TRANSPLANT INTERNATIONAL

Transplant International ISSN 0934-0874

ORIGINAL ARTICLE

# Are health professionals responsible for the shortage of organs from deceased donors in Malaysia?

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**Keywords**
brain death, donation, education, organ, procurement.

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**Conflict of Interest**
There is no conflict of interest.

Received: 9 June 2012
Revision requested: 17 July 2012
Accepted: 21 October 2012
Published online: 3 December 2012

doi:10.1111/tri.12019

## Summary

The rate of organ donations from deceased donors in Malaysia is among the lowest in the world. This may be because of the passivity among health professionals in approaching families of potential donors. A questionnaire-based study was conducted amongst health professionals in two tertiary hospitals in Kuala Lumpur, Malaysia. Four hundred and sixty-two questionnaires were completed. 93.3% of health professionals acknowledged a need for organ transplantation in Malaysia. 47.8% were willing to donate their organs (with ethnic and religious differences). Factors which may be influencing the shortage of organs from deceased donors include: nonrecognition of brainstem death (38.5%), no knowledge on how to contact the Organ Transplant Coordinator (82.3%), and never approaching families of a potential donor (63.9%). There was a general attitude of passivity in approaching families of potential donors and activating transplant teams among many of the health professionals. A misunderstanding of brainstem death and its definition hinder identification of a potential donor. Continuing medical education and highlighting the role of the Organ Transplant Coordinator, as well as increasing awareness of the public through religion and the media were identified as essential in improving the rate of organ donations from deceased donors in Malaysia.

## Introduction

Organ replacement via transplantation is currently the best available treatment for endstage organ failure [1,2]. More than 15 000 Malaysians are currently waiting for organ transplants [3]. Organ donation is an established practice in the Western world but remains limited in developing countries, especially among Asians [4]. The rate of organ donations from deceased donors in Malaysia is among the lowest in the world with only 39 actual donors in 2009 for a population of 28.3 million [5]. This translates to a donation rate of 1.38 per million population (pmp), far behind many countries such as Spain (33–35 pmp), the USA (16–28 pmp), and Singapore (7–9 pmp) [6].

Malaysia adopts the 'opt-in' policy whereby a person has to give consent to become a donor; anyone who has not given consent is not a donor. There are currently around 192 000 pledged organ donors in Malaysia [7]. Presumed consent or the 'opt-out' policy is practiced in countries such as neighboring Singapore where one's organs are recovered automatically unless there is an advanced formal objection to having organs removed post mortem. In both cases the families' wishes are taken into consideration. Loch *et al.* showed that 43.6% of Malaysians were willing to donate their organs, and 90.6% of the study population would accept an organ to save their life [8]. It seems unlikely that Asian cultural and social values are solely responsible for the low rates of donation in Malaysia.

According to the Malaysian National Transplant Registry, road accident-related injury was the most common cause of death among the organ donors [9]. In 2009, Malaysia had the highest road deaths among 33 countries – 23.8 per 100 000 inhabitants [10] or almost 7000 road deaths [11]. Unfortunately with only 152 organ donor referrals and 38 actual organ donors in that year the huge number of potential donors was not translated into a high actual organ donation rate.

Are health professionals at least partly responsible for the shortage of organ donors? There is evidence that the shortage of organ donors is not primarily the result of a lack of suitable donors but rather the result of the failure to identify them, obtain consent and procure the organs [12]. We hypothesize that the severe shortage of organ donors in Malaysia is largely because of passivity among health professionals in identifying suitable donors and activating the organ donation process. To date there have been no studies in Asia to demonstrate the role of health professionals in the success (or failure) of organ donation and transplant programs.

