

Compensated Living Kidney Donation in Iran Donor's Attitude and Short-Term Follow-up

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Introduction. Living unrelated kidney donation has a high rate in Iran, where a unique organ procurement model is running. We evaluated feelings and attitude of these donors after kidney donation.

Materials and Methods. A questionnaire was sent to 25 kidney transplantation centers in Iran. It was designed to assess kidney allograft donors in terms of their reason for donation, their feeling after donation, and their attitude on keeping in touch with the recipients. Of 721 donors recorded in the national registry during the study period, we collected data of 600 living donors and their answers to the questionnaire.

Results. Of 600 donors, 495 (82.5%) were men and 568 (94.8%) were unrelated to the recipients. Motivation for donation was stated to be purely financial by 224 respondents (37.3%) and purely altruistic by 11 (1.9%). Their feelings before discharge were complete satisfaction in 519 (86.5%), relative satisfaction in 69 (11.5%), regret in 9 (1.5%), and indifference in 3 (0.5%). Willingness to get informed of the transplant outcome and make connection with the recipient following transplantation was chosen by 457 (76.2%) and 400 (66.7%) donors, respectively.

Conclusions. We found that satisfaction of donors shortly after donation, on the one hand, and no reportedly serious complications in long-term follow-up of donors, on the other hand, may give the impression that the Iranian model may solve the problem of increasing demand for kidney allograft. Nevertheless, every country should build its own standards for living unrelated kidney donation consistent with its capacities and resources.

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INTRODUCTION

As a consequence of the growing gap between organ supply and demand, living kidney donor transplantations are increasing in the world and unrelated living donor transplantation and even ABO blood group-incompatible donors have been reintroduced.¹⁻⁴ Conversely, living kidney donation has led us to ask to what extent physical injury to a healthy donor can be justified for the benefit of a sick recipient regardless of the fact that both

conventional nephrectomy and laparoscopic living donor nephrectomy are safe procedures.⁵⁻⁷ Although there were some concerns,⁶ a meta-analysis of reduced renal mass in humans undertaken by Kasiske and colleagues illustrated that unilateral nephrectomy caused a decrement of 17 mL/min on average in the glomerular filtration rate that tended to improve with each 10 years of follow-up (average increase, 1.4 mL/min per decade).⁸ Further, the increase in proteinuria was negligible

after nephrectomy for trauma or kidney donation (average, 76 mg/10 y). There are also other studies on the long-term follow-up of living donors with similar results.^{9,10}

Iran was the first country with governmental incentive living kidney donation program, legislated in 1997. The Iranian model of paid kidney donation program not only solved the problem of the increasing demand for organs, but also was successful to disavow transplant tourism.^{2,11,12} However; different disadvantages are visible in the Iranian system, like the other human designed systems. The prevalence and incidence of end-stage renal disease (ESRD) have increased in Iran from 238 per million people (pmp) and 49.9 pmp in 2000, respectively, to 357 pmp and 63.8 pmp in 2006. At the time of this study, 48.5% of the patients with ESRD were living with a transplanted kidney.^{13,14}

In Iran, the government presents some amount of money and 1-year health insurance to donors under the title of “gift for altruism,”^{2,13,15} and provides the hospital with the operation costs. In general, the donor and the recipient are introduced to each other, and the donor also receives a negotiated payment from the recipient as compensation through the Patient Kidney Foundations. The donor must also have the consent of his or her next of kin and both the donor and the family member or relative are required to provide identification to the foundation.¹⁶

Despite the emergence of extensive research on the recipients, there remain many unanswered questions about the psychosocial aspects of the experience of donors both before and after donation. A survey of donors at a later time would seem to be much more realistic about their attitudes in some aspects, and especially medical ones, although it is difficult to find donors after they leave the hospital. We designed a questionnaire in 2005 to become standard to be used as the form for national registry of donors, which regardless of its limitations can clarify the donor’s feelings in the Iranian model of transplantation, especially soon after their decision comes true and the possible change of their body image and physical sensations is recognized.

MATERIALS AND METHODS

A provisional questionnaire was designed

(Appendix) for assessment of the kidney allograft donors in terms of their reason for donation, their feeling after donation, and their attitude on keeping in touch with the recipients. The questionnaire was tested in pilot study on a low number of participants, and accordingly, some revisions were made. The study was approved by the ethics committee of the Urology and Nephrology Research Center, affiliated to Shahid Beheshti University of Medical Sciences. The questionnaire and an instruction document were sent in 2005 to all the 25 transplantation centers of the country and it was requested that the head nurse in every transplant center to be in charge of its administration to the patient to be filled before discharge.

