Attitudes and predictive factors for live kidney donation in British Columbia. A comparison of recipients and wait-list patients

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Introduction: *Live donor kidney transplantation (LDKT) is both medically and economically superior to cadaver kidney transplantation in the treatment of patients with chronic renal failure. Unfortunately, fewer than 50% of patients on the transplant waiting list have a relative or friend who contacts the transplant program about possible donation. We hypothesized that both the potential recipient and potential donor have identifiable and modifiable characteristics that contribute to the likelihood of a live donor transplant.*

Materials and methods: *Specifically-designed and validated questionnaires addressing personal characteristics, knowledge and beliefs about LDKT were mailed to patients who had previously received a LDKT (N=163) and patients on the cadaver transplant waiting list (N=251). Response rates were 81% and 67% respectively.*

Results: *There were significant differences between groups in age, ethnicity, marital status, hours worked per week, annual income, and time on the waiting list. Significant differences were found between groups in both knowledge and beliefs about live donor kidney transplantation. All wait-list patients could identify at least one family member (mean = 7 potential donors per wait-list patient) who might serve as a live kidney donor but less than 13% of these potential donors have actually undergone an evaluation.*

Conclusions: *In British Columbia, an enormous pool of potential live kidney donors exists for patients who are currently waiting for a cadaver kidney transplant. Educational strategies designed for wait-list patients may correct knowledge deficits and alter unfavorable beliefs about LDKT which, in turn, may increase their willingness to seek and accept an offer of live kidney donation.*

Key Words: attitudes, beliefs, personal characteristics, live donor kidney transplantation

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Introduction

In North America, there is an increasing need for kidney donors as the number of new diagnoses of chronic renal failure increases annually.[1,2] The number of suitable cadaveric organ donors is not going to meet the requirements for kidney transplantation, no matter how efficient the retrieval process.[3] Live donor renal transplantation (LDKT) is playing an increasingly prominent role[1,2] but this may simply be a reflection

of the increasing number of patients with renal failure and not an indication that live kidney donation is gaining greater acceptance. Over the last decade, a number of changes have taken place in the demographics of LDKT, including greater acceptance of unrelated donors and the possibility of anonymous live donors.[4,5] Since the potential to increase the number of live donor kidney transplants greatly exceeds the potential to increase cadaveric kidney transplants, we believe that initiatives directed towards understanding and recruiting live kidney donors will prove of great benefit to patients with kidney disease. The advantages of LDKT over cadaveric transplantation include improved patient and graft survival, improved quality of life and the possibility of avoiding dialysis completely.[6-12] The possibility of pre-emptive transplantation and improved graft survival carry economic advantages such as reduced time on dialysis, reduced number of surgeries for hemodialysis access and reduced requirement for medical therapies for disorders such as anaemia and osteomalacia.[13-16] We hypothesized that potential recipients and potential donors have identifiable and modifiable factors that contribute to the likelihood of a LDKT. This study was initiated in order to characterize and quantify these factors and to determine how these factors influence decisions about LDKT. The data presented here are a comparison between patients who were previous LDKT recipients versus patients currently on the waiting list for cadaver kidney transplantation.

Materials and methods

This study had institutional clinical ethics review approval (certificate #B98-0181). The study groups were previous LDKT recipients and patients on the cadaver kidney transplant waiting list. All potential subjects received a letter describing the study and inviting their participation. Confidentiality was guaranteed and potential subjects were assured that the study was not being conducted to persuade or influence people to become kidney donors. All subjects provided informed consent.

Questionnaires

Standardized, self-administered questionnaires were developed for each group.

Each questionnaire comprised four sections: 1) Knowledge and belief tests, which consisted of 7 statements testing knowledge and 11 statements assessing beliefs about LDKT, scored on a 5 point scale (strongly agree, agree, disagree, strongly disagree and don't know); 2) Questions about family situation and attitude toward live kidney donation; 3) Questions about personal, physical and psychological characteristics; 4) General demographic questions.

