Strategies targeted at motivating unrelated living kidney donation

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Summary

Background: This paper aimed to assess the willingness of Malaysians with post-secondary education to be living kidney donors.

Material/Methods: From the total of 1,310 living kidney donor respondents in Kuala Lumpur and its suburbs, we focused on 688 respondents with post-secondary education. These 688 respondents were asked whether they were willing to become living kidney donors if the government provides a reasonable amount of financial incentive. Those who were not willing to be donors (490) were then asked the reasons for their unwillingness. Six options were given and respondents can choose more than 1 option.

Results: Malaysians with post-secondary education remain unconvinced to be living donors even when provided with monetized incentives. The main reason cited was they are not convinced that individuals can live with just 1 kidney.

Conclusions: There is a need for the government to develop new ways to promote organ donation. These include strengthening government coordination of medical procedures and creating public awareness about the safety of living with 1 kidney. Setting up new institutions such as donor clinics, creating a living donor registry, and having independent donor advocates are also instrumental.

Key words: incentives • living kidney donation • Malaysia • living donor registry • donor clinic • independent donor advocate

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Background

Countries are increasingly relying on living organ donation, be it related or unrelated donation [1], to meet the growing organ shortage. This is largely due to difficulties in obtaining organs from deceased donation, and with the increasing number of studies that produce scientific assurance that people can lead normal lives with only 1 kidney [2–4]. There is also scientific assurance that organs from the living are superior to organs from deceased sources, such as the better graft functioning and better graft response after transplantation from living donors compared to deceased sources [5].

In the case of Malaysia, the need to rely on living organ donation is even greater. In Malaysia, the low level of organ donation is worrying. As of 31 July 2012, there were about 15,493 patients waiting for organ transplant – the majority of whom are kidney patients (15,489), 2 heart and lung patients and 2 lung patients [6]. Most donations come from living donors. The rate of living donation is higher than deceased donation, which was only 0.64 donations per million population in 2010 (80% of kidneys for transplantation were from living donors) [7]. As of the end of 2010, over 1081 organ transplants involving living donors were conducted in Malaysia, clearly outnumbering the number of transplants from deceased donations, which was 320 [8].

Given the huge shortfall in organ donation, Malaysia has taken steps to encourage living donation not only from related but also from unrelated donors. In 2007, Malaysia came up with a policy statement on unrelated living donation (Article 6.2.3) [9]. In 2011, Malaysia produced a specific policy and procedures for its implementation. The government also introduced a reimbursement policy (Section 6(2) of the Unrelated Living Organ Donation: Policy and Procedures) to encourage living donation from good Samaritans [7].

Furthermore, to prevent possible abuse of organ transplant involving non-related donors, the government has also instituted safeguards. The existing policy allows for unrelated organ donation only after the Ministry of Health finds reasonable grounds that the transplant patient could not obtain organs from a deceased donor or could not find a compatible donor from family. Donation from unrelated donors must be approved by the Malaysian Health Ministry Unrelated Transplant Approval Committee (UTAC) [7].

But despite the introduction of the law allowing unrelated organ donation and the introduction of a reimbursement policy, the number of donations from unrelated living donors remains unacceptably low. The past two and a half years have not seen any donation involving unrelated living donors. Clearly, more needs to be done if the government does not want to rely solely on deceased and related organ donation. Perhaps, one way to encourage organ donation is to introduce more attractive government-sanctioned incentives (monetized or non-monetized) for living donors.

There is a valid concern or fear that unrelated donations could encourage organ trafficking, promote transplant tourism, and cause overall abuse of donors/ recipients. Indeed, according to bioethics principles, live donation from an unrelated donor is not easily justified and the removal of a healthy kidney from an individual who has no medical reason for or health benefit from such removal can only be viewed in terms of ‘harm’ (the relevant bioethics principle is “non-maleficence”) [10]. Despite these concerns, the case of Malaysia (extremely low donation rate plus long transplant waiting lists) forces the government to look into all possibilities for improving organ donation, which includes the need for the government to turn to non-related living donors to improve the donation rate.

Scholarly discussion on organ transplants continues to favor introducing some form of incentive-based organ donation [11–13]. Although it is true that providing incentives poses another set of challenges, and makes scholars and policy makers uneasy, provision of incentives does surface in policy considerations. For example, the Declaration of Istanbul in 2008 (under the sixth proposal to ensure the protection and safety of living donors) did not ‘close the door’ to the use of financial incentives as a ‘comprehensive reimbursement’ mechanism. While calling for initiatives to raise deceased donations, the Declaration of Istanbul also called for comprehensive reimbursement, but it noted that any incentivizing policy must not victimize donors or recipients and must not encourage organ trafficking and transplant tourism [14].

Will compensation in the form of government-sanctioned monetized or non-monetized incentives be enough to address the zero rates of organ donations from unrelated donors in Malaysia? This is the primary concern of this paper, which
is the product of a survey that attempted to do 2 things. First, it tried to assess whether Malaysians with post-secondary education were willing to be living donors, and second, it tried to assess whether incentives in any form can influence the decision to be a living donor.

