Altruistic Kidney Donation to a Stranger: Psychosocial and Functional Outcomes at Two US Transplant Centers

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Background. The number of living kidney donors with no preexisting relationship to the recipient has increased sharply. This study compared the psychosocial and functional outcomes of these altruistic donors to a stranger (ADs) with donors with a longstanding relationship with the recipient (traditional donors [TDs]).
Methods. ADs (n=39) and TDs (n=52), who were similar on age, sex, and year of donation, were recruited from two transplant programs in the United States. Participants completed validated measures of psychosocial and functional outcomes a median of 5 years after donation (range, 1–12 years).
Results. ADs and TDs did not differ significantly in the total number of donation motives. Both were motivated by a desire to help, the benefits to the recipient outweighing the risks to the donor, a sense of moral duty, and imagining oneself in the position of the recipient. Psychological benefits were endorsed equally by both types of donors, although TDs reported higher Quid Pro Quo scores relative to ADs (P=0.04). ADs and TDs did not differ significantly on any of the Short Form-36, Version 2 scales (P values ranged from 0.19 to 0.85). Few donors (3 ADs and 1 TD) regretted their donation decision.
Conclusion. Overall, findings indicate that carefully screened ADs experience psychosocial and functional outcomes comparable with those of TDs and should not be systematically excluded from the opportunity to donate.

Keywords: Kidney donor, Living donation, Anonymous, Quality of life.

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The number of living kidney donors who are biologically unrelated to their recipient has increased substantially, and now accounts for one third of all live donor kidney transplants in the United States (*1*, *2*). One subgroup of unrelated kidney donors is the altruistic donor to a stranger (AD), who does not have a preexisting genetic or emotional relationship to the intended recipient. Although still relatively small in comparison with more traditional donors (TDs) who have a longstanding preexisting relationship with the recipient, the number of ADs in both the United States (*2*) and Europe (*3*) has increased sharply in recent years. Transplant programs are increasingly willing to evaluate and use ADs to facilitate more transplants (*4*).

The transplant community recognizes the importance of assessing the psychological and quality of life of all living kidney donors (*4*, *5*). In the absence of a preexisting relationship with the recipient, the motives and psychological functioning of ADs have been the focus of considerable dialogue and consideration (*6*, *7*). Guidelines exist to facilitate careful psychological assessment and additional safeguards in evaluating and selecting these donors (*8*, *9*). However, little attention has been given to examining the psychological and quality-of-life outcomes of ADs (*10*). Therefore, we assessed the psychological and functional outcomes of ADs relative to a comparison group of TDs.

RESULTS

Participant Recruitment and Sociodemographic Characteristics

Thirty-nine (75%) of the 52 ADs returned completed study questionnaires. We could not locate four ADs, one was deceased, and eight did not return study questionnaires by the study endpoint. Fifty (48%) of 104 TDs returned completed questionnaires. Fourteen TDs were not found and 40 did not return questionnaires. Study participants did not differ significantly from nonparticipants on age, sex, or year of

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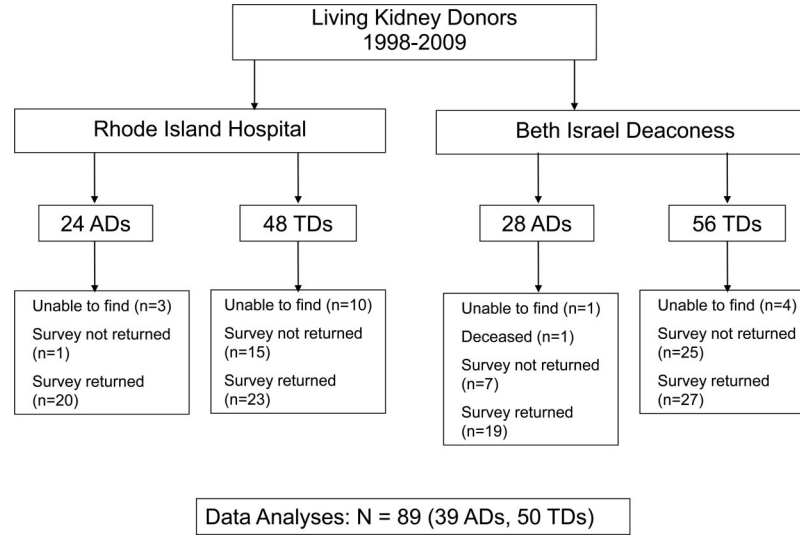

