Paid Donation: A Global View

Nasrollah Ghahramani, S. Adibul Hasan Rizvi, and Benita Padilla

Paying for kidney or other organ donation has lead to heated debates about donor and recipient welfare. Many have argued that paying for donation leads to coercion and exploitation of the poor, and, in the end, produces more harm than good. Others have said that payment helps the poor, and we should all have sovereignty over our bodies and, thus, should be allowed to donate for remuneration. Although World Health Organizations and governments in many countries have now banned the process of paying for donation, there is still ongoing payment legally and illegally. Thus, this timely set of three articles from Iran, Pakistan, and the Philippines, where paid donation has been extensively performed, will allow the reader to decide for themselves whether the benefits and/or harms of this practice are now clear.

Key Words: Donor, Incentive, Kidney, Transplantation, Unrelated

Paid Donation in Iran

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Introduction

The first kidney transplant (KT) in Iran was performed in Shiraz in 1967. Between 1967 and 1985, approximately 100 KTs were performed. To accommodate the large number of patients with no living related donor (LRD), and owing to the lack of legislation for deceased donor KT (DD KT), Iran instituted a government-funded compensated living unrelated kidney donation program in 1988.1 ESRD patients with no willing related donors are referred to Dialysis and Transplant Patients Association (DATPA), a charitable organization consisting of ESRD patients. Potential donors also register with the DATPA and undergo evaluation in the foundation’s clinics.1 The KT candidates and their living unrelated donors (LURDs) are referred by DATPA to the KT teams. DATPA receives no incentives for identifying or for referring the donor–recipient pair to KT teams.1 KT teams belong to university hospitals, and all expenses are paid by the government.1 The LURD receives a fixed award from the government (approximately US$1200) and 1 year of health insurance. The donor and recipient meet at DATPA before donation to negotiate the amount of supplemental “rewarding gift” (US$2300-US$4500). For recipients without adequate means, DATPA recruits assistance from charitable organizations.1 Only the Shiraz Transplant Center requires all KT candidates to wait for 6 months for DD KT before referring to DATPA for LURD.2 The ESRD office maintains demographic data on transplantation,3 but lacks centralized data on outcomes. Reports from single centers indicate excellent patient and graft survival rates.2,4-6

Characteristics of Donors

Approximately 90% of the LURDs are male, 80% are married, the majority have completed at least high school education (6.2% postsecondary), and 84% are categorized as poor.6,8 The mean monthly income is US$175.0 ± US$68.5 (concurrent national average: US$225), >60% live below the poverty line, and 25% are unemployed (national rate: 11.2%).8,9 Financial factors are the sole motives for donation in approximately 40% of donors.8 In a national study of 500 donors, 95% had experienced at least 1 stressful life event, most frequently financial hardship, during the 6 months before donation.10 The main financial needs were medical expenses and debt relief.5,9 The payment had a moderate effect on the donor’s finances in 63% of cases.9 The quality-of-life scores among LURDs in Iran are lower than those of the general population.10 This is in contrast to previous studies that have identified a positive impact of donation on psychological outcomes11,12 and likely reflects the large proportion of LURDs who expect financial gain.10 Although an older study (N = 300) found that 85% of donors were dissatisfied with their donation,13 2 recent larger studies (combined N = 1046) report satisfaction in approximately 90% of the donors.8,9 More than 75% of donors expressed interest in receiving information about the outcome of the transplant and the recipient.8 There has been concern about coercion of women into donation in the Iranian LURD program. Although much of the available data suggest that, worldwide, women are more likely to donate and less likely to receive a kidney, the situation is reverse in Iran. Data from Norway indicate that the majority of living donors are female, whereas the
majority of recipients are male. In the United States, women are more likely to donate but less likely to receive a kidney than men. This is true for LRDs, LURDs, and spousal pairs. In Iran, for LURD KTs, 16% of the donors and 39% of the recipients are female. Although this data might suggest a bias against offering transplant to female patients, it alleviates the concern about exploitation of women as paid donors. A likely explanation for the predominance of male donors in Iran is the incentive that would be more relevant to the male as the traditional head of household responsible for family finances. In summary, the donors tend to be poor young married men, who are financially motivated toward donation. Despite financial motivation, most of them maintain an interest in the outcome of the transplantation and the patient. There is no required organized follow-up of the donors, and the vast majority of nephrologists surveyed perceive the 1 year of insurance to be insufficient for long-term follow-up. A 10-year pilot study of annual follow-up of 408 donors was launched by the Iranian Academy of Medical Sciences in 2006; first-year preliminary results on 90 donors have been reported in abstract form.

