Live kidney donation: managing the “tyranny of the gift”

Justin Roake, John Morton

The benefits of kidney transplantation from living donors are substantial for the recipient, for society and arguably for the donor. Recipients of live donor transplantation have a better chance of survival and of good kidney function than after deceased donor transplantation, and also a realistic prospect of preemptive transplantation before the need for dialysis. Society benefits because transplantation is cheaper than dialysis and living donation potentially frees deceased donor kidneys for recipients without realistic prospects of finding a living donor. Donors report that the act of giving enriches their lives and improves their self-esteem.

Initially, live donor transplantation was exclusively between blood relatives, and the health professionals involved often felt ambivalent about encouraging gifts of organs by living donors and about their own role in the process. However, as the risk of graft failure from rejection or technical complications and the risks of donor surgery have reduced, the practice has become more widely accepted and extended to donation by emotional relatives, especially spouses, and subsequently to the acceptance of well-motivated strangers—also known as altruistic or non-directed donors. Live donor transplants are now well established in New Zealand and account for nearly half of all kidney transplants. This is partly because of low rates of deceased-donor transplantation in New Zealand in comparison to other developed countries but also because of active promotion of living donation by transplanting centres as the best option for prospective recipients. Live donation is now accepted to the extent that the Ministry of Health is supporting a nationally coordinated programme to promote living donor transplantation and increase the number of transplants. This is an important initiative because the demand for kidney transplantation far exceeds the supply of donated organs.

Living donor transplantation is predicated on the simple concept of a gift freely given without coercion or any thought for reparation. However, this is too simplistic and it has long been recognised that the transaction between donor and recipient takes place within a complex network of interpersonal relationships including families and health professionals and that “a complex exchange occurs through which considerably more than the organ is transferred”. The gift of organs for transplantation occurs within a paradigm of ‘symmetrical and reciprocal’ obligations; to offer and give; to receive and accept; to seek and find an appropriate way to repay. Failure to meet any of these obligations can lead to strains affecting the donor, the recipient and their associates. We know for example that prospective donors and their families feel strong internal and external pressure to donate. Often it is the simple fact that live donor transplantation offers the recipient the best chance of normal or near normal life that creates this powerful pressure. A common manifestation of this is an almost instantaneous decision to donate without any actual request or process of informed consent. Perhaps more troubling is that many recipients describe a sense of indebtedness and obligation to repay their donors where there can be no reciprocity. Fox used ‘tyranny of the gift’ to describe the sense of debt that recipients feel and noted that this may impact on the relationship between donor and recipient in unforeseen ways. The potential for harm suggests that the engagement between donor and recipient requires careful management from the earliest stages.
In relation to organ donation, the way in which information is presented or requests are made can be major determinants of the outcome. For instance we know from studies of requests for organs from deceased donors that factors such as the timing of the request, the specific words that are used, and who makes the request can be critical determinants of whether consent is given.\textsuperscript{4,5} Although the circumstances in living donation are very different, it seems likely that the specifics of how and when information is presented, the information itself and whether a direct request is made may impact directly on the outcomes.

Obviously potential recipients may not be cognisant of these complexities but it is not surprising that they find it difficult to raise the subject of their need for a transplant with their family and friends as described in the article in this edition titled It’s hard to ask.\textsuperscript{6} We see that the themes emerging from this research in New Zealand echo those identified by Fox.\textsuperscript{3} The ‘difficulty’ that potential recipients identify may reflect a deep sense that in some way this type of request is inapt—the ‘gift of life’ is too great and cannot be repaid. We also recognise that in New Zealand there are unique cultural and ethnic factors that come into play.

Given our knowledge of the complexity involved in approaching family or friends on the subject of donation it seems inappropriate to leave this to potential recipients without providing substantial guidance and resources. We, the authors, believe that it is unwise, unreasonable and possibly unethical for us as professionals to expect patients to request donation from relatives or friends although we accept that patients have freedom to make such requests. In contrast we think it is acceptable, and to be encouraged, that relevant, factually accurate information is provided to family and friends and that genuine offers are accepted. We acknowledge that this is a rather nuanced argument and that patients and professionals alike may require education to understand the importance of the distinction. It is concerning that in the drive to do the best for potential recipients and achieve high rates of transplantation we, as a profession, have projected ‘a need to ask’ rather than to provide information and receive offers. This is conveyed by our words and actions. Words are powerful and need to be chosen carefully—for example, is it right to talk about ‘recruitment’ of living donors?

New Zealand’s transplanting centres provide ample, good quality and appropriate information on the processes and protocols involved in organ donation and transplantation including a discussion on the balance of risks and benefits as part of obtaining informed consent. Additionally, potential donors are required to have a psychological assessment and counseling, but there is no consistent approach delivering culturally safe practices, counseling and support to potential recipients as they begin to engage with their family and friends on the delicate subject of donation. In 2014, renal transplantation in New Zealand became a nationally organised service. This provides an opportunity for the National Renal Transplant Leadership Team to respond to the concerns identified above and develop a nationally consistent framework and resources in support of potential recipients and the health professionals involved in their care.
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Nil.

Author information:
Justin A Roake, Professor of Surgery, Department of Vascular, Endovascular and Transplant Surgery, Christchurch Hospital, Christchurch; John B Morton, Retired Associate Professor of Surgery, Christchurch Hospital, Christchurch.

Corresponding author:
Prof Justin Roake, Vascular Endovascular and Transplant Surgery, Christchurch Hospital, Riccarton Avenue, Christchurch.
justin.roake@cdhb.health.nz

URL:

REFERENCES: