ORIGINAL ARTICLE

Assessment of donor satisfaction as an essential part of living donor kidney transplantation: an eleven-year retrospective study

Ana Menjivar^{1,2,*} (b), Xavier Torres^{3,*} (b), David Paredes^{1,4}, Nuria Avinyo⁵, Josep Maria Peri³, Erika De Sousa-Amorim⁶, Federico Oppenheimer^{2,6}, Marti Manyalich^{1,7}, Fritz Diekmann^{2,6} & Ignacio Revuelta^{1,2,6}

1 Medical School, University of Barcelona, Barcelona, Spain 2 Laboratori Experimental de Nefrologia i Trasplantament (LENIT), Institut d'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), Barcelona, Spain 3 Psychiatry and Clinical Psychology Service, Institut Clinic de Neurociencies, Hospital Clinic of Barcelona, Barcelona, Spain 4 Donation and Transplant Coordination Section, Hospital Clinic of Barcelona, Barcelona, Spain 5 Fundació Clínic per a la Recerca Biomèdica, Barcelona, Spain 6 Department of Nephrology and Renal Transplantation, Hospital Clinic of Barcelona, Barcelona, Spain 7 Transplant Assessorial Unit, Medical Direction, Hospital Clinic of Barcelona, Barcelona, Spain

Correspondence

Ignacio Revuelta, Hospital Clinic of Barcelona, 170 Villarroel St. 12/5, Barcelona 08036, Spain. Tel.: +34 639139850; fax: +34 932 275498; e-mail: irevuelt@clinic.ub.es

*Both authors contributed in the same proportion.

SUMMARY

Living kidney donors seem highly satisfied with donation. However, previous studies measure satisfaction by a single-item or by simply questioning donors' willingness to donate again or to recommend living donation. With the aim of analyzing whether satisfaction with donation is a multidimensional construct, thus allowing a more specific characterization of dissatisfied donors, 332 living kidney donors (2005-2015) answered a renewed version of the European Living Donation and Public Health Project satisfaction survey. Exploratory factor-analyses suggested that satisfaction was composed of three-factors: violation of donors' expectancies about donation; interference of donation on daily activities, and pain and discomfort. Donors reported high levels of satisfaction. However, clusteranalysis identified a subgroup characterized by a higher discrepancy between the expected and the actually experienced during donation, higher interference on daily activities, and higher pain and discomfort. Most of them considered that hospital discharge was premature, suffered economic losses and perceived worse health outcomes of their recipients. Single questions assessing donors' willingness to donate again or to recommend living donation were unable to differentiate between clusters. In summary, donor's satisfaction seems better characterized by three dimensions than by single questions.

Transplant International 2018; 31: 1332–1344

Key words

kidney transplantation, living kidney donation, living kidney donor satisfaction

Received: 27 February 2018; Revision requested: 30 March 2018; Accepted: 21 August 2018; Published online: 10 September 2018

Introduction

Transplantation from the unselfish donation of living kidney donors (LKDs) is the best treatment for endstage renal disease. Living kidney donation (LKDo) also helps overcome the shortage of organs from deceased donors, prolonged time until transplantation, and reducing morbidity and mortality rates [1]. After more than five decades of experience, LKDo seems to be the best option in terms of cost-efficiency for the healthcare system and posttransplant recipient outcomes such as quality of life [2–4]. Assessment of donors' satisfaction seems necessary, both from an ethical and a moral point of view. Considering the lifelong consequences of living with a single kidney without direct medical benefits, LKDs might be the weaker point of this therapeutic option [5–7]. Assessment of satisfaction might also facilitate the prompt detection of negative outcomes, such as financial burden, wage losses or emotional disorders [8]. Low levels of satisfaction have been proposed as a predictor of an increased fear of postdonation kidney-related health problems [9]. This fear might negatively affect the well-being and quality of life of LKDs and might cause donation regret, which in turn might negatively influence the availability of future LKDo [10].

Previous studies have reported high levels of satisfaction among LKDs, with 78-96% of donors feeling "very" or "extremely" satisfied [8,9,11-15]. However, some of these studies measure LKDs' satisfaction relying on a single five-option item [9] or, indirectly, by questioning their willingness to donate again [12,15]. The assessment of satisfaction based on a single-item might be at risk of being too general, thus, missing specific features included in this concept, such as the satisfaction with the medical attention or with the information received. In fact, LKDs have proposed several potential improvements. For example, an increased attention from hospital staff, being able to talk with former LKDs, and improving the information on medical evaluations, recovery, scars, diet and lifestyle changes, aftercare and risks [16]. Assessing satisfaction with a single-item might also be at risk of obtaining a weighted response. Therefore unable to detect, for instance, potential differences between satisfactions with the attention received predonation compared with the attention received postdonation. As a matter of fact, about 25% of kidney recipients report feeling dissatisfied with the medical attention received by their donors postdonation compared with that received predonation and claim for improvements in their followup [17].

Therefore, our aim was to analyze LKDs' satisfaction with their donation process, assess whether satisfaction includes several specific components rather than being a unidimensional construct, and define the characteristics of donors dissatisfied with donation. According to previous studies [8,9,11–15], we expected low levels of LKDs' dissatisfaction. We also expected that dissatisfied LKDs would be those who suffered economic losses related to donation, felt that the hospital discharge was premature and those whose recipient suffered a worsening of his/her health status.

