

# Measuring the Expectations of Kidney Donors: Initial Psychometric Properties of the Living Donation Expectancies Questionnaire

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We report on the initial development and validation of the Living Donation Expectancies Questionnaire (LDEQ), designed to measure the expectations of living kidney donor candidates. Potential living donors (n=443) at two transplant centers were administered the LDEQ and other questionnaires, and their medical records were reviewed. Factor analysis provides support for six LDEQ scales: Interpersonal Benefit, Personal Growth, Spiritual Growth, Quid Pro Quo, Health Consequences, and Miscellaneous Consequences. All but one scale showed good internal consistency. Expected benefits of donation were associated with higher optimism and lower mental health; expected consequences of donation were associated with lower optimism and lower physical and mental health. More potential donors with relative or absolute contraindications had high Interpersonal Benefit ( $P<0.0001$ ), Personal Growth ( $P<0.01$ ), Quid Pro Quo ( $P<0.0001$ ), and Health Consequences ( $P<0.0001$ ) expectations. The LDEQ has promise in evaluating donor candidates' expectations.

**Keywords:** Living kidney donation, Psychosocial assessment, Organ donation, Motivations, Expectations.

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Living donor kidney transplantation has emerged as the preferred intervention for patients with end-stage renal disease in need of transplantation (1–9), and now accounts for more than one third of all kidney transplants in the United States (1). The landscape of living donation has changed over the last several years (10, 11). Once restricted to immediate family members, living donation now involves donor-recipient pairs who are distant relatives, coworkers, friends, and even strangers. Consequently, the transplant community has emphasized the critical importance of the psychosocial assess-

ment in the context of the donor evaluation (12–17). Particular attention has been given to assessing the potential donor's motivations and expectations for the donation experience, and how the donation decision is influenced by these expectations. In addition to expecting an improvement in the health and quality of life of the recipient, potential living donors may expect the donation experience to yield some personal, spiritual, or relationship benefits as well (18).

We developed a questionnaire, the Living Donation Expectancies Questionnaire (LDEQ), designed to measure potential donors' expectancies during the evaluation process. Our goal was to provide clinicians with a standardized format in which the motivations and expectations of potential living donors could be assessed. The current study examined the initial psychometric properties of the LDEQ, and assessed the relationship of LDEQ scores to other psychological constructs and key sociodemographic variables. In addition, we examined the LDEQ's ability to differentiate potential donors with relative, absolute, or no psychosocial contraindications to donation.

## METHODS

### Development of the Living Donation Expectancies Questionnaire

We used the following methods to generate LDEQ items: (a) a review of publications describing the expectations of living kidney donors, (b) input from three transplant physicians, three nurse coordinators, four psychologists, and one social worker with extensive experience in the evaluation and care of living kidney donors, and (c) input from four adult living kidney do-

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nors. These individuals generated questionnaire items in response to the following stem: “As an organ donor, I expect. . .” The primary author (J.R.R.) generated additional items that reflected findings in the literature regarding donor motivations and expectations. This led to an initial pool of 57 items, each having five response options—“strongly disagree,” “disagree,” “neutral,” “agree,” and “strongly agree.”

Twelve living kidney donors and two kidney transplant physicians completed the initial 57-item measure and provided feedback about its design, length, wording, and ease of completion. This led us to remove, add, and reword items to capture the full range of donor expectations, improve readability, and facilitate administration. The final questionnaire comprised 42 items that were conceptually grouped into six scales: Interpersonal Benefit (7 items), Personal Growth (13 items), Spiritual Benefit (6 items), Quid Pro Quo (5 items), Health Consequences (6 items), and Miscellaneous Consequences (5 items). Each item had five response options (strongly disagree to strongly agree), with higher scores indicating higher expectations.

**Living Donation Expectancies Questionnaire Reliability and Validity**

Study participants were adults undergoing evaluation for living kidney donation at the University of Florida in Gainesville, FL (1999–2005) and Beth Israel Deaconess Medical Center in Boston, MA (2005–2007). At both transplant centers, potential donors complete a psychosocial evaluation that includes a clinical interview with a social worker and/or psychologist and the completion of several questionnaires, including the LDEQ (both centers), the SF-36 Health Survey (19) (both centers), and the Life Orientation Test—Revised (LOT-R) (20) (University of Florida only). The SF-36 is a generic measure of health-related quality of life. For purposes of this study, we used only the two summary scores: the Physical Component Summary and the Mental Component Summary. The LOT-R is a widely used measure of optimism. In addition to the questionnaire data, we extracted the following information from the potential donor’s medical record: age, gender, race, marital status, education, employment status, relationship to the prospective recipient, and current donor registration status.