Malaysia is unique; unlike the more homogenous populations in Asia it is a diverse multicultural country made up of three distinct ethnic groups – Malays, Chinese, and Indians. This diversity was created during British colonial rule in the 18th and 19th centuries when large numbers of Chinese and Indians were brought to then Malaya to satisfy labor demands in mines and rubber plantations. The current distribution of ethnic groups is as follows: Malays 60.3%, Chinese 22.9%, and Indians 6.8% [13]. Malays are Muslims whereas the main religions for the Chinese and Indians are Buddhism and Hinduism, respectively, although other religions such as Christianity are also represented. Malaysia therefore further provides an interesting opportunity in examining cultural and religious differences in attitude and perception toward organ donation from deceased donors, as well as its effect on organ transplantation.

## Objectives

**1.** To assess the attitudes, knowledge, and understanding of health professionals in Malaysia in organ transplantation, identifying suitable donors and activating the organ donation process.
**2.** To examine the frequency in requesting for organ donation to the families of the potential donors.

## Methods

The cross-sectional study was conducted in two maximum-capacity urban hospitals in Kuala Lumpur, Malaysia – University Malaya Medical Centre (UMMC) and Hospital Kuala Lumpur (HKL). Both hospitals were tertiary referral centers equipped with transplant facilities. The doctors, staff nurses and medical assistants were recruited by convenient sampling and were asked to answer a standardized self-administered closed-ended questionnaire. The questionnaire was pilot-tested, revised, and the final version distributed to all subjects. The study was conducted for a 6-month period from January 2010 to June 2010. The questions were designed to assess the knowledge of health professionals in organ transplantation, as well as their attitudes toward organ transplantation itself. Baseline demography was recorded. The study was approved for both hospitals by the University of Malaya ethics committee (MEC Ref. No: 818.21).

Statistical analyses were carried out using SPSS 17.0 (SPSS Inc, Chicago, IL, USA). Potential factors associated with the main outcome variable were analyzed using the Chi-squared test (univariate analysis) to obtain a crude odds ratio. This was followed by multiple logistic regression where applicable to identify independent factors associated with the main outcome variable by eliminating possible confounding factors (adjusted odds ratio, no correction factor). A $P$-value of $<0.05$ was taken as significant.

## Results

Five hundred questionnaires were distributed; 462 were completed (92.4% response rate). The youngest respondent was 18 years old and the oldest 64 years old. The median age was 29; mean age was 30.7. There was no correlation between age and willingness to donate ($P > 0.05$). The majority of respondents were Muslim (66.7%), Malay (59.1%), and from the Department of Emergency Medicine (49.6%).

47.8% of the respondents were willing to donate their organs. 36.4% were unsure, and only 15.8% categorically refused to donate their organs. Doctors were more willing to donate their organs (54.6%) than other healthcare workers (34.8%). Men were more willing to donate their organs (59.5%) than women (40.8%). Most departments were similar in their willingness to donate organs; however, an obvious exception was Obstetrics and Gynecology with only 25% willing to donate organs and 66.7% unsure (Fig. 1). Senior doctors (consultants, specialists) were more willing to donate organs (63.2%) than junior doctors (53.9%).

Distributed by race, the Chinese and Indians were more willing to donate their organs (71.4% and 71.6%, respectively) compared with only 35.9% of the Malays. The majority of Malays were unsure (45.4%). Statistically the Chinese were four times more likely to donate their organs as the Malays (aOR 4.09, 95% CI 1.28–13.09, $P = 0.018$; Table 1). Distributed by religion, most Christians stated that they would donate their organs (80%, cOR 6.64,

