

Knowledge and attitudes towards kidney donation: A cross-sectional study from a single Sri Lankan centre

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ABSTRACT

Introduction: Kidney transplantation is considered the definitive and most cost-effective treatment for end-stage renal failure. However, transplantation programmes are highly dependent on the availability of donor organs. Public knowledge and attitudes toward organ donation significantly affect the size of the potential donor pool. In Sri Lanka, no prior studies have explored this topic.

Methods: A self-administered pre-tested questionnaire; a modified, simplified version of the original questionnaire developed by Khalid *et al.*, was distributed among the relatives of the non-CKD patients in selected wards of National Hospital of Sri Lanka Colombo, upon discharge of the patient. The study was conducted on five consecutive days in January 2018.

Results: Out of the 250 questionnaires distributed, 194 were returned completed (response rate: 77.6%). The majority of respondents were male (77.6%), Sinhalese (89.8%), Buddhists (76.1%), and university graduates (51.1%). While 83.2% were willing to donate a kidney to a relative, only 36.5% were willing to donate to a stranger. Awareness that kidney failure can be treated with transplantation was high (97.5%), and 83.2% had heard of brain death. Awareness of brain death was associated with the level of education. A high proportion (94.9%) were willing to be deceased donors, and 82.1% wanted to declare this intention while alive. This intention was significantly associated with gender ($p=0.002$), civil status ($p=0.039$), and ethnicity ($p=0.001$).

More than half (55.3%) believed that kidney donation could lead to long-term health issues. A significant proportion expected compensation for live (66.2%) or deceased (25.9%) donation, and these beliefs were associated with lower education levels ($p=0.042$).

Conclusions: Relatives of patients presenting to National Hospital of Sri Lanka, Colombo demonstrated both a strong willingness to donate and a notable expectation of compensation; an unusual combination. More research is needed to inform policies specific to the Sri Lankan context.

Keywords: Chronic kidney disease, Compensation, Deceased donor, Kidney transplantation, Live donor.

Introduction

Chronic Kidney disease is a global problem and is one of the leading causes of in hospital deaths in Sri Lanka. Once the disease is advanced, the economic burden of treatment – in the form of dialysis – is costly both for patients and the state. Kidney transplantation is regarded as the definitive and most cost-effective treatment for end-stage renal disease (ESRD) (1). However, transplantation programmes rely entirely on the availability of donor organs, and public attitudes toward donation are key factors influencing donation rates (2). In Sri Lanka, most organ donations come from living donors; the deceased donor programme remains underdeveloped and contribute to less than 10% of kidney transplantations. There is cultural acceptance of donations such as blood and cornea donation (3), but the pool for kidney donors is limited. Prior studies have shown that attitudes toward organ donation are influenced by demographic factors such as age, gender, education, religion, and awareness of transplantation and brain death (4).

No studies have been conducted in Sri Lanka to examine these factors. A robust policy on organ donation – live or cadaveric – can only be formed only when the characteristics of the donor population is known. Therefore, we conducted this pilot study to get a glimpse into public knowledge and attitudes towards kidney donation.

Methods

Study design and sampling methods

This study was carried out in January 2018, at the National Hospital of Sri Lanka, Colombo. We used stratified sampling on visitors of the in-ward patients, who have been admitted to medical wards, with no history of chronic renal failure. The stratification was performed according to the type of ward - medical, surgical, gynaecology, neurosurgery and ENT. The number of questionnaires per each ward was 10. Eight medical and surgical wards each, four ENT wards, three neurosurgical and two gynaecology wards were covered for the study. Altogether, a total of 250 questionnaires were distributed. One relative per patient was selected, upon discharge of each patient. Relatives were

asked to fill out the questionnaire. Each relative was asked the language they prefer to communicate in and questionnaires were supplied accordingly.

Data collection

Data were collected using a self-administered, pre-tested questionnaire available in Sinhala and Tamil. It was adapted and simplified from the tool developed by Khalid *et al.* (4). The questionnaire was translated to and from English to Sinhala/ Tamil and was pre-tested among 25 randomly selected relatives of the patients, for reliability, language, understanding and cultural appropriateness. The item difficulty, item total correlation and missing data frequency were all acceptable. A Cronbach alpha value for reliability was 0.68. The content was discussed with a senior nephrologist for the expert opinion. The necessary updates to the questionnaire were made accordingly.

