Determinants of Willingness to Become Organ Donors among Dialysis Patients' Family Members

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Purpose: This study explores the factors affecting the willingness of dialysis patients' family members to become involved in living and deceased organ donation.

Materials and Methods: We utilize cross sectional data on 350 family members of dialysis patients collected through self-administered survey from June to October 2013. The factors affecting willingness to become deceased and living organ donors among respondents were identified by running logistic regressions.

Results: The findings reveal that ethnicity, education and role in family are significant factors explaining willingness for living donation, while ethnicity, knowledge of organ donation and donor age drive willingness for deceased donation. We also find that the reasons of respondents being unwilling to donate center on the lack of information and family objections for deceased donation, while being medically unfit, scared of surgery and family objections are the reasons for unwillingness to donate living organs.

Conclusion: In light of our findings, educational efforts are suggested to decrease the reluctance to become involved in living and deceased donation.

Keywords: health knowledge; attitudes; practice; decision making; motivation; tissue donors; psychology; tissue and organ procurement; kidney transplantation; living donors.

INTRODUCTION

Many countries including Malaysia are facing severe shortages of donated organs. Indeed, Malaysia has one of the lowest donation rates in the world. In 2008, the deceased donation rate only stood at 0.48 per million population (PMP) which is much lower than the donation rates in other countries, such as Spain, (34.13 PMP) the United States (26.27 PMP), and Singapore (6 PMP).[1] Although modern medical technologies allow transferring organs from living bodies, this process does not help increase supply. Further, while in some countries including Malaysia, incentives have been used to increase living and deceased, the outcomes remain minimal. This finding suggests that a deeper understanding of the factors affecting potential donors' willingness to become involved in living and deceased organ donation is vital.

Previous studies indicate that many factors explain people's willingness to donate organs, such as relational ties for living donations,[1,2] gender, income,[1,3] cultural and religious beliefs,[4-6] and educational level.[1] However, knowledge of organ donation and transplantation and family influence on organ donation decisions have been found to be the most important factors influencing living and deceased organ donation.[2,3,6-9] Previous studies of the factors influencing decisions to become an organ donor have also highlighted the importance of knowledge, values, attitudes and social norms towards donation, as found by Ghorbani and colleagues,[10] Trompeta and colleagues[11] and Morgan and Miller.[12,13] Rodrigue and colleagues[14] compare the characteristics of donor and non-donor families, finding that in addition to race, marital status and employment status, attitudes towards organ donation play a significant role in explaining the probability of consenting to donation. They also find that family members with more favorable attitudes towards organ donation are more likely to give their consent. Morgan[15] and Trompeta and colleagues[11] studied the importance of communication about organ donation in the family to increase the likelihood of them giving their consent and thus influence the rate of organ donation.

In parallel, for the Malaysian case, earlier studies have shown that a lack of knowledge of the medical issues related to organ donation is the primary reason behind Malaysians' reluctance to donate their organs after death.[16] On the other hand, some studies have found that in multiethnic communities, ethnicity could be a significant factor in determining willingness to donate, for both living and deceased donations.[1,3,17]

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Received: November 2014 & Accepted: June 2015

Table 1. Elements of the 'knowledge of organ donation' variables.

No	Statement	Correct Answer
1	Healthy individuals can lead a normal life with one kidney.	True
2	Organs from a deceased donor could be harvested even without consent of the donor's family.	False
3	A person is actually dead if his/her brain stopped functioning, even though his/her heart is still beating with the help of a machine.	True
4	An organ donated by a Malay, Chinese, Indian, or other ethnicity would only be transplanted to a patient of the same ethnicity.	False
5	If we do not complete a form declaring that we do not want our organs to be transplanted to others upon death, the government can procure our organs for the purpose of transplantation without our consent.	False
6	The deceased body of a donor will not remain intact (with some mutilation or disfigurement) after their organs have been harvested.	False
7	Completing a form from certified medical officers is the only method for a person to become a deceased donor.	False

The present paper examines the factors affecting the decision to donate living and deceased organs among dialysis patients' family members. Specifically, it explores the determining factors affecting organ donation willingness by using logistic regressions and analyzes the reasons behind unwillingness to become a donor in Malaysia. This study examines willingness to donate among those who have personal experience of kidney failure patients, specifically whether such personal contact leads to altruistic behavior.