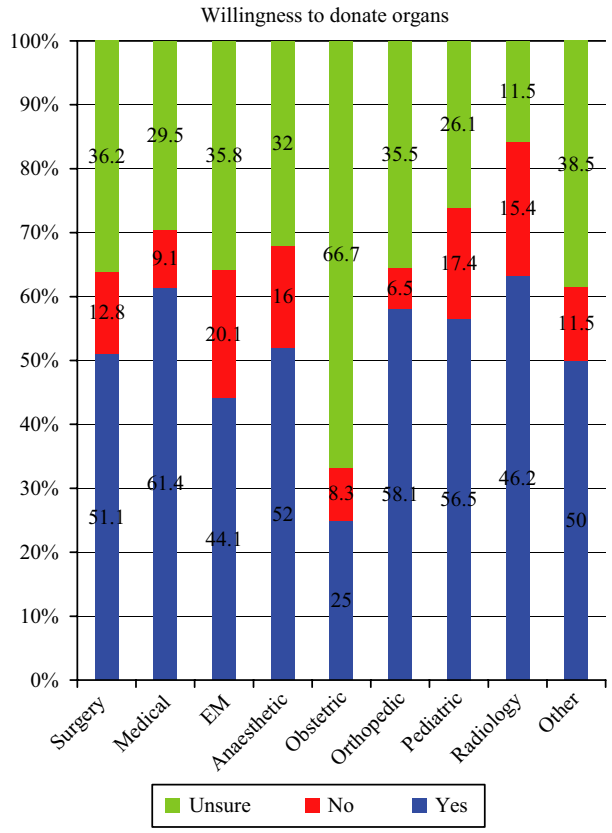


**Figure 1** Willingness to donate organs according to department.

$P < 0.001$), and almost 70% of Buddhists (cOR 3.64, $P < 0.001$) and Hindus (cOR 3.51, $P < 0.001$) would donate their organs compared to only 37% of Muslims. However, the adjusted odds ratio has shown religion to be of no significance because of confounding race, too many categories and an uneven distribution.

**Table 2.** Source of knowledge about organ transplantation.

| | School/University/ Hospital | Media | Colleagues | Organ Transplant Society |
|---|---|---|---|---|
| Occupation | | | | |
| Doctor | 44.7% | 36.8% | 11.8% | 6.6% |
| Others | 44.3% | 39.2% | 6.3% | 10.1% |

45% of the health professionals acquired their knowledge about organ transplantation from school, university, or their hospitals. The media was a close second (37% for doctors and 39% for other health professionals; Table 2).

The respondents were asked about the definition of death in terms of organ transplantation; in total, 284 (61.5%) gave the correct response: 'when the criteria for brainstem death has been fulfilled'. Seventy per cent of doctors, and 44% of the other health professionals answered this correctly. The doctors showed better understanding and the difference was statistically significant. Twenty-one per cent of the doctors and 43% of the other healthcare workers stated that cardiac death (no heartbeat) was the final criterion of death. The majority correctly recognized the criteria for brain death (77.5%; Table 3). There was no statistical difference in knowledge of brainstem death between Muslims (77.6%) and health professionals of other religious faiths (77.3%, $P = 0.937$).

Across the board all agreed that the person to contact in the presence of an organ donor was the Organ Transplant Coordinator (86.5% for doctors and 87.3% for the other healthcare workers). However, only 82 respondents, or

**Table 1.** Categories of healthcare professionals willing to donate organs.

| | % within group willing to donate (vs. unwilling/unsure) | cOR | CI | *P*-value | aOR | CI | *P*-value |
|---|---|---|---|---|---|---|---|
| <45 years | 210/438 (47.9%) | 1.05 | 0.67–1.63 | 0.840 | – | – | – |
| ≥45 years | 11/24 (45.8%) | 1.00 | | | | | |
| Men | 103/173 (59.5%) | 1.46 | 1.21–1.75 | <0.001 | 1.67 | 1.08–2.63 | **0.021** |
| Women | 118/289 (40.8%) | 1.00 | | | 1.00 | | |
| Malays | 98/273 (35.9%) | 1.00 | | | 1.00 | | |
| Chinese | 55/77 (71.4%) | 4.46 | 2.49–8.07 | <0.001 | **4.09** | 1.28–13.09 | **0.018** |
| Indians | 48/67 (71.6%) | 4.51 | 2.42–8.47 | <0.001 | 3.41 | 0.97–11.97 | 0.056 |
| Islam | 115/308 (37.3%) | 1.00 | | | | | |
| Buddhist | 46/67 (68.7%) | **3.64** | 2.00–6.67 | <0.001 | – | – | **NS** |
| Hindu | 38/56 (67.9%) | **3.51** | 1.84–6.73 | <0.001 | – | – | |
| Christian | 16/20 (80.0%) | **6.64** | 2.02–24.14 | <0.001 | – | – | |
| Doctor | 166/304 (54.6%) | 2.25 | 1.51–3.35 | <0.001 | 1.48 | 0.94–2.33 | 0.88 |
| Other | 55/158 (34.8%) | 1.00 | | | | | |
| UMMC | 119/254 (46.9%) | 1.00 | | | | | |
| HKL | 102/208 (49.0%) | 1.09 | 0.76–1.57 | 0.639 | – | – | – |

