Nephrol Dial Transplant (2016) 1–8
doi: 10.1093/ndt/gfw421

ndt
Nephrology Dialysis Transplantation

Original Article

Pre-donation cognitions of potential living organ donors: the development of the Donation Cognition Instrument in potential kidney donors

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ABSTRACT

Background. Cognitions surrounding living organ donation, including the motivation to donate, expectations of donation and worries about donation, are relevant themes during living donor evaluation. However, there is no reliable psychometric instrument assessing all these different cognitions. This study developed and validated a questionnaire to assess pre-donation motivations, expectations and worries regarding donation, entitled the Donation Cognition Instrument (DCI).

Methods. Psychometric properties of the DCI were examined using exploratory factor analysis for scale structure and associations with validated questionnaires for construct validity assessment.

Results. From seven Dutch transplantation centres, 719 potential living kidney donors were included. The DCI distinguishes cognitions about donor benefits, recipient benefits, idealistic incentives, gratitude and worries about donation (Cronbach's alpha 0.76–0.81). Scores on pre-donation cognitions differed with regard to gender, age, marital status, religion and donation type. With regard to construct validity, the DCI was moderately correlated with expectations regarding donor's personal well-being and slightly to moderately to health-related quality of life.

Conclusions. The DCI is found to be a reliable instrument assessing cognitions surrounding living organ donation, which might add to pre-donation quality of life measures in facilitating psychosocial donor evaluation by healthcare professionals.

Keywords: expectations, living kidney donors, motivation, quality of life, worries

INTRODUCTION

According to international guidelines for psychosocial donor evaluation, it is essential for transplant professionals to discuss the motivations and expectations of potential donors, as well as possible worries about donation [1–4]. They state that the motivation for donation must be clearly altruistic and genuine, and that the decision to donate must be well-informed and without pressure from the environment [4–6]. Further, expectations of

the donation should be realistic with regard to transplantation outcomes for the recipient, possible physical consequences for the donor and possible impact on relationships [1–3]. However, psychosocial guidelines do not indicate how to operationalize and assess these cognitions [5].

Generally, the motivation for donation is based on wishing to improve the quality of life of the recipient or being idealistic, based on a feeling of moral duty or religious convictions [7–9]. In addition, donors could be motivated by potential personal benefits, such as a higher self-esteem or an increase of their own quality of life due to the improvement of the recipient's health [10, 11].

Previous studies on the expectations of living kidney donors showed that donors generally have quite realistic expectations about the donation, mainly based on personal benefits and on improving the quality of life of the recipient [12–15]. Donors generally did not expect gratitude for the donation consisting of financial or symbolic rewards [13].

A small proportion of donors also experiences ambivalence about the donation decision because of worries about temporary limitations due to the surgery, postsurgical pain, their future health, the results of medical examinations, or recipients' health or lifestyle [11, 16–21]. In addition, potential donors in kidney exchange procedures have also been found to potentially worry about waiting times, kidney quality equity and the retraction from reciprocal donation by the donor of a matching couple [22].

Unrealistic cognitions (e.g. unrealistic expectations on recipient outcomes or motivations based on a desire for recognition) could increase the risk of poor psychosocial outcomes after donation, and therefore be a contra-indication.

Most of the limited knowledge on pre-donation cognitions of potential donors is based on qualitative research by means of focus groups or interviews [23], or retrospective assessments [24]. Also, some cross-sectional studies have been performed using the Living Donation Expectancies Questionnaire (LDEQ), which focuses on pre-donation expectations of personal well-being after donation [14]. These studies have shown that expecting benefits from the donation (e.g. Personal Growth) is related to higher levels of optimism and worse mental health [14]. Although the LDEQ is a valid instrument to assess pre-donation expectations with regard to a donor's personal well-being, it does not include either recipient-related expectations or motivations and worries about donation.

