

Knowledge, attitude and factors influencing public willingness towards organ donation among hospital patients and relatives in Negeri Sembilan, Malaysia

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ABSTRACT

Background: Malaysia continues to have a very low cadaveric organ donation rate of 0.48 per million population. The aim of this paper is to assess the attitude, beliefs and knowledge of patients and relatives at three different hospitals in Negeri Sembilan towards organ donation to increase the acceptability of organ transplant.

Methods: A cross-sectional descriptive study with convenient sampling was carried out Hospital Tuanku Ja'afar, Hospital Port Dickson and Hospital Tuanku Ampuan Najihah in Negeri Sembilan, Malaysia. The participants answered a questionnaire regarding the source of their information about organ donation, their knowledge about brain death and willingness to donate. The association between variables was tested using chi-squared test or Fischer's exact test as appropriate.

Results: A total of 385 individuals completed the survey of whom 134 (35%) were willing to donate their organs upon death and 25(19%) were registered donors. Higher educational level (41%), age 30 and below (42%) and people who attended organ donation awareness campaigns (60%) were more willing to donate their organs. Correct understanding of brain death was associated with willingness to be an organ donor. The commonest reason cited for unwillingness to donate was opposition from family members.

Conclusion: Marital status, religion, source of knowledge and occupation are significant factors in willingness to donate organs among Malaysians. Lower age and higher educational level were positive factors towards organ donation. Direct personal contact through awareness campaigns, family and friends has a potential for greater positive impact on organ donation.

KEY WORDS:

Organ donation, knowledge, attitude, public willingness

INTRODUCTION

Organ transplant is life saving and restores health for some patients with no other recourse for relief from their disease. In 2010, Malaysia had one of the lowest cadaver organ donation rates in the world of only 0.48 donation per million population (pmp) as compared to Spain (34.13pmp), the

United States of America (26.27) and Australia (12.10) and even among Muslim countries like Kuwait (4.48), Saudi Arabia (4.15), and Iran (2.81).¹ In Malaysia, organ transplantation began as early as the 1970's, however, the number remains less than 500 annually.

According to the National Transplant Resource Centre of Malaysia, there are currently 18,444 potential recipients. The largest number consist of patients waiting for kidney donations (18,418), followed by liver (12), lungs (6) and finally heart (5).² There were 47,298 pledged organ donors in Malaysia in the year 2015, and only 5.45% were from Negeri Sembilan.²

Religious concerns can be an obstacle to organ donation, religious leaders from all major religions and their edicts are supportive of both organ donation and transplantation.³ Several studies have been conducted in Malaysia regarding factors affecting organ donation. These studies were conducted only in Kuala Lumpur and around the Klang Valley. Studies have highlighted various findings in terms of why people may be willing or unwilling to donate organs. For example, one study found religious and cultural beliefs were not the prime reasons to not donate organs.⁴ In another, a lack of proper procurement methods and education were thought to be important reasons for unwillingness to donate organs.⁵ A study that focused on Muslims, found that lack of information on organ donation and distrust towards the system to carry out correct procurement protocols were important.⁶ Focus group discussions discovered that although organ donation is perceived to be a good thing, in addition to the reasons above, misconception, cultural myths and ethnic sensitivities were important factors limiting organ donation.⁷ Lack of awareness was also cited but cultural and religious values were also to be blamed.^{6,8} Many of these factors, however are viewed as barriers that can be overcome when approached positively.⁹

This study intends to focus on the knowledge, attitudes and behaviour of the general population in Negeri Sembilan towards organ donation.

METHODOLOGY

A cross sectional study was done to evaluate attitude, beliefs and knowledge towards organ donation in Negeri Sembilan among the patients and their relatives visiting hospitals in

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Seremban, Kuala Pilah and Port Dickson over a period of three months in 2016. The sample size was calculated using Raosoft Sample Size Calculator based on Negeri Sembilan's population in 2015 of 1,098,400.¹⁰ Expecting a response rate of 52.5% willing to be donors as was observed by a previous study,⁴ with a 95% confidence interval and margin error of $\pm 5\%$, it was determined that the sample size should be 385.

The enumerators were asked to approach respondents willing to be interviewed at these three designated hospitals to select a diverse demographic of respondents. The pretested questionnaire was presented in either English or in the Bahasa Malaysia translation. It was tested on nine individuals to note and remove ambiguities.

