

Original Article

The expectancies of living kidney donors: do they differ as a function of relational status and gender?

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Abstract

Background. While two-thirds of the living kidney donors continue to be genetically related to the recipient, there has been a 300% increase in unrelated living donors over the last 10 years. Also, women continue to represent more than half of all the living kidney donors. This study examined whether donor expectancies varied as a function of relational status or gender.

Methods. 362 kidney donor candidates (232 related, 130 unrelated) completed the Living Donation Expectancies Questionnaire (LDEQ). A 2 (relational status: related or unrelated) × 2 (gender: male or female) multivariate analysis of variance was conducted to examine main and interaction effects across the six domains of the LDEQ: interpersonal benefit (IB), personal growth (PG), spiritual benefit (SB), quid pro quo (QPQ), health consequences (HC) and miscellaneous consequences (MC).

Results. The highest expectancies were for PG (54.1%) and IB (29.8%), followed by expectations of MC (18.2%), SB (16.9%), HC (14.4%), and QPQ (4.4%). Multivariate analyses showed a relational main effect [$F=4.18$, $P=0.02$] and a gender main effect [$F=5.09$, $P=0.01$]. Subsequent univariate analyses showed significant effects ($P<0.05$) for IB (related > unrelated), QPQ (men > women), HC (unrelated > related, men > women) and MC (unrelated > related).

Conclusion. Overall, donor candidate expectancies appear to be realistic in light of previous findings of donor benefit. However, some living donor expectancies may vary as a function of donor relational status and gender. It may be important to assess and

appropriately address both positive and negative expectancies at the time of donor evaluation. The LDEQ may be a useful clinical tool for assessing such expectancies.

Keywords: donor expectancies; living donation; organ donation

Introduction

Kidney transplantation from the living donors now accounts for approximately half of all kidney transplants performed in USA [1]. In 2004, there were 6648 living kidney donors, a 121% increase over the 3009 living kidney donors reported only 10 years earlier [2]. Compared with deceased donor transplantation, living donor transplantation yields better graft and patient survival rates, can preempt the use of dialysis, avoids transplant listing altogether or limits time on the waiting list, allows the deceased donor kidneys to be used for those without a living donor match and is associated with lower rates of acute rejection [1,3,4]. When combined with low donor morbidity/mortality and potential economic advantages to the society, these factors make living kidney donation and transplantation a viable option for patients, transplant centres and payers.

While living kidney donation was limited largely to those who were genetically related to the recipient in the first three decades of kidney transplantation, the percentage of unrelated living donors has since then increased sharply. Unrelated donors include spouses, significant others, friends, co-workers and donors who are otherwise anonymous or strangers to the recipient. In USA, most (67%) living donors are genetically related to the recipient, but there has been a 300%

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increase in unrelated donors over the last 10 years [2]. This trend toward accepting more unrelated donors is largely due to the finding that graft and patient survival rates are comparable for living related and living unrelated donor transplantation [3,5,6].

A more stable historical trend is that the living kidney donor population is comprised primarily of women. Women represent ~60% of all the living donors in USA each year [2], and about 65% of all the living donors internationally [4]. More men than women have end-stage renal disease, which may account for the greater number of women donating to their spouses. Also, men might be more often ruled out as the potential living donors because of a higher incidence of hypertension and ischaemic heart disease [7]. However, other factors, including sex-role biases, subtle family coercion, societal expectations and income disparity, may also help to explain this phenomenon [8–10].

Perhaps because of these relational status and gender trends in living donation, the authors of the 2000 *Consensus Statement on the Live Organ Donor* articulated the need for research to further examine whether motivational factors and expectations that potentially influence the donation decision vary as a function of certain donor characteristics [11]. A better understanding of donor expectancies and their association to certain sociodemographic characteristics, including relational status and gender, might facilitate the development or refinement of donor educational materials and strategies for optimizing the donation experience. Therefore, we conducted this study to examine whether the expectancies about the donation experience differed based on the relational status and the gender of the prospective donor.