Although current guidelines for psychosocial donor evaluation underline the need to assess pre-donation cognitions and mention unrealistic cognitions as a relative or absolute contra-indication to donation [25–27], no assessment methods or criteria are provided. Current practice is mainly based on a clinical perspective. Evidence-based instruments to reliably assess pre-donation cognitions would aid clinicians in defining which cognitions could be unrealistic and predictive of adjustment problems after donation. Therefore, the aim of the current study was to develop a short but comprehensive questionnaire to assess different types of pre-donation cognitions (expectations, motivations and worries).

MATERIALS AND METHODS

Procedure

A pilot study was conducted in one Dutch transplantation centre (Radboud University Medical Center) in 2010–11 to develop a new questionnaire on donation cognitions, followed by a multicentre study in seven Dutch transplantation centres (Radboud University Medical Center, University Medical Center Utrecht, Leiden University Medical Center, University Medical Center Groningen, Maastricht University Medical Center, Academic Medical Center Amsterdam and VU University Medical Center Amsterdam).

All potential donors attending the first information consultation were invited to participate in the study through an information letter. Exclusion criteria were not being able to read or write the Dutch language and refusal to sign informed consent. After signing informed consent, potential donors who wanted to participate in the study were asked if they preferred a paper or a digital format of the questionnaire booklet. The ethics committee of the Radboud University Medical Center decided that the study did not fall under the scope of the Medical Research Involving Human Subjects Act. Therefore, approval by an ethics committee was not indicated for this study, because of the absence of any risk for the participants. In all participating centres, the board approved the execution of the study.

Item generation and scale construction of the donation cognitions questionnaire

Questionnaire items to assess pre-donation cognitions were generated from the literature and clinical practice. The resulting items were judged on comprehensibility and relevance by healthcare professionals and kidney transplantation researchers. In a pilot study, this questionnaire was evaluated by a small group of potential donors to test its feasibility, relevance and readability. After revision, the final questionnaire consisted of 46 items, of which 28 assessed agreement with statements about different motivations and expectations of donation, including two open response items, measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), and 18 items on worries about the donation, including three open response items, measured on a 4-point Likert scale (1 = not at all to 4 = very much).

Other instruments

The following validated questionnaires were used to assess the cross-sectional construct validity of the newly developed questionnaire on pre-donation cognitions.

Donor expectations. Donor expectations regarding personal well-being were assessed by the LDEQ [14]. The LDEQ consists of 42 items starting with 'As an organ donor, ...', measured on a 5-point Likert scale (0=strongly disagree to 4=strongly agree), distinguishing six scales: Interpersonal Benefits (e.g. 'I expect to be respected and admired by family and friends'), Personal Growth (e.g. 'I expect to improve my lifestyle and take better care of my health'), Spiritual Benefits (e.g. 'I expect my donation to be seen as a way of honoring my God'), Quid Pro Quo (e.g. 'I expect preferential treatment by the recipient after donation'),

Health Consequences (e.g. 'I expect to experience a great deal of pain and discomfort') and Miscellaneous Consequences (e.g. 'I expect to have more financial problems'). Higher scores represent higher expectations in that domain. Cronbach's alpha in the present study varied between 0.65 (Quid Pro Quo and Miscellaneous Consequences) and 0.93 (total LDEQ).

HRQoL.

Physical functioning. The physical functioning of Health-related Quality of Life (HRQoL) potential donors was assessed by the Physical Health Composite score and its subscales of the RAND Short Form-36 Health Status Inventory (RAND SF-36) [28] and the short version of the Checklist Individual Strength-Fatigue (CIS) [29, 30]. The RAND SF-36 is a widely used 36-item questionnaire assessing eight aspects of health-related quality of life (HRQoL), of which four assess physical health and are summarized into a composite score: Physical Functioning, Role Limitations due to Physical Health Problems, Pain and General Health Perceptions. The Hays norm-based scoring algorithm was applied, using item response theory with raw scores being transformed into *T*-scores with an average of 50 and a standard deviation (SD) of 10 in the general population [28]. Higher scores represent better HRQoL. Cronbach's alpha varied between 0.61 (General Health Perceptions) and 0.86 (Role Limitations due to Physical Health Problems). The short version of the CIS assesses fatigue by means of four items (e.g. 'I feel tired') on a 7-point scale (1 = strongly agree to 7 = strongly disagree). Higher scores represent more fatigue. Cronbach's alpha was 0.86.

