Case Report

Controversies in organ donation: the altruistic living donor

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Introduction

Renal transplantation is now widely considered the preferred mode of renal replacement therapy. Previous analyses of comparative mortality risks for dialysis and transplant patients have demonstrated that renal transplantation confers a superior long-term survival benefit compared with similar patients on dialysis [1,2]. Unfortunately, the most important obstacle facing transplantation today is the great shortage of organs throughout the world. Currently, approximately 35,000 patients are waiting for kidneys in the United States, which represents a 2.5-fold increase from 1988 to 1997 [3]. The shortage of cadaver organs imposes a severe limit to the number of patients who could potentially benefit from transplantation. In an attempt to address this problem, the majority of transplant centres continue to rely on living donors as an important kidney source. Thus far, the majority of kidneys from living donors have been from relatives, because of the excellent long-term results attributed to the varying degrees of matching of haplotypes of the major histocompatibility complex in consanguineous donor–recipient pairs. However, more recently, many transplant centres have started programs utilizing living-unrelated donors, persons who are related to the recipients emotionally rather than by blood, because of mounting evidence of unexpectedly high survival rates, despite high degrees of HLA-mismatch [4]. Nevertheless, widespread acceptance of such unconventional donors has not occurred because of the difficult ethical issues raised by this practice. An even more difficult ethical dilemma arises if the donor happens to be a stranger. Thus far, the use of altruistic strangers has been considered to be an impenetrable taboo. The following describes one such case with unique aspects and offers a strategy as to how such volunteers should be handled.

Case

A 50-year-old white woman (the volunteer) contacted our transplant centre offering to donate one of her kidneys to any eligible person on our cadaver transplant list. When asked about her motivation, she stated that she was an ordained Buddhist monk and as part of her faith, placed a high value on helping mankind to the best of her ability. She had carefully thought about donating and had done a fair amount of research on living kidney donation on the Internet, thereby acquiring a good understanding of the risks involved. Notably, she had made a similar request to a transplant centre closer to her home but had been turned down. The volunteer subsequently set up an interview with the transplant team at our institution to discuss her possible donation further.

The volunteer kept her scheduled appointment. She was interviewed by the transplant co-ordinator, social worker, transplant nephrologist, and transplant surgeon. She was found to be sincere in her request and her judgement and insight were considered to be sound. She had discussed her intention with her husband, who was supportive of her decision. Her medical history was significant for a previous ectopic pregnancy necessitating a left salpingectomy in 1975, tonsillectomy and adenoidectomy, fibrocystic breast disease, and recent right knee arthroscopy for chronic right knee pain. However, she did mention an adverse reaction to Valium while undergoing a sigmoidoscopy, which apparently resulted in significant respiratory depression. She had no history of psychiatric illness nor did she have current psychological problems.

The patient placed only two conditions prior to donating. She requested that the donation be entirely anonymous in nature without public media consideration and the recipient be a person who is not associated with a killing vocation of any type (e.g. hunter,
fisherman, military person). Although she preferred that the recipient be of an ethnic or racial minority, this was not a major consideration in her mind.

The patient underwent tissue typing and agreed to undergo a complete transplant donor evaluation. The living donor process was discussed in detail with her. The risks of living donor nephrectomy, both in the short and long term were discussed with her. She demonstrated a good understanding of the risks involved and remained committed to her decision to donate a kidney to a stranger. Her work-up was unremarkable. Her renal ultrasound demonstrated normal kidneys bilaterally in size, morphology, and echotexture, and the patient had a 24-h urine creatinine clearance of 88 ml/min.

The transplant committee met to discuss her offer. All members agreed that her decision was made out of a motivation of pure altruism and agreed that the patient should be permitted to donate. The selection of an appropriate recipient was more problematic and it was decided that this should be based on the criteria used for selection of a cadaver recipient in our local organ bank (New England Organ Bank).

The living donor transplant was performed on February 8, 1999. Both donor and recipient did extremely well surgically. The donor was discharged from hospital care on postoperative day 4 and had an uneventful recovery. On 1-year follow-up, she continues to feel quite well, without any residual discomfort from the surgical procedure. She states that her recovery time was limited to 4 weeks, after which time she returned to her usual, productive lifestyle.

Discussion

The number of patients with end-stage renal disease continues to increase at a rate of 7–8% per year in the United States [2]. It is well established that renal transplantation confers a robust survival advantage over dialysis treatment for patients with ESRD [1]. Unfortunately, the number of kidneys available for transplantation remains limited, and therefore there has been a growing discrepancy between the number of transplantations requested and the number actually performed. This underscores the need not to only maximize graft survival, but to increase the number of donors available. For this reason, living donors remain an indispensable arm of kidney transplantation. In fact, it has been estimated that if one in 12,000 Americans were to donate one kidney as live donors, there would be no on left on the waiting list in the United States [5]. Indeed, the number of live donors has increased more than 100% in the last 10 years [6]. Even if there were an adequate supply of cadaver kidneys, many centres would probably continue to use living donors for a number of reasons. Not only do living kidneys provide superior results when compared with cadaver ones, it is also the most cost-effective renal replacement therapy available [7,8]. Recently, there has been mounting evidence of unexpectedly high rates of survival of kidney grafts from living unrelated donors, despite high degrees of HLA mismatch. These donors include individuals such as spouses, emotionally related individuals, and even altruistic donors. In a survey published in 1994, all adult renal transplant centres in the United States were asked for their views and practices regarding unrelated living kidney donation. Of those responding, the majority would accept either spouses or friends ( > 60% of responding centres) as donors, but only 15% would even consider using emotionally unrelated altruistic donors [9].

