Published in final edited form as:

Clin Transplant. 2011 ; 25(5): 786–793. doi:10.1111/j.1399-0012.2010.01342.x.

Accepting a Donor Kidney: an Evaluation of Patients' and Transplant Surgeons' Priorities

Daniel A. Solomon¹, Nicole Rabidou¹, Sanjay Kulkarni², Richard Formica¹, and Liana Fraenkel^{1,3}

¹Department of Medicine, Yale University School of Medicine, New Haven, CT

²Section of Organ Transplantation & Immunology, Yale University School of Medicine, New Haven, CT

³Clinical Epidemiology Research Center, VA Connecticut Healthcare System, West Haven, CT

Abstract

Background—Despite a trend towards patient autonomy in clinical practice, the decision whether or not to accept a kidney for transplantation is made predominantly by the transplant surgeon. The purpose of this study is to examine how patients and surgeons prioritize relevant factors when deciding to accept or decline an available kidney.

Methods—We elicited patient and surgeon rankings for a list of factors involved in the decision using a validated computer survey. We computed the relative importance of each factor and examined associations between patient characteristics and priorities using Spearman's correlation coefficient and the Mann Whitney U test for continuous and categorical variables, respectively.

Results—Patients placed the greatest value on kidney quality and predictors of transplant outcome. Patients who were on the waiting list longer gave less importance to kidney quality and function. Surgeons placed the greatest value on kidney quality, difficulty for the patient to be matched to a kidney, and the age of the donor.

Conclusion—The results of this study suggest that decision support tools can be used to improve understanding of patient priorities in the decision to accept a donor kidney.

Keywords

Kidney transplant; Patient preferences; Communication

Respecting individual preferences and autonomy is paramount in the current culture of medicine, and involving patients in medical decisions has become an important goal of providing ethical medical care (1–6). Patient participation drives personalized medical care, and ideally results in increased patient knowledge, satisfaction, adherence to treatment, and improved outcomes (7–9). While shared decision-making has been widely adopted, the

decision whether or not to accept a kidney when it becomes available to a patient awaiting transplant is made predominantly by the transplant surgeon.

When a patient is offered a kidney for transplantation there are two medically viable options: to accept the kidney or to decline the kidney and remain on dialysis. Accepting the kidney offers tremendous potential benefits including better long-term survival (10), better quality of life, and lower cost (11). There are, however, two elements of the decision that validate declining the kidney as a reasonable alternative: change in patient characteristics over time, and heterogeneity of donor kidneys. Changes in health or personal circumstances might cause the same person to make a different decision in different contexts (12). For example, as patients adapt to dialysis over time they may evaluate the incremental risks and benefits associated with transplantation differently from when they initiated dialysis treatment.

The second element that validates the choice to decline a kidney is the heterogeneity of donor kidneys. While surgeons only offer kidneys that are of 'acceptable' quality, there remains a broad spectrum of kidneys with regards to baseline function, risk of contracting a disease, likelihood of rejection, and expected graft survival time (13). In addition, a zero-antigen mismatched kidney has a lower risk of rejection and greater overall graft survival (14, 15). Thus, a patient may choose to minimize the risk of graft rejection and maximize the chance of graft survival by holding out for a kidney that is a closer match and of higher quality. Owing to the significant impact the decision will have on the patient's life, it is important for patients to consider the choices through the lens of their personal values, perspective and context.

One could argue that because the medical factors doctors consider are detailed, nuanced and embedded in uncertainty, patients should not be involved in the decision. Indeed, it may be unreasonable to expect patients to make a decision involving complex and unfamiliar information. Given the need for medical expertise, we support a model of shared decision-making where both parties contribute information and ideas, and both parties agree on the final choice (2). The challenging role of the physician would be to guide patients through the relevant medical details, and encourage patients to consider personal factors that might contribute to a better-informed decision.

Organ allocation models and mathematical accept/reject decision rules have previously been developed (16–18); only one accounted for theoretical patient preferences for health outcomes (18). However, actual patient opinions, values, beliefs or perspectives about the decision making process have never been explicitly examined. In order to best engage patients into the decision-making process, it is critical to understand which factors patients consider important.

