Development of a survey to identify barriers to living donation in kidney transplant candidates

Background—Kidney transplantation from living donors, compared with deceased donors, has improved health care outcomes for patients with end-stage renal disease; however, less than 40% of transplants come from living donors. Numerous barriers may impede the identification of, and transplantation from, living donors.
Objective—To develop and validate a survey to identify barriers that transplant candidates may encounter when seeking a living donor for kidney transplantation.
Methods—The survey was developed in 3 phases: item identification by using persons with a stake in the process to identify key components; survey refinement, including assessment of content and face validity; and assessment of test-retest reliability by using the kappa coefficient and percent agreement for each of the scaled response items.
Results—The final survey contained 10 items with a Likert scale response and 5 open-ended questions. Expert nephrologists in the field confirmed face validity and content validity of the survey. The overall kappa coefficient for the scale was 0.76, reflecting excellent agreement, with an overall percent agreement of 88.7%.
Conclusion—We developed a survey to identify barriers that kidney transplant candidates may experience when seeking a living donor, which demonstrated content and face validity as well as reproducibility. This survey can by used by end-stage renal disease programs to identify barriers in candidates seeking a transplant. The results of the survey can be used to develop interventions to overcome such barriers with an ultimate goal of increasing rates of living kidney donation.
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Living donor kidney transplantation improves health care outcomes for patients with end-stage renal disease (ESRD) and reduces health care costs.[1] However, only 35% of kidney transplants in Canada and about 40% in the United States are from a living donor. Although the rates of living kidney donation have grown since the late 1990s, waiting lists for kidney transplantation have also grown as the incidence of ESRD has increased. In Canada, approximately 3000 patients are waiting for a kidney and more than 30 000 patients are living with ESRD[2]; in the United States, almost 80 000 patients are waiting for a kidney and more than half a million live with ESRD.[3] Thus a huge potential exists to improve the rates of kidney transplantation by increasing the rates of living donor kidney transplantation.

The advantages of living donor kidney transplantation are numerous and include superior clinical outcomes for recipients such as lower risk of acute rejection, a greater likelihood of long-term survival, and optimal timing of the transplant.[4,5] Despite these advantages, the low rate of living kidney donation suggests that potential recipients may be experiencing "barriers" to seeking a transplant from a live donor. A limited number of studies have been conducted in this area, and available evidence indicates that recipients' knowledge about transplantation and living donation in particular, is important. Specifically, recipients who support living kidney transplantation are more likely to understand the risks and benefits to recipients and donors,[6] although many recipients are not aware of the potential benefits to the donor and the reasons that donors

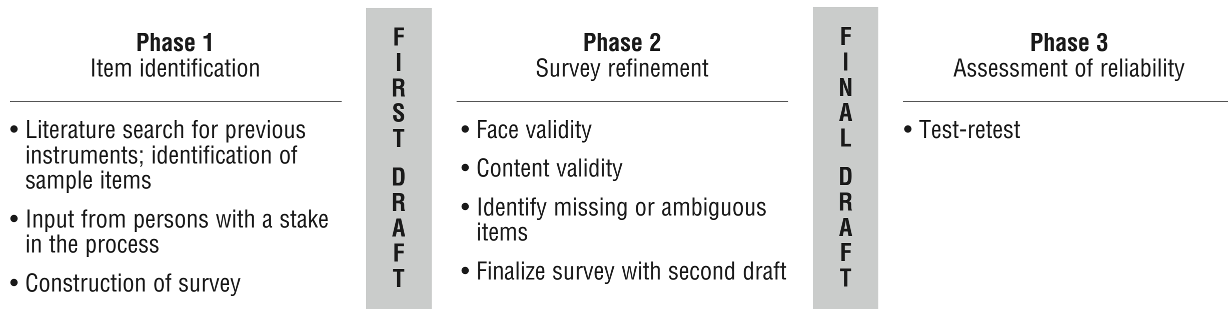

Figure 1 Overview of phases for the development and validation of a survey to assess barriers to living donation in kidney transplant candidates.