An open-ended section was provided for writing comments in all questionnaires. Questions in Sections 1 and 4 were the same for both groups. Questions in Sections 2 and 3 were specific to each group.

The questionnaires were reviewed by three expert focus groups that included physicians, surgeons, nurses and social workers. All members of the focus groups had extensive experience in the care and management of renal transplant patients and their families. Their review indicated that all known important and potentially modifiable factors that might influence decisions about live kidney transplantation had been included in the questionnaires and the questions were easily understood and answered. Questions were designed so that previous experience with LDKT was not an advantage in answering. All study subjects received the information necessary to answer the 'knowledge' questions, in the form of both written material and verbal discussions, at the time of the patients' suitability assessment for transplantation.

Questionnaires were translated into Chinese, Punjabi and French, and reverse-translated from Chinese to English to ensure that the translation accurately reflected the intent of the questions. Arrangements were made for translation of questionnaires into other languages if needed.A pilot study was conducted to test content reliability and validity. Test/retest analysis demonstrated excellent internal consistency. Kappa scores for the statements of knowledge and belief test were all >0.90. There was no evidence of 'skew' or 'halo' effect on any subset of statements.

Data analysis

Socio-economic characteristics of recipients and waiting list patients were compared using Chi-square test for categorical variables and one-way ANOVA or Student's t-test for continuous variables. Using a two-tailed test, $p<0.05$ was considered a significant difference between groups. For each person, a "knowledge score" was calculated by adding the number of correct answers to seven knowledge statements. For example, in response to the question "a person cannot spare a kidney since they are vital organs and both are required for normal health", responses of strongly disagree and disagree were considered correct and all other responses were incorrect. A knowledge score of 7 indicates all statements were answered correctly. Responses to belief statements

were analyzed by assigning a score of 1 (for the least positive attitude towards LDKT) through 5 (for the most positive attitude toward LDKT) for each of the 11 statements. The scores for each statement were then totaled to obtain the "belief score" for each individual.Data were entered into SPSS 11.0. Pearson's Chi square was used to compare the two groups. Multiple regression analysis was carried out to adjust for the possible effects of sex and ethnicity on knowledge and beliefs. Ethnicity was categorized as caucasian, oriental, and other/no response, using dummy variables for entry into the multiple regression model.

Survey

Potential subjects for this study were patients who had been recipients of live donor kidney transplants at St. Paul's Hospital in Vancouver, Canada (a tertiary care, university-affiliated teaching hospital) between January 1997 and June 2001 (n=163) and all patients placed on the hospital's cadaveric kidney waiting list during the same time period (n=251). All potential subjects were mailed letters inviting them to participate in the study, and asking them to return a signed informed consent in a self-addressed, stamped envelope. If no response was received within 3 months, a second contact letter was sent.

Results

Questionnaires were returned by 132 recipients and 167 patients on the waiting list. The response rates were 81.0% and 66.5% respectively.

Table 1 compares the socio-economic characteristics of the two groups. There were significant differences

TABLE 1. **Socioeconomic characteristics of live kidney transplant recipients versus wait-list patients**

Characteristics		**Recipients n=132**	**Dialysis n=167**	**P value**
Gender	Male:female	52.7:47.3	56.6:43.4	0.783[a]
Age (yrs)	Mean±SD	46.0±12.4	52.0±12.9	0.000[a]
Ethnic group (%)	Caucasian	85.4	65.0	0.011[b]
	Asian	8.5	21.9	
	East Indian	3.1	5.6	
	Others	3.0	7.6	
Marital status (%)	Married	77.9	68.9	0.021[b]
	Single	16.8	12.4	
	Divorced/Widowed	5.3	18.6	
Education (%)	Elementary school	4.6	11.3	0.137[b]
	High school	36.6	31.3	
	College/University	58.8	57.5	
Working hours per week (%)	Not working	43.3	66.1	0.000[b]
	1-10 hours	3.9	3.6	
	11-25 hours	6.3	7.9	
	26-40 hours	25.2	16.4	
	More than 40	21.3	6.1	
Annual income (CN$)	>100,000	7.8	1.9	0.015[b]
	60,000-99,999	10.2	6.8	
	30,000-59,999	32.0	24.7	
	18,000-29,999	22.7	21.6	
	<18,000	21.1	35.2	
	Unknown	6.3	9.9	
Principle income earner of household (%)	No	47.2	45.5	0.914[b]
	Yes	39.4	41.8	
	Equally shared	13.4	12.7	