Methods

Phase I: Generating the list of factors

To generate a comprehensive list of factors that patients might consider when deciding whether or not to accept a kidney we sent letters to 40 subjects from the Yale-New Haven Transplant Center transplant list informing them of the study and offering them the choice to

opt-out of a telephone interview. Patients were purposely sampled to get input from male and female subjects, and both pre-transplant and post-transplant subjects. Age and race data were not available. Patients were contacted by telephone within one week after receiving the letters. Three attempts were made to contact each patient. Once contacted, patients were given the following prompt: Imagine a kidney has become available. Assuming it is of acceptable quality and acceptable match, what factors – *either about the kidney or about yourself* – would be important to you when deciding whether or not to accept the kidney? Additional prompts were used as needed to enable subjects to express their thoughts and opinions. Interviews were conducted until thematic saturation was reached.

The data gathered from patient subjects were added to a checklist used by Yale transplant surgeons. Medical jargon was modified, and technical categories were combined in order to develop a list that was comprehensive and easily interpreted by doctors and patients alike. The list was reviewed by four people with complementary expertise: a patient-oriented researcher with expertise in medical decision making (LF), a transplant surgeon (SK), a transplant nephrologist (RF), and the investigator who conducted the qualitative surveys with patients (DS). The list, provided in Table 1, was pilot tested for comprehension. An analogous list of factors for the surgeons was compiled by altering the language appropriately, and by removing the factor 'How strongly my transplant surgeon feels I should accept the kidney.'

Phase II: Quantifying the importance of each factor

Subjects—Patient subjects were recruited from the active transplant waiting list for Yale-New Haven Hospital (compiled May 2009). Patients who had already received a transplant were excluded from the study to avoid the hindsight knowledge of potential success or complications. Non-English speakers and subjects with impaired hearing were also excluded.

A letter describing the study was sent to all patients with the option to opt-out of the study. Patients were contacted by telephone within one week after receiving the letters. Three attempts were made to contact patients on the list. For subjects who agreed to participate, but could not complete the survey at the given time, an appointment to complete the survey was made.

Surgeon subjects were identified through the American Society of Transplant Surgeons. Three attempts were made to contact surgeons on the list. For surgeons who agreed to participate, but could not complete the survey at the given time, an appointment to complete the survey was made.

Data Collection—The survey consisted of a Maximum Differences Scaling (MDS) task and an assessment of demographic and clinical characteristics. MDS is a task that enables subjects to assign a value to a set of factors relevant to a specific decision. Based on random utility theory, MDS was developed as an alternative to rating and ranking tasks by Jordan Louviere in 1987 as an extension of Thurstone's law of comparative judgment (19). MDS is able to effectively discriminate between ratings of different factors involved in complex decisions (20).

The task prompts subjects to choose the best item from a series of sets containing four items from a master list (see Figure 1). Because the MDS task does not ask subjects to rate any one factor using numbers or a rating scale, there is no concern for scale-related bias. MDS was used because it simplifies the task for the subject, it is well suited to phone interviews and, unlike ranking tasks, is able to incorporate numerous factors.

The survey was administered in one session, lasting between 10 and 35 minutes for patients and between 8 and 15 minutes for surgeons. After pilot testing, the survey was reduced from 18 to 14 sets for patients due to subject fatigue. No incentive was offered to participants.

After completing the MDS survey, the following patient characteristics were recorded: age, gender, race, employment, education, general health status (on a 5 point scale ranging from excellent to poor), time on waiting list (**in years**) and time on dialysis (**in years**). For surgeons, the following characteristics were recorded: age, gender, race, how long they have been practicing, and whether they work in an academic or private setting.

Statistical Analysis—Descriptive statistics of the distribution of patient and surgeon characteristics were computed. The rank order of attributes and the mean ($\pm$ SD) relative importance of each factor were generated using Hierarchical Bayes (HB) analysis (Sawtooth Software© HB module). HB modeling can derive stable scores at the individual level even though each respondent evaluates a fraction of all possible subsets of items. In HB modeling the averages are used to update the individual utilities in a number of iterations until estimates are stabilized. After this convergence, the cycle is run a few thousand more times and the estimates of each iteration are saved and averaged (21, 22). The scores were rescaled to sum to 100 to facilitate interpretation.

We examined associations between subject characteristics and relative importance ratings for the five top ranked factors. The independent variables examined were: age, education (college education versus no college education), race (white versus non-white), gender, self-reported overall health status (excellent/very good versus good/fair/poor), and waiting time. Finally, the factor 'How strongly my transplant surgeon feels you should accept the kidney' was removed from the analysis and the raw data were rescaled in order to compare the importance of the top five variables for patients and surgeons.

