

The Cost of Organ Donation: Potential Living Kidney Donors' Perspectives

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Living kidney transplantation is a treatment option for some people with end-stage kidney disease. The procedure has low complication rates and positive outcomes; despite this evidence, the number of living kidney donations has decreased in recent years, and the causes are not well understood. This qualitative study sought to explore the experiences of potential living kidney donors before the transplantation. A total of 19 semistructured interviews were conducted with potential living kidney donors in Perth, Western Australia. Results reported here relate to participants' experience of the employment and financial implications of living kidney donation. Participants incurred direct and indirect costs during the time leading up to the transplantation, and many had concerns about the potential financial impact during the recovery period. Employment status, occupation type, and financial commitments affected participants' experiences, and financial concerns were exacerbated for those who were donating to their partners. Results suggest that potential living kidney donors would benefit from tailored financial planning advice to help them prepare for the time of the surgery and the recovery period.

KEY WORDS: *economic costs; financial implications; potential living kidney donors; work implications*

Following a worldwide trend (Jha et al., 2013), the incidence of end-stage kidney disease (ESKD) is on the rise in Australia, with the annual number of new ESKD cases increasing by 29 percent between 2000 and 2010 (ANZDATA, 2011). An increase in the number of people affected by ESKD who require a kidney transplant has resulted in a shortage of kidneys and longer waiting lists (Mathew, Faull, & Snelling, 2005). With improvements in medical treatments, a growing demand for kidney donors, and an unchanging number of deceased kidney donors available, living kidney donation is increasingly considered as an alternative, cost-effective source for kidney transplantations (National Health and Medical Research Council [NHMRC], 2007). Living kidney donation has an extremely low surgical complication rate, positive outcomes for the donor, and excellent survival rate for the recipient (Johnson et al., 1999; Johnson et al., 1997).

Despite this evidence, the number of living kidney transplants (LKTs) has decreased in recent years (Rodrigue, Schold, & Maldenbrot, 2013). Australian data show a downward trend in the number of LKTs, both in absolute terms and as a proportion of the total number of kidney transplants (ANZDATA,

2011, 2013). The reasons behind this decline are not clear, and may include an increase in medical unsuitability, shifting practice patterns, public policies, and financial disincentives (Rodrigue et al., 2013). There is evidence that some populations' beliefs may be incongruent with organ donation (Alvaro et al., 2008; Fahrenwald & Stabnow, 2005). In addition, multilevel influences contributing to barriers to living kidney donation have been identified; among these are the economic costs associated with the transplant evaluation and the availability of mandated sick leave and donor reimbursement (Purnell, Hall, & Boulware, 2012). Living kidney donors (LKDs) incur both direct and indirect costs; direct costs include travel, accommodation, long-distance phone calls, and medical expenses, whereas indirect costs include lost income, dependent care (child, elder, and spousal), cost for domestic help hired to undertake housework, and other miscellaneous services (Clarke, Klarenback, Vlaicu, Yang, & Garg, 2006). Furthermore, evidence shows that it takes approximately five weeks for LKDs to be able to return to work after the operation (Tooher, Boulton, Maddern, & Rao, 2004), which may exacerbate any income loss experienced during the work-up (that is, the assessment of kidney donor suitability).

Although this research informs our understanding of some emerging issues, there is scarce qualitative evidence on the financial implications of living kidney donation. In a review of living donors' and recipients' experience of donation, Ummel and colleagues found 15 qualitative studies conducted with donors and/or recipients (Ummel, Achille, & Mekkelholt, 2011). However, their metasummary of results did not report on any data related to the financial cost of living kidney donation. Qualitative research conducted among African Americans has shown that LKDs have financial concerns related to having to take time off work (Adams-Leander, 2011; Lunsford et al., 2007), and a study conducted in Western Australia found that donors perceived support from work as essential, as they needed to take time away before, during, and after the surgery (Williams, Colefax, & O'Driscoll, 2010). More recently, a qualitative study conducted in Queensland explored the financial impact of transplantation on LKDs and found that donors living outside the metropolitan area incurred greater economic costs related to testing, hospitalization, and surgery (McGrath & Holewa, 2012). This finding suggests that the LKD's place of residence may exacerbate the financial losses experienced and is a salient factor in Australia, where 31 percent of people live in regional and remote areas (Baxter, Gray, & Hayes, 2011).

