

Attitudes of Parents of Schoolgoing Children in Federal Territory of Kuala Lumpur to Kidney Donation

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Summary

We surveyed 900 parents of schoolgoing children to determine their attitudes to kidney donation. 632 parents replied. Only 22% of parents would donate their own kidneys, 24% their spouses' and 25% their children's. 46% would allow doctors to remove kidneys from a relative who had signed a kidney-donor card but only 19% would if the relative had not signed. 52% were in favour of introducing 'required request' law but only 26% were in favour of introducing 'presumed consent' law. Common reasons cited by parents for not willing to donate kidneys were dislike of body parts missing after death (51 %) and against religious beliefs (26%).

Key Words: Kidney donation, Organ donation, Renal transplantation, Public attitudes

Introduction

Renal transplant is undoubtedly the best form of renal replacement therapy in terms of cost and quality of life¹. Unfortunately, the Malaysian Dialysis and Transplant Registry data shows that total live-related renal transplant varied from 25 to 50 per year from 1984 to 1994. There were only 22 cadaveric renal transplants over the same period of time².

Attitudes toward organ donation are often cited as an impediment to the procurement of organs for transplantation. We therefore conducted a questionnaire survey to determine various sections of the Malaysian public's attitudes to kidney donation and related issues.

Methods

The questionnaire survey was conducted on 4 separate study populations. They were members of the general public, opinion leaders, doctors and politicians.

General public

A two-stage cluster sampling design was employed. At

the first stage, five schools out of 74 in Federal Territory of Kuala Lumpur were selected by simple random sampling. At the second stage, 4 to 5 classes were selected by simple random sampling from each of the selected 5 schools. All the pupils from each selected class were sampled. The pupils were instructed by their class teacher to hand-over a set of questionnaire to be completed by either of their parents. A total of 900 questionnaires were distributed to parents who represent the general public for the purpose of this survey. The sample size was calculated based on 5% type I error, 5% precision and estimated design effect of 2 and 50% prevalence of willingness to donate kidneys. Since there is no previous local data, the latter two estimates are conservative (tending to inflate sample size).

Opinion leaders, doctors and politicians

All committee members of various Malaysian professional bodies affiliated with the Malaysian Professional Centre, as well as all director-generals and chief secretaries of all government ministries were regarded as opinion leaders for the purpose of this

survey. Membership list of the Malaysian Medical Association was used as sampling frame for doctors. A one in ten systematic sample was selected from the list. A total of 253 questionnaires were sent to opinion leaders and 353 questionnaires to doctors. A reminder was also sent 6 weeks later to both groups. The response rates were 51% and 40% respectively. These rates are inadequate³ and hence both groups were omitted from analysis. Politicians were all members of the Malaysian parliament and senate. Each was sent a questionnaire by post. The response rate from the politicians was so poor it was not considered worthwhile to send a reminder. They were also omitted from analysis.

Each questionnaire was accompanied by a letter from the Director General of Health which explained the purpose of the survey. A separate information sheet explained to the respondents the problems of end-stage renal failure in Malaysia, the availability and nature of renal replacement therapy with emphasis on renal transplantation and the procedures for the procurement and removal of cadaveric organs for transplantation.

Issues relating to the law on consent for organ removal - the Human Tissue Act 1974 - which states that regardless of the potential donor's wishes, consent from the next of kin is needed for organ removal was also explained. Two legislative changes practised in other countries were added. The first is the so called 'presumed consent' or 'opting out' law whereby consent for organ removal is presumed unless a specific objection was raised by the next of kin or by the deceased before death. The second is the "required request" law which requires medical staff to approach the next of kin of every patient in whom brain death is imminent or established to request for organ donation.

Subjects were requested to provide details on their age, sex, race and other sociodemographic characteristics. The questionnaire contained 9 questions with space for comments. The questions are briefly summarised as follows:

- (1) Are you willing to donate your kidneys upon death?
- (2) If so, what motivated you to do so? and if not why not?

- (3) Would you allow your spouse or children to pledge their kidneys? (i.e. to sign a kidney donor card)
- (4) Would you allow doctors to remove the organ of a relative who had recently died and who had previously signed a kidney donor card?
- (5) Would you object to doctors approaching you to request for kidney donation from a relative?, and would you donate the kidneys of a relative who had recently died but who had not signed a kidney donor card?
- (6) Would you accept cadaveric kidney transplantation should you need one?
- (7) Are you in favour of the introduction of "required request" law in Malaysia?
- (8) Are you in favour of the introduction of "presumed consent" law in Malaysia?
- (9) Is kidney trading (that is, commercialised living non-related renal transplantation) acceptable to you?

Prevalence estimates and their standard errors (SE) were calculated by method appropriate to the 2 stage cluster sampling design employed^{4,5}. Sampling weights were adjusted for class level non-response⁶. For testing of overall differences in prevalence among groups (e.g. among age groups, ethnic groups etc), we used Wald statistic with degree of freedom correction^{5,7}. Statistical significance was accepted at 5% level. The analyses were implemented by STATA statistical software⁸.