This protocol was approved by the Yale Human Investigation Committee.

Results

Patients

Patient characteristics—A total of 337 patients were contacted by mail. Four patients opted out before they were contacted for the study. 141 patients could not be reached to complete the survey; 70 patients declined to participate; 7 patients had already been transplanted; 11 patients were excluded for poor comprehension. A total of 104 patients participated in the study.

Patients in the study ranged from age 22 to 79 with a mean ($\pm$ SD) of 55.2 ± 12.6 , mean time on dialysis ($\pm$ SD) was 3.27 ± 4.25 years, and mean time on the waiting list was 2.61 ± 2.60 years. Further details regarding patient characteristics are provided in Table 2.

Relative importance of factors—Patients' importance scores, ranked from most to least important, are provided in Table 3. Overall kidney quality was the most important to patients, followed by the function of the kidney at time of death, and the proximity of match. The surgeon's opinion and the risk of contracting a disease both play a significant role in patients' decision making. Patients gave very little importance to the smoking and drinking habits of the donor. Although it was raised as a potential factor in phase I, the donor's race/ethnicity was of no importance to patients.

Associations between subject characteristics and relative importance scores

—No associations were found between age, ethnicity, education, gender or health status, and the relative importance of the different factors. The amount of time patients had been on the waiting list was inversely related to the relative importance of the *quality of the donor kidney* ($r=-0.30$, $p=0.002$), and *function of the donor kidney* (-0.31 , $p=0.002$). These associations persisted when demographic factors (age, gender, education, ethnicity, health status) were included in the model (Table 4).

Surgeons

Surgeon characteristics—A total of 176 surgeons were called, 110 could not be reached, and 4 refused to participate in the study. A total of 62 surgeons participated in the study. The mean age ($\pm$ SD) of the surgeons was 43.19 ± 6.8 , and they had been practicing for a mean ($\pm$ SD) of 10.0 ± 7.5 years. Fifty-nine (95.1%) were male, 44 (71.0%) were White, 2 (3.2%) were Black, and 11 (17.7%) were Asian. Fifty-one (82.3%) worked in an academic setting.

Relative importance of factors—Surgeons' importance scores are provided in Table 5. Surgeons were most concerned with overall kidney quality and baseline function, how difficult it is for the patient to find a match (i.e. whether or not the patient is sensitized), and the age of the donor. Of note, the risk of contracting a disease was very important to surgeons and drug use was the only donor habit they found important.

A comparison between the importance scores of the top five factors for patients and surgeons is depicted in Table 6. The patient and surgeon rankings were strikingly similar, sharing five of the first seven factors in common, and seven of the last eight. Both patients and surgeons thought *kidney quality* was most important, and gave statistically comparable importance to that factor ($p=0.70$). Patients and surgeons gave similarly high value to the risk of contracting a disease from the donor kidney ($p=0.69$). Neither patients nor surgeons found the race of the donor, or the drinking or smoking habits of the donor important.

There were, however, a few differences. Surgeons gave greater importance to the *age of the donor* ($p<0.0001$) and how difficult it is for a patient to be matched to a kidney (i.e. whether or not the patient is sensitized) ($p<0.0001$), whereas patients gave more importance to the function of the donor kidney at the time of death ($p<0.0001$), *how closely you are matched*

to the donor ($p<0.0001$) and how long the kidney is expected to last ($p=0.001$). These associations remained significant when retested using non-parametric statistics (Mann Whitney U test).

Discussion

In this pilot study, we used MDS to measure the different factors patients and surgeons consider when deciding whether or not to accept a kidney for transplantation. This is the first study, to our knowledge, that explores the patient's perspective of this unique decision.

Patients were most concerned with kidney quality and factors that affect transplant outcome or graft survival. Our data also show that the surgeon's opinion was very important to patients in general. Patient demographics were not associated with the relative importance assigned to specific factors; however, **a greater number of years** on the waiting list was associated with less importance being assigned to donor quality and function. Furthermore, we found that surgeons value similar factors to patients, with kidney quality being the most important.

One aim of the present study was to examine associations between patient characteristics and the importance of different factors. Previous studies of patient perspectives of treatment decisions have shown variation in preferences based on age, socioeconomic status and education (23). One prior study on disparity of access to kidney transplantation found that patients' treatment preferences and outcome expectations differed by race, with Black patients significantly less likely than White patients to want a transplant (24).