Psychological functioning. The psychological functioning of potential donors was assessed using the RAND SF-36 Mental Health Composite and its subscales [28], the Hospital Anxiety and Depression Scale (HADS) [31], and neuroticism as assessed with the NEO Personality Inventory-Revised (NEO-PI-R) [32, 33].

Of the RAND SF-36, four subscales assess mental health, which are summarized into a composite score: Emotional Well-being, Role Limitations due to Emotional Problems, Social Functioning and Energy [28]. Cronbach's alphas varied between 0.71 (Social Functioning) and 0.87 (Mental Health Composite). The HADS is a widely used, short screening questionnaire for symptoms of anxiety and depression [31], consisting of two seven-item subscales with a score range of 0–21. Higher scores represent more anxiety or depression. Cronbach's alpha varied between 0.73 (depression) and 0.83 (total HADS). The NEO-PI-R assesses the personality characteristic of neuroticism by means of eight items on a 5-point Likert scale [32, 33]. Higher scores represent higher sensitivity for stressful situations. Cronbach's alpha was 0.77.

Social–relational functioning. Social–relational functioning of donors was assessed with the Interpersonal Sensitivity Measure (IPSM) [34] and the Inventory for Social Reliance (ISR) [35]. Two subscales of the IPSM were used, Interpersonal Awareness (seven items; e.g. 'I worry about the effect I have on other people') and Timidity (eight items; for example, 'I will do something I do not want to do rather than offend or upset someone') [34]. Scores were rated on a 4-point Likert scale (1=very unlike me to 4=very like me), with higher scores representing more Interpersonal Awareness and Timidity. Cronbach's alpha was 0.80 for Interpersonal Awareness and 0.65 for Timidity. The Perceived Support scale of the ISR assesses the level of perceived social support by means of five items, rated on a 4-point Likert scale (1=almost never to 4=almost always), with higher scores representing better interpersonal functioning [36]. Cronbach's alpha was 0.87.

Statistical analyses

Not n-normally distributed scales were transformed with (reflected) logarithmic transformations. The suitability of the data for principal component analysis was evaluated by the Barlett's Test of Sphericity [37] and the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy [38, 39]. Two principal component exploratory factor analyses with promax rotation and Kaiser normalization for scale structure assessment were conducted, one on donor motivation and expectation items and one on the items on donor worries, as these were formulated and scored distinctively. The selection of factors was based on the Eigenvalues, Cattell's scree test and factor interpretability. Of the resulting factors, internal consistency was assessed by Cronbach's alpha. Factors were transformed into subscale scores by averaging the included items when at least two-thirds of the items were filled in. To examine whether cognitions about donation were associated with demographic and donation-related characteristics, depending on the measurement level, correlational analyses (e.g. age), independent samples *t*-tests (using Welch's *t*-test in case of violation of homogeneity of variances; e.g. marital status) or one-way analyses of variance (e.g. educational level) were conducted. Pearson and Spearman correlation coefficients with the LDEQ and HRQoL were calculated for construct validity. A P-value <0.05 was considered significant. Data analyses were conducted using IBM SPSS Statistics 20.0 [40].

RESULTS

Participant characteristics

A total of 940 questionnaires were sent to potential donors, of which 719 were returned (response rate: 76%). The majority (57%) of the 221 potential donors not returning the questionnaire withdrew from the donation procedure because of medical reasons (58%), preference for another living donor (20%), donor personal reasons (17%) or availability of a postmortal donor (6%). Demographic characteristics did not differ between participants and non-participants (Table 1). Both sexes were almost equally represented in the study (57% was female), the mean age of the participants was 54.2 (SD = 11.4; range 19–76) years, and most had secondary level education (64.4%). The majority (79.6%) intended to donate directly to a recipient they knew.

Table 1. Demographic characteristics of the potential donors ($n = 719$)

Donor Demographics	Descriptives
Age, years [mean ± SD (range)]	54.2 ± 11.4 (19–76)
Gender (% female)	57
Marital status[a]	
Single	21.7
With partner	78.3
Educational level[a]	
Primary education	4.8
Secondary education	64.4
Tertiary education	30.8
Donation type	
Direct	79.6
Kidney exchange procedure	12.2
Anonymous	8.2
Donor–recipient relationship	
Spouse	29.3
Parent	17.9
Sibling	18.5
Child	5.6
Other—related	4.3
Other—unrelated	16.1
Anonymous	8.2
Being religious[a]	52.4

Values given are mean ± SD (range) or percentages
[a]Added after pilot study ($n = 624$).

Exploratory principal component analysis of the donation cognitions questionnaire

Donation Cognition Instrument—Motivation and Expectations (DCI-ME). Principal component analysis was permitted (KMO = 0.75, Bartlett P < 0.001) on the 25 items assessing donor motivations and expectations (the item 'I have no specific expectations of the donation' was excluded from analysis and the two open response options did not indicate any relevant missing motivations and expectations). Based on factor loadings below 0.40 or a difference of less than 0.20 between the highest two factor loadings, three items were excluded from the final questionnaire, resulting in the 22-item Donation Cognition Instrument—Motivation and Expectations (DCI-ME; Table 2). Four factors were distinguished, explaining a total variance of 52.8%, namely Donor Benefits (seven items, cognitions on improving donor's own well-being), Recipient Benefits (six items, cognitions on improving recipient's well-being), Idealistic Incentives (six items, cognitions about living according to one's ideals or religious convictions) and Gratitude (three items, cognitions on expressions of gratitude from the recipient or others). Scales were normally distributed, except for the Recipient Benefits scale, which was transformed using reflected logarithmic transformation. Descriptive statistics are presented in Table 2, showing cognitions about Recipient Benefits being most commonly reported (mean = 4.57, SD = 0.4 on a 5-point scale) and cognitions about Donor Benefits least commonly (mean = 1.96, SD = 0.7). The internal consistency varied between 0.76 and 0.81. Intercorrelations between the subscales revealed non-significant to moderate associations ($0.14 \leq r \leq 30$).

Donation Cognition Instrument—Worries (DCI-W). Principal component analysis was permitted (KMO = 0.73, Bartlett P < 0.001) on the 15 donor worries about themselves, the recipient, or future relationship changes (the three open response options did not indicate relevant missing worries). Five items were excluded for having a kurtosis higher than 10 ('I am worried about the reaction of my relatives to the donation'; 'I am worried that my relationship with the recipient will deteriorate'; 'I am worried that there will be more pressure and more tension in the relationship'; 'I am worried that the relations within the family and/or relationship will change for the worse following the donation'; 'I am worried that the division of roles within the family and/or relationship will change for the worse following the donation'). One item had a factor loading below 0.40, resulting in a nine-item Donation Cognition Instrument—Worries (DCI-W; Table 3). One factor could be distinguished, which was normally distributed after logarithmic transformation, explaining a total variance of 33.5%. Donors in general reported minimal worries about the donation (mean = 1.47, SD = 0.3 on a 4-point scale). The internal consistency was 0.74. Non-significant to small correlations between the DCI-W and subscales of the DCI-ME were found (r-values varying from 0.04 to 0.18).

Relationship of pre-donation cognitions with demographic and donation-related variables. Significantly higher scores on donor benefit cognitions were reported by potential donors with a steady partner [$t(609) = -2.37$, P = 0.02], and those with a religious conviction [$t(610) = -2.01$, P = 0.045]. Higher scores on recipient benefit cognitions were associated with a higher age ($r = 0.08$, P = 0.04). More idealistic incentives were reported by religious [$t(612) = -6.96$, P <0.001] and anonymous [$F(2,706) = 9.96$, P < 0.001] potential donors. Expectations of gratitude were reported more by males than females [$t(691.52) = 6.35$, P < 0.001]. No significant associations were found between worries about donation and demographic or donation-related variables (P-values >0.19; Table 4).

