

# IRANIAN KIDNEY DONORS: MOTIVATIONS AND RELATIONS WITH RECIPIENTS

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## ABSTRACT

**Purpose:** The motivations of Iranian kidney donors and donor-recipient relationships are clarified.

**Materials and Methods:** A 13-page 69-item questionnaire was completed by 100 donors and interviews were videotaped.

**Results:** Of the donors 90% did not know the recipients preoperatively and only 13% had any information on recipient fate postoperatively. In 87% of cases there was no postoperative relationship. Because of recipient failure to appreciate the donors and refusal to realize preoperative promises 51% of donors hated the recipients and 82% were unsatisfied with their behavior. Motivations for donating were purely financial in 43% of cases and mainly financial with a minor altruistic component in another 40%. Of the donors 76% agreed that kidney sale should be banned and if there was another chance they would prefer to beg (39%) or obtain a loan from usurers (60%) instead of vending a kidney. All 6 related donors were paid. The goals of vending were achieved not at all by 75% of donors.

**Conclusions:** None of the donors studied fulfilled the criteria of compensated donation or donation with an incentive and 97% were vendors. All evidence shows that the donor-recipient relationship in Iran is pathological with no similarity to the emotionally related category of transplantation. Reports by the reformist Iranian press, which have all been banned, show that our sample is a good representative of other Iranian donors. Almost none of the criteria of an acceptable living unrelated renal donor transplant program is met in Iran. The opinion of kidney donors should be regarded as the final arbiter when labeling the act as a sale or donation and it should be considered in discussions of living unrelated donor transplantation.

**KEY WORDS:** kidney, kidney transplantation, living donors, quality of life, commerce

Based on a MEDLINE search from 1966 to April 2000 there are no previous empirical studies of kidney vendors in contrast to living related renal donors. To clarify this overlooked area we performed a survey to evaluate the donor-recipient relationship and motivations for donating, among other items. We use the words donor and donation when referring to the study sample and Iranian donors, although it is apparent from our results and from extensive reports in the progressive Iranian press, all of which have been banned, that by far the majority of donors in Iran are vendors and not donors. To our knowledge our survey is the first to study kidney vendors systematically and directly.

longer. We thought that after this arbitrary period there would be sufficient stabilization of donor opinion.

None of the 100 donors refused to participate in the study. Hospital record demographic data on other donors who were not located did not differ significantly from those on located donors. Also, we continued to interview donors after the study ended and up to the time of this report. Thus, another 215 of 575 donors overall, of whom most underwent surgery after 1995, have been interviewed with essentially the same results. In these 215 cases we omitted the study criterion of nephrectomy done 2 years ago. Instead we interviewed all donors visited. The table shows the characteristics of the donor sample. Donors were healthy with a 1% addiction rate.

## MATERIALS AND METHODS

From mid 1989 to late 1995, 305 living renal transplantations were performed at the renal transplantation unit of a public medical center in Kermanshah, Iran. Of these cases 94% involved living unrelated donor transplantation. At the beginning of the study a team of medical students observed that only 5% of donors had provided an accurate address and 95% had provided an unclear or false address for the hospital records. Retrospectively we determined that the reason was donor unwillingness to be known as donors. Thus, we relied on other sources to locate donors. During a 3-month period we located 150 donors, of whom 100 fulfilled our study inclusion criterion of nephrectomy performed 24 months ago or

*Demographic characteristics of donors*

Characteristics	Donors
% Men/% women	67/33
Mean age ± SD	31 ± 12
Mean yrs. since transplant ± SD	4 ± 2
% Currently married	90
% Insured	7
% Drug addicted	1
% Employment status:	
Unemployed	15
Home duties	22
Part-time work	46
Full-time work	16
Unable to work	1
% Education:	
Illiterate	29
Less than high school	60
High school degree	11
% Recipient related/unrelated	6/94

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Informed consent was obtained from all donors and they were assured that their responses were confidential. We made it clear to all participants that their replies would not create any benefit or harm to them, we are not planning to allocate financial resource to them and our objective was not to identify those needing help or a job.

Based on our clinical experience and items suggested by others we designed a preliminary questionnaire. We contacted representative samples of donors, comprising several 6 to 8-person focus groups, to clarify study objectives, correct misunderstandings, and discuss the suitability, applicability and fluency of the questions, degree of coverage of donor problems and the best way of asking questions. We then performed a pilot study and modified the preliminary questionnaire accordingly. The result was a 13-page 69-item questionnaire, which we administered in the final study. Pilot and final studies were performed by visiting donors directly. All donors were interviewed by the author and they also underwent a preliminary interview done by a team of medical students. The author has no relationship to the transplant program.

