsen, Schrupf, & Boberg, 2010).

In May 2007, the donor married her long-term boyfriend and soon after they noticed marked deterioration in his condition. By September 2007, the recipient was in need of a liver transplant and placed on the national liver transplant waiting list. After four months of waiting for a suitable cadaveric liver donation to become available, the recipient's healthy wife became his liver donor.

Procedure

Both the donor and recipient were individually sent information about the study and an invitation to take part, following notification from the transplant unit of their interest in pursuing LLD. Approximately one week after the invitation was sent, the first author telephoned both the donor and recipient separately to enquire about their interest in taking part and to arrange a date and time for their first interview. It was explained to both the donor and recipient that this research was being conducted independently from the hospital and, therefore, would not influence the evaluation of their suitability for LLD.

An in-depth semi-structured interview was conducted with each member of the donor-recipient dyad separately to allow intrapersonal as well as interpersonal perspectives to be captured. Interviews took place during the period of the transplant team's evaluation of the donor's suitability for LLD, six weeks post operation and six months post operation. Each interview was conducted by a 28-year-old female researcher (first author) within the home of the interviewee and was recorded for later transcription. Interviews lasted an average of 70 min (range 46–99 min). Each transcript was subjected to interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009).

Written consent was obtained from both the donor and recipient prior to commencing their study participation. Ethical approval was obtained from the appropriate regional NHS board.

Materials

A semi-structured interview schedule was developed for each interview time point and was adapted for use with each member of the partner dyad. Topics for inclusion were

Table 1. Key topics to be covered in each interview.

Pre operation	Post operation (six weeks and six months)
Background to current situation	Build up to day of operation*
Decision to donate/accept donation	The surgical/hospital experience*
Perceived views of others	Current wellbeing
Body image	Body image
Relationship and social implications	Relationship and social implications
Expectations and concerns	Expectations and concerns
Attitude towards medical care	Attitude towards medical care
Anticipated reactions to possible outcomes	Reflections on experience
Additional comments	Additional comments

*Six weeks only.

generated from a review of the available literature and discussion between the authors and colleagues within the transplant unit (see Table 1).

Interpretative phenomenological analysis

Transcripts were analysed by the second and third author for recurrent themes using IPA (Smith et al., 2009). IPA acknowledges that the interaction between the participant's narrative and the interpretation of the analyst is fundamental to the analytic approach. IPA is concerned with the individual's *own* account of the phenomenon under investigation: it is not concerned with producing an objective record of the phenomenon. The aim is to present recurring themes in order to achieve this. Verbatim extracts provide credence for the researchers' claims (Osborn & Smith, 1998).

The second and third authors took the lead on analysis, analysing all of the transcripts but the first author also provided credibility checks (e.g. ensuring coding was appropriate). The process of analysis involved several key stages, as suggested by Smith et al. (2009) (see Dickson, Allan, & O'Carroll, 2008; Dickson, O'Brien, Ward, Flowers, & Allan, 2012 for details on this analytic process).

The data presented herein will explore, in detail, the consideration of risk in the decision-making process and its meaning for each individual separately but also within the partner dyad. The focus will then turn to the psychosocial outcome of the decision to proceed with LLD (at six weeks follow-up) and then to the process of change and adaptation (at six months follow-up). These themes will be presented as follows: (1) pre surgery: time, control and relational dynamics; (2) recovery: making sense of unanticipated outcomes; and (3) living with the consequences of LLD: adapting to change. For the purpose of anonymity, the donor will be referred to as Debbie and the recipient as Ryan throughout.

Results

Pre surgery: time, control and relational dynamics

Overall, a series of intra- and interpersonal negotiations were reported as the participants grappled to make a decision about LLD. In terms of interpersonal negotiations, both members highlighted that it was the donor, Debbie, who drove this bargaining

process; she was the one who was 'pushing hard for it' while Ryan reported 'sitting back' and 'burying his head in the sand'. For Debbie, the decision to proceed with LLD was an instantaneous one. As soon as she was aware of the procedure being an option and she knew she was a suitable match, she was ready to go ahead: 'I didn't have to think twice about it'. For her, LLD presented an opportunity to take back control of their situation, to secure a sense of certainty in a predominantly uncertain situation and to move on with the rest of their lives:

If I can help him I'm damn well sure I'm going to do it (...) and then I think as the weeks go on and he's not getting a call, he's getting worse, he can feel he's getting worse, you can see that he's getting worse and he thinks well, 'When is this call going to come?', you know 'Am I going to be fit for surgery?', 'What sort of liver am I going to get?' [Debbie]

LLD allowed the dyad to identify a date when the transplant would occur, providing an opportunity to focus on the future and the ability to plan for the rest of their lives. In essence, LLD presented an opportunity to reclaim their imagined future. While Debbie was fully aware of the risks involved in the procedure for her, risks entirely avoidable if the dyad were to wait for a cadaver liver, they were deemed to be necessary risks. Debbie's account of intrapersonal negotiation centres upon a costs/benefits analysis, both in terms of her own future quality of life as well as protecting the future of the dyad, as a couple:

It's a risk that I suppose you've got to take and you know, like I said, you can walk into a car and you might not come back from walking into the car, you might walk into surgery and you might not walk back out but, if we don't do this and he doesn't get a call, what's the alternative? I don't have a husband? Not much of a life. [Debbie]

The clear intention to pursue LLD is marked, not by any tangible moral or affective imperative, but instead by the language of logic, rationality and perhaps a hint of consumerism. In terms of taking control of her husband's survival, Debbie highlighted the bio-capital associated with her own liver: it was guaranteed to be a 'good liver' which would still have 'some miles on the clock':

Quality of liver is important. If it has to be me, you know at least it will be a healthy liver because you have to go through all these tests. It is pretty much a young liver (...) the liver re-generates but an eighty-six year old liver is not going to be as well as a twenty-six year old liver and it will be eight minutes rather than hours [in terms of time from removal to transplant]. [Debbie]

Debbie asserted she had the power to ensure her husband received a quality 'Marks and Spencer liver' as opposed to a 'Tesco value one'.¹ In contrast, for Ryan the decision to progress with LLD was not so straightforward. Ryan's account is marked with ambiguity although still firmly embedded within a temporal framework of decisions and dilemmas. He reports that his initial reaction was one of shock and disapproval but at the same time, this was enmeshed with an element of relief and hope. As such, he reported feeling 'a bit up and down about it':

It was a big shock to me and I was still taking it in. I just kind of pushed it to the side and I said 'Look, that's a last resort' sort of thing. And I'm still looking at it as a last resort. It's a safety net basically ... Obviously I'd much rather her not have to go through that. [Ryan]

And then later ...

I thought 'Oh, that sounds good' I thought 'but not if my wife had to do it'. [Ryan]

What emerges from these accounts is a marked divergence in the way that Debbie and Ryan frame their accounts. Debbie is clear, forthright and adamant about what she wants while Ryan appears uncertain, hesitant and keen to avoid LLD if at all possible. Despite this, both accounts are framed around the relational (the importance of maintaining the couple and the respective partner) and both are steeped with the importance of the temporal aspects of degenerative liver disease. Arguably, some of Ryan's ambivalence related to gender dynamics and the protective qualities associated with hegemonic masculinity:

I would have felt more comfortable my brother doing it than her, just because I know he's physically big and strong and eh, it's just the thought of the girl, you know ... she's my other half and the thought of, if anything could possibly could happen to her, it's just the process of going through it. I don't like the idea of it (...) I can't get the thought of it out of my head, of her having to lie on a table and getting cut open with a scalpel. [Ryan]

This graphic account emphasises the sense of Ryan's perceived culpability in regard to the surgery. This notion extends beyond the surgery itself to span any possible complications that may arise from the procedure afterwards:

For me, the really hard part to deal with is just the thought of her being in pain, just going through surgery in general and then having a scar afterwards and any possible pain. [Ryan]

Therefore, calculations concerning the risk of complications and adverse effects on his wife's health and quality of life post surgery appeared to dominate Ryan's thoughts. For him, a major part in his decision to proceed related to acceptable levels of risk for his wife:

If there was a strong chance that would happen [health issues arising from donating], say 50/50, there would be no way. It's more like if it's one per cent chance something could go wrong I could probably live with that but if it was a significant chance that she was going to have issues pertaining to it, I probably wouldn't want to go ahead with it. Even though it's a safety net, I'd just try my chances in the normal donor. [Ryan]