Construct validity of the DCI. Correlation coefficients of the DCI with the only other questionnaire assessing pre-donation expectations (LDEQ) and HRQoL measures are presented in Table 5. Correlations between the DCI and LDEQ subscales were mostly moderate (40% of correlation coefficients between 0.30 and 0.50) or small (40% between 0.10 and 0.30), whereas only non-significant (67% between 0.00 and 0.10) to small correlations (33%) were found for the recipient benefits subscale of the DCI and the LDEQ. Higher scores on donor benefit cognitions showed small associations with worse psychological and social–relational functioning. Higher scores on recipient benefit cognitions were slightly associated with better physical and psychological functioning. More idealistic incentives showed only a small association with more timidity, whereas correlations for gratitude did not reach the 0.10 threshold. More worries showed moderate correlations with worse psychological and social–relational functioning, and small correlations with worse physical functioning.

DISCUSSION

Guidelines for psychosocial donor evaluation advise an appraisal of cognitions regarding the donation, including donor

Table 2. Principal components analysis with promax rotation on the Donation Cognition Instrument-Motivation and Expectations (DCI-ME) ($n = 719$)[a]

	Item[b]	Donor benefits	Recipient benefits	Idealistic incentives	Gratitude
Factor I				Factor loadings	
5	I wish to improve my relationship with the recipient through the donation.	**0.81**	−0.02	−0.09	0.04
6	I wish to improve my relationship with others (for instance family members of the recipient) through the donation.	**0.73**	−0.13	0.01	0.03
19	I expect my relationship with the recipient to improve as a result of the donation.	**0.73**	−0.08	−0.04	0.20
20	I expect my relationship with family members/friends (for example of the recipient) to improve as a result of the donation.	**0.70**	−0.11	0.08	0.17
4	I wish to donate in order to improve the quality of my own life.	**0.70**	0.28	−0.06	−0.28
18	I expect my own quality of life to improve as a result of the donation.	**0.68**	0.21	0.04	−0.16
24	I expect to receive a contribution (immaterial or symbolic) for the donation.	**0.45**	−0.14	0.03	0.17
Factor II					
17	I expect the health risks for the recipient to decrease significantly as a result of the donation.	0.02	**0.71**	−0.08	0.19
16	I expect the disease burden of the recipient in everyday life to decrease significantly.	0.04	**0.70**	−0.15	0.21
3	I wish to donate in order to reduce the health risks for the recipient.	−0.03	**0.66**	0.11	−0.13
2	I wish to donate in order to reduce the disease burden of the recipient in everyday life.	−0.03	**0.65**	0.12	−0.04
1	I wish to donate in order to improve the quality of life of the recipient.	−0.10	**0.61**	0.14	−0.11
15	I expect the quality of life of the recipient to improve greatly.	−0.02	**0.61**	−0.21	0.36
Factor III					
11	I wish to make a contribution to a better world.	0.08	−0.06	**0.72**	0.03
10	I am acting in accordance with my religion or beliefs.	0.02	0.00	**0.71**	−0.17
12	Other donors are an example for me of love for one's fellow humans.	0.03	0.07	**0.68**	0.12
13	I am glad to be able to help someone.	−0.16	0.17	**0.60**	0.11
25	I expect to be strengthened in my religious or other beliefs as a result of the donation.	0.24	−0.12	**0.50**	0.00
26	I expect that I will serve as a good example for others through the donation.	0.07	0.07	**0.48**	0.29
Factor IV					
23	I expect relatives of the recipient to be very grateful for the donation.	0.04	−0.05	0.10	**0.83**
22	I expect the recipient to be very grateful for the donation.	0.06	0.00	0.03	**0.82**
21	I expect that as a result of the donation, I will be able to make a real difference for the recipient.	0.03	0.18	0.08	**0.55**
Excluded items					
7	I wish to help a stranger/acquaintance/friend/family member.	−0.26	−0.06	0.42	0.16
8	I am doing this out of love for the recipient.	0.11	0.36	0.18	−0.19
9	I find it self-evident to do this for a fellow human being.	−0.03	0.30	0.41	−0.04
	Mean (SD) (range 1–5)[c]	1.96 (0.72)	4.57 (0.41)	2.87 (0.84)	3.44 (1.03)
	Cronbach's alpha	0.81	0.78	0.76	0.77
	Percentage of variance explained	22.1	13.9	8.9	7.9

[a]Factor loadings on corresponding factors are in boldface type.
[b]Item number of original questionnaire, with item 14 and 26 being open response items.
[c]Higher means correspond with more cognitions in that domain.

Table 3. Principal components analysis with promax rotation on the DCI-W ($n = 719$)[a]

	Item[b]	Worries about the donation
Factor I		Factor loadings
3	I am worried about the operation.	**0.72**
4	I am worried about the physical consequences of the donation, such as a possible infection or pain.	**0.70**
7	I am worried that the kidney will be rejected by the recipient.	**0.64**
10	I am worried about the high expectations of the recipient regarding the transplant.	**0.57**
9	I am worried that the recipient will have the idea that s/he should always remain grateful.	**0.53**
2	I am worried about the results of the medical tests.	**0.51**
5	I am worried about the reaction of my partner and/or children to the donation.	**0.51**
1	I am worried that I will feel guilty if I decide not to go ahead with the donation.	**0.49**
12	I am worried that there will be constant pressure to be grateful.	**0.46**
Excluded item		
8	I am worried about the lifestyle of the recipient after the transplant, for instance smoking or engaging in risky sports.	0.31
	Mean (SD) (range 1–4)[c]	1.47 (0.33)
	Cronbach's alpha	0.74
	Percentage of variance explained	33.5

[a]Factor loadings on corresponding factor are in boldface type.
[b]Item number of original questionnaire, as stated on page 12, five items were not included in the principal components analysis.
[c]Higher means correspond with more worrying.

Table 4. Relationship of pre-donation cognitions with demographic and donation-related variables

	Donor Benefits				Recipient Benefits				Idealistic Incentives				Gratitude				Worries			
	Mean[a,b]	*F*	*t*	P	Mean[a,b]	*F*	*t*	P	Mean[a,b]	*F*	*t*	P	Mean[a,b]	*F*	*t*	P	Mean[a,b]	*F*	*t*	P
Gender																				
Male	2.02	6.06	1.82	0.08	4.57	1.61	−0.46	0.64	2.84	0.92	−0.82	0.41	3.71	7.02	6.35	<0.001***	1.46	0.64	−1.31	0.19
Female	1.92				4.56				2.90				3.24				1.49			
Marital status																				
Single	1.82	0.11	−2.37	0.02*	4.57	0.28	0.13	0.90	2.93	0.06	1.05	0.30	3.31	6.05	−1.57	0.12	1.46	0.05	−0.79	0.43
Steady partner	1.99				4.57				2.85				3.48				1.49			
Educational level																				
Primary	2.25	2.53		0.08	4.43	1.61		0.20	2.99	1.76		0.17	3.85	2.31		0.10	1.45	0.51		0.60
Secondary	1.96				4.59				2.89				3.42				1.48			
Tertiary	1.93				4.55				2.77				3.46				1.49			
Donation type																				
Direct	1.98	1.48		0.23	4.57	0.13		0.88	2.82	9.96		<0.001***	3.44	1.16		0.31	1.48	0.06		0.94
Kidney exchange	1.99				4.58				2.90				3.35				1.47			
procedure													3.61				1.45			
Anonymous	1.81				4.55				3.33											
Being religious																				
Yes	2.01	2.58	−2.01	0.045*	4.58	0.82	0.77	0.45	3.08	0.51	−6.96	<0.001***	3.45	0.00	−0.26	0.80	1.48	0.70	0.25	0.80
No	1.89				4.56				2.63				3.43				1.48			

[a]Higher scores correspond to more cognitions in that domain.
[b]Donor Benefits (range 1–5), Recipient Benefits (range 1–5), Idealistic Incentives (range 1–5), Gratitude (range 1–5), Worries (range 1–4).
*P < 0.05, **P < 0.01, ***P < 0.001.

