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Deceased Donor Organs: What Can Be Done to Raise Donation Rates Using Evidence From Malaysia?

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Organ donation rates have continued to fall seriously short of needs worldwide, with the lowest rates recorded among developing economies. This study seeks to analyze evidence from a developing economy to explore the usefulness of social psychological theory to solve the problem. The study deployed a large survey (n = 10,412) using a convenience sampling procedure targeted at increasing the number of Malaysians registered with the Ministry of Health, Malaysia who are willing to donate organs upon death. Structural equation modeling was deployed to estimate simultaneously the relative influence of cognitive and noncognitive variables on willingness to donate deceased organs. The cognitive factors of donation perception, socioeconomic status and financial incentives, and the noncognitive factors of demography and fear showed a high statistically significant (1%) relationship with willingness to donate organs after death. While financial incentives were significant, cash rewards showed the least impact. Donation perception showed the highest impact, which shows that the development of effective pedagogic programs with simultaneous improvements to the quality of services provided by medical personnel engaged in retrieving and transplanting deceased donor organs can help raise organ donation rates.

Abbreviations: ANOVA, analysis of variance; AVE, average variance extracted; CFI, comparative fit index; CR, composite reliability; GFI, goodness-of-fit index; RMSEA, root mean square error of approximation; RWLS, robust weighted least square; SEM, structural equation modeling; SES, socioeconomic status

Received 25 August 2015, revised 02 October 2015 and accepted for publication 31 October 2015

Introduction

Organ transplantation has led to remarkable improvements in the survival and quality of life of patients. Not only has it raised life-years gained, it has also generated economic benefits. However, end-stage organ failure has continued to spiral out of control with growing deficits facing those in need compared to the supply available. For instance, up until May 15, 2015, 123,398 organ seekers were registered, 79,398 were actively awaiting transplants, and 4,743 transplantations were performed in the United States (1). Organ donation rates vary across the world, with Spain reporting the highest rate of 36.0 organs per million persons (2), while Malaysia is among the lowest countries at 0.7 organs per million persons in 2014 (3).

Also, most research on organ donation is limited to analyzing the relationship between socioeconomic and demographic variables and willingness to donate (WTD). These studies have rarely broached strategies to raise organ donation rates. Few have explored the use of psychological theory to change peoples’ conduct to achieve this goal so that strategies can be formulated to increase donation rates. Thus, this study aims to fill this lacuna by analyzing the sociopsychological factors that can be transformed to raise deceased donor organ donation rates.

For the purpose of empirical investigation, we use Malaysia where the interest in transplanting organs has risen after 1970 (4), but particularly since 1997 when the National Transplant Center was set up at the Kuala Lumpur General Hospital (5). Malaysia offers a good laboratory to analyze the potential impact of behavioral psychological theory of reasoned action and planned behavior on organ donation rates. The country’s population is culturally diverse. The Muslim Malay population is considered religiously conservative and hence, reluctant to donate organs. The distribution of ethnic groups by ethnicity is Malays (60.3%), Chinese (22.9%), Indians (6.8%) and other (10.0%) (6).

Malaysia can also offer lessons for Islamic countries where deceased donation rates are extremely low. While living-donor transplantation has evolved strongly in Muslim nations, similar levels of development have not occurred in deceased donations (7,8). For example, Pakistan, Egypt, Saudi Arabia, and Egypt have a strong
living organ donor model for assisting end-stage organ failure, but deceased donations are either underdeveloped or banned (7, 9). Indeed, deceased organ transplantation has been carried out in only 11 out of 57 member countries of the Organization of Islamic Cooperation (9). Therefore, while living kidney transplantation rates per million persons in 2013 of Iran, Kuwait, Turkey, and Saudi Arabia were 19.5, 19.3, 30.6, and 16.5, respectively, the commensurate deceased donor organ donation rates were 8.7, 8.0, 5.4, and 3.3, respectively (2). In several Islamic countries, approval from religious leaders was superior to organ transplant laws in attracting deceased donors (10). The choice of deceased donor organ donations also allows us to address health dangers faced by living donors, as well as problems associated with international organ trafficking and medical tourism (11).