Beside demographic data, the respondents were presented with a specific question, "Have you ever considered being an organ donor?" This question was asked to categorise respondents who were willing and unwilling to donate. Following that, those unwilling to be donors were asked their reasons for not registering as organ donors, despite being aware of the humane motives of organ donation. Eight options were given to them and they were allowed to choose more than one option or give other answers. The options were: (1) fear of doctors not doing their best to treat due to knowledge of patient being a donor, (2) organ donated will not bring any benefit to society, (3) goes against my religious/cultural believes, (4) family will not agree, (5) fear of body mutilation, (6) delay in burial of the deceased, (7) experiencing pain after death and (8) others. The other half of the questionnaire evaluated the knowledge of respondents about brain death. Respondents were asked to select the correct statement (the brain fails to function and requires machines to continue life) from among multiple choices.

The demographic data such as age, ethnicity, monthly income, education level and occupation were collected in more than two categories. For statistical analysis, the categories of the homogenous groups were collapsed into one to re-perform analysis. Hence for religion, the categories were Muslim and Non-Muslims, race as Malay and non-Malay. The average salary of the participant was approximately RM2000 and this was captured in 4 different groups as <RM1000, RM1000 to RM2000, RM2001 to RM3000 and > RM3000. SPSS, version 23 for Windows, (SPSS Inc., and Chicago, Illinois, USA) was used to analyse data. Logistic regression was used to determine statistically significant relations, quantify relationship, and predict the probability between willingness to donate organs upon death, and donor demography, behavioural and religious parameters captured in survey.

RESULTS

A total of 385 adults from different demographics, behaviours, religion and race participated in the survey (Table I). The respondents consist of Malays (68.4%), Chinese (8.9%), Indians (20.9%) and others 1.8 %. All the responders were 18 years and above and the distribution 18–30 (132, 34%), 31–40 (93, 24%), 41–50 (59, 15%) and >50 (101, 26%). Male and Female ratio was almost 50:50. Among the

respondents 44% university graduates, 47% secondary school and 9% primary school attendees. Almost all the participants had knowledge on organ donation, 62% from media (Radio, Newspaper & TV) and others from different sources like awareness campaigns, family and friends, the internet and others.

Among 385 participants, 134 (35 %) were willing to donate their organs upon death, of whom 25 (6%) were registered donors.

Table II shows the results of univariate logistic regression for sociodemographic characteristics, source of information on organ donation and brain death awareness on willingness to donate organs at death among participants. It is evident that education, marital status, religion, race, source of knowledge and occupation are statistically significant factors in showing willingness to donate organs at death. Source of knowledge also had a highly significant overall effect in willingness to be organ donors followed by occupation, race, religion, education and marital status.

Multivariate Logistic regression also performed on the significant variables (Table III) to determine the effects of age, gender, education, marital status, income, source of knowledge, brain death awareness, religion, race and occupation with the participants showing willingness to donate organs upon death.

The logistic regression model was statistically significant, $\chi^2 = 49.311$, $p < 0.001$. Overall parameters like marital status ($p=0.046$), occupation ($p=0.034$), Source of Information ($p<0.000$) and religion ($p=0.017$) were found to be significant, and stepwise selection method retained the same and omitted remaining non-significant parameters.

Source of information had a highly significant overall effect (Wald=24.013, $df = 5$, $p<0.001$). Participants who knew about organ donation through awareness campaigns were 2.9 times more likely to be willing to donate than those who gained their knowledge from newspapers. Unmarried respondents were 1.61 times more likely to show willingness to donate than the married ones.

The influence of occupation is mixed. Private sector employees were 2.25 times more likely to show willingness than those not working. Non-Muslim participants are 1.8 times more likely to donate compared to Muslim religion.

The reason each respondent ranked first for being unwilling to donate is shown in Figure 1. Only 254 responded to this question. 'Family disapproval' and 'fear of mutilating the corpse' were the leading choices. More Chinese (4/20 [20%]) and Indians (8/45[17.8%]) cited fear of decreased quality of care by doctors compared to Malays (18/188 [9.6%]). More Malays (26/188 [13.8%]) cited religion and tradition as the reason for not becoming organ donors compared to Chinese (1/20 [5%]) and Indians (2/45 [4.4%]). However, the difference was not statistically significant.