Although they may have provided a false and/or inaccessible address for the hospital records, after they were made aware of our study objectives all visited donors agreed not only to participate in the study, but also to enhance documentation. They allowed their statements and living conditions to be recorded on videotape and all stated that they are ready to repeat and defend their statements again. Also, in most cases we interviewed independent sources who confirmed donor statements. We repeated the final study phase 1 month later with the same donors. Computer software was used for statistical analysis.

#### RESULTS

Certain questions were offered with choices, as indicated. In the remainder of the questions we sorted responses. Because donors answered more than 1 choice to some questions, the sum is more than 100% on some items.

For the question on preoperative relationship with the recipient 90% of respondents had no relationship at all except during preparation for the operation (cross matching and so forth), 6% were related (long-standing relationship), 4% had casual contacts and 0% had friendship. For the question on living unrelated renal donor postoperative relationship with the recipient 54% of donors had no contact at all after hospital discharge and 6% had a new close relationship, while 18%, 18% and 4% had 1, 2 to 5 and 5 to 10 visits, respectively. Feelings toward the recipient were hate and anger in 51% of respondents, no feeling at all in 20%, and tenderness and love in 29%. Causes of donor bad feelings toward recipients was a drastic shift in recipient behavior toward coldness, or not appreciating or visiting the donor postoperatively in 95% of cases, the refusal to realize preoperative promises in 65% and disclosure of secret donor vending of the kidney to others in 20% (sum greater than 100%).

Preoperative recipient interactions with the donor were charming with many promises in 80% of cases, involved relatively warm conduct in 5%, were matter of fact and ordinary in 10%, and cold and indifferent in 5%. In 65% of early recipient postoperative interactions with the donor the recipient did not express any gratitude and considered the event a matter of fact, like a buyer and not like a recipient, while 10% were derogatory, offensive, and/or critical of the donor or kidney, 2% acted as though the donor owed them something, 20% were moderately respectful and 3% showed intense gratitude. There was no late postoperative relationship in 87% of cases. Of the donors 2%, 4%, 12% and 82% were very satisfied, moderately satisfied, moderately dissatisfied and very unsatisfied with postoperative recipient behavior, respectively. Recipient postoperative behavior was

very, somewhat, a little and not at all important for 75%, 10%, 7% and 8% of donors, respectively. Of the living unrelated renal donors 87% had no information at all about the fate of the recipient, 7% had some information and 6% were fully informed.

The motivation for donating was purely financial in 43% of respondents, mainly financial with a minor altruistic component in 40%, equivalent financial and altruistic incentives in 5%, mainly altruistic with a minor financial component in 9% and purely altruistic in 3% who were related to the recipient. The immediate reasons for vending the kidney was settling debts in 51% of cases, paying blood money and compensating car accident damages in 9%, dwelling in 10%, medical expenditure in 8%, buying work tools, cars and/or workplaces in 7%, buying the necessities of life in 5%, marriage expenditure and/or raising a dowry in 5%, medical leave from obligatory armed forces service in 2%, compensating for stolen home goods in 2% and divorce expenditure in 1%.

To the question "What is your current opinion regarding the banning of organ sales?" 76% of donors agreed, 22% disagreed and 2% had no opinion. To the question "If you would not choose again to vend the kidney or if living unrelated renal donor transplantation were banned, how would you manage your financial difficulties?" the response was by begging in 39% of respondents, asking help from relatives in 19%, working under any conditions and for any wage in 42%, usurer loans in 60% and asking again for help from public sources in 5% (sum greater than 100%). To the question "Did you reach the goals you had when vending?" 75% of respondents answered not at all, 20% answered yes, somewhat and 5% answered yes, completely.

Six vendors were a first degree relative of the recipient who was paid by the recipient. However, 3 respondents regarded themselves as donors, not as vendors, and stated that their motivation had been purely altruistic. All donors studied defended their statements 1 month after the final phase of the study.

#### DISCUSSION

In Iran living unrelated renal donor transplantation comprises approximately 90% of renal transplants. The main reason has been rejection of the cadaveric transplantation act (see Appendix). Because of easily obtainable kidneys for sale, living related donation is not even considered by the relatives of recipients. The current state of availability of cheap kidneys for sale is the greatest obstacle to establishing a cadaveric transplant program in Iran. However, some domestic pioneers of sold kidney transplantation blame such unfounded reasons as religious and strong cultural reluctance of the society to accept cadaveric organ donation as well as special social and cultural problems. They state that few Iranian recipients may buy live donor kidneys from India but continue that on the other hand we have a large number of unrelated donors with true voluntarism.

