

ORIGINAL RESEARCH

‘It’s a regional thing’: financial impact of renal transplantation on live donors

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A B S T R A C T

Introduction: There has been no research exploring the financial impact on the live renal donor in terms of testing, hospitalisation and surgery for kidney removal (known as nephrectomy). The only mention of financial issues in relation to live renal transplantation is the recipients’ concerns in relation to monetary payment for the gift of a kidney and the recipients’ desire to pay for the costs associated with the nephrectomy. The discussion in this article posits a new direction in live renal donor research; that of understanding the financial impact of live renal donation on the donor to inform health policy and supportive care service delivery. The findings have specific relevance for live renal donors living in rural and remote locations of Australia.

Methods: The findings are presented from the first interview (time 1: T1) of a set of four times (time 1 to time 4: T1–T4) from a longitudinal study that explored the experience of live renal donors who were undergoing kidney removal (nephrectomy) at the Renal Transplantation Unit at the Princess Alexandra Hospital, Brisbane, Australia. A qualitative methodological approach was used that involved semi-structured interviews with prospective living kidney donors ($n=20$). The resulting data were analysed using the qualitative research methods of coding and thematic analysis.

Results: The findings indicate that live renal donors in non-metropolitan areas report significant financial concerns in relation to testing, hospitalisation and surgery for nephrectomy. These include the fact that bulk billing (no cost to the patient for practitioner’s service) is not always available, that individuals have to pay up-front and that free testing at local public hospitals is not available in some areas. In addition, non-metropolitan donors have to fund the extra cost of travel and accommodation when relocating for the nephrectomy to the specialist metropolitan hospital.



Conclusion: Live renal transplantation is an important new direction in medical care that has excellent long-term results for individuals diagnosed with end-stage renal disease. An essential element of the transplantation procedure is the voluntary donation of a healthy kidney by the live renal donor. Such an altruistic gift, which has no personal health benefit for the donor, is to be applauded and supported. The present research demonstrates that for some donors, particularly those living outside the metropolitan area, the gift may also include a range of financial costs to the donor. There is no prior research available on the financial impact of live renal donation for individuals living in non-metropolitan areas. Thus, this article is a seminal work in the area. The findings affirm 'rural disadvantage' by demonstrating that it is the live renal donors in non-metropolitan areas who are reporting financial concerns in relation to testing, hospitalisation and surgery for nephrectomy. It is the hope and expectation that the reporting on these costs will encourage further work in this area and the findings will be used for health policy and service delivery considerations.

Key words: Australia, financial impact, live renal donor, qualitative research.

Introduction

Live kidney donors have become a critical source of organs for renal transplantation due to the scarcity of organs from deceased donors¹. Indeed, in Australia and internationally, live kidney donation is assuming an increasingly prominent role in kidney transplantation programs²⁻⁴. In Australia, live kidney donation is a routine and common procedure with low morbidity and excellent long-term results, and with better clinical outcomes than using kidneys from deceased donors⁵.

There is limited research conducted on the experience of live renal transplantation from the perspectives of the donors^{6,7}. Of specific relevance to this paper, there has been no research exploring the financial impact on the live renal donor in terms of testing, hospitalisation and surgery for kidney removal (known as nephrectomy). The only mention of financial issues in relation to live renal transplantation is the recipients' concerns in relation to monetary payment for the gift of a kidney and the recipients' desire to pay for the costs associated with the nephrectomy^{7,8}. The discussion in this article posits a new direction in live renal donor research; that of understanding the financial impact of live renal donation on the donor to inform health policy and supportive care service delivery. As the findings indicate that the major financial difficulties were experienced by regional, rural and

remote donors, the research makes a contribution towards deepening the understanding of the challenges faced by non-metropolitan people who have to relocate for specialist medical care. The findings reported in this article are from the first interview (T1) of a set of interviews (T1-T4) conducted over time with each participant from a longitudinal, qualitative study that explored the experience of live renal donors who were undergoing a nephrectomy at the Renal Transplantation Unit at the Princess Alexandra Hospital (PAH), Brisbane, Queensland.