We found no association between demographic characteristics and how patients ranked any of the factors. This suggests that the survey design, format and length were equally accessible to subjects regardless of their demographic characteristics or level of education, which supports the validity of this study, and reinforces the concept that MDS can be used effectively for investigational or educational purposes (20). Furthermore, while we are sensitive to the importance of individual patient variability, there were no conflicting preferences of different patient subgroups. Thus, a common approach to care and education can be used for all patients facing kidney transplantation.

A greater number of years on the waiting time was independently associated with decreased importance of donor kidney quality and function: the longer patients were waiting, the less they cared about the quality of the kidney they receive. Physical and psychological quality of life have been shown to decline over time on dialysis (25). Patients likely tire of dialysis, the waiting process, and the decreased quality of life, and thus favor the risks of transplantation with a lower quality kidney.

Based on Organ Procurement and Transplantation Network data as of March 3, 2010, the mean age of patients willing to accept extended criteria donor (ECD) kidneys is 56.5, whereas the mean age of patients unwilling to accept an ECD kidney is 48.3. Given that older patients constitute the majority of candidates on the extended-criteria donor list (26), it is interesting to note that increased age was not associated with a decreased importance of kidney quality in our study. Perhaps this discrepancy was not elucidated in our study because

older patients make the decision to list for an ECD kidney at the time of initial evaluation for kidney transplantation. The reasoning supporting this decision is an effort to balance the trade off of a lesser quality kidney against the benefit of a shorter waiting time. However once listed, when a kidney offer arises, the patient priority is to receive the best quality kidney from the available pool. Finally, it is further possible that we did not have a large enough pool of older patients in order to illustrate this association.

It is worth reemphasizing the significant overlap between the factors the surgeons and patients considered important. The notion that doctors and patients seem to consider the same types of factors important is encouraging because it indicates that there is common ground on which to build educational materials such as decision aids to streamline communication.

It is particularly interesting to note that both patients and surgeons are very concerned with the risk of contracting a disease from the donor kidney, even though, with current screening methods, the risk is extremely low. Estimates, based on recent data, for contracting a disease from a donor kidney range from low risk at 1:315,000 to high risk at 1:10,000 (27). Therefore, our finding is likely explained by the “affect heuristic” which predicts that people estimate risks based on emotional reactions rather than cognitive appraisal of probabilities (28). Furthermore, studies from the core decision-making literature demonstrate that increased perception of volition, defined as ‘command over exposure to risk,’ is associated with increased perception of risk (29, 30). When armed with the responsibility of choosing whether to accept or decline a donor kidney, both patients and surgeons overvalue the risk of contracting a disease as a contributing factor.

Although patients and surgeons significantly overlap in their priorities, there were several noteworthy differences. First, transplant surgeons are more concerned about the age of the donor. It has been well established that kidneys from donors greater than 56 years old have a significantly decreased graft survival at 1 and 2 years post transplant. Because this is likely due to decreased functional reserve at the time of transplant, increased donor age is a predictor for decreased graft survival (15, 31, 32). While surgeons are familiar with the current literature on importance of donor age, patients might have attached less importance because they did not view age of donor as a marker of quality.

Another distinction is that patients valued *how closely you are matched to the donor* greater than surgeons. This discrepancy likely indicates patients' belief that proximity of match is a predictor of transplant outcome or risk of rejection. While there is a substantial graft survival benefit for zero-antigen and one-antigen mismatched kidneys (14), there is only a minimal survival difference associated with a small change in proximity of match thereafter. One study showed that mean graft survival of 1–4 antigen mismatch (9.6 years) was only slightly greater than mean survival of 5–6 antigen mismatch (8.6 years) (15). Matching at the DR locus is also associated with improved graft survival, and while it may influence organ acceptance from a surgeon's perspective, it is not well understood in the patient population (33). Surgeons would likely prefer a fully matched transplant, but their understanding of the overall impact of limited matching resulted in a less emphasis on matching than found in the

patient population. These differences between patients and surgeons point to important areas for further patient education.

Despite the use of a robust measure of preferences, there are several limitations to our study. As in previous research involving physicians, the participation rate was 35%, thereby possibly limiting the generalizability of the surgeons' opinions. In addition, while we are able to recruit over 100 patients, they are all from the same geographic area which may also limit generalizability. We did not collect information on patients' blood types and therefore cannot report whether this variable had an effect on their priorities. Our data were not stratified to the recipient population wishing to accept ECD kidneys alone; however, the finding that quality played a major role was not dependent on age, which one would expect if those wishing ECD kidneys viewed quality as less important. In addition, though ECD kidneys do have a higher graft failure rate than standard criteria donor kidneys, within ECD kidneys there is a large amount of variability in quality. Thus, the differing donor quality indices within ECD results in a reasonable extension of our findings.