FIGURE 1. CONSORT diagram showing recruitment and participation rates for altruistic donors (ADs) to a stranger and traditional donors (TDs) at both study sites.

donation ($P>0.10$). The participation rates for both ADs and TDs did not differ significantly by center (Fig. 1).

Of the 39 ADs, 19 (49%) were anonymous nondirected donors and 20 (51%) were directed donors to a stranger. Anonymous nondirected donors were more likely to be single (26% vs. 10%, $P=0.01$) and to be on the national marrow donor registry (53% vs. 20%, $P=0.04$), but there were no other differences on sociodemographic characteristics or any of the other outcome measures. Therefore, these two types of ADs were combined for all subsequent analyses.

ADs and TDs did not differ significantly on sociodemographic characteristics (Table 1). Most donors were women, white, married, well educated, employed, and self-described as religious. Household income exceeded $50,000 for most donors. All except three donors (2 ADs and 1 TD) had health insurance currently. Median time since donation was 5 years (range, 1–12 years).

Donation Motives

ADs and TDs did not differ significantly in the total number of donation motives (Table 2) endorsed when the results were examined independently ($P=0.46$), or when adjusted for center, sex, age, and time since donation ($P=0.50$). A desire to help, the benefits to the recipient outweighing the risks to the donor, a sense of moral duty, and imagining oneself in the position of the recipient were identified by both ADs and TDs alike as the primary donation motives.

Altruistic Behaviors

ADs were significantly more likely than TDs to be regular blood donors ($P=0.03$), enrolled in the National Marrow Donor Registry ($P=0.05$), and registered as a deceased organ donor ($P=0.05$; Table 1). They did not differ in whether they are involved in regular volunteer work.

Psychosocial Outcomes

ADs and TDs reported similar levels of Interpersonal Benefit, Personal Growth, Spiritual Benefit, and Health Consequences on the Living Donation Expectancies Questionnaire (LDEQ; *P* values ranged from 0.06 to 0.92). In the independent analysis, TDs had significantly higher Quid Pro Quo scores (7.2 vs. 5.8, $P=0.04$) and significantly lower Miscellaneous Consequences scores (3.0 vs. 4.5, $P=0.03$) than ADs. However, when results were adjusted for center, sex, age, and time since donation, the only significant difference between the two groups was on the Quid Pro Quo scale, whereby TDs had higher scores than ADs (7.2 ± 3.0 vs. 5.8 ± 3.4, $P=0.04$). There were no statistical differences between groups on the other LDEQ scales (*P* values ranged from 0.06 to 0.98).

We dichotomized the LDEQ rating scale to reflect whether donors agreed or disagreed with the item. The psychological benefits from donation most commonly reported by ADs were feeling proud of myself (87%), donation adding extra meaning to my life (80%), and feeling better about myself (74%). For TDs, the most commonly reported benefits were feeling proud of myself (82%), being more respected and admired by family and friends (76%), having an increased appreciation for the value of my own life (72%), and feeling a greater sense of closeness with the recipient (66%). Regarding other notable findings, one donor (1 AD) reported receiving money from the recipient for donation, nine donors (3 ADs and 6 TDs) reported receiving preferential treatment from the recipient, and 30 donors (9 ADs and 21 TDs) reported the expectation that the recipient will now help them in the future if they need it.