Renal transplantation at the Princess Alexandra Hospital

The Princess Alexandra Hospital (PAH) is a 600 bed, public hospital located in Brisbane, Australia. The PAH Renal Transplant Unit adopts a multi-disciplinary and collaborative approach to patient care, providing comprehensive pre- and post-transplantation services. The PAH Renal Transplant Unit performs over 110 renal transplants each year, of which 40 are from living kidney donors. The Renal Transplant Unit maintains the highest survival rate for kidney transplants within Australia and New Zealand. With close affiliation with the hospital's Urology Department and Nephrology Department, the Renal Transplant Unit provides intensive short- and long-term follow-up for renal transplant recipients and their families⁹. In Queensland, there are 1592 patients on dialysis out of a total of 8528 in Australia; at the PAH alone,



there are 397 patients on dialysis¹⁰. By April 2009, the number of transplants performed at the PAH had reached 3000, with the hospital's first living kidney donor transplant having occurred in 1981¹⁰.

Methods

The participants were enrolled through the project officer for the study, who was under contract with CQUniversity and, thus, independent of the PAH. The project officer was provided with a list of potential donors who were being tested for compatibility with the recipient, along with their telephone numbers. This information was provided by the transplant coordinator at the hospital, who had gained verbal consent for this from each potential participant. All potential participants had been informed about the study from the hospital, both verbally from the coordinator and in writing through a letter outlining the details of the study. The participants were enrolled from this list through an initial telephone call, followed by the project officer providing a written project description of the project and an invitation for voluntary participation in the research. At this stage, signed consent forms from the participants were collected and enrolment occurred. Participants were not screened for the study per se, but all participants had to undergo both clinical and psycho-social assessment to be accepted as suitable to be a living kidney donor in the PAH Renal Transplant program. The psycho-social assessment, conducted by the liaison psychiatrist and social worker attached to the renal unit, explores through interviews the individual's decision making with regards to that individual's desire to donate. Prior to interviewing for the research, participants were again informed of their ethical rights (eg informed consent, confidentiality, right to withdraw).

A total of 20 participants ($n=20$) were enrolled at T1 (pre-transplant interview) and followed-up longitudinally for the study over three points in time: time 2 (T2) – 3 months post-transplant; time 3 (T3) – 1 year following T2; time 4 (T4) – 1 year following T3. One of the participants died during the study, leaving the final group of 19 at T4. All participants

were enthusiastic about their involvement in the study, chose to participate through telephone interviews, noted the time for the next interview at the close of each interview, and were welcoming when contacted by telephone for subsequent interviews. The T1 enrolment procedure was complicated by the fact that it was difficult to identify the ultimate donor when there were several potential donors for the one recipient under assessment or where the potential participant under assessment was eventually found to be clinically incompatible. The waiting time for the transplant was in many cases immediate once the donor was assessed as compatible. Thus, in order to obtain the pre-transplant interview for the correct donor who would undergo the transplant and be followed up, it was necessary to interview some participants who did not progress to the transplant stage. Thirteen ($n=13$) interviews were conducted with potential T1 participants who did not become donors.

The participants were all of adult age and had the following range of relationships with the transplant recipient: daughter ($n=4$), son ($n=1$), husband ($n=6$), wife ($n=4$), sister ($n=2$), nephew ($n=1$), partner ($n=1$) and friend ($n=1$). Because the participants were enrolled from a small, identifiable group at the hospital, the informed consent procedures gave a strict commitment to confidentiality and a guarantee that no further identifying information would be presented or published with the findings. Hence, further demographic descriptions will not be provided in order to protect the identity of the participants.

Research design

An open-ended, exploratory qualitative design was utilised for the study. Qualitative research is used to provide in-depth insights on consumer experiences and perceptions and, thus, is an effective means of gaining rich insights into the experience of living kidney donors^{11,12}.

Interviews

The exploration of the renal donors' experience was conducted through an iterative, qualitative research



methodology using open-ended interviews conducted at the time and location chosen by each participant. The telephone interviews were conducted by an experienced researcher with a background in psycho-social health research employed by CQUniversity and, thus, independent of the hospital. All participants chose to do the interviews through speakerphone.

