Self-interest, self-abnegation and self-esteem: towards a new moral economy of non-directed kidney donation

Sue Rabbitt Roff

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As of September 2006, non-directed donation of kidneys and other tissues and organs is permitted in the UK under the new Human Tissue Acts. At the same time as making provision for psychiatric and clinical assessment of so-called "altruistic" donations to complete strangers, the Acts intensify assessments required for familial, genetically related donations, which will now require the same level as genetically unrelated but "emotionally" connected donations by locally based independent assessors reporting to the newly constituted Human Tissue Authority. But there will also need to be considerable reflection on the criteria for "stranger donation", which may lead us to a new understanding of the moral economy of altruistic organ donation, no matter how mixed the motives of the donor may be. This paper looks at some of the issues that will have to be accommodated in such a framework.

These new regulations are intended to address the escalating need for live kidney and other donors. In the case of kidneys, Ponticelli¹ notes that the use of kidneys from live donors is recommended wherever possible in the European guidelines for renal transplantation, because of the consensus that "when compared with cadaveric renal transplantation living donor transplantation reduces the incidence of delayed graft function and acute rejection, allows longer graft survival and minimizes the risk of transmitting infections and cancer" (p S7). There is an increasing move to pre-emptive kidney transplantation, since "the longer the waiting time on dialysis the worse the results of renal transplantation". Indeed it is now considered that "Pre-emptive transplantation without dialysis offers the best results." (p S8) Ponticelli points out that studies have shown that live kidney donors have longer life expectancy than the general population, probably because the donors are healthy subjects.

The effect of these trends can be seen in the statistics of the UK Unrelated Live Transplant Regulatory Authority (on which the present writer has served since 2003), where more than half (423) of the 804 kidney transplantations permitted between unrelated donors over the past 8 years were authorised in the past 3 years. In 1998/9, 35 such transplants were authorised; in 2005/6, 156 unrelated kidney donations were approved.

The Unrelated Live Transplant Regulatory Authority was asked to consider a specific non-directed offer of a kidney in 2003, together with an

application for a paired exchange between two couples because of incompatibility between the two primary pairs. It was agreed that "It was clear that the practice was becoming established in some countries. The risks to the donor of severe complications were already relatively low and reducing as surgical techniques improved. The risks in the case of paired donation were no greater to the donor than if he or she had been able to donate to someone else. It was therefore agreed that, in principle, there was no objection to living donation to a stranger being considered." But there must be strong safeguards to preserve, indeed insist upon, the anonymity of the donor and to assess such potential donors very carefully, "possibly to include a psychiatric assessment".²

This view was congruent with that of the British Transplant Society (BTS) in its response to the government consultation document about proposals for the new Human Tissue Act in England and Wales, entitled *Human bodies human choices*,³ except that the BTS would be satisfied with psychological assessments of non-directed donors (NDDs). The Code of Practice for Independent Assessors issued by the Human Tissue Authority in July 2006 requires psychiatric assessments.

Altruistic organ donation poses no more difficulty than living related or unrelated donation. The same safeguards and principles should apply. Donation should be anonymous unless both parties agree otherwise. Donation should be non-directed and unconditional. The individual must be assessed properly and this should include a psychological assessment of capacity. The organs should be allocated through existing national allocation principles and in paired donation it would be preferable if the procedures were carried out simultaneously in different centres. These latter considerations are practicalities rather than principles as there is ethically no objection to this situation."⁴

Indeed, the BTS pointed out that "Donation of organs from a dead person should always be on the basis of unconditional non-directed gift."⁵ In July 1999 the then UK Health Minister Frank Dobson ordered an inquiry after a transplant coordinator agreed to a family's request that the organs of a dead person be given to a white person. The enquiry concluded "To attach any condition to a

Abbreviations: BTS, British Transplant Society; NDD, non-directed donor

Correspondence to:
S R Roff, Centre for Medical
Education, Dundee
University Medical School,
484 Perth Road, Dundee
KY10 3BD, UK;
s.l.roff@dundee.ac.uk

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donation is unacceptable because it offends against the fundamental principle that organs are donated altruistically, and should go to patients in the greatest need.”⁶ More than 30 years ago, American researchers⁷ suggested that “the use of the living, genetically unrelated donor as an organ source, without any ties of law or love to the recipient, is in all likelihood as moral as that of the cadaver donor. Indeed, it is probably more moral than the use of the genetically related donor because of the reduced chances for his moral coercion as a result of his family position” (p 99).

