Perceptions in Living Kidney Donation: What Protagonists Think and Feel

I.C. Frade, A. Lopes, L. Teixeira, J. Rodrigues, M. Almeida, L. Dias, and A.C. Henriques

ABSTRACT

Background. Although donor perceptions of donation have been evaluated in several programs, evaluation of associated recipients has not been as frequent.

Purpose. Our aim was to evaluate and compare after transplantation, donor and recipient perceptions of donation.

Methods. After transplantation 35 recipients and 45 donors completed a sociodemographic and a donation perception questionnaire. We applied the Fisher test to descriptive (absolute and relative frequency) data.

Results. 57.8% of donors were female and 62.9% of recipients male. 53.3% of donors were siblings, 44.5% parents, and 2.2% a daughter. Most recipients (71.9%) thought that the donation was the donors' initiative and 21.9% that it was suggested by medical team. 96.4% responded that it was the donor's wish that determined their decision; 51.4% had serious or some doubts about accepting the option, but for 48.6% it was an easy decision. Among the donors, 88.9% decided by themselves and 8.9% were asked for donation. For 91.1%, their wish was the main reason of the decision, but 8.9% felt a moral obligation; 77.8% thought it was an easy decision, and 17.8% hesitated a little 84.4% were not worried about their future health.

Conclusions. Altruistic motivations were predominant in both groups. Most recipients thought that the motivation for donation was self-determined, a finding that agreed with donor perceptions. Perceptions about the quality of and changes in emotional relationship were the same in both groups. Donors and recipients referred to the donation process as positive, but there were some negative emotions and perceptions.

Scarcity of organs from deceased donors has become a critical problem, encouraging living kidney donation programs.[1] Cultural differences and public policies strongly influence this issue, namely, different legislation regarding donation from deceased or living donors in various countries. Living unrelated donation in addition to living related donation programs have brought more complexity to ethical consideration in the evaluation and psychosocial impact among donors.[2,3]

Psychosocial evaluation of candidates for living kidney donation has been an important issue.[4–6] The minimization of possible harmful aspects depends on careful selection and follow-up of donation candidates. The decision process must be voluntary and informed; comprehension of personal experiences during all aspects of the donation process are important issues.[7] For donors, the donation process evolves from first perception of recipient needs through internal decision making to nephrectomy.[8]

The possible psychologic, emotional, or other benefits of organ donation have been established.[9] Despite the altruistic impact of donation, the strong emotional impact sometimes includes loss and grief experiences.[10] The access

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From the Liaison Psychiatry and Health Psychology Unit (I.C.F., A.L., J.R.), Renal Transplant Unit, Nephrology Service, (M.A., L.D., A.C.H.), Oporto Hospital Center, Hospital de Santo António Unit; and Instituto de Ciências Biomédicas Abel Salazar, Unidade de Investigação e Formação sobre Adultos e Idosos (L.T.), Oporto, Portugal.

Address reprint requests to Inês Carvalho Frade, Unidade de Psiquiatria de Ligaçãoe Psicologia da Saúde, Hospital Geral de Santo António, Largo do Prof. Abel Salazar, 4099-001 Porto, Portugal. E-mail: inescarvalho.psi@gmail.com

360 Park Avenue South, New York, NY 10010-1710

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and perception of delivered information has usually come from medical information or through public media, patient associations, or the internet.[11]

In Portugal, organ transplantation is entirely supported by the national health system. Portuguese law (1993, revised in 2007) established opting in as its foundation. Since 2007, living unrelated donations have been permitted.

In our hospital, a protocol of psychosocial donor and recipient, evaluation was integrated into the clinical and immunologic assessments. Pairs are reevaluated 1 year after transplantation, when a perceptions questionnaire is applied to each member of the pair to explore donor and recipient motives and decision-making processes, attitudes and expectations, as well as coping processes. The results of this questionnaire are presented in this study.