A strategy to address these financial barriers consists of establishing provisions for the remuneration of donors' out-of-pocket expenses. Countries such as Belgium, Canada, France, Spain, and the United States have legislation allowing donors to receive reimbursement for expenses and lost income; in contrast, other countries such as Portugal and Turkey have legislation that expressly forbids any compensation to donors (Klarenbach et al., 2006). Seeking to alleviate some of the financial burden incurred by LKDs, in 2013 the Australian government introduced a pilot initiative designed to support living donors by providing a payment of up to six weeks at up to the National Minimum Wage, which was \$16.37 per hour as of July 1, 2013 (Australian Government Department of Health, 2013).

The results reported here are part of a broader study exploring the experiences of potential LKDs (PLKDs) before the transplant. This article discusses PLKDs' reports of the costs incurred during the work-up process, and their expectations of the financial and work implications of the transplant operation.

METHOD

The study adopted a qualitative methodology and, insofar as it was interested in participants' lived experiences, it was informed by the principles of phenomenology (Starks & Trinidad, 2007) and naturalistic inquiry (Lincoln & Guba, 1985).

Sample and Recruitment

The work-up is conducted in stages and includes medical and immunological testing, as well as psychological and social screening (NHMRC, 2007). This study sought to explore the experiences of PLKDs as they undergo the work-up, regardless of the outcome of the assessment; thus, both those who had been deemed suitable to donate and those assessed as unsuitable were eligible to participate. Study participants were recruited from a renal transplant unit of a public teaching hospital in Perth, Western Australia. Recruitment occurred once the assessment process had been completed and a minimum of two weeks before the transplant operation. One of the principal investigators—a nephrology consultant who had no further involvement in data collection—contacted potential participants by telephone and obtained verbal consent for their contact details to be forwarded to the study coordinator. The study coordinator followed up with a telephone call, explained the aim of the study to potential participants, mailed an information sheet describing the study and a consent form to those interested in taking part in the study, and gained written consent prior to the interviews.

Data Collection

Data were collected through in-depth interviews, which have widely been used to explore the experiences of PLKDs (Sanner, 2005; Tong et al., 2012; Williams, Colefax, O'Driscoll, & Dawson, 2009). The interviews adopted a semistructured format to capitalize on the richness of participants' responses while ensuring a complete understanding of the topic (English, Ball, & Crawford, 2005). The interview schedule comprised a series of open-ended questions designed to trigger conversation, providing a framework within which participants could express their experiences in their own terms (Patton, 2002). The interviews were conducted at participants' convenience, either at home or at the hospital. Interviews with participants living outside the metropolitan area were conducted over the telephone. The interviews

had an average duration of 45 minutes and were audio-recorded.

Data Analysis

All interviews were transcribed verbatim, and the resulting transcripts were imported into NVivo 10 (QSR International, 2014) and subjected to thematic analysis. An inductive approach was adopted to develop an initial list of coding categories; this list was subsequently reviewed by the research team until consensus was reached. In addition, the transcripts were periodically reviewed to identify any additional category. Once the coding of the data was completed, connections between categories and patterns were identified, ultimately leading to a theoretical explanation (Green et al., 2007). Member checking, coding validation, and peer debriefing were used to attain trustworthiness (Morse, Barrett, Mayan, Olson, & Spiers, 2002). In addition, using NVivo 10 enhanced the rigor of the data analysis by adding transparency to the data analysis process (Siccama & Penna, 2008).

RESULTS

Sample

A total of 19 participants took part in the study. Their characteristics are shown in Table 1. All participants were either genetically or emotionally related to the potential recipient. The majority ($n = 13$) were going to donate directly to the recipient, and the remainder ($n = 6$) were part of a paired kidney exchange program whereby potential donor-recipient pairs who are incompatible with each other can be matched with other incompatible pairs (NHMRC, 2007).