MATERIALS AND METHODS

Sampling and Data Collection

A survey of the views of family members of dialysis patients regarding their willingness to donate living and deceased organs was carried out, involving 350 individuals. Three nurses informed 175 dialysis patients that two of their family members (one man, one woman) would be asked to participate in the survey. The questionnaire was prepared in three languages (Malay, English, and Mandarin). Patients that had no family members present were excluded from the survey. We started the survey in June 2013 and had collected 350 responses by October 2013. First, we asked respondents about their willingness to donate living and deceased organs, finding that 51.7% (181) are willing to be deceased organ donors (P = .521), while a significantly higher number are willing to become living donors 60.9% (213) (P = .00). Unwilling donors were asked to indicate the reasons behind their refusal. Six reasons were given for refusing to donate living organs (medically unfit, against religion, do not trust hospital procedures, believe humans cannot live with one kidney, scared of surgery, objection by family) and five reasons were stated for refusing to donate deceased organs (do not trust hospital procedures, against religion, inadequate information, objection by family, do not want to donate).

Estimation Approach

To understand the factors influencing respondents' willingness to become organ donors, we estimated two logistic regression. We estimated their willingness to become organ donor (1 = agree, 0 = disagree) against their demographic backgrounds, patients' characteristics and knowledge of organ donation. The first estimation concerns living donation and the second estimation is for deceased donation. The logistic regressions were carried out by using the Statistical Package for the Social Science (SPSS Inc, Chicago, Illinois, USA) version 21.0. The estimated model is presented as follows:

Willingness = f (age of respondent, education, gender, ethnicity, role in the family, marital status, knowledge about organ donation, age of patient, relationship with patient, importance of patient's income). To gauge the level of knowledge of organ donation among the family members of dialysis patients, we constructed a seven-item knowledge statement, as shown in **Table 1**. For every correct statement, a point was given and the total score was computed to ascertain the knowledge scores. The remaining variables of the models are described in **Table 2**.

RESULTS

Before illustrating the results, it is worthy describing respondents' socioeconomic and sociodemographic backgrounds. Of the 350 respondents, 58.9% are women. The ethnic composition resembles that of Malaysia's population, where Malays comprise the largest proportion (54.7%), followed by Chinese (32.0%) and

Table 2. Description of the model variables.

Variables	Description
Willingness	1 – willing, 0 – unwilling
Education	Secondary and lower, tertiary, other (tertiary as base)
Gender	Male – 1, female – 0
Role in the family	Spouse / parents, children, others (spouse / parents as base)
Marital status	Single, married, other (married as base)
Relationship with patient	Close – 1, not close – 0
Importance of patient's income	Very important, important, not important (not important as base)

Table 3. Willingness to become living donor.

Variables	B	Standard Error	Wald Test**	Significance	Exp(B)
Role in the family					
Child	.748	.325	5.287	.021*	2.113
Other	.814	.723	1.266	.260	2.257
Education					
Primary	-.815	.349	5.452	.020*	.443
Other	.530	.713	.552	.457	1.698
Ethnicity					
Chinese	1.119	.339	10.892	.001*	3.063
Indian	.293	.464	.398	.528	1.340
Other	1.105	.875	1.593	.207	3.019
Constant	.292	.338	.747	.388	1.339

The relationship between the odds ratio and the coefficient (given in the column labeled "B").
Exp(B) - This is the exponentiation of the B coefficient, which is an odds ratio.
* Significant at the 5% significance level.
** The Wald test in the context of logistic regression is used to determine whether a certain predictor variable is significant or not. It rejects the null hypothesis of the corresponding coefficient being zero.

Indians (10.8%), with the remaining 2.5% from other ethnic groups. The majority of respondents have secondary and primary education. Respondents' are typically low-income earners, while the reported household income shows that many of them earn more than Malaysian Ringgit (MYR) 4000 per month (1000 MYR = 265 USD). Married respondents are predominantly represented in the sample. The age of respondents ranges between 17 and 76 years old, the average age is 41 years old and 54.6% of respondents are aged below 40 years. Just over half (54.6%) of respondents stated that they are either a parent or a spouse (i.e. the main decision makers of the household), with 40.6% of respondents declaring they are children in the family (the majority aged between 21 and 30 years old), which means most of the children are already financially independent.