Few donors identified other psychosocial problems secondary to kidney donation, including problems getting life (n=6) or health (n=2) insurance, depression (n=6), anxiety (n=5), and financial problems (n=4) (Table 3). Regarding "other" psychosocial problems, two ADs (both directed donors to a stranger) reported heightened conflict with family members about the decision to be a donor. Thirty-three (85%) ADs made contact with the recipient after donation, with all but two of them describing the experience as positive.

Functional Status

All donors who were employed before surgery (n=77, 87%) returned to their same job or started a new job for reasons unrelated to donation. Overall, donors missed a me-

TABLE 1. Sociodemographic characteristics and altruistic behaviors of altruistic donors to a stranger and traditional donors

	AD (n=39)	TD (n=50)	P
Sociodemographic characteristics			
Age	49.7±11.6	53.5±10.3	0.11
Gender			
Female	24 (62)	37 (74)	0.25
Male	15 (38)	13 (26)	
Time since donation (yr)			
1–3	17 (44)	20 (40)	0.73
4–6	11 (28)	12 (24)	
>6	11 (28)	18 (36)	
Race			
White	38 (97)	47 (94)	0.63
Non-white	1 (1)	3 (6)	
Marital status			
Single	7 (18)	5 (10)	0.35
Married	24 (61)	38 (76)	
Divorced	5 (13)	6 (12)	
Widowed	3 (8)	1 (2)	
Highest education completed[a]			
<High school	2 (5)	0 (0)	0.32
High school	5 (13)	9 (18)	
College	25 (64)	28 (57)	
Professional degree	7 (18)	12 (24)	
Employment status[a]			
Full time	24 (61)	31 (64)	0.91
Part time	7 (18)	10 (20)	
Unemployed	5 (13)	4 (8)	
Retired	3 (8)	4 (8)	
Household income[b]			
<$25,000	3 (8)	2 (4)	0.08
$25,000–$49,000	15 (39)	7 (15)	
$50,000–$74,000	6 (15)	10 (21)	
$75,000–$99,00	4 (10)	4 (9)	
≥$100,000	11 (28)	24 (51)	
Describe self as religious[c]			
Yes	27 (71)	36 (72)	0.92
No	11 (29)	14 (28)	
Current health insurance[a]			
Private	34 (87)	40 (82)	0.37
Federal or state	3 (8)	8 (16)	
No coverage	2 (5)	1 (2)	
Altruistic behaviors			
Regular volunteer work			
Yes	16 (41)	21 (42)	0.92
No	23 (59)	29 (58)	
Regular blood donation			
Yes	12 (31)	6 (12)	0.03
No	27 (69)	44 (88)	
National marrow donor registry[a]			
Yes	14 (36)	9 (18)	0.05
No	25 (64)	40 (82)	
Registered as deceased organ donor			
Yes	35 (90)	37 (74)	0.05
No	4 (10)	13 (26)	

Data expressed as mean±SD or as n (%).
[a] Data missing from one TD.
[b] Data missing from three TDs.
[c] Data missing from one AD.
AD, altruistic donor; TD, traditional donor.

TABLE 2. Total donation motivation and individual item scores of altruistic donors to a stranger and traditional donors

	AD (n=39)	TD (n=50)
Total donation motivation score	16.5±4.5	15.5±4.5
Individual items		
A desire to help	3.8±0.5	3.7±0.6
The benefits to the recipient outweigh the risks to me as a donor	3.0±1.2	3.5±0.9
A sense of moral duty	2.9±1.2	2.1±1.5
Imagining myself in the position of the recipient	2.3±1.7	2.6±1.2
An improved self-esteem from doing a good deed	1.3±1.3	1.3±1.2
Religious beliefs	1.0±1.3	0.5±1.0
Someone close to me benefited from a medical procedure and I wanted to give back	0.9±1.5	0.4±1.2
So that others would view me more positively	0.5±0.9	0.6±0.2
Personal gain from improvements in the recipient's health	0.4±1.1	1.3±1.5
Time away from work	0.1±0.3	0.1±0.2
Guilt from past relationships	0.1±0.5	0.2±0.5
Pressure from others	0.1±0.3	0.1±0.3
Attention from the media	0.1±0.2	0.0±0.0