The results are presented in two sections: The first discusses participants' reports of any economic costs incurred during the time leading up to the transplant; the second discusses participants' expectations of the likely employment and financial impact at the time of transplant surgery and during the recovery period. All quotes are contextualized by a pseudonym and an indication of the participant's employment status. Given that participants were recruited from a small pool, for confidentiality reasons, no further demographic information is provided.

Employment and Financial Implications of the Work-Up

Most participants in our study ($n = 16$) were employed at the time of the interview. Participants who worked full-time had to take time off work during the work-up to undergo tests and attend hospital

Table 1: Selected Characteristics of Study Participants ($N = 19$)

Characteristic	Participants n (%)
Gender	
Female	9 (47.4)
Male	10 (52.6)
Age group	
25–34	3 (15.8)
35–44	3 (15.8)
45–54	9 (47.4)
55–64	3 (15.8)
65+	1 (5.3)
Country of birth	
Australia	7 (36.8)
Overseas	12 (63.2)
Recipient	
Partner	7 (36.8)
Parent	4 (21.1)
Sibling	3 (15.8)
Other relative	3 (15.8)
Friend	2 (10.5)
Donation type	
Direct	13 (68.4)
Paired exchange	6 (31.6)
Suitability status	
Suitable	17 (89.5)
Unsuitable	2 (10.5)
Employment	
Casual work	2 (10.5)
Full-time work	9 (47.4)
Part-time work	5 (26.3)
Retired/no longer in workforce	3 (15.8)
Location of residence	
Metropolitan area	15 (78.9)
Outside metropolitan area	4 (21.1)

appointments; however, most reported having supportive and flexible employers who had allowed them to take time off as needed. The impact on work was minimized for those working shifts, as they reported being able to swap shifts if needed. Working part time and being self-employed also mitigated any impact on work, as participants reported being able to fit their appointments around their work schedule.

Participants reported incurring some direct costs related to travel, such as fuel, public transport, and parking fees. Although four participants lived outside of the metropolitan area requiring a two- to four-hour drive (one way) to attend their hospital appointments, travel expenses were not reported as a major concern. Only one participant reported having accessed the Patient Assisted Travel Scheme, an Australian government initiative that provides travel

subsidies to patients living outside the metropolitan areas (Government of Western Australia, 2011).

There were a few reports of out-of-pocket medical expenses related to some medical tests, although most participants reported having had all tests fully covered by Medicare, Australia's publicly funded universal health care system. It is noteworthy that, regardless of their private insurance status, all participants in our study underwent all major medical tests at the public tertiary hospital where the transplant surgery was due to take place, and were thus covered by Medicare. Participants were appreciative of this: Molly, for example, described it as "a shock" to find out that Medicare would cover the cost of all the testing, as she expected she would incur out-of-pocket expenses, and Stan reflected,

Years ago we used to think, oh, when this comes around, you know, we'll be up for thousands like, you know, like if it was a wedding or something [chuckles]. . . . It was nice to know that it's pretty much cost-free, yeah. That's good.

The most significant financial impact associated with the work-up was the indirect cost related to loss of income reported by two participants who were employed in casual work (a form of employment characterized by lack of access to certain rights and benefits) and contract work, respectively. Tony, a single father of two young children, described his situation as he spoke of his experience:

It was actually frustrating to me because I'm a casual worker and every time I went to book up for a test it would cost me about four or five hundred dollars in lost work, just to make that particular test. Because it would always happen on a Thursday or a Friday, or even a Wednesday, and I'd have to book off work for it, and it cost me thousands. . . . I don't care about the fuel driving up or anything like that, that was nothing, or parking or whatever, it was just that it couldn't all be done on a particular day or squeezed into like a two- or three-day block, the whole process.

Tony estimated the loss of income incurred throughout the work-up at "five or six grand," and this was exacerbated by the fact that, because of the nature of his work, he was unable to schedule his shifts in advance, and thus had to forego any shifts

that clashed with his tests and appointments. Similarly, Greg, a full-time contract worker, explained,

I only have certain days that I can do tests. I can't . . . and I'm a contractor doing this, so when I take a day off work, I don't get paid. . . I can't take sick leave or anything like that.