Materials and methods

Participants

All LKDs who donated at the Hospital Clinic of Barcelona (HCB) between 2005 and 2015. LKDs were excluded if: (i) they did not live in Spain, (ii) were illiterate, (iii) they did not understand/speak Spanish, and (iv) they had suffered mental and/or medical illness postdonation that might interfere with their ability to answer the survey (e.g., dementia, psychoses).

Due to the low numbers, LKDs to pediatric recipients (n = 14) and to the Spanish paired exchange program (SPEP) (n = 20) were excluded. The SPEP was started in 2009 [18].

Procedure

The study was approved by the HCB ethics committee. All donors provided written consent to participate.

Living kidney donors demographic information was obtained from medical records. All participants were recruited by phone at least 1 year postdonation. LKDs who agreed to participate were mailed an informative sheet, the satisfaction survey, the informed consent form and a prepaid envelope to send back the survey. LKDs that did not send the survey back in 1 month were contacted either to confirm their participation or to document their reasons for declining their participation.

Instruments

Donors' satisfaction was assessed by a renewed version of the European Living Donation and Public Health Project (EULID) Satisfaction Survey (ESS) [19]. The ESS included 54 questions developed using Delphi methodology. The ESS evaluated 245 donors from nine European countries. It assessed their perception and acceptance of the donation process, satisfaction with the information received, decision-making and potential impact of donation on their lifestyle, their ability to obtain future insurability, employment, financial barriers and relationship with their recipients [20].

EULID satisfaction survey was developed in Spanish and then translated into: Cypriot, English (available at www.eulivingdonor.eu/eulid/eulid-cd.html), French, Italian Portuguese, Polish, Romanian and Swedish.

| Table 1. Modifications to the original EULID satisfaction survey. | |
|--|---|
| Items of EULID survey | Items of the renewed EULID survey |
| Items deleted 33- In the case your country doesn't have a universal public health system, did yo have any problems with your health insurer related to donation costs reimbursement or medical follow-ups 36- What do you think about your quality of life before and after donation? 43- What do you think about your current health, compared to before donation? 45- In general, would you say that currently your health is: excellent, very good, good, fair, bad 46- Do you think you get sick more easily than anybody else? 47- Do you think you are as healthy as anybody else? 48- In the last 4 weeks, how much did your physical health or emotional problem make it difficult to manage your social activity with family, friends, neighbors or other people | pu , ns |
| Items rephrased | |
| 15- Were all your family members/close friends informed about your decision? | 15- Were all your relatives informed about your decision?16- Were all your close people informed about your decision? |
| 27- What do you think about pain and recovery after the surgery? | 28- How much pain did you suffer during the postoperative period?29- How much discomfort did you suffer after surgery? |
| 39- Have your daily works or hobbies changed after donation? | 41- In what measure have your daily activities changed after donation?42- In what measure have your leisure activities changed after donation? |
| Items consolidated into a single question | |
| 12- Did you seek advice from any relative or friend about becoming a living kidne donor | ey 14- Did you seek advice from any relative or friend about becoming a living kidney donor? |
| 13- If you did, what was your relationship to that person? | 14a- If you did, what was your relationship to that person? |
| 14- If you didn't seek advice, why not? | 14b- If you didn't seek advice, why not? |
| items added | 1- Employment situation at donation |
| | 2- Which is the current health status of your recipient? 31- Did you feel recovered at hospital discharge? 32- Do you think that the hospital discharge was premature? 44- Do you think that the medical care received after the donation has been enough? |

The renewed version included 53 items. Several items were deleted and/or rephrased (Table 1). One item assessing inaccessibility to healthcare system was deleted because Spanish citizens are covered by the public healthcare system. Six items extracted from 36-Item Short Form Survey were deleted to avoid compromising the content validity with items intended to assess health-related quality of life. Three items assessed two concepts with a single question and thus each of them was split into two items. Three items assessing several aspects of the same variable were consolidated into a single question. Five items were added to assess neglected variables (job status at donation, LKDs' perception of their recipients' health, feeling recovered at discharge, feeling that discharge was premature and satisfaction with postdonation medical care). The fourpoint Likert scales of the ESS were replaced with 0–10 centimeter visual analogue scales (VAS). The renewed survey included 29 items assessed by VAS; 14 items with a dichotomous response option (yes/no); five items with a multiple choice response option (e.g., job status); three items assessing numbers of days (e.g., hospital stay); and two open questions.

Statistical analysis

Factorability was assessed with Bartlett's test and the Kaiser-Meyer-Olkin measure. The potential multiple factor structure was assessed by exploratory factor-analyses. The internal consistency of each factor was reassessed by Cronbach's alphas to verify homogeneity and interdependence between items.

The potential classification of LKDs according to their level of satisfaction was assessed with a clusteranalysis. Mean or proportion differences between clusters were analyzed to characterize those donors with lower satisfaction.