It would seem that all of the barriers to LLD for Ryan related to concerns for his wife. In this way, for this couple, there is a marked concern for the dyad and a clear relational quality to every decision that is made. Ryan acknowledged that he would have to go through the surgical procedure regardless but he didn't want to expose his wife to something that could compromise her quality of life perhaps unnecessarily. However, as time lapsed and his condition deteriorated, and due to the extreme perseverance of his wife, he did eventually agree to LLD, again reiterating the relational and temporal aspects of such decision-making:

I was like 'Oh I don't want you to do that for me'. But now, eh, as time's going on, we're realising well, you know, I don't know how long I might be on the list and I don't know how long my condition's going to stay this good. [Ryan]

While, in terms of interpersonal negotiations within the dyad, Debbie was the driving force in advocating LLD, despite her persistence, the final decision rested with Ryan. In the end, Debbie claimed that her husband was 'letting her do it'. The extract below signals this tentative period, the starkness of the decision made and the distress associated with uncertainty. These findings speak to the importance of theoretical concepts such as health locus of control (Wallston & Wallston, 1982) and the beneficial aspects of perceptions of control in managing stress (Lazarus & Folkman, 1984):

We were so fed up with, it was just being in limbo, we couldn't take anymore really. It was like one way or the other we've got to do something, it was wanting control, we wanted to feel like we could do something and (...) we really started to feel like if we didn't do something soon I was going to have to be on my death bed (...) so it was like basically life or death and we felt this was our only option. [Ryan]

In summary, this theme has highlighted in detail the intra- and interpersonal process of decision-making in LLD. We have focused here on the meanings associated with the cognitive process of how costs/benefits are calculated – both in terms of each individual as well as within the dyad itself. It is clear from the accounts above that this cost/benefit analysis is a tentative psychosocial and communicative process which unfolds over time and there are clear implications here for decision-making aids in LLD.

Recovery: making sense of unanticipated outcomes

At six weeks post transplant, the focus was centred on the overall consequences of the decision to proceed with LLD. The outcomes appeared much more diffuse than the cost/benefit analysis reported previously. Again, this theme follows a chronological trajectory: we begin with a focus on the initial psychological impact of the LLD decision. For Debbie, the decision brought with it a sense of relief and calm and she reported a feeling of regaining an element of certainty. For Ryan, however, this was juxtaposed with a mounting feeling of anxiety as the magnitude of his decision began to permeate all of his concerns for his partner:

I was freaking out about her but I wasn't letting it take over my thoughts because the whole reason I'd said I was willing to go ahead with this was because I thought she was going to be okay and I never wanted to let those thoughts enter my head, 'Oh, what if something goes wrong?', it was more trying to be positive and thinking 'This is going to work, this is going to work'. [Ryan]

Ryan's perceived culpability is again evident here. The inner turmoil that he experiences is ongoing, even after the decision to proceed with LLD has been made. There is a real sense here of the outcome of the decision resting firmly on Ryan's shoulders and, for him, there remains a desperate need for the decision made to be the 'right' one.

The dyad's narrative then shifted focus to more personal, idiographic accounts of how the LLD procedure had changed them as individuals, as opposed to as a dyad.

At the forefront was a focus on how the participants' bodies had been changed after the surgery. Both participants commented on their scars displaying divergent and stereotypically gendered responses. For the donor, the scar obviously detracted from her self-image and self-esteem; there is a prevailing notion of her being 'damaged' both physically and mentally by the experience. Again, a cost/benefit analysis appears to offset this consequence as Debbie contemplates the alternative (a life as a widow). There is a sense here that the physical cost to her appearance is a small price to pay for a future with her husband. In contrast, for the recipient, the scar represented 'a badge of honour':

It is big, it goes from here to here and my body's not healing as well as it should be. He has a lovely little pink line whereas mine mine's still quite inflamed and red (...) and that's probably my biggest issue is the scar, I'll need to keep it covered up (...) but that was the price to pay for having my husband back. [Debbie]

It's no big deal to me because I know it will fade over time anyways and I've got all the little staple marks and everything as well so it looks as if I got bitten by a shark. [Ryan]