Factors Affecting the Probability of Being an Organ Donor

We estimated the model to understand the determinants of willingness to donate, using binary logistic regressionsunder the stepwise method to examine the most influential factors. The results of the regressions for living and deceased donation (**Tables 3 and 4**) revealed that none of the patient's characteristics influenced the probability of their family members becoming an organ donor.

The estimation found that the decision to become a living organ donor is influenced by education level, ethnicity and role in the family. Based on the regression results, the signs of the estimated coefficient suggested that Chinese are more likely to become organ donors compared with Malays (P =.01), while there is no significant difference between Malays and Indians (P =.528) and other races (P =.207). In terms of education, those with lower education are less likely to be organ donors compared with respondents with higher education (P =.020). The findings also showed that if the respondent is a child in the family, she/he is more likely to be an organ donor compared with being a spouse or

Table 4. Willingness to become a deceased donor.

Variables	B	Standard Error	Wald Test**	Significance	Exp(B)
Knowledge	.229	.104	4.825	.028*	1.258
Age	.051	.011	20.990	.000*	.950
Ethnicity					
Chinese	1.466	.342	18.401	.000*	4.334
Indian	1.256	.481	6.815	.009*	3.512
Other	1.891	.915	4.272	.039*	6.629
Constant	.246	.725	.115	.735	1.278

The relationship between the odds ratio and the coefficient (given in the column labeled "B").
Exp(B) - This is the exponentiation of the B coefficient, which is an odds ratio.
* Significant at the 5% significance level.
** The Wald test in the context of logistic regression is used to determine whether a certain predictor variable is significant or not. It rejects the null hypothesis of the corresponding coefficient being zero.

Table 5. Reasons behind being unwilling to be a living donor, by ethnic group.*

Reasons	Ethnicity				Total
	Malay	Chinese	Indian	Other	
Medically unfit	60 (32.3)	62 (53.4)	12 (30.8)	4 (44.4)	138 (39.4)
Against religion	8 (4.3)	4 (3.4)	0 (0.0)	0 (0.0)	12 (3.4)
Do not trust hospital procedures	7 (3.8)	2 (1.7)	1 (2.6)	0 (0.0)	10 (2.9)
Believe that humans cannot live with one kidney	6 (3.2)	1 (9.0)	1 (2.6)	0 (0.0)	8 (0.0)
Scared of surgery	56 (30.1)	25 (21.6)	12 (30.8)	2 (22.2)	95 (27.1)
Objection from family	49 (26.3)	22 (19.0)	13 (33.3)	3 (33.3)	87 (24.9)
Total	186 (100.0)	116 (100.0)	39 (100.0)	9 (100.0)	350 (100.0)

* Data are presented as no (%).

a parent (P = .021).

By running the same regression for deceased donation, we found that knowledge, age and ethnicity explain the probability of becoming a deceased donor. As for ethnicity, similar to living donation, Chinese are more likely to become organ donors compared with Malays (P = .000). We also found that the probability of becoming a deceased donor is higher for Indians (P = .010) and other ethnic groups (P = .039) compared with Malays. In the decision to become a deceased donor, we found that knowledge plays a role. As expected, the higher the knowledge, the more likely the individual is to be an organ donor (P = .028). The coefficient estimate for age indicates that the older the age of the respondent, the less likely he will be a deceased organ donor. Further examination of the age factor revealed that respondents aged below 30 years (P = .002) and between 31 and 40 years (P = .084) have a greater tendency to agree to deceased donation, while there is no significant difference on the choice of becoming a deceased donor for respondents aged between 41 and 50 years. On the contrary, the oldest age group (above 50 years) recorded a significantly higher number of respondents being unwilling to become involved in organ donation (P = .005).

Reluctance to Become a Donor

Altogether, 39.4% of reluctant respondents indicated that they are 'medically unfit' to be organ donors. Other reasons behind their unwillingness to be living donors included being 'scared of surgery' (27.1%) and 'objection by family' (24.9%). As for deceased donation, the most cited reason among respondents was 'inadequate information' (42.0%), followed by 'objection by family' (33.4%).