Subjects and methods

Consistent with the international guidelines [4,11], all adults undergoing evaluation for living kidney donation at the University of Florida receive a comprehensive psychological assessment. The psychological evaluation is conducted after the donor candidate has met with the nurse coordinator,

nephrologist and surgeon. Upon providing consent, prospective donors complete a clinical interview and a series of questionnaires as part of the evaluation. Participants in this study presented for evaluation at the University of Florida between February 1999 and June 2004.

As a part of this study, we gathered information about donor candidate’s relationship with the prospective recipient, gender, age, race, marital status, education, employment status and current donor registration status. Also, we examined the responses to the Living Donation Expectancies Questionnaire (LDEQ), which we developed to assess a living donor candidate’s expectancies about the overall donation process. LDEQ comprises 42 statements to which respondents indicate their level of agreement using a 5-point Likert-type scale: 0 (strongly disagree)–4 (strongly agree). While a detailed review of the development and validation of this instrument is beyond the scope of the present paper, it is important to highlight that the LDEQ has excellent internal consistency ($\alpha=0.93$, in this study) and six-factor analytically derived domains. Each of these domains, their internal consistency and sample items are shown in Table 1.

For various reasons, not all donor candidates who were evaluated during the study period were included in the sample. These reasons included meeting with a psychologist not affiliated with our programme (i.e. one who was more geographically proximal to the donor), not completing the LDEQ due to time constraints, illiteracy or language barriers and lack of consent to access the evaluation record for research purposes. This study was approved by the University of Florida’s Institutional Review Board.

Data analysis

First, reliability coefficients were calculated for the LDEQ and its factors to assess the degree of internal consistency. Second, descriptive statistics were performed to summarize sample sociodemographic characteristics and responses to the LDEQ. Third, after appropriate log transformations for non-normalized data, a 2 (related, unrelated) \times 2 (male, female) multivariate analysis of variance (MANOVA) was conducted to examine whether there were any relational status or gender differences on the LDEQ factors. A MANOVA was used because the LDEQ factor scores were significantly correlated and we were interested in examining any relational status by gender interaction effects. A significant MANOVA finding

Table 1. LDEQ: No. of items, internal consistency and sample items

Domain	No. of items	Internal consistency (α coefficient)	Sample items (*As an organ donor, I expect...)
Interpersonal benefit (IB)	7	0.81	...to be respected and admired by family and friends.’ ...more compassion and understanding from family members.’
Personal growth (PG)	13	0.94	...my priorities about what is important will change.’ ...an increased appreciation for the value of my own life.’
Spiritual benefit (SB)	6	0.80	...my donation to be seen as a way of honouring my God.’ ...a better understanding of spiritual matters.’
Quid pro quo (QPQ)	5	0.69	...preferential treatment by the recipient after donation.’ ...that my donation will positively affect the health care I receive in the future.’
Health consequences (HC)	6	0.89	...to experience a great deal of pain and discomfort.’ ...that losing an organ will take years off my life.’
Miscellaneous consequences (MC)	5	0.81	...to have more financial problems.’ ...to have more conflict with my family members.’

was followed with univariate one-way analysis of variance. In all instances, statistical significance was set at $P < 0.05$. The Statistical Package for the Social Sciences (SPSS), Version 11, was used for all analyses.