[a]t-test
[b]Pearson's Chi Square

between groups in age, ethnicity, marital status, work hours per week and annual income. No differences were noted in gender, amount of education or whether the patient was the principal income earner for the family.

Responses to the knowledge statements are presented in Table 2. The mean total knowledge scores were 3.0+/- 0.12 and 4.1+/-0.13 in the wait-list and recipient groups respectively (p=0.00, t-test). Responses to the belief statements are presented in Table 3. The mean total knowledge scores were 35.1+/- 0.74 and 38.7+/-0.74 in the wait-list and recipient groups respectively (p=0.001, t-test). Previous LDKT recipients had significantly higher scores on both the knowledge and belief tests compared to wait-list patients. More wait-list patients than recipients believed that the donor often agrees to donate due to feelings of guilt or family pressure (22.1% versus 5.3%).

Knowledge scores and belief scores were also evaluated by level of success in seeking a kidney donor Table 4. Wait-list patients with no interested donors had the lowest knowledge and belief scores whereas those patients with interested or committed donors had progressively higher scores. Patients who actually received a LDKT had the highest scores.

Multiple regression using group (recipient vs. wait list), sex, and ethnicity as predictors of knowledge had an R^2 of 16.4%. However, only group and ethnicity (Caucasian) were significant predictors. Stepwise regression removed sex and ethnicity (oriental) from the model, leaving a final R^2 of 16.1%. Hence there is still a statistically significant difference between study groups after adjustment for ethnicity and sex.

Multiple regression using group (recipient versus wait list), sex, and ethnicity as predictors of beliefs had an R^2 of only 6.4%, significantly different from zero, but weak. Stepwise regression once again removed sex and ethnicity (oriental) from the model leaving a final R^2 of 6.3%. The difference between groups was still statistically significant even after adjustment for ethnicity and sex.

Self-perception of general physical and psychological health status of respondents prior to

TABLE 2. **Responses to knowledge test statements (%) of live kidney transplant recipients versus wait-list patients**

Statement	Group	Strongly disagree	→		Strongly agree	Don't know
Kidney transplantation is preferred over dialysis for the treatment of kidney failure.	W (n=167) R (n=132)	0.6 0.0	0.6 0.0	12.9 6.8	78.5 88.6	7.3 4.6
A person cannot spare a kidney since they are vital organs and are required for a healthy life.	W R	52.8 78.0	16.6 11.4	4.3 0.8	9.8 0.8	16.5 9.1
Only immediate family members (brothers, sisters, parents or children) can be live kidney donors.	W R	60.7 77.3	11.0 6.1	4.9 3.0	12.9 8.3	10.4 5.3
Long-term health problems in live donors are very rare after kidney donation (e.g. high BP, kidney disease).	W R	6.7 12.1	11.0 8.3	17.2 16.7	12.3 31.1	52.7 30.8
Immediate surgical complications in the donors are common and may be life-threatening.	W R	24.5 37.1	19.0 33.3	2.5 1.5	4.9 7.6	49.1 20.4
Women may have difficulty with future pregnancies if they donate a kidney.	W R	20.9 28.8	15.3 20.5	4.9 5.3	4.9 6.8	54.0 38.7
The success rates of live-donor and cadaver donor kidney transplant are about the same.	W R	17.2 31.8	14.7 22.7	10.4 12.9	11.0 6.1	46.7 26.5