It has been pointed out that, like the Unrelated Live Transplant Regulatory Authority, “Ethics Committees in transplantation centers worldwide try to estimate the existence of a psychological relationship between donor and recipient that could justify the act of living donation and would exclude any possibility of trade.”⁸ But it is also acknowledged, including the new UK Human Tissue Act (at www.hta.gov.uk) with its new provision for vetting of related donors, that “anonymous donation may be the only form of living donation in which consent can be fully autonomous.”⁹ (p 204)¹⁰ Indeed there may be family pressures against non-directed donation rather than emotional pressures to donate to a relative.¹¹

As the BTS puts it, “The distinction between the genetic relation and emotional relationship is artificial as coercion can apply in any situation. It is therefore suggested that the bureaucratic framework be streamlined and changed to reinforce the importance of informed consent and autonomy of the individual. An independent scrutineer could be designated to check and balance such procedures whether related or unrelated.”¹² The new Act does this in the Code of Practice 2, July 2006 (http://www.hta.gov.uk/guidance/codes_of_practice.cfm).

WHO IS LIKELY TO BECOME AN NDD?

What sort of person is likely to make a non-directed (stranger) donation of a kidney? There is surprisingly a long experience of such donations in the US, where a paper¹³ published 35 years ago reviewed 18 donors, 9 of whom were completely unknown to the recipients. Most of these had responded to public appeals for donors. A further 22 potential donors who had responded to similar appeals were surveyed, of whom “18 were rated as having no psychiatric illness, three were character disorders, and one was homosexual. Although these candidates were not used, the sample shows a group of middle class citizens of remarkable social and personal stability.” (p 94) Nevertheless, “In spite of these findings and the data supporting them, most physicians who discussed this paper at a scientific meeting, and many transplant surgeons, in response to the prepublication article, have continued to maintain that no matter what you show, these people must be abnormal—to do such a thing.” (p 98). The researchers concluded that “Perhaps the greatest discrepancy found in this study revolves around two poles: a voluntary, altruistic, and personally rewarding act of donating a kidney to an unrelated person is viewed by most physicians as impulsive, suspect and repugnant—although the public does not share their view.” (p 99). Thirty years later, Spital¹⁴ reported that American transplant centres were “still reluctant to accept kidneys” (p 1063) on a non-directed basis.

In 1990, two other American researchers published a case study of an unsolicited organ donor.¹⁵ His psychological profile was that of a normal person with full capacity for informed consent, although he had “significant personal adjustment problems. His quest to become an organ donor appeared to be a means of resolving both his desire to reach unrealistically high goals and his low self-esteem and is consistent with his other altruistic activities. It is fascinating that he had not signed his uniform donor card. We see this as an indication that Mr X was

seeking gratification in “the here and now”; the prospect of posthumous donation apparently did not provide that for him.” (p 57). They asked: “Is it excessively paternalistic to interfere with his autonomous choice to be an organ donor because we believe the benefits to be illusory? Or is it professionally irresponsible to encourage a person like this to pursue his quest?” (p 57). In the event, the transplant programme lost contact with the potential donor.

Gohh *et al*¹⁶ report another American case, that of a 50-year-old white woman of strong Buddhist beliefs who did proceed with the donation, having stipulated that it be entirely anonymous and that the recipient be a person who was not associated with a killing vocation of any type such as hunting, fishing or the armed services.

A more complex case is described in a long journalistic profile in *The New Yorker*.¹⁷ A multi-millionaire property developer, who was something of a polymath with a tendency to reduce most analyses to mathematical principles, seemed to be committed to “total divestment” of his property and assets, progressing to his kidney. “He made one other calculation: there was a chance that one of his four children—then aged between three and eleven—might need a kidney that only he could supply. Kravinsky took into account the rarity of childhood kidney disease, the fact that he had only ten or so years left as a viable donor, and the fact that siblings tend to be the best kidney matches—his children were well provided with siblings. He decided that the risk was not greater than one in two hundred and fifty thousand, and that it was a risk he could accept. In fact, Kravinsky began to think of a donation as ‘a treat to myself. I really thought of it as something pleasurable.’” (p 59). The author of the profile suggests: “The rest was math and poetry: Kravinsky has said that he was driven by ‘the mathematical calculus of utilitarianism,’ which gives primacy to the idea of the ‘greatest good.’ But he acknowledges, too, another impulse, which emanated from what he calls his romantic or neurotic self: to give a kidney was a self-sacrificing, self-dramatizing act.” (p 60). His wife did not support him in his intention. Even so, “The consensus was, if this is what he wants to do and he’s a competent individual, you can’t deny him this right just because someone doesn’t want to do it,” Radi Zaki, the director of the Centre for Renal Disease at the Albert Einstein Medical Center, PA, USA said. “But we made the process hard for him. We delayed, we put him off. The more impatient he got, the more delay I gave him. You want to make sure this is the real deal.” (p 61). The donor did not inform his wife or family, but he did contact the *Philadelphia Daily News*, which ran a story on the transplantation. Like an Indian *sadhu*, the donor told his profiler, “The real test of my vanity would be if I gave everything away. Not just to the point of a working-class existence but to the point of poverty.” (p 63).

