Ethical problems in renal transplantation: a personal view

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The golden age of medicine for the individual medical man was the last century. There were few effective drugs available and all the doctor could do was to 'cure sometimes, to relieve often, to comfort always.' No one expected a doctor to prolong life, and the profession had little responsibility and every opportunity to be noble. Medicine was an art and hardly a science.

The last fifty years have been a golden age of a different sort. There has been a logarithmic increase in our knowledge of diseases and in our therapeutic armamentarium. It has not been an unmixed blessing.

Primum non nocere (First, do no harm)

The power to do good always carries with it the capacity to injure. Effective medicines have horrendous side effects and we often do active harm to our patients in our efforts to help them. Many of us face torturous decisions day after day. Should I put a patient on cyclophosphamide for glomerulonephritis? Will he suffer some serious infection and die as a result? If I withhold the drug, will he die of renal failure which could have been prevented? Should a surgeon take a patient for an operation which carries risk to life? Is he sure the patient will die of the disease and cannot recover with conservative treatment?

All these dilemmas pale into insignificance beside the predicament in which transplantation places us. The worst of all is renal transplantation, because the kidney, being a paired organ of which we need only one for life, can so easily be removed from a living person. This leads us to perpetrate the ultimate in horrors, a hazardous operation on a healthy person, grievous hurt by the 'healing profession'. A few of us have been catalysts in the development of renal transplantation in this country. I do not know whether to pride myself on this, or to hang my head in shame.

The patient with chronic renal failure: options and costs

Let me begin by stating a few basic facts. The patient with chronic renal failure has three options, each with subdivisions. First, he can receive a renal transplant, which could be from a relation, a live unrelated donor, or a cadaver.

The main difference between these is that he has a good chance of success with a related donor even if he uses azathioprine, which would cost him approximately Rs. 5000/- a year, but the unrelated kidney from a live or cadaver source will be successfully grafted only if he uses cyclosporine for a period, and this drug costs Rs. 100,000/- a year. Many doctors claim to have successfully weaned their patients off the drug after some time, usually a year, but that still means an additional cost of Rs. 100,000/-.

What must be stressed is that cyclosporine has only made a difference to short term survival of the graft. Long term survival depends on the degree of matching between the donor and the recipient. A full-match sibling-graft has a half life of 25 years. Any other half-matched relation has a half life of 12 years. The unmatched cadaver or unrelated live donor graft has a half life of 6.5 years, even if cyclosporine is the immunosuppressive used.

Second, the patient can stay on dialysis. This could be hemodialysis, which he could take in hospital for a cost of Rs. 120,000/- a year, or at home for a cost of Rs. 250,000/- to buy a machine, and then Rs. 50,000/- a year for its running. He could go on Continuous Ambulatory Peritoneal Dialysis for a cost of Rs. 130,000/- a year and could carry out this treatment at home.

Both these modalities are now available in some centres in India, and the long term survival is good, with a reasonable quality of life.

Third, the patient could quietly go home and die. From the point of view of the family, this is often the best option. Whatever the treatment, it is expensive, and usually the family is poorer for it. Treatment often requires the sale of property or the need to take large loans, and only a few people in our country earn enough to repay them and leave the family richer than it was before the illness struck them.

The only option at least a few Indians can manage on their own income is a related donor transplant with azathioprine. I have seen gold chains disappearing from the necks of ladies and being replaced by a yellow cord to hold the mangalsutra, and silks yielding to faded cottons and I have been left with the guilty feeling of having pushed a family into poverty. Ethical dilemma No. 1.

The kidney donor

Let us now turn our attention to the donor. We always reassure him or her that the donation of an organ is quite safe and that life can be carried on safely with one kidney. True, but the kidney is removed by a major operation and all major surgery carries a definite though small risk to life, perhaps 1 in 1000.

The newspapers carried reports of two donor deaths in Madras during the last few years and there might have been others which did not attain public knowledge.

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Hospitals and transplanting doctors do not publicise their failures, especially donor deaths. If the donor of a kidney gets a renal disease himself later in life, he has a smaller renal reserve and will go into renal failure much faster than if he had both kidneys available. It is mandatory that we should stress the risks when we talk to the prospective donor, and that our conversation should be confidential and that he should be given the option of telling the doctor that he does not wish to donate the organ. The doctor should then invent a medical reason for not accepting the donation, so that the family should not be aware of the reluctance of the donor designate. This is ethical dilemma No. 2.