Results

Sample characteristics

Of the 362 living kidney donor candidates who presented for evaluation at the University of Florida during the study time period, 232 (64.1%) were genetically related to the prospective recipient and 130 were unrelated. The sociodemographic characteristics of the two donor samples, broken down by gender, are reported in Table 2. The sample was predominantly white, married, employed and had at least a high school diploma. The mean age was 40.4 years, with a range of 18–60 years. Approximately half (53.0%) of the donor candidates had a donor designation on their driver’s license or had signed a donor card. Siblings and adult offspring comprised the majority of genetically related donor candidates, while the vast majority of unrelated donor candidates were spouses. The gender (58.8% female) and relational breakdown of our sample is comparable to the gender and donor relational status reported in the US (57.8% female, 12.1% parents,

17.0% offspring, 29.5% siblings, 7.3% other relatives, 10.9% spouse and 21.4% other unrelated), except we had a higher proportion of spouses in our sample (2). Unrelated donor candidates (67.7%) were significantly more likely than related donor candidates (44.8%) to be registered organ donors ($P < 0.0001$) and to be married (89.2 vs 78.0%). There were no other significant relational status or gender differences across the demographic characteristics ($P > 0.05$).

Internal consistency of the LDEQ

As noted in Table 1, the LDEQ had acceptable (i.e. $\alpha > 0.70$) internal consistency estimates, with Cronbach’s alpha coefficients (α) ranging from 0.80 to 0.94 for five of the factors and 0.93 for the total measure. The Quid Pro Quo factor was the least internally consistent, with $\alpha = 0.69$.

Donor expectancies

Table 3 presents the means and standard deviations of the LDEQ factors for the entire sample, as well as the percentage of donor candidates reporting higher than neutral expectancies. A mean factor score > 2.0 indicates that the donor candidate has some expectation for either personal benefit or consequence

Table 2. Sociodemographic characteristics, broken down by relational status and gender

	Total sample ($n = 362$) Mean \pm SD or No. (%)	Related ($N = 232$)		Unrelated ($N = 130$)	
		Male ($n = 97$) Mean \pm SD or No. (%)	Female ($n = 135$) Mean \pm SD or No. (%)	Male ($n = 52$) Mean \pm SD or No. (%)	Female ($n = 78$) Mean \pm SD or No. (%)
Age	40.4 \pm 11.3	39.6 \pm 11.2	40.7 \pm 10.5	39.0 \pm 11.9	41.7 \pm 12.4
Race, white	289 (79.8)	76 (78.4)	113 (83.7)	42 (80.8)	58 (74.4)
Marital status, married	297 (82.0)	79 (81.4)	102 (75.6)	47 (90.4)	69 (88.5)
Education, ≥ 12 years	304 (84.0)	75 (77.3)	118 (87.4)	44 (84.6)	67 (85.9)
Employed	298 (82.3)	81 (83.5)	104 (77.0)	48 (92.3)	65 (83.3)
Registered donor, yes	192 (53.0)	41 (42.3)	63 (46.7)	32 (61.5)	56 (71.8)
Relational status					
Parent	43 (11.9)	21 (21.6)	22 (16.3)		
Offspring	71 (19.6)	31 (32.0)	40 (29.6)		
Sibling	81 (22.4)	33 (34.0)	48 (35.6)		
Other relative	37 (10.2)	12 (12.4)	25 (18.5)		
Spouse	95 (26.2)			39 (75.0)	56 (71.8)
Other unrelated	35 (9.7)			13 (25.0)	22 (28.2)

Table 3. LDEQ means, SD and possible range, by factor

LDEQ factor	Mean \pm SD	Possible range	No. (%) reporting expectancies $>$ neutral ^a
Interpersonal benefit (IB)	10.7 \pm 4.8	0–28	108 (29.8)
Personal growth (PG)	28.4 \pm 8.4	0–52	196 (54.1)
Spiritual benefit (SB)	8.5 \pm 4.5	0–24	61 (16.9)
Quid pro quo (QPQ)	4.5 \pm 2.8	0–20	16 (4.4)
Health consequences (HC)	6.4 \pm 3.1	0–24	52 (14.4)
Miscellaneous consequences (MC)	5.6 \pm 3.7	0–20	66 (18.2)

^aPercentage of sample with higher than a mean neutral response (i.e. mean factor score is greater than the total number of items multiplied by 2). $n = 362$.

