

Differences in attitude towards cadaveric organ donation: observations in a multiracial Malaysian society

在馬來西亞多種族社會的觀察：對屍體器官捐贈態度的分別

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Background: Willingness to donate organs is affected by socio-cultural and religious values. The Malaysian society is made up of three ethnic groups: Malay, Chinese, and Indian, with Islam, Buddhism and Hinduism as their religions respectively. This study examined the knowledge and perception towards organ donation for each group. **Methods:** This study was conducted at University Malaya Medical Centre, Kuala Lumpur, Malaysia. Relatives of patients awaiting treatment at the emergency department answered a questionnaire on knowledge and attitude on organ transplantation. **Results:** A total of 904 questionnaires were completed; 90.6% would accept organs, 43.6% would donate, and 4.0% carried donor cards. The reasons for reluctance to donate included: fear of organs being used for research (18.8%), desire to be buried whole (18.0%), fear of less active treatment if patient is known to be a donor (12.8%). Malays were less willing to accept organs from a different race (63.5%) compared to Chinese (83.3%) and Indians (83.8%) (OR=0.35, 95%CI: 0.23-0.54 and OR=0.34, 95%CI: 0.22-0.51 respectively) and also less likely to donate organs (29.8%) as compared to Chinese (42.1%) and Indians (63.2%) (OR=0.57, 95%CI 0.40-0.83 and OR=0.24, 95%CI 0.17-0.35 respectively). Malays were less willing to donate organs to another race compared to Chinese or Indians (OR=0.48, 95%CI 0.33-0.70 and OR=0.22, 95%CI 0.15-0.31 respectively). Only 34.7% of Muslims are aware of fatwa supporting organ donation. **Conclusions:** The awareness of organ donation was low. Clear differences exist among ethnic groups. Cultural-religious attitudes and lack of trust in the medical systems were reasons for reluctance to donation. Identifying socio-cultural barriers and reassuring donors regarding medical care are required. (*Hong Kong j.emerg.med.* 2010;17:236-243)

引言：捐贈器官的意願是受社會文化及宗教價值的影響。馬來西亞社會由三個種族組成：馬來人、華人及印度人，分別的宗教為伊斯蘭教、佛教及印度教。本研究審查各組對器官捐贈的知識及理解。**方法：**本研究在馬來西亞吉隆坡馬來亞大學醫學中心進行。在急症室等候治療病人的親屬，對器官移植知識及態度的問卷作答。**結果：**共完成 904 份問卷，90.6% 會接受器官，43.6% 會捐贈器官，4.0% 攜有捐贈卡。不願捐贈的原因包括：恐懼器官被用作研究（18.8%），全屍埋葬的意慾（18.0%），及恐懼如病人被知悉為捐贈者後，治療會不積極（12.8%）。比較華人（83.3%）及印度人（83.8%），馬來人較不願意接受不同種族的器官（63.5%），機會率分別為 0.35（95% 置信區間 0.23，0.54）及 0.34

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(95% 置信區間 0.22, 0.51)。馬來人捐贈器官的可能 (29.8%) 亦較華人 (42.1%) 及印度人 (63.2%) 為低，機會率分別為 0.57 (95% 置信區間 0.40, 0.83) 及 0.24 (95% 置信區間 0.17, 0.35)；馬來人比華人或印度人較不願意捐贈器官給另一個種族，機會率分別為 0.48 (95% 置信區間 0.33, 0.70) 及 0.22 (95% 置信區間 0.15, 0.31)。只有 34.7% 的伊斯蘭教徒知道教令是支持器官捐贈的。**結論：**器官捐贈的認知度低，在種族組別間存有明顯的分別。不願意捐贈的原因為文化宗教的態度及對醫療系統的不信任；需要識別社會文化的障礙及在醫療護理方面對捐贈者再作保證。

Keywords: Attitude, ethnic groups, Malaysia, transplants, tissue and organ procurement

關鍵詞：態度、種族群、馬來西亞、移植、取得組織及器官

Introduction

Organ donation is an established practice in the Western world but remains limited in developing countries. The major limiting factor next to financial constraints within the governing bodies and limited expertise in transplantation medicine appears to be donor availability. It is generally believed that the main reasons for this are the social and cultural differences in the Asian population compared to the West.

Malaysia is no exception as a developing country in that there is a huge gap between the number of transplants that are being carried out and the needs of the population. Despite the fact that it has been over 30 years since the first organ transplant was carried out, the total number of transplants remains low for the current population of 28.31 millions.¹ Transplantation from organ donation after death is extremely rare. In 2006, there were only 25 cadaveric donors resulting in a donation rate of 1.01 donations per million population.² The main bulk of transplantation is from commercial donors from countries such as China or from live related donors.²

The method of obtaining consent for donation in Malaysia is the 'opting in method' whereby a person states the intention to donate organs when he is alive, registers with the National Donor Registry and is issued a donor card.³ This is in contrast to the 'opt out' policy practised in neighbouring Singapore where one's organs are harvested automatically unless there is an advanced formal objection to having organs removed post mortem. In both cases however, it is also standard

practice to take into account the immediate relatives' wishes.

Perception toward organ donation encompasses many factors; mainly education, religion and culture. Malaysia is unique – unlike the more homogenous populations in Asia – as it is made up of three large, separate ethnic groups; Malays, Chinese and Indians. This diversity was created by the British colonialism in the 18th and 19th centuries when large numbers of Chinese and Indians were brought to the Malaysian peninsula to satisfy labour demands in mines and rubber plantations. The current distribution of the ethnic groups are as follows; Malays 65%, Chinese 26% and Indians 8%.¹ Although they have lived harmoniously together for at least three generations, there are many differences in their cultural and religious beliefs. All Malays are Muslims whereas the main religions for the Chinese and Indians is Buddhism and Hinduism respectively, although other religions such as Christianity are also becoming increasingly more popular among the non-Malay races. The fact that Malaysia has a large population of three very different races therefore provides an interesting opportunity to examine differences in attitude and perception towards cadaveric organ donation in these three racial groups and its implications in terms of organ transplantation.

The aims of our study were to look at the overall knowledge with regards to cadaveric organ transplantation as well as the attitudes towards cadaveric organ donation in the general population and in each of the three major ethnic groups. We also sought to identify potential factors associated with

unwillingness or reluctance to donate organs after death.

Methodology

This study was conducted at the University of Malaya Medical Centre (UMMC) in Kuala Lumpur, Malaysia. Relatives of patients awaiting treatment in the emergency department were consecutively recruited. A standard questionnaire both in English and in Bahasa Malaysia (the national language for the country) was distributed to the subjects. The areas covered in the questionnaire were as follows: knowledge about cadaveric organ donation, attitude towards becoming a cadaveric organ recipient and attitude towards becoming a cadaveric organ donor. A pilot study was carried out and based on the findings, a modified questionnaire was distributed. The subjects were considered to have good knowledge of organ donation in the country only if they were aware of the existence of the National Donor Program and/or donor cards. Baseline demography of the subjects was recorded, in particular ethnicity and education level.

Statistical results were analysed using SPSS. A p value less than 0.05 was considered as significant.

Results

A total of 1000 questionnaires were distributed and 904 subjects completed the questionnaires from December 2007 until September 2008. Baseline demography was as follows: Malays 329 (36.4%), Chinese 228 (25.2%), Indians 272 (30.1%), others 75 (8.3%); male 447 (49.4%) female 457 (50.6%). Mean age was 35.9 (\pm 14.8).

General knowledge in organ transplantation and donation

Overall, 798 (88.3%) participants were aware of organ transplantation in general, 563 (62.3%) answered that they were aware that they could donate their organs after death as a method of organ procurement, and 497 (55.0%) were aware of campaigns to promote

organ donation. However, only 226 (25.0%) had heard of the National Donor Program and 250 (27.7%) were aware of the feasibility of obtaining a donor card. The concept of brainstem death was accurately defined by only 91 (10.1%) respondents, however 253 (28.0%) knew that brainstem death is an irreversible condition.

An Islamic fatwa was issued in 1969, supporting organ donation; 163 (49.5%) of the 329 Malays interviewed knew that there was a fatwa on organ donation, but what was actually decreed (i.e. that organ donation is acceptable) was only known by 114 (34.7%) of the Malays interviewed. Subjects with a low education level (no schooling, primary school and secondary school) and Hindus (compared to Muslims) were found to have a significantly lower knowledge regarding cadaveric organ donation on univariate analysis. A low education level was the only independent factor associated with knowledge of organ donation on multiple logistic regression (Table 1).

Attitude towards organ donation

Overall, 845 (93.5%) respondents felt that donating one's organs can save lives, and 819 (90.6%) would accept an organ to save their life. However, only 690 (76.3%) would accept an organ from a donor that is not of the same race or religion, meaning that 14.3% of the respondents were willing to accept an organ but would not accept this from a person of a different race or religion.

In terms of organ donation, 394 (43.6%) answered that they would donate their organs, 96 (10.6%) would definitely not donate their organs and 414 (45.8%) were not sure. Out of those willing to donate organs, 369 (40.8%) would do this for a person of a different race or religion. In addition, 214 (23.7%) would agree to the procurement of organs of their relatives, 69 (7.6%) would not and 621 (68.7%) were not sure. Although 313 (34.6%) of the subjects answered that they had discussed donating their organs with family or friends, only 36 (4.0%) actually had donor cards.

The main reasons given for reluctance to donate organs after death were as follows: "organs might be used for medical research" – 170 (18.8%); "desire to be buried

Table 1. Factors associated with good knowledge of organ donation on univariate analysis (crude odds ratio) and multiple logistic regression (adjusted odds ratio)

		% with good knowledge within group	cOR	95%CI	p value	aOR	95%CI	p value
Age	<50 yrs	9.8	1.00					
	≥50 yrs	11.3	1.16	0.74-1.83	0.512	–	–	NS
Gender	Male	8.8	1.00					
	Female	11.7	1.38	0.89-2.13	0.145	–	–	NS
Ethnicity	Malay	27.3	1.00					
	Chinese	21.9	0.75	0.49-1.13	0.146	–	–	NS
	Indian	27.2	0.99	0.68-1.45	0.967	–	–	NS
Education level	Low	6.0	1.00					
	High	13.7	2.51	1.53-4.10	<0.001	2.53	1.51-4.23	<0.001
Religion	Muslim	12.8	1.00					
	Buddhist	8.1	0.60	0.29-1.21	0.126	–	–	NS
	Hindu	6.7	0.49	0.25-0.94	0.020	–	–	NS

aOR=adjusted odds ratio; CI=confidence interval; cOR=crude odds ratio; NS=not significant

whole" – 163 (18.0%); fear that "doctors would not do everything possible to save one's life if they know that the patient would be a donor" – 116 (12.8%); the opinion that "organ donation violated one's sanctity" – 107 (11.8%); fear of being "cut up alive or having pain after death" – 98 (10.8%); and that organ donation was "against one's belief/religion" – 76 (8.4%). Less common reasons stated included "dislike one's organs in someone else's body" – 35 (3.9%); concern that it was "against the wishes of the family" – 15 (1.7%); "mentally unprepared" or "have not given the matter serious thought" – 15 (1.7%); the opinion that the respondent's organs were "not in good condition" or that he "was too old" – 13 (1.4%). In addition, 19 (2.1%) answered that the reason for not donating was that they "did not know how to go about doing so" and 4 (0.4%) were afraid that their "organs might be traded or sold" (Figure 1).

Factors associated with reluctance towards donating one's organs after death on univariate analysis were low education level, Malay race, older age (≥50 years old) and Muslim religion (compared to Hindus). Multiple logistic regression analysis confirmed that all the above factors were independently associated with attitude towards organ donation. Knowledge of

brainstem death and knowledge regarding organ donation were not found to be significantly associated with the willingness to donate one's organs after death (Table 2).

Ethnic differences and organ donation

The data were categorised according to the three major ethnic groups (Table 3). The percentage of subjects who were considered to have a high education level (tertiary) was highest in the Chinese when compared

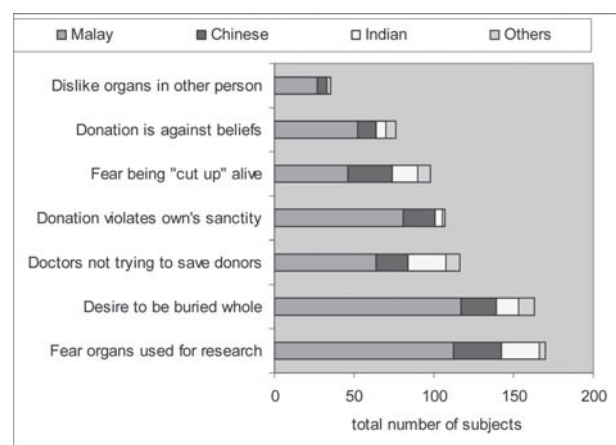


Figure 1. Common reasons for unwillingness to donate organs (multiple answers allowed).

Table 2. Factors associated with a positive attitude toward cadaveric organ donation on univariate analysis (crude odds ratio) and multiple logistic regression (adjusted odds ratio)

		% willing to donate	cOR	95%CI	p value	aOR	95%CI	p value
Age	<50 yrs	46.5	1.00					
	≥50 yrs	37.9	0.70	0.50	0.015	0.67	0.48-0.92	0.02
Gender	Male	45.2	1.00					
	Female	42.5	0.89	0.69-1.16	0.398	–	–	NS
Ethnicity	Malay	29.1	1.00					
	Chinese	42.9	1.83	1.28-2.61	<0.001	1.91	1.31-2.76	0.001
	Indian	63.2	4.20	2.98-5.90	<0.001	5.38	3.74-7.75	<0.001
Education level	Low	38.0	1.00					
	High	49.2	1.58	1.21-2.08	0.001	1.81	1.32-2.47	<0.001
Religion	Muslim	30.8	1.00					
	Buddhist	36.7	1.31	0.86-1.99	0.190	–	–	NS
	Hindu	63.8	3.96	2.73-5.77	<0.001	4.23	2.92-7.23	<0.001
Good knowledge of organ donation	No	43.1	1.00					
	Yes	50.5	1.35	0.88-2.08	0.168	–	–	NS
Good knowledge of brainstem death	No	41.9	1.00					
	Yes	46.5	1.21	0.93-1.59	0.164	–	–	NS

aOR=adjusted odds ratio; CI=confidence interval; cOR=crude odds ratio; NS=not significant

Table 3. Knowledge and attitude towards organ donation of the three major ethnic groups in Malaysia

	Total	Malay	Chinese	Indian	p value
n	904	329	228	272	
Male: Female	447: 457	156: 173	102: 126	138: 134	
Age	35.9 (±14.8)	32.88 (±12.3)	39.52 (±16.25)	36.32 (±14.9)	
Education level					<0.001
Primary and secondary	385 (42.6%)	133 (40.4%)	84 (36.8%)	150 (55.1%)	
Tertiary	519 (57.4%)	196 (59.6%)	144 (63.2%)	122 (44.9%)	
Good knowledge of organ donation	232 (25.7%)	90 (27.4%)	50 (21.9%)	74 (27.2%)	0.283
Good knowledge of brainstem death	93 (10.3%)	40 (12.2%)	26 (11.4%)	10 (3.7%)	0.090
Yes to receive organ	819 (90.6%)	302 (91.8%)	206 (90.4%)	242 (89.0%)	0.500
Yes to receive organs from a different race	690 (76.3%)	209 (63.5%)	190 (83.3%)	228 (83.8%)	<0.001
Yes to donate organs	394 (43.6%)	98 (29.8%)	96 (42.1%)	172 (63.2%)	<0.001
Yes to donate organs to different race	369 (40.8%)	83 (25.2%)	94 (41.2%)	166 (61.0%)	0.001
Yes to donate relative's organs	214 (23.7%)	42 (12.8%)	52 (22.8%)	96 (35.3%)	<0.001
Has a donor card	36 (4.0%)	8 (2.4%)	10 (4.4%)	16 (5.9%)	0.548

Data expressed as number (%) or mean (SD) where appropriate. The total consists of the 3 ethnic groups plus 75 subjects not classified by the three main races.

to the Malays and the Indians. However, there was no statistical difference in the general knowledge overall with regards to organ donation between the three ethnic groups. There was no statistical difference in terms of becoming an organ recipient in general, although Malays were less likely to accept organs from a different race compared to the Chinese (OR=0.35, 95% CI 0.23-0.54) and the Indians (OR=0.34, 95% CI 0.22-0.51). The Malays were also less willing to donate their organs as compared to the Chinese and the Indians in general (OR=0.57, 95% CI 0.40-0.83 and OR=0.24, 95% CI 0.17-0.35 respectively) and to a different race (OR=0.48, 95% CI 0.33-0.70 and OR=0.22, 95% CI 0.15-0.31 respectively). Similarly, the Chinese were less likely to donate their organs compared to the Indians, both in general (OR=0.42, 95% CI 0.29-0.62) and to a different race (OR=0.45, 95% CI 0.31-0.65). The Malays were also less willing to allow the procurement of organs from their relatives compared to the two other ethnic groups (OR=0.50, 95% CI 0.31-0.79 and OR=0.27, 95% CI 0.17-0.41 respectively) and the Chinese were less likely to allow the procurement of organs from their relatives compared to the Indians (OR=0.54, 95% CI 0.36-0.82).

Discussion

Although most people in Malaysia were aware of organ transplantation, it is clear that most subjects interviewed did not have an in depth knowledge of organ transplantation, particularly the idea of donating one's organs after death. Most of the subjects only had a very vague concept of brainstem death and its irreversibility. Only very few people have discussed organ donation which can be either due to the fact that there is lack of awareness or that it is not considered an important decision to make. Not surprisingly, a higher education level was associated with a better knowledge with regards to organ donation. This is of particular significance as UMMC hospital serves an urban population which is mainly made up of the middle social class. The main bulk of the Malaysian society still resides in 'kampung' or small villages where the education level and exposure to the media are below those of urban areas. Therefore, this

study is likely to overestimate the general level of knowledge of the Malaysian people.

When looking at the attitudes towards organ donation in general, almost half of the subjects interviewed answered that they were willing to donate their organs after death although in reality, only a very small number of the subjects actually had donor cards. For those who were reluctant or unsure, the reasons given were similar to those found in other studies⁴⁻⁹ and interestingly one major reason is lack of confidence in the medical profession. The educational level was associated with willingness to donate but it was also found that the younger age group was more willing to donate compared to the older age group. From our study, knowledge either of cadaveric organ donation in general or the concept of brainstem death did not appear to be associated with one's attitude towards cadaveric organ donation. This is in contrast to other studies.^{8,10-12} There is however other data suggesting that knowledge of cadaveric donation alone is not sufficient to determine one's willingness to donate organs after death.⁹

An interesting observation is that subjects were almost twice as likely to express willingness to donate organ themselves as compared to when they had to consent for donation from a family member. This is very relevant in real life as unless the patient has a donor card, consent has to be sought from the patient's family. Unawareness of the attitudes of close family members towards donation and lack of communication within families regarding death and donation seem plausible to explain this.

This study clearly demonstrates that there are ethnic differences in attitude towards organ donation. When we looked specifically at the three major ethnic groups, there was no statistical difference in terms of knowledge of organ donation or brainstem death, although the percentage of Chinese with tertiary education was higher compared to the Malays and Indians. Malays were less willing to donate their organs compared to the Indians and Chinese although Malays were equally willing to become organ recipients. This finding concurs completely with data from the National

Transplant Registry, where in 2006, only one out the 25 actual cadaveric organ donors was Malay.² In contrast however, Malays make up the bulk of the recipients in many areas of organ transplantation.

The three major groups studied practice very different religions. The Hindu teaching overall supports organ donation as part of a concept of "selfless giving".¹³ Although there are no clear guidelines on organ donation, it appears that Buddhism overall also supports organ donation.¹³ From the Islamic point of view, a fatwa (decree) on organ donation had been issued in Malaysia in 1969 stating that organ donation was not haram (forbidden) in Islam and was in fact permitted not only for the benefit of other fellow Muslims, but also for non-Muslims.¹⁴ This is in keeping with similar fatwas in other Muslim countries.¹⁴ However, it appears that there are still widely held belief that it is forbidden in Islam.^{6,15} Even a recent review article in the medical setting erroneously stated that organ donation was forbidden in Islam as the human body is considered sacred after death.¹⁶ Less than half of the Malay subjects interviewed were aware that a fatwa on organ donation even existed and even in those who answered that they were aware of the fatwa, one third of them wrongly thought that the fatwa was against organ donation. Subgroup analysis revealed that Malays who were aware of the correct Islamic fatwa on organ donation were more willing to donate than those who did not and a study in Saudi Arabia found that the Islamic view supporting concepts of transplantation provided the strongest positive influence for organ donation both during life and at death.¹⁷ This sends out a very strong message that if the Islamic fatwa was more effectively disseminated among the Muslim community, the Muslim community might be more amenable to donating organs after death.

The study also demonstrated that Chinese were less willing than Indians to donate their organs after death. Studies that looked at other Chinese populations found similar negative perceptions as those found in the Muslim community, particularly with regards to the sanctity of the human body,^{5,9,18} but whether or not this is due to the teachings of a specific religion per se is far from clear. It is well known that socio-cultural

beliefs are a combination of many and often intangible factors; therefore detailed, qualitative studies are required to further examine these beliefs within each ethnic population. Not surprisingly, those with a negative perception towards cadaveric organ donation were also reluctant to allow the procurement of organs from their loved ones.

Another interesting observation is that a significant number of the subjects were less willing to become an organ recipient or an organ donor if it were to involve a race other than their own. As mentioned previously, the three races have lived harmoniously for three generations but it is clear from this study that there is still a sense of racial segregation that is maintained.

In Western countries, differences in attitudes towards organ donation have been observed but those who were least likely to donate usually consist of the ethnic minorities.¹⁹⁻²¹ The reluctance of Malays to donate, however, is particularly significant in Malaysia as this ethnic group by far forms the majority of the population and improving the perception in this particular ethnic group would be the most beneficial. Without the supply of cadaveric organs, it would be impossible for procedures such as heart or liver transplants to be carried out. Transplant medicine is extremely complex, both in terms of the surgery itself as well as the after care and a sufficient volume is required in a transplant centre in order to ensure optimum management for the patient. As the Malaysian government does not plan to adopt an opt out policy for organ donation any time in the near future; increasing awareness, improving methods to register and making sure that family members are involved in the decision making process are also important steps that must be taken if Malaysia is to progress in the field of organ transplantation. It is also essential to address specific concerns such as the public's apparent lack of confidence in the methods of organ procurement by the medical profession.

There are several limitations to the study. UMMC serves an urban population and the ethnic distribution and education level is not representative of Malaysia. Therefore, one cannot extrapolate all the results of the

study to the country in general. In addition to this, there were a significant number who did not fill out or complete the questionnaires. The missing data included vital information such as ethnicity and education level and was therefore excluded from analysis. It is likely that those who did not complete the questionnaire either had lack of knowledge or a negative perception towards organ donation which has implications in terms of the accuracy of the study leading to an overestimation of the number of subjects willing to donate their organs or skewing the data in terms of ethnic differences. What the study highlights however, are the potential areas which need to be targeted in order to improve the cadaveric donation rate in the country.

In conclusion, awareness in terms of cadaveric organ donation is low in Malaysia and there are differences in the acceptability among the three major ethnic groups; Malay, Chinese and Indian. Addressing social barriers to cadaveric organ donation is essential in order to establish a successful and sustainable nationwide program that is acceptable to these three groups.

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