It is possible that the aesthetic appearance of the scar affected the participants differently in terms of their expectations. Debbie was particularly surprised at the size of her scar and, for both members of the dyad, recovery was slower than expected. This created a sense of frustration but these particular costs were again offset by hope about the success of the surgery:

I probably, obviously not doing as much as I could do, or would be doing, but at the same time I can sacrifice that for another month if it means I've got my husband back again. It's not a big issue, but quality of life, physically it's less but because I have him back my quality of life is so much better than it was. [Debbie]

Although neither member of the dyad had recovered physically to the level they had previously anticipated, there was a feeling of triumph and victory nonetheless. This came from the fact that the dyad had taken control of their situation and had reclaimed their life, enabling them to shape their own future:

You can actually step in and do something yourself instead of sitting back and watching your loved one just deteriorating. When they're at death's door, you can actually do something about it. [Debbie]

Living with the consequences: adapting to change

At six months post transplant, the dyad concentrated on the outcome of LLD and how their lives (as individuals and as a couple) had changed for the better. Both participants reflected back on their lives prior to the surgery and used it as benchmark for gauging both their post-transplant quality of life and whether the risk they had taken had been recompensed. For both participants, physical outcome was limited to some extent by health-related complications of the surgery (e.g. post-surgical pain), but this was displaced by the improvement to their own (and the dyad's) overall quality of life and a new sense of biographical course and anticipated future. As individuals, the dyad were on their way to having their lives 'back on track':

I've got my hubby back, I can do what I want, I've done my training, I'm qualified, I've done that and I'm chuffed with myself that I've done that and I've passed all my exams on top of all this recovery and exams and stress. So, yes, just plodding along as usual and we've got so much to look forward to, our travels, emigration, and a house to build. I'm quite happy! [Debbie]

I had no quality of life really, so it was basically I guess I was slowly dying almost (...) so my quality of life is just totally, I've got my life back effectively from it. [Ryan]

There appears to be a complete intrapersonal transformation in terms of quality of life for the participants post transplant. An anticipated future and a sense of optimism for that future feature strongly. As individuals, the participants appear to have a new lease of life, physically as well as metaphorically. However, while as individuals the participants reported an improvement in terms of quality of life, as a dyad, there was a still an element of restraint:

It still feels like, we're just waiting to get out of the gates. I've had the transplant, everything is working, we've both done really well, now it's waiting for to get started, get a place of our own, go travelling again that sort of thing, so there's a lot, we've been doing a lot of planning and that's been keeping us going. [Ryan]

Again, this frustration may be related to unrealistic expectations regarding recovery. Recovery had been slower than expected (largely due to unpredictable post-surgical complications). However, the overall feeling from these accounts is that the risk the dyad had taken had been 'worth it'.

In contrast, the dyad reported that psychological adjustment to post-LLD life was much more complex. For Debbie, the surrealism of the experience was evident while for Ryan, there was a sudden and startling realisation of the gravity of the procedure he had agreed to subject his wife to:

It's still surreal and I'm waiting for it to hit me one of these days and I don't think it has. I don't really think it has sunk in (...) I still feel like it hasn't happened. [Debbie]

I was lifting weights in the garage the other morning and I just had a sudden thought and it was like anything could have happened to her, she could have like has something major happen, she could have died on the table, her liver might not have grown back. How could I have put her through that? And I had this big thing of emotion, it was like 'Oh my God!' and it just totally freaked me out and I went out and spoke to her, she was like 'It's done now so nothing to worry about' but you do get, it does mess with your head a little bit. [Ryan]

The emotional complexity in confronting the decision to proceed with LLD is evident here. Debbie appears emotionally overwhelmed while Ryan grapples with a sense of guilt – his account is peppered with a sense of disbelief (in his actions). Despite the guilt, Ryan reported not regretting his decision to proceed with LLD per se. He did, however, find it difficult to digest exposing his wife to such a high-risk procedure:

I don't regret it. I regret that she had to do the operation but I don't regret what we did. [Ryan]

By means of justifying his decision, Ryan emphasised the lack of alternative options available to him, the failure of the current organ donation system and a desire to respect his wife's wishes. He understood her position:

If she has been in that position it would have given me a chance to save her life and I would have had to stand by and watch her die effectively, so ideally there would be enough organ donors where it [LLD] wouldn't be needed and you go on a list and two weeks later you got an organ, that would be an ideal world. [Ryan]

Comparisons with an ideal world present a stark contrast to the harsh reality that the dyad were experiencing. Again, the magnitude of Ryan's decision is evident here and once more, there is an emphasis of temporal positionality across time. The lack of alternative options for the dyad plague Ryan's decision-making process and a deep sense of resonance and empathy with his wife's circumstance appear to finalise the decision for him.