In Iran the Charity Association for Support of Kidney Patients (CASKP) performs all preparatory steps for arranging such transplants. The founding members of this charity are mainly recipients. The official CASKP organ admits that CASKP is involved in more than 90% of kidney transplantations in Iran.<sup>1</sup> According to CASKP officials CASKP has the role of a real estate agency<sup>2</sup> to which sellers and buyers refer.<sup>1</sup> Potential donors call or visit CASKP to ask whether kidneys are being bought. The reply is always yes. CASKP sends the donor to the recipient nephrologist, who evaluates the donor. Standard medical criteria, including absent significant mental dysfunction, significant renal disease, significant transmissible disease, ABO incompatibility or a positive cross match, are used to select donors. The potential donor is then referred back to CASKP to be placed on the donor list.

At this stage in Kermanshah the donor provides CASKP a promissory note of US\$244 (2 million Rials with \$US1 equal to approximately 8,200 Rials). If the potential donor refuses donation after the preoperative evaluations and laboratory tests, which are done at recipient expense, the donor should pay this money, which prevents potential donors from refusing donation after entering the preoperative phase. This practice is in contrast to that at many transplantation centers internationally, where a medical excuse is provided for those who do not wish to donate at any phase to prevent embarrassment. In other provinces donors pay for the preoperative evaluation and reclaim the cost postoperatively from recipients, in addition to the standard US\$1,219 (10 million Rials) given to each donor by the Charity Foundation for Special Diseases (CFSD). However, in Kermanshah potential donors are so poor that they are unable to pay. To prevent noncompliance they provide a promissory note.

The same nephrologist refers recipients to CASKP to be included on the recipient waiting list. Similarly patients who are candidates for receiving a kidney directly call or visit CASKP to ask whether a good kidney is available. CASKP introduces the recipient to a donor with same blood group to be co-visited by the nephrologist. Donor-recipient contact begins immediately after they are introduced by CASKP. After laboratory evaluation the nephrologist refers them for cross matching and, if results are satisfactory, to angiography.

At the beginning of the transplant program in Kermanshah in 1989 the price of each kidney was 2.5 million Rials, ranking the so-called Kermanshahian kidney as one of the cheapest in the world by any standard. This amount was paid directly by the recipient. It increased to 4.5 million Rials. Beginning in early 1997, 10 million Rials (US\$1,219) were allocated to each donor. CASKP officials have claimed, "Before the [Iranian solar year] 1375 (1996) we had no problem as buying and selling almost 350,000 Tomans was given as a gift (hedye) to each donor by recipient."<sup>2</sup> However, in most current cases surgery was performed before 1996 and what CASKP officials referred to as a gift was the price of each kidney in those years.

CASKP officials present these monetary claims during their challenges with CFSD. CFSD covers diseases such as hemophilia, thalassemia, hepatic failure, diabetes, epilepsy, AIDS, cancer and end stage renal disease. The main cause of CASKP and other charity association conflict with CFSD is financial problems. It has been said, "CFSD has deprived the 'patients' support associations' from [financial] help by other institutions."<sup>3</sup> CASKP demands to share with CFSD when receiving the money. Its officials have said, "The [fifth] parliament gives the money to CFSD and wants work from us."<sup>2</sup>

The law requiring that 10 million Rials should be given to vendors was passed in the Rafsanjani cabinet on February 2, 1997 and ratified by the fifth parliament. The cabinet ordered that this money should be given to vendors through the CFSD, which was determined as a nongovernmental organization (NGO) by the fifth parliament. However, this money is obtained from the governmental budget. Fatemeh Hashemi Rafsanjani, the head of the CFSD, declared that in Iranian year 1377 (1998) the amount allocated by the government for this purpose was 8 billion Rials (US\$975,609) and during a 2-year period an additional 4 billion Rials (US\$487,804) were collected from donations.<sup>4</sup> CFSD advertises extensively to obtain financial aid from various sources in addition to its allocated budget. The governmental budget for year 1378 (1999) was 21.3 billion Rials (US\$2,597,560).<sup>5</sup> In an interview Rafsanjani stated, "With the support and help of the cabinet of Mr. Hashemi [Rafsanjani, her father, the former Iranian President] it passed [a law] that 10,000,000 Rials be given to each donor through CFSD and this caused raising of kidney transplants from 750 in 1375 (1996) to more than 1,150 in 1376 (1997)."<sup>6</sup> She continued, "Few if any are able to

donate only for God's sake. Every day many persons come to CFSD asking for financial help and some of these ask to give one of their organs in exchange for this financial help. In the past the recipient was not sure that the donor would not refer to him asking for more money. CFSD has arranged so that the possible donor and recipient are prevented from visiting each other and they undergo operation without any relationship and only through submitting applicant forms in CFSD."

Defending the current use of living unrelated renal donors, a directive board member of CFSD, who is also a transplant, contradicted the Rafsanjani statements on the donor-recipient relationship. Replying to a reporter who asked whether kidney trade is a bad thing, he said, "Buying and selling is present when it is organized. Persons from all over the world come to a certain place, and buying and selling of human organs are done by a corporation, with the donor and recipient unknown. In that case, brokers appear. In Iran, however, there is no buying and selling [because] donor and recipient are both known and the donor knows the recipient and the money is for reimbursement."<sup>7</sup> He continued, "You put under question a very important principle, because of your very narrow vision. We are not lawyers of people and every person has control of his own. The principal thing is that the kidney sale [in Iran] is done with good intentions and the end result is saving the life of 1 person."

