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Organ donation in Muslim countries: The case of Malaysia

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Summary

Background:

The aim of this paper is to look into the factors influencing Malaysian Muslims' decision to become deceased organ donors in Malaysia.

Material/Methods:

We approached 900 Malaysian Muslims and 779 participated in our survey, conducted in Kuala Lumpur and its suburb. We examined their willingness to become donors and the willing donors were asked why they did not pledge to become donors. Non-donors were asked why they refuse to become donors.

Results:

The survey found the main reason for Malaysian Muslims not pledging their organs was due to their lack of information on organ donation and/or their lack of confidence in the government's ability to properly administer organ donation procedures. Another interesting finding is that religion is not a main deterrent to organ donation.

Conclusions:

The survey suggests that Malaysia can explore many ways to encourage organ donation without having to resort to the highly controversial financial incentive option. A key to Malaysia's success or failure to increase organ donation rate lies in its ability to persuade its Muslim population (its largest population) to donate organs. This can be done by adopting a segmented, focused, and highly localized form of public education and by leveraging on existing networks involving local religious and community leaders as well as government and non-governmental institutions.

Key words:

community leaders • Muslim donor • organ donation • public education • religious leaders

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BACKGROUND

Malaysia's low deceased organ donation rate needs serious attention. Malaysia's deceased donation rate stands at 0.48 donations per million populations (pmp), a figure that places Malaysia amongst countries with the lowest deceased organ donation rates in the world. The problem is more acute when one considers that over 15 200 Malaysians (up to March 2012) are waiting for organ transplantation. These include 15 196 kidney patients, 3 heart and lung patients, and 1 lung patient [1].

Despite nationwide public campaigns to recruit deceased organ donors, the increase in the rate of organ donation in Malaysia has been marginal. Malaysia's donation rate is miniscule when compared to developed economies like Spain (34.13 pmp), Portugal (26.7 pmp), Belgium (25.61 pmp), and Estonia (23.5 pmp) [2]. Malaysia's donation rate is also the lowest among Muslim countries. Kuwait, Saudi Arabia, and Iran recorded 4.48, 4.15, and 2.81 donations pmp, respectively [2]. Difficulties in obtaining deceased donation organs has led some Muslim countries to start focusing on the idea of a financially compensated living donation program, as has been implemented in Iran (1988), Pakistan (the 1990s), and Saudi Arabia (2007). An interesting feature of Malaysia's organ donation pattern is that non-Muslims make up the bulk of Malaysia's organ donors. Chinese and Indians make up 60.4% and 25.1%, respectively, while Muslims represented only 5.5% of donors, a figure that is extremely low when we consider that Muslims make up almost 60% of Malaysia's total population.

The above issues raise a few concerns. First, the low rate of donation suggests that the government may not have done enough to encourage organ donation. Second, the very low base donation rate suggests that the government has huge opportunities to improve organ donation. This naturally begs the obvious question – What could be Malaysia's answer to improve its organ donation rate, or at least the deceased organ donation rate?

We believe the low donation rate among Malaysian Muslims is both a concern as well as a solution to Malaysia's organ donation problem. It is a solution because simple arithmetic suggests that an increase in Muslim organ donors would help improve Malaysia's chronic shortage of organ donors, given that Muslims make

up almost 60% of the population. It is a solution because Malaysia is among the few Muslim countries that have been proactive in coming up with fatwas (Muslim edicts) that promote organ donation. It is ironic that despite its low organ donation rate among Muslims countries, Malaysia in fact is one of the pioneer countries that permit organ donation. As far back as June 1970, Malaysia's fatwa council (Islamic religious council) passed an order allowing organ donation and transplantation [3]. In 1974, Malaysia established the Organ Donation Act, which was further improved in 2007. In 2011, an organ donation guideline for living unrelated donation was introduced [4]. Specific guidelines for Muslims were also designed in 2011, in which Muslims are allowed to donate organs to non-Muslims (this is to address one of the major concerns of Muslims about whether Islam permits organs from a Muslim to be donated to a non-Muslim or vice versa) [5].

Despite the strings of laws and policies to address organ donation and the fatwa council's approval with regards to organ donations, deceased organ donations among Muslims in Malaysia remain low. This raises the question of why Malaysians in general and Muslims in particular are reluctant to be organ donors. Is Islam the main impediment to their decision to be an organ donor? If Islam is not a factor, are there deeper reasons why Malaysians decide not to donate their organs? Also, should Malaysia follow Iran, Pakistan, and Saudi Arabia in introducing policies based on financial incentive?