W= wait list, R = recipient

TABLE 3. **Belief question responses of live kidney transplant recipients versus wait-list patients**

Statement	Group	Strongly disagree	→		Strongly agree	Don't know
It is ethically acceptable to take a kidney from a healthy person.	W (n=167)	3.1	3.7	17.2	62.0	14.1
	R (n=132)	1.5	0.0	10.6	82.6	5.3
Since there is a life after death, people should enter the next life with a complete body.	W	73.0	4.9	1.2	6.1	14.7
	R	78.0	6.8	0.8	1.5	12.9
Donors often agree to donate due to feelings of guilt or family pressure.	W	25.8	14.1	12.3	9.8	38.8
	R	41.7	19.7	2.3	3.0	33.4
Donating a kidney is a rewarding experience for the live donors.	W	3.7	1.8	27.6	35.0	31.9
	R	0.8		31.8	48.5	18.9
Donating a kidney to someone requires an extremely close personal relationship.	W	8.6	7.4	10.4	54.0	19.6
	R	4.5	6.8	25.0	43.9	19.7
A live donor kidney transplant may strengthen the relationship between the donor and recipient.	W	4.9	1.2	23.9	39.9	30.1
	R	1.5		29.5	54.5	14.4
Approaching a potential donor who then says no will change the relationship between the two people.	W	31.3	14.7	11.0	7.4	35.5
	R	30.3	18.2	10.6	6.1	34.9
Asking someone to donate makes the recipient seem selfish or greedy.	W	29.4	13.5	11.0	11.7	34.3
	R	33.3	15.2	12.1	10.6	28.7
It is acceptable for a parent to receive a kidney from his/her child (over 18 years old).	W	8.0	5.5	16.6	50.9	19.0
	R	0.8	1.5	18.9	59.9	19.7
Decision about donation should be made by the donor alone. The recipient should not ask for a kidney.	W	13.5	4.9	9.2	53.4	19.0
	R	14.4	11.4	14.4	34.8	25.0
Since the donor operation is not risk free, someone who needs a kidney transplant should wait for a cadaver donor kidney.	W	38.7	12.9	8.0	9.2	31.3
	R	58.3	18.2	2.3	6.1	15.1

W= wait list, R = recipient

TABLE 4. **Knowledge score and belief score by level of success in seeking a kidney donor**

Commitment	Number of respondents (n=299)	Knowledge score (mean±SD)	Belief score (mean±SD)
Transplanted	132	4.09±1.51	38.76±8.53
Had someone evaluated	75	3.40±1.35	36.84±7.66
Had someone interested	47	3.09±1.72	35.32±8.39
Had no one evaluated or interested	45	2.33±1.25	31.93±12.62

kidney transplant is shown in Table 5. Previous recipients had been on dialysis for a significantly shorter period than wait-list patients (p=0.000) and rated their health status as significantly poorer while on dialysis (p=0.000). There were no significant differences in incidence of self-reported co-morbid conditions except for depression. Significantly more wait-list patients reported being depressed (p=0.02).

Willingness to receive a LDKT was high among those currently on the transplant waiting list. Among 167 wait-list patients, 32% reported that they would prefer LDKT to cadaveric transplant if they had a choice, 10% preferred cadaveric transplant and 58% had no preference (data not shown). Thus, 90% of wait-list patients would accept a live donor kidney if it were available.

Both wait-list patients and previous LDKT recipients identified a mean of seven potential donors within their families. Fewer relatives of wait-list patients were interested in becoming live donors than LDKT recipients' relatives Figure 1. Wait-list patients and LDKT recipients identified similar numbers of friends who might serve as potential donors Figure 2.