**Literature Review**

Cognitive and noncognitive factors influence organ donation. The recognition of cognitive-based variables in shaping health is grounded in the theory of reasoned action and its subsequent development into the theory of planned behavior. The logic advanced by these theories suggests that the conduct of humans can be shaped by changing their attitudes, which has since been applied to organ donation (12–14).

**Cognitive factors**

Although several studies show significant impact of socioeconomic variables on WTD (15), there is lack of consensus on the sign of influence. Evidence from Switzerland (16) shows education as a significant predictor of organ donation, but others show no such link (17). Another study on Canada found a positive link between income and WTD (18). Nevertheless, it is only logical that better-educated individuals will be more knowledgeable about organ donation and thus, may be in a better position to recognize the benefits of deceased donation. Moreover, an extensive body of literature discusses the role of knowledge in shaping attitudes toward organ donation.

Some studies show that financial incentives can be used to change peoples’ attitude toward donating organs. For example, it is posited that organ supply shortages can be brought to equilibrium by increasing prices from zero so that the market clears (19). While the poor may be willing to donate organs in return for financial incentives, people earning higher incomes may actually be better educated and hence, more aware and willing to donate organs.

However, the market-based logic “that people will be willing to sell organs when their incomes fall below a certain threshold” has come under heavy criticism. It has been argued that decisions to sell organs under market conditions will be undertaken primarily by the poor and desperate. Therefore, it is argued that market exchange in human organs will act as an “undue inducement” that will expose the poor and desperate to organ trafficking (20).

Critics also claim that the ethical underpinning behind organ procurement is individual autonomy and virtue, which would be undermined if financial inducements are introduced. This stems from a deviation of the ideal standard of altruism from commercialization. Meanwhile, there is concern that financial compensation may reduce organ donation rates by “crowding out” donors who may become disenchanted as a consequence (21).

One study argues that attitudes toward donation do not change from positive to negative along an axis, as people could simultaneously hold positive and negative attitudes at the same time (22). The balance of factors matters in influencing people to make rational decisions. It is important to identify the cognitive variables of donation perception, socioeconomic status (SES), and financial incentives, as they could be deployed to raise donation rates.

**Noncognitive factors**

Several studies posit that visceral factors impact on people’s WTD organs, which often appear as subconscious beliefs that people find hard to articulate. For example, fears of posthumous mutilation are deeply rooted in beliefs that people cannot express rationally. Thus, theories of human behavior in public health campaigns must attempt to include noncognitive variables. Visceral factors refer to instinctive and superstitious beliefs that are different from religious beliefs, as such fears have persisted despite declaration by clerics that religions do not prohibit organ donation (23). In view of the paradox between what religions preach and the beliefs people carry, it becomes the task of policy makers to raise awareness so that such noncognitive obstacles can be removed.

Some fears that inhibit organ donation arise from a lack of confidence in the competence of health officials undertaking transplantation and the quality of medical equipment and procedures used. For example, one common fear involving organ donation is that doctors kill patients to obtain their organs. Such fears are caused by hospitals ill-equipped to undertake organ transplantation in general and surgery in particular. While the first fear requires improvements to the competence of health officials and quality of medical equipment and procedures (24), the second problem can be addressed by improving access to information.

The organ donation process is complex, as such decisions often conflict with prevailing knowledge. For example, the meaning of brain dead, first defined in
1968 as “irreversible coma,” is not understood adequately by ordinary people (25). A large number of people unwilling to donate believe that patients classified as brain dead are not really dead (23). Yet, brain-dead donors are the principal source of transplanted organs in the world.

The stellar Spanish model is an example of an outstanding coordination network anchored by intensive-care physicians in every major and minor hospital in the country (26). In addition to being responsible for public education and media relations, this network identifies every potential donor in Spain and offers them the opportunity to donate. This system helped raise the number of organ donors from 550 in 1989 to 1577 in 2008 (27). Figure 1 summarizes the cognitive and noncognitive factors affecting WTD.

Materials and Methods

The choice of methodology is important because an exhaustive understanding of influential variables is critical to calibrate them with the right sociopsychological approaches to achieve desired outcomes. We use structural equation modeling (SEM) to estimate the relative influence of particular variables simultaneously because people make decisions on the basis of several factors at the same time (28).

Although SEM primarily uses the Maximum Likelihood estimation procedure, it can only be done with the use of continuous or ratio scale variables. To use non-normal, ordinal, binary, and categorical variables, we used the robust weighted least square (RWLS) method. Past studies have indicated that RWLS is the right method to be used in SEM when data are noncontinuous (29). The RWLS estimates parameters, standard errors, and chi-square, and model fit indices based on the diagonal elements of the weight matrix, which are derived from asymptotic variances of the threshold and latent correlation estimates (30). The binary and categorical variables were loaded without conversion from the survey responses. The Mplus software package determined the factor loadings. The results of comparative fit index (CFI), goodness-of-fit index (GFI), and root mean square error of approximation (RMSEA) were used to examine the significance of the model fit. The reliability of the constructs was tested using the composite reliability (CR) and average variance extracted (AVE) instruments. CR estimates the extent to which a set of latent indicators share in the measurement of a construct, while AVE refers to the ratio of the total variance related to the latent variable.

To analyze whether WTD differs by religion and ethnicity, we deployed the one-way analysis of variance (ANOVA) test so as to compare the variance between and within groups. The F-statistics were computed by dividing the variance between groups with the variance within groups. High F-values denote the rejection of the null hypothesis, which shows that no differences exist between the groups (31).

Analytical framework

A path model was first constructed based on hypothesized relationships between the latent variables. The SEM was structured by cognitive and noncognitive variables, and their relationship with WTD is illustrated in Figure 2. It shows the indicators of each latent construct and explains the relationship between the exogenous variables and the indigenous variable of WTD. WTD is the dependent variable while SES, financial incentives, donation perception, and demography are latent independent variables.

![Figure 1: Classification of factors influencing WTD.](image)

WTD, willingness to donate.

![Figure 2: Effect of latent variables on WTD.](image)

WTD, willingness to donate.

American Journal of Transplantation 2016; 16: 1540–1547
Fear has been taken as an observed independent variable. For in-depth analysis, we developed and estimated Model 2 (Figure 3), which shows the effect of individual indicators on WTD, not captured in Model 1.

**Sampling**

The data for analysis were collected through a survey conducted in Kuala Lumpur for the High Impact Research project, University of Malaya. To test the robustness of the questionnaire, a pilot study was conducted in which 100 persons were drawn from the telephone registry to participate in face-to-face interviews. The pilot study indicated that a randomly stratified sampling procedure through telephone calls would be difficult to manage as 29 persons could not be reached at their home phones at different times during the day, while an additional 33 persons refused to participate in the survey. Therefore, the team proceeded to use a convenience sampling procedure, whereby respondents were approached from five hypermarkets, five government hospitals, two universities (one public and one private), and two locations with large concentrations of shopping and commercial operations.

There was no attempt to influence the selection process. Respondents were briefed that this was a survey conducted by academics and that they need not answer any of the questions. We only asked those who pledged to donate organs after death if they wanted to fill in their names, addresses, identity card numbers, and telephone contact details in a separate form distributed by the Ministry of Health, Malaysia. We did not distribute the living donor form that the Ministry had with them. The study was approved by the University of Malaya ethics committee.

The survey lasted from April 2, 2013, until February 29, 2014, resulting in 10,412 respondents. All questions attracted between 88% and 100% responses, which easily passed the Cronbach-Alpha sample validity statistics of 70% (32). The sample can be considered representative since we did not attempt to influence the selection of the respondents.

