

# Factors That Hinder Organ Donation: Religio-Cultural or Lack of Information and Trust

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## Abstract

**Objectives:** This paper examines factors that influence Malaysian persons with a tertiary level of education on their willingness to donate organs.

**Materials and Methods:** A survey was done in the Klang Valley (Kuala Lumpur and its suburbs) at several designated locations. A total of 1420 people were approached, and we focused the sample of 688 respondents with a tertiary level of education. Respondents were given 2 sets of answers: (1) a religio-cultural category and (2) a structural category. They were allowed to choose more than 1 reason.

**Results:** Our findings revealed that only 47.5 percent of respondents declined becoming organ donors. The highest frequency recorded was "I am not convinced that my body part will be used beneficially" (30.1%), followed by "I do not have enough access to information" (29.2%), "I want my body to remain intact after death" (16.9%), and "It is against my religion" (9.9%).

**Conclusions:** Our study revealed that religio-cultural factors are not a prime explanation for the lack of organ donation in the Malaysian case. This study suggests that better procurement methods used by dedicated agencies, as well as better education, could reduce the shortage between organ supply and demand.

**Key words:** Organ donation, Donation rate, Education, Public awareness, Malaysia

## Introduction

The gap between organ supply and demand for transplant is a global concern. As of May 2012, Malaysia has some 15399 patients awaiting organ transplants, with kidney patients topping the list.<sup>1</sup> Malaysia has one of the lowest deceased organ donation rates. In 2010, the organ donation rate stood at 0.48 donations per million population, lower compared to countries like Spain (34.13), the United States (26.27), the United Kingdom (14.70), and Australia (12.10).<sup>2</sup>

The growing number of patients on the waiting list and the shortage in organ donation come despite Malaysia's efforts to narrow the gap in supply and demand for organs. In 1974, Malaysia introduced the Human Tissue Act to facilitate organ donation, followed by a national transplant program in 1975. In 2007, it strengthened existing transplant policy by introducing the National Organ, Tissue and Cell Transplantation Policy. In 2011, the government issued a policy and procedures to embark on "unrelated living donation."

Aside from formal enactments to facilitate organ donation, Malaysia also embarked on a public relation drive to raise public awareness of organ donation. Since 1999, it established the Action Committee for Public Awareness on Organ Donation, which involved healthcare providers at both the state and federal level. There were several program done under this initiative: using living donors as role models in campaigns, organizing talk shows to raise public awareness, and having an organ awareness week by organizing sports events. These efforts have not turned in the desired result, judging from the low number of Malaysians

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willing to donate their organs at death. To date, there are only 366 transplants involving deceased donors.<sup>1</sup> To think that Malaysia's first deceased donation took place over 30 years ago, the number of deceased organs donated is low.

What prevents Malaysians from pledging to donate their organs upon death? Could religio-cultural factors be the main impediments? Can better education be a more dominant factor influencing one's decision to donate? Wong, for instance, conducted a focus group in Klang Valley, Malaysia, in 2008, and identified religio-cultural factors as the prime reason for Malaysia's low deceased-organ donations.<sup>3</sup> But can better education cancel out religio-cultural considerations and encourage a higher rate of organ donation?

Various studies have shown a correlation between educational attainment and higher donation. A study on American society shows education attainment as a strong predictor of positive attitudes toward organ donation.<sup>4</sup> Another study conducted on 938 participants from Ertugrugazi, in western Turkey, also indicates that increased education was positively related to awareness of organ donation.<sup>5</sup> In addition, another study done in Nigeria also suggests that knowledge about organ donation and willingness to become organ donors is higher among those with a tertiary level of education than it is among those with a pretertiary level.<sup>6</sup>

This paper is a result of a survey that was done to assess the views of better-educated persons in Malaysia with the hope of identifying factors that influence educated Malaysians (people with most access to information) to donate or not to donate their organs.

## Materials and Methods

The survey was done in Klang Valley (Kuala Lumpur and its suburbs) from October to December 2010. Klang Valley was chosen because its mixed ethnic population mirrored Malaysia's demographic profile. The survey was conducted at several designated locations: university campuses, hospitals, and restaurants. Respondents were assisted in completing the questionnaire. During the survey, 1420 people were approached and 1311 agreed to participate in the survey, giving a response rate of 92.3%.