Results

We received replies to the questionnaire from 632 (70%) parents.

Table I shows the characteristics of parents. As expected for parents of school going children, the parents were in their middle ages. More fathers responded than mothers.

Table II shows the parents' responses to the questionnaire. In general, only about a quarter of parents would donate their own or family members' kidneys. They were less likely (19%) to donate if a relative had not signed a donor card. However, even if a relative had signed a donor card, 27% would still not allow doctors to remove the kidneys. 53% of parents were in favour of introduction of "required request" law, however, 45% opposed "presumed

Table I
Parent characteristics

	Parents (n=632)
Age (mean \pm SD)	45 (6)
Sex: No. (%)	
Male	453 (73)
Female	171 (27)
Race: No. (%)	
Malay	223 (36)
Chinese	297 (48)
Indian	82 (13)
Others	15 (2)
Religion: No. (%)	
Muslim	229 (37)
Buddhist	212 (35)
Christian	74 (12)
Hindu	62 (10)
Others	33 (5)
Monthly income: No. (%)	
< \$500	81 (13)
\$500 - \$1000	190 (31)
\$1000 - \$2000	138 (23)
> \$2000	196 (32)
Education: No. (%)	
Primary level	91 (15)
Secondary level	343 (55)
Tertiary level	185 (30)
Previous blood donation: No. (%)	
Yes	176 (28)
No	445 (72)

consent" law and 53% considered kidney trading unacceptable.

The reasons why parents would not donate their kidneys are shown in Table III. The dislike of body parts missing after death was the commonest reason cited, followed by the belief that kidney donation was against one's religious belief. Muslims who would not donate were more likely to cite this reason than non-Muslims (39% of Muslim non-donor versus 14% of non-Muslim non-donor. $X^2 = 23.5$ $p < 0.001$). Surprisingly, lack of awareness of kidney donation was

rarely cited (1%) as the reason for not willing to donate. On the other hand, 32% of those who were willing to donate their kidneys were glad their body parts could still be of help to others and 18% were motivated by the desire to help other people.

Table IV shows parents' attitude to kidney donation according to age, gender and other characteristics. Non-Malays, non-Muslim, respondents with higher income or higher education and previous blood donors were more willing to donate their kidneys.

Discussion

The results of this survey should be interpreted with caution bearing in mind the constraints it faced. Firstly, as with any attitudinal questionnaire survey, there is always the concern that what people say may not accord with how they actually behave. No attitudinal questionnaire on kidney donation has ever been validated. Nevertheless it has been observed that attitudinal responses according to socio-demographic characteristics are consistent with socio-demographic composition of actual organ donors⁹. From this, one may infer that attitudinal data are predictive of actual behaviour in the circumstances. A greater constraint is the choice of parents of schoolgoing children as the study population. The choice was dictated by the desire for high response rate and by the need to ensure a reasonable level of educational attainment among the subjects so that they can actually complete this self-administered questionnaire. The resulting sample was however not representative of the general public. Thirdly, parents' response rate to the questionnaire was 70%. Though sampling weight was adjusted for non-response, the adjustment procedure was insufficient to correct for potential non-response bias. The resulting prevalence is likely to be overestimated as non-respondents are more likely to be unwilling to donate kidneys. We estimated this non-response bias pessimistically by assuming non-responders were all unwilling to donate or undecided; the resulting adjusted prevalence of willingness to donate was only 16%.

The survey finding of 22% of parents willing to donate kidneys is undoubtedly an overestimate, the adjusted estimate of 16% is probably nearer the truth.

Table II
Parents' attitudes to kidney donation and related issues

QUESTION	Prevalence of response		
	Yes % (95% CI)	No % (95% CI)	Don't know % (95% CI)
1 Would donate own kidneys?	22 (19-26)	45 (41-50)	32 (28-36)
2 Would allow spouse to donate his or her kidneys?	24 (21-27)	44 (36-52)	32 (23-40)
3 Would allow children to donate their kidneys?	25 (21-30)	44 (37-50)	31 (22-40)
4 Would allow doctor to remove kidneys from a relative who had signed kidney-donor card?	46 (41-52)	27 (19-35)	26 (20-33)
5 Would object to doctor approaching to request for kidney donation from a relative?	25 (23-27)	36 (28-45)	38 (31-46)
6 Would donate the kidneys of a relative who had not signed kidney-donor card ?	19 (14-25)	39 (32-46)	41 (35-47)
7 Would accept cadaveric kidney transplantation for oneself?	40 (35-45)	20 (13-28)	39 (35-43)
8 In favour of "required request" law	53 (46-59)	19 (13-26)	28 (23-33)
9 In favour of "presumed consent or opting out" law?	27 (20-33)	45 (39-51)	28 (25-31)
10 Consider kidney trading (commercial living non- related renal transplantation) acceptable?	20 (16-24)	53 (51-56)	26 (24-29)

This is a low figure and compares unfavourably with figures from other surveys: USA 50%, Sweden 65%, Canada 53%, UK 68%, Hong Kong 53%⁹⁻¹¹. 46% of our respondents were unwilling to donate and this figure is much higher than those of other surveys too. These figures do not augur well for the future of cadaveric transplant programme in this country. The potential organ donation rate is likely to be negligible, which has been borne out by past experience². We need to consider various approaches to help improve the organ donation rate in this country.