Impact on DD and LRD Transplantation

A flourishing paid LURD KT program is likely to lead to stagnation of the DD programs and fewer LRD transplants. In Iran, brain death legislation in 2000 allowed DD transplantation; by the end of 2006, 1546 DD organ transplantations (1066 KT) were performed. The number of DD transplants has increased at disappointingly slow pace, with the majority being performed in Shiraz. Nationally, DD KTs account for 5% to 10% of the total annual KTs, whereas review of 10-year data from Shiraz shows that of 1355 KTs, 38% were from DDs. Also, although only 15% of KTs in Iran are from LRDs, 30% of KTs from Shiraz are from LRDs.

Transplant Tourism

Recognizing the potential for commercialization, and in accordance with the Istanbul Declaration, transplantation of foreigners was completely prohibited in April 2010. The largest number of foreigners who underwent transplant in Iran consists of Afghan refugees, who were allowed to receive KT from Afghan donors; they were not allowed to volunteer as donors to Iranians. Before the prohibition, despite scrutiny to avoid transplant tourism, there were reports of foreign nationals receiving KT from Iranian paid donors. Data from one of the largest programs indicate that approximately 2.5% of the KTs were performed on foreigners (refugees: 1%; Iranian expatriates: 0.9%; others: 0.6%). Citizens from neighboring countries with inadequate or nonexistent KT program (mainly Afghanistan and Azerbaijan) have undergone LURD transplantation in Iran without supervision of DATPA. It is suspected that brokers inside Azerbaijan made arrangements for 18 patients from Azerbaijan to receive kidneys from paid Azeri donors in Iran. In 2008, the Ministry of Health closed a university transplant unit owing to allegations of irregularities.

Discussion

The LURD program has succeeded in increasing the number of KTs. Iran has one of the largest numbers of living donor transplantations. With an annual ESRD incidence of 57 per million population and annual KT rate of 28 per million population, the waiting list is negligible. Despite its success, the system has definite flaws and limitations. The reward is not inflation-adjusted, and the recipient bears the major burden of payment. In the absence of a required organized follow-up of donors (a major flaw in the model and a major flaw in transplant programs of many industrialized countries) donor outcome data are limited. Nephrologists discourage patients from contacting random donors, and centers only accept donors referred by DATPA. However, potential donors publically post flyers, and the highest bidding patient may contact them before meeting in DATPA. The program has moved from serving the needs during a period of turmoil to become the primary form of transplantation. It has shifted from bridging the gap between demand and supply to the most convenient choice for the patient and the government. The combination of a LURD program and the deficiency of national infrastructure for DD
transplantation has impeded establishment of the latter. DD transplantation has lagged behind total transplants, with no noticeable efforts toward public education about DD and LRD transplantation, and the proportion of LRD KTs has progressively declined. A goal of the model was to provide transplantation to patients with no LRD. However, 81% of LURD KT recipients have a potential LRD. This mentality of “convenience” has overshadowed medical and ethical benefits of LRD KT. The policy of “no questions asked” before LURD KT should be replaced by a mandatory waiting period, as required in Shiraz. This has led to a significant increase in DD and LRD transplantsations. In conclusion, the pioneers in Iran should be commended for developing a unique model during a period of postrevolution, war, and sanctions. In such a setting, the model with proactive supervision and dynamic revisions prevented inevitable rampant commercialization. Although Iran was never a significant market, restriction of transplants to Iranians further minimizes the chance of transplant tourism. Directed donation and lack of safeguards against mutual exploitation are major flaws. The program in Shiraz, with a mandatory waiting period, and an established DD multiorgan transplant infrastructure addresses some of the pitfalls and should be used as a model for the rest of the country.

