Still an Abhorrent Practice?

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Although it is only some four years since I wrote about the difficult medical and ethical considerations raised by rewarded live-donor kidney transplantation the debate has moved on significantly so that an update seems appropriate. It is disappointing, but unsurprising, that the underlying problem is unaltered or, indeed, somewhat worse; the number of kidneys available for transplantation has shown little increase, more patients are developing end-stage renal failure and the waiting list continues to grow. An adult patient who is not blessed with either a partner or relative to donate a kidney will probably wait between two and five years for their first transplant and, of course, some will die during this time because dialysis becomes impossible. A telling statistic comes from the United States Department of Health: “Each day, about 74 people receive an organ transplant. However, 17 people die each day waiting for transplants that cannot take place because of the shortage of donated organs.” The situation in the United Kingdom is probably even worse.

The Human Tissue Act (September 2006) is supposed to reduce the influence of the next of kin in preventing the removal of organs from a potential donor who has previously recorded this clear wish during their lifetime. There are about 1,000 potential donors each year in Britain, although only about 600 actually provide organs, usually because of opposition by the family at the very difficult time when decisions have to be made. The availability of another 400 donors each year would have a significant effect on all transplant programs and would, incidentally, dramatically reduce the size of the dialysis population and the money spent to sustain these patients, currently about 2–3% of the entire NHS budget. However, such is the corporate sensitivity of the transplant establishment that it seems very unlikely that transplant co-ordinators and surgeons will be prepared to increase the encouragement to donate that they give to next of kin, for fear of the shock/horror story which will inevitably follow in the tabloids. Why is there such a disparity between the clearly-expressed wishes of the majority of the population and the “spin” inevitably placed on this story?

Recent initiatives aim to increase the use of “marginal” (non-heart beating) donors, patients in whom the kidneys have been rapidly retrieved after death has occurred, with perfusion of the organs in vivo in an attempt to preserve their viability. Other marginal donors, both cadaveric and live-related, include older patients and those known to be suffering from diabetes, hypertension or significant renal impairment. Even if all of these marginal kidneys were used for transplantation the numbers are not large and, more importantly, there is a greater risk of problems and smaller chance of long-term graft survival. A potential recipient of such a kidney will need carefully to have considered the risk/benefit analysis long in advance of the event and their “informed consent” will probably need to be written in blood and witnessed by at least three Law Lords if litigation is not to follow an adverse outcome as surely as night follows day.

Rewarded kidney donation is now an accepted fact in many countries, although proscribed in America and most of Europe. The arguments against it usually include exploitation of the poor by the rich, dangerous medical and surgical practice, the real risk of coercion and the involvement of criminal middlemen. All surgical transplant associations and many religious authorities denounce the paid use of paid human organs in terms such as “morally and ethically irresponsible” or “inhumane and unacceptable”. One American anthropologist has described legalisation of organ sales as the assertion of property rights by one relatively privileged group over the bodies of the disadvantaged.

Those in favour of donor reward usually emphasise the increasing importance accorded to patient autonomy, the freedom for people to engage in dangerous and even life-threatening pursuits if they wish and the fact that donation of renewable tissues such as sperm, ova and blood is universally accepted. An increasing body of respected transplant opinion in the West
is coming to an acceptance that rewarded kidney donation is a reality and that it is the very illegality which causes most of the problems. Rather akin to the Volstead Act, unrealistic legislation has driven the procedure underground, or at least overseas, creating a situation that is ripe for criminal exploitation. There is, regrettably, some evidence of kidneys being removed incompetently from donors who have been inadequately assessed and then receive no long-term follow-up. Although the money paid by the recipient is often substantial in local terms, the amount actually received by the donor is usually very much less. (It would take a very jaded author to substitute “claimant” for donor and “defendant” for recipient!)

The debate about rewarded kidney donation was reignited in America about one year ago in articles from some leading transplant doctors and ethicists. The attempt to move the discussion on from the blanket prohibition which is usual in the West has, so far, been met with the predictable and conventional arguments. One perhaps unexpected objection has come from a number of developing countries where cadaver transplant programs are in their infancy and there is concern about the negative effects of establishing an alternative pathway based on paid, unrelated donors. This system has been established in Iran for many years and explains why most Iranian patients with end-stage renal failure are treated with kidney transplants and why the size of the dialysis population is very small, because it is usually necessary only as a holding treatment until the patient can be successfully transplanted. The investigation, reimbursement and allocation of kidney donors is a function of central government, although it is likely that a degree of undesirable commercial interference with the process may also take place. Nevertheless, the Iranian transplant community is no longer regarded as a pariah on the world stage and the successes and failures of the system are now being hotly debated around the world. The United Kingdom will not be exempt from this debate.

The proposal is, quite simply, that potential kidney donors should receive an agreed and appropriate financial reimbursement for the risk and discomfort involved in a donor nephrectomy. Donor assessment and surgery would be performed only in accredited centres using strict guidelines agreed at a national level and, most importantly, the donated organ would not be targeted at any particular recipient; the kidney would go into the national donor pool and be allocated according to the currently established criteria which emphasise the importance of a good tissue match and, to lesser extent, waiting time on dialysis and difficulty of transplantation. Detailed cost analysis in America suggests that an appropriate reimbursement for donating a kidney would be about $45,000. This assumes a typical annual income of $40,000, a life value of $3,000,000, a 5% decrease in quality of life, modest loss of income during convalescence and a 1% risk of death following nephrectomy. In fact the actual risk is probably only about 0.03% but, even assuming a figure ten times greater, the calculated reimbursement to the donor would then be about $20,000. This cost is trivial compared to the £20,000/yr cost of keeping a patient alive on dialysis, quite apart from the inferior quality of life which is achieved.

I can remember the moral outrage that led to the Human Organ Transplant Act in 1989 and the unshakable conviction that such commerce in organ donation would forever be beyond the pale. The equivalent outrage previously accorded to conditional/contingency fee arrangements for lawyers and, dare I say it, conditional reimbursement of expert witness fees comes inevitably to mind. Times change and so do apparently-immutable received wisdoms. For Confucius it was “Study the past if you would define the future” but for the Editor of the BMJ, after Bristol, it was “All is changed, changed utterly”. Watch this space.

Addendum


References