Results

Three hundred thirty-two (72%) out of 463 eligible LKDs returned usable surveys (Fig. 1). All donors underwent laparoscopic surgery, but in two cases the surgical approach was changed to an open one in the operating room.

Table 2 shows that most participants were women with a mean (SD) age of 56 (10.5) years at survey completion, most of them (60%) were occupationally active at donation. All LKDs were genetically or emotionally related to their recipient. The mean time from donation to the satisfaction survey was four (2.2) years. LKDs' perceptions of their own recipients' health status were quite good with a mean of 7.5 (2.6). Some LKDs (21%) felt that hospital discharge was premature. One-third (32%) reported economic losses related to donation. The majority (98%) seemed satisfied with donation according to their willingness to donate again, and most (99%) would recommend LKDo.

Factorability

Twenty-five out of 53 items assessed by VAS were included. Every VAS produced a range of responses

from 0 to 10. Two items (#3 and #4) were eliminated due to missing values higher than 10% (Table 3).

Based on Bartlett's test approximate chisquare = 1889.43; P < 0.001, and the Kaiser-Meyer-Olkin measure (0.78), the item-set appeared factorable.

The initial principal components analysis with varimax rotation led to the extraction of four-factors, accounting for 46.3% of the variance in the item-set (Table 4). Factors accounted for 19.7%, 9.8%, 9.8%, and 7% of variance respectively.

Internal consistency was acceptable (Alpha for Factor 1 = 0.81; Factor 2 = 0.67; Factor 3 = 0.69), except for the Factor 4 (Alpha = 0.44). The content of items composing Factor 4 showed one item assessed LKDs' impression of their recipient's current health status, one item assessed having regretted donation while staying at the hospital, two items assessed LKDs' current perception of their relationship with recipients (e.g., feeling in debt), and one item assessed whether donors felt that people valued them better for having donated. Due to content discrepancies and low internal consistency, Factor 4 was discarded, and its items were independently analyzed.

The three factor structure was easily interpretable. Factor 1 included 11 items assessing discrepancies of donors' expectancies about donation (i.e., to what extent did the information received predonation closely reflect their actual experiences during and after donation). Factor 2 included four items describing donors' perception of donation interference on their daily activities, both before and after donation. Factor 3 included five items measuring pain and discomfort; including the perception of sufficient recovery at hospital discharge and the degree of discomfort due to medical tests and studies they underwent to become a donor. Item #19 showed positive high-loads in Factors 2 and 3, and item #27 showed a positive high-load on Factors 1 and negative on 3. Therefore, these items were included in both factors. Factors' scores were transformed to fit a scale from 0 to 100.

Cluster-analysis

As a whole group, LKDs were highly satisfied with their donation process (Table 2). That is, LKDs did not observe significant discrepancies between what was expected and what they actually experienced (Factor 1: Mean (SD) = 99.10(11.11)); they did not observe a relevant interference of donation on their daily activities (Factor 2: 7.84(7.45)); and did not suffer excessive pain and discomfort (Factor 3: 14.68(9.05)).



Figure 1 Participants flowchart. HCB, Hospital Clinic of Barcelona; LKDs, living kidney donors. *Excluding LKDs for pediatric recipients and kidney pair exchange donors.

However, the cluster-analysis identified two groups of LKDs. Due to incomplete data, 46 (14%) LKDs could not be included in the cluster-analysis. Table 2 shows the results for the two clusters regarding participants' characteristics, Factors 1–3, items of the discarded

Factor 4, items identified as relevant to donor satisfaction in previous studies, and items previously used to assess satisfaction.

Donors in cluster 1 (n = 116, 40.6%) reported a higher discrepancy between what they expected and

| Table 2. Participant characteristics and comparison betw | veen clusters. | | | | |
|--|---|---|---|--------------------------|-------------------------|
| | All sample (<i>n</i> = 332) Mean (SD)/ <i>n</i> (%) | Cluster 1 ($n = 116$) Mean (SD)/ n (%) | Cluster 2 ($n = 170$) Mean (SD)/ n (%) | t/χ^2 | Р |
| Gender (female) Age (years) Donor-recipient relationship (genetically related) | 216 (65.1%) 56.43 (10.52) 209 (63.0%) | 74 (63.8%) 54.80 (10.76) 68 (58.6%) | 113 (66.5%) 56.91 (10.49) 108 (63.5%) | 0.218 -1.654 0.702 | 0.640 0.099 0.402 |
| Employment situation at donation Active Retired Jobless | 196 (59.6%) 73 (22.2%) 30 (9.1%) | 84 (72.4%) 20 (17.2%) 6 (5.2%) | 90 (52.9%)* 43 (25.3%) 21 (12.4%)† | 11.638 | 0.009 |
| Housewrite Years between donation and satisfaction survey Satisfaction survey | 3.85 (2.18) 3.85 (2.18) | 0 (2.24) 3.90 (2.24) | 16 (9.4%) 3.80 (2.19) | 0.371 | 0.711 |
| Factor 1: non-discrepancies of expectancies about donation (0–100) | 99.10 (11.11) | 83.54 (12.18) | 94.51 (4.76) | -9.23 | <0.001 |
| Factor 2: donation interference on daily activities | 7.84 (7.45) | 34.07 (19.11) | 9.46 (8.92) | 12.94 | <0.001 |
| Factor 3: pain and discomfort (0–100) Perception of the current recipient health status (VAS 0–10 cm; verv bad or died to excellent) | 14.68 (9.05) 7.47 (2.61) | 44.25 (15.83) 6.97 (2.72) | 19.73 (12.13) 7.80 (2.48) | 14.09 2.69 | <0.001 0.008 |
| Recipient died (yes) Repentance of having donated while staying at the hospital (VAS 0–10 cm; strongly disagree to stronaly agree) | 16 (4.8%) 0.98 (2.38) | 8 (6.9%) 1.03 (2.16) | 6 (3.5%) 1.02 (2.61) | 1.67 0.06 | 0.195 0.95 |
| Feeling that the recipient was in debt or has created some dependency with you for having received your kidney (VAS 0–10 cm; strongly disagree to strongly agree) | 2.52 (3.32) | 2.73 (3.07) | 2.28 (3.38) | 1.11 | 0.27 |
| Feeling that being a living donor makes people around value you more (VAS 0–10 cm; nothing to a lot) | 5.24 (3.43) | 5.15 (3.37) | 5.17 (3.46) | -0.07 | 0.945 |
| Current relationship with the recipient (VAS 0–10 cm; much worse to much better) | 7.44 (2.23) | 7.14 (2.29) | 7.61 (2.26) | -1.69 | 0.092 |
| Feeling that hospital discharge was premature (yes) Economic losses related to donation (yes) Willingness to donate again (no) | 69 (20.8%) 107 (32.2%) 7 (2.1%) | 37 (31.9%) 50 (43.1%) 6 (5.2%) | 21 (12.3%) 46 (27.1%) 0 (0%) | 16.22 7.77 8.98 | <0.001 0.05 ‡ |
| Recommendation of living kidney donation to others (no) | 4 (1.2%) | 4 (3.5%) | 0 (0%) | 5.96 | ** |
| * Cluster2 < 1. | | | | | |

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*Non-comparable due to limited frequency in Cluster 2.

 \ddagger Cluster 2 > Cluster 1.

| Table | 3. Characteristics of the visual analogue items of the renewed EULID satisfaction survey. | | | | |
|----------|--|----------------|--------------|------------|--------------|
| Item | | Missing | Mean | Median | SD |
| 2 | Which is the current health status of your recipient? (VAS 0–10 cm; very bad or died to Excellent) | 1 | 7.46 | 8.00 | 2.61 |
| m | What did you think about cadaveric organ donation for transplant before you were a living kidney donor? (VAS 0–10 cm: completely against to completely in favor) | 44 | 9.11 | 9.60 | 1.73 |
| 4 | What did you think about living organ donation for transplant before you were a living kidney donor? (VAS | 40 | 9.17 | 9.60 | 1.60 |
| ~ | 0–10 cm; completely against to completely in favor) Do vou think that vou were clearly explained about the tests and medical studies vou would undergo to be a living | - | с С | 050 | 1 14 |
| | donor? (VAS 0–10 cm; strongly disagree to Strongly agree) | - |) | 2 | F |
| ∞ | Did the medical tests you underwent interfere with your daily life? (VAS 0–10 cm; nothing to a lot) | , - | 3.38 | 2.00 | 2.28 |
| თ | Do you think you were clearly explained about surgery risks, even about the probability of risking your life even thouch this was minimum? (VAS 0–10 cm: stronoly disearee to stronoly acree) | , - | 9.17 | 9.50 | 1.50 |
| 10 | Did vou take the decision of donating after thinking it over well? (VAS 0–10 cm: strongly disagree to strongly agree) | m | 9.33 | 9.60 | 1.39 |
| 11 | Were you clearly explained that after surgery you would stay in the hospital, isolated, with catheter, tubes, monitors, | 4 | 8.20 | 9.50 | 2.70 |
| | and even pain? (VAS 0–10 cm; strongly disagree to strongly agree) | | | | |
| 12 | Were you clearly explained that your donation did not guarantee a successful outcome for your recipient? (VAS 0– 10 cm: stronoliv disagree to stronoliv agree) | 9 | 8.89 | 9.50 | 2.07 |
| 17 | To cirry strongly disagree to strongly agree? Did the information volt were diven by health professionals hefore donation make volt feel sectire? (VAS 0–10 cm: | ſ | 0 14 | 050 | 1 41 |
| 2 | stronally disagree to stronally agree) | n | t i | 2 | - - |
| 19 | What do you think about the medical tests and studies you underwent to become a donor? (VAS 0-10 cm; less | 7 | 2.26 | 0.80 | 2.80 |
| | annoying than expected to more annoying than expected) | | | | |
| 20 | Did you feel well taken care of during your stay at the Hospital? (VAS 0–10 cm; strongly disagree to strongly agree) | 9 | 8.92 | 9.50 | 2.01 |
| 21 | Do you think that the procedures and steps to become a living donor were appropriate (for example, the visit to the | 7 | 9.20 | 9.50 | 1.45 |
| 1 | Judge with the medical team)? (VAS 0–10 cm; strongly disagree to strongly agree) | I | L T Q | (| |
| 77 | Did the explanations you were given before donating, related with the donation process, correspond with your | ~ | ۲/.8 | 9.50 | 1.93 |
| 00 | actual experience? (VAS U-TU CIII, suoligiy disagree to suorigiy agree) Have much main aid voir cuffor during the portportation marinal? (AAS O 10 mm mathing to a lot) | ~ | | | L0 C |
| | | t r | 07.4 1 | |)) (L |
| 2 08 | How much alscornion and you sumer after surgery? (VAS 0-10 cm, nouning to a jou) At some point while staving in hospital did you regret baying dopated? (VAS 0-10 cm: strongly disagree to strongly | 04 | 00.5 80 U | 0.30 | 2.00 |
|) | agree) | | | |) |
| 31 | Did you feel recovered at hospital discharge? (VAS 0–10 cm; non-recovered to completely recovered) | IJ | 6.56 | 7.00 | 2.81 |
| 37 | Are you fully recovered after donation? (VAS 0–10 cm; strongly disagree to strongly agree) | 15 | 9.24 | 9.50 | 1.36 |
| 41 | In what measure have your daily activities changed after donation? (VAS 0–10 cm; nothing to a lot) | 11 | 1.01 | 0.50 | 1.98 |
| 42 | In what measure have your leisure activities changed after donation? (VAS 0–10 cm; nothing to a lot) | 11 | 1.18 | 0.50 | 2.24 |
| 44 | Do you think that the medical care received after donation has been enough? (VAS 0–10 cm; insufficient to sufficient) | 20 | 8.86 | 9.50 | 1.95 |
| 46 | Do you think that your recipient feels in debt or has created some dependency with you for having received your | 21 | 2.52 | 0.60 | 3.32 |
| 47 | kianey? (vAS V-10 cm; strongly alsagree to strongly agree) Do you think that being a living donor makes people around value you more? (VAS 0–10 cm; nothing to a lot) How is your current rolationship to the recipion? (VAS 0-10 cm; much worso to much hottor) | 10 | 5.24 | 5.50 | 3.43 5.43 |
| - | חטע וא אטטו בעורבות ובומנוטואווף נט נווב ובכוףובות: (עאש ט-דט כווו, ווועכוו אטואב נט ווועכוו שבתבו) | 0 | 1.44 | CD. / | C7.2 |