cOR, crude odds ratio; aOR, adjusted odds ratio; CI, confidence interval; NS, not significant; UMMC, University of Malaya Medical Centre; HKL, Hospital Kuala Lumpur.

**Table 3.** Knowledge and attitude of healthcare professionals relating to procurement of organs.

| | *n* (% within group) | cOR | CI | *P*-value | aOR | CI | *P*-value |
|---|---|---|---|---|---|---|---|
| Good knowledge of brainstem death | | | | | | | |
| Doctors | 242/304 (79.6%) | 1.41 | 0.90–2.21 | 0.131 | N/A | N/A | N/A |
| Other health professionals | 116/158 (73.4%) | | | | | | |
| Knowledge of how to contact organ transplant coordinator | | | | | | | |
| Doctors | 56/304 **(18.4%)** | 1.15 | 0.69–1.91 | 0.600 | N/A | N/A | N/A |
| Other health professionals | 26/158 **(16.5%)** | 1.00 | | | | | |
| Ever approached family of potential donor | | | | | | | |
| Doctors | 117/394 (38.5%) | 1.35 | 0.90–2.03 | 0.147 | _ | _ | NS |
| Other health professionals | 50/158 (31.6%) | 1.00 | | | | | |
| Willing to donate own organs | 94/221 (42.5%) | **1.70** | 1.16–2.50 | **0.006** | **1.60** | 1.08–2.37 | **0.019** |
| Unwilling or unsure whether to donate own organs | 73/241 (30.3%) | 1.00 | | | | | |
| Good knowledge of brainstem death | 132/358 (36.9%) | 1.15 | 0.72–1.82 | 0.548 | _ | _ | _ |
| Poor knowledge of brainstem death | 35/104 (33.7%) | | | | | | |
| Knowledge on how to contact OTC | **41/82** (50%) | 1.51 | 1.16–1.95 | **0.004** | **1.95** | 1.20–3.17 | **0.007** |
| No knowledge on how to contact OTC | 126/380 (33.2%) | 1.00 | | | 1.00 | | |

17.7% knew how to contact the Organ Transplant Coordinator (OTC). The majority (86.8%) did not know. There was no statistical difference between the two occupation groups. In our subgroup analysis, more subjects in HKL (23%) knew how to contact coordinator compared to UMMC (13%) (*P*-value < 0.05).

63.9% of the respondents had never approached the families of the deceased patient regarding organ donation. Both occupation groups were more likely to never ask families about organ donation, regardless of whether they knew how to contact the coordinator or not ($P < 0.05$). Interestingly, respondents who knew how to contact the coordinator were almost twice as likely to approach the family of a potential donor compared with those who did not (aOR 1.95, CI 1.20–3.17, $P = 0.007$; Table 3). Therefore, there was a positive correlation between the subject's knowledge and the likelihood of approaching the potential donor's family.

Among the respondents willing to donate organs, 42% have approached family members regarding organ donation. In comparison, only 30.3% of those who were unwilling or unsure to donate organs had ever done so. This correlation between willingness to donate organs and approaching families of potential donors was statistically significant (aOR 1.60, CI 1.08–2.37, $P = 0.019$; Table 3).

