OPINION

ETHICAL ASPECTS OF UNRELATED KIDNEY DONOR PROGRAMME

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A visit to India in early 1995, particularly to New Delhi and Madras cities, on a World Health Organisation sponsored study tour, prompted me to write this article. Towards early 1995 the Indian press had been giving a very wide and an adverse publicity to unrelated kidney donor programme. An incident at Bangalore, another South Indian State capital, had resulted in such a massive campaign against the above programme. According to this, a person had alleged that his kidney was "robbed" by some doctors when he had gone to a private hospital to donate blood. Leave aside the truthfulness of the above allegation, this particular episode had created so much of controversy in India which ultimately brought to a standstill all unrelated kidney transplantation programmes. Incidentally, by the Transplantation of Human Organs Bill of 1992, the Government of India had banned the unrelated kidney donor programme using live donors, at least in some states, which became operative towards early 1995(1).

Transplantation of human organs not only has civil and criminal implications but has great ethical considerations as well (2,3). I trust that determining the implications of this important advance in medical science, which not only helps to improve the quality of life but also saves life, should not be left in the hands of the politicians and the judiciary alone. Public should be made aware of what organ transplantation is all about. It is the responsibility of the mass media to correctly educate the public on this area and to high light the advantage and disadvantage of this procedure. The impact on the donor and the recipients should be well understood.

Transplantation of human organs in some form are in operation for decades. Here I refer to blood transfusion, bone marrow implant etc. which are regenerative tissues. However, the issue is not the same with non-regenerative tissues such as kidney. Presently donation of human organs are governed by human tissue act and each country has its own guide lines based on the basic principles. When tissues are obtained from the living or the dead for the purpose of transplantation, such tissues are used on other individuals to either save life or to improve the quality of life. This procedure cannot be obviously equated with cosmetic surgery and hence it is not a luxury. Therefore, when restrains are placed on transplantation surgery, care should be exhibited not to disturb the programme. The objective for introducing restrains should be to prevent unethical practices, malpractices, frauds and exploitation.

The main issue at hand today is pertaining to renal transplantation. There are thousands of patients who die around the world with chronic renal failure and many more suffer with failing kidneys. The medical science has advanced to such an extent that these unfortunate patients could be salvaged by effective renal transplantation. Therefore, it is the responsibility of the society to explore all possible means to look for ways and means of obtaining such organs for transplantation.

The procedure here is termed homotransplantation, which involves the transfer of viable tissue from one human being to another. We are also aware of heterotransplantation, where attempts are made to transfer organs such as heart from other animals like monkeys to human. Autotransplantation is well known to all, where tissues such as skin graft are resited in another part of the same body. In homotransplantation the ethical aspect remains an important issue on one hand while on the other hand the biological issues such as overcoming tissue immunity, availability of normal donor organ and thirdly its viability, pose technical problems. Viable organs for transplantation could be obtained either from the dead (cadaver donation) or from the living (live donor). With the concept of brain stem death being well established as the criteria of death in most parts of the world, cadavers have become the best available source for harvesting good quality organs for transplantation (4). When young, healthy individuals die under tragic circumstances such as accidents and who are diagnosed as brain stem dead, then their bodies could be maintained in a life support machine until the organs such as kidneys, liver, etc., could be harvested for transplantation. The dead body, where the diagnosis of brain stem death is made, when maintained in a life support machine is called the "beating heart cadaver". The above victims are often young and thus the organs are of good quality, and the "warm anoxic period" could be reduced to a very minimum. Tissue matching could be carried out at leisure, recipient could be prepared for surgery as a routine operation rather than an emergency procedure. But one has to accept the fact that the availability of such organs are far short of the present

day needs (5). The other best source to obtain organs such as kidneys are from the young living donors. But this has legal, moral, ethical, religious and cultural implications (6,7,8,9). A minor who is under the age of 16 years or a mentally retarded person usually cannot be a donor unless under certain circumstances (10,11). Even if they are permitted to donate a kidney, the recipient should be an immediate family member such as brother or sister. In the case of a minor the parental consent alone may not be acceptable as valid. Parental consent by proxy usually refers to treatment for the advantage of the child. The United Kingdom and the United States are slightly relaxed in the question of minor donors. However, various safeguards are present to prevent abuse (12). Certain countries have altogether banned the donation by minors. The Ontario Human Tissue Gift Act provides an example of statutory prohibition of minor donors (13). Countries like Australia and France have placed heavy restrictions on minor donors (12). In the case of adults, the situation is much easier. What generally matters is the valid consent on the part of the donor and the recipient usually be a close family member. As mentioned earlier, the Indian Transplantation of Human Organs Bill of 1992 has banned unrelated organ transplantation programmes using live donors. Exceptions could, however, be made if the recipient is specified by the donor by reason of affection or attachment or any other special reason, but yet the organ cannot be removed or transplanted without prior state approval. The legislation also bans making or receiving any payment for the supply, or even an offer for the supply, of any human organs and publication of any sort of advertisement relating to human organ transplantations with monetary considerations (1). It is estimated that around six hundred thousand kidney transplantations using live donors have taken place in India during a period of 25 years up to 1995. The Human Tissue Act of 1961 is the statute law that governs cadaver donations in the United Kingdom (14). Even this law has its own problem in interpretation (15).