donate.[7] The donors in studies in the United States and Korea reported the main reason they donated was to improve the health of the recipient[7,8]; donors also felt proud of their donation and were glad they were able to help.[7,9] Another benefit to the donors included an increased appreciation of life.[7] Recipients' feelings of guilt for needing a transplant or if the graft failed, feeling indebted to the donor, and worrying about financial repercussions for the donor after donation and the donor's suffering have been identified as potential barriers.[6,7,10-14] Other researchers[15] have noted that patients are less willing to pursue living donation when they have concerns about the transplant team's experience. These barriers can be significant enough for a patient to not pursue living donation and can lead to years of waiting for a deceased donor kidney, despite an expressed interest from family members or friends to donate a kidney.[16] Potential donors, in fact, were more likely than patients to initiate conversations about living donation,[17] and some evidence indicates that patients are unlikely to ask family members about becoming potential donors.[7,11,18,19]

Although studies have been conducted in the past, none have comprehensively and concisely evaluated potential barriers to living donation among transplant candidates. The purpose of this study was to develop and validate a survey that could be used to identify potentially modifiable barriers for candidates seeking kidney transplantation. Improved understanding of barriers to living donation among kidney transplant candidates could lead to increased opportunities for living kidney donation, thereby improving recipients' outcomes and decreasing the waiting list for kidney transplantation.

Methods

The Conjoint Medical and Research Ethics Board at the University of Calgary (Alberta, Canada) approved the study protocol. Survey development and validation occurred in 3 distinct phases: item identification and construction, refinement of the first draft of the survey, and testing the reliability of the survey (Figure 1).

Phase 1: Item Identification and Preliminary Development of the Survey

Survey development initially included use of persons with a stake in the process to identify key components to determine why kidney transplant recipients may not seek living donation. Five such people were included from each of the following areas: medical professionals, nursing staff, and hemodialysis patients who were not currently eligible for a kidney transplant. Nephrologists discuss all treatment options for ESRD with their patients at the start of renal replacement therapy, even though the patients are not eligible for transplant at that time. Nephrologists would therefore be able to still identify items that determine why some patients do not seek living donation as a treatment option. All persons with a stake in the process were presented with a form containing 20 sample items gathered from the literature,[6,16,20,21] that were possible reasons kidney transplant candidates may not choose living donation as a treatment option for ESRD. Participants were asked to select items that they felt were barriers to living donation and to indicate other relevant items. Medical professionals and nursing staff were e-mailed the form and a convenience sample of hemodialysis patients were approached (no a priori identification) during their hemodialysis treatment session. Consent of all participants was implied with completion of the form.

Throughout development of the survey, we employed strategies to reduce bias and errors in responding. Specifically, as rating scales are subject to the halo effect (respondents rate all items on the basis of an a priori global impression of the instrument), successive questions were randomly reversed in the positive and negative direction to minimize this possibility. Randomly reversing questions also avoids acquiescence bias, which occurs when the respondent answers all questions in a positive manner. In addition, the final item for the Likert scale was an item to assess "social desirability," also known as a "lie detector." This item was used to help identify those who answer the survey only with the intent of pleasing the

researcher. The item that was used was: I never eat anything I am not supposed to eat.

Phase 2: Instrument Refinement

Face validity, or the extent to which a survey appears to be assessing the desired qualities, and content validity, whether enough items are included to adequately cover each domain,[22] were determined by having 3 nephrologists who were familiar with transplantation and donation independently review the survey to confirm the items chosen.

The next step in refining the instrument consisted of identifying missing or ambiguous items. A convenience sample of 10 adult, English-speaking patients on hemodialysis who were interested in, but deemed not eligible for, a kidney transplant were identified. These patients were chosen as we intended to administer the instrument in the next phase of the study to patients who were eligible for a kidney transplant, thus we did not want to reduce the sample of eligible participants by using them for testing of the survey.

Each consenting participant was read the questions, which allowed the researcher (L.B.) to identify verbal cues that indicated whether a question was unclear or improperly worded. Participants were also asked to answer the qualitative, open-ended questions. Finally, participants were asked for feedback on the clarity, brevity, congruency, and relevance of the survey to the topic.

Phase 3: Testing the Reliability of the Survey

In phase 3, the intraobserver reliability of the survey was assessed by using the test-retest technique with scores generated on 2 separate occasions. The survey was administered to the same 10 people just identified, 1 week after the first review of the survey was completed. The same individuals were used as only minor changes were made to the survey and the number of potential individuals to complete this step was limited.