The anesthetic and pediatric departments scored highest, with 64% and 60.8%, respectively, having ever approached family members when an organ donor was identified. Conversely, the lowest scores came from the orthopedic (22.6%) and emergency departments (28%). Seventy-two per cent of emergency personnel had never approached family members regarding organ donation (Fig. 2).

Many respondents (65.8%) still preferred to maintain the opt-in policy while 34.2% felt a change to the opt-out policy was necessary. 54.1% agreed that there should NOT be financial rewards for families in organ donation,

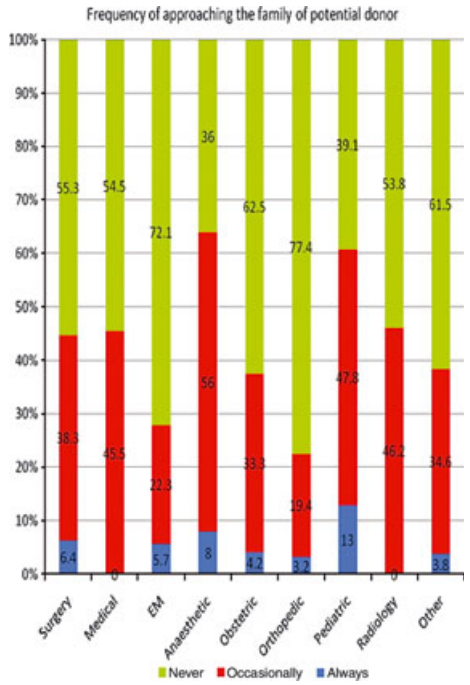


**Figure 2** Frequency of approaching families of potential donors according to department.

although interestingly nurses and medical assistants were more likely to agree that financial rewards should be provided to the donors' families compared with the doctors (53% to 42%, cOR 1.339; 95% CI 1.039–1.724).

Most of the respondents (93.3%) agreed that there was a need for organ transplantation in Malaysia. The overwhelming majority (94.2%) thought that continuing medical education (CME) regarding organ transplantation was critically needed in the hospitals.

**Table 4.** Role of religion in educating the public about organ donation according to the main religions in Malaysia.

| | Total | Muslims | Buddhists | Hindus | Christians | Others | *P*-value |
|---|---|---|---|---|---|---|---|
| Religion should play a role | 79.7% | 84.7% | 71.6% | 69.6% | 65.0% | 63.6% | <0.05 |

The majority of the respondents (79.7%) thought that religion should play a role in educating the public about organ donation and transplantation (Table 4). The majority of Muslims especially (84.7%) felt religion should play a role in public education regarding organ transplantation compared with other religions.

## Discussion

### Attitudes of health professionals

Health professionals are fundamental in the process of organ procurement. They represent a highly educated and trained subgroup of society, and more importantly their input determines whether a transplantation program succeeds or fails. They are the first individuals to establish a relationship with the potential donors' family and to have the opportunity to raise the option of organ donation. As stated by Dominguez-Gil *et al.*, the first step in the critical pathway for organ donation is identification or referral of a potential donor by the treating physician [14]. Their attitudes and perceptions can in addition influence the public opinion and hence influence the organ donation rate. Rumsey *et al.* have shown that patients have a more 'positive' attitude toward organ donation if they know that the doctors are willing to donate organs themselves [15]. Most health professionals in this study agreed that there was a need for organ transplantation in Malaysia, but less than half were willing to donate their organs. In this respect, the attitude of the medical profession was very similar to the attitudes of the Malaysian public [8], despite health professionals being more knowledgeable and exposed to organ donation in their day to day practice. Doctors were significantly more willing to donate their organs compared with the other health professionals. There was a significant connection between personal preferences regarding willingness to donate their organs and the frequency in which they approached families of potential organ donors.

