THE IMPORTANCE OF LONG-TERM FOLLOW-UP VISITS FOR KIDNEY DONORS

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ABSTRACT

Background: This paper examined the importance and influence of post-transplantation follow-up visits on the quality-of-life (QoL) of living kidney donors in Malaysia.

Methods: Based on data collected from 80 living kidney donors, the relationship between QoL and the frequency of follow-up visits was examined. QoL was measured using standard SF-8 questions to capture its different dimensions.

Results: Donors in the 1991–1998 donation cohort have low QoL, especially in the domains of physical and vitality, compared with the other two cohorts (1999–2005 and 2006–2012). The mean scores showed that donors who never went for any follow-up activities visits experience low QoL in most of the categories, particularly those related to physical activities, implying the importance of follow-up activities visits in influencing the donors’ QoL. Lower QoL was recorded for respondents that never received post-transplant treatment.

Conclusion: Although this study found no serious post-transplant QoL issues in Malaysia, it is still important to set up a donor registry and provide free and mandatory follow-up visits for all donors in order to adequately monitor their health.

Keywords: kidney donation, living donors, Malaysia, quality of life, sociology

Introduction

Developments in organ-transplant technology are of less significance if there is a negligible supply of organs. In Malaysia, although 15,489 people were on the waiting list for organ transplantation in July 2012 (1), the deceased donation rate was only 0.64 per million people (2). The short supply of transplant organs from deceased donors necessitates alternative methods of harvesting organs, and living donation seems to be a better option than other possible alternatives. Although living donation is acknowledged as a harmless procedure and donors are generally assumed to be safe physically and mentally post-transplant (3-10), it is worth noting that such a surgical procedure is certainly not risk-free. As of December 2012, there were 1,894 functioning transplanted kidneys in Malaysia, and all were sourced from related donors (11).

Although Malaysia’s National Organ, Tissue and Cell Transplantation Policy of 2007, under Article 2.5 (Aim of the Policy) and 2.4 (General Statement of the Policy), stipulated that living donors must attend post-transplantation follow-up health monitoring visits and that the government would attend to their welfare (12), the implementation of this policy remains almost nonexistent. The first living donation took place in 1975 (12), but only from November 2012 were free medical services provided to living donors (10), and even then services were only provided to Malaysians who donated their organs from November 2012 onwards.
Donors' QoL was also assessed based on their follow-up visit frequencies. Donors' follow-up activities in terms of percentages were as follows: 31.25% of respondents had regular follow-up visits (n=25); 62.5% (n=50) had one visit in several years; and only 6.25% (n=5) had never had any follow-up visits. The mean scores for each of the QoL categories are presented in Table 3 and suggest a significant difference in three of the QoL categories: (1) physical function; (2) role physical; and (3) vitality.

The mean scores show that donors who never went for any follow-up visits experience low QoL in most categories, particularly those related to physical activities, implying the importance of follow-up visits in influencing donors' QoL (Figure 3).

Table 3: Respondents' QoL by domain, based on frequency of follow-up attendance (%)

<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>Regular</th>
<th>Non-regular</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical function</td>
<td>40.7</td>
<td>44.4</td>
<td>72</td>
</tr>
<tr>
<td>Role physical</td>
<td>40.7</td>
<td>44.4</td>
<td>72</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>37.5</td>
<td>43.3</td>
<td>40</td>
</tr>
<tr>
<td>General health</td>
<td>58.2</td>
<td>56.7</td>
<td>44</td>
</tr>
<tr>
<td>Vitality</td>
<td>67.4</td>
<td>61.1</td>
<td>76</td>
</tr>
<tr>
<td>Social function</td>
<td>34.4</td>
<td>41.1</td>
<td>20</td>
</tr>
<tr>
<td>Role emotional</td>
<td>22.2</td>
<td>26.8</td>
<td>26.4</td>
</tr>
<tr>
<td>Mental health</td>
<td>37.3</td>
<td>33.9</td>
<td>41.6</td>
</tr>
</tbody>
</table>

There is evidence that long-term follow-up appointments lower donors' morbidity risk (25). The findings of this study add to this evidence. Thus, serious calls have been made by donors and policymakers regarding the importance of follow-up visits post-transplantation (26). In fact, some developed countries have established special donor clinics to cater to the physical and psychological needs of donors and also to provide consultation services for them. The above findings urge Malaysia towards serious efforts to establish a national donor registry with mandated follow-up attendance, since this is the only method to ensure that the health of living donors is monitored. The government should provide all living donors with free medical services (at all levels, including secondary and tertiary), regardless of their date of donation, in order to guarantee that living donors—who are the majority of donors—attend their follow-up visits. The literature reveals that eligible donors may not donate due to their fear of facing financial problems after donation (27-28), so we expect that providing free follow-up care would tend to increase the number of living donations.

Conclusion

This study revealed two important findings. Firstly, living kidney donors' QoL was found to decline over the long run. Secondly, living donors with higher commitments to post-donation follow-up visits enjoy better QoL than those who never or infrequently attend follow-ups. Hence, this study suggests that officials should take the initiative to establish a living-donor registry and to make follow-up attendance mandatory and free of charge for all donors. These changes would enhance donors' QoL.

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