Greg's account revealed his frustration at what he described as a process lacking in flexibility and unable to accommodate his work and personal circumstances. This perception was shared by Tony and other participants, and although for most it was just an inconvenience, for Tony and Greg this lack of flexibility had major financial implications. It has to be noted that throughout the interview, Greg was very critical of the work-up process, and his account was punctuated by reports of lack of flexibility and communication issues that marred his experience.

There was also evidence of further work and financial impact for PLKDs who were donating to their partners. Financial difficulties were compounded when the intended recipient was too unwell to remain in the workplace or had to transition from full-time to part-time work. Elizabeth, who was donating to her husband following a first kidney rejection, became emotional while discussing financial issues. Her husband had lost his job twice because of his kidney condition, first when he became too unwell to work before the first transplant, and more recently when his body had rejected the kidney. This had compounded their financial difficulties. Elizabeth, who was self-employed, reflected on the protracted nature of the work-up:

Especially if [the recipients] lose their job or they can't work, you know, it's. . . when they say it can be anything from six to twelve months in the work-up, that's a long time out of people's lives to, you know, try and get through, and, you know, if the person's not working for twelve months, you know, it'd be a big strain on people.

Similarly, Claire reported that her husband was unable to work full-time following recent health complications; however, she reported that her husband's workplace had been very supportive, allowing him to adopt a work schedule that suited him.

Donors whose surgeries were delayed because the intended recipients were stable also reported additional stresses. Mary reported feeling "slightly frustrated"

about not knowing when the surgery would take place, especially as she had just returned to work and felt that she had to keep her employers informed of what lay ahead. Similarly, Leyla spoke of the “waiting game” until the surgery would take place and the impact on her work:

I’m happy doing my casual hours and stuff, but when I look online and look at jobs and stuff, I think, “Oh, full-time permanent, should I go for it?” you know? And you go, I don’t want to start a job and having to say, you know, “I need time off,” ’cause that’s not the person I am, I don’t like doing that, you know, you commit to something and you wanna finish it, so yeah, that plays on my mind as well, ’cause it’s a waiting game.

Leyla reported that she had quit her job and was now doing casual work. She explained,

I made the decision to leave my full-time job, not because of the testing process, but because I wasn’t happy in it, so, it’s worked out now that I can do my testing and doing work at the same time, so that was good.

Expectations of Posttransplant Employment and Financial Impact

Participants who were still in the workforce had the expectation that becoming an LKD would have an impact on their finances at the time of the surgery and during the recovery period. This perception was a source of concern to participants and was influenced by their understanding of the recovery time, the nature of their work, and whether they had adequate sick leave to cover their living expenses during the recovery time.

Participants reported having been advised that it might take them up to six weeks to get back to their normal routine after the transplant surgery. However, consistent with their perception of themselves as “fit and healthy”—a common feature in our sample—many appeared to expect that they would recover more quickly. For example, Daniel, a shift worker, thought he would “probably be OK after a week,” although he had given himself two weeks before returning to work; similarly, Joe, an office worker, hoped to be “up and about” doing his “normal things” within a couple of weeks.

Participants’ expectations of the financial impact of donation were influenced by the nature of the

work and whether it involved manual labor. Thus, participants perceived that those employed in office work would be more likely to return to work sooner, and the ability to work from home during the recovery time was also seen as mitigating the financial impact of donation. In contrast, those working in more physically demanding jobs expected that it would take them longer to be fit enough to return to work. Jim, a full-time worker whose job required him to use machinery and climb ladders, reflected,

I have heard of people saying that they were back at work in three weeks’ time after donating a kidney, but those might, you know, their jobs are fairly different to mine, and everyone is different, people recover in different ways.

Similarly, Jacinta had a physically demanding full-time job; however, she believed that her employers—who had been very supportive throughout the work-up—would be willing to allocate her other tasks when she returned to work. She explained,

My job is easy anyway, so I can go back and if there’s any hard work that I can’t do, they’ll just say, “OK, don’t do it; we’ll get other carers to do the hard work.”