Subjects were also asked about their preferred source for information about LDKT. The most highly-desired sources were previous LDKT recipients

TABLE 5. **General physical and psychological health status of live kidney transplant recipients versus patients on the wait-list in British Columbia**

Health status		Patients on wait-list (%)	Recipients (%)	P-value
Form of dialysis undergone	Not on dialysis	7.7	12.3	0.001
	HD in centre	49.4	36.4	
	HD self-care	13.8	7.0	
	PD	29.1	36.6	
	PD+HD	0.0	7.6	
Time of being on dialysis	<3 months	0.7	9.5	0.000
	3-12 months	7.7	38.8	
	1-2 years	23.6	23.3	
	2-4 years	46.5	19.8	
	>4 years	21.5	8.6	
Self-reported comorbid conditions	Hypertension	67.1	76.5	0.073
	Heart disease	11.4	8.3	0.384
	Lung disease	1.8	3.8	0.289
	Diabetes	18.6	13.6	0.253
	Liver disease	2.4	1.5	0.590
	Cancer	0.6	0.8	0.867
	Depression	13.2	9.7	0.022
Difficulties with daily activities	Not at all	12.7	4.0	0.000
	A little	56.4	43.7	
	A lot	27.9	41.3	
	Unable to do any	3.0	11.1	
Feeling of a burden to others	Not at all	29.7	25.6	0.648
	A little	49.1	54.4	
	A lot	21.1	20.0	
Self-rated general health status while waiting for kidney transplant	Excellent	4.8	1.6	0.000
	Very good	16.3	7.9	
	Good	37.3	18.3	
	Fair	35.5	40.5	
	Poor	6.0	31.7	

HD = hemodialysis
PD = peritoneal dialysis

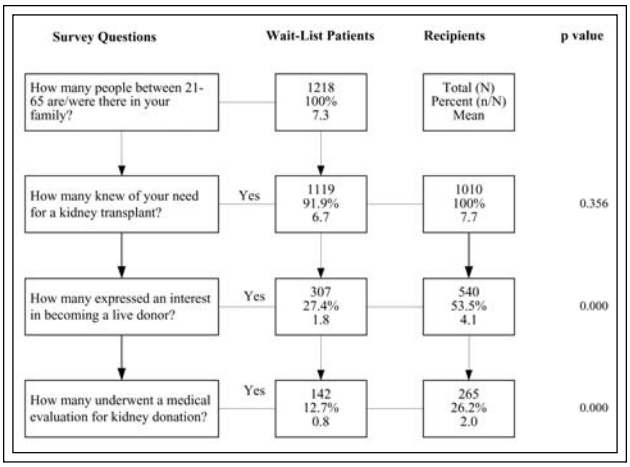

Figure 1. Estimation of potential living donor pool of families based on the responses from patients and previous recipients.

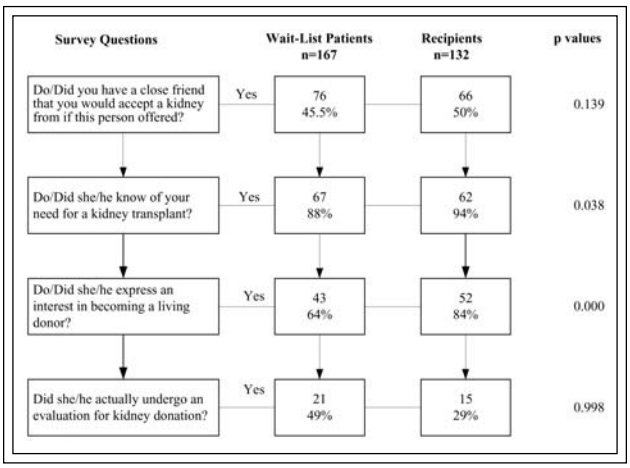

Figure 2. Estimation of potential living donor pool of friends based on the responses from patients and previous recipients.

followed by previous donors then transplant surgeons or nephrologists. Family doctors scored lowest as a possible source of information by both recipient and wait-list groups.