**Measurement**

The measurement of factors that influence WTD organs decisions are explained in this section. Demographic factors are ethnicity, religion, age, and gender. Ethnicity was classified as Malay (1), Chinese (2), Indian (3), and other (4). We integrated the Indian category with other in the analysis because of too few responses in the other category. Religion was classified as Muslim (1), Buddhist (2), Hindu (3), and other (4). Gender was classified as male (0) and female (1). Age was treated as a continuous variable denoted by years since birth in 2014.

Indicators of socioeconomic factors used in this study are personal income, education, and occupation. The highest education attained was classified by the categories of primary (1), secondary (2), higher secondary (3), and tertiary (4). Occupation was recorded as unemployed (1); clerical, supervisory, and general (2); and professional and managerial (3). Income was recorded as monthly earnings.

Donation perception was estimated through measuring attitude toward donation, which constitutes general knowledge about organ donation, trust in the system, altruistic value attached to organ donation, and awareness of the brain-dead. General knowledge about organ donation was recorded on a 5-point Likert scale score ranging from nonexistent (1), poor (2), scant (3), average (4), and good (5). The question of whether a brain-dead person can live normally was captured as a multinomial logistic variable, which was quantified as follows: no (1), not sure (2), and yes (3). Altruistic value attached to organ donation was measured the same way, quantified as no (1), not sure (2), and yes (3). Trust in the system was recorded by checking whether procedures deployed to register WTD are reliable, the organ transplant unit will be fair in allocating organs and the physicians deployed to retrieve and transplant organs are competent, which were scored as no (1), not sure (2), and yes (3). Responses to fear were recorded as a binary dummy variable, which was quantified as yes (1) if respondents were unwilling to donate because they may be killed to extract their organs, or that it is God’s will and no (0) otherwise.

Information on financial incentives was gathered by checking whether respondents would change their response from negative to positive if they were compensated with cash rewards, their funeral costs were financed, or financial support was offered to one dependent of the deceased. Responses for each of the three incentives were recorded as a binary variable of no (0) or yes (1). WTD was loaded as a binary dummy variable, which was quantified as no (0) or yes (1).
Results

Table 1 presents the sampled data by demographic and socioeconomic characteristics. There were more females (58.8%) than males (41.2%) in the sample. Mean age was 34 years. Ethnic breakdown was 71.9% Malay, 14.0% Chinese, and 14.1% other. We added Indian to the other category because their numbers were small. The breakdown by religion was 71.6% Muslim, 12% Hindu, 9.4% Buddhist, and 7% other.

The breakdown by education was 17.9% tertiary, 55.9% higher secondary, 24.1% secondary, and 2.8% primary. The breakdown by occupation was 19.0% professional and managerial; 61.4% general, supervisory, and clerical; and 18.7% unemployed. The mean annual income was MYR36 436 with a standard deviation of MYR35 512.

Model validation

The model fits the data well with RMSEA of 0.077, CFI of 0.89, and GFI of 0.92. The AVE and CR values (which denote the reliability of the constructs) exceeded 0.5 and 0.6, respectively, indicating high validity of both the construct and the individual variables (Table 2). Values of AVE for SES and financial incentives are lower than 0.50 but are reliable because their CR value is >0.60 (32).

Model estimation

Table 3 presents the results of the association between the construct and component variables and WTD. The cognitive factors that showed the highest statistical significance (1%) are donation perception, financial incentives, and SES (Table 3A). The donation perception variables of general knowledge about organ donation, trust in the transplantation system, knowledge about brain death and altruistic value, and the SES variables of education and income were highly statistically significant (1%) (Table 3B). Occupation was also significant (5%). Among financial incentive variables, funeral expenses and support for a dependent family member were highly statistically significant (1%).

Noncognitive factors were also important with age, showing the highest statistical significance (1%). Gender, ethnicity, and religion were statistically significant at the 5% level. Fear showed the right sign as its impact was negative. These results are consistent with findings from other studies (19,26,27).