In 5 months, of 721 donors, 600 living kidney donors from 17 transplant centers consented and filled the questionnaire. Filling the form was denied by the authorities of the remaining 8 centers (and not by their donors), because of either shortages in staff or disagreement on performing the survey. The questions would be asked by the transplant nurse if the donors could not fill the questionnaire by themselves. Also, demographic and clinical data of the donors were collected, including age, sex, nationality, relation with the recipients, education level, income, employment status, accommodation status, marital status, and health insurance status. The collected data were analyzed using the SPSS software (Statistical Package for the Social Sciences, version 11.5, SPSS Inc, Chicago, Ill, USA).

RESULTS

The mean age of the participants in this study was 28.0 ± 5.2 years (range, 17 to 50 years). They were 495 men (82.5%) and 105 women (17.5%). Thirty-two of the donors were related to the recipients (5.3%), including 4 parents, 18 siblings, 2 children, 2 spouses, and 6 emotionally-related people. The remaining 568 donors (94.8%) were unrelated to the recipients. The nationality of 580 donors (96.7%) was Iranian (as the recipient and donor should have the same nationality). Regarding marital status, 468 donors (79.9%) were married, 101 (16.9%) were single, and 19 (3.2%) were divorced. Of the participants, 488 (82.6%) did not have any health insurance program.

Of the donors, 118 (22.5%) were unemployed or not working (including 9 students and 79 house keepers), 173 (33.0%) had a part-time job, and

146 (27.9%) had a full-time job. The educational level of the participants was as follows: 4.6% were illiterate, 65.2% had a secondary school degree, 23.7% had finished high school, and 6.5% had a university degree. Their mean monthly income was US \$ 175.0 ± 68.5 (range, US \$ 43.5 to US \$ 380.4). Thirteen percent of the donors owned their living place, while 82.2% had hired a place and 4.8% were living in their relatives' places.

Motivation for donation was stated to be purely financial by 224 respondents (37.3%); both financial and emotional/altruistic, each to some degrees, by 365 (60.8%); and purely emotional/altruistic by 11 (1.9%). The items mentioned as "others" by the respondents could be all classified as financial or altruistic. Therefore, they were included in the above figures. Financial motivations were to afford money for medical purposes (disease in need of hospitalization in one of the family member), to maintain family reputation, to solve personal problems, to pay back a debt, and to be exempted from the military service. Altruistic motivations were mainly God satisfaction, God forgiveness, and emotional relationship with the recipient.

The donors' feelings prior to discharge from the hospital were complete satisfaction in 519 (86.5%), relative satisfaction in 69 (11.5%), regret in 9 (1.5%), and indifference in 3 (0.5%). Willingness to get informed of the transplant outcome of the recipient was chosen by 457 donors (76.2%). Also, 400 donors (66.7%) were willing to make connection with the recipient following transplantation. No report of mortality in donors was received. There were minor complications occurred in 15 donors (2.5%) including long duration of hospital stay, pain, skin erythema, and conditions that needed administration of antibiotics.

DISCUSSION

The present study, similar to other studies in Iran,^{12,13,16} showed that most of the donors were young men; male-female ratio of donors was 4.7:1. The recently approved strategy is to promote living kidney donation by applying compensative programs,¹⁷⁻¹⁹ but gender disparity in organ donation is a warning which suggests that socioeconomic and cultural factors influence the rate at which women voluntarily donate their kidneys.^{20,21} Motivation for donation is another important issue. Despite of serious accusations made against the Iranian

living unrelated program for not achieving ethical propriety in some studies, money, albeit playing an important role, was not the sole motivator. The donors mentioned their altruistic motivation (two-thirds) and willingness to get informed of the transplant outcome (76.2%). Some experts believe that the use of self-interest (ie, financial incentives) to shape human behavior is much better understood than the use of pure altruism. The forces of self-interest are basic for almost all of our daily activities.^{12,18,22} Although the time of discharge following the donor nephrectomy is not the best time to survey living donors' feelings regarding their experience and decision, it can show us some important items and a guide to more comprehensive studies in the future to evaluate how long their positive or negative feelings may last.

Interpretations of sacred and other religions texts have led the experts to varying conclusions about the moral duty to provide organs for transplantation. The verse in Holy Quran (verse 7:32), "[...] whoever saves the life of one, it shall be as if he had saved the life of all mankind" is referred by many Moslem experts. Therefore, it is useful to place these results in the context of the values to a society with increasing number of patients with ESRD who can get transplants without prolonged waiting times. Furthermore, the government considers this model preferable to dialysis from its own point of view.^{2,12} Such a model could undoubtedly prevent or diminish shortcomings of illegal markets by means of the implementation of some proper safeguards against exploitation of donors, and also, living related donors often get over the feel of immense pressure from their families to donate a kidney.^{2,5}

On the other hand, the total health expenditure in Iran is 6% of the gross domestic product.¹³ Different modalities of renal replacement therapy are free of charge and are accessible for all in Iran. The government pays for hospital admission and transplantation costs, and also provides essential immunosuppressive drugs at a greatly subsidized and reduced price to the transplant recipients. Otherwise, recipients cannot afford it and transplantation does not work. Furthermore, the reward and health insurance to the donor are on the shoulder of the government and nonprofit charitable organizations to acknowledge the altruism of the donors. It is apparent that the

1-year insurance package for donors is insufficient to cover complications that may arise later. We should try to save our resources to extend this health insurance to a lifetime program. In that case, the financial relationship between the donor and the recipient may more or less be over.