Since the logistic regression results suggest that the likelihood of being a living or deceased organ donor differs by ethnicity, it is worth analyzing ethnic differences. The results shown in **Table 5** and **Figure 1** report that Malays and Chinese cited 'medically unfit' as the main reason for being unwilling to donate. Indians cited 'objection by family' the most, although this reason was less influential for Malays (26.3%) and Chinese (19%). On the contrary, Chinese (21.6%) appeared to be less 'scared of surgery' than Malays (30.1%) and Indians (30.8%). Finally, over half (53.4%) of Chinese-believe they are 'medically unfit' compared with Malays (32.3%) and Indians (30.8%).

For deceased donation, all ethnicities cited 'inadequate

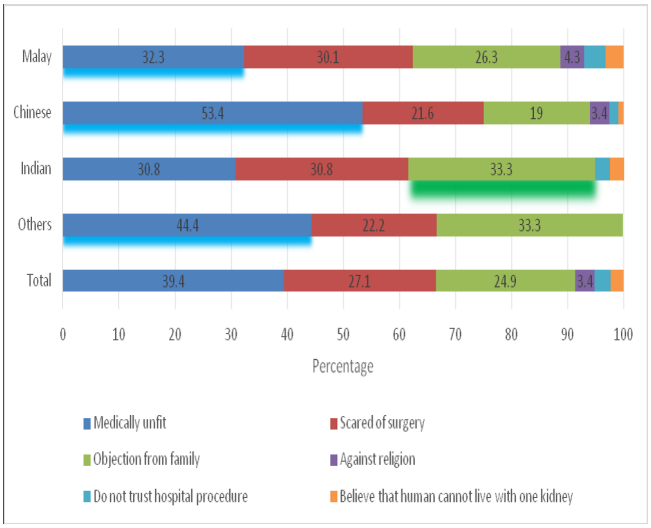

Figure 1. Reasons behind being unwilling to be a living donor, by ethnic group; percentages.

All numbers are within-group percentages. Shaded rectangles represent the within-group most cited statement.

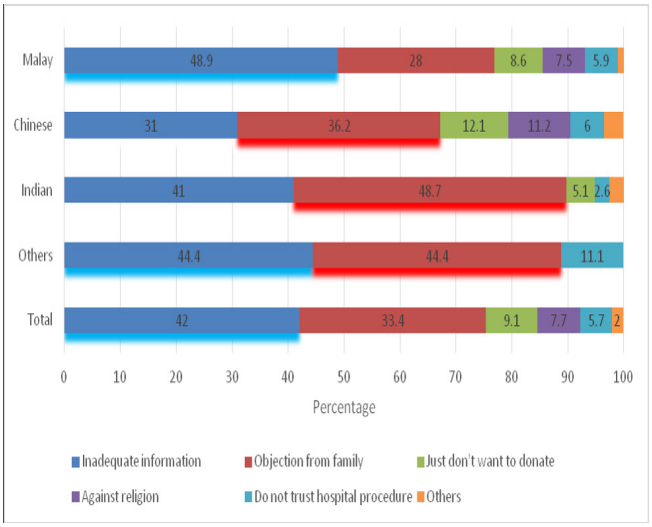

Figure 2. Reasons behind being unwilling to be a deceased donor, by ethnic group; percentages.

All numbers are within-group percentages. Shaded rectangles represent the within-group most cited statement.

Table 6. Reasons behind being unwilling to be a deceased donor, by ethnic group.

Reasons	Ethnicity				Total
	Malay	Chinese	Indian	Other	
Do not trust hospital procedures	11 (5.9)	7 (6.0)	1 (2.6)	1 (11.1)	20 (5.7)
Against religion	14 (7.5)	13 (11.2)	0 (0.0)	0 (0.0)	27 (7.7)
Inadequate information	91 (48.9)	36 (31.0)	16 (41.0)	4 (44.4)	147 (42.0)
Objection by family	52 (28.0)	42 (36.2)	19 (48.7)	4 (44.4)	117 (33.4)
Just don't want to donate	16 (8.6)	14 (12.1)	2 (5.1)	0 (0.0)	32 (9.1)
Other	2 (1.1)	4 (3.4)	1 (2.6)	0 (0.0)	7 (2.0)
Total	186 (100.0)	116 (100.0)	39 (100.0)	9 (100.0)	350 (100.0)

information' and 'objection by family objection' as their main obstacles to becoming a deceased donor. However, Chinese (36.2%), Indians (48%), and other ethnicities stressed 'objection by family' more than Malays (28%) and the other minor ethnic groups. The reason 'inadequate information' comprised about half of Malays' reluctance to be deceased organ donors. However, in a general sense, the variations among ethnicities were not as significantly high as expected see **Table 6** and **Figure 2**.