### Ethnic and religious differences

The majority who were unwilling or unsure to donate their organs were Malay and Muslim, and conversely the Chinese and Buddhists formed the majority willing to donate their organs. Even in this select subgroup of educated people were the racial and religious differences clear. This is mirrored in the general population, where only 8% of organ donors in 2009 were Malay and two-thirds were Chinese [16]. The majority of health professionals across the board, especially the Muslims, thought that religion should play a role in educating the public regarding organ donation. This is in keeping with a recent study conducted in UMMC where all three ethnic groups especially the Malays required community and religious leaders for support in organ donation awareness and education [17]. For example, there was an exceptional increase in Malay donors to 20% in 2007, attributed to the media blitz following the organ donation of a 15-year-old Malay boy, which was supported by three state Muftis (religious Muslim leaders) and the director general of the Department of Islamic Development Malaysia (JAKIM) [18]. From the Islamic point of view, a fatwa (decree) on organ donation was issued in Malaysia stating that organ donation was not forbidden in Islam and was in fact permitted not only for the benefit of other fellow Muslims, but also for non-Muslims [19]. This was in keeping with similar fatwas in other Muslim countries [20]. However, there still seems to be the widely held belief that it is forbidden in Islam, including a review article which incorrectly stated that organ donation was forbidden in Islam as the human body is considered sacred after death [21]. If the Islamic fatwa was better disseminated among the Muslim community, they might be more amenable to donating organs after death.

### Brain death

The controversy in removing viable organs from 'live' patients with an intact (albeit artificial) cardiorespiratory system prompted an ad hoc committee at Harvard Medical School to define the term 'irreversible coma' in 1968 [22], which has gradually gained consensus toward what is now known as brain death. Direct brainstem testing was introduced in 1976, and organ recovery was rapidly switched from cardiac death donors to brain dead patients. These donors have become the principal source of organs for transplantation in the last 30 years [23], whereas in donations after cardiac death only tissues can be recovered [7]. In 1996, The Malaysian Medical Council published guidelines and recommended that the concept and entity of brain death must be recognized and accepted [24].

The majority of the health professionals showed good understanding regarding the definition of death and criteria for brain death, with doctors scoring higher than the nurses or medical assistants. This is consistent with a study by Schaeffner *et al.* which showed that higher medical

education was associated with greater knowledge of organ donation [25]. However, almost a third of the health professionals in this study still seemed unwilling to accept the concept of brain death. 10.6% of health professionals thought only neurologists could certify brain death, although the Malaysian Medical Council guidelines state that any specialist with at least 3 years of postgraduate clinical experience, trained in brain death assessment and diagnosis, is qualified to certify brain death [26]. This misunderstanding of the concept of brain death, and the uncertainty in diagnosis and assessment may mean missing the window of opportunity to recruit a potential viable organ donor.

### Approaching families of potential organ donors

Almost two-thirds of the respondents had never approached the family of brain dead patients to ask for organ donation. Siminoff *et al.* showed that in over 50% of cases, healthcare providers were unable to predict the family's initial reaction to the request to donate organs [27]. Other factors included fear of litigation [28] and fear of 'upsetting' a grieving family [29]. The referral of potential organ donors from the emergency department (ED) is associated with an increased likelihood of successful organ recovery compared with the inpatients ward [30]. Unfortunately, many of the ED personnel in this study had never approached the families of the potential donors. Commonly cited reasons specific to the ED include difficulties in locating family, lack of patient identification, minimal time to develop rapport with families, and competing demands on ED staff as barriers to organ recovery from ED [31]. A common assumption was that family members of gravely ill or newly deceased patients in the ED might be overwhelmed by emotion that they would be rendered unwilling to give consent. This fear may well be overemphasized- Stouder *et al.* showed that most people indicated that they agreed to donation so that something positive could result from their loss [32]. Only a small minority indicated that the donation process interfered with funeral or memorial arrangements, that the discussion about organ donation added more emotional stress to their overall experience and that they still had unanswered questions about aspects of donation. Still, giving consent for the removal of organs in a loved one is a sensitive and emotional issue; perhaps many healthcare workers feel inappropriately trained or have inadequate time to deal with this in their busy schedules.