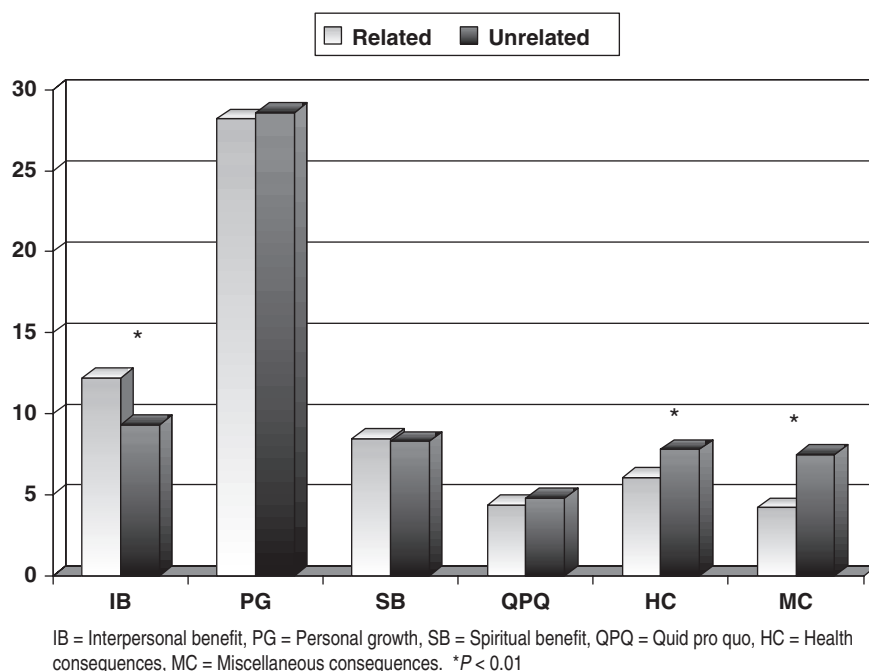


Fig. 1. LDEQ factor scores, by relational status.

secondary to donation. Proportional data showed that the highest expectancies were for personal growth (PG) (54.1%) and interpersonal benefit (IB) (29.8%). These were followed by expectations of miscellaneous consequences (MC) (18.2%), spiritual benefit (SB) (16.9%), health consequences (HC) (14.4%) and quid pro quo (QPQ) (4.4%).

Differences in donor expectancies by relational status and gender

The MANOVA revealed a significant main effect for relational status ($F=4.18$, $P=0.02$) and gender ($P=5.09$, $P=0.01$). Regarding the relational status main effect, univariate analyses showed significant effects ($P < 0.05$) for IB, HC and MC (Figure 1). Related donor candidates had higher expectations for interpersonal benefit than did unrelated donor candidates, who in turn had higher expectancies for health and miscellaneous consequences. Regarding the gender main effect, there were significant univariate effects ($P < 0.05$) for QPQ and HC (Figure 2). Compared with women, men had higher expectations for getting something in return and for health consequences after donation. There was no significant relational status by gender interaction effect.

Discussion

The donation of a kidney represents a considerable sacrifice involving physical discomfort, inconvenience and some inherent risk to physical and emotional well-being for the living donor. Donors are largely

motivated by the desire to improve the lives of those to whom they are donating [10,12]. Heretofore, little was known about the expectations that donor candidates have about the donation experience, other than the improved health of the recipient. In this study, there were four primary findings: (1) donor candidate expectancies are highest for personal growth and interpersonal benefit, (2) unrelated donor candidates expect less interpersonal benefit and more negative health and miscellaneous consequences after donation than genetically related donors, (3) men expect more QPQ and negative health consequences than women and (4) the LDEQ may be a useful tool in evaluating expectancies prior to donation.