We believe that Malaysia's donation rate suffers from the lack of appropriate policy choices and options which, if rectified, could help change perceptions of organ donation. Malaysia's low donation rate could be due to the fact that Muslims are unsure on Islam's stance with regards to organ donation. Malaysian Muslims' hesitancy is not misguided, because Muslims' views on organ donation are far from homogenous [6–8]. Islamic jurists have diverse views on deceased organ donation, ranging from total denial of its permissibility to absolute approval with monetary compensation [9]. For instance, Sheikh Mohamed Mutwali al-Sharawi, a well-known religious leader in the Muslim world, condemns organ donation and claims it is a misuse of our bodies, which belong to God, while treating it as an attempt to change God's will. On the other hand, Sheikh Mohamed Sayed Tantawi, the Grand Sheikh of Al-Azhar Mosque and University, consents to

organ donation activities provided they are done to save another person's life [10].

Given the situation described above, we hypothesize that Malaysia's low rate of organ donation is due to 2 main factors: 1) the level of education of would-be-donors and 2) the lack of use of various government or non-government instruments to communicate about organ donation. We will now consider a study conducted in the Klang Valley, Malaysia to gain greater insights into Muslims' views on organ donation.

MATERIAL AND METHODS

In late 2010 a survey was carried out in Kuala Lumpur and surrounding suburbs to gauge public opinion on organ donation. The survey was carried out in designated locations: university campuses (including the Centre of Islamic Studies), hospitals, and eateries. The Centre of Islamic Studies was chosen because it is well suited to sample young Muslim's views on organ donation. Hospitals were chosen for obvious reasons: a capture area for potential organ donors and for those with strong views on health issues. The eateries were chosen to provide a wider spectrum of respondents. All respondents were helped by enumerators to fill in the questionnaires.

We began by asking whether the respondents are willing to donate their organs upon death. They were then asked 3 further questions and we examined their reasons by their level of education (pre-tertiary and post-secondary). The first question asked respondents why they did not register as a donor despite saying "yes" to organ donation. In answering the question, the respondents were given 5 options and were allowed to choose more than 1 option. The options were: 1) do not know the procedures on how to register; 2) waiting for family's consent; 3) time constraints; 4) no motivation; and 5) other.

The second question was then directed to respondents who said "no" to organ donation. These respondents were further asked why they say "no" to organ donation. They were given 4 options and may choose more than 1 option. The first 2 options were reflective of religion and culture and the latter 2 were more structural considerations. The options given were: "It is against my religion"; "I want my body to remain intact after death"; "I am not convinced that my organ/body part will be used beneficially"; and "I do not have access to the information".

The third question was still directed to those who said "no" to organ donation: "Would you be willing to donate your organ if you are sure the act of donation is permissible in Islam?" This question is important to test whether the reason Muslims in this country are not willing to become donors is that they are not sure whether there is endorsement by the religious authority that organ donation is permissible in Islam. We wanted to know whether they would change their minds if they were sure about the endorsement. Like the previous questions for all the follow-up questions, respondents were also allowed to choose more than 1 option, thus the results reported represent scores of each questionnaire item.

RESULTS

A total of 900 Malaysian Muslims were approached, but only 779 agreed to be interviewed, giving a response rate of about 86.6%. Slightly more than half of the respondents were females (53.4%). Almost half of the respondents (43.9%) were 25 years old or younger, 35.8% were aged 26–35 years, 12% were 36–45 years, and the rest (8.3%) were 46 and older. The majority of those who participated had post-secondary education (57.5%) and half of them were still searching for a better job. Secondary education had been completed by 39.7% of respondents; the rest (2.8%) had only primary or religious or non-formal education. In terms of monthly income, 29.4% of respondents earned MYR 1000 and below, 27.1% earned MYR 1001–MYR2000, 24.6% earned MYR 2001–MYR 3000, and the remaining 18.9% earned more than MYR 3001 per month.

The respondents were first asked if they were willing to become organ donors. Out of 779 respondents, 508 (65.2%) said 'no' to organ donation, while the remaining 34.8% said 'yes' to organ donation. Nonetheless, among those who said 'yes' to organ donation, a sizeable number have not pledged their organs for donation. Table 1 indicates the reasons why respondents who said 'yes' to organ donation did not register as organ donors.

Table 1 indicates clearly that the majority of the respondents who said 'yes' to organ donation but did not register did so because they were not aware of the organ donation procedures. This lack of knowledge on the organ donation procedures is irrespective respondent level of education. Another often-cited reason is the absence of motivation to register as an organ donor, in

Table 1. Factors not to register as an organ donor by educational attainment among willing donors.

Factor	Pre-tertiary	Post-secondary	Total
Do not know the procedures on how to register	74 (41.3%)	88 (34.8%)	162 (37.5%)
Waiting for family's consent	23 (12.8%)	24 (9.5%)	47 (10.9%)
Time constraints	18 (10.1%)	36 (14.2%)	54 (12.5%)
No motivation	41 (23.0%)	63 (24.9%)	104 (24.1%)
Others	23 (12.8%)	42 (16.6%)	65 (15.0%)
Total	179 (41.4%)	253 (58.6%)	n=432

Source: Authors' survey. Others include: (i) – it is not my problem; (ii) – I just do not know why; (iii) – others.