In an interview the head of CFSD said, "Now, in Iran, donors outnumber recipients. The reason for allocating money to donors by parliament as 'gift for altruism' (hedyeye iisaar) is poverty."<sup>8</sup> On another occasion she said, "From the past the subject of buying and selling was that for this organ [the kidney] 300,000 Tomans were given. We discussed this problem with Mr. Hashemi [Rafsanjani, her father]. He replied that we should pay every amount we can to such persons [donors]. As a result, a law was passed [in the Rafsanjani cabinet] that 1,000,000 Tomans [US\$1,219] be given."<sup>9</sup>

There are 2 contracts regarding payment. One contract is the official contract that the donor should receive the equivalent of US\$1,219 from the governmental budget. This money is paid immediately postoperatively. The operated donor submits hospital documents confirming the operation to CASKP, which then introduces the operated donor to the governor office of the province that acts as the local CFSD representative. The donor is then referred to the Tehran headquarters of CFSD to receive the money or the donor may wait until the money is sent to him or her from Tehran. However, since they are in desperate need of money, most donors do not wait. They go personally to Tehran to receive the money earlier than expected via the mail and bank.

The other contract is what goes on between the donor and recipient. Often the recipient promises the donor that if the donor agrees to vend the kidney, the recipient or recipient relatives would compensate the donor by giving some extra money,<sup>10</sup> providing work for unemployed donors and so forth. This part of the contract is also influential in persuading the potential donor to agree to donation and it is the part of the agreement that is not realized in the majority of instances, causing donor dissatisfaction. The government, CFSD, CASKP and transplant center have no control over this part of the contract. In other words, they have no control over what goes on between the donor and recipient on a personal basis.

Experts in the Health Ministry declared that it is possible to launch a cadaver program with 4 to 5 billion of the 24 billion Rials yearly allocated to the CFSD budget for vendors.<sup>11</sup> The Health Ministry of President Khatami has expressed its objection to kidney sales and the unchecked activities of the CFSD. The Deputy Minister of Health, a reformist nephrologist, said in an interview that "CFSD is an 'NGO' but its budget is more than many governmental institutions. There is no check on CFSD's expenditures of these moneys."<sup>11</sup> As it became certain of CFSD resistance to Health

Ministry policies, in a position statement the Khatami Health Ministry ordered universities to boycott CFSD and declared that CFSD policies have spread organ trading.<sup>12</sup>

However, the CFSD response to the criticism of Health Ministry officials was to accuse them of “lying,” “weakening and dishonoring the CFSD,” “accusing authorities of abuse” and “spreading illogical doubts.”<sup>13</sup> The CFSD continued, “The responsible [Health Ministry] authorities should not expect that the CFSD ask Ministry opinion for conducting its daily activities and ‘small-scale policies.’” Interestingly this NGO declared that “We cannot spend the CFSD [governmental] budget in those areas [the areas that the Ministry recognizes as priorities] that ‘detailed expert evaluations’ do not show their priority. Objections are personal and many ‘experts’ believe that this [allocating a budget for vendors] is a ‘development’ in donor-recipient relationship and an ‘innovation’ made in the Islamic Republic.”<sup>13</sup> CFSD then named these experts. “We [CFSD] too, like Mr. Hashemi [Rafsanjani], Velayati [Rafsanjani’s Secretary of State], and Fazel [Rafsanjani’s Health Minister] regard this [allocating a budget for vendors and using paid living unrelated renal donors] as a new way in transplantation.”<sup>13</sup> Fazel and Velayati are members of the CFSD directive board.<sup>9</sup> Another pioneer of sold kidney transplantation claimed that using paid living unrelated renal donors is a “new chapter in the world’s transplantation history” and “the critics of this trend are evil-intended and are unable to see our country’s progress” [in performing paid living unrelated renal donor transplantation in huge numbers].