Conclusion

Our study shows that patients awaiting transplant highly value the quality and function of the donor kidney, the proximity of match, and the opinion of their transplant surgeon, and these patient preferences did not differ based on socio-demographic characteristics. Patients did not value the age of the donor or the difficulty of finding a match as much as surgeons. From a clinical perspective, these results will help transplant physicians ensure that patients on the waiting list understand the implications of the latter two characteristics when being informed of a potential donor. In addition, given that patients' priorities did not vary by sociodemographic features, our results suggest that it should be possible to develop a standardized decision aid that can be introduced to patients upon placement on the transplant waiting list. The objective of this decision support tool would be to ensure that all patients are provided with 1) complete and standardized information, 2) the support to ensure that patients understand the spectrum of factors that surgeons consider when formulating their recommendation, and 3) a mechanism to optimize communication with their surgeon. Utilization of such a tool would help prepare patients to make the best possible decision when they are ultimately presented with this difficult choice.

Acknowledgments

Funding sources: Dr. Fraenkel is supported by K23 AR048826. This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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Considering only these 4 factors, which do you feel is the Most Important in deciding whether or not to accept the kidney.

	Most Important
How closely matched I am with the donor	☐
The age of the donor	☐
How much the donor weighed	☐
How long I would have to wait for another kidney	☐

Figure 1.
Example of MDS

Table 1

Final list of factors for patients

The age of the donor
How difficult it is for you to be matched to a kidney (i.e. whether or not you are sensitized)
How much the donor weighed
How closely matched you are to the donor
How the donor died
The amount of time the kidney is outside the body before your transplant surgery
The amount of time it would take for the kidney to start working in your body
The overall quality of the kidney
The function of the donor kidney at the time of death
Whether the donor smoked cigarettes
Whether the donor drank excessive alcohol
Whether the donor used drugs
The race or ethnicity of the donor
The general health of the donor
The risk of contracting a disease from the donor kidney
How well you are able to tolerate dialysis
The burden that you feel dialysis puts on your family or your caregivers
How healthy you feel in general when the kidney becomes available
The results of your most recent blood tests
How strongly your transplant surgeon feels that you should accept the kidney
Whether or not your family thinks you should accept the kidney
How long you have already been waiting on the waiting list
How long you would have to wait for another kidney if you pass on this one
How long the kidney is expected to last
How old you are

Table 2

Subjects' Characteristics

Characteristic	N (Total=104)
Age (mean $\pm$ SD)	55.2 $\pm$ 12.61
Male (%)	58 (56)
Race (%)	
White	68 (65.4)
Black	26 (25)
Hispanic	10 (9.6)
College Graduate (%)	41 (39.4)
Currently employed (%)	41 (39.4)
Perceived Health (%)	
Excellent/Very Good	44 (42.3)

Table 3

Patients' Relative Importance Scores

Rank	Factor	Importance Score (mean $\pm$ SD)*
1	The overall quality of the kidney	9.83 $\pm$ 0.77
2	The function of the donor kidney at the time of death	9.27 $\pm$ 1.04
3	How closely matched you are to the donor	8.87 $\pm$ 1.36
4	How strongly your transplant surgeon feels that you should take the kidney	7.71 $\pm$ 2.77
5	How long the kidney is expected to last	7.64 $\pm$ 2.04
6	The risk of contracting a disease from the donor kidney	7.49 $\pm$ 2.56
7	The general health of the donor	6.80 $\pm$ 2.17
8	How long you would have to wait for another kidney if you pass on this one	5.35 $\pm$ 2.61
9	Your ability to tolerate dialysis	4.66 $\pm$ 3.05
10	How difficult it is for you to be matched to a kidney	4.43 $\pm$ 3.11
11	How healthy you currently feel in general	4.29 $\pm$ 2.68
12	Whether the donor used drugs	4.03 $\pm$ 3.24
13	The amount of time the kidney is outside the body before your transplant surgery	3.62 $\pm$ 2.04
14	The amount of time it would take the kidney to start working in your body	3.09 $\pm$ 2.22
15	How long you have already been waiting on the waiting list	2.98 $\pm$ 2.44
16	The age of the donor	2.86 $\pm$ 2.37
17	How the donor died	1.62 $\pm$ 1.92
18	The burden you feel dialysis puts on your family or caregivers	1.54 $\pm$ 2.40
19	Whether the donor drank excessive alcohol	1.24 $\pm$ 2.07
20	The results of your most recent blood tests	0.81 $\pm$ 0.91
21	Whether the donor smoked cigarettes	0.63 $\pm$ 1.36
22	How old you are	0.59 $\pm$ 0.92
23	Whether or not your family thinks you should accept the kidney	0.44 $\pm$ 0.99
24	How much the donor weighed	0.23 $\pm$ 0.46
25	The race or ethnicity of the donor	0.00 $\pm$ 0.00