### Organ transplant coordinators

Organ transplant coordinators (OTCs) are health professionals responsible for informing the brain death assessment team, activating ICU, approaching and counseling the donor's family (before the consent is taken by the transplant surgeon), informing recipient teams and getting medico-legal clearance especially for accident casualties and updating the brain death registry [workflow for organ procurement from deceased donors in UMMC]. They must be specially trained in communication skills and be the first port of call when a potential organ donor is identified. Matesanz and Miranda showed that 78% of family members who initially refused consent changed their mind after discussion with the OTC [33]. A similar finding was noted by Michael *et al.*, where the families who met with organ procurement organization requesters were three times more likely to donate than those who did not [30]. In this study, the majority of respondents would contact the OTC in the presence of a potential donor, but 82% did not know how to. Health professionals who knew how to contact the OTC were twice as likely to approach families regarding organ donation compared with those who did not know or who were unaware of the protocol, when confronted with a potential donor.

### Improvement strategies

This study identifies three main areas for improvement in donor recruitment. First, health professionals need to be educated and trained in potential donor identification as well as changing attitudes toward transplantation [34]. In our opinion, this is the rate-limiting step in the chain of events leading up to organ donation. This could be done through regular continuing medical education (CME) and specific training courses on organ transplantation [35], as it has been shown to achieve the highest and most immediate impact on organ donation [36]. They should understand the definition of brain death and agree with the concept. They have to be aware of this possibility when treating patients, and be able to recognize and diagnose brain death in the presence of a potential organ donor.

Second, the role of the OTC should be emphasized. Health professionals, especially in the Emergency Department and ICU must be informed on how to contact the OTC, who should be notified as soon as a potential organ donor is identified. This should be the next step of action, and bypasses the hurdle of approaching grieving families. This ensures that the OTC becomes the first point of contact for the families, avoiding misinterpretations or misunderstandings which can interfere or spoil the organ donation process. Furthermore, the OTC together with the hospital coordination team must be carefully chosen and trained to optimize the organ donation process [37].

The third area of improvement is increasing public awareness especially through the media and religious events, for example in the 'khutbah', or sermon, during

Friday prayers. This is particularly important for the Malay-Muslim community in Malaysia, as they make up the largest percentage of the population and continue to have prevailing misconceptions about organ donation.

## Limitations

Thirty-eight questionnaires (7.6%) were not completed; the nonresponse rate was small but could nevertheless have resulted in a slight potential bias, as health professionals who did not complete them may have no interest, or be against organ donation. In addition, although this study was performed in two of the largest tertiary hospitals in Kuala Lumpur, it may not be representative of other government and private hospitals in Malaysia.

## Conclusion

Health professionals play a very important role in ensuring the success of an organ transplantation program. Clearly the demand for an organ transplantation program in Malaysia is high, but it has many obstacles and a long way to go before its organ donation rates improve and reach levels to those seen in the Western world. This study highlights the obvious cultural and religious differences affecting the attitudes and understanding of health professionals. There is a general attitude of passivity in approaching families of brain dead patients and activating transplant teams among many of the health professionals in this study. A misunderstanding of brainstem death and its definition may hinder identification of a potential donor. Recognition of brain death is a rate-limiting step; health professionals need to recognize brain death to start the chain of events leading up to organ donation. Continuing medical education and increasing awareness (especially through religion and the media), as well as highlighting the role of the Organ Transplant Coordinator were identified as key in improving the rate of organ donations from deceased donors in Malaysia.

## Authorship

ZLZA and IH: analyzed data and wrote paper. WTM: performed study, analyzed data, wrote paper. AL: designed research. OH: collator, supervisor.

## Funding

This study has had no funding.

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