A total of 14 participants had been deemed suitable to donate and were still in the workforce. The narratives of seven of these participants suggested that the operation would have a significant impact on their finances because they had either inadequate or no sick leave. Mary, for example, explained that as a part-time worker she was not entitled to any sick leave, while Daniel spoke of having less than two weeks’ paid leave. As a contractor, Greg was not entitled to sick leave, and although he had income protection insurance, this would not go into effect until 10 weeks after he stopped earning an income and would, thus, not apply in this instance. Similarly, Jim, a full-time maintenance worker, reported that he was unsure whether a living donation was covered by his income protection insurance. He understood that his policy covered sickness or injury, but not a voluntary procedure such as an organ donation. Reflecting on what the financial impact of the transplant surgery would be if he was not covered, Jim noted,

It would have a very negative effect on me, ’cause I would run out of money quite quickly, I would

think, and I would have many questions asked by, you know, I've got payments, I've got food to provide for my family, and the money is not an endless pit, it will run out eventually and I'm sure . . . you know, the banks they're not interested in how my health is going, they're only interested in what they're owed.

The financial impact of the transplant was a strong theme throughout Jim's interview. He was supportive of providing financial assistance to living donors to alleviate the cost of the donation, and at the time of the interview he was seeking clarification on his situation through his employer. Asked whether he had contacted the hospital's social worker to seek advice on this matter, Jim replied,

I'm not that concerned about myself, I know I'm going to be . . . financially I'm going to be fine, but for the others, I mean, I know this study is all about trying to make things better for others and that sort of stuff, so . . . I'm just speaking on behalf of the next person, they might not be in the position I'm in, and they might find that they really want to help, whether it's a mother or a father or a brother or a sister, whatever, they might say, look I would be interested but being off work would make things awfully hard for my family or . . . or whatever, you know.

This response is revealing, as it appears to contradict Jim's previous statements and suggests that he found it easier to reflect on potential financial stress by deflecting the discussion to what "the next person" might experience rather than focusing on his own circumstances. This was not unique to Jim, as participants tended to speak about what difficulties others might experience rather than disclosing their own.

Faced with no or inadequate sick leave, participants were forced to take time off without leave. Some participants spoke of their planned strategies, including putting money aside, and working more hours during the time leading up to the operation "to compensate for later." Molly reported that a relative had offered financial support, while Mary shared the following:

We've inherited not a huge amount of money, but it's a substantial amount of money . . . my husband doesn't want to spend any money on getting a new shed or anything like that until after the operation to make sure everything's OK.

In Mary's case, the financial cost of donation was aggravated by the fact that her husband would need to take time off to care for her and their children at the time of the operation. Because Mary's husband was self-employed, he would stop earning an income until he went back to work, compounding the financial impact on their family because, as a part-time worker, Mary was not eligible for sick leave. Similarly, Greg and his wife were both contract workers, and they faced a significant combined loss of income as Greg's wife would need to take some time off to care for him as he recovered from the operation.

Finally, for those living outside the metropolitan area, the financial impact of donation was aggravated by accommodation costs at the time of the operation. In our study, of the four donors who lived outside the metropolitan area, two were donating to their spouses, and these couples were planning to relocate to Perth for several weeks to be close to the hospital during the recovery time.

At the time of the interviews, the Australian government was about to implement a pilot scheme aimed at providing financial support to living donors. Participants in our study were aware of the scheme, and although they supported it, the payment was widely perceived as inadequate. Jim summed up this sentiment, when he reflected on how quickly that six weeks' pay would be spent:

In all honesty, the minimum wage, and the way the price of living is at the moment, is not enough, it's far from enough. I know how much I have to pay with my wife and two kids, and that wouldn't cover it a week.