In summary, both individuals reflected back on their decision-making process and reported that in the end, it had been the 'right decision'. The overall feeling was that their lives had been reclaimed: the donor had her 'husband back' and the recipient had his health back. They had achieved their goal and LLD had been a great success. The risk (to both Debbie and the dyad) had been 'worth it'.

Discussion

This paper has described the story of an LLD donor-recipient dyad, and is the first in-depth, qualitative, phenomenological evaluation of the LLD experience in the UK. By focusing on one donor and their corresponding recipient across a defined timeline, we have been able to capture both the intrapersonal and interpersonal perspective on how and why the decision to proceed with LLD is made, and its consequences. This study is the first of its kind, with the results offering a unique insight into the option of LLD and subsequently makes an important contribution to a limited research domain.

In an earlier qualitative study with 'potential' LLD donors in the UK it was found that consideration of becoming a donor was a result of a recognised urgency to save the life of a loved one/recipient (McGregor et al., 2009). What becomes clear in this case study is that this need is not necessarily a simple altruistic act but is a personal endeavour to maintain the quality of life of the donor, by taking direct action to save the life of their partner. The donor acts to reclaim her life and build the future she envisioned for herself and her husband. This finding is similar to that of other studies focusing on donor motivation for LLD, whereby the donor's need to preserve their relationship with the recipient is a key incentive (e.g. Kusakabe, Irie, Ito, & Kazuma, 2008; Papachristou et al., 2004). In a qualitative study with 11 living kidney donors and recipients, Gill and Lowes (2008) concluded that the process of living donation could be imbedded within the concept of 'gift exchange' as both the donor and recipient were set to benefit from the 'gift of life'. A similar concept is suggested within this LLD case study as the donor here wants to save not just 'the recipient' but more importantly, 'her husband': by her husband accepting her donation and surviving, she receives her life back in return. In this current study, we were able to gain insight into the anxieties and complexities of each person's decision and how they accumulated into the final joint decision to proceed.

Few studies have considered the perspective of the recipient during the decision to proceed with LLD or not and yet their acceptance of the donor's offer is essential if the procedure is to go ahead. Including the recipient's perspective here was an essential part of our aim to understand not only their own decision-making process but also their influence on that of the donor's decision. In a study interviewing potential living kidney recipients, a reluctance to accept an offer of a living kidney donation, due to the fear of harming the donor, was evident, but in an emergency situation they would be in a position to change their minds (Gordon, 2001). In contrast, LLD recipients are in a state of emergency from an earlier time point as, unlike many patients with end stage kidney disease, patients on the liver transplant waiting list do not have the option of dialysis (or equivalent) to subsidise the wait for a cadaveric/deceased donation. The urgency in obtaining a new liver is therefore heightened and the risk of dying before a cadaveric liver is found is very real. However, despite this extreme situation, one should not assume that the offer of LLD is automatically accepted. The recipient still has an important decision to make: risk their own life by waiting, or that of their proposed donor by accepting. In one of the few studies that has gathered the views of patients on a liver transplant waiting list about the possibility of living donation, similar to that found in Gordon (2001), the option of LLD was admittedly ignored due to the risk to the donor, but was not disregarded completely. The recipients did not want to die and therefore considered LLD to be a last option, when the recipient themselves felt confident that their own death was imminent (McGregor et al., 2009). The recipient in this case study also referred to LLD a 'last resort'. He describes a struggle with the decision to accept his wife's offer of a donation and justifies his eventual agreement with the belief that there were no other avenues to pursue. Deterioration can be sudden and, for many, when the time to resort to the 'last option' arrives, LLD may no longer be an option as time is needed to prepare a donor, and the recipient must be well enough to withstand major surgery (McGregor et al., 2009). It is, therefore, important to understand the position of the recipient when faced with LLD and subsequently learn how to support them in making such an important decision within a suitable time frame. The recipient here recognised this and acted accordingly.