SUBJECTS AND METHODS

From 2002 to 2008, the 75 pairs (donors and recipients) who completed living donor kidney transplantation (LKDT) all underwent pretransplantation psychosocial evaluation, but only 45 donors and 35 recipients completed the second assessment at 1 year after transplant. These populations constituted the samples in the present study to assess perceptions related to donation.

Evaluative Instruments

A sociodemographic questionnaire included age, gender, school level, professional activity, and current employment situation, marital status, and relatedness to the recipient. Participants were evaluated with a donation perception questionnaire composed of 13 multiple-choice questions and three open questions regarding emotions and feelings related to donation. Information regarding donor and recipient postoperative courses and complications was collected from participant medical records.

Statistical Analysis

Descriptive data are reported as frequency distributions to characterize donor and recipient perceptions of donation. The Fisher test was used to compare donor versus recipient groups. It was applied as a descriptive study of the results of the 13 multiple-choice questions, Content analysis was applied to the results of open questions. In all analyses, $P < .05$ was considered to be statistically significant. The analysis was performed using SPSS, version 17.0.

RESULTS

Demographic and Social Data

The sample comprised 80 participants: 35 (43.8%) recipients and 45 (56.2%) donors. Considering the total sample, 51.3% (n = 41) were male subjects, 63.8% (n = 51) were ≤40 years old, 76.3% (n = 61) were married or in union of fact, and 66.3% (n = 53) had ≤9 years of school. Considering the same analysis for recipients *vs* donors, there were no significant differences among the sociodemographic variables (Table 1).

Complications Following Living Donor Kidney Transplantation

There were no deaths in the donor population, and none of them suffered major postoperative complications. One recipient died as a result of septic shock, and four recipients experienced major complications: rejections and vascular thromboses, one corresponding to graft failure.

Recipient Perceptions about Donation

Most recipients (71.9%; n = 23) reported that the donation was the donor's initiative and 21.9% (n = 7) that it was suggested by the medical team; 96.4% (n = 27) thought that donation was the donor's will; 48.6% (n = 17) thought it was an easy decision to accept donation, 17.8% (n = 8) had doubts, and only 4.4% (n = 2) thought was a difficult decision. The total recipient sample (100%; n = 35) classified their relationship with the donor as special, and 80.0% (n = 28) reported that it had not changed after donation. Ten recipients (28.6%) had no fear and 71.5% (n = 25) some (weak to strong) fear of kidney rejection. Appropriate information was received by 91.4% (n = 32) about the donation process, although 48.6% (n = 17) thought that they had little information about the surgical procedures. Most recipients (77.1%; n = 27) thought that after transplantation, the donor's health was the same; 8.6% (n = 3) thought that it became worse.

Donors' Perceptions about Donation

Among donors, 88.9% (n = 40) reported that the idea of donation was their own initiative and 8.9% (n = 4) were asked for donation by the recipient. The decision was their own will for 91.1% (n = 41); but 8.9% felt it was a moral obligation. The decision to donate was easy for 77.8%, and 22.2% (n = 10) had many or some doubts. When asked about the fear that donation could reduce their lifetime, 84.4% (n = 38) did not agree, 11.1% (n = 5) weakly agreed, 1 (2.2%) moderately agreed, and 1 (2.2%) strongly agreed. Thirty seven donors (82.2%) did not believe that donation would damage their health, and 17.8% (n = 8) were concerned about that. Thirty-two (71.1%) trusted that the recipient could take care of the donated kidney, and 28.8% (n = 13) had some doubts about this.