It seems that the success of the Spanish model of deceased donation program is not due to passing the presumed consent law, but it is because of its realistic approach of providing hospitals with specific budgets for organ donation and mandating placement of trained staff that are responsible for the donation process.²³ Therefore, apart from the fact that its law was passed in 2000, this program had to be started later in Iran, because of limitation of budget. At present, implementation of deceased donation program require less budget than before as highly professional transplantation units are running.

In most developing countries, starting an effective dialysis and kidney transplantation program as an expensive and modern treatment has always created profound socioeconomic problems. They should set priorities for different health programs and serve necessary adjustments when new technologies are introduced in order to integrate the changes into their own conditions. Considering ongoing ethical arguments, paid organ transplantation may be denied completely; thus, the commercial transplantation may be endorsed unwillingly.²⁴ Condemnation of all forms of compensated living unrelated transplantations might result in death of many patients with ESRD, which underlines the importance of Iranian model. It seems that involvement of both governmental and nongovernmental organizations in providing money for the humanitarian act of unrelated kidney donation is pivotal; their efforts significantly facilitate the process of finding an appropriate kidney graft for patients with ESRD in a timely manner.

In 2006, the average monthly salary in Iran was US \$ 225 and unemployment rate in the country was 11.2%,²⁵ while we found that the donors' average income was US \$ 175 and about one-fifth of them did not have a job. It is so optimistic that we suppose this average rate of unemployment can be extrapolated to the patients with ESRD whose disabilities due to their disease make it almost impossible for them to work full time. In

another study that we performed on 247 patients on hemodialysis in Tehran, Iran, we found that 11.4% of them had a job, 29.8% were retired due to ESRD, and 26.9% were unemployed.²⁶ Less than 5% of the donors in this study were illiterate, while 28.3% of the patients on dialysis in Tehran province were illiterate. These facts imply that although the mean income of donors is low, their recipients are in no ways better than them in terms of income. Meanwhile the percentage of patients on ESRD who go for transplantation is around 50% in our country. Ghods and colleagues showed that recipients can be as poor as their donors; their study of 1000 donors and recipients revealed that while 84% of donors were poor, so were over 50% of recipients.²⁷ Poverty has a lot of definitions inside each country, and we merely compared donors' monthly income with the average income in the general population. In another study of dialysis patients in Tehran province (2630 patients), we recorded that of 36% of medically eligible patients for transplantation, only 7% registered for kidney transplantation in the waiting list of cadaveric donor transplantation.¹⁴ It means that most patients prefer to have kidneys from living donors regardless of their economic status. Simforoosh and colleagues also emphasized that patients prefer to be transplanted as soon as possible, rather than years later.²⁸

Still there are some who argue that the extremely low theoretical risk to the donor, especially with laparoscopic donor nephrectomy does not compensate for the evident socioeconomic advantages and increased quality of life of the recipient.²⁷ However, donors' feelings following donation and prior to discharge from hospital were satisfaction in 98% of our cohort, in agreement with other studies.^{3,11,29} However, feeling of satisfaction needs to be followed by comprehensive studies to investigate how long it may last. Some emphasize the following disadvantages of the program: connection between donor and recipient, donors' unwillingness to be followed up, and short-term support following donation. In our judgment, lack of long-term medical follow-up of the donors is the main weak point of this model in our country. Thus, if we could designate some budget for it, many concerns would be passed over.

CONCLUSIONS

We argue that organ shortage problems can

partly be solved by establishing controlled donor compensation programs, which may also prevent exploitation of the donors. However, it is impossible to suggest a concrete solution for all countries due to diversity in economic status as well as in social and cultural values. Thus, every country should build its own ethical standards for living unrelated kidney donation. The support of the donors with long-term medical insurance must be taken into account.

APPENDIX

Summarized Questionnaire

1. Reasons (Motivations) for donation:
 - Financial problems: (a) high (b) medium (c) low (d) null
 - Emotional/altruistic: (a) high (b) medium (c) low (d) null
 - Others:
2. Feelings following donation:
 - (a) complete satisfaction
 - (b) relative satisfaction
 - (c) regret
 - (d) indifference
3. Willingness to get informed of the transplant outcome:
 - (a) yes
 - (b) no
4. Willingness to make connection with the recipient following transplant:
 - (a) yes
 - (b) no

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CONFLICT OF INTEREST

None declared.

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