In reviewing medical records, potential donors also were classified into one of three categories by one of the authors (J.R.R.): no psychosocial contraindications identified, relative psychosocial contraindications identified, or absolute psychosocial contraindications identified and donor ruled out. The first (no contraindications) and third (absolute contraindications) categories were easy to identify in the medical records and potential donors were so classified. Potential donors were classified in the second category (relative contraindications) if one or more evaluators raised concern about some aspect of their past, current, or future psychological stability, the stability of the donor-recipient relationship, inadequate support, high donor ambivalence, or questionable motives. Also, if the evaluation team recommended an extended “cooling off” period or psychological treatment as a condition of further evaluation or donation, the potential donor was classified as having relative contraindications.

Not all donor candidates who were evaluated during the study period were included in the sample because of: meeting with a psychologist not affiliated with our program (i.e., one who

was more geographically proximal to the donor; n=12), not completing the LDEQ because of time constraints (n=17), illiteracy (n=2), or language barrier (n=22). This study was approved by the institutional review boards at both the University of Florida and Beth Israel Deaconess Medical Center.

**Statistical Analyses**

Data were analyzed using SPSS software (Version 14.0, SPSS, Inc., Chicago, IL) and AMOS 6.0. First, a confirmatory factor analysis (CFA) was conducted specifying the factor structure identified previously. Model fit was examined using several indicators, including the chi-square, the comparative fit index (CFI), the normed fit index (NFI), the Tucker-Lewis index (TLI), and the root mean square error of approximation (RMSEA). Conventional guidelines were followed, whereby a good fit is indicated by chi-square  $P > 0.05$ , CFI and NFI values greater than 0.90, TLI value greater than 0.95, and RMSEA value less than 0.08. Second, Cronbach’s alphas were calculated to assess internal consistency. Third, LDEQ was correlated with the SF-36 and LOT-R to examine convergent validity. Fourth, correlational analyses and multivariate analyses of variance were conducted to examine whether sociodemographic characteristics were associated with LDEQ scaled scores. Fifth, analyses were conducted to examine whether LDEQ scores differentiated between potential donors based on the psychosocial contraindications classification (no contraindications, relative contraindications, absolute contraindications). A potential donor was considered to have “high expectations” on an LDEQ scale if the mean scale score was greater than the total number of items for that scale multiplied by 2, which reflects expectations that are higher than a neutral response.

**RESULTS**

**Sample Characteristics**

The LDEQ was administered to 443 (396 at the University of Florida, 47 at Beth Israel Deaconess Medical Center)

**TABLE 1. Sociodemographic characteristics, broken down by center**

	Total sample (N=443)	UF (n=396)	BIDMC (n=47)
Age	40.2±11.2	40.0±11.2	42.2±11.2
Sex, female	265 (59.8)	236 (59.6)	29 (61.7)
Race, white	349 (78.8)	313 (79.0)	36 (76.6)
Marital status, married <sup>a</sup>	347 (78.3)	316 (79.9)	31 (66.0)
Education, ≥12 yr	371 (83.7)	332 (83.8)	39 (83.0)
Employed	390 (88.0)	346 (87.4)	44 (93.6)
Registered donor, yes	234 (52.8)	214 (54.0)	20 (42.6)
Relational status <sup>b</sup>			
Parent	55 (12.4)	51 (12.9)	4 (8.5)
Offspring	77 (17.4)	74 (18.7)	3 (6.4)
Sibling	106 (23.9)	91 (23.0)	15 (31.9)
Other relative	44 (9.9)	42 (10.6)	2 (4.3)
Spouse	114 (25.7)	102 (25.7)	12 (25.5)
Other unrelated	47 (10.6)	36 (9.1)	11 (23.4)

Values given are mean±SD or N (%) values.  
<sup>a</sup>  $P < 0.05$ ; <sup>b</sup>  $P < 0.0001$ .