In interpreting these study findings, it is important to bear in mind that the sample comprised donor candidates who had passed the initial screening (i.e. a review of medical and psychosocial history form) and were now undergoing formal evaluation. The LDEQ was not administered to those who otherwise were deemed inappropriate donor candidates based on a preliminary review of their medical history, so we do not know whether the expectancies vary as a function of the prospective donor's evaluation stage. The demand characteristics of such a situation pull for some individuals to present favourably to evaluators and to respond in ways that will allow donation to proceed. Consequently, donor candidates may have under-reported both the positive and negative expectancies about the donation experience. Also, some of the donor candidates in this sample were undoubtedly ruled out for medical or psychological reasons after the evaluation process. It is important, therefore, to emphasize that this is a sample of donor candidates and not exclusively one of adults who have been

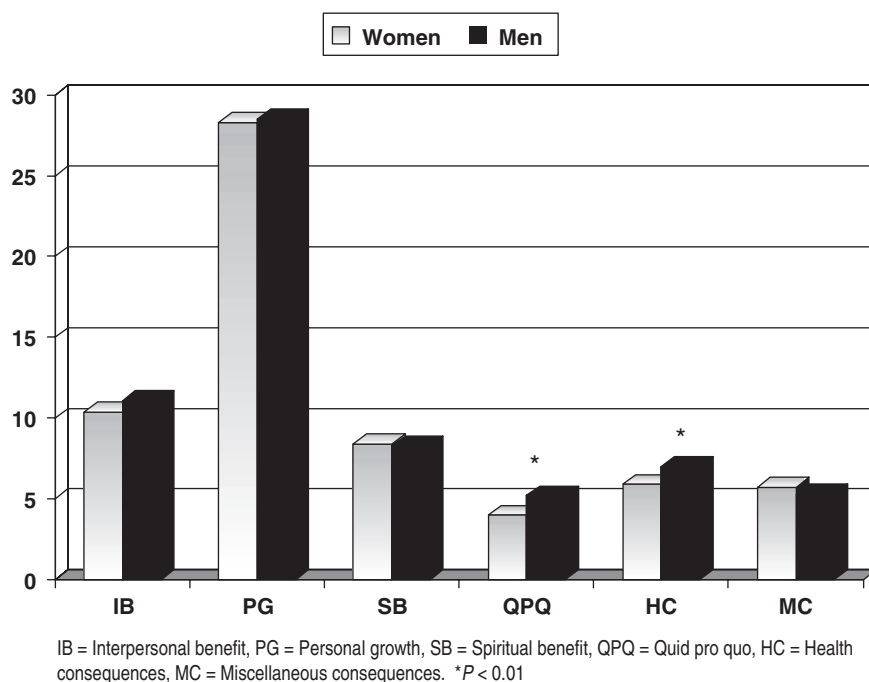


Fig. 2. LDEQ factor scores, by gender.

medically cleared for living donation. Another limiting factor of the study is that the unrelated donor candidates were a largely homogenous group of spouses. The University of Florida programme typically requires a strong donor–recipient emotional bond to be considered for unrelated living donation and it does not consider anonymous or stranger donation. Thus, the degree to which our findings can be generalized to acquaintances or anonymous donors is unknown. This is an important area of further scientific inquiry in light of the increased use of anonymous donors and the general public's acceptance of it [13–16]. Finally, this is a study conducted in a single transplant centre, with a predominantly Caucasian donor population. Our findings may not generalize well to programmes in which there is a more ethnically diverse donor population.

Notwithstanding these limitations, our findings suggest that donor candidates, overall, do not have unrealistically high expectancies about personally benefiting from the donation experience. Half of the donor candidates expected some personal growth secondary to this experience, which may have included a re-evaluation of the priorities of one's own life, increased self-esteem, stronger commitment to a healthier lifestyle, greater appreciation for life and a tendency to appreciate each day more fully. Additionally, some donor candidates expected to benefit interpersonally via less conflict with family members, heightened respect and admiration by others and a closer relationship with the recipient. Moreover, they also expected to benefit by an enhanced sense of spiritual well-being, although we did not systematically gather religion data that would allow us to examine this religion-expectancies relationship in greater detail.