It is clear that in the end both the recipient and donor felt they had no real choice but to pursue LLD, a theme found in earlier research with LLD donors in Japan (Fujita et al., 2006). In Japan, the removal of organs from a brain-dead person for transplant remains, for many, culturally unacceptable and, therefore, LLD really is the only option. While this is not the case in the UK, whereby a deceased donation is the preferred option due to the removal of any risk to the donor, the low availability of suitable organs is a marked limitation (McGregor et al., 2009; McGregor, Swanson, Forsythe, Hayes, & O'Carroll, 2014). As the recipient stated during his interview 'it's not like you can walk into a shop and get one' and so the lack of supply emphasised the lack of real choice. From the donor's perspective, while she confirms no coercion in her decision to donate, she stated she 'wouldn't feel she had to do it if there was enough donor pool out there' emphasising her perception of a lack of alternatives, as well as her identified need to take control of the situation.

For both the donor and recipient, the decision to proceed was a fluid process but with constructs from theoretical models of health behaviour evident within their narratives. Consideration of the seriousness of their situation, the risks involved, the perceived benefits of proceeding with LLD, and the costs of this proposed action were all part of the

decision-making and reflection process, linking their experience to expectancy value frameworks such as the health belief model (HBM) (Rosenstock, 1966). In addition, the deterioration in the recipient's health acted as a cue to action which was supported by their belief that they were able to take control of the situation. This latter point also links to theories of stress management (Lazarus & Folkman, 1984) and concepts such as health locus of control (Wallston & Wallston, 1982). Further research as to how the HBM and other theories of behaviour can be applied to LLD is warranted to help advance our understanding of both the decision to proceed and our theoretical knowledge.

Previous articles with LLD donors have analysed the pre-donation interviews conducted as part of the corresponding transplant unit's evaluation of donor suitability, but here the interview was purposively separated from the evaluation process. This was done to allow donors the opportunity to speak freely about their thoughts and beliefs without the pressure to present themselves positively and hence influence the transplant team's decision to recommend them as candidates for LLD. Although both the donor and recipient were informed of the independence of the interview and the interviewer, it is possible that their responses may still have included an element of social bias. However, the authors believe this was minimised with open and clear instruction from the interviewer and a good rapport with both interviewees. The interviewer had experience of conducting interviews with a transplant patient population, and personally arranged and conducted all interviews. The interviewer was also of a similar age and stage in life to both the donor and recipient, which, upon reflection, was felt to enhance the interviewer-interviewee relationship and encouraged the interview to proceed in a more informal, open manner.

A further limitation is contained within the very nature of a qualitative case study design. While it delivers depth and idiographic complexity it does not, and cannot, control for unique biographical factors that shape the data. Accordingly, the direct transferability of findings is ill advised but additional studies with alternative methods are called for (for example, those which address generalisability). Additionally, the donor-recipient dyad described here is perhaps even more unique given their young age and newly married status. For example, the risk assessment may have taken on a new dimension if the couple had been older and/or had children. The subsequent restricted generalisability of the results is noted but, in situations where a procedure is quite rare, it is essential to capture the decision-making experience whenever possible so we can question and adapt our theoretical knowledge accordingly. The results also offer transplant teams offering LLD to future patients a point of reference in their understanding of the dynamics of a decision to proceed with LLD and provides a platform from which relevant supports can be considered.

At the end of May 2014, 483 adults were on a liver transplant waiting list in the UK (NHS Blood and Transplant, 2014). This number is unlikely to significantly reduce in the near future with unhealthy lifestyles (i.e. excessive alcohol consumption, drug use and obesity) adding to the prevalence of liver disease and a need for liver transplants over and above that associated with inherited or viral causes (Williams, 2006). It is therefore imperative that research continues to develop and investigate alternative treatments to subsidise the shortfall of suitable donated livers and does so not only with physical implications in mind but also from a psychological perspective.