The aristocratic CFSD is an example of a broader problem of power splitting in Iran and it represents one of many parallel, nondemocratic, nonresponsible power centers that interfere with the official decisions of the Khatami cabinet. The objections of the Khatami Health Ministry go unnoticed and are ineffective, while CFSD activities proliferate and it has even been given the privilege to participate in writing the executive rules of transplantation act.<sup>14</sup> The Khatami Health Ministry objections have apparently led only to some minor restrictions and regulations on how the CFSD budget should be spent.<sup>5</sup>

The declaration of allocating the equivalent of US\$1,219 to donors officially recognized kidney buying and selling,<sup>5</sup> which was followed by the clearance of recipient waiting lists, establishment of an open black market,<sup>1</sup> stoppage of living related renal donor transplantation,<sup>1</sup> appearance of professional brokers<sup>1</sup> who “whisper to offer a young, healthy kidney”<sup>15</sup> and establishment of long donor waiting lists due to the rush of destitute donors, for whose dispersion CASKP occasionally asks the help of police.<sup>16</sup> The head of CFSD projected the clearance of the recipient waiting list by 2,400 transplantations performed during the 2-year period of 1377 to 1378 [1998 to 1999] after the allocation of 10 million Rials.<sup>17</sup> CASKP officials admitted that after it was announced that 10 million Rials would be given to buy a kidney, “Iran’s [condition] is worse than India and that [altruistic] donation is an exception.”<sup>10</sup> The latter statement is now true.

Certain controls have been proposed for any living unrelated renal donor transplant program to even begin to be acceptable.<sup>18</sup> There should be no middlemen or advertising. There must be the priority of medical criteria, independent medical and psychiatric review of donors and recipients, an independent team of surgeons and physicians caring for donors, long-term medical insurance for donors, a surgeon charge that is normal for an operation of similar magnitude, external financial auditing, open inspection and periodic publishing of the results of the program, and banning of transplantation across countries.

Kidney sales<sup>1, 7, 10, 15, 19</sup> and professional brokers<sup>1, 15</sup> have been documented extensively in the Iranian press and brokers are easily identifiable<sup>15</sup> around CFSD and CASKP. Advertisements for receiving a kidney are routine in Iran. There

is no independent team to care for donors, who are cared for by transplanters and recipient nephrologists. Regarding long-term medical insurance, CASKP officials admit that in reality there is only a 1-year insurance plan, although 10-year insurance is officially claimed.<sup>10</sup> This 1-year insurance plan is the only postoperative health care offered to donors. There is no independent medical or psychiatric review of donors and recipients, and medical reviews are done by recipient nephrologists. Rare proponents of such transplantations have claimed internationally that there exists a chimerical donor assessment panel consisting of the transplant surgeon, nephrologist and so forth to assess the true voluntarism of consent.

However, such gross falsifications are not unique to Iran. In India the term rewarded gifting was coined to give such payments an air of respectability, whereby the donor signs an affidavit stating that the donation was made due to “deep love and affection for the patient.”<sup>20</sup> Rewarded gifting is nothing but a terminological subterfuge meant to obfuscate the issue.<sup>21</sup> Even some of those who claimed to practice rewarded gifting in India have expressed concern that in India today it would be difficult to have rewarded gifting without it being exploited by brokers into rampant commercialism.<sup>22</sup> This scenario is also true in Iran. However, rare Iranian counterparts prefer to deny all gross facts and claim that “if any gift was exchanged between donors and recipients, they were not aware of it. Patients have been told that if they talked about money transfer, surgery would be canceled.” For such persons and their supporters it is talking, writing about and acknowledging the facts that is intolerable, not the facts themselves. No operations are canceled. If there was a hint of truth in these statements, there would be almost no transplantations performed in Iran. It has been claimed, “In our social condition, living unrelated renal donor transplantation is the only way of continuing successful transplantation of these patients [recipients].” Hiding behind hypocritical concern for recipients, it has been claimed, “One side of the problem is always a desperate patient who needs a new life.” Our study participants responded angrily to such statements. They typically stated, “Why should we young be victimized for the generally old recipients who have passed most of their life? What about us?” They said, “The donors do not know the true value of their kidneys. Otherwise they would not regard their act as sale.” The final arbiter of donor actions and motivations are donors. If donors were not competent enough to describe their actions and motivations, they would be even more incompetent to provide informed consent for nephrectomy. Our study donors said clearly that they regard themselves as vendors. They were not thinking that they were reimbursed, but only paid for their goods (the kidney) according to the supply and demand of the market. The claimants are well informed of the gross fallacy of their statements and they do not dare to present them to audiences inside Iran.

The transplanters involved with the current patients were honest enough not to rationalize such practices or name them rewarded gifting. Some have proposed that transplantation should be initiated predominantly in public sector hospitals as an important way of checking commercialism in poorer countries because in public hospitals professionals are salaried and not paid per transplant.<sup>23</sup> We agree in concept. However, when in addition to salaries, fee for service rules are applied and transplanters are paid far more than for operations of similar magnitude, as in Iran,<sup>16</sup> the attributes cited for private hospitals also apply to public hospitals. In Iran almost all transplantations are performed in public hospitals. When professionals are paid per transplant, ethical standards cannot avoid the slippery slope toward commercialism.<sup>23</sup> Governmental supervision does not preclude commerce. In many countries the government controls everything and government agencies, some masquerading as

NGOs, perfectly play the role of middlemen. Governmental supervision does not guarantee high standards and any governmental supervision must also be compared with internationally accepted standards. An incorruptible panel of societal and professional peers entrusted with the task of approving cases of unrelated donor transplantation would be subject to all of the pressures that cause corruption in developing societies in the first place, including the tribal or feudal structure of society, lack of education and unequal economic opportunities for all members of the society.<sup>23</sup> Results reported by the proponents of these operations are at serious risk for flaws and fabrications. We recommend a healthy skepticism and mistrust when dealing with reports of unrelated donors or combined related and unrelated donors as well as various gray basket, "unconventional" and "new" categories of transplantation in so-called developing countries. Independent researchers who have no tie to the enterprise should report the results.