Data are presented as mean (±SD).
Mean scores are based on responses using a scale (0, not at all; 1, a little; 2, moderately; 3, quite a bit; and 4, extremely) to indicate the degree to which each item motivated respondents to donate a kidney.
AD, altruistic donor; TD, traditional donor.

dian of 20 work days (range, 3–120 days), and there was no difference between ADs and TDs when controlling for center, sex, age, and time since donation ($P=0.29$). Most (n=57, 74%) employed donors reported that they had sufficient medical or vacation leave for donation hospitalization and recovery.

Independent analysis showed that the ADs and TDs did not differ significantly on the SF-36 version 2 scales (P values ranged from 0.19 to 0.85). Mean scores on all scales were higher than the standardized general population mean of 50 (Fig. 2). When adjusted for center, sex, age, and time since

TABLE 3. Other donation-related psychosocial problems endorsed by altruistic donors to a stranger and traditional donors

	AD (n=39)	TD (n=50)
Relationship problems with the recipient	3 (8)	6 (12)
Problems getting life insurance	3 (8)	3 (6)
Depression	3 (8)	3 (6)
Anxiety	3 (8)	2 (4)
Marital problems	3 (8)	0 (0)
Financial problems	3 (8)	1 (2)
Change in job plans	2 (5)	1 (2)
Decision not to have children	1 (3)	0 (0)
Loss of educational opportunities	1 (3)	0 (0)
Loss of employment opportunities	1 (3)	0 (0)
Problems getting health insurance	1 (3)	1 (2)
Problems finding work	1 (3)	0 (0)
Other social problems	3 (8)	0 (0)

Data expressed as n (%).
AD, altruistic donor; TD, traditional donor.

donation, the two groups remained very similar (adjusted *P* values ranged from 0.17 to 0.99).

Twelve donors (5 ADs and 7 TDs) reported new-onset health problems that they perceived to be due to kidney donation. In some instances, they reported more than one problem. These problems included hypertension (4 ADs and 2 TDs), prolonged pain and discomfort (1 AD and 5 TDs), pulmonary problems or exercise intolerance (1 AD and 3 TDs), surgical positioning injury (1 AD and 2 TDs), hernia (2 TDs), stroke (1 AD), and migraines (1 AD).

Donation Experience and Decision Stability

Most ADs (n=33, 85%) and TDs (n=44, 88%) felt that they had been fully informed about the risks and benefits of donation. Six donors (3 ADs and 3 TDs) reported having presurgery fears that they did not feel comfortable discussing with the transplant team, and five donors (1 AD and 4 TDs) felt pressured by the recipients or their family to go through with donation. Most ADs (n=33, 85%) and TDs (n=47, 94%) felt "very" or "extremely" satisfied with the donation experience overall. While most donors would make the same decision again, three (8%) ADs and one (2%) TD regretted their decision. Additionally, two (4%) TDs were uncertain if they would make the same decision again.

DISCUSSION

Adults with no previous relationship to the recipient are donating a kidney at an increasingly higher rate in the United States and elsewhere. In one of the most comprehensive studies of ADs to date, Massey et al. (*10*) found high levels of psychological well-being among these donors. Our study findings extend those of Massey et al. by showing that ADs have comparably favorable postdonation outcomes to TDs who had a genetic or preexisting emotional relationship with the recipient, even after controlling for transplant center, age, sex, and year of donation. Together, these two studies suggest that there is no distinction in the outcomes of TDs and carefully screened ADs.