I have always regarded a medical certificate as a sacred document and think poorly of doctors who attest to falsehoods and yet I have to tell a lie to preserve harmony in the family. I have done this on at least three occasions. Once, the prospective donor told me, three days before the operation, that she had changed her mind. I hurriedly ordered a test and in collusion with the biochemist, had it reported marginally abnormal and therefore declared the donor medically unfit. I had to listen to a well justified diatribe from the husband of the patient for my carelessness in not having done this essential test earlier and for having put the family to great inconvenience and costly delay.

The unrelated live donor: adequate compensation for risk?

The greatest problem lies with the unrelated live donor. The idea of someone having to sell a part of his body for any purpose is repugnant to us and our reflex reaction is to abhor it. Let us think it over rationally.

There are three parties involved. The donor who sells his kidney, the patient with renal failure who buys it and the medical man who serves as a broker, a commission agent who effects the transfer of ownership. In view of the multitude of active programs all over the country, it is clear that all three parties are happy about the present situation and are willing and even keen on perpetuating the present practice. What right has any one else to intervene? The patient is a man or woman on the verge of death, clinging desperately to a hope that this operation will bring him or her back to a full life and not necessarily one treacherously exploiting the working classes. The donor is a poor man with the laudable objective of earning some money by the sale of his only asset, perhaps to educate his son, perhaps to get his daughter or his sister married, perhaps to pay for an operation on his wife. He or she is not necessarily a drug addict seeking the wherewithal for the next fix. The doctor is a noble soul, desperately trying to save his patients at great difficulty to himself and not necessarily one who is interested only in the money he can, extract from the recipient and in retaining for himself the lion's share of the proceeds. Unless otherwise proved, we have no right to view any of the three as anything other than what they claim to be.

But nagging doubts continue to assail me. Let us begin with the patient. Has he or she been informed that the half life of the kidney will be only 6.5 years, in other words, that he or she has only a 50% chance of the kidney lasting more than six years? Has the doctor mentioned the fact that there is no certain way of establishing whether the donor has some viral disease which could cost the life of the recipient, that the tests now available are not 100% reliable and that the person intent on selling an organ is not going to release information which would preclude the sale of the organ? Has the patient been told that there are excellent alternatives with less of such risks, the different forms of long term dialysis?

The biggest source of doubt, of course, is the donor. Would he be as willing to give his kidney if he knew that donors can die as a direct result of the operation? The chances of dying are small, but not negligible. What about the risk of his developing renal failure himself, due to some renal disease developing later? I have seen renal failure years after nephrectomy in three of my donors. Two went into the end stage and needed renal replacement. My donors are all related and the family rallied round and someone else offered each of them a kidney. What is the chance of this happening with an unrelated donor?

We are, of course, exploiting poverty all the time. I do not climb the coconut palms in my garden, but pay someone else to pick the nuts which I enjoy. We pay people to entertain us at the risk of their lives, trapeze artistes and lion tamers, for instance. There is a difference. They are living by their skills, the renal donor is at the mercy of the surgeon. Is he being paid a realistic sum for his sacrifice? Who decides that Rs. 5,000/- or Rs. 10,000/-, or even Rs. 50,000/- is adequate compensation for an irreplaceable asset, for life itself? This is a buyers' market, where the buyers are all rich and the sellers are all making distress sales.

Noble medical profession?

The greatest mistake mankind ever made was in describing the medical profession as noble. We now claim nobility in all our actions and doctors doing unrelated donor transplants say they have to do it because they are committed to their patients and have to do it to save their lives, however distasteful the means.

The argument is specious. We do transplants only for some fraction of the people -with renal failure in the country, maybe 2 or 3%. Have we no duty to the rest, who are too poor to come to us in the first place? Have we no duty to the donor? We ease our conscience by saying that the donor is well rewarded by being given the wherewithal to pay his debts or to buy a hut or a bicycle. If we were really interested in the donor, would

we not organise an international auction for his kidney? Surely the rich Arabs and Chinese who buy our kidneys could pay lakhs for them instead of this pittance. Should not the donor receive more for the transplant than the medical man who is merely a broker in the deal? If a broker helps me to buy or sell a car, he receives only a fraction of the price, not the lion's share.