**TABLE 2.** Cronbach's alpha coefficients and sample items for the LDEQ scales

Domain	Items	Mean±SD	$\alpha$	Sample items ("As an organ donor, I expect . . .")
Interpersonal benefit (IB)	7	11.6±4.9	0.81	. . . to be respected and admired by family and friends." . . . to be seen as heroic." . . . more compassion and understanding from family members."
Personal growth (PG)	13	28.1±8.3	0.93	. . . my priorities about what is important will change." . . . to improve my lifestyle and take better care of my health." . . . an increased appreciation for the value of my own life."
Spiritual benefit (SB)	6	9.3±4.5	0.79	. . . my donation to be seen as a way of honoring my God." . . . that my donation will help atone for past wrong-doings." . . . a better understanding of spiritual matters."
Quid pro quo (QPQ)	5	5.6±2.7	0.67	. . . preferential treatment by the recipient after donation." . . . that my donation will positively affect the health care I receive in the future." . . . to receive money from the recipient in the future."
Health consequences (HC)	6	7.4±3.1	0.86	. . . to experience a great deal of pain and discomfort." . . . to feel depressed or anxious after donation." . . . that losing an organ will take years off my life."
Miscellaneous consequences (MC)	5	5.7±2.8	0.73	. . . to have more financial problems." . . . to spend less time with friends." . . . to have more conflict with my family members."
LDEQ total	42	68.9±21.3	0.82	

adults undergoing evaluation for possible living kidney donation. Mean age was 40.2±11.2 years, and the majority was women (59.8%), white (78.8%), married (78.3%), and genetically related to the intended recipient (63.7%; Table 1). Half (52.8%) had a donor designation on their driver's license. Potential donors at the University of Florida were more likely to be married ( $\chi^2=4.7$ ,  $P<0.05$ ) and genetically related to the recipient ( $\chi^2=28.3$ ,  $P<0.0001$ ) than those at Beth Israel Deaconess Medical Center, but otherwise the two samples had comparable sociodemographic characteristics.

Two hundred seventeen participants (197 at the University of Florida, 20 at Beth Israel Deaconess Medical Center) subsequently underwent donor nephrectomy. The remaining potential donors were excluded based on medical and/or psychosocial findings, withdrew from further consideration, or were approved for donation but had not yet been scheduled for surgery.

### Factor Analysis and Internal Consistency of the Living Donation Expectancies Questionnaire

Confirmatory factor analysis model showed a good fit ( $\chi^2=273.4$ ,  $P=0.31$ ; CFI=0.95; NFI=0.96; TLI=0.92; RMSEA=0.06). All factor loadings were statistically significant and the model supported the a priori conceptually derived factor structure. Factor intercorrelations ranged from  $r=0.16$  to  $r=0.52$ . The Interpersonal Benefit scale had a large positive correlation with the Personal Growth ( $r=0.52$ ,  $P<0.001$ ) and Spiritual Growth ( $r=0.43$ ,  $P<0.001$ ) scales. The Quid Pro Quo and Health Consequences scales were significantly positively correlated ( $r=0.39$ ,  $P<0.001$ ). The Health Consequences scale had a moderate positive correlation with the Miscellaneous Consequences scale ( $r=0.28$ ,  $P<0.01$ ). Table 2 shows the number of items, means, stan-

**TABLE 3.** Correlations of the LDEQ with the SF-36 and LOT-R

	SF-36 <sup>a</sup>		LOT-R <sup>b</sup>
	Physical	Mental	
Interpersonal benefit	0.09	-0.21 <sup>c</sup>	0.26 <sup>c</sup>
Personal growth	0.09	-0.26 <sup>c</sup>	0.23 <sup>c</sup>
Spiritual benefit	-0.15 <sup>d</sup>	-0.22 <sup>c</sup>	0.33 <sup>c</sup>
Quid pro quo	-0.19 <sup>d</sup>	-0.16 <sup>d</sup>	-0.35 <sup>c</sup>
Health consequences	-0.21 <sup>c</sup>	-0.34 <sup>c</sup>	-0.35 <sup>c</sup>
Miscellaneous consequences	-0.11	-0.25 <sup>c</sup>	-0.29 <sup>c</sup>

<sup>a</sup> Higher scores correspond to better quality of life.