Table I: Sociodemographic characteristics of respondents of survey

	n	Willing to donate organ, (%)	Registered as organ donor, (%)
Age:			
18-30 years	132	55 (41.7)	11 (8.3)
31-40 years	93	34 (36.6)	5 (5.4)
41-50 years	59	19 (32.2)	3 (5.1)
> 50 years	101	26 (25.7)	6 (5.9)
Gender:			
Female	193	63 (32.6)	13 (6.7)
Male	192	71 (37.0)	12 (6.3)
Education:			
Primary	33	7 (21.2)	0 (0)
Secondary	181	57 (31.5)	17 (9.4)
University	171	70 (40.9)	8 (4.7)
Marital status:			
Married	257	83 (33.3)	16 (6.2)
Unmarried	115	50 (43.5)	9 (7.8)
Widowed	13	1(7.7)	0 (0)
Monthly income:			
< RM 1000	158	46 (29.1)	6 (3.8)
RM 1000-2000	96	43(44.8)	11 (2.9)
RM 2001-3000	62	22 (35.5)	6 (1.6)
> RM 3000	69	23 (33.3)	2 (2.9)
Source of knowledge			
Newspaper	131	43 (32.8)	4 (3.1)
Radio/TV	107	24 (22.4)	4 (3.7)
Awareness campaign	62	37 (59.7)	11 (17.7)
Internet	36	13 (36.1)	2 (5.6)
Family/Friends	30	12 (40.6)	3 (10.0)
Other	19	5 (26.3)	1 (5.3)
Brain death awareness			
No	207	70 (33.8)	14 (6.8)
Yes	178	64 (36.0)	11 (6.2)
Race:			
Chinese	34	15 (44.1)	3 (8.8)
Indian	82	37 (45.1)	8 (9.8)
Malay	262	79 (30.2)	13 (5.0)
Others	7	3 (42.9)	1 (14.3)
Religion:			
Buddhist	28	12(42.9)	2 (7.1)
Christian	14	8 (57.1)	1 (7.1)
Hindu	67	31 (46.3)	8 (11.9)
Muslim	268	82 (30.6)	13 (4.9)
Others	8	1(12.5)	1(12.5)
Occupation:			
Not Working	132	37 (28.0)	5 (0.04)
Private Sector	123	54 (43.9)	12 (9.8)
Government Worker	88	32 (36.4)	6 (6.8)
Retired	42	11 (26.2)	2 (4.8)
Total	385	134 (34.8)	25 (6.5)

DISCUSSION

We found a slightly lower rate of willingness to donate organs (35%) among people in Negeri Sembilan in comparison to those in Kuala Lumpur in studies done between 2008 and 2010 by Tumin (44.3%)⁵ and Loch (43.6%).⁸ On a positive note, this rate is higher than what Lim found in Kuala Lumpur (22%) in 1998. In that survey, however, Lim had an option of 'don't know (32%) for their subjects which may account for the lower rate they found. We had fewer Chinese (9%) compared to the other studies (25-48%)^{5,8,11} but, age, income and education level were comparable. This compares unfavourably with Turkey (57%)¹² and the United States (59%)¹³ but is better than Nigeria (30%).¹⁴

The higher rate of willingness to donate among the young and those with tertiary education is comparable to other local studies^{4,5,8} as well as elsewhere.^{12,13} Similarly, it has been previously found that Malays and Muslims are less willing to be donors^{5,6,8,15} A survey among health care professionals found Malays were also less inclined to accept organ donation.¹⁵

Awareness campaigns appear to be the most effective means of influencing actual donor registration and willingness (59.7%) but the method is costly. Newspapers, radio and television were the more common sources of information, but they were less effective when donor registration and willingness was considered. Because of the positive effect

Table II: Univariate Logistic Regression analysis of factors to determine effect of on willingness to donate organs

Parameter	Category	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper
Age	18 - 30 years	1		
	> 50 years	0.49	0.28	0.85
	31 - 40 years	0.81	0.47	1.39
	41 - 50 years	0.67	0.35	1.27
Gender	Female	1		
	Male	1.21	0.80	1.84
Education	Secondary	1		
	Primary	0.59	0.24	1.43
	University	1.51	0.97	2.33
Marital status	Married	1		
	Un-married	1.61	1.03	2.53
	Widowed	0.17	0.02	1.37
Income	< RM 1000	1		
	> RM 3000	1.22	0.66	2.23
	RM 1001 - RM 2000	1.98	1.16	3.35
	RM 2001 - RM 3000	1.34	0.72	2.50
Religion	Muslim	1		
	Non-Muslim	1.87	1.20	2.93
Race	Malay	1		
	Non-Malay	1.87	1.20	2.92
Occupation	Not working	1		
	Government	1.47	0.82	2.61
	Private	2.01	1.19	3.38
	Retired	0.91	0.42	2.00
Source of knowledge regarding organ donation	News paper	1		
	Awareness campaign	3.03	1.62	5.66
	Family and friends	1.36	0.60	3.09
	Internet	1.16	0.53	2.50
	Others	0.73	0.25	2.16
	Radio & TV	0.59	0.33	1.06
Brain death awareness	No	1		
	Yes	1.10	0.72	1.67