LLD is one such treatment alternative that draws on the benefits of accessibility, quality control, and reduced ischemic time, but is hampered by the significant risk of

death and morbidity for the otherwise healthy donor (Belghiti & Durand, 2000). This paper serves to provide an in-sight into the psychological implications of the option of LLD, and demonstrates what the associated risks mean for each person involved and how they influenced the decision to proceed. In this case study, the LLD operation was successful and despite unexpected changes in bodily appearance and limited functioning at six weeks post operation, by six months both participants described their lives as having changed for the better and this change was the direct result of their joint decision to proceed with LLD. Both the donor and recipient have succeeded in getting their life and their future back and so no regrets were noted. From suggestion and deliberation, to consequences and reflection, this case study has offered a unique insight into the psychosocial impact of LLD and the results can help support future risk assessment and decision-making demands.

Funding

This work was supported by the Chief Scientist Office [grant number CZH/4/348].

Note

1. 'Marks and Spencer' and 'Tesco' are two supermarkets operating in the UK. The former is generally understood as being more upmarket than the latter.

References

- Abouna, G. M. (2008). Organ shortage crisis: Problems and possible solutions. *Transplantation Proceedings*, *40*, 34–38. doi:10.1016/j.transproceed.2007.11.067
- Belghiti, J., & Durand, F. (2000). Living donor liver transplantation: Present and future. *British Journal of Surgery*, *87*, 1441–1443. doi:10.1046/j.1365-2168.2000.01603.x
- Cronin, D. C., Millis, J. M., & Siegler, M. (2001). Transplantation of liver grafts from living donors into adults – Too much, too soon. *New England Journal of Medicine*, *344*, 1633–1637. doi:10.1056/NEJM200105243442112
- Dickson, A., Allan, D., & O'Carroll, R. E. (2008). Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis. *Psychology and Health*, *23*, 407–425. doi:10.1080/14768320701219136
- Dickson, A., O'Brien, G., Ward, R., Flowers, P., & Allan, D. (2012). Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: An interpretative phenomenological analysis. *Journal of Health Psychology*, *17*, 247–257. doi:10.1177/1359105311411115
- Fournier, V., Foureur, N., & Rari, E. (2013). The ethics of living donation for liver transplant: Beyond donor autonomy. *Medicine, Health Care and Philosophy*, *16*, 45–54. doi:10.1007/s11019-012-9430-8
- Fujita, M., Akabayashi, A., Slingsby, B. T., Kosugi, S., Fujimoto, Y., & Tanaka, K. (2006). A model of donors' decision-making in adult-to-adult living donor liver transplantation in Japan: Having no choice. *Liver Transplantation*, *12*, 768–774. doi:10.1002/lt.20689
- 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. doi:10.1016/j.ijnurstu.2008.03.004