In 2003, Leeds (UK) consultant renal physician Dr Charles Newstead told the press that he had a candidate altruistic donor, and Professor Nadey Hakim, head of transplant surgery at St Mary’s Hospital in west London, UK, said they had had several such offers.¹⁸ A Canadian group reported¹⁹ that they received 4–6 calls a month from people wanting to be NDDs. This provoked them to undertake a telephone survey of 500 British Columbia residents, of whom 29% said they could contemplate donation to a stranger. Although the researchers point out that this was a very hypothetical situation, they suggested from their data that there were differences between those willing to contemplate such donation and those who were not: potential donors were more likely than others “to report trusting the safety of transplant procedures, wanting to help others by donating their organs after death, believing that their organs could be used to help somebody live a healthy life, having thought more about organ donation in general. These

results suggest that they [potential donors] hold attitudes that are consistent with an ethic of altruism and that they have taken some concrete steps that are congruent with their ideology." (p 1694). They point out that "It may be that the decision to donate a kidney (whether hypothetical or real) is not entirely a rational decision-making process. Evidence suggests this is true in the case of [emotionally/genetically related] donors.... It may be that questions about an emotion-laden subject such as organ donation are processed, metaphorically more by the 'heart' than by the 'head'." (p 1694). They consider that their study "also suggests that legitimate motivations appear at the root of [respondents'] reported willingness to donate to a stranger, which gives less credence to any assumption of psychopathology ... people may indeed be genuinely caring, even in the face of a significant personal cost to themselves. Caring can be motivated by genuine compassion and need not be manipulatively self-serving, or born of psychopathology. Conceivably, the transplant community's reluctance to embrace living anonymous donation to date may be found to be unduly cautious." (p 1695).

HOW MANY NDDs ARE THERE LIKELY TO BE?

A Minnesota group has reported²⁰ that they received 360 inquiries about NDD in the period 1997–2003. In all, 42 detailed evaluations were made, resulting in 22 NDD kidney transplants. They describe the psychosocial evaluation, which is more extensive than that for directed donors. "Of the 42 assessed candidates, nearly 40% (n = 16) had a strong religious and/or Christian conviction and believed that donating was an act of living out their faith and their dedication to serving others (ie, an act to benefit a recipient). A further six candidates were motivated to donate in response to their feelings about someone important in their life who had died; some saw donating as a way to effectively grieve. In addition, two hoped that donating might impress others significant to them; two thought donating might aid in publicising organ donation; and two saw donating as a way to bolster their self-esteem. (Wanting to impress others or bolster self-esteem was considered a contraindication to donation.)" (p 1112). They noted that two of the 22 accepted candidates later sought media attention and engaged in self-promotion. Out of the 22 NDDs, 15 were males, all but one were white Americans, the one remaining was a native American. Their average age was 40 years, and 15 were single, although three of them had children aged <18 years. They noted that 117 NDD kidney transplants had been reported in the USA as of May 2003.

Reflecting on their experience²¹ in Minnesota, the researchers acknowledged²² that "we were extremely cautious, conservative, and possibly paternalistic when we developed our initial protocol" (p 284). They remark that "As our NDD programme has evolved, we have become less concerned about (or less suspicious of) donor motives, since most NDDs have truly been motivated by altruistic or humanitarian reasons." (p 287). They were inclined to agree that "the willingness to be a donor might often reflect a healthy altruism derived from genuine moral concern rather than psychopathology." (p 287).

Another American transplant group has reported²³ that 17 out of 62 potential NDDs were eliminated by screening. Of the remaining 45 NDDs, 16 failed to follow through with the psychiatric evaluation, which eliminated a further 9 donors. One of the remaining 20 potential donors dropped out, and 9 were found to be medically unsuitable. The remaining 10 NDDs amounted to a 3–5% increase in the kidney procurement pool for the organisation, but the group still considered that "We have demonstrated that there is sufficient community interest to support an ND living donor programme for patients with end-stage renal disease." (p 173). Half the 20 NDDs were male

and half were female, whereas 9 out of 10 donors in 'bonded/emotional' relationships in the study were female. The ages of NDDs ranged from 29 to 51 years, and averaged 40.3 years, not very different from that of the bonded donors (emotionally/genetically bonded donors).