Since religion and ethnicity do not explain intravariant differences, we analyze them separately by deploying the ANOVA. The ANOVA test results confirm that statistical differences exist between these categories and WTD, which are highly significant (1%) (Table 4). On religion, the significant value of the Box test ($F = 3.236$, sig. = 0.000) shows that the data suffer from homogeneity. The Levene’s two-tailed t-test revealed

### Table 1: Demographic and socioeconomic characteristics, sample 2014

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Population (%)</th>
<th>Sample % (N)</th>
<th>Mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>10 353</td>
<td>34.35 ± 8.25</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>60.3</td>
<td>71.9 (7491)</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>22.9</td>
<td>14.0 (1459)</td>
<td></td>
</tr>
<tr>
<td>Others (mainly Indian)</td>
<td>16.8</td>
<td>14.1 (1462)</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Islam</td>
<td>61.3</td>
<td>71.6 (7453)</td>
<td></td>
</tr>
<tr>
<td>Buddhist</td>
<td>19.8</td>
<td>9.4 (979)</td>
<td></td>
</tr>
<tr>
<td>Hindu</td>
<td>6.3</td>
<td>12.0 (1254)</td>
<td></td>
</tr>
<tr>
<td>Others (mainly Christian)</td>
<td>9.2</td>
<td>7.0 (726)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>41.2</td>
<td>(4293)</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>58.8</td>
<td>(6119)</td>
<td></td>
</tr>
<tr>
<td>Socioeconomic status</td>
<td></td>
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<tr>
<td>Educational level</td>
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<td></td>
<td></td>
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<tr>
<td>Primary</td>
<td>2.8</td>
<td>(295)</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>24.1</td>
<td>(2507)</td>
<td></td>
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<tr>
<td>Higher secondary</td>
<td>55.9</td>
<td>(5821)</td>
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<tr>
<td>Tertiary</td>
<td>17.2</td>
<td>(1789)</td>
<td></td>
</tr>
<tr>
<td>Occupational status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>18.7</td>
<td>(1949)</td>
<td></td>
</tr>
<tr>
<td>Clerical and general work</td>
<td>61.4</td>
<td>(6398)</td>
<td></td>
</tr>
<tr>
<td>Professionals and managerial</td>
<td>19.9</td>
<td>(2065)</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>10 337</td>
<td>36 436.4 ± 35 512.27</td>
<td></td>
</tr>
</tbody>
</table>

Values in parentheses show number of respondents. Source: Computed from High Impact Research (HIR) survey (36).
that the categories had unequal variances, which is why we opted for the one-way ANOVA method using the Games-Howell post-hoc test (Table 5). The highly significant F-value (1%) shows that WTD differs across religions. The estimates show that WTD among Buddhists is higher by 43.6% and 45.2%, respectively, than among Hindus and Muslims. Also, WTD is higher among other religions compared to Hindus and Muslims by 45.2% and 43.8%, respectively. In addition, the results show that WTD also differed ethnically, as Indians had the lowest WTD compared to Malays and Chinese (Table 6).

Taken together, the results show that donation perception, SES, and demographic and fear variables explain why most Malaysians are unwilling to donate organs. Financial incentives showed the least impact on WTD organs after death. Cash incentives were especially not a major predictor of WTD.

Discussion and Conclusion

The analysis of factors that simultaneously shape WTD decisions helped identify the variables by their degree of influence. Donation perception, SES, demographics, and fear were important, which show that strategies should focus on transforming the cognitive factors of donation perception and SES so as to stimulate reasoned decision-making on organ donation. Targeting the cognitive factors could help reduce the negative influence of noncognitive factors. The successful awareness campaigns in the United States can be adapted to raise organ donation rates in other countries.