The lack of any, let alone a long-lasting, donor-recipient relationship preoperatively, donor unawareness of recipient fate postoperatively, donor hatred toward recipients and donor dissatisfaction with unappreciative recipient behavior are evidence of a pathological relationship that has no hint of similarity with the emotionally related category of transplantation. Abject poverty, unemployment (according to official figures Kermanshah has the highest rate of unemployment in Iran at 22.5%<sup>24</sup>) and the lack of social support (a 7% insurance rate and frustration with social support agency help, indicated by the fact that only 5% of those who ask for help ever ask again) urge people to sell a kidney, which represents their only reserve. Our participants are true heroes. Many of them stated in recorded interviews that they were able to steal but their conscience prevented them from doing it and they preferred to lose a kidney instead. However, when facing postoperative realities, they stated that given another chance they would prefer to beg or obtain a loan from usurers rather than sell a kidney. All related donors received money and they insisted that the recipients should buy a kidney from them because they had priority over strangers for receiving the money. Only a minority of donors reached their goals of vending and the money was not sufficient to cause any change in their lives.

Rare proponents of living unrelated renal donor transplantation try to benefit from the revival of living unrelated renal donor transplantation and monetary incentives in the United States to justify and legitimize their practices. However, the enormous socioeconomic and regulatory differences make such attempts futile. "The voluntary and even legislative controls are likely to be ignored in any society where the involved institutions are not yet strong enough, where the relevant laws are in a state of flux, where the numbers of transplants is grossly inadequate to cope with the numbers of patients, where the distribution of wealth is grossly skewed and thus massive wealth is juxtaposed to dire poverty, and where both petty and major corruption at all levels of society is a much talked about subject . . . any society which has at least several of these features is not a place to attempt a practical distinction between category IV ('rewarded gifting') and category V (rampant commercialism) transplantations."<sup>25</sup> In Iran no variant of the gray basket category may be practiced without degenerating into rampant commercialism, as evidenced by our empirical research, observations of honest transplanters and reports in the reformist Iranian press, of which all have been banned, including 12 in a single night.

We think that merely banning organ sale is not a panacea. At best it is like an analgesic for a deep-seated infection. Banning or not banning is merely a technical matter. The root lies in poverty. As long as there is abject poverty, there is fertile soil for such practices as selling kidneys. In Iranian year 1377 (1998) 23,000,000 Iranians or 35% of the Iranian

population lived beneath the poverty line, even by Iranian standards, while the richest 10% of the population consume 31% and the poorest 10% consume 1.5% of total goods.<sup>26</sup> The sale of children and blood as well as prostitution are other reported expressions of poverty. These factors should be considered in discussions of the effects of banning or legalizing the sale of organs to place the total effects of an organ trade ban or legalization in proper perspective without overestimating the effects. Banning kidney sales is like symptomatic therapy for a tuberculosis cough. In addition, an emphasis on banning or legalizing the sale of organs is unjustified and banning is a superficial, inadequate remedy. At the same time the effects of governmental regulation of the trade are modest when considering the bias of the officials of many developing countries as well as the active participation of some governments in the organ trade.

Radcliffe-Richards et al has stated that none of the familiar arguments against organ selling is effective and until good arguments appear the presumption must be that the trade should be regulated rather than banned altogether.<sup>27</sup> She said, "The only way to improve matters is to lessen the poverty until organ selling is no longer seems the best option, and if that could be achieved, prohibition would be irrelevant because nobody would want to sell . . . trying to end exploitation by prohibition is rather like ending slum dwelling by bulldozing slums; it ends the evil in that form, but only to making things worse for the victims. If we want to protect the exploited, we can do it only by removing the poverty that makes them vulnerable, or, failing that, by controlling the trade. There is much more scope for exploitation and abuse when a supply of desperately wanted goods is made illegal."<sup>27</sup> We agree with the latter statement that emphasizes the role of poverty and with the unimportance of banning.