In 2002, a National Conference Report²⁴ of the American transplant community commented that "additional psychosocial scrutiny of the NDD before and after surgery is necessary because there are no data yet available that describe similarities or differences between the directed and nondirected donation experience. In directed donation, there is a defined benefit for the donor who has knowledge of and observes a family member or loved one regain health. Whereas most people in the transplant community also view the directed donor as performing an altruistic act, it is well known that because of the nature of family dynamics or relationships, some family members may feel pressured to donate. The motives of the NDD are, presumably, more heavily weighted by an altruistic standard. As there is no potential pressure or coercion from a recipient or family member who is known to them, there is no direct relationship to the recipient, not are there expectations of seeing firsthand the postoperative benefits to the recipient. On the other hand, altruism was not the only acceptable motive for the NDD that was considered by the conference participants. Several other ethically acceptable motives for the NDD could be identified such as religious beliefs, wishing to reciprocate to society, or wishing to honour an individual who died waiting for a transplant. Notwithstanding these considerations, the motives of an NDD warrant a thorough exploration to determine psychosocial suitability." (p 585).

This National Conference also pointed out that "Although long-term data regarding the well-being of directed donors has been established, it is not yet clear what the psychosocial impact of donation will be on the NDD who may not have the reward of seeing the health of their recipients improve." (p 588).

WHY ARE WE SO SUSPICIOUS OF NDDs?

It has been noted that "transplant teams have generally been suspicious of living, genetically unrelated donors—not only strangers and acquaintances, but often even spouses and friends who are emotionally related donors. This suspicion has various sources, including concerns about donors' motives and worries about their competence to decide and the voluntariness of their decisions, as though such supererogatory actions signal problematic motives, incompetence or involuntariness. In contrast to professionals' attitudes, a majority of the public holds that the gift of a kidney to a stranger is reasonable and proper and that the transplant team should accept it." (p 50). This suspicion and ambivalence was very apparent to a German transplant surgeon when he made such a donation "as an act of Christian charity", albeit with publicity of his own seeking, although the publicity is thought to have increased live kidney donation fivefold in Germany. However, the German Transplant Act that came into operation a year later banned such non-directed donations.²⁶

The Canadian group, who developed psychological profiles of potential NDDs consider that their study "dispels the notion that psychological health is irreconcilable with altruism. As a result, we now need to weigh into the cost/benefit ratio the intangible worth of altruism that motivates the LAD [Living Anonymous Donor]... the recognition that altruism is a legitimate motivation, and can be part of an individual's fulfilment of their moral agency, provides a strong ethical case for LADs." (p 207). Furthermore, they point out that potential NDDs have rights too—"anonymous donation may lead to psychosocial or moral benefits for the donor, the denial of

which would contravene the principle of nonmalevolence." (p 204).

Scandinavian researchers²⁸⁻²⁹ have identified several categories of motives in individuals desiring to become living kidney donors: a desire to help, increased self-esteem from doing good deeds, identification with the recipient, logic, external pressure and a feeling of moral duty. And often, the motives for donation were mixed.

It has been argued that "The main moral argument to support solid organ donations by strangers is based on the principle of respect for autonomy. If a competent adult seeks to act altruistically and offers to donate a solid organ unconditionally, and the adult understands the risks and benefits of the procedure, and voluntarily consents to the procurement, then his or her wishes should be respected. Although organ donation confers no physical benefits, studies have shown that donor experience increased self-esteem and feelings of well-being. A related autonomy argument stems from the current practice that permits families to override an individual's declaration to donate even if his intentions are competently stated on a driver's license or valid organ donor card. As such, the only way for an individual to ensure that his or her interest in being a donor is respected is to donate while alive."³⁰

Equally, "The final decision to perform the living-donor transplant nevertheless rests with the transplant physician, who is not obligated to perform a transplant when he or she believes that the harm to the donor may outweigh the benefits. These benefits include the satisfaction of helping another person via an altruistic act, psychological benefits and any tangible benefits such as increased family income when a recipient returns to work, freedom to travel with the recipient or freedom from caring for a sick relative. In our view, none of these practical benefits necessarily reduces the level of altruism in donation, but altruism must be present."³¹

More than five years ago, the Consensus Statement on Live Organ Donors noted that the majority of US health insurance companies do not consider healthy kidney donors to be at increased risk for medical problems and do not raise their premiums.³² The risk of death in donating a kidney is currently cited at 0.03%.³³ Many operations are now laparoscopic, which has been widely held to have enhanced the willingness of individuals to donate.