While past studies have shown that health-related decision-making is driven largely by noncognitive factors (23,33), this study reveals that the impact of both the negative cognitive and noncognitive factors can be reduced through planned behavior. Even the adverse impact of religion could be overcome, as there are institutions in all religions that support organ donation (23). Fear, too, could be argued to be rooted in the lack of
knowledge. The results support a study that showed that the main obstacle to organ donation arises from a lack of public awareness of the donation process (34). However, the results also question findings claiming that organ donation knowledge is a weak predictor of WTD.

Since donation perception and knowledge are important, strategies to generate and diffuse knowledge should involve participation of a wide range of stakeholders, including medical authorities, the media, healthcare personnel, schools, universities, and religious bodies (27). While intensive-care experts acted as coordination anchors in the Spanish model, connectivity between the different stakeholders and potential donors will also be critical in the developing economies.

Consistent with the theory of reasoned action and planned behavior, having a profound knowledge and the right donation perceptions play a significant role in increasing WTD. People must be made aware that it is acceptable to retrieve and transplant deceased donor organs into living persons. Therefore, the simultaneous development of effective pedagogic programs with improvements to the quality of services provided by medical personnel engaged in recovering and transplanting deceased organs is essential to raise organ donation rates.

In light of the significant impact of donation perception on WTD, we recommend the following strategies that policymakers should consider to address the organ shortage crisis.

First, general health education should be made mandatory in schools, where organ donation should be taught as a key topic. The altruistic importance of deceased donors to save other human lives from ethical, medical, and religious considerations should be covered under this topic. This way the general public shall also be exposed to the meaning of brain dead.

Second, as with the experience in the Spanish model, the role of clinical physicians and paramedical staff in the organ donation process should be strengthened. Such personnel should be trained to play a major role to improve trust in the transplantation system through professional and scientific illustrations to the public. Health authorities in Malaysia have produced a pamphlet that offers information on organ donation and how and where to register as a potential organ donor. However, such an effort should be augmented by information on the number of people seeking organ donation, the number of people who have registered to donate, time series of transplantations, the countries’ organ procurement system, allocation procedures, and doctors’ expertise in handling the donation process. There should also be testimonials by selected successful organ recipients who are willing to state physicians’ competence and integrity in undertaking their transplantation so as to enhance trust among the public.

Third, hospitals designated to handle organ transplantation should also hire counselors equipped with excellent communication skills to assist physicians and nurses to strengthen the organ donation system. The counselors may have to come from different ethnic and religious backgrounds and should be available fairly quickly, as accident victims are a major source of deceased donor organs.

Fourth, the media should be enlisted to raise public awareness about organ retrieval from terminally ill or accident victims. Media plays an essential role. Pedagogic programs targeting organ donation should be organized to raise awareness among the public. The support of religious clerics can help as well. In Malaysia, a leading Muslim cleric advocates that organ donation should be encouraged in Islam (35), which can offer lessons for other Islamic countries.

Future studies on organ donation should surmount some of the limitations of this study. The responses used are affected by subjectivity, suggesting the need to augment these results with a study of perceptions of actual donors and recipients. Also, the findings can be strengthened by a time series assessment of changes in the impact, if any, of donor perceptions on WTD.

**Acknowledgments**

We are grateful to the Higher Education Ministry, Malaysia, for awarding us the funding, and the Organ Transplant Unit, Ministry of Health, Malaysia, for endorsing the survey. We would also like to thank two anonymous referees for their constructive comments. Funding for this project was made by the Higher Education Ministry, Malaysia, under the High Impact Research Grant. Project No. UM. C/825/1/HIR/ MOHE/ASHS/05, UM/MOHE High Impact Research Grant. Funding bodies had no role in the study design, data collection and analysis, or in the writing of the paper. R.R., R.M., and S.K.C. conceived the project. N.N. and S.M. assisted with the modeling of the statistical analysis and literature search. R.R. led the project, including the writing of the paper and interpretation of the statistical results. All authors commented on the paper.

**Disclosure**

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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American Journal of Transplantation 2016; 16: 1540–1547