The hesitancy to perform this procedure from these unconventional donors arises from a number of concerns. One of the arguments is the appropriate concern for the safety and welfare of the donor, particularly since the donor has a less favourable risk–benefit profile. Since donor nephrectomy is a major surgical procedure, there is no doubt that living organ donation requires the intentional infliction of transient physical harm on these individuals. However, a number of studies have demonstrated the excellent safety of this procedure, both in the short and long term. From a survey examining living donor evaluation procedures in US transplant centres, the risk of living donor operative mortality is estimated to be 0.03%. Furthermore, the vast majority of donors have excellent long-term survival, at least as good as that of the general population [10,11]. Barring any obvious medical contraindications to donation, there is no reason to think that the medical risk to an altruistic donor should be any greater than that of the more conventional living donor.

The other major argument against the use of altruistic donors is based on ethical considerations. In some cases, there is concern about the donor’s motivation, and that the establishment of using strangers as donors would set transplant medicine on a slippery slope toward commercialism of vital organs. However, there is no reason to believe that the desire to donate an organ to a stranger is necessarily a pathological obsession. Sadler et al. [12] in a study of 18 unrelated living donors (nine of which were altruistic strangers), found no evidence of psychopathology, and post-hoc, none experienced psychological complications or regret following donation. Secondly, since the offer to donate is being made altruistically, there is a greater likelihood that the patient is truly acting autonomously without external pressure to undergoing the procedure; likewise, it may be argued that these individuals are the only living donors that can truly give an informed consent, since there is are no underlying emotional concerns or sense of obligation that would invalidate voluntary consent.

What about the benefits of donation for this person? Does the altruistic nature of the kidney offer alter in any way the psychological benefit of performing a morally good act? Indeed, Spital [13] suggests that unrelated donors may experience an even more enhanced sense of self-esteem compared to related
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... since no sense of obligation exists, making the act of donation truly extraordinary.

The final issue to tackle is the concern that acceptance of unrelated donors will open the door to commercialism in transplantation. To avoid this problem, we enlisted the aid of the local organ procurement organization (the New England Organ Bank) to help in selecting an appropriate recipient based on tissue typing, waiting times and the percentage of panel reactive antibodies. It should be noted that this decision was blinded to both the potential donor and the transplant recipient. Although the donor, for reasons related to her own moral beliefs, imparted some restriction on her gift, she did not exclude a group of persons based on sex, creed or colour. Such a requirement would have been deemed unacceptable by our institution and would violate the policy for altruistic live donor renal donation recently adopted by our organ procurement officer. Finally, while our donor requested that the entire procedure remain anonymous and entered the hospital under a pseudonym without ever meeting the potential recipient, we do not necessarily advocate this. The meeting between potential donor and recipient may help place a tangible face to this truly noble deed.

A particularly important influence in the field of altruistic living donation is the work of the German Interdisziplinare Arbeitsgruppe Lebensspende, which was established to investigate in depth, the ethical, legal, psychological, and medical aspects of living organ donation. This group has concluded that, in principle, there are no ethical or medical grounds on which to exclude genetically unrelated living donors; rather, they have emphasized the need for a firm demarcation between acceptable and unacceptable types of living donation, based on reliable models and instruments that can objectively confirm altruistic motivation, genuine voluntariness and absence of coercion [14]. This has been incorporated into a prospective clinical trial that involves a series of lengthy interviews involving the potential donor and recipient and a mediating psychologist, leading to the signing of a transplantation contract. It is noteworthy that the German parliament has incorporated aspects of investigators’ model into a bill making it unconstitutional to categorically exclude potential unrelated living donors if living donation is contemplated. The work of the Munich interdisciplinary investigators culminated in the extraordinary act of altruism by Dr Jochem Hoyer, the German professor of surgery and the head of the transplant centre in Lubeck, who in 1996 voluntarily donated a kidney to an unknown recipient, chosen according to blood group and HLA matching from the Munich waiting list.

Admittedly, our experience is too limited to allow sweeping generalizations. Nonetheless, the following statement from our donor expresses eloquently the perspective of an individual most closely involved in the process, and supports our contention that this type of kidney transplant is ethically justifiable and should be welcomed where clinically appropriate:

‘I feel an enormous debt of gratitude to each and every one of you for allowing me to make this donation and for all the work you did to make it happen. Indeed, no one can give an organ by himself or herself. It was the doctors, nurses, secretaries, surgeons, janitorial staff, cooks, families, and on and on who donated the kidney. My body was merely the conduit.

‘I’ve been wondering whether this donation could be used, as we Buddhists say, for the greater good. There must be others who would want to make a free-and-clear gift like this, one that has the potential to make an enormous difference in someone’s life. Is there some way to let others know that it can be done? So far I haven’t come up with any answers.’

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