Transplant International 2018; 31: 1332-1344 © 2018 Steunstichting ESOT Table 4. Factorability of the items-set of the renewed EULID satisfaction survey. Bold values are the items cross-loaded in each factor.

| | | Factorial ar | ıalysis | | |
|----------------|--|---------------------------|-------------------------|--|--------------------------------|
| ltem | | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
| 7 2 | Which is the current health status of your recipient? (VAS 0–10 cm; very bad or died to excellent) Do you think that you were clearly explained about the tests and medical studies you would undergo | 0.106 0.712 | -0.197 -0.081 | -0.050 -0.011 | 0.369 0.115 |
| 80 | to be a living donor? (VAS 0–10 cm; strongly disagree to strongly agree) Did the medical tests you underwent interfere with your daily life? (VAS 0–10 cm; nothing to a lot) Do you think you were clearly explained about surgery risks, even about the probability of risking | -0.090 0.835 | 0.507 0.017 | 0.205 —0.152 | 0.031 -0.057 |
| 10 | your life even though this was minimum? (VAS 0–10 cm; strongly alsagree to strongly agree) Did you take the decision of donating after thinking it over well? (VAS 0–10 cm; strongly disagree to | 0.713 | 0.028 | 0.020 | -0.052 |
| 1 | Were you clearly explained that after surgery you would stay in the hospital, isolated, with catheter, | 0.604 | 0.057 | -0.100 | -0.067 |
| 12 | tubes, monitors, and even pain? (VAS U-TU cm; strongly disagree to strongly agree) Were you clearly explained that your donation did not guarantee a successful outcome for your radioiant? (VAS 0-10 cm; stronoly disparae to stronoly acree) | 0.518 | -0.057 | 0.029 | 0.016 |
| 17 | Did the information you were given by health professionals before donation make you feel secure? | 0.757 | -0.082 | -0.137 | 0.071 |
| 19 | What do you think about the medical tests and studies you underwent to become a donor? (VAS 0- 10 cm·locr annoving than availed to more annoving than available | -0.202 | 0.399 | 0.406 | -0.124 |
| 20 | Did you feel well taken care of during your stay at the hospital? (VAS 0–10 cm; strongly disagree to | 0.594 | -0.098 | -0.030 | -0.119 |
| 21 | Do you think that the procedures and steps to become a living donor were appropriate (for example, the wist to the index with the modical team)? AAS 0-10 cm: strengly discusse to strengly arready | 0.596 | -0.015 | -0.072 | 0.151 |
| 27 | Did the explanations you were given before donating, related with the donation process, correspond with vour actual experience? (VAS 0-10 cm; strongly disarree to strongly agree) | 0.607 | -0.026 | -0.425 | 0.038 |
| 28 29 30 | How much pain did you suffer during the postoperative period? (VAS 0–10 cm; nothing to a lot) How much pain did you suffer during the postoperative period? (VAS 0–10 cm; nothing to a lot) How much discomfort did you suffer after surgery? (VAS 0–10 cm; nothing to a lot) At some point, while staying in hospital, did you regret having donated? (VAS 0–10 cm; strongly | 0.030 -0.053 -0.117 | 0.136 0.154 0.074 | 0.809 0.862 -0.097 | 0.053 0.025 0.464 |
| 31 | Did you feel recovered at hospital discharge? (VAS 0–10 cm; non-recovered to completely recovered) | 0.124 | -0.025 | -0.601 | 0.033 |
| 37 41 | Are you fully recovered after donation? (VAS 0–10 cm; strongly disagree to strongly agree) In what measure have vour daily activities changed after donation? (VAS 0–10 cm; nothing to a lot) | 0.541 -0.046 | -0.185 0.900 | 0.006 0.065 | 0.044 0.010 |
| 42 44 | In what measure have your leisure activities changed after donation? (VAS 0–10 cm; nothing to a lot) Do you think that the medical care received after donation has been enough? (VAS 0–10 cm; | -0.059 0.367 | 0.898 -0.196 | 0.042 0.000 | 0.002 0.099 |
| 46 | Do you think that your recipient feels in debt or has created some dependency with you for having | 0.000 | 0.167 | 0.148 | 0.598 |
| 47 | received your klaney? (VAS V–10 cm; strongly alsagree to strongly agree) Do you think that being a living donor makes people around value you more? (VAS 0–10 cm; nothing to a lot) | 0.005 | -0.028 | -0.003 | 0.652 |
| 51 | How is your current relationship to the recipient? (VAS 0–10 cm; much worse to much better) | 0.127 | -0.072 | 0.018 | 0.621 |