WHOSE ALTRUISM IS IT?

Discussions of altruism in the West were dominated in the middle of the 20th century by economists who construed rational behaviour as the making of choices on the basis of motives of narrow self-interest, which in itself was viewed from very narrow economic perspectives. "Scholars in this tradition see a fundamental disconnect between rationality and morality. They view society's attempts to articulate and enforce moral norms as attempts to avoid the losses inherent in social dilemmas—situations in which the rational pursuit of individual self-interest leads to outcomes that are undesirable from the perspectives of larger groups."³⁴ (p ix). It has been pointed out that "Narrow versions of the rational choice approach leave the moral emotions completely out of the picture. Naked self-interest is not an unimportant motive of course, and these models can help us understand much of the observed human behavioral repertoire. But there is also much that is simply beyond the reach of these models."³⁷ (p 27). And indeed of their makers, since economists have been shown to be "less likely than others to cooperate in social dilemmas and that this difference is at least in part a consequence of their training." (p 71).

Altruistic behaviour has been observed in a wide range of animals, birds and insects. While it has been suggested that

these behaviours are strongly correlated with kinship and preservation of the species, there are exchange societies in these species just as there is in human society from the most primitive to the most sophisticated. Anthropologists such as Mauss, Levi Strauss, Simmel and others have described a wide range of exchange networks in societies on every continent that are not dissimilar to the systems described in biological altruism.

And as the communitarian economists of the later decades of the 20th century capitalism realised, "The purely economic man is indeed close to being a social moron."³⁵ (p 37). Such a "rational fool" would be friendless at best and probably psychopathological. Although it has been commented that in the West, at least in the last half of the 20th century, "the dominant modern psychological theories of motivation are fundamentally egotistical and hedonistic"³⁶ (p 148), common-sense and observational studies have also led to the statement of the obvious: "people are driven by a combination of selfish and altruistic motives" (see Frank,³⁴ p 111). We leave tips at restaurants we never expect to visit again; most of us look for various forms of job satisfaction over and above the actual pay cheque. Our motivations are not narrowly economic.

There are other "currencies" beyond the economic determinist models of altruism, such as our need—as pointed out by Maslow³⁷—to maintain and enhance our self-esteem as individuals, and our dependence on the maintenance of social trust for even the most simple activities—such as eating food prepared by others or crossing a busy street. And these currencies can mean that altruistic acts are reciprocated: every study of live kidney donors from Turkey to Scotland has reported enhanced self-esteem among the donors.

In discussing the ethics of financial incentives for cadaver organ donation, a panel of the American Society of Transplant Surgeons "gave unanimous support for the concept of altruism" and did not want to jeopardise it by financial incentives.³⁸ They define their notion of altruism as follows:

"Altruism is considered to be an action that is motivated primarily or solely by concern for the needs of others, and is freely chosen rather than done out of duty, obligation, persuasion or exploitation. This definition conveys the concept of doing good for someone else by one's own accord that may carry some cost or risk to the agent. Altruism assumes that there can be conflict between what promote one's self-interest and the well being of others, and encourages individuals to consider primarily the interests and well being of others. This commendable good action on behalf of another has been the underpinning of organ donation as a non-obligatory virtue. Maintaining altruism as the central incentive to donation has averted the donation of organs from becoming a commodified exchange, which could be exploitive in nature, as noted earlier, could bring an unacceptable commerce to the value of human life." (p 1365–6).

Is it so difficult to extrapolate the notion of altruism as something that is not cost-free but which is made as an autonomous choice by live, non-directed kidney donors?

It has been noted^{39–41} that most major religions view organ donation as something that is permissible, and indeed that it can be "really voluntary and altruistic, can be the ideal expression of love to each other." Equally, no religion (with the possible exception of sects such as the Jesus Christians) makes organ donation a duty or even an obligation. Because we cannot refer to deontological⁴² guidance, we often resort to consequentialist arguments to encourage organ donation—"the correct choice is the one that produces the best overall consequences"—by a utilitarian calculation of the number of recipients who could be helped by the donation of organs or tissues. Yet, as was pointed out above, we still tend to react "as

though such supererogatory actions [ie, offering to donate a 'spare kidney' to an unknown recipient] signal problematic motives, incompetence or involuntariness." Although robust safeguards clearly must be in place (as they are in the Code of Practice for Independent Assessors for the new Human Tissue Act), we might also consider the possibility that we need a new moral economy to encompass the generosity of live kidney donors, no matter how mixed their motives are.

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