In a recent survey of kidney transplant programs in the United States, Rodrigue et al. (*4*) found that 39% do not consider nondirected stranger donation and 70% do not evaluate potential directed donors to a stranger. The reluctance of some to consider anonymous living donors is borne from concern about ulterior motives and the lack of data substantiating any benefits for these donors (*11*, *12*). However, our data support earlier findings (*12*) that ADs who undergo careful psychological or psychiatric evaluation are, like most TDs, primarily motivated by a desire to help others in need, by their determination that the risks to them were outweighed by the potential benefits to the recipient, and by a perceived moral obligation. Although some ADs reported being partially motivated by secondary gain (e.g., time away from work, media attention, and being seen by others in a more favorable light), these motives were heavily outweighed by more altruistic motives. Indeed, their history of altruistic behaviors (e.g., regular blood donation, registered bone marrow donor, and deceased donor designation) exceeded that of TDs in the current study, replicating a similar finding reported by Henderson et al. (*12*). Additionally, many ADs and TDs in the current study reported heightened levels of self-esteem, personal satisfaction, strength and resiliency, compassion for others, and respect and admiration from others after donation. There are clear and measurable personal growth and interpersonal benefits for different types of living

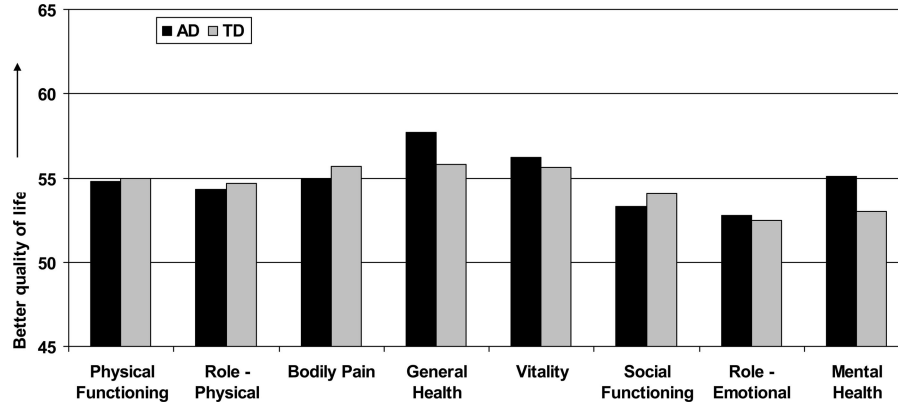

FIGURE 2. Mean SF-36 scores across all domains for both altruistic donors (ADs) to a stranger and traditional donors (TDs). For the general US population, SF-36 mean score=50 and SD=10 (*17*).

kidney donors. The LDEQ has been shown to be a useful validated tool for assessing donor expectations across multiple dimensions and evaluating whether these expectations are realized in the months and years after donor nephrectomy (*13*, *14*). We recommend its use in assessing donor outcomes, both in clinical and research settings.

The majority of ADs reported being satisfied with the donation process and they expressed strong sentiment that they would make the same decision again. Unfortunately, our survey did not address the reasons why three ADs (8%) regretted their decision to donate, so this is something we would encourage in future studies. In one instance, however, an AD learned of a patient's need for a transplant via a church bulletin and underwent donor evaluation. Predonation contact with the recipient and her family was facilitated by the clergyman. The donor felt pressured by both the recipient and the recipient's family to continue with the evaluation process and donation. She did not inform the transplant program of this perceived pressure and was one of the three ADs who regretted the donation decision. It is noteworthy that this particular individual donated nearly a decade ago, when additional safeguards (e.g., living donor advocate) were not implemented.

Our study included two types of ADs—anonymous nondirected donors and directed donors to a stranger. Many of the directed donors to a stranger had established brief contact (by phone, e-mail, or in person) with the intended recipient before surgery. Although it was not their expectation that the relationship would continue beyond transplantation, most (18 of 20, 90%) had at least one additional contact with the recipient after transplantation. Anonymous nondirected donors did not have any contact with the recipient before surgery, although 15 of 19 (79%) had contact sometime after the transplant. All but one of these donors found this to be a positive experience. During the evaluation process at our two centers, all ADs must acknowledge and accept the possibility of no contact with the recipient in the months or years after donation. However, we will facilitate such a meeting if both the donor and recipient independently request it and have both fully recovered from surgery, but we highlight the potential psychological risks for them (and their families) that future contact may carry.