The test-retest reliability was calculated by using the kappa coefficient, which represents agreement obtained between 2 tests (intrarater or interrater) beyond that which would be expected by chance alone.[23] A kappa coefficient of 1.0 represents perfect agreement, and a value of 0.0 represents no agreement at all. For the purpose of this study, and consistent with related studies, a kappa coefficient greater than 0.75 was considered to indicate excellent reproducibility.

To calculate the kappa coefficient, the 5 Likert scale response categories were collapsed: strongly disagree, disagree, and neutral were combined into one category, whereas agree and strongly agree formed the second category. The rationale for collapsing the response categories was that the responses were viewed as qualitative information, and by collapsing the scale and having fewer categories, inferences about decision making in terms of distinct levels of agreement-disagreement are facilitated.[24] A 2-by-2 contingency table was then constructed for each item.

Results

Phase 1: Item Identification for the Instrument

Twelve of 15 persons approached (80%) completed the form. A list of items identified by participants as potential barriers to living donation was compiled. We achieved "saturation"; at the end of the compilation, no new items were identified. Duplicate items were removed, and items were coded by using inductive codes, as opposed to defining codes a priori. Using Spradley's method of transcribing and summarizing free-text data, we divided the statements into meaningful codes.[25,26] We identified 12 codes, and these codes were then categorized into 4 categories: lack of knowledge, lack of opportunity, fear for the donor, and feelings of guilt. The semantic relationship between the codes, categories, and outcome (failure to identify a living donor) is shown in Figure 2.

At least 2 items from each category were selected to ensure adequate representation in the final survey. The items were ranked according to frequency, and this order was used to determine the importance of each item; the top-rated items were selected to form the survey blueprint (Table 1). The blueprint was constructed to provide content validity and was used as the basis for developing the survey and aided in assessing whether each category was adequately represented in the survey. Given the frequency of items addressing knowledge of living donation, this category ended up with 5 items on the final survey.

Each item was then assessed for its suitability as a statement with a Likert scale response by 2 researchers (L.B., K.M.) experienced in survey development. Using a Likert scale for certain items, despite collapsing the categories after, provides participants with a range of responses to reflect their intensity in their answer. Items that were highly ranked but not suitable to be answered with a Likert scale were included as open-ended questions. Ten items were selected for the Likert scale responses, and 5 open-ended questions were included for the domains of opportunity, guilt, and fear. Basic demographics, in the form of 5 questions at the end of the survey, were also included.

Phase 2: Survey Refinement

To assess face and content validity, 10 nephrologists who were familiar with donation and transplantation independently reviewed the survey and confirmed that the items chosen were relevant to the outcome with sufficient items representing each domain. Also in this phase, the open-ended responses from the participants were reviewed to ensure that no new ideas emerged that were necessary to include in the final

Figure 2 Semantic relationship between codes, categories, and outcome.

survey. Minor changes were made on the basis of feedback from patients, including a restructuring of the order of the items to improve flow as well as rephrasing of 2 items. Three medical experts in the area of transplantation then reviewed the revised survey to ensure that the changes did not alter the face or content validity.

Phase 3: Testing the Reliability of the Survey

With respect to test-retest, the overall kappa coefficient for the scale was 0.76, reflecting excellent or substantial agreement,[23] with an overall agreement of 88.7% (Table 2). The percent agreement was calculated in addition to the kappa, given limitations in the validity of the kappa if results are predominantly in 1 cell or if there are 0 cells. As this was the case for some of the items in our survey, we chose to report and consider both percent agreement and kappa coefficient when evaluating whether an item was reliable.

Table 1 Survey blueprint to determine content validity

Domain	Barrier
Knowledge	Not knowing enough about living donation Not knowing availability of living donation Not knowing how to ask for a kidney Not knowing that living donor kidneys have better outcomes Not knowing how to contact living donation program
Opportunity	No suitable family members No suitable friends
Fear	Fear for health implications for donor Fear of inconveniencing donor Fear of rejecting kidney
Guilt	Guilt about needing a transplant Guilt about asking for a transplant

Discussion

Using a 3-phase approach, we developed a survey to identify barriers to seeking living kidney donation in kidney transplant candidates that demonstrated face and content validity with excellent overall intraobserver reliability. Importantly, we were able to capture a comprehensive group of items that included 10 scaled-response items and 5 open-ended questions. The qualitative aspects of this survey will be valuable in identifying barriers to kidney transplant candidates' seeking living kidney donation that may vary between transplant sites.