One of the topics explored during the TI interviews was the financial impact of the testing and nephrectomy. The interviews lasted for approximately 1 hour and were audio-recorded. The interviews were transcribed verbatim by a research assistant independent of the hospital.

Analysis

The language texts were entered into the QSR NUD*IST (N5 1995; www.qsrinternational.com) computer program and analysed thematically. All of the participants' comments were coded into 'free nodes', which are category files that have not been pre-organised but are freely created from the data. The list of codes was then transported to a Microsoft Word document (Word 97) and organised under thematic headings. The coding was established by a qualitative researcher and completed by the project officer, who had extensive experience with coding qualitative data. There was complete agreement between researcher and project officer on the coding and emergent themes. The findings from the codes developed from the TI pre-transplant interviews in relation to the financial impact on the donor are presented in this article. Further findings on different topics from the longitudinal study based on the same methodology are currently being published¹³.

Ethics approval

The University Ethics Committee and the Queensland Health Department, Human Research Ethics Committee approved the study (no. H07/07/068).

Results

There were two main groups of participants in terms of financial impact: those who experienced financial strain from the costs associated with nephrectomy and those who were financially well off and, thus, did not experience financial concerns (Table 1).

The major factors associated with financial concern were the cost of testing, the extra costs for donors living in non-metropolitan locations, and the loss of income during nephrectomy and recovery (Table 2). For donors living in the regional, rural and remote areas there were extra costs associated with the fact that bulk billing (no cost to the patient for practitioner's service) is not always available, that individuals have to pay up-front first, that free testing at local public hospitals is not available in some areas and that non-metropolitan donors have to fund the extra cost of travel and accommodation when relocating for the nephrectomy to the specialist metropolitan hospital. There were also financial difficulties associated with employment. These included taking time out for those who were self-employed; loss of income during operation and recovery; lack of income because of lack of sick leave or long periods off work from a loss of job post-transplant; and the double financial impact from loss of income when recipient and donor were partners dependent on each other for income.

There were a number of buffers that deflected negative financial impact for donors in regards to the cost of testing and nephrectomy, and loss of income (Table 3). A major buffer was the fact that both testing and the nephrectomy were funded by the public hospital system. The reasons why individuals chose to avoid this financial benefit to go into the private system are outlined (Table 4). It is important to note that one of the reasons for choosing to do testing in the private system for non-metropolitan donors was that public hospital testing was not locally available.



Table 1: Financial impact on live donor

Impact	Participant statement
Financial strain	<ul style="list-style-type: none"> We're not short of a dollar but at the same time um it's a bit of a strain and it's going to impact on us financially It'll have a financial impact on both of us Well we do actually expect it to be quite a large financial [impact]
Financially well off (so no impact)	<ul style="list-style-type: none"> Financially, we're... everything is paid off. Because our home has been paid off for many years and we have a good bit of my husband's superannuation. So financially we have no problems. Well we're self-funded retirees. We'll never get the pension, put it that way But you know luckily for us money is not an issue Yeah, they give us six months... and full pay everything else. And like, we haven't got a mortgage these days because Dad ended up selling his house and paid my mortgage off...there's not a financial worry there, yeah, we haven't got any worry actually Yeah, financially that's all good. We're not worried about any of that