Although our findings portend favorable outcomes for living kidney donors, we would be remiss in not discussing a few concerning observations. First, four TDs and one AD experienced pressure from the intended recipient or others to proceed with donation. Previous research (*15*) and our own anecdotal experiences suggest that patients and family members can exert both subtle and direct pressure on other family members to be evaluated as potential donors. Some programs that suspect subtle pressure or coercion will offer otherwise medically suitable donors "a general statement of lack of suitability" (*16*) to discontinue the process and to preserve family relationships. Second, nearly one half of TDs and one fourth of ADs expect the recipient now to help them in the future if needed. This expectation may be rooted in the knowledge that their recipient may feel "indebted" to them, but it also may place the donor at higher risk for disappointment and relationship problems, especially if the recipient does not provide the expected help when requested. One AD received money from the recipient after surgery. Some types of financial compensation from recipient to donor are permitted (e.g., payment for lost wages, unreimbursed medical expenses, and travel expenses). Unfortunately, the manner in which we asked this question does not allow us to determine whether the compensation acknowledged in this case was within the constraints of federal law. Third, six donors reported problems getting life insurance and two donors experienced difficulty getting health insurance due to their donation status. All but one of these donors was without any physical health limitations and had health-related quality of life scores exceeding that of the general population. Difficulty in acquiring life or health insurance may be a disincentive to future potential donors and may alter the follow-up care received by those who have donated. Fourth, despite the overall high health-related quality of life, 7% of donors reported new-onset hypertension and several others experienced health problems that they attributed to donor nephrectomy (e.g., exercise intolerance, positional injury requiring rehabilitation, and stroke). Unfortunately, the way in which we worded the survey questions did not allow us to determine the timing or chronicity of the health problem or whether it was completely resolved. We were not previously aware of the stroke event reported by one of the donors, but follow-up showed that it occurred 4 years after donor nephrectomy, at 60 years of age, and likely unrelated to donation.

Careful psychological screening is an essential component of the living donor evaluation and additional safeguards have been described for nondirected donors (*9*). Both transplant programs in this study require all potential donors to undergo evaluation by a psychiatrist (Rhode Island Hospital [RIH]) or a psychologist (Beth Israel Deaconess Medical Center [BIDMC]). Potential donors with active mental health issues are excluded altogether or they must receive treatment from a mental health provider unaffiliated with the transplant program before further donor evaluation. The decision to deny or defer donor candidacy based on psychological grounds is dependent on the nature, severity, and chronicity of the mental health problem.

This study benefits from a high rate of participation by ADs, the comparison with TDs with similar sociodemographic characteristics, the use of validated questionnaires to assess psychosocial and functional outcomes, and the recruitment of donors from two different transplant programs. Nevertheless, findings should be considered within the context of a few methodological limitations. Although our recruitment rate was high for ADs, proportionally fewer TDs chose to participate in the study. ADs may have been more likely to respond to survey requests based on their higher level of volunteerism observed in the current study (e.g., regular blood donation, marrow and organ donation registries). It is possible that the TDs who chose not to participate would have altered our psychosocial and functional outcomes. Another important limitation is that our sample was almost all White. While few minorities have been ADs (*2*), the lack of minority representation does not permit us to carefully examine differential outcomes based on race and ethnicity and our data may not be generalizable to non-Whites. Moreover, our sample is from a Western society with good access to healthcare, high level of education and relative socioeconomic independence and who made informed choices. The findings, therefore, have a limited global applicability, especially in areas with

large socioeconomic disparities and poor access to healthcare. Issues regarding pressure and financial exchange are likely to have different implications in less egalitarian societies. Finally, any assessment of donor motivations months or years earlier may be influenced by justification or memory biases, and may not accurately reflect the motives that were present at the time of considering living donation. We strongly support the need for more prospective study and we anticipate reporting our own longitudinal data in the near future.