A limited number of instruments have been developed to address barriers to living donation in kidney transplant candidates.[6,27] Gourlay et al[27] developed and validated an instrument that addressed recipients' personal characteristics as well as knowledge and beliefs about living donation.[27] Their instrument included barriers similar to those identified in our survey, thus supporting the robustness of the items within our survey.

In addition to the scaled response items within our survey, we also elected to include 5 open-ended questions, a unique component of our instrument compared with the survey by Gourlay et al.[27] We did so to ensure that the responses obtained from the survey would be of sufficient detail to guide the design of an

Table 2 Kappa coefficient and percent agreement of individual items

Item	Kappa coefficient[a]	% agreement
A family member can donate a kidney to a patient with kidney disease	—	100
A friend can donate a kidney to a patient with kidney disease	—	90
Kidneys from living donors do NOT last longer than kidneys from deceased donors	0.53	78[b]
The sooner I get a kidney transplant, the better off I will be	1.00	100[b]
Patients who have a living donor wait less time for a kidney than those without	0.55	80
I understand that living donation means that a kidney is donated by a living person	0.44	70
Individuals who donate a kidney are more likely to end up with kidney failure themselves	—	100
Individuals who donate a kidney are more likely to end up with high blood pressure	—	100
I could tell someone who is interested in donating a kidney how to contact the living donor program	0.44	70
I know how I would ask someone to donate their kidney	1.00	100

[a] Dash indicates unable to calculate because 0 cells were present.
[b] One answer missing.

education intervention for barriers to living donation. Incorporating qualitative research into survey design, as represented by open-ended questions, helps the researcher "understand the social world from the viewpoint of the respondent, through their detailed descriptions."[28] Gourlay et al reported that potential recipients feel guilty about needing a transplant and that donors experience long-term health consequences; both of these domains were explored further in our survey by using open-ended questions around the domains of fear (for the recipient and donor) and guilt (about needing and asking for a transplant).

Zimmerman et al[6] developed a mail survey that assessed participants' sociodemographic characteristics, perception of dialysis, and perception of deceased and living kidney transplantation among patients being assessed for living donor kidney transplantation as well as those on the waiting list for a deceased donor transplant. The authors reported lack of knowledge and inability to identify a donor as potentially modifiable barriers, similar to the barriers identified within our study. Although their survey was comprehensive in content, it was not validated and the majority of their questions were scaled responses with no opportunity for respondents to expand on specific domains.

Limitations

First, although the sample size may be considered small, no formal consensus has been reported as to how many patients are needed to validate the content and to test the reliability of an instrument. However, it has been shown that 10 subjects, with 2 separate measurements, will yield a correlation of more than 0.8, with 80% power.[29] Further, the purpose of this study was to develop a survey that would enable qualitative assessment of barriers in kidney transplant candidates with no intent to measure change over time or differences between 2 groups. We also did not want to draw from the same population that we were intending to administer this survey to in the next phase of our research. Because the patients who were used were medically ineligible for transplant, as opposed to not being interested in pursuing transplant, we felt that they were still an appropriate sample in which to test our instrument. A second limitation of our survey was that it was not possible to evaluate for construct validity because of the absence of a reference standard for comparison. We were, however, able to confirm both face and content validity, confirming that the survey is able to measure what it intends to measure; that is, the opinions of kidney transplant candidates on why patients do not choose living donation. Third, we used the kappa coefficient as a measure of the test-retest reliability of the survey, despite the acknowledged limitations of this measure.[23,30,31] In instances when response distribution is favored by one category, the kappa coefficient is greatly reduced. For example, if almost all respondents agreed between the 2 items, a smaller kappa would be produced than if half of the respondents disagreed and the other half agreed (on both occasions). We avoided some of these limitations of the kappa coefficient by examining it in conjunction with the percent agreement, which does not take into account the agreement occurring due to chance alone. Ninety percent agreement represents excellent reproducibility, and when interpreted with the kappa coefficient, agreement is substantial with all of the items.[31]

Summary

We developed a survey (see Appendix) that has content and face validity as well as excellent overall test-retest reliability to assess barriers to living donation in kidney transplant candidates. This survey can be applied to eligible kidney transplant candidates to identify barriers that may affect their ability and willingness to seek and identify a living donor. Future educational interventions aimed at overcoming these barriers, similar to those conducted in related settings,[32,33] may increase the rate of living kidney donation.