The traditional approach is through intensive public education campaign. The campaign can be targeted at the undecided members of the public, that 32% of respondents who were uncertain about kidney donation. Educational efforts should specifically counter the negative influences against donation. The public must be dissuaded of irrational beliefs such as dislike of body parts missing after death, fear of an operation after death, and dislike of body parts being transferred

into another person, these were commonly cited reasons for not willing to donate. Religious objection figured prominently too especially among the Muslims. Religious bodies will need to participate actively in any public education programme to help counter religious misconceptions. However, it is doubtful public education programme alone will work; in this survey only 1% of respondents who were unwilling to donate cited lack of awareness as a reason against donation. We should consider other methods.

Legislative means to increase organ donation have been attempted in various countries. In this respect, "opting-out" law, which has been in force in several countries like Belgium, Austria, Finland, France, Norway, Denmark and Singapore, would appear the best bet. For example, in Belgium, in the 3 years since implementation of "opting-out" law, organ donation has increased by 119%¹². Undoubtedly, "opting-out" law would be unpopular with the Malaysian public, in this survey only 26% of respondents were in favour

Table III
Reasons cited by parents for not willing to donate kidneys

Reason (in descending order of frequency)	Parents (n = 288) No. (%)
1 Do not like parts of body missing after death.	146 (51)
2 Against religious beliefs.	75 (26)
3 Have not thought about it.	71 (25)
4 Do not like being operated upon after death.	65 (22)
5 Consider it wrong or disrespectful to remove parts of body from the dead.	51 (18)
6 Don't like kidneys being transferred into another person's body	47 (16)
7 Husband or wife would object.	44 (15)
8 Against traditional or cultural beliefs	27 (9)
9 Have not heard of kidney donation before this survey.	4 (1)

* Percentages total more than 100% because respondents may cite more than one reason

of this law as opposed to 45% against. However, no countries in the world had ever introduced this law on the basis of popular request.

Another method worth considering is providing incentive for organ donation¹³. Various incentives to encourage organ donation have been proposed; such as 'preferred' status on a transplant waiting list, tax rebates, life insurance policies and even cash compensation. A little known alternative method also worth considering is the so-called mandated choice¹⁴ or routine request¹⁵ system. Under such a system, all competent adults are legally required to make a formal decision concerning organ donation after death when they renew their driving licence and/or when they fill in their income-tax returns. Such a system would ensure that almost everyone would be given the

opportunity to participate in the process of organ donation. Each individual would then be required to address the question of organ donation directly for himself/herself. This would free his or her family from the emotional burden of having to consider whether to consent to organ donation upon the individual's death. It would also reduce the emotional stress felt by hospital staff members when requesting consent for organ donation from grieving relatives. Such an approach would preserve the principles of autonomy and voluntarism upon which ideally organ donation should be based.

Finally, we should not forget that the medical profession itself may be an obstacle to organ donation¹⁶. The organ procurement system in this country is still ineffective. Many in the profession are still sceptical about brain stem death. There are few well-trained requesting staff and few medical staff are willing to initiate organ salvage. To improve organ procurement rate, apart from professional education, legislative changes like the "required request" law that had been introduced in the USA¹⁷ will help. The law requires medical staff to approach the next of kin of every patient in whom brain death is imminent or established to request for organ donation. As shown in this survey, 52% of parents were in favour of the introduction of "required request" law.

In conclusion, this survey has shown that parents were generally unwilling to donate kidneys. Alternative approaches need to be considered to help improve organ donation rate in this country.

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Table IV
Parents' attitude to kidney donation according to age, gender and other characteristics

	N	Prevalence of willingness to donate own kidneys % (95% CI)	P value*
Age:			
<40	131	24 (10-37)	NS**
41-50	352	23 (18-28)	
>50	94	24 (4-43)	
Sex:			
Male	453	22 (16-28)	NS
Female	171	23 (17-29)	
Race:			
Malay	223	9 (6-13)	<0.05
Chinese	297	26 (21-32)	
Indian	82	38 (23-54)	
Others	15	59 (43-76)	
Religion:			
Muslim	229	11 (6-15)	<0.05
Buddhist	212	23 (16-29)	
Christian	74	42 (30-54)	
Hindu	62	37 (19-55)	
Others	33	40 (25-55)	
Monthly income:			
<RM 500	81	6 (2-15)	<0.05
RM500 - 1000	190	17 (9-25)	
RM1000 - 2000	138	28 (20-36)	
RM2000	196	32 (23-40)	
Education:			
Primary	91	4 (0-12)	<0.01
Secondary	343	24 (19-28)	
Tertiary	185	30 (21-38)	
Previous blood donation:			
Yes	176	34 (24-45)	<0.05
No	445	18 (13-23)	

* : computed using adjusted Wald test for overall comparison; not for pairwise comparison in group with more than two categories.

** : NS is non-significant

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