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motivation, expectations and worries about donation. However, no instruments or criteria on how to judge these cognitions are provided. To meet this need, the DCI was developed. Five factors could be distinguished, measuring cognitions regarding donors' own HRQoL improvement (Donor Benefits), recipient's well-being improvement (Recipient Benefits), living according to one's ideals or religious convictions (Idealistic Incentives), expectations of gratitude in exchange for donation (Gratitude) and donation worries. Reliability of the DCI was verified by high internal consistency. Validity of the DCI was supported by small to moderate relationships with pre-donation cognitions and HRQoL, supporting the potential added value of the DCI for psychosocial evaluation in potential living organ donors.

Pre-donation motivations and expectations were mainly based on improving the recipient's health, which is in line with previous research showing that donors are more focused on recipient's functioning than on their own health [9]. Expectations of gratitude for donation were also common. Potential donors mentioned their own HRQoL improvement less often as a primary motivation to donate, and generally indicated few worries about the consequences of donation. This may be due to the fact that the questionnaires were completed at the beginning of the donor evaluation procedure, when the wish to donate dominates. Possibly, worries about surgery or recipient outcomes arise later when the surgery is planned.

Gender differences on pre-donation cognitions were found, with males expecting more gratitude for donation. This is in line with research on the existing expectancies questionnaire (LDEQ), which found men to score higher on the subscale Quid Pro Quo, which also encompasses expecting something in return for the donation [14]. Further, religious and anonymous donors reported more idealistic motivations. This was to be expected due to the presence of religious convictions in this scale and the fact that anonymous donors have been found to donate out of their ideals with regard to helping others [24, 41].

The validation of the DCI with the other validated questionnaire on pre-donation expectations regarding a donor's personal well-being (LDEQ) [14] showed a small to moderate overlap between most subscales. The low associations between recipient benefit cognitions and the LDEQ subscales indicate that the previous instrument does not yet assess these cognitions. Considering that they were the most often reported donor motivations or expectations and were related to better pre-donation HRQoL supports the potential value of this new, more encompassing instrument. To provide first indications that the DCI measures something additional to HRQoL, validity was assessed between the DCI and physical, psychological and social–relational functioning. More worries were moderately associated with a worse pre-donation HRQoL. This is in line with research showing that HRQoL is related to worrying in other health conditions [42]. The overall small associations between pre-donation cognitions and HRQoL support the notion of unique dimensions of potential donors' attitudes being assessed by the DCI.

Strengths of the current study include the large sample from seven transplantation centres, the use of validated questionnaires, and the applicability of the questionnaire for other donor populations due to the generalized formulation of items. The generalizability of the results is limited to the Dutch living kidney donor population and needs to be confirmed in alternative donor populations from other countries. Further, because the questionnaires were administered at the beginning of the donor evaluation, responses might be influenced by social desirability to positively influence healthcare professionals in the donation decision [8]. Last, recent studies indicate that non-altruistic donor motives and expectations about finances and insurance are relevant themes for donor evaluation that are currently not

Table 5. Correlation coefficients of the DCI subscales DCI-ME and DCI-W with validated questionnaires[a]