References

Paid Donation in Pakistan
S. Adibul Hasan Rizvi

Kidney transplantation in Pakistan started in 1979 from living related donors in public sector hospitals. In 1980s, the activity was low at <50 cases per year but gradually increased to >100 cases per year by the
mid-1990s. Low activity in the public sector, developing expertise, and absence of transplant legislation moved the activity to the private sector. Initially, transplants were from live related donors; however, within a few years, commercial unrelated paid donor transplants took over, where the poor and impoverished of society were exploited to sell kidneys for US$1000 to US$2000. By the year 2000, 1000 transplants were performed yearly, where >70% were from kidney vendors. Initially, the majority of the recipients were locals; however, by 2005, >1500 rich buyers came to Pakistan from Europe, the Middle East, and India, paying US$20,000 to US$30,000 for transplant package, and transplant tourism became an industry in the country.

Several reports in the literature highlighted the poor outcome of recipients of kidney transplants from Pakistan. However, the outcome of kidney vendors of these recipients remained unknown. Reports identified kidney vendors in the north of Pakistan, the agricultural heartland and an area that is overpopulated, with low socioeconomic development. The unknown outcome of the vendors motivated us to undertake a study in northern Pakistan, where we evaluated the socioeconomic parameters and general health status of kidney vendors. Our Institute is a tertiary care public sector organization that offers dialysis, living related transplant, and immunosuppressive drugs to all patients free of cost, with lifelong follow-up. This study on 239 vendors showed that 90% of them were illiterate, and 69% were bonded laborers who were virtual slaves to landlords. Their monthly income was only US$15.4 ± US$8.9, with 2 to 11 dependents per family. For the majority (93%), the reason for vending was to pay debt, with a mean debt amount of US$1311.4 ± US$819. Unfortunately, after vending, 88% of them reported no economic improvement, and general health status deteriorated in 98%. This prompted us to undertake a second study in the same region, where a detailed short- and long-term health evaluation and postdonation renal function was assessed in 104 vendors. The findings in vendors were also compared with those in 184 living related donors who were regularly followed up at our institute. Comparison of vendors and control subjects is given in Table 1. Of the vendors, 67% were bonded laborers earning <US$50 per month, whereas 68% of the control subjects were self-employed skilled laborers earning >US$100 per month. History of vendors has revealed presence of jaundice in 8%, stone disease in 2%, and urinary tract symptoms in 4.8%. A quarter of the vendors were hepatitis C positive, with almost half with deranged enzymes. These findings are important because positivity in general population is 3% for hepatitis C virus. Because we do not know their status before vending, it is difficult to speculate whether they were seropositive before donation. However, high rates of posttransplant hepatitis C virus infection in tourists indicate this to be highly possible. This study concluded that vendors had compromised renal function, suggesting inferior selection and high risk for developing chronic kidney disease in the long term. Although these studies only gave a snapshot of thousands of kidney vendors, it did show the exploitation of the poor for commercial gains by private transplant centers in the country. They also highlighted the compromised donor acceptance criteria and the lack of follow-up care of these poor and unprivileged people.

Our long-term study on living related donors had shown that hypertension and proteinuria appear >5 years after donation. In contrast, these appear earlier in vendors (mean duration: <3 years; median: 2 years). Hypertension was more prevalent in vendors (17%) after donation as compared with living related donors (9%); other studies have shown that 6% of living related donors suffer from hypertension. Similarly, proteinuria (protein-to-creatinine ratio >0.3) was present in 8% of vendors compared with 5% in related donors reported in studies with longer nephrectomy periods. Mean glomerular filtration rate (70 mL/min) was also lower than that in some other studies (>85 mL/min). In fact, a quarter of the vendors had a glomerular filtration rate of <60 mL/min; 30% had protein-to-creatinine ratio >0.3.

| Table 1. Postnephrectomy Complaints and Renal Function in Vendors |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Complaint                | Kidney Vendors n = 104   | Control Donors n = 184   | P Value                  |
| Mean age                 | 30.5 ± 8.1               | 30.6 ± 7.8               | 0.91                     |
| Male:female              | 4.5:1                    | 4.2:1                    |                          |
| Physical weakness        | 71 (68.3%)               | 4 (2.1%)                 | 0.0001                   |
| Fatigue                  | 11 (10.5%)               | 0 (0%)                   | 0.0001                   |
| Urinary tract symptoms   | 50 (48.1%)               | 6 (3.2%)                 | 0.0001                   |
| Depressions              | 5 (4.8%)                 | 1 (0.5%)                 | 0.010                    |
| Body mass index          | 20.02 ± 2.84             | 23.02 ± 4.27             | 0.0001                   |
| Hypertension             | 18 (17.3%)               | 17 (9.2%)                | 0.04                     |
| GFR by Cockcroft–Gault formula, mL/min | 70.94 ± 14.2 | 95.4 ± 20.44 | 0.0001 |
| Urine protein-to-creatinine ratio | 0.15 ± 0.11 | 0.10 ± 0.10 | 0.0001 |
| Deranged liver functions | 14 (13.4%)               | 5 (2.7%)                 | 0.0001                   |
| Anti-HCV positive        | 25 (24%)                 | 2 (1.0%)                 | 0.0001                   |