This study demonstrates that ADs experience similar psychosocial outcomes to, and no greater adverse consequences than, TDs. Further, ADs proceed to donation with a lesser sense of pressure or coercion. They are motivated by altruism that derives its source outside the realm of the recipient and they are less likely to perceive a quid pro quo from their act. Psychological wellness of ADs did not differ from TDs. These data support the continued use of ADs in live donor kidney transplantation.

MATERIALS AND METHODS

Study Participants

Study participants were recruited from the kidney transplant programs at RIH in Providence, RI, and BIDMC in Boston, MA. Between 1998 and 2009, there were 52 ADs at these two programs (24 at RIH and 28 at BIDMC). We defined AD as someone who (1) donated a kidney anonymously to a complete stranger on the transplant waiting list (anonymous nondirected donation), or (2) became aware of an individual in need of transplant (e.g., by church bulletin, newspaper article, internet matching site), but with whom they had no previous relationship (directed donation to a stranger).

We recruited a comparison group of TDs. For each AD, we identified two TDs who were from the same center, the same sex, and close in age (±5 years) and year of donation (±2 years). We defined a TD as someone who donated a kidney to an individual with whom they had a genetic or longstanding emotional relationship before considering kidney donation.

Procedures and Measures

All ADs and selected TDs were mailed a letter and study questionnaires. Those who did not return completed questionnaires were sent a reminder letter and a new packet 6 weeks after the initial mailing. The study was approved by the RIH and BIDMC institutional review boards.

Sociodemographic Characteristics

Data were obtained on age, sex, donation year, race, ethnicity, marital status, education level, employment status, household income, health insurance, and religious affiliation at the time of survey completion.

Donation Motives

Using a 5-point rating scale (0, not at all; 1, a little; 2, moderately; 3, quite a bit; and 4, extremely), participants indicated the degree to which 13 different motives was important in their decision to be a kidney donor.

Altruistic Behaviors

Participants were asked whether they participated in volunteer activities, donated blood regularly, were registered with the National Marrow Donor Program, or were registered deceased organ donors.

Psychosocial Outcomes

The postdonation version of the LDEQ (*14*) comprises 42 statements about the donation experience, and participants indicated their relative agreement or disagreement with these statements. Individual items comprise six scales: Interpersonal Benefit, Personal Growth, Spiritual Benefit, Quid Pro Quo, Health Consequences, and Miscellaneous Consequences. Additionally, participants indicated whether being a donor contributed to other psychosocial problems (e.g., depression, problems getting health insurance, and relationship problems with the recipient). For AD participants, we asked whether they had contact with the recipient after donation, whether this was a positive experience, and whether this impacted their perception of the donation experience.

Functional Outcomes

Information was gathered about employment status before donor surgery, whether donors returned to the same job, how long they were out of work, and whether they had enough sick leave or vacation. The widely used SF-36 version 2 (*17*) measured current health-related quality of life, with higher scores reflecting better quality of life. Donors also provided information about any health problems related to donation.

Donation Experience and Decision Stability

We asked donors whether they had felt informed about donation risks/benefits, uncomfortable discussing their fears with others, or pressure to go through with donation. Also, donors rated their satisfaction with the donation experience and indicated their agreement or disagreement with the following statement: "If I had to make the decision again, I would still decide to be a living donor."

Statistical Analyses

First, we compared the two types of ADs (anonymous non-directed donation, directed donation to a stranger) using *t* tests for continuous variables, the Fisher's exact test for variables with two categories, or a two-tailed chi-square test for variables with three or more categories. Next, we combined AD types and compared ADs and TDs using *t* tests, the Fisher's exact test, or a two-tailed chi-square test. We used independent analysis because our strategy of identifying TDs, whereas designed to reduce the influence of confounding variables, was not a true matching or paired control approach. Linear regression models were generated to examine for differences between ADs and TDs after adjusting for transplant center, sex, age, and time since donation. In all instances, a *P* value less than or equal to 0.05 was considered statistically significant.

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