	DCI-ME				DCI-W
	Donor Benefits	Recipient Benefits	Idealistic Incentives	Gratitude	Worries about donation
LDEQ					
Interpersonal Benefit	0.47***	−0.03	0.32***	0.37***	0.32***
Personal Growth	0.44***	0.07	0.37***	0.28***	0.28***
Spiritual Benefit	0.38***	0.06	0.52***	0.23***	0.14**
Quid Pro Quo	0.45***	−0.02	0.26***	0.35***	0.26***
Health Consequences	0.34***	−0.17***	0.12**	0.15**	0.43***
Miscellaneous Consequences	0.21***	−0.23***	0.13**	0.01	0.30***
Physical functioning					
RAND SF-36					
Physical functioning	0.00	0.07	0.01	0.08*	−0.10**
Role limitations — Physical health problems[b]	−0.14***	0.00	−0.02	−0.08*	−0.15***
Pain	0.00	0.07	0.01	0.03	−0.15***
General health perceptions	−0.07	0.11**	0.03	0.04	−0.29***
Physical health composite	−0.06	0.10**	0.03	0.04	−0.26***
Short CIS fatigue					
Fatigue	0.09*	−0.11**	−0.09*	−0.07	0.30***
Psychological functioning					
RAND SF-36					
Emotional well-being	−0.13**	0.12**	−0.02	0.04	−0.37***
Role limitations — Emotional problems[b]	−0.05	0.08*	0.02	0.05	−0.14***
Energy/fatigue	−0.05	0.12**	0.05	0.04	−0.32***
Social functioning	−0.09*	0.05	−0.07	−0.01	−0.32***
Mental health composite	−0.09*	0.13**	0.00	0.03	−0.37***
HADS					
Anxiety	0.12**	−0.07	0.02	0.04	0.44***
Depression	0.10**	−0.10**	−0.05	0.01	0.24***
Social–relational functioning					
NEO-PI-R					
Neuroticism — vulnerability	0.15***	−0.16***	−0.02	−0.01	0.35***
IPSM					
Interpersonal awareness	0.12**	−0.07	0.05	0.04	0.42***
Timidity	0.08*	−0.06	0.12**	0.03	0.27***
ISR					
Perceived support	−0.06	0.08*	−0.01	−0.04	−0.18***

[a]DCI-ME, DCI-W (higher scores correspond to more cognitions in that domain); LDEQ (higher scores correspond to more expectations on that domain); RAND SF-36 (higher scores correspond to better HRQoL); CIS (higher scores correspond to more fatigue); HADS (higher scores correspond to more anxiety or depression); NEO-PI-R (higher scores correspond to more neuroticism); IPSM (higher scores correspond to more interpersonal sensitivity); ISR (higher scores correspond to better interpersonal functioning).
[b]Spearman correlation coefficients.
*P < 0.05, **P < 0.01, ***P < 0.001.

included in the DCI. Future studies could add items on these themes to optimize the DCI.

At this moment no gold standard or longitudinal studies on donor cognitions are available, and possible risk or resilience factors for longer-term donor functioning are not yet clearly defined. Therefore, no valid cutoff criteria for the DCI could be formulated based on this cross-sectional study. Future prospective studies should examine the potential of the DCI to predict longer-term adjustment problems in living donors and to identify unfavourable cognitions that are contra-indications for donor eligibility [1, 27]. Through this, donors who might benefit from psychosocial interventions could be identified. However, as a first step in this process, the construct validity indices used in this study indicate the potential of the DCI to systematically assess pre-donation cognitions in clinical practice that might add to existing questionnaires on donor expectations and HRQoL. Further, the DCI could provide potential donors more insight into their own motivations, expectations and worries, and might aid in the process of donation decision-making. Lastly, it could offer discussion themes for healthcare professionals during donor evaluation consultation, when potential donors report unfavourable motivations, unrealistic expectations or excessive worries about donation. In these cases, means and SDs provided from the current study could be used as norm scores, because of the large and representative sample that was used. To conclude, the DCI is a reliable instrument to assess pre-donation cognitions, which has the potential to become part of the psychosocial donor evaluation to aid donor decisions and suggest donor intervention needs.

ACKNOWLEDGEMENTS

The authors would like to thank all potential donors that participated in the study and the following colleagues for their contributions in the study performance: Desiree Pilzecker, Heinrich Kloke, Ine Dooper, Sabine Hopman, Gerben van den Bosch, Simon van Duin, Franka van Reekum, Bep Vink,

Judith Wierdsma, Hans de Fijter, Regien Meijer, Annemarie Roelofs, Ellen Jansen, Dominique Rodenhuis, Philip Ulrichts, Elly van Duijnhoven, Carla Schrauwers, Azam Nurmohamed, Marjon van Vliet, Tessa de Jong-Pulskens, and Janneke Vervelde.

FUNDING

This research was funded by the Dutch Kidney Foundation.

CONFLICT OF INTEREST STATEMENT

None declared.

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Received for publication: 23.8.2016; Accepted in revised form: 7.11.2016