For this paper, we focused on 688 people with a tertiary education. Slightly more than half were

women (52.7%). Muslims comprised 65.1%, Christians another 9.5%, Hindus 9.0%, Buddhists 16%, and others 0.4%. Those who were 25 years old comprised 32%; 26- to 25-year-olds comprised 44.2%; 36- to 45-year-olds were 14.1%; and the rest were 46 years old and older (9.7%). Approximately 9.3% of respondents earned Malaysian Ringgit (MYR) 1000 (USD \$321.61) or less (most were fresh graduates still searching for a better job), 26% earned between MYR 1001 and 2000; those earning MYR 2001 to 3000 comprised 30.7%; and the remaining earning more than MYR 3000 comprised 34.0%.

From the total sample of 688 respondents from the tertiary level group, we then focused our analyses on those who said "No" to deceased organ donation. We provide respondents with 2 choices under religio-cultural factors: (1) "It is against my religion," and (2) "I want my body to remain intact after death"; and another 2 choices under structural factors: (1) "I do not have enough access to information," and (2) "I am not convinced that my body parts will be used beneficially." Respondents were allowed to cite more than 1 reason.

## Results

Slightly more than half (52.5%) said that they were "willing to be an organ donor upon death." We then asked the 47.5% who declined to become deceased organ donors the prime reason that influenced their decisions. The highest frequency recorded was "I am not convinced that my body part will be used beneficially (30.1%)." The second highest was "I do not have enough access to information (29.2%)," followed by "I want my body to remain intact after death (16.9%)," and "It is against my religion (9.9%)." The rest (13.9%) said "Other reason," which was subdivided into 3 categories: "Family members might get upset over their decision to donate (5%)," "Do not really see the urgent need to become a deceased donor (5%)," and "No specific reason (3.9%)" (Table 1).

## Discussion

This study refutes Wong's claims that the religio-cultural factors were an impediment to organ donation in Malaysia. Second, the results also confirm existing studies that claim better education can encourage organ donations (53% of the

**Table 1.** Factors Deterring Educated People From Becoming Organ Donors: October Through December 2010

Factors	Frequency	Percentage
It is against my religion	45	9.9
I do not have enough access to information	133	29.2
I want my body to remain intact after death	77	16.9
I am not convinced that my body parts will be used beneficially	137	30.1
Others	63	13.9
Total	455*	100.0

\*Because respondents were allowed to choose more than 1 factor, the total frequency (455) exceeds the total respondents (327) who refused to donate their organ.

respondents with a tertiary level of education in Malaysia were willing to become organ donors). Third, the results also reveal that contributing factors to the low donation rate in Malaysia are a combination of the public's lack of trust in the state's ability to carry out proper organ procurement and medical procedures, and a lack of medical information on organ donation.

This lack of information is especially telling because the majority of respondents had little knowledge on deceased organ donation. More than 80% of respondents we approached during the survey thought that organ donation was about donating organs while they were still alive. These respondents had to be convinced that the state's organ drive is for organ donation upon the donor's death.

The 30.1% frequency recorded on the statement, "I am not convinced that my body part will be used beneficially" revealed that more needs to be done by the state to create public confidence. The results seem to suggest that Malaysia's failure to get donors could be structural in nature; that is, it suggests that state's inability to communicate with the public regarding organ donation and a lack of trust in the health care system. The above could explain the low number of deceased donations in this country, which was 0.48 donations per million population in 2010.

This suggests a review of current policies where the state should play a more-involved role in educating the public on organ donation and instill public confidence in the state's ability to carry out organ procurement. Perhaps Malaysia must review its Public Awareness Action Committee for Organ and Tissue Donation that was set up in 1999 whose task it was to increase public awareness on the importance of organ/tissue donation at death and to

increase the number of deceased donors.<sup>7</sup> Perhaps the committee should look not only at the content of the campaigns but also the target group, specifically the better educated.

Second, Malaysia could take the experience of Massachusetts' organ donation initiative. The initiative involves setting up an independent organ procurement organization whose task involves working with hospitals and the state's health care providers to identify potential donors by intervening at critical points with patients and caregivers. The initiative so far has been a huge success in increasing the supply of organs.<sup>8</sup>

Malaysia is in the best position possible to replicate such an initiative. The state has numerous nongovernmental organizations that work on organ donation, and these organizations, given their knowledge on organ donation, could act as procurement agencies by closely working with state health providers and major hospitals. Having such close collaboration would be helpful because there are no efforts to directly target the families of chronic patients who might potentially be amenable to organ donation.

With proper intervention, the state could look at a ready pool of potential donors (families of chronic patients, such as families of dialysis patients) who understand the need for organ donation. Malaysia has more than 20 000 dialysis patients, and if 3 family members remain with a dialysis patient, that makes 60 000 potential donors. For greater success, the state could target the better educated for organ donation. This study clearly suggests that targeting the better educated and establishing procurement agencies can narrow the gap between organ demand and supply.

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