DISCUSSION

Consistent with existing evidence (Adams-Leander, 2011; Clarke et al., 2006; Klarenbach et al., 2006; McGrath & Holewa, 2012), our findings showed that there are direct and indirect economic costs associated with the assessment for donor suitability. In contrast with other Australian evidence (McGrath & Holewa, 2012), participants in our study did not incur significant direct costs related to the work-up. Our participants did not report significant medical expenses, and travel costs were not reported as being of concern, including among those living outside the metropolitan area. Two participants reported a significant loss of income incurred during the assessment, and the employment and financial implications of the

work-up were aggravated for those whose surgeries were on hold and those donating to their partner.

Participants in our study had financial concerns relating to the time of the surgery and the recovery time. These financial worries may add to what is already a stressful period in donors' lives (Sanner, 2005), and they are of concern because pretransplant life stress has been associated with delayed wound healing in donors (Maple et al., 2015). Somewhat in contrast with findings from research conducted in the United States (Lunsford et al., 2007), participants were concerned about the time away from work at the time of the surgery, and many reported not having adequate sick leave. In this context, and consistent with findings from Williams et al. (2010), support from work was seen to be essential in mitigating the financial impact posttransplant. Our findings also suggest that donors may have somewhat unrealistic expectations about recovery time and side effects of the operation. This is of concern as there is evidence that donors may experience physical and emotional discomfort after the transplant (Andersen et al., 2007; Heck, Schweitzer, & Seidel-Wiesel, 2004; Williams et al., 2009), and on average, donors return to work five weeks after undergoing laparoscopic nephrectomy (Tooher et al., 2004).

In addition, our findings show that some donors may be at higher risk of financial stress; these include contract and casual workers, those employed in physically demanding jobs, and those intending to donate to their partners. Our finding on the financial vulnerability of contract and casual workers is of particular salience in Australia, a country characterized by the prominence of its casual (Campbell, 2004) and part-time workforce (Burgess, 2005). Casual work is common in Australia, with 20 percent of the Australian workforce (approximately 2 million employees) having no paid leave entitlements (Australian Bureau of Statistics, 2008).

Other studies have limited their exploration of financial barriers to donations to disadvantaged minority groups (Adams-Leander, 2011; Purnell et al., 2012). Our study shows that there are financial considerations that operate not only at the recipient-donor level (direct and indirect costs incurred during the work-up), but also at the community level (availability of sick leave from work and donor reimbursement) (Purnell et al., 2012), which may be barriers to living kidney donation across the population. Furthermore, our results lend support to the view that living kidney donation does not occur in isolation,

but rather in the context of "myriad sets of everyday family obligations" (Crombie & Franklin, 2006, p. 206). We acknowledge that our study does not provide evidence on actual economic costs after donation, given that we interviewed potential donor prior to transplantation. Further research is warranted to explore how actual costs match potential donors' expectations.

Participants reported having limited information on the financial implications of donation, and our findings suggest that discussing financial matters was a sensitive issue. Our results suggest that PLKDs would benefit from tailored practical and financial advice relating to the economic implications of donation, especially regarding the loss of income associated with the recovery time. Our participants were aware of and supported the new government Supporting Leave for Living Organ Donors pilot program; however, the payment was widely perceived as inadequate. This pilot program was evaluated in 2014 and has been extended until June 30, 2017 (ACIL Allen Consulting, 2014). Further qualitative research is warranted to examine donors' perspectives on the implementation of the program.

The role of social workers in the decision-making process and pretransplant preparation of living donors has been noted (Brown et al., 2008a, 2008b). Social workers play an important role in the psychosocial care of donors, helping to minimize the risk of negative outcomes, including financial issues (van Hardeveld & Tong, 2010). Results from this study suggest that social workers may play an important role in providing tailored practical and financial advice to PLKDs. However, at the time of the interviews, the psychosocial assessment protocol at the renal unit where we recruited our participants had been amended so that a screening questionnaire flagged at-risk donors, and only those had a formal session with a social worker. This is of concern, as PLKDs who could benefit from discussing employment, financial, and legal matters with a social worker might lose that opportunity.

In conclusion, our study sheds light on ways in which potential economic barriers to living kidney donation operate, and provides new evidence regarding donors who may be at higher risk of financial stress. Our results support the need for tailored practical and financial advice for donors that takes into account donors' individual contextual circumstances and is responsive to the current employment landscape. **HSW**

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