Table 2: Financial concerns associated with nephrectomy

Cost factor	Participant statement
Cost of the testing	<ul style="list-style-type: none"> It [tests] did cost me a bit of money actually... it was done privately, you know I haven't had any public testing done yet. Because we're in the private health system that covers everything in the hospital, however all these tests that have been carried out by private companies like Southern X-Ray and QML I'm out of pocket about seven or eight thousand for that
Extra costs associated with living in non-metropolitan area: <ul style="list-style-type: none"> Bulk billing not available Have to pay up-front first Free testing at local public hospital not available in some areas Cost of accommodation for self and carer 	<ul style="list-style-type: none"> It got to the point where just the local doctor found something wrong, he said, 'Oh we need to get an MRI'. That was going to cost me \$1000 because everything up [in regional area]. What people in Brisbane don't understand is that everything that happens outside of Brisbane is not bulk billed Went for the MRI. It cost a thousand dollars. However what they did is you go and you get an \$800 rebate so that made it less and they don't do this [in regional area]. I've never heard of this before and actually made me just pay the difference. I think we were out of pocket 130 something dollars. They sent it off for, they sent this bill straight off to Medicare. Now in [in regional area] they're not meant to do that. You normally have to pay first and then you send and try and recoup your money But I've had numerous test visits, lots of tests. All the pathology here all had to be paid for. Where for somebody in Brisbane that's all paid for through the public hospital system. You know if you go and get your blood tests done at the PA Hospital it's all bulk billed. So out of pocket expenses for somebody who's not living in Brisbane can be quite high However, people in Brisbane aren't out of pocket at all. It's just... it's a regional thing So we live in a regional area. When [recipient] goes up there his wife is entitled to stay in the units across the road from the PA. Hospital and a subsidy of \$60 a day for weeks and weeks and whether he's living in the unit or not. But for the donor they'll give you \$30 a day but only while the donor is actually living in the unit. And I thought that that probably wasn't quite right We're not going to bother with it [accommodation]. [Carer] going to commute every day [from non-metropolitan location] while I'm in hospital If I'd wanted to recuperate near the hospital for a few days afterwards [to be near recipient], they only pay \$30 a day. So you think, 'Oh where am I going to get \$90?' People perhaps that lived in Rockhampton or something basically they're... the carer or the partner or the wife, whatever, that's only going to get \$30 a day. So it's about \$85 a day if you stay for a week in the units across the road [from the hospital]



Table 2: Cont'd

Cost factor	Participant statement
<p>The loss of income from employment during and post nephrectomy</p> <ul style="list-style-type: none"> • Difficulties associated with taking time out for the self-employed • Loss of income during operation and recovery • Lack of income from loss of job post-transplant • Financial impact from loss of income is doubled when recipient and donor are partners dependent on each other for income 	<ul style="list-style-type: none"> • But it's just running the business. We thought we were going to have to pay out quite a bit in wages. [Name of donor] is not entitled to any sickness cover because no insurance cover company would cover him. So it's something we've just got to cover the cost of wages and things like that. So we will have to pay him a wage because it's not a business that you can employ somebody to run because it just doesn't make that much money. So we expect it will cost us financially • Probably if he didn't have a job, yes [it would have a major financial impact]. All he was worried about was keeping his job, not his health. Worried about keeping his job. And keeping his family happy that they've got a roof over their head, food on the table. He wasn't worried about his health at all; his job: 'Oh, I'm not going to have a job. I'm not going to have a job' • It is to the extent that whether you're in a job or whether you're well, you've got your own business you're going to be affected work wise for probably six weeks. That's going to be a long time without a lot of income • I'm in a situation where if I don't work, I don't get paid. So more or less a contractor • [Recipient] has had all of her sick days for probably the last two or three years. She's always had to access those days. So there's no build up of sick leave and she's going to have to take recreational leave and leave without pay for the duration of the time when she's off work, that's her expected time off work. That may be affected certainly financially it will. It'll be difficult for me [donor]. I might even find that seriously I might not be able to continue working

Individuals did express gratitude for the fact that live renal transplant is to a degree publicly funded, for example:

I'm always conscious of the fact that the public purse is paying for this very expensive operation. I'm very grateful that it is for us not costing us anything. If I'm out of pocket you know a couple of thousand dollars for flights and tests and things like that, in the big scheme of things we're still getting off. In the big picture we're still getting off very lightly.

However, even for those individuals who were well off and without financial strain, they acknowledged that the costs associated with being a living renal donor would potentially be too expensive for those on limited finances. For example:

But a normal ... like my son could never have done it because they live week to week. I mean they've got a mortgage, a baby...

But the average person could not possibly do it.

You may find that some people that are prepared to do it may find that they can't afford to do it (because of loss of income during operation and recovery).

The financial difficulties were considered particularly acute for those living outside the metropolitan area, for example:

...a lot of people out there that are prepared to donate an organ, if they aren't all that wealthy and they live in an out of Brisbane area, they are going to find that if they've got to pay all the accommodation costs themselves that could impact on them quite a bit.