Table 2. Scores on factors influencing respondent's decision not to donate (by education attainment) among non-willing donors (religio-cultural and structural consideration).

Factor	Pre-tertiary	Post-secondary	Total
<i>Religio-cultural</i>			
It is against my religion	37 (12.4%)	31 (8.2%)	68 (10.1%)
I want my body to remain intact after death	53 (17.8%)	60 (15.9%)	113 (16.7%)
<i>Structural</i>			
I am not convinced that my organ/body part will be used beneficially	79 (26.5%)	107 (28.3%)	186 (27.5%)
I do not have access to the information	76 (25.5%)	111 (29.4%)	187 (27.7%)
Others	53 (17.8%)	69 (18.2%)	122 (18.0%)
Total	298 (44.1%)	378 (55.9%)	n=676

Source: Authors' survey. (a) – respondents are allowed to choose more than one option, therefore the number of observations, n, in this case refers to score for each item. (b) – other factors included in the questionnaire are (i) – I do not think it concerns me and my family; (ii) – others.

Table 3. Response of non-willing donors (by education attainment) to become organ donors under permission of the religious authority.

Religio-cultural factor	Pre-tertiary	Post-secondary	Total
It is against my religion	9 (37)	9 (31)	18 (68) (26.5%)
I want my body to remain intact after death	19 (53)	20 (60)	39 (113) (34.5%)
Total	28	29	57

Source: Authors' survey. Number in parenthesis is the score recorded by each factor (as in Table 2).

which the difference between respondents from different educational levels is more prevalent.

We next asked the unwilling respondents to indicate the reasons behind their refusal to become an organ donor. Table 2 suggests that respondents who said 'No' to organ donation did so for 2 main reasons; first, they did not have access to information and second, they remained unconvinced that their organs would be used beneficially.

A more interesting finding from Table 2 is that religious consideration is not a significant factor in respondents' decision not to donate. Only 68 pointed indicated that the reason they said 'No' to organ donation is because they believe it is against their religion. Most (113) of the respondents indicated that they were not willing to donate because they want their body to remain intact after death. In fact, as Table 3 points out, respondents reiterated that they were still not willing to donate even if they now know that

organ donation is permitted in Islam, suggesting yet again that Islam or religious factors are not strong determinants in the decision to donate or not to donate. From the initial 68 respondents who indicated “No” to organ donation, only 18 indicated willingness to change their decision if given permission from religious authority.

DISCUSSION

The survey results have important implications. First, the Malaysian survey shows that, contrary to popular belief, religious and cultural factors are not significant determinants of Malaysian Muslims’ decision to donate their organs. Second, and heavily related to the first point, the survey shows that Malaysia’s inability to improve its organ donation is due more to structural rather than to religious or cultural considerations. Third, Malaysian Muslims exhibit the same attitude towards organ donation regardless of level of education. Finally, the findings suggest that effective public education on organ donation could be Malaysia’s best way to improve its organ donation rate.

These findings are indeed encouraging, because they tell us that Malaysia has a lot more room to manoeuvre in when it comes to employing various policy options other than having to resort to providing financial incentives to increase organ donation, which is an option currently being explored by many Muslim countries. One obvious method that Malaysia can use to improve organ donation is to have a more aggressive and comprehensive public education drive for organ donation that uses both government and non-government groups to disseminate this information, a conclusion supported by the fact that the reasons indicated by the respondents do not vary across levels of education.

Unlike Iran and countries like Saudi Arabia and Pakistan that face developmental challenges and lack of infrastructural support that force them to use the highly unpopular financial incentive, Malaysia can rely on its experience in preventive medicine, the support of governmental and non-governmental groups for organ transplantation, its established networks of medical practitioners that deal with organ transplantation, its comprehensive regulatory and legislative framework on organ transplantation, and its effective health insurance to improve organ donation (e.g., Iran’s religious ruling allows for cadaveric organ donation without the consent of the deceased or

his families, provided that financial incentives be used to settle the debts of the deceased person) [11–15].

Given the reservoir of ready resources, the use of financial incentives should only be used as a last option, saving the government from having to confront ethical concerns and issues like organ commercialization and the promotion of transplant tourism.

CONCLUSIONS

Lastly, a method by which Malaysia can greatly improve its organ donation rate is to adopt a segmented policy engagement when dealing with its largest population, its Muslims. Our results suggest that if Malaysia is to be successful at increasing organ donations, it must come from a more focussed and nuanced policy engagement or public education targeting the Muslim population. Malaysia could, for instance, employ its Muslim doctors to spread the message of organ donation. Educating medical practitioners on Malaysia’s existing regulatory framework and providing these practitioners with adequate patient counselling techniques could be an effective way of assuaging fear of organ donation and encouraging people to donate.

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