Discussion

The results of our study clearly show that, in British Columbia, patients with renal failure who desire a kidney transplant can identify several relatives or friends who could potentially serve as live kidney donors. This is equally true of patients who receive a LDKT or those who wait for years for a cadaver kidney transplant Figure 1. This was the fundamental observation that prompted our research proposal. We hypothesized that relatives/friends of wait-list patients would demonstrate reluctance, ignorance or both regarding live kidney donation but that the patients themselves would be relatively well informed about live kidney donation (as it was a primary focus of the transplant assessment that all patients be well informed before being approved for the cadaveric waiting list). Similarly, we felt that the patients would be motivated to promote or cultivate any potential offers of live kidney donation within their own family or friends. In fact, this appears not to be the case as our data suggest that many wait-list patients have beliefs that are contrary or non-committal with respect to LDKT and many have a poor understanding of the safety of LDKT. Surprisingly, 10% of renal patients awaiting cadaver transplantation state unequivocally that they would prefer a cadaver transplant over a live donor. Some of the notable differences between recipients of a LDKT and wait-list patients are;

- Many wait-list patients believe that offers to donate are made out of guilt and/or family pressure.
- A commonly held belief among wait-list patients is that parents should not receive kidneys from their adult children.
- Over 60% of wait-list patients believe that the decisions should be made by the donor and that recipients should not ask for a kidney.
- Over 80% of wait-list patients either don't know or think that live kidney donors experience long-term health problems as a result of donation.

Lack of knowledge and ambivalence regarding LDKT exhibited by wait-list patients will likely negatively influence potential donors within the family. This is supported by the finding that wait-list patients with higher knowledge and belief scores were more likely to have a family member who expressed interest in donation or who actually underwent medical testing whereas those with the lowest scores were more likely to have no interest among family or friends. Table 4. A number of investigators have attempted to characterize the decision-making process for families considering LDKT.[16-19] In many cases, the decision is "straightforward"[17] but requires the family to agree that a live donor transplant is preferred over cadaver transplantation or dialysis. Conrad and Murray suggested that dialysis patients with "knowledge gaps" concerning the success of transplantation will demonstrate ambivalence about LDKT.[20] Another perspective, not addressed by our questionnaire, is the recipients' desire not to financially burden their donor. Pradel et al have

suggested that the availability of laparoscopic nephrectomy, with a faster convalescence and return to work compared to standard open nephrectomy, has positively influenced attitudes about LDKT among dialysis patients.[21] Griva et al have studied recipients of cadaver and live donor kidney transplants and found that feelings of guilt (about donor morbidity and financial hardship) are prominent among LDKT recipients.[22] These feelings of guilt may explain ambivalence about LDKT in dialysis patients and may be modifiable with the use of minimally invasive donor surgery.

Another important finding was that significantly greater numbers of wait-list patients report being depressed compared to previous LDKT recipients while the self-reported prevalence of all other co-morbid diseases was equal in both groups. While this does not prove causation, it does imply that depressed patients (perhaps lacking in self-esteem) may not feel worthy of receiving a live donor transplant. An alternative explanation would be that renal patients become increasingly depressed as they wait for a cadaveric renal transplant. Depression is known to be prevalent among renal-failure patients[23, 24] and other investigators have found that those with depression often manifest ambivalence, passivity and denial of the severity of their illness and consequently, are unwilling to discuss LDKT with family or friends.[25,26] The finding in this study that wait-list patients rate their health status higher than previous recipients (before the transplant) is consistent with denial of the severity of the illness Table 5.

The demographic comparisons Table 1 show that LDKT recipients in British Columbia are more likely to be Caucasian, married, employed and have a higher income than patients waiting for a cadaver kidney transplant. Our multivariate analysis shows that ethnicity does contribute to knowledge and beliefs, but does not fully explain the difference. The disparity between different racial groups' access to kidney transplantation has been discussed in a number of high profile publications.[27,28] Yuen et al suggest that minorities are equally accepting of organ donation compared to Caucasians (in surveys)[29] yet it is clear that minorities do not donate organs at the same rate.[30] Arthur has suggested that the social networks of minorities are less likely to include members with knowledge of transplantation or organ donation; therefore minorities are more likely to respond unfavorably when presented with an opportunity to donate.[31]