Table 3: Buffers reducing the impact of financial stress

Buffer factors	Participant statement
<p>Buffer for testing</p> <ul style="list-style-type: none"> • Costs covered by public health system • For those doing tests in private system the financial buffer is provided by Medicare and private health insurance • Bulk billing covers costs for tests 	<ul style="list-style-type: none"> • Because they were done through the Base - the government hospital. So they picked up the tab for those. So, no, not really [any financial impact] • It's all under Medicare. That'll cover everything. We won't be out of pocket a lot of money • Ah well, we're in medical benefits, so we get a bit back on that. They do cover a bit, yeah. No, no big deal, no • Basically all the tests that I've had I haven't had to pay for any of them. They bulk bill me for everything basically
<p>Buffer for operation</p> <ul style="list-style-type: none"> • Operation is in public hospital • Health insurance cover will fully meet costs of operation • Same specialist and health care team for operation in either public or private so no incentive to 'go private' • Can work over time (rostered days off) to cover cost of nephrectomy. 	<ul style="list-style-type: none"> • The operation's free... because of the public hospital. Yeah, the specialist said, 'You're not going through your private health,' and we said, 'Why not?' Because I was prepared to mortgage the house and everything to get the money and do all that and he said, 'No it's the same—if you do it public it's the same doctors, same ward, same everything'. So I was booked in for the public • Yeah, one...sort of, basically told us, you know, I am the donor, you know, I basically slipped out and go see the bank and get the money for it, do all this and that, and he stomped it straight on the head and said, 'No, you're going through public'. So one less thing to worry about, you know • ...well medical costs, is not going to... It's going to be very minimal. We do have private health insurance, I'm quite happy to go privately and even if we do it will be fully covered • But that wasn't a problem at all... the transplant. [Name of donor] has insurance • I don't care because we're in private health care cover, it doesn't bother me • No great financial impact – can take RDO [rostered days off] days to cover operation
<p>Buffer for the cost of loss of income from employment leave</p> <ul style="list-style-type: none"> • Sick leave owing • Recreation leave owing • Position remaining open for return post-transplant 	<ul style="list-style-type: none"> • I've got sick pay and holiday pay that I'd probably be okay with • ...financially that's all good ...some sick leave and long service leave • Job remaining open...

A recommendation documented in the research is that addressing the financial impact for donors may help to increase the number of people who are prepared to become a living renal donor, particularly for those outside the metropolitan area, for example:

Oh well I think that probably from the perspective of increasing the number of donors or whatever ... For live donors that[s] probably a little bit more support for them financially, might at least bring them up to square one.

If there was some sort of financial help it would (help) ... because the costs are even though it's through the public system there are costs and particularly for a person that has to drive up from [name of non-metropolitan area] and all of that and like having the time off work. Even though I have got some sick leave the rest of it is going to be without pay. It's not even like an illness you have, it's something you are contributing to somebody else so your costs should be totally covered.



Table 4: Reasons for choosing private health system for testing

Reason for 'going private' rather than public	Participant statement
The process is quicker	<ul style="list-style-type: none"> Had to pay for a few of them but you get most of it back. There's a couple that I suppose I probably put out about a few hundred dollars But that never bothered me. I would prefer to get the tests done quicker and pay for them myself rather than to take six weeks and go public... because I didn't want to wait
Wanted to do everything possible to assist recipient's recovery	<ul style="list-style-type: none"> You know because I was just wanted [recipient's name] to get better. Quite often I'd say, 'Oh well I'll just go private and pay for that then because I'm not in a health fund' and sometimes I'd do that, you know, and it didn't bother me
Public hospital testing is too far away for non-metropolitan donors	<ul style="list-style-type: none"> Well I've gone privately for whatever I could, especially because [name] hospital is such a long way away and there were some tests I just had to have done locally
Reaching Medicare 'safety net' limit provides incentive to go private for those with health insurance	<ul style="list-style-type: none"> And by the time I got to kidney biopsy we'd reached our safety net anyway... we all have private health you see. So there was no reason not to have the biopsy privately and I had to see private nephrologists to be referred for that anyway