- Gordon, E. J. (2001). 'They don't have to suffer for me': Why dialysis patients refuse offers of living donor kidneys. *Medical Anthropology Quarterly*, *15*, 245–267. doi:10.1525/maq.2001.15.2.245
- Gordon, E. J. (2013). Ethical considerations in live donor transplantation. *Current Opinion in Organ Transplantation*, *18*, 235–240. doi:10.1097/MOT.0b013e32835f3f2c
- Gordon, E. J., Daud, A., Caicedo, J. C., Cameron, K. A., Jay, C., Fryer, J., ... Baker, T. (2011). Informed consent and decision-making about adult-to-adult living donor liver transplantation: A systematic review of empirical research. *Transplantation*, *92*, 1285–1296. <http://journals.lww.com/transplantjournal/pages/default.aspx>
- Jin, S., Xiang, B., Zhong, L., Yan, L., Chen, Z., Wang, W., ... Yang, J. (2013). Quality of life and psychological distress of adult recipients after living donor liver transplantation. *Transplantation Proceedings*, *45*, 281–285. doi:10.1016/j.transproceed.2012.05.076
- Karlsen, T. H., Schrupf, E., & Boberg, K. M. (2010). Primary sclerosing cholangitis. *Best Practice Research Clinical Gastroenterology*, *24*, 655–666. doi:10.1016/j.bpg.2010.07.005
- Kusakabe, T., Irie, S., Ito, N., & Kazuma, K. (2008). Feelings of living donors about adult-to-adult living donor liver transplantation. *Gastroenterology Nursing*, *31*, 263–272. doi:10.1097/01.SGA.0000334032.48629.c0
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.
- McGregor, L. M., Swanson, V., Forsythe, J. R., Hayes, P. C., & O'Carroll, R. E. (2014). *Providing living donor liver transplantation: A qualitative study with medical staff*. Unpublished manuscript.
- McGregor, L. M., Swanson, V., Hayes, P. C., Forsythe, J. R., & O'Carroll, R. E. (2009). Considering adult living donor liver transplantation: A qualitative study of patients and their potential donors. *Psychology and Health*, *25*, 751–766. doi:10.1080/08870440902822921
- Middleton, P. F., Duffield, M., Lynch, S. V., Padbury, R. T., House, T., Stanton, P., ... Maddern, G. (2006). Living donor liver transplantation – Adult donor outcomes: A systematic review. *Liver Transplantation*, *12*, 24–30. doi:10.1002/lt.20663
- Muzaale, A. D., Dagher, N. N., Montgomery, R. A., Taranto, S. E., McBride, M. A., & Segev, D. L. (2012). Estimates of early death, acute liver failure, and long-term mortality among live liver donors. *Gastroenterology*, *142*, 273–280. doi:10.1053/j.gastro.2011.11.015
- Neuberger, J., & Price, D. (2003). Role of living liver donation in the United Kingdom. *British Medical Journal*, *327*, 676–679. doi:10.1136/bmj.327.7416.676
- NHS Blood and Transplant. (2014). *Organ donation and transplantation – Activity figures for the UK as at 30th May 2014 [weekly statistics]*. Retrieved June 4, 2014, from http://www.organ-donation.nhs.uk/statistics/latest_statistics/
- Olfhoff, K. M., Merion, R. M., Ghobrial, R. M., Abecassis, M. M., Fair, J. H., Fisher, R., ... the A2ALL Study Group. (2005). Outcomes of 385 adult-to-adult living donor liver transplant recipients: A report from the A2ALL consortium. *Annals of Surgery*, *242*, 314–325. doi:10.1097/01.sla.0000179646.37145.ef
- Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, *3*, 65–83. doi:10.1111/j.2044-8287.1998.tb00556.x
- Papachristou, C., Marc, W., Frommer, J., & Klapp, B. F. (2010). Decision-making and risk-assessment in living liver donation: How informed if the informed consent of donors? A qualitative study. *Psychosomatics*, *51*, 312–319. doi:10.1176/appi.psy.51.4.312
- Papachristou, C., Walter, M., Dietrich, K., Danzer, G., Klupp, J., Klapp, B. F., & Frommer, J. (2004). Motivation for living-donor liver transplantation from the donor's perspective: An in-depth qualitative research study. *Transplantation*, *78*, 1506–1514. <http://journals.lww.com/transplantjournal/Pages/default.aspx>

- Papachristou, C., Walter, M., Frommer, J., & Klapp, B. F. (2009). A model of risk and protective factors influencing the postoperative course of living liver donors. *Transplantation Proceedings*, *41*, 1682–1686. doi:10.1016/j.transproceed.2009.02.096
- Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly*, *44*, 94–124. doi:10.2307/3348967
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Uehara, M., Hayashi, A., Murai, T., & Noma, S. (2011). Psychological factors influencing donor's decision-making pattern in living-donor liver transplantation. *Transplantation*, *92*, 936–942. <http://journals.lww.com/transplantjournal/Pages/default.aspx>
- Wallston, K. A., & Wallston, B. S. (1982). Who is responsible for your health? The contract of health locus of control. In G. S. Sanders & J. Suls (Eds.), *Social psychology of health and illness* (pp. 65–98). Hillsdale, NJ: Erlbaum.
- Watanabe, A., & Inoue, T. (2010). Transformational experiences in adult-to-adult living-donor liver transplant recipients. *Journal of Advanced Nursing*, *66*, 69–81. doi:10.1111/j.1365-2648.2009.05143
- Williams, R. (2006). Global challenges in liver disease. *Hepatology*, *44*, 521–526. doi:10.1002/hep.21347