Kidneys from cadavers

We are told that the country is not ready for cadaver transplantation because it is costly and requires a complicated technological set up. This is nonsense, an argument raised by vested interests. The set up in the West today is elaborate and well beyond our means, but so is every aspect of medicine. Even a live related donor transplant in the West is done with a degree of sophistication beyond us, at a cost at least twenty times as much as here. I was involved in a cadaver transplant program in Australia when transplantation was in its infancy all over the world. The concept of brain death did-not exist. We waited for a person to die in the old fashioned way, by entire and continuous cessation of respiration and circulation and then took the kidneys within an hour of death and got a reasonable 60% one year graft survival, using only azathioprine. There are units all over the world which are using such donors today, people who die outside hospitals or before they get on respirators and their results are only marginally worse than those with heart-beating donors. In 1968, Australia did not have sophisticated computers and transnational movement of organs. All kidneys harvested were used within the city, within eight hours and I see no difficulty in establishing the same system in Madras. The cost would be rather less than that of the unrelated live donor, as we can do without a number of investigations needed to safeguard the life of the donor. We need to have the backing of the public for this, with wholehearted willingness to donate organs after death. The effort that the unrelated donor lobby is using to prevent cadaver legislation would better be utilised to persuade the public to accept the concept of donating all organs after death.

We have an Act to regulate transplantation now. It is a far sighted piece of legislation, bringing in the concept of brain death, making it possible for us to decide during life that we wish to donate organs after death, firmly prohibiting commerce in transplantation and introducing some regulation of the whole transplant industry. Of course it has flaws and many people on both sides of the question have spent much time pointing out where the law would be misused. It is up to us to put it to good use and the effort we have spent arguing about it would have been better utilised had we got on with the job of making it work.

The gift of life

Unrelated live donor transplantation should be banned because there is an alternative for the patient with terminal renal failure in the form of dialysis or cadaver transplantation, because the donor will always be a poor and ignorant man who will be exploited by the doctor, the patient and the broker and because we will never have cadaver transplantation unless the easy way of buying a kidney is closed to the rich and influential. They will then turn their efforts to establishing cadaver donation in the country. A time will come when it will seem quite natural for every one of us to give life even as we leave the world, with gifts of kidneys, livers, hearts, lungs and to give sight to the blind. Our organs will live on after us.

This is truly the path to immortality.

Resolution on kidney transplantations

On 14 February 1995 the Medical Service Centre of Karnataka State, organised a convention in Bangalore to discuss the problems arising from renal transplantation. The following excerpts have been taken from the resolution passed at the close of the meeting:

'This convention... expresses its strong protest against the sale of human kidneys reported in the city and elsewhere.

'This convention... expresses profound admiration and deep gratitude to all (those). . . whose priceless dedication and tireless work has made organ transplantation a reality, resulting in the saving of thousands of lives. At the same time we cannot but condemn the sale of organs and the crass commercialism (now bedeviling) this extraordinary achievement.

'We express our strong and indignant condemnation of the nefarious sale of organs not only because it goes against human dignity and . . . medical ethics but also because concrete evidence has demonstrated beyond any shade of doubt that this practice has resulted in exploitation of the donor, exploitation of the recipient, poor quality of medical care, a negative impact on the progress of live, related transplant and cadaveric transplant and increasing foul play and crime.

'We note with shock and dismay the occasional voices . . . from the higher echelons of our society subtly arguing in support of sale of organs. . ..We cannot but reject their misplaced concern for a small section of rich and privileged patients who would benefit from the sale of organs which... would irreparably damage the interests of society at large. Medical ethics cannot be perverted to benefit the few at the cost of the interests of humanity at large.

'This convention reiterates the view held by the World Health Organisation, the International Society of Transplant Surgeons and others that cadaveric transplants and those from live, related donors are the only medically and ethically acceptable procedures.

'We ask the medical community to isolate its black sheep. Firm steps are needed to uphold medical ethics in a rapidly deteriorating situation. Only thus can we restore the cherished doctor-patient relationship. '

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