Discussion

At present there is limited work documenting the financial factors associated with live renal transplantation. A study by Coorey and associates¹⁴ demonstrated that a lack of financial resources can be a substantial barrier to pre-emptive kidney transplantation. However, on the financial impact of live renal transplant, the work of Coorey and associates is not specifically focused on regional issues and is from the recipients' perspective¹⁴. The work of White and associates¹⁵ focused on the financial and resource issues associated with global equity in the provision of renal replacement therapy. Bond¹⁶ points out that cost-containment will be an ongoing issue in the environment of fiscal constraint in which renal transplant centres operate. Although all of these issues are important, they do not address the financial concerns of live renal donors. With regards to the topic of the present article, there is no research available on the financial impact of live renal donation for individuals living in non-metropolitan areas. Thus, this article is a seminal work in the area that raises a highly important and relevant concern for the long-term future of live renal donation. The hope and expectation is that this preliminary work will encourage more detailed research in different geographical locations and populations.

Known as the 'rural disadvantage', there is now acknowledgement in the literature of the socioeconomic difficulties, inequitable access to services and geographic factors that make access to specialist medical care problematic for those in non-metropolitan areas¹⁷. The findings reported in this paper affirm this disadvantage by demonstrating that it is the live renal donors in non-metropolitan areas who are reporting financial concerns in relation to testing, hospitalisation and surgery for nephrectomy.

Australian-based research indicates that there can be considerable financial distress for non-metropolitan families that have to relocate for specialist medical care^{18,19}. Although most of the research completed in this area is in relation to cancer patients, it is now well documented that rural and remote residents often have to take time off work, travel long distances, and pay for accommodation and other relocation expenses in order to access specialist care in a metropolitan area¹⁹⁻²². The financial hardships for non-metropolitan live renal donors documented in the present findings include that bulk billing is not always available, individuals have to pay up front first, free testing at local public hospitals is not available in some areas, non-metropolitan donors have to fund the extra cost of travel and accommodation when relocating for the nephrectomy to the specialist metropolitan hospital, and



return trips to the metropolitan hospital have to be funded for follow-up care.

Hiller and associates²³ noted that live renal donors in the USA expressed concern about the number of days off work that they would require. The present findings posit a range of work-related financial concerns for live renal donors, including difficulties associated with taking time out for the self-employed, loss of income during operation and recovery, lack of income from a loss of job post-transplant, and the double financial impact from loss of income when recipient and donor are partners dependent on each other for income.

It is a concern that the focus of research to date has not included the financial impact of nephrectomy in the exploration of the live renal donor's experience. Recent UK research by Mazaris and associates²⁴ indicates that any financial reward, even as compensation of expenses, is a controversial ethical topic from the health professional's perspective. It is acknowledged that one of the difficulties in advocating for financial support for live renal donors is the conflation of the issue with the discussion of payment or reward for the donation of a live kidney^{7,8}. However, as noted by Walsh, the investigation of the live renal donor's experience is important so that potential donors are supported appropriately by the healthcare system²⁵. It is argued in this article that for all live renal donors, and especially for those living in non-metropolitan areas, it is essential to understand the financial implications of nephrectomy. Knowledge of the financial impact is essential to ensure that costs are not a barrier to the decision to become a live renal donor, there is equity in the opportunity to participate as a donor, appropriate practical support is provided to donors, and issues of relocation for non-metropolitan donors are addressed.

Conclusion

Live renal transplantation is an important new direction in medical care that has excellent long-term results for individuals diagnosed with end-stage renal disease. An

essential element of the transplantation procedure is the voluntary donation of a healthy kidney by the live renal donor. Such an altruistic gift, which has no personal health benefit for the donor, is to be applauded and supported. The present research demonstrates that for some donors, particularly those living outside the metropolitan area, the gift may also include a range of financial costs to the donor. It is the hope and expectation that the reporting on these costs will encourage further qualitative and quantitative work in this area and that the findings will be used for future health policy and service delivery considerations.

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