Survey about living kidney donation

- **What is living kidney donation?** Living kidney donation is a surgical procedure in which a healthy kidney is transplanted from a living person into a person with advanced kidney disease. Living kidney donation is an alternative treatment to dialysis for patients with end-stage kidney disease. Living donor kidneys for transplantation can be donated by family members or friends of the person with kidney disease.
- **What is the purpose of this survey?** This survey is being given to patients to find out ways to increase the organ donation rates. Your responses in this questionnaire will not influence your treatment. Responses will be used for two purposes:

1. **Quality assurance.** This tells us if we are doing the best we can for our patients.
2. **Research.** This will help us understand how to do better for our patients.

- **Can I discuss these questions with someone?** Yes. However, it is important that you give us your opinion, not that of another person. It is also important that you tell us how you really feel about these statements and not what you think we would like to read.

Instructions for completing the questionnaire:

To answer some of the questions in this survey you should indicate your degree of agreement or disagreement with each statement by **circling the number corresponding to your choice.** The choice of "Neutral" (number 3) should be made if you do not know the answer to the question, or you do not have an opinion. For example:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The Calgary Flames are the BEST hockey team in Alberta	1	2	3	4	5

Calgarians would probably circle 4 or 5 whereas Edmonton fans would probably circle 1 or 2. Toronto fans might circle 3.

For questions that require a written answer, respond with as much detail and clarity as you feel comfortable sharing. Your opinion is **valid and important**.

It is important to realize that there is no "right" or "wrong" answer as we are asking for YOUR OWN PERSONAL OPINION. Your responses will be looked anonymously and only once all questionnaires have been completed.

If you do not wish to participate in this research study, please check the following box ❑

For each of the following statements, please indicate your degree of agreement or disagreement:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A family member can donate a kidney to a patient with kidney disease in Calgary	1	2	3	4	5
A friend can donate a kidney to a patient with kidney disease in Calgary	1	2	3	4	5
Kidneys from living donors do NOT last longer than kidneys from deceased donors	1	2	3	4	5
The sooner I get a kidney transplant, the better off I will be	1	2	3	4	5
Patients who have a living donor wait less time for a kidney than those without	1	2	3	4	5
I understand that living donation means that a kidney is donated by a living person	1	2	3	4	5
Individuals who donate a kidney are more likely to end up with kidney failure themselves	1	2	3	4	5
Individuals who donate a kidney are more likely to end up with high blood pressure	1	2	3	4	5
I could tell someone who is interested in donating a kidney how to contact the living donor program	1	2	3	4	5
I never eat anything that I am not supposed to	1	2	3	4	5
I know how I would ask someone to donate their kidney	1	2	3	4	5

Continued

Appendix Southern Alberta renal program: survey about living kidney donation.

Please answer the following questions in the space provided:

Do you have any family or friends who could donate a kidney to you? In no, please explain why not.

Do you feel guilty about needing a kidney transplant? If yes, please explain why.

Do you feel guilty about asking someone to donate their kidney to you? If yes, please explain why.

What do you fear most for YOURSELF (the recipient) about kidney transplantation, both at the time of the transplant and in the future following transplant?

What do you fear most for the DONOR about kidney transplantation, both at the time of the transplant and in the future following transplant?

Please circle either yes or no for each of the following questions. You may write in comments below.

I have DISCUSSED living kidney donation with my family and/or friends	Yes	No
If yes, I have IDENTIFIED a living kidney donor	Yes	No

Additional comments or feedback (please write in space below):

And finally…
Please indicate which of the following best describes you (please circle the appropriate term or interval):

I am	Male	Female		
I am aged	<20	20 - 40	41 - 60	>60
I am	Married/Significant other	Single	Widowed	Separated/Divorced
I am	Presently employed	Presently unemployed	Retired	Student
I am currently on dialysis If yes, for how long	Yes Less than 6 months	No More than 6 months – less than 1 year	Between 1 – 4 years	Greater than 4 years

THANK YOU FOR YOUR TIME AND YOUR VALUABLE CONTRIBUTION

Appendix *Continued*

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