Our data suggest that renal patients may be categorized at the time of diagnosis into two groups: those that are inclined towards receiving a live donor transplant and those that are disinclined towards receiving a live donor transplant. At our centre, renal patients receive information about live donor transplantation during a single 3 hour assessment when they are also given a great deal of information about other aspects of transplantation. They are also provided with reading material about renal transplantation which contains information about live donor transplantation. There are no other structured educational sessions with the transplant nephrologists or surgeons after the patients have been evaluated and approved for transplantation. In other words, patients who are not inclined towards receiving a live donor transplant after the initial evaluation and educational meeting do not have any other formal educational opportunities to learn more about live kidney donation. There are, no doubt, many informal educational opportunities between patients and their local nephrologists, dialysis nurses, social workers and other patients but these encounters may not have the same potential to influence opinion or beliefs as a structured, formal meeting with a dedicated transplant nephrologist, surgeon, nurse or social worker. In our study, wait-list patients reported that the preferred source of information about LDKT would be to speak personally with someone who had previously received a LDKT. Perhaps previous LDKT recipients and donors are an under-utilized resource that might serve as ambassadors or spokespersons for LDKT as part of a scheduled educational meeting.

The primary limitation for interpretation of this study's results is that the groups were substantially different in exposure to information. Questions such as those in Table 2 ("a person cannot spare a kidney since they are vital organs"; "health problems are rare"; and "surgical complications in donors are common") would be strongly influenced by the experience of the recipient and what the recipient might want to believe was true because of the choice he or she made. The level of knowledge may or may not have been pre-existing, but there is no way to determine this post hoc. Previous recipients of a LDKT are usually more knowledgeable than dialysis patients since they have experienced the process directly. To compensate for this, we made every effort to design the questionnaires so that the 'knowledge' questions focused on issues that did not require first hand experience, but the extent of the effect of recipient experience remains unknown. The questions were felt to be typical of the concerns of all end stage renal

disease (ESRD) patients who are considering a LDKT. The fact that dialysis patients had low scores indicates that either they did not seek out the answers or they were given the wrong information.

In addition, those who responded were not a random sample from the relevant populations but were self-selected. However, the level of bias is likely small because the response rates were very high (81% and 66%) and the demographic factors associated with LDKT in our study (married, Caucasian, younger age, employed, higher household income) have been confirmed by other studies.[22] Therefore, we believe the results are valid and can be extrapolated to the donor and wait list populations.

The ethnicity of the ESRD patient population in British Columbia is substantially different from the United States, where African American and Hispanic populations represent a significant minority of patients requiring kidney transplantation.[2] Beliefs and attitudes about LDKT may vary between ethnic groups and there is no way to ascertain, from our study, whether the questionnaire responses would be similar in transplant centres with large African American or Hispanic populations. A larger, multi-institutional study would be required to further investigate this possibility. Although every effort was made to encourage and enable the participation of those whose first language was not English, there may have been some bias based on comfort with the English language.

Conclusion

A somewhat unexpected finding was the ambivalence and lack of knowledge about live donor transplantation exhibited by renal patients awaiting cadaver kidney transplantation in British Columbia, and we believe this exerts a powerful negative influence on family/friends regarding possible kidney donation. Our current method of educating patients about LDKT is inadequate and likely does not make a very significant impact on patients who are not already inclined towards receiving a live donor transplant. We suggest that patients on the cadaver kidney waiting list receive periodic, formal interviews where they have an opportunity to ask questions about the procedure and speak to previous LDKT recipients or donors if they wish. In particular, patients should be provided with clear information that morbidity and mortality among donors is very low; that donors agree to donate willingly; and that renal patients' current health status is often perceived as better than it is in reality. Renal patients who exhibit signs of depression or who are being treated for depression should have the idea of live donor transplantation reviewed at a time when their depression is under control and less likely to influence their decisions. □

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