The reason to survey those who are better educated came after recent studies suggesting that high level of education is a positive determinant of a wide range of pro-social behaviors. Results of a study conducted in Nigeria showed that knowledge on organ donation and willingness to become a donor are higher among those with a tertiary level of education [15]. A study of 938 participants from Ertugrulgazi, in western Turkey, indicated that an awareness of organ donation was positively related to increase in education [16]. Likewise, studies carried out in the United States and the European Union show educational attainment as a strong predictor of positive attitude towards organ donation [17]. Furthermore, there is evidence to suggest it is important to target the better educated groups (particularly medical students and physicians), since these groups would potentially be able to influence society on organ donation issues [18].

**Material and Methods**

A survey to gauge public opinion on both deceased and living donation was carried out in the capital city of Malaysia, Kuala Lumpur, and its surrounding area in late 2010. The location was chosen because its demographic profile reflects that of Malaysia. During the survey, enumerators were told to approach people at 3 designated spots: hospitals (a capture area for potential organ donors and for those with strong views on health issues), restaurants (to provide a wider spectrum of respondents), and university campuses (well suited to take in young peoples' views on organ donation). The enumerators were told to mirror Malaysia's ethnic and education breakdown when approaching potential respondents. They were also told to cease approaching people of particular ethnic and education groups if the quota for both categories was met (ethnic Malay were used as a predetermined number). All respondents were helped by enumerators to fill out questionnaires.

We approached 1,420 people and 1,310 filled out the living kidney donation section. However, for the purpose of this paper, we only focused on the 688 people who have tertiary education and who answered the section on living kidney donation. The study started by asking respondents a pertinent question: “Are you willing to donate one of your kidneys if the government provides Malaysian Ringgit (MYR) 50,000.00 (US Dollar $16,233.00) given the scientific assurance that donors would lead a normal life after transplantation?”

We then investigated those who said “no” by examining their reasons for not being willing to donate. Six options were given and they were allowed to choose more than 1 option. The options were: (i) I’m not medically fit; (ii) I’m not convinced that humans can live with only 1 kidney; (iii) I don’t think religious authorities will allow it; (iv) I’m not convinced that I will receive the financial incentives when I donate my kidney; (v) I’m scared of surgery/operation, and, (vi) others. We were also interested to know whether different groups in Malaysia (Malay, Chinese, Indian, and others) with post-secondary education would choose a different option for the question asked. In doing so, we hope to understand how better-educated Malaysians might respond to a government-coordinated incentive-based living donation policy and the reason(s) for their response.

**Results**

Most of the focus group (63.8%) were Malays and 21.7% were Chinese, 11.3% Indians, and 3.2% others. Slightly more than half (52.7%) of them were women; 65.2% of them were Muslims, 9.4% Christians, 9.0% Hindus, 16.0% Buddhists and 0.4% others; 32.0% of the respondents were 25 years old or younger, 44.2% were aged 26–35 years, 14.1% were 36–45 years old, and the rest (9.7%) were 46 years old and older. Approximately 35.3% of respondents earned MYR2,000 and below (most of whom were recent graduates); 30.7% earned MYR2,001–3,000; with the remaining 34.0% earning more than MYR3,000.

Out of the 688 respondents, only 198 (28.8%) were willing to become living kidney donors. The overwhelming majority, 490 (71.2%), said “No” to organ donation. The study then asked those who were not willing to be donors the reasons for their unwillingness. Table 1 presents the results.

Table 1 clearly indicates that the highest score recorded was for the reason “I am not convinced that humans can live with only 1 kidney” (37.4%). The second highest was “I am not medically fit”
(19.8%), followed by “I am scared of surgery/operations” (15%). The 3 reasons with the highest responses were mainly reasons associated with lack of knowledge of medical issues. This suggests that willingness to donate could be improved with proper education on medical procedures and safety of organ donation. Also encouraging are results showing similar response patterns across all major ethnic groups in Malaysia, suggesting the possibility of a synchronized public education program on organ donation.

Table 1 also shows that only 14% of the unwilling donors said “I am not convinced that I will receive financial incentives when I donate my kidney” and 8.3% said “I do not think religious authorities will allow it.” Most of those in the category of “others” said that “The body given by God should not be tampered with for money” (5.5%).

The result of the survey is contrary to studies conducted elsewhere. Malaysians who are better educated are unconvinced to become living organ donors. One of the reasons could be due to their lack of knowledge on organ donation, particularly living renal transplantation. The high response to “I am not convinced that humans can live with only 1 kidney” suggest that not enough is being done to educate the Malaysian public that it is medically proven that a person can live with a single kidney, thus suggesting that current programs at increasing organ donation are insufficient. The survey also found that incentives may not be the sole determinant of the decision to be an organ donor. Put differently, incentives may not be sufficient to increase organ donation. Another interesting finding of the survey is that among the better educated, religious and cultural factors are not strong determinants in the decision to donate. Only 8.3% of respondents cited these factors as a deterrent to being a donor.