Transplant International 2018; 31: 1332–1344 © 2018 Steunstichting ESOT what they actually went through during the donation, a higher interference of donation on daily activities, and higher pain and discomfort. Also, a higher proportion of LKDs in cluster 1 believed that hospital discharge was premature, and suffered more economic losses related to the donation. Regarding the items composing the discarded Factor 4, the clusters differed only in LKDs' impression of their recipient's health status, which was worse in cluster 1. No significant differences were observed regarding the repentance of having donated while staying at the hospital; the feeling that the recipient was in debt with his/her donor; the feeling that people around valued them more due the donation; and the perceived quality of their relationship with their recipients. Notably, variables previously used as a single question to assess LKDs' satisfaction were unable to differentiate between clusters. Thereby, all satisfied donors in cluster 2 would be willing to donate again and would recommend LKDo, while only 6 (5.2%) and 4 (3.5%) dissatisfied donors would not.

To identify other sources of dissatisfaction, an additional cluster-analysis was calculated in the subgroup of dissatisfied donors. Four subgroups were identified: subgroup 1 (n = 7; 6%) regretted more having donated while staying at hospital; subgroup 2 (n = 26; 22.4%) thought that recipient felt in debt or had created some dependency with them; subgroup 3 (n = 44; 37.9%) did not feel especially valued by others as a donor. A final subgroup (n = 32; 27.6%) was characterized by moderate scores in these variables.

Discussion

Our results suggest that taken as a whole, LKDs are highly satisfied with their donation process. In spite of the high level of LKDs' satisfaction, a subgroup was somewhat dissatisfied.

Medical service users' satisfaction is recognized as a valid appraisal of the quality of healthcare [21]. Satisfaction is, however, a somewhat elusive concept that has been defined in different ways. LKDs' satisfaction may be even more complex because health outcomes include also those related to their recipients.

Satisfaction with care might be better understood as one specific component of the broader construct of health-related quality of life (e.g., one may be satisfied with the medical attention received and outcomes obtained, and still perceive that health interferes with the expected live conditions). Therefore, though satisfaction with care influences health-related quality of life, relations between them seem moderate [22–24]. However, identifying sources of patients' dissatisfaction might help defining specific, and sometimes simple, corrective strategies that would also improve patients' health-related quality of life. This is especially relevant considering that simply improving quality of care (which is not necessarily followed by an increase of satisfaction with care) has not shown to be unequivocally followed by the improvement of health-related quality of life [25]. Altogether, reaching a comprehensive clinical picture recommends combining satisfaction measures with quality of life instruments.

Satisfaction with donation seemed to be composed of three-factors: discrepancies between LKDs' expectancies about donation and their actual experiences; interference of donation on daily activities both before and after donation; and pain and discomfort. These results add to previous doubts on the measurement of LKDs' satisfaction by a single-item [26]. In fact, and as previously observed [8,9,11-15], the majority of our LKDs would donate again and would recommend LKDo despite feeling somewhat dissatisfied. Simply questioning the willingness to donate again might be flawed by obviating the context of the decision to donate. Willingness to donate again might be related to motives scarcely related to satisfaction, such as the absence of alternative donors, or to prevent the donation of younger relatives. Also, recommending donation to others might not exclude dissatisfaction and, as such, its content validity might be compromised. Therefore, it might not be incompatible feeling that LKDo is a recommendable treatment while, at the same time, feeling that some aspects of donation, might be improved.

