

The Living Kidney Donor Perspective in a Transplant Programme in Trinidad and Tobago: Seeing Donation through the Donor's Eyes

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ABSTRACT

Objectives: To evaluate the views of kidney donors in a local programme.

Methods: Living kidney donors between June 2006 and March 2011 were given an un-standardized questionnaire. Of the 72 donors, 43 responded and information about their demographics, their motivation to donate and their transplant experiences were collated.

Results: Forty-nine per cent of the donors were in the 40–60-year age group and 54% had attained secondary school education. In just over 50% of the cases, the motivation for transplant was for health reasons and love of family. All the responding donors were satisfied that the National Organ Transplant Unit (NOTU) gave them adequate information throughout the evaluation process and would recommend to a friend the act of donation. However, 9% of these donors, would not give an undirected donation at death. Thirty-three of the transplant patients had excellent transplant experiences. An unsatisfactory experience was registered for two patients, (a) when the recipient died post-transplant and (b) when the time needed to return to work was prolonged. Once the recipient either returned to dialysis or died, the donor registered transplantation, as not being an excellent experience, completely oblivious to the period when the kidney was functional.

Conclusion: The NOTU as a specialized unit for conveying education and information, met the approval of all the living donors. A major reason for a negative experience was poor graft outcome with recipient death or return to dialysis. In such high-risk groups, arrangements for appropriate counselling must be established to ensure good donor psycho-morbidity post-transplant.

Keywords: Fledgling programme, living kidney donor, Trinidad and Tobago

Perspectiva del Donante Vivo de Riñón en un Programa de Trasplante en Trinidad y Tobago: Ver la Donación a Través de los Ojos del Donante

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RESUMEN

Objetivos: Evaluar los puntos de vista de donantes reales en nuestro programa local, que pueden tener un impacto psicológico en la donación de riñón.

Métodos: A donantes vivos de riñón se les dio a responder un cuestionario no estandarizado entre junio de 2006 y marzo de 2011. De los 72 donantes, 43 respondieron y la información

sobre su demografía, su motivación para donar y sus experiencias de trasplante fueron cotejadas.

Resultados: El 49 por ciento de los donantes se encontraban en el grupo de edades de 40 a 60 años y el 54% había alcanzado la enseñanza secundaria. En poco más del 50% de los casos, la motivación para el trasplante fue por razones de salud y amor a la familia. Todos los donantes que respondieron expresaron satisfacción de que la Unidad Nacional de Trasplante de Órganos (UNTO) les diera información adecuada en todo el proceso de evaluación, y recomendarían a un amigo el acto de donación. Sin embargo, el 9% de estos donantes, no daría una donación indirecta (i.e. altruista, sin conocer al receptor) en caso de muerte. Treinta y tres de los pacientes de trasplante, tuvieron excelentes experiencias de trasplante. Una experiencia no satisfactoria fue registrada en relación con dos pacientes cuando el receptor murió posteriormente al trasplante y cuando se prolongó el tiempo necesario para volver al trabajo. Una vez que el receptor regresó a diálisis o murió, el donante registró que el trasplante no era una experiencia excelente, completamente ajeno al período en que el riñón era funcional.

Conclusión: La UNTO como unidad especializada para transmitir educación e información, cumplió con las expectativas y contó con la aprobación de todos los donantes vivos. Una razón importante para una experiencia negativa fue el resultado deficiente de un injerto, es decir, la muerte del receptor o el regreso a la diálisis. En tales grupos de alto riesgo, deben establecerse disposiciones para un asesoramiento adecuado a fin de garantizar una buena psico-morbilidad de los donantes después del trasplante.

Palabras clave: Programa incipiente, donante vivo de riñón, Trinidad y Tobago

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INTRODUCTION

In January 2006, the National Organ Transplant Unit (NOTU) was established to facilitate kidney transplants for the nationals of the Trinidad and Tobago. Renal transplantation is the treatment of choice for patients who suffer with end-stage renal failure as it prolongs survival, decreases morbidity and improves their quality of life (1, 2). It is, however, limited by the availability of donors.

The fastest growing category of donors used in kidney transplantation, has been living donors (3, 4). The transplant programme in Trinidad and Tobago predominantly utilizes living donors; only eight of the 111 patients transplanted as of January 2014 utilized a deceased donor.

The short and long-term physiological consequences for the living donor having had a nephrectomy had been well documented (5, 6). There is minimal physiological disturbance to the living donor, although the eventual medical outcome may be affected by racial variation (6). The psychosocial issues of the donor after kidney transplantation are also of critical importance. Intrinsic and extrinsic factors such as selflessness, wishing to save the recipient and seeking improved relationships are

generally the motivating factors for donation. Reviews detailing living donor experiences (7, 8) have been useful in the education of prospective donors and assisting transplant programmes to obtain donors' informed consent.

Ali *et al* (9) detailed the short-term changes in protein excretion and creatinine clearance seen in the Trinidad donor following nephrectomy but the donors' perspectives were not addressed. Donor experiences found from meta-analyses and systematic reviews (7, 8) will not automatically predict donor characteristics in our national programme, or assist in getting informed donors' consent since none of the studies had been done in a fledgling programme or in a country of similar size and cultural background as Trinidad and Tobago.

As there is no legal regulation on how much risk is ethically acceptable for the donor, transplant centres must set their own national standards and acceptance for donation would be based on the ability to give informed consent. Therefore, in an attempt to guide the development of their new transplant programme and to determine the best clinical practice, the donors' perspective is critical.

We therefore, sought to examine the psycho-social aspects of living donors in this national programme.

The feedback obtained from the living donor experience during the evaluation process, the surgical experience, and their well-being after discharge and any resultant life decisions made would assist in predicting the post-transplant psycho-morbidity.

SUBJECTS AND METHODS

An unstandardized questionnaire survey was distributed in June 2011 to all 72 living kidney donors who underwent surgery under the National Organ Transplant Unit (NOTU) between June 2006 and March 2011. Copies of the questionnaire were distributed to the donors either directly at the Donor Follow-up clinic, *via* their recipient pair or by e-mail. Forty-three copies of the questionnaire were returned after a minimum of two reminders and thus formed the subject of this analysis.

The 14-item questionnaire was set-up to survey the total experience of a living donor and thus, the following information was collated:

- The gender, age at the time of transplantation and the standard of education of the living donor
- The donor-recipient relationship
- The year in which the transplant occurred
- An assessment of pain related to the surgery to the present time, how long the donor took to return to work
- The overall transplant experience of the donor and his/her current view on the recipient’s outcome
- Would the donor donate any other organ again having gone through the experience?
- Would the donor recommend donation to a friend?
- The donors’ outcomes were examined and comparisons as to whether these were affected depending on whether the donors were genetically related or not were made.

RESULTS

There were 72 living donors between June 2006 and March 2011. Forty-three donors (59.7%) submitted their questionnaire responses. The majority of the responses came from donors who had their surgeries in 2010, 11 responses, followed by the years 2007 and 2009, nine and eight, respectively.

Of the 43 donors in the analysis, there were 25 females and 18 males. The majority of the responders were in the 40 to 60-year age group (48.8%). The majority of the donors (51%), had secondary school education, followed by 33% reaching tertiary level education and 16% reached the primary school level (Table 1).

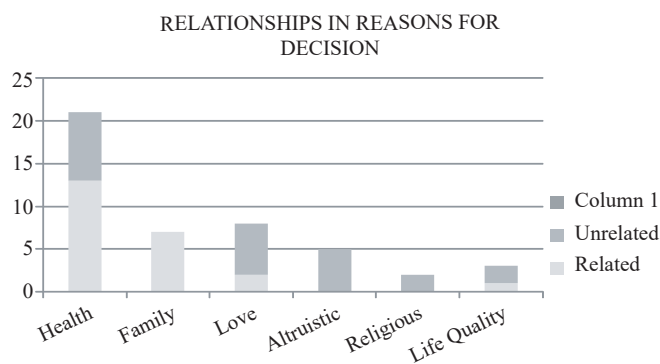
Table 1: Demographics of the renal transplant living donors (n = 43)

	PATIENTS	n (%)
Gender	Male	18 (42%)
	Female	25 (58%)
Age (years)	18–25	7 (16%)
	26–39	15 (35%)
	40–60	21 (49%)
Education	Primary	7 (16%)
	Secondary	23 (54%)
	Tertiary	13 (30%)
Donor relationship	Living (Related)	24 (56%)
	Living (Unrelated)	19 (54%)

Twenty-four donors genetically related and 19 unrelated responded to the questionnaire. The reasons for the donation were as follows:

- Health reasons: 21
- Family and succession: 7
- Because of love for the recipient: 8
- Altruistic reasons: 2
- Religious reasons: 2
- Improved quality of life for recipient: 3

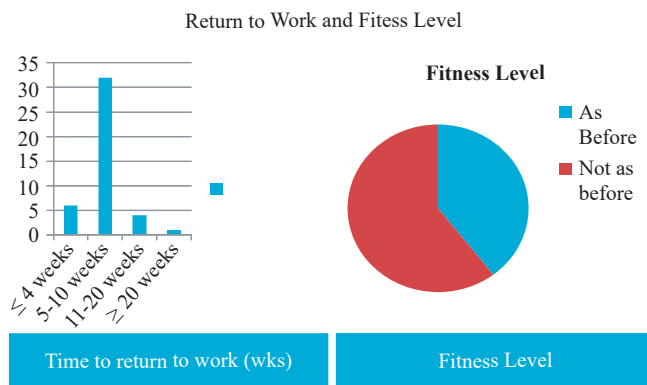
In the above groups, apart from family reasons, where all the donors were related and altruistic reasons, where all the donors were unrelated, there was no difference between the related and unrelated donors’ reasons (Table 2).



One hundred per cent of the responders would recommend kidney donation to a friend. For 33 of the responders (76%), the donation experience was excellent, for seven (13.9%), the experience was good, one patient found the experience satisfactory while two others had an unsatisfactory donation experience. The two donors with unsatisfactory experiences; one lost the recipient, while the other described significant pain

postoperatively, returned to work after eight months and felt his needs postoperatively were not addressed.

Two major concerns for the donors were their reduced fitness after surgery and the length of time they needed from work. Sixty per cent of the responders stated that they experienced decreased fitness after surgery. The donors returned to work after four to 32 weeks. The majority of the donors 31 (72%), returned to work after five to ten weeks (Table 3).



Three responders did not feel that the recipients' quality of life was improved as in two cases the recipients had to return to dialysis and in the third the recipient died. Seven donors admitted to still having pain at the time of questionnaire. Pain intensity was low and not greater than that experienced at the start.

All the donors would recommend transplantation to a friend but all would not consider donation on decease. Four donors indicated they would not donate on their death to someone they did not know.

DISCUSSION

Potential donors need to be aware of not only the physiological changes that occur after kidney donation, but also the psychological. They would thus, be better positioned to give informed consent and possibly increase the donor pool. There is a lack of uniformity (10) in the protocols which determine a donor's psychosocial status and suitability to donate. Hence, an examination of our local situation was conducted to determine NOTU's approach.

For 94% of the donors in our study, the experience of donation was a positive one. This was similar to that found in many other studies (8, 10) where the donors said they would repeat the process, had an improved sense of well-being and experienced a boost in self-esteem following their donation.

All but two donors stated a positive experience with donation. The death of the recipient and the return of a recipient to dialysis were the negative outcomes for the donor. It is instructive to note that even though the allograft might have initially functioned, once the allograft failed, the initial successful period is negated. This illustrates the need for "worst case scenarios" to be highlighted in pre-transplant education and for those donors whose recipients may not have had positive outcomes, to be paid special attention. Such recall donor visits may need to be more frequent, differently structured and held in peer-related sessions. The NOTU would need to promote a stronger donor advocacy and involve community liaison units and patients' support groups to effect closer donor follow-up.

Donation was seen in a negative light when the expectations of the donor were not met. A frank and full disclosure of the donors' expectations is critical. Worries about costs and financial hardships, although occurring in the minority of the donors, have been reported (12), particularly if return to work is delayed for eight months as was seen in one instance. Other characteristics which would predict a negative outcome for the donor such as ambivalent donors, those who have vacillated about the donation and "black sheep" donors (10) were not seen in our sample of donors.

Predicting donors' psychosocial morbidity is complex and may be inconsistent but the above mentioned characteristics are robust psychosocial predictors of poor post-donor outcomes.

The reasons for the living donation are governed by multiple factors which are both intrinsic and extrinsic and can operate simultaneously. Similar to most studies over the past 30 years (10), saving a life or relieving patients suffering, were the major reasons for donation in our sample. The altruistic reasons such as improving the recipients' quality of life was the second most common motivator (21%) and seen only in unrelated donors. Interestingly, no one commented that donation would raise his or her self-esteem, make his/her lives more worthwhile, or as a compensation of guilt for previous actions. Religious and spiritual reasons did not play a major role but this could be due to the small sample size. The predominant reasons expressed by our living donors were similar to those expressed by other types of medical and social volunteers (11).

Four donors expressed a negative inclination to deceased donation, although they all had no regret about their living donation. The donation in these cases, was

undirected and may thus, be a factor contributing to the reluctance for donation after death. The unifying factor among this group was that they had all given kidneys to family members.

Significant postoperative concerns for the donors were the degree of pain and its duration, the length of time needed to return to work and their level of fitness after surgery. The time taken for recovery after surgery is important since a delayed return to work accounted for the negative experience of transplantation at the NOTU. The evolution of Laparoscopic techniques seeks to minimize postoperative effects on the donors. These effects included: less time in the hospital, smaller scars, pain reduction and early return to work (12). The reason for the delay was not cited, and we surmise it was related to the transplantation process.

The positive outcomes had been mainly recorded and although the limitations of this survey included the fact that it was retrospective and there was likely bias recall, useful information was obtained. By utilizing the views of the donors, the strengthening of the existing transplant programme is inevitable and would inform best practice in dealing with potential pitfalls of living kidney donors before and after kidney transplantation.

The expectations of the donors with regards to their individual outcomes as well as those of the recipients must be transparently laid out prior to the donation. The pitfalls of graft delay, failed graft function and loss of financial independence of the donors are important features that must be identified prior to kidney donation.

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