<sup>b</sup> Higher scores correspond to more optimism.

<sup>c</sup>  $P<0.0001$ ; <sup>d</sup>  $P<0.01$ .

dard deviations, Cronbach's alphas ( $\alpha$ ), and sample items of the LDEQ scales and Total scale. Scale reliabilities ranged from 0.67 to 0.93 with an LDEQ Total scale alpha of 0.82. Five scales demonstrated acceptable internal consistency ( $\alpha\geq 0.70$ ). The only exception was the Quid Pro Quo scale (0.67). Flesch-Kincaid reading grade level was 6.1.

### Convergent Validity

Table 3 shows the correlations between the LDEQ scales and the SF-36 and LOT-R. Potential donors with higher physical well-being scores had lower expectations regarding Spiritual Benefit, Quid Pro Quo, and Health Consequences. Those with higher emotional well-being had lower expectations on all LDEQ scales. Higher optimism was associated with higher expectations regarding Interpersonal Benefit, Personal Growth, and Spiritual Benefit, but lower expecta-

**TABLE 4.** Proportion of potential donors with high expectations,<sup>a</sup> by psychosocial contraindication status

	No contraindications (n=377), n (%)	Relative contraindications (n=54), n (%)	Absolute contraindications (n=45), n (%)
Interpersonal benefit <sup>b</sup>	71 (18.8)	18 (33.3)	25 (55.6)
Personal growth <sup>c</sup>	143 (37.9)	32 (59.3)	29 (64.4)
Spiritual benefit	64 (17.0)	9 (16.7)	9 (20.0)
Quid pro quo <sup>b</sup>	8 (2.1)	5 (9.3)	11 (24.4)
Health consequences <sup>b</sup>	37 (9.8)	9 (16.7)	16 (35.6)
Miscellaneous consequences	58 (15.4)	7 (13.0)	7 (15.6)

<sup>a</sup> High expectations were defined as a mean scale score greater than the total number of items multiplied by 2 (i.e., higher than neutral response).

<sup>b</sup>  $P < 0.0001$ ; <sup>c</sup>  $P < 0.01$ .

tions regarding Quid Pro Quo, Health Consequences, and Miscellaneous Consequences.

### Relationship Between Living Donation Expectancies Questionnaire and Sociodemographic Characteristics

Age was correlated with Personal Growth ( $r = -0.24$ ,  $P < 0.0001$ ) and Miscellaneous Consequences ( $r = 0.21$ ,  $P < 0.001$ ). Younger adults had higher Personal Growth expectations, whereas older adults expected more miscellaneous consequences. There was a significant multivariate effect for sex ( $F = 7.0$ ,  $P < 0.0001$ ) and relational status ( $F = 4.6$ ,  $P < 0.0001$ ). Compared with women, men had lower Interpersonal Benefit scores ( $P < 0.03$ ) and higher scores on the Quid Pro Quo ( $P < 0.01$ ) and Health Consequences scales ( $P = 0.01$ ). Compared with unrelated donors, genetically related donors had higher Interpersonal Benefit scores ( $P < 0.05$ ) and lower Health Consequences ( $P < 0.02$ ) and Miscellaneous Consequences ( $P < 0.0001$ ) scores. Race, marital status, education, employment status, and donor registration status were not significantly correlated with any LDEQ scales (all  $P$  values  $> 0.05$ ).

### Living Donation Expectancies Questionnaire Scores and Psychosocial Contraindications

Most potential donors ( $n = 377$ , 78%) did not have any psychosocial contraindications, whereas 54 (12%) and 45 (10%) had relative and absolute psychosocial contraindications, respectively. As highlighted in Table 4, four LDEQ scales distinguished potential donors based on psychosocial contraindications. Potential donors classified as having relative or absolute contraindications had higher expectations regarding Interpersonal Benefit ( $\chi^2 = 32.7$ ,  $P < 0.0001$ ), Personal Growth ( $\chi^2 = 11.5$ ,  $P < 0.01$ ), Quid Pro Quo ( $\chi^2 = 44.1$ ,  $P < 0.0001$ ), and Health Consequences ( $\chi^2 = 24.2$ ,  $P < 0.0001$ ).