**DISCUSSION**

What can be done by the government to improve living donation? A key to improving living organ donation is for Malaysia to address psychosocial issues involved in living donation. There is a real concern that while living donation can provide altruistic benefits to donors, there is also the fear that such donation can lead to depression, anxiety, and medical complications.

A recent study [19] shed light on those concerns by suggesting that, with proper government safeguards, those fears are misplaced. There is evidence that a large majority of living kidney donors did not experience depression and none of the donors needed medical attention [19].

These findings give greater hope that Malaysia can embark on a successful living organ donation, while at the same time ensuring that donors continue to live normal and meaningful lives. Several methods deserve consideration.

First, Malaysia could put greater effort into creating awareness of organ donation. Although the government has put some efforts into creating awareness, the activities are generally targeted at encouraging deceased donation, with little focus on living donation, either related or unrelated. The government could use existing infrastructure such as the Health Ministry’s Public Awareness

### Table 1. Reasons for saying no to kidney donation among respondents with post-secondary education, by ethnicity.

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Malay</th>
<th>Chinese</th>
<th>Indian</th>
<th>Others</th>
<th>Total score</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am not medically fit</td>
<td>65</td>
<td>35</td>
<td>11</td>
<td>1</td>
<td>112</td>
<td>19.8</td>
</tr>
<tr>
<td>b. I am not convinced that humans can live with only one kidney</td>
<td>135</td>
<td>42</td>
<td>26</td>
<td>9</td>
<td>212</td>
<td>37.4</td>
</tr>
<tr>
<td>c. I do not think religious authorities will allow it</td>
<td>37</td>
<td>7</td>
<td>3</td>
<td>0</td>
<td>47</td>
<td>8.3</td>
</tr>
<tr>
<td>d. I am not convinced that I will receive the financial incentives when I donate my kidney</td>
<td>58</td>
<td>12</td>
<td>7</td>
<td>2</td>
<td>79</td>
<td>14.0</td>
</tr>
<tr>
<td>e. I am scared of surgery/operation</td>
<td>44</td>
<td>25</td>
<td>13</td>
<td>3</td>
<td>85</td>
<td>15.0</td>
</tr>
<tr>
<td>f. Others</td>
<td>15</td>
<td>10</td>
<td>6</td>
<td>0</td>
<td>31</td>
<td>5.5</td>
</tr>
<tr>
<td>Total</td>
<td>566</td>
<td>100.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Authors’ database.
Action Committee for Organ and Tissue Donation to promote living donation. The committee could also continue to work with non-government organizations (such as the National Kidney Foundation) and local hospitals to promote donation.

To motivate relatives and good Samaritans to become donors, Malaysia can perhaps have more targeted programs. It could launch an aggressive public relations campaign promoting the fact that people can actually have normal healthy lifestyles with just 1 kidney. Perhaps it could follow the Iranian model, which produces the highest number of non-related kidney donors [20]. Malaysia can also depict its own story by portraying the health condition of the 1,081 donors in the country who are living with only 1 kidney. The Ministry can also engage in various public relations campaigns to raise public awareness, for instance, by having living donors as role models, hosting talk shows, and holding sport competitions during Organ Awareness Week.

One other method to assuage the would-be donor’s fear of health risk and high medical costs would be for the government to establish a donors’ clinic—a dedicated clinic that offers donors ready access to medical treatment. Our separate survey (conducted from June to August 2012) [21] with 80 related kidney donors who donated their kidney in 1 transplant centre in Malaysia from 1991 to 2012 also confirmed that having such a facility and providing greater assurance regarding medical costs would help relieve some apprehension about organ donation. In the survey, only 3 respondents did not support the idea of a donor clinic and issues surrounding it [21].

Another measure to relieve would-be donors’ fear is for the government to provide an independent donor advocacy service, which would give the assurance that donors will be provided with proper advice and management at every point of the organ donation processes—from when donors consented to organ donation until when they do post-transplant follow-up medical procedures.

Lastly, Malaysia could establish a living donor registry, an institution that allows ready access to track the well-being of donors after transplantation. With such a registry, donor health could be systematically monitored and donors could readily be called at any point of time when treatment is required. The donors’ clinic, advocacy service, and the living donor registry can also be a part of a new legal framework on organ donation and transplantation that is benchmarked to international standards and incorporates the concerns raised in the Istanbul Declaration in 2008. Indeed, this legal framework can further add to raising public trust in the organ donation process and procedures.

Conclusions

Our study identified the underlying deterrents among better-educated Malaysians to becoming living kidney donors. It found that more is needed than just a one-time cash payment to induce better educated donors, and suggests that the government employ multi-pronged strategies that raise the awareness about organ donation and provide public confidence and assuage public fears about the safety of organ donation.

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References:

21. Authors’ survey from July to September 2012 under the University of Malaya Research Grant Scheme 2011 (Project No: RG183/11HTM)