The questionnaire consisted of nine (Q1-Q9) questions on demographic details and 11 questions on three domains; knowledge (5 questions; Q10, Q13, Q15-17, attitudes (3 questions; Q11, Q12, Q18) and intentions. (3 questions; Q14, Q19, Q20).

The responses to each individual question was individually analysed and described (the items were not given individual scores to get a cumulative score to obtain the overall level of knowledge/ attitudes).

Data analysis

Responses were entered into a *Microsoft Access*[™] database and analysed using *SPSS*[™] version 21.0. Categorical variables were grouped (*e.g.*, Yes/ No), and key demographics were recorded, education, income, ethnicity and religion.

Descriptive statistics were reported using means, standard deviations (SD), medians, and interquartile ranges (IQR). Significance was set at $p < 0.05$. Variables with more than one significant association were included in a binary logistic regression model. All factors with kidney $p < 0.1$ were included.

Results

Of the 250 questionnaires distributed among subjects, 194 were returned with a response rate of 77.6%. Males comprised of 74.6% of the respondents. Most were Sinhalese (89.8%) followed by, Tamil (5%), Muslim (4%) and others (1%). Buddhists constitute 77%, followed by

Atheist/ Non-Religious 12%, Hindu 5%, Islam 4% and Cristian/Catholic 2%. Mean age of the respondents was 34.2 years (SD 12.0), and median was 32 years with IQR 27-38 years. Of the respondents 38.6% were unmarried, and 51.3% had received university or higher education (Figure 1). Majority (55.4%) received a monthly income of less than Rs. 100,000/- and 16.1% were either students or dependents (Figure 2). Mean number of children was 1.40 (SD 1.06). Responses regarding knowledge, attitudes, and donation intentions are summarized in Table 1.

Educational level of the study group

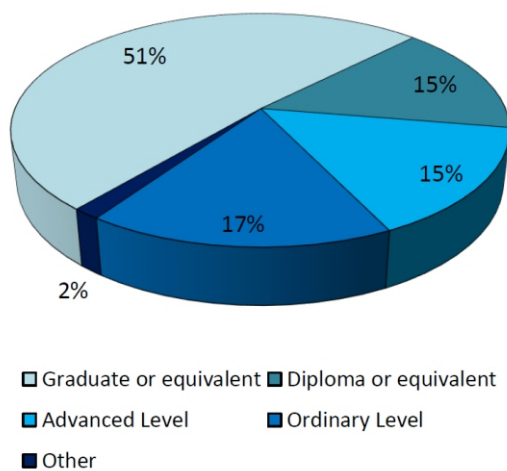


Figure 1: Educational level of the respondents of the survey

Univariate analyses were conducted using demographic variables (age, gender, income, education, marital status, ethnicity, and religion) as independent variables. Significant associations are summarized in Table 2. Belief that kidney donation leads to long-term complications (Q15) was significantly associated with the expectation of compensation (Q13) (OR = 1.95; 95% CI: 1.07-3.56, $p = 0.028$).

Binary logistic regression models were created according to the description given in data analysis for each question. Table 3 summarizes the model outcomes. Awareness of brain death (Q16) was significantly associated with a higher level of education (OR = 4.52, CI: 1.33-15.35, $p = 0.016$). Awareness that organs from brain-dead donors can be used for transplantation (Q17) was significantly associated with gender (OR = 6.73, CI: 1.45-31.30, $p = 0.015$) and education (OR = 4.65, CI: 1.69-12.79, $p = 0.003$). Although religion, race, and education were initially significant, they became non-significant in the regression model concerning willingness to donate organs after brain death. Willingness to declare organ donation as an advanced directive (Q19), was significantly associated with being female (OR = 7.36, CI: 1.34-40.31, $p = 0.021$), unmarried (OR = 3.53, CI: 1.07-11.63, $p = 0.039$), and Sinhalese (OR = 81.00, CI: 6.79-965.65, $p = 0.001$). Expecting compensation after living donation (Q13) was significantly associated with lower education (OR = 2.50, CI: 1.18-5.30, $p = 0.016$). Expectation of state compensation (Q14) increased with advancing age (OR = 1.037, CI: 1.002-1.074, $p = 0.038$). Desire for compensation for dependents after deceased donation (Q20) was also significantly associated with lower education (OR = 2.33, CI: 1.03-5.26, $p = 0.042$). The whole data set was checked for reliability with Cronbach alpha of 0.67, showing a moderately high reliability.