However, we disagree with many of her untested assumptions. She has stated, "The poorer a potential vendor, the more likely it is that the sale of a kidney will be worth whatever risk there is."<sup>27</sup> As described, a reference to the immediate causes of sale in our study would lead anyone, including our study participants postoperatively, to agree that such causes were not commensurate with losing a kidney. We also disagree with her statement, "If the rich are free to engage in dangerous sports for pleasure . . . it is difficult to see why the poor who take the lesser risk of kidney selling for greater rewards—perhaps saving relatives' lives or extricating themselves from poverty and debt—should be thought so misguided as to need saving from themselves." Radcliffe-Richards has provided no empirical evidence to support her claim but we have presented evidence to the contrary. The majority of donors in our study said that they have not reached any of their goals, such as extricating themselves from poverty or debt and so forth. Thus, there were no greater rewards at all.

In addition, we disagree that "It is alleged that allowing the trade would lessen the supply of donated cadaveric kidneys. But although some possible donors might decide to sell instead, their organs would be available, so there would be no loss in the total and in the meantime, many people will agree to sell who would not otherwise donate."<sup>27</sup> Allowing the trade would hinder the establishment of a cadaveric program and the growth of living related donation. When cheap vendor kidneys are available, there is no incentive for the former 2 options. Vendors may provide kidneys but potential related donors may decide to buy a kidney rather than sell their own kidney, and so the total number of organs would not increase dramatically.

Furthermore, we disagree with the statement of Radcliffe-Richards that, "It is said that selling kidneys would set us on a slippery slope to selling vital organs. But that argument would apply equally to the case of unpaid kidney donation, and nobody is afraid that that will result in the donation of hearts."<sup>27</sup> The title of a documented report in the CASKP

organ is "Professionals spare only their hearts from selling."<sup>1</sup> The article documents the existence of brokers and represents an eyewitness account in Tehran of "a young man who sold his kidney and one of his vessels and was preparing to sell his cornea too."<sup>1</sup> Such cases are not too rare and they are testimony to the real risk of the slippery slope, at least in Iran. In unpaid related donation there is no poverty pressure to act as the driving force for giving vital organs or indiscriminately selling multiple organs.

Moreover, we disagree that, "Another objection is that allowing organ sales is impossible because it would outrage public opinion. But this claim is about western public opinion. In many potential vendor communities, organ selling is more acceptable than cadaveric donation, and this argument amounts to a claim that other people should follow western cultural preferences rather than their own."<sup>27</sup> Radcliffe-Richards et al have presented no objective data to support such claims. The claims represent a double standard and serve to justify the practices of rare domestic proponents of organ sale under the cover of "their country's especial social and cultural conditions and ethical codes." As reported by Chugh and Jha, Thiagarajan and Reddy argued that consent obtained from a related donor under emotional pressure was no better than that obtained after a financial inducement.<sup>20</sup> Proponents also argue that the related donor sense of fulfillment after the act of donation may be compared with the satisfaction of a paid donor due to improving the family standard of living. Another argument often advanced in favor of paid unrelated transplants is that paid donors use the benefit (money) obtained by contracting the kidney to do good to a third person, such as settling a family debt, arranging the dowry for the marriage of a sister and so forth, thus, justifying the principle of so-called indirect altruism.<sup>20</sup> Moreover, it is argued that in addition to paying money to donors, wealthy recipients feel obliged to provide additional relief to an impoverished society, thus, exhibiting a sense of so-called mandated philanthropy.<sup>20</sup> The fact remains that after the process of gaining a kidney is over the indirect altruism or mandated philanthropy vanishes. These phrases are only an attempt to put a veil over the ugly commercialism behind the practice.<sup>20</sup> We insist that the domestic presenters of such claims are aware of these fallacies and do not believe them.

We suggest that a clear line should be drawn between principled authorities from developed countries who are genuinely grappling with living unrelated renal donor transplantation issues and who do not benefit from kidney sales, and domestic opportunists who are trying to justify unjustifiable practices in developing countries. The latter individuals sometimes present the appearance of representatives of the other five-sixths of the less fortunate of mankind who because of involvement in sold kidney transplantation have the right to advise on the ethics of transplantation. The advocates of transplantation using sold kidneys argue that if donors are carefully selected, a middleman is not involved and if surgery is performed at a good hospital, recipients and donors benefit. However, the reality of the situation is revealing to the point of satire.<sup>28</sup> An alternative to an organ market is "to presume passive consent to [cadaveric] organ donation with the right to informed refusal."<sup>29</sup> We support the Transplantation Society position, which remains unchanged with respect to more general issues, that "organs and tissues should be freely given without commercial consideration or financial profit."<sup>30</sup>

#### CONCLUSIONS

By far the majority of living unrelated renal donors in Iran are vendors and not donors. Almost none of the criteria of an acceptable living unrelated renal donor transplant program is met in Iran. Globally empirical studies of vendors are at least as useful as theoretical discussions.