## DISCUSSION

The Living Donation Expectancies Questionnaire (LDEQ) was designed to measure the expectations of potential living donors, and these study findings provide initial support for its reliability and validity. Potential living donors undergo careful psychosocial evaluation to examine knowledge of the risks and benefits of donation, psychological functioning, motivations, expectations, and competency issues. It is important for the transplant community to develop well-designed and psychometrically sound tools to assess these

constructs. The LDEQ was developed and refined to assess donor expectancies specifically, and it provides a useful tool for clinicians involved in the assessment of donor candidates.

Administering the LDEQ at the time of evaluation may help to identify expectations that are unrealistic or that warrant further assessment. We use the LDEQ to guide our discussions with potential donors about anticipated changes in the donor-recipient relationship, health-related concerns, and how life may or may not change in the months ahead. Such discussions may temper the expectations of donor candidates and provide them with a more balanced picture of the donation experience. This seems particularly relevant considering that many decisions to pursue living donation evaluation are made spontaneously (21).

Expectations for a situation or experience often influence emotional and behavioral reactions to it (22). One might reasonably assume that favorable expectations about the donation experience, such as re-evaluation of life priorities, increased self-esteem, commitment to a healthier lifestyle, heightened respect and admiration by others, or a greater appreciation for life, would predict a more favorable donation experience. Although data about the predictive use of the LDEQ are not yet available, our current findings suggest that high expectations should trigger further inquiry of the potential donor's motives. Donor candidates who have high expectations about interpersonal benefit, personal growth, quid pro quo, or health consequences were more likely to be classified as having some level of psychosocial risk. This is consistent with findings from a recent survey in which 66% and 29% of U. S. transplant centers identified unrealistic expectations as a relative or absolute contraindication to donation, respectively (11). We should caution that this study did not specifically identify the clinical thresholds at which expectations should be regarded as unrealistic. This is a decision that should be made within each program.

Donor candidates who expect too much from the experience may be at risk for a hard psychological fall in the months and years after donation. However, with a few notable exceptions (21), we lack sufficient data to definitively state whether such expectations lead to unfavorable donor outcomes in either the short- or the long-term. Indeed, donation is often considered a positive highlight of one's life, with many potential personal benefits (18, 21, 23, 24). Also, as our data indicate, those who expect to derive some personal benefit from the donation experience may have a predisposition to more optimism, a characteristic known to have important

health benefits (25–27). There may be an optimal level of expectations, with low expectations precluding donation, and excessive expectations causing eventual regret. Clearly, more research is needed and the next step in our research program is to examine the use of the LDEQ in predicting donor satisfaction, QOL, and the stability of the donor-recipient relationship over time.

Consistent with earlier findings (18), we found that women expect to benefit more in their interpersonal relationships after living donation, whereas men have higher expectations that they will get something in return—directly or indirectly. Related donor candidates also expect more interpersonal benefit than unrelated donors. The expectation of interpersonal benefit is not surprising considering the high caregiving burden and strain experienced by some family members of patients with chronic illness. It may be a realistic expectation for family members that their relationship with the recipient will improve or change once the attendant limitations of chronic kidney disease have been lifted by live donor kidney transplantation.

This study has several limitations. Our two centers and the living donor evaluation processes may not be representative of other programs and, therefore, the generalizability of these findings is limited. Also, these LDEQ findings represent a snapshot view of donor expectancies, which may change depending on the stage of their evaluation. For instance, expected health consequences may differ based on whether the donor candidate meets with the transplant nephrologist before or after completing the LDEQ. In the current study, we did not code the timing of LDEQ administration, although donor candidates at both institutions typically undergo psychosocial evaluation after meeting with the transplant nephrologist. Another limitation is that only one clinician examined the medical records to classify potential donors by psychosocial contraindication status, which did not allow us to examine coding reliability. Finally, our sample comprised those adults who met telephone screening criteria to undergo full donor evaluation. Not all donor inquiries lead to evaluation—our sample, therefore, may represent a select group of potential donors who met certain medical and psychosocial screening criteria, which may have reduced variability in questionnaire scores. Despite these limitations, we believe the development of a reliable and valid measure of donor expectations, accompanied by normative data for objective interpretation, will likely enhance the donor evaluation process.

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