Monthly income of the study group

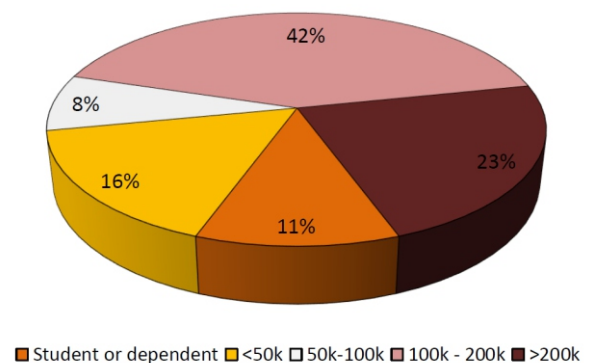


Figure 2: Monthly income of the respondents of the survey

Table 1: Responses to the questions assessing knowledge and attitudes towards transplantation and kidney donation. (The numbers answered “Yes” and the percentages are *indicated*.)

	n	%
Knowledge about donation		
Q10: Do you know that patients with kidney failure can be cured by kidney transplantation?	192	97.5
Q15: Do you think kidney donation will lead to long term illnesses in future?	109	55.3
Q16: Have you ever heard about brain death?	164	83.2
Q17: Do you know that kidneys of a brain dead could be transplanted?	153	77.7
Q13: If you were to donate a kidney, are you eligible for compensation?	129	66.2
Attitude towards donation		
Q11: Do you wish to donate a kidney to a family member while you are alive?	164	83.2
Q12: Do you wish to donate a kidney to a non-family member while you are alive?	72	36.5
Q18: If you were to become brain dead, do you wish your kidneys to be utilized for transplant?	187	94.9
Intentions		
Q14: If you were to become a living kidney donor, do you expect compensation from state?	77	39.1
Q19: If you were to become a cadaveric donor, do you wish to declare in advance?	160	81.2
Q20: If you were to become a cadaveric donor, do you wish your dependents to be compensated?	51	25.9

Table 2: Summary of the results of the Univariate analysis of variables

Variable	Odds Ratio	95% CI	p value
Knowledge about donation			
Q10: Do you know that patients with kidney failure can be cured by kidney transplantation?			
No significant associations			
Q15: Do you think kidney donation will lead to long term illnesses in future?			
No significant associations			
Q16: Have you ever heard about brain death?			
Female gender	OR = 5.95	1.37 – 25.91	0.008
Lower educational status*	OR = 0.01	3.40 – 30.2	< 0.001
Lower income ⁺	OR = 0.15	1.49 – 28.4	0.005
Q17: Do you know that kidneys of a brain dead could be transplanted?			
Age	t = - 2.147		0.037
Female gender	OR = 4.11	1.39 – 12.2	0.007
Lower educational status*	OR = 8.42	3.53 – 20.1	<0.001
Lower income ⁺	OR = 4.67	1.58 – 13.8	0.003
Q13: If you were to donate a kidney, are you eligible for compensation?			
Lower educational status*	OR = 2.53	1.36 – 4.69	0.004
Attitude about donation			
Q11: Do you wish to donate a kidney to a family member while you are alive?			
No significant associations			
Q12: Do you wish to donate a kidney to a non-family member while you are alive?			
Unmarried	OR = 2.00	1.10 – 3.64	0.023
Q18: If you were to become brain dead, do you wish your organs to be utilized for transplant?			
Lower education status*	OR = 10.35	1.29 – 83.29	0.007
Buddhist	OR = 5.34	1.44 – 19.83	0.013
Sinhalese	OR = 6.67	1.71 – 25.97	0.013
Intentions			
Q14: If you were to become a living kidney donor, do you expect state to compensate?			
No significant associations			
Q19: If you were to become a cadaveric donor, do you wish to declare in advance?			
Age	t = -2.25		0.031
Female gender	OR = 5.98	1.37 – 26.1	0.008
Unmarried	OR = 2.42	1.03 – 5.70	0.039
Lower educational status*	OR = 3.68	1.58 – 8.26	0.002
Buddhist	OR = 2.50	1.13 – 5.55	0.021
Sinhalese	OR = 9.59	3.61 – 25.5	<0.001
Q20: If you were to become a cadaveric donor, do you wish your dependents to be compensated?			
Lower educational status*	OR = 2.90	1.48 – 5.67	0.002

*Lower educational status was defined as not having a degree in this population.