Table 1. Sample Sociodemographic Characteristics by Group

	Group				
	Recipients		Donors		*P* value
	n	%	n	%	
Gender					
Male	22	62,9	19	42,2	.067
Female	13	37,1	26	57,8	
Age group					
≤40 y	13	37,1	16	35,6	.884
>40 y	22	62,9	29	64,4	
Level of school					
≤9 y	22	62,9	31	68,9	.571
>9 y	13	37,1	14	31,1	
Marital status					
Other	9	25,7	10	22,2	.716
Married/union of fact	26	74,3	35	77,8	

Regarding medical and surgical procedure information, 80.0% (n = 36) thought that they received sufficient information and 19.9% (n = 9) little information. Twenty-nine (64.4%) were not and 35.5% (n = 16) were afraid that the surgery could go wrong; 40.0% (n = 18) were not and 60.0% (n = 27) were afraid of kidney rejection. Most donors (86.4%; n = 38) were not and 13.7% (n = 6) were afraid of family disapproval. For 12 donors (26.6%), donation had implications on their financial situation, and did not for most donors (73.3%; n = 33). Forty-one (91.1%) considered the provided information about the process to be appropriate; 8.9% (n = 4) thought that it was partly insufficient.

Regarding the relationship between donor and recipient, 86.7% classified it as special, 6.7% (n = 3) as usually tense, and 6.7% (n = 3) as not good. Thirty-two (72.7%) stated that the relationship had not changed after transplantation; 25% (n = 11) considered it to have become little to much better, with only one donor (2.3%) admitting that it had become worse. Most donors (93.2%; n = 41) thought that after transplantation the recipient's health became much better, 2.3% (n = 1) little better, 2.3% (n = 1) the same, and 2.3% (n = 1) worse. Forty-four donors (97.8%) would without hesitation donate again if it was possible; only one donor (2.2%) had some doubts.

Qualitative Analysis

The open questions asked donors and recipients to give in a few words: 1) the meaning of donation; 2) their feelings toward the pair; and 3) the quality of provided information. Recipients (34%) expressed emotions toward: the donor of gratitude (26%) with feelings of a better quality of their relationship (34%); 74% expressed feelings about themselves, namely, feelings of a better quality of life (37%) and positive life changes (46%) with positive emotions of joy and elation (23%). Donors expressed positive feelings toward recipients, namely improved emotional life (56%) and having improved quality of life or giving life, and toward themselves of a better self-esteem (31%). Only a few wrote something about the given information; most recipients and donors reported it as adequate.

DISCUSSION

There were no significant differences between the biographic data of donors and recipients. Although there were more women donors and more male recipients, but the difference had no statistical significance. Most donors were siblings, which corresponded to the literature,[12] despite different legal backgrounds.

Similar perceptions about altruistic motives for donation were observed in donors and recipients. The idea for donation had generally appeared from the donor; it was not provoked by external causes. Our results showed that it was easier for donors to donate the organ than for recipients to accept it. The quality of relationship between recipients and donors was thought to not have been changed, which suggests that the idea of donation comes from an established strong relationship.

Regarding the perception of given information about medical and surgical procedures to make a decision, more recipients considered it to be adequate whereas fewer donors considered it to be adequate. We may think that recipients are more familiar with medical procedures with closer more established therapeutic relationships. This observation could suggest the necessity of more careful and better-quality information for donors. We must carefully evaluate how information has been received and interpreted by these particular "patients."

The fear of rejection was greater among recipients. In our program, the question of rejection is always discussed with donors during the evaluation process. It is important that they separate, as much as possible, the intention and act of donation from the independent result of the graft outcome, even if there is an inevitable emotional impact of that event.

In our sample, recipients had more fear of family disapproval, which may raise the question of guilt feelings that might arise from feeling they have "harmed" their beloved ones. All of the donors stated that they would donate again and would strongly encourage donation as an individual and conscious decision. Two recipients would not receive again; those were the patients who experienced graft failure.

In conclusion, altruistic motivations were felt by both groups to be predominant. Most recipients believed that the motivation for donation was self-determined, which agreed with donors' perceptions. Perceptions about quality of and changes in emotional relationships were the same for both groups and did not change for most of them with transplantation. Donors and recipients referred to the donation process in a positive way, especially regarding quality of life and emotional improvements Some negative emotions and perceptions were also mentioned, which implied that psychosocial assessment and support are essential issues in LKDT. It is important to continue to discuss psychologic issues and offer careful assessment of candidates for LKDT.

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