Another issue about the measurement of satisfaction is the application of generic or specific instruments. Generic instruments include key dimensions of the overall model of satisfaction and might allow comparisons between conditions. However, it is uncertain whether they can capture subtleties of specific conditions. Also, overall satisfaction seems better characterized as a stable assessment rather than as a momentary judgment [27]. Indeed, non-significant changes in overall satisfaction have been observed between predonation and postdonation [28]. Complementing the generic instruments with donation-specific measurement of satisfaction might allow discerning the concrete sources of an eventual worsening of satisfaction, even in LKDs with an acceptable overall satisfaction with life.

Cluster-analysis classified LKDs into two subgroups. LKDs somewhat dissatisfied were characterized by perceiving a higher discrepancy between the information received, and their actual experiences; along with feeling somewhat worse attended both before and after donation.

Discrepancies between patients' expectancies and their actual experiences seem a main component of satisfaction. Previous assessments of LKDs' satisfaction have applied the five-item Satisfaction with Life Scale [28,29]. At least, three items seem to measure the degree of discrepancy between respondent's expectancies and current life circumstances. This content seems quite akin to the factor identified in our study. Indeed, most definitions of satisfaction with care suggest that it is mediated by patients' preferences and prior expectancies [30]. Notably, some authors suggest that dissatisfaction arises with patients' perception of incongruence between their desires and expectancies, and real conditions of care [31].

Previous studies also suggest that LKDs with the highest predonation expectations about personal growth and interpersonal and spiritual benefits may be less aware of these anticipated benefits which, in turn, may increase the possibility of feeling dissatisfied after donation [32]. Our results add to these recommendations by suggesting the importance of assessing donors' expectancies about the degree of medical attention and the discomfort associated with medical procedures. It also suggests that elevated expectancies should be addressed before donation to reduce their potential negative influence on donors' psychosocial outcomes [33]. Predonation discussion between donors, recipients and their healthcare team might allow individualizing the information provided to those donors with unrealistic expectancies (e.g., lower-than-usual discomfort or higher-than-available medical attention). This simple intervention might also help improving the informed consent process and, thus, minimize a possible discrepancy between expectancies and real experiences.

Donors less satisfied perceived that predonation tests were more annoying and caused higher interference on their daily activities. Daily and leisure activities after donation also changed for worse in this subgroup. This factor seems quite similar to the degree of interference of healthcare in the patient's personal sense of self included by others in the definition of satisfaction [34]. Interference on the performance of daily activities has been also reported as a crucial component of satisfaction after medical procedures such as hand surgery [35]. In our center, predonation assessments, and information about the donation process and risks are usually conducted within 2–3 days in different hospital facilities. This protocol might be overwhelming for some donors [16]. Also, a higher percentage of dissatisfied donors were professionally active at donation, which might have contributed to a higher interference in their workdays. More of them suffered economic losses, including sick-leave expenses. Relevant expenses due to donation might disincentive donation [6,36], and almost 50% of the donors claim for additional information about donation financial costs [16]. Both concentrating assessment in nearby medical facilities and further individualization of assessment procedures, might help to improve this aspect of donors' satisfaction [14].

Pain and discomfort expressed by dissatisfied LKDs almost doubled those expressed by LKDs satisfied. Laparoscopic surgical procedures have contributed to reduce these perioperative morbidities and thus to improve donor satisfaction [37]. However, pain and discomfort are still unresolved issues in LKDo, to the point that some suggest that donors should be paid for surgical pain and suffering [38]. According to our results, pain and discomfort influenced donors' satisfaction even several years postdonation. We assessed pain and discomfort retrospectively. Hence, we have assessed the memory of the pain and distress which, as such, might be influenced by other variables not directly related to the actual experience. At least, one study suggests that although LKDs tend to attribute subsequent physical problems to donation, this relationship is not always clear-cut [14]. Preliminary results suggest that addressing psychological factors such as residual ambivalence about donation might reduce poor psychosocial outcomes, including pain and discomfort [39]. In the field of acute and chronic pain, this subjective experience seems to be influenced by catastrophic thoughts. Catastrophizing has been defined as overvaluing the noxious and disabling potential of pain [40]. In our knowledge, the influence of catastrophizing on postdonation pain and discomfort has not been assessed.

A higher proportion of dissatisfied LKDs felt that their hospital discharge had been untimely scheduled. LKDs' expectancies, including discharge scheduling, seem especially amenable to simple predonation interventions. Indeed, if these presumptions were carefully defined, they could be adjusted by educating donors when found unrealistic expectancies (e.g., longer than the reasonable length of hospitalization) or it could help guide the medical setting (e.g., scheduling shorter follow-ups visits). In our center, average length of hospitalization is discussed at the beginning of assessment and throughout the donation process until hospital admission. Discharge might be coordinated with the donors to assure that they feel ready. Cases in which the donor feels unready for discharge, exploration of his/her reasons might help find a solution that fits both the donor and the physician. Our results have improved our donation processes by including the assessment of LKDs' expectancies, along with individualizing the assessment protocol to minimize the interference on donors' activities.