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#### APPENDIX

On October 23, 1995 the Transplantation Act was rejected by the fourth parliament. This long awaited act legalizing cadaveric and brain-dead organ donation was presented again on April 5, 2000 and passed by the fifth parliament. According to this act, written consent of the donor in a will or of his or her guardian is required, and there should be written permission from the Health Ministry for each hospital to perform such transplantations. However, none of the laws passed by the Iranian parliament is valid and effectual until and unless ratified by the Council of Guardians. The passed act was presented to the Council for ratification, and on November 26, 2000 the Council announced rejection of the transplantation act "because of its disagreement with Islamic laws." In many Islamic countries, however, the religious leaders have announced that there is no religious contraindication to brain death and cadaveric transplantation.

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## EDITORIAL COMMENTS

The author reports commercial living unrelated renal donation. He has documented the significant problems that may occur with the buying and selling of kidney transplants. The transplant communities in most countries deny the use of kidneys from paid living donors. Because of the shortage of transplantable kidneys, the concept of paid living donors is being cautiously revisited. It should be possible to have laws and professional practices that allow the selling of nonvital organs for transplantation. Lu has constructed a framework for the sale of kidneys from living donors<sup>1</sup> that has been modified and presented.<sup>2</sup> A framework for the sale of kidneys from living donors may be that all parties are citizens of the same country, no brokers or contractors are allowed, the donor and recipient are unknown to each other, a nonprofit agency or voluntary organization, such as the United Network for Organ Sharing or the Red Cross, oversees the transaction, an algorithm to ensure the physical and mental health of the donor, and prevent disease transmission is followed, the donor and recipient have independent teams of physicians and long-term care for health problems arising from donor nephrectomy is provided for the donor. For example, a kidney transplant would be purchased from a living donor by the United Network for Organ Sharing or the Red Cross. That kidney would then be packaged in the same way as a cadaveric kidney transplant and shipped to another area of the country, where it would be transplanted into the most qualified recipient based on the point system currently used for distributing cadaveric kidney transplants.

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The author has written an account of nonaltruistic living renal donation for transplantation at a single center in Iran. The results of this study support the current International Transplantation Society ban on the selling of organs for transplantation. When the sale of organs is allowed in an impoverished nation without sufficient governmental oversight, the poor are exploited.

The author administered a questionnaire to living unrelated renal transplant donors at least 2 years after surgery. During the study period 305 living donor renal transplants were performed and 100 donors participated in the study. Although there may be bias in the donors who agreed to the study, the author claims that none of the donors he contacted refused to participate in the study. He also states that 215 additional donors have been interviewed with similar conclusions. It is shocking that 76% of the donors believe that the sale of organs should be banned and only 5% thought that their goals of vending a kidney were completely met. The major causes of dissatisfaction were a lack of recipient appreciation, refusal of recipients to realize preoperative promises and a breach of secrecy regard-

ing the transaction. The expressed need to be appreciated by the donor is noteworthy in that only 9% of living unrelated donors stated that altruism was a major motivation for donation, while 85% were primarily motivated by a financial incentive. The donors were predominantly young healthy married men with minimal education. Only 16% of the donors were fully employed. It is interesting to compare this population to the altruistic living donor population in the United States. In 1998 4,154 living donor kidney transplants were performed with 93.7% 1-year graft survival.<sup>1</sup> Donors were predominantly white (58%), female (58%), and between ages 18 and 49 (62%).

The discussion in this report exposes some financial and social realities controlling renal transplantation in Iran. To some extent donor dissatisfaction stems from the poor regulation of contracts between donors and recipients. Despite government payment for donation the donor agrees to vend the kidney only if provided with additional compensation from the recipient. When these additional promises are not kept or the bureaucracy delays compensation, benefits to the donor are markedly decreased.

With the growing disparity between the demand for organ transplantation and the supply of cadaveric organs the temptations of buying an organ may increase in all nations. In the last few years a few patients at our center have gone abroad to receive renal transplants rather than suffer the effects of prolonged dialysis. Transplantation professionals are considering various options of compensation to increase cadaveric donation.<sup>2</sup> However, in developing nations the cost of developing a cadaveric organ donor network may be prohibitive. If dialysis facilities are scarce, living renal donation may be the only option for survival. To some extent the Iranian government should be commended for the effort to regulate the living organ donor trade and protect its citizens. They have significantly increased the reimbursement for donation, which has eliminated the renal transplant waiting list in their country. Of the donors 5% believed that their goals of vending were completely met. I strongly support the author conclusion that compensated organ donor programs should be carefully studied to minimize human suffering. Countries that have traditionally relied on cadaveric donor organs for transplantation may benefit from the experience of countries such as Iran as they experiment with compensation plans to increase the rate of organ donation. Despite the governmental safeguards to protect nonaltruistic donor patients in this study clearly felt exploited. The ethical questions raised by this report suggest to me that the ends of increasing renal transplantation do not justify the means of obtaining suitable organs.

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