Table III: Multivariate Logistic Regression for significant variables affecting willingness to donate organs

Parameter	Category	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper
Marital status	Married	1		
	Un-married	1.61	0.97	2.69
	Widowed	0.19	0.02	1.60
Source of knowledge regarding organ donation	News paper	1		
	Awareness campaign	2.95	1.53	5.69
	Family and friends	1.15	0.49	2.71
	Internet	0.89	0.39	2.04
	Others	0.56	0.18	1.72
	Radio & TV	0.54	0.29	0.99
Religion	Muslim	1		
	Non-Muslim	1.83	1.12	3.00
Occupation	Not working	1		
	Government	1.60	0.86	2.97
	Private	2.25	1.28	3.97
	Retired	1.14	0.49	2.67

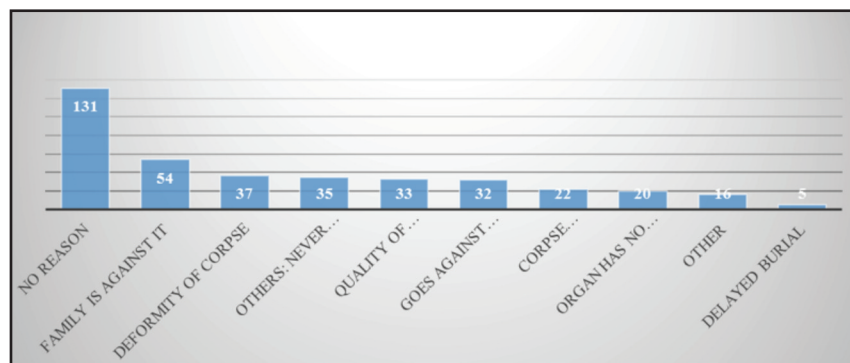


Fig. 1: Reasons for not registering as organ donors
Awareness regarding brain death was found to have no significant impact towards willingness to donate organs.

family influence has on individuals (40%), and its potential as a deterrent, it might be advisable to promote organ donation in family-centred venues. The influence of the internet on willingness to donate may account for better response among the younger age group. Studies conducted in the United States has recognised communication within families regarding organ donation resulted in more willingness to allow family members to pledge their organs for donation.^{16,17} Non-governmental organizations (NGO's) are important in playing a vital role in creating awareness by educating the public on various issues related to organ donation.¹⁸ In our study this aspect was not looked at, hence we suggest that NGOs may be involved in future awareness campaign.

Knowledge about brain death was not significant in influencing the willingness towards organ donation, which is similar to what Loch reported.⁸ Since this was not a primary endpoint that was taken into account in our sample size calculation the results may be inconclusive as the survey sample may not have been large enough. Knowledge of brain death may not necessarily make a person more likely to donate organs but at least it would enable the person to be better informed to make their choice. The concept of brain death is poorly understood. Many think they understand, but in fact they may not know. Such a misconception is a barrier to organ donation.

LIMITATIONS

Our methods of selecting hospital patients and their relatives is not the ideal method of sampling among the Negeri Sembilan population. Furthermore, a person's unwillingness to participate would confound any sampling method and we chose not to give any incentive for participation, but only willing subjects were enrolled. The reasons for unwillingness to be organ donors were chosen from a list, and not spontaneous statements from the respondents. Unwillingness to donate may not have a rational reason. A person's choice may be influenced by emotions and hidden fears and prejudices. The choice of the irrational statement that 'the corpse may experience pain' suggests that. Wong⁷ and Tumin⁵ noted that Chinese were most likely to express family disapproval as a reason for being unwilling to donate, but we found that it was the most common reason given by all races.

Our findings differ from that of Loch⁸ and Tumin^{4,5} who found that there was mistrust, expressed in statements like "organs might be used for medical research" and "I am not convinced that my body parts will be used beneficially". Such mistrust was also prominent in Nigeria.¹⁴ Religious misconceptions have been reported to be an important cause for low organ procurement in other countries like Turkey.

One caution about generalising our findings is that despite reaching a sample size to represent the population of Negeri Sembilan, the ethnic distribution of our sample did not reflect the general population well as participants were recruited in a hospital setting. The questionnaire was administered through enumerators, because respondents were not all literate, and the reading of the questions and explanation to them might affect their answers.

CONCLUSION

Marital status, religion, source of knowledge and occupation are significant factors in willingness to donate organs among Malaysians. Direct personal contact through awareness campaigns, family and friends all have potential for greater positive impact on organ donation.

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