Perception of their recipients' current health status as being low also characterized LKDs that where somewhat dissatisfied. Contrary to our expectations, and previous studies [41,42], differences between clusters were statistically significant but such low that seemed to be clinically non-relevant. To further assess the relevance, its ability to differentiate between clusters was analyzed by ROC curve which showed that donor perception of their recipient's health was unable to differentiate between groups (data not shown). Accordingly, our results suggest that this variable might not be as strongly related to donors' satisfaction as previously suggested. Donors' perception of worsening of their recipients' health has been related to an increased risk of psychological problems [41,42]. However, few studies assess this relationship so far, and several of them assess donors' satisfaction by a single question.

In our study, donors from cluster 1 seemed only slightly dissatisfied with donation. This finding leaves us with a skewed dependent variable with very little variance. To find ways of improvement by focusing on dimensions of dissatisfaction, a tentative cluster-analysis was calculated only in cluster one. Results showed that potentially relevant variables such as postdonation lost wages [43,44] did not differentiate between dissatisfied donors. Variables subgrouping dissatisfied donors included: regret having donated while staying at hospital; feeling that recipient felt in debt with the donor; and the feeling that others did not value the donor more because of donation. The temporal stability of these variables is questionable. Additional research is needed to replicate the factor solution along with defining potential subgroups of dissatisfied donors.

Living kidney donors' satisfaction is not routinely evaluated during the clinical follow-up. Unaddressed LKDs' dissatisfaction may lead to psychosocial distress and might compromise the "do no harm" principle [14]. Detecting dissatisfaction might help to implement prompt and timely supportive interventions. Clarification of the importance of every source of dissatisfaction might guide these interventions by individualizing the therapeutic procedures. Also, an increase in the understanding of sources of dissatisfaction might contribute to improving the informed consent of future donors by emphasizing those aspects that are most relevant to donors.

Limitations: Incomplete data prevented 46 (14%) LKDs from being included in the cluster-analysis. We may not be sure whether the inclusion of these donors would change the clusters' structure.

We did not assess factors such as short and long-term complications, whether the recipient lost his graft or whether kidney function was routinely monitored, all which might determine low levels of LKDs' satisfaction by potentially influencing donors' perception of donation [9].

Our study is retrospective and, thus, susceptible to recall error. However, we did not find differences between clusters in the elapsed time since donation. Accordingly, it might well be that a potential recall error had similarly affected both groups.

Sample size impeded a segmented analysis by time of follow-up. The inclusion of other centers might increase the number of participants to help solve this issue. The cross-sectional design precludes the assessment of the stability of LKDs' satisfaction. Further studies assessing the longitudinal trend of dissatisfaction might help: (i) detecting which donors previously dissatisfied develop a healthy adjustment by applying their own coping resources: Identifying these resources might guide specific interventions for future donors; (ii) uncovering resistant cases in need of specific interventions, indeed, the maintenance of other adverse psychosocial outcomes, such as fear of kidney failure, has been suggested to reflect a resistance to spontaneous adjustment [9]; and (iii) assessing which donors previously satisfied become later dissatisfied, the definition of those factors that worsen satisfaction, if any, might help to implement prevention strategies.

Two-items cross-loaded in two factors. Item #19 (discomfort due to medical tests) showed an expectable high-load in factor 3, but also in factor 2, probably expressing that these discomfort might have interfered on daily activities. It seems necessary to increase its content specificity with a more concrete definition of discomfort. Item #27 (correspondence between the predonation explanations and actual experience) showed a high-load in Factor 1, but also a negative load in Factor 3, suggesting that the expected discomfort did not coincide with what they actually went through. This finding might stress the importance of providing donors with adequate information (e.g., no downplaying of risks and/or discomfort).

Living kidney donors less satisfied believed that hospital discharge was premature and medical care was also lower than expected. We did not assess factors that could influence these discrepancies (e.g., quality of the information received, or donors' degree of understanding that information).

Our factor structure coincides with main components of satisfaction defined by previous studies. We may not, however, assure that our factor solution applies to other populations.

Our participants come from a single center. We do not know if center-specific practices compromise generalization of our results. However, HCB represented 18% of all LKDo in Spain [45] and 39% in Catalonia [46] during this period.

Living kidney donors for pediatric recipients and to SPEP were excluded. It would be interesting to assess satisfaction in these groups.

Sample size might be limited for a retrospective study. However, our 72% response rate was higher than the 46% usually obtained in postal-survey health studies [47].

Conclusion: Donor's satisfaction seems better characterized by three dimensions than by single questions.

Authorship

AM: designed the study, performed the study, collected data, analyzed data and wrote the paper. XT: designed

the study, performed the study, collected data, analyzed data and wrote the paper. DP: designed the study, performed the study and wrote the paper. NA: performed the study, collected data and wrote the paper. JMP: designed the study, performed the study and wrote the paper. EDS-A: designed the study, performed the study and wrote the paper. FO: designed the study, performed the study, and wrote the paper. FD: designed the study, performed the study, and wrote the paper. IR: designed the study, performed the study, collected data, analyzed data and wrote the paper.

Funding

The authors have declared no funding.

Conflict of interest

The authors have declared no conflicts of interest.

Acknowledgements

Our gratitude goes to all the LKDs who participated in this study.

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