Abbreviations: GFR, glomerular filtration rate; HCV, hepatitis C virus.
A number of reports had shown poor outcome and high infectious complications in tourist recipients who have purchased kidneys from Pakistan. Because there was no report on the outcome of our local Pakistani recipients of commercial transplants, a study was conducted on the socioeconomic status and transplant outcome of 126 of such recipients who presented at our institute between 1997 and 2007. Unlike the foreign tourists who return home and are cared for in specialist centers, local vended kidney recipients often find themselves unable to obtain specialist care and proper follow-up, especially in case of complications requiring hospitalization. The outcome of vended kidney recipients were compared with that of recipients of living related donor transplants performed at our center (Table 2). The majority of the recipients of vended kidneys (92%) underwent transplant in northern Pakistan, paying US$7271 ± US$2198. All were educated, with 50% being graduates or more and rich, earning a monthly salary of US$517 ± US$518, and 44% earning >US$500. Comparison of commercial recipients with control subjects revealed more comorbidities (35 [28%] vs. 14 [8%]; P = 0.0001) in commercial recipients (e.g., diabetes, hepatitis C, and cardiovascular diseases). Infections were also more prevalent in commercial recipients (tuberculosis: 14 [11%] vs. 6 [6%], P = 0.007; acute hepatitis: 20 [16%] vs. 3 [2%], P = 0.0001; cytomegalovirus: 33 [26%] vs. 21 [11%], P = 0.001; recurrent urinary tract infection: 35 [28%] vs. 30 [16%], P = 0.034). This study showed that recipients of the vended kidneys were poor candidates for transplantation, educate, rich, and often self-selecting, with poor outcomes, as compared with living related donor transplants.

During the course of these studies on vendors, a parallel ethnographic study was conducted by our Centre for Biomedical Ethics and Culture. This study provided insights into the negative psychological consequences and social ethos of selling an organ, the ramifications of which go beyond the vendor to family and community.

Conclusions

Developing countries have relied mostly on living donors. Therefore, it is important that in donor selection, all criteria are met so that there is minimal risk of renal impairment to the donor. Unfortunately, in Pakistan, the absence of transplant law allowed unrelated commercial transplants to flourish, where both recipients as well as vendors were exploited. Although the Amsterdam Forum established guidelines for donor selection and follow-up, in developing countries, vendor donors have neither the means nor access to facilities for follow-up care. Transplant legislation in Pakistan in 2007 has largely curtailed this exploitation of the poor. Unrelated commercial transplants have decreased to negligible numbers in clandestine back-alley centers.

In conclusion, general health status of paid vendors was poor and renal function was compromised after nephrectomy. Nearly a third of these donors would have failed selection as donors if recommended guidelines were followed. Our findings suggest that the paid donors are at risk for development of renal impairment and failure in the long term; therefore, their care is essential. Unfortunately, there remain thousands of paid donors in Pakistan whose fate remains unknown.

References


Table 2. Comparison of Outcome of Vended Kidneys Recipients With That of Living Related Donor Transplant Recipients

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Recipients of Vended Donors n = 126</th>
<th>Recipients of Living Related Donors n = 180</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute rejection, n (%)</td>
<td>42 (33%)</td>
<td>31 (17%)</td>
<td>0.005</td>
</tr>
<tr>
<td>Creatinine at 1 year, mg/dL</td>
<td>1.84 ± 1.28</td>
<td>1.27 ± 0.44</td>
<td>0.0001</td>
</tr>
<tr>
<td>Surgical complication, n (%)</td>
<td>28 (22%)</td>
<td>14 (8%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Medical comorbid, n (%)</td>
<td>35 (28%)</td>
<td>14 (8%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Total deaths</td>
<td>34 (27%)</td>
<td>12 (6.0%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Death with function</td>
<td>13 (10%)</td>
<td>2 (1.0%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Graft survival</td>
<td></td>
<td></td>
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<tr>
<td>At 1 year</td>
<td>86%</td>
<td>94%</td>
<td>0.0001</td>
</tr>
<tr>
<td>At 5 years</td>
<td>45%</td>
<td>80%</td>
<td>0.00001</td>
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</table>
Paid Donation in the Philippines