Overall, these expectancies are consistent with findings that there are significant gains in personal growth, interpersonal relationships and psychological health after living donation [17–19]. Therefore, they do not appear to be unrealistic in nature, and donor candidates should be informed about these potential benefits during the consenting process. Indeed, some have argued that deriving personal benefit is the only ethical justification for proceeding with living donation [20].

The fact that expectancies likely vary as a function of donor relational status has several implications. Genetically related donor candidates appear to expect more interpersonal benefit from the donation experience. As highlighted in the seminal work of Simmons and her colleagues [10,17], the family dynamics surrounding the living organ donation can be very complex. Subtle family pressure or coercion, fear of future disapproval if they do not donate and guilt for past actions may serve as motives for family members to undergo donor evaluation, although this has not consistently been found to be the case [12]. We found that many genetically related donors expect family members to view them as heroic, show them more respect and compassion and want more interpersonal closeness. Again, these expectancies may be realistic [17], but they nevertheless should serve to highlight the need to carefully evaluate the family dynamics and the degree to which the donor perceives that these dynamics will change after living donation. If there is a concern as to whether the expectations are unrealistic, we would recommend the donor candidate to have one or more additional sessions with a transplant psychologist or social worker, so that these expectations can be further explored and evaluated in advance of the team's approval or denial decision.

Unrelated donors, predominantly spouses in this study, seem to have higher expectancies for more negative outcomes. Although the absolute differences were not large, unrelated donors expected longer recovery time, more psychological problems and more pain and discomfort associated with surgery and recovery than did genetically related donors. Not surprisingly, unrelated donor candidates reported feeling more responsible for the recipient's health and welfare after donation than did related donor candidates. This may be largely due to the dual role that spouses may play in this context, i.e. being both the living donor and the caregiver of the recipient. Moreover, unrelated donors expected more financial problems secondary to donation. Again, this could be secondary to the potential for more financial hardship in a donor–recipient spouse pair because both adults in the family are unable to work for a period of time following surgery.

Previous research has shown that men and women approach living donation in different ways [17]. Simmons *et al.* [17] found that women were more likely to make a spontaneous decision to pursue donation and to view the decision as consistent with the sex-role expectations of society or as an extension of their family obligations. Men, on the other hand, were more deliberative and ambivalent about donation. We found that men and women have similar expectancies about interpersonal benefit, personal growth and spiritual benefit. However, men expect to experience more negative health consequences and QPQ after donation than women. In our society, many women have an experience that is psychologically equivalent to a living organ donation, *vis-à-vis*, giving birth (i.e. life) to an infant. In the absence of such an experience, men may anticipate more negative health consequences related to living donation. Particularly compelling is the finding that men are more likely than women to expect some form of 'pay back' after donation (e.g. preferential treatment, practical help in the future), although the overall rate of QPQ expectancies was very low. Perhaps, this is because living donation for men, more so than for women, may represent more of a 'sacrifice' or an exceptional act [17].

In conclusion, expectancies are important to assess because they may be related to how the donor perceives the experience later. To the degree that such expectancies are not met in the weeks or months after donation, living donors may experience feelings of sadness, depression or dissatisfaction with the process. Consequently, a tempering of possibly unrealistic expectancies prior to donation may have significant clinical benefit for living donors at some later point in time. The LDEQ shows some promise as a useful tool in evaluating these expectancies, although clearly it needs to be further evaluated in a more culturally and ethnically diverse donor population. As shown in this study, it has very good internal consistency and we are presently conducting additional psychometric evaluation. To date, we have used it to screen for expectancies that are potentially worrisome or otherwise unrealistic,

thus yielding a more targeted discussion with the donor candidate about such expectancies. Often, this has allowed us to clarify misperceptions about the donation process, what personal benefits can reasonably be expected and lingering or persistent concerns about health risks. We recommend that research continues to enhance our understanding of the motives, expectancies and decision-making processes of the donor candidates in order to maximize the potential for positive donor outcomes.

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