At this point it is relevant to discuss the reality of the transplantation programme. In spite of the acceptance of brain death concept and hence the availability of good quality organs, yet the demand is so high. It is estimated that in the UK 30 percent of patients with renal failure are denied the benefit of renal transplant (5). In the US only one in eight of the brain dead are actually made available for transplantation (5). The problem in third world countries are more acute, as there are no facilities available to maintain brain dead individuals until arrangements are made to remove the viable organs. Religious, cultural and other beliefs further reduce the availability of cadaver donors. Since the care of the living should be the main aim of the society and the medical science, it is important for us to look for various ways to overcome this problem. Effecting necessary law reforms, changing public attitudes and broadening the scope of medical ethics to meet the present day reality are some of the areas to be tackled (16,17). Payment for tissues have provoked so much of debate and argument (18). Attempts have been made to circumvent the above ethical restriction on the sale of organs, from the dead or living by calling them as paying for the services rendered rather than for the tissues or selling tissues to kidney banks.

The best way to obtain kidney is from a very close relative specially within the family, who is young and healthy, which doubtless is the ideal method and morally, technically and prognostically satisfying. But such a facility is not available to all. This is why people look for unrelated donors. With the concept of brain death becoming more acceptable together with the change in attitude in donating cadaver organs, a time will probably come when there will be enough organs to meet the demand. But certainly it will take time. To get the best use of the brain death concept to obtain good quality organs, there need to be a highly effective and efficient infrastructure organised on an international level. The system should develop advanced techniques for harvesting, storing, matching and transporting the organs to wherever it is needed. In the United States all cadaver kidneys are collected by a federal Government organisation called the United Network Organ Sharing System which operates through 25 regional networks. This network gives permission to extract the cadaver's kidney which is then routed to a transplanting centre based on a certificate of need. Every kidney transplant is registered and every hospital that conducts such transplants has to be approved by the relevant State Government as well as the Federal Government. The cost of the transplant is borne by the Federal Government.

Purely based on common sense and reality of the present situation, I suggest that unrelated kidney donor programme be permitted to continue for a while until the ideal situation is reached. However, it is the responsibility of the state to carefully control and monitor the programme so that abuse and exploitation of the system is prevented or at least reduced. The unrelated donor programme will obviously involve money transaction and it is a hard truth that we have to accept. It is difficult to accept the argument that this programme will only benefit the rich. How many die due to ischaemic heart disease because they could not afford a coronary by pass surgery, while others get the surgery done in the best centres available either locally or abroad!

I suggest the following protocol for unrelated kidney donor programme:

1. Institutions performing the transplantation programme be registered with the health authority and

to be closely monitored.

2. A panel of independent doctors to assess the donor. Even a senior psychiatrist to be included.

3. A donor should be able to register direct to an authority and there should never be a middle man.

4. A predetermined amount of money to be paid direct to the donor through the authority. This amount should adequately compensate the donor. In addition other incidental expenses, loss of earning capacity during recovery from surgery etc., be included.

5. Full insurance cover to the donor.

6. Long term follow up of donor to be covered through an insurance scheme.

7. Minors and mentally handicapped to be excluded from being donors.

8. Women of child bearing age too should be excluded from being donors.

There is no doubt that commercialism is unacceptable in organ transplantation programmes. But when a patient is dying of renal failure, no principle is going to console him. I repeat here the news item that appeared in a news paper in India after the introduction of the bill banning the unrelated kidney donor programme. A group of 90 patients waiting for renal transplantation through the unrelated donor programme made a fervent plea to the State Government against the ban. Their memorandum stated, "True, hard destiny forces people to sell their kidneys. But by this act they bless ill-fated people like us with a new lease of life. This country has the distinction of giving rebirth to end-stage renal failure patients". They also made it clear that they are not opposed to the bill, but urges the State Government to allow also the unrelated donor programme till such time as all hospitals switch over totally to the cadaveric programme.

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