DISCUSSION

The literature on the determinants of organ donation has found that many socioeconomic and sociodemographic factors affect willingness to donate organs. However, influencing factors seem to be country-specific rather than globally standardized. In this sense, our results accord with one part of the literature and refute another. The logistic regressions proved the significance of ethnicity in explaining willingness to be involved in living and deceased donations, which concurs with the research findings.[1,3,16] Similarly, educational level and role in the family were found to affect living organ donation, as stated in previous works such as Boulware and colleagues,[2] Irving and colleagues,[2] Mossialos and colleagues[18] and Trompeta and colleagues.[11] These results suggest that knowledge of organ donation and age of donors are also contributing factors in explaining willingness to be involved in deceased donation, which match the findings of Irving and colleagues,[2] Simpkin and colleagues[9] and Ghorbani and colleagues.[10] By contrast, the findings of our logistic regression refute that gender, marital status, income or relationship with the patient explain the willingness of family members to donate their organs, ether in living or in deceased donation.

Respondents' stated reasons for being unwilling donors strengthened the notion that a lack of information is a vital factor causing the low donation rates in Malaysia. This finding accords with our logistic analysis on deceased donation. Additionally, matching a large part of the literature, objection by family appeared to be another vital factor influencing the deceased donation decision. In this context, we suggest that family rejection is a part of the lack of information problem. In other words, when family members are not well informed about organ donation, they will refuse it, not only for themselves but also for their relatives. Some studies go further on this point, stating that peoples' willingness to donate their organs is higher than their willingness to donate those of their relative.[18,19]

Family objections to deceased donation may apply to living donation as well. This factor was cited by about 24% of respondents and ranked as the third most important driving force of rejecting living donation. However, the lack of information on living donation seems to be less influential than that on deceased donation, since our living logistic analysis didnot list this factor among the significant variables. Furthermore, other factors were cited as more influential than knowledge for the living donation case, namely 'medically unfit' and 'scared of surgery.'

The results of both estimations and elaboration of respondent's reasoning suggests that ethnicity should be taken into consideration in any effort to increase the rate of organ donation. The majority of Malays seem to be in need of information on organ donation, while the objection by family issue seems to influence Chinese and Indians on deceased donations to a greater extent. For living donations, assuming that being medically unfit is based on the opinion of health professionals, solving the family objection issue seems to be more influential for encouraging donations from Indians than from Malays and Chinese, conquering being 'scared of surgery' for the latter two ethnicities may result in decreasing refusal rates for living donation.

In sum, our regression analysis of the responses of 350 family members of dialysis patients showed that willingness for deceased donation is driven by ethnicity, knowledge of donation and age of donor, while for living donation willingness is affected by ethnicity, role in the family and level of education. In parallel, the elaboration of unwilling respondents' reasoning revealed that being 'medically unfit' and 'scared of surgery' are the most cited reasons for being unwilling to donate living organs. A lack of information was the most cited reason for deceased donations. Objection by family is a commonly cited reason for both living and deceased donations. Further, ethnicity-specific variations hold, too. Nonetheless, we admit that our findings have some limitations. It would have been more comprehensive to collect data on level of altruism as well as on the values and attitudes of respondents towards organ donation. Since many recent studies have discussed the role of communicating organ donation in the family, we aimed to extend these findings by including the elements of communication in our survey.

CONCLUSIONS

The outcomes of this study suggest that providing peo-

ple with suitable information on organ donation could be a channel to overcome the low deceased organ donation rates in Malaysia. An educational effort is also suggested for living donation to relax the negative attitudes towards living donation surgery of about 27% of potential donors. Moreover, we suggest that providing potential donors with adequate medical education on living and deceased organ donation may increase donation rates indirectly by reducing the huge influence of family objection to donations.

ACKNOWLEDGMENTS

The authors wish to thank the Ministry of Higher Education Malaysia and the University of Malaya for funding this research under the Exploratory Research Grant Scheme (Project Number: ER019-2012A).

CONFLICT OF INTEREST

None declared.

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