* The importance score is a relative value score that compares the importance of each factor *relative* to all the others. The total value of importance is set as a constant at 100, thus all scores will sum to 100. The relative importance scores are measures of how important each factor is in the context of all factors.

Table 4

Association between Importance of Donor Kidney Quality and Function and Waiting time.

Factor	Standardized beta estimate*	P value
The overall quality of the kidney	−0.29	0.007
The function of the donor kidney at the time of death	−0.26	0.01

Model contains factor plus age, gender, education, ethnicity and health status.

Table 5

Surgeons' Relative Importance Scores

Rank	Factor	Importance Score (mean $\pm$ SD)*
1	The overall quality of the kidney	10.05 $\pm$ 0.39
2	How difficult it is for the patient to be matched to a kidney	9.07 $\pm$ 1.48
3	The function of the donor kidney at the time of death	8.91 $\pm$ 1.29
4	The age of the donor	8.47 $\pm$ 1.37
5	The risk of contracting a disease from the donor kidney	7.71 $\pm$ 2.84
6	How long the kidney is expected to last	7.29 $\pm$ 2.05
7	The general health of the donor	7.14 $\pm$ 2.46
8	The patient's current general health	6.87 $\pm$ 2.18
9	Cold ischemic time	6.14 $\pm$ 2.88
10	How long the patient would have to wait for another kidney if he/she passes on this one	5.40 $\pm$ 2.54
11	Patient's ability to tolerate dialysis	4.25 $\pm$ 2.73
12	Whether the donor used drugs	3.44 $\pm$ 3.26
13	How long the patient has already been waiting on the waiting list	3.24 $\pm$ 2.27
14	How the donor died	3.09 $\pm$ 1.95
15	How closely matched the patient is to the donor	2.16 $\pm$ 2.17
16	The age of the patient	2.12 $\pm$ 1.11
17	Delayed graft function	1.76 $\pm$ 1.75
18	Whether or not the patient's family thinks he/she should accept the kidney	1.12 $\pm$ 1.45
19	The results of the patient's most recent blood tests	0.58 $\pm$ 0.89
20	The burden the patient feels dialysis puts on his/her family or caregivers	0.51 $\pm$ 1.29
21	How much the donor weighed	0.38 $\pm$ 0.33
22	Whether the donor smoked cigarettes	0.25 $\pm$ 0.87
23	The race or ethnicity of the donor	0.04 $\pm$ 0.05
24	Whether the donor drank excessive alcohol	0.00 $\pm$ 0.00

Table 6

Comparison of Factors between Patients and Surgeons

Factor	Patient Importance Score* (Rank)	Surgeon Importance Score (Rank)	p value
The overall quality of the kidney	5.22 ± 1.03 (1)	5.15 ± 1.26 (1)	0.70
The function of the donor kidney at the time of death	4.51 ± 1.98 (2)	3.25 ± 0.99 (3)	<0.0001
How closely matched the patient is to the donor	3.97 ± 1.61 (3)	-0.83 ± 1.32 (15)	<0.0001
How difficult it is for the patient to be matched to a kidney	1.14 ± 1.72 (10)	3.66 ± 1.50 (2)	<0.0001
The risk of contracting a disease from the donor kidney	2.92 ± 1.74 (5)	3.05 ± 2.21 (4)	0.69
The age of the donor	0.18 ± 1.44 (16)	2.71 ± 1.06 (5)	<0.0001
How long the kidney is expected to last	2.98 ± 1.65 (4)	2.30 ± 1.02 (6)	0.001

*These are mean raw scores, not rescaled to 100