⁺Lower income was defined as a monthly income less than Rs. 100,000

Table 3: Results of the binary logistic regression model. The numbers are the R² values for each variable against each response. The bolded R² values are significant associations at $p < 0.05$

	Age	Gender	Civil status	Education	Income	Religion	Race
Q13: If you were to donate a kidney, are you eligible for compensation?	0.514	0.883	0.722	0.016	0.280	0.828	0.076
Q14: If you were to become a living kidney donor, do you expect compensation from state?	0.038	0.956	0.248	0.567	0.393	0.858	0.595
Q16: Have you ever heard about brain death?	0.606	0.997	0.533	0.016	0.075	0.115	0.086
Q17: Do you know that kidneys of a brain dead could be transplanted?	0.813	0.015	0.128	0.003	0.094	0.095	0.180
Q19: If you are to become a cadaveric donor, do you wish to declare in advance?	0.849	0.021	0.039	0.181	0.077	0.159	0.001
Q20: If you are to become a cadaveric donor, do you wish your dependents to be compensated?	0.606	0.285	0.696	0.042	0.359	0.998	0.998

Discussion

This study assessed knowledge, attitudes, and donation intentions among patients' relatives at Sri Lanka's largest hospital. The large majority had heard of brain death (83.2%); knew that kidney failure is treatable with transplantation (97.5%), and were aware that kidneys from brain-dead individuals could be transplanted (77.7%). Despite this, 55.3% believed that kidney donation leads to long-term health problems. Alarming, 66.2% believed they were entitled to compensation for donation, which is prohibited under Sri Lanka's Transplantation of Human Tissues Act No. 48 of 1987. However, only 39.5% expected compensation from the state. A strong association was found between fear of health complications and the belief in entitlement to compensation (OR = 1.95; CI 1.07-3.56). Lower education levels and older age were associated with the fear of health complications.

While 83.2% were willing to donate a kidney to a family member, only 36.5% were willing to do so for a stranger. In contrast, 94.5% were willing to be deceased donors. These figures are much higher than those reported in studies from other South Asian and international contexts, such as Pakistan (26.8%), Saudi Arabia (62.2%), Sweden (73%), and the UK (64%) (4, 5), and comparable with Morocco (91.2%) (1).

Among respondents, 82.1% were willing to declare their intent to donate organs following a possible brain death. About 25.9% expected compensation for their dependents after deceased donation. Factors positively associated with willingness to donate organs, included being female, unmarried, or from the Sinhalese majority. It compares favourably with other countries such as Ghana (71.6%) (6), Iran (75%) (7), and Vietnam (77%) (8).

Compensation for living kidney donation remains ethically contentious. In our study, 66.2% believed they were entitled to compensation, although fewer expected it from the state (39.1%). In comparison, 59% of respondents in a study done in the USA, supported a \$ 50,000 compensation (9), while only 25% in the Netherlands found compensation desirable (10). In contrast, Middle Eastern studies

show a lower demand for compensation (17.9%) (5) with donation seen as a religious act. This highlights Sri Lanka's unique situation: a population highly willing to donate but also with strong expectations of compensation. This puts the legislative and ethical frame work in a difficult situation. This unique situation in Sri Lanka warrants innovative approach for live donation, such as state-funded compensation, or non-monetary compensation such as allowing the donors to be preferential recipients of organs in the case of need. Similarly, cadaveric donations can be compensated by allowing first-degree relatives of the donor to be given preference for cadaveric organ recipients.

Limitations

Our sample size is relatively small compared to global studies. The high percentage of graduates reflects response bias, where the most educated family member completed the questionnaire. Being a single center, hospital-based study of patients' relatives (of whom over 50% were graduates) questions the generalisability of the findings. This warrants multi-centre study/studies that would provide results which could be generalised more readily.

Rationale behind assessing each item depends on that firstly, the original English language questionnaire and many others were done as such. Secondly, there is no way to validate relative importance of each question in a domain, in a pilot study. We could have made assumptions of equal importance, but this is statistically unsound. Hence, we used the way to minimise the assumptions.

Conclusions

Willingness to donate organs in Sri Lanka is influenced by education, civil status, income, ethnicity, and religion. A striking eighty percent plus respondents like to declare their willingness to be cadaveric donors well in advance and a similar percentage of respondents wish to donate a kidney for a family member while they were alive.

However, a substantial portion believed they were entitled to compensation, a pattern uncommon in most countries. This warrants either updating the public on compensation for organ donation as per Tissue Act of 1987, or accepting donor compensation as a national policy, as monetary or non-monetary benefits.

Recommendations

Given the unique attitudes and beliefs observed in this population, we recommend conducting further research and developing locally appropriate guidelines and legislation to address the associated ethical, legal, and moral issues.

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