Benita Padilla

Between 2002 and 2008, the Philippine Department of Health administered an organ donation program that allowed prospective kidney providers to sign up, be allocated to prospective recipients, and receive a “gratuity package” for their kidney. Although the administrative order that created this program specifically stated that “sale and purchase of kidneys is prohibited,” the “incentives” offered were so generous that they represented valuable consideration for the average Filipino. These consisted of P100,000 ( Philippine peso) for reimbursement of lost income for 4 months, P75,000 for livelihood assistance, P100,000 as life insurance, 10-year membership with the government health insurance system, and free annual checkup for 10 years. This was at a time when the national average income for the whole family for an entire year was reported to be P172,000.

The government was not equipped to monitor this program closely and was quite unprepared for the consequences. Transplant tourists began to pour in as many desperately poor Filipinos queued to give up a kidney for an imagined chance at a better life. During this period, the number of transplants to foreigners increased by 1200%, whereas the number of transplants to Filipinos increased by only 89%.1 This occurred despite a regulation that foreign recipients should not comprise >10% of all transplant recipients in every transplant facility.

Two community-based studies have reported on the outcomes of kidney vendors in the Philippines. In 2008, a cluster of kidney vendors was identified in 3 towns in Quezon province located 220 km southeast of Manila. As of 2011, 198 kidney vendors have been identified and are being given regular follow-up through a joint project of the Philippine Society of Nephrology, nongovernment organizations, and government units. Among these kidney vendors, 73% reported no improvement in their financial status, 74% would not sell a kidney again if given the chance to revisit their decision, and 96% would not recommend that others sell a kidney. Many reported being transported to Manila by an agent in groups and being instructed to thwart normal screening procedures, such as by taking medication to mask a hypertensive condition or submitting the chest radiographs of another individual.2 In another study performed in several communities between 2007 and 2008, 311 kidney vendors were found through snowball sampling. In this population, 36% reported no improvement in their financial status, whereas 41% reported improvement that was fleeting; 80% regretted their decision to sell a kidney. Brokers were involved in 86% of the transactions. Although 69% were advised to seek medical follow-up, only 40% actually did so.3 In both these studies, agents were reported to withhold part of the donor payment until the donor brings in a new recruit.

Because these 2 studies reported on mostly unregulated commercial transactions, a third study was designed to assess the success of the government incentive program administered through the National Kidney and Transplant Institute. In 2009, an effort was made to determine the status of the 164 individuals who received “gratitudinal gifts” between 2004 and 2007. In contrast to the other studies, this article reported that 90% of the donors do not regret their decision, and 65% said that their financial situation was better 1 year after donation.4 However, the validity of these findings is seriously hampered by the fact that only 81 donors, or 49% of those who participated in the program, could be interviewed. The effort to find the donors was described to be “aggressive and well-funded,” and the fact that less than half of them could be evaluated for the study is testimony to the reality that donor follow-up is still poor even within the government-regulated program.

Although the Philippine government was unambiguously in its intention not to allow organ sale, and statements from religious, professional, and civic organizations make it clear that the Philippine public is not in favor of transplant commercialism, there was apparently a failure to recognize that the nature and dangers of any valuable...
consideration given in exchange for an organ does not change, regardless of whether it is called a gift, reward, gratuity, or incentive. As the accompanying commentary to principle 5 of the World Health Organization Guiding Principles state, “national law should ensure that any gifts or rewards are not, in fact, disguised forms of payment for donated cells, tissues or organs.”

From 2008 onward, revisions in the implementing rules and regulations of the Anti–Human Trafficking Law, a presidential directive disallowing foreigners to receive organs from Filipino living donors, and new administrative orders from the Department of Health have effectively ended this experiment in “incentivized” kidney donation in the Philippines.

References