

## Organ Transplantation: ethical issues and the Indian scenario

Sanjay Nagral

There are many who believe that transplantation represents one of the most spectacular achievements of modern medical science. Advances from many fields of medicine have contributed to a tremendous improvement in results over the decades. This has led to a steep rise in the numbers of transplants being performed. Transplantation has also raised some of the fiercest ethical controversies in modern medicine. In a way it is not surprising that a field which involves the removal of human organs from a living or dead individual to save the life of another individual should throw up strange ethical dilemmas. Perhaps no other field of medicine has raised so many complex and intertwined ethical, moral, legal and social issues. Even from the Indian perspective the 'kidney bazaar' as it was rather crudely but aptly termed remains one of the biggest ethical controversies to hit the public domain in the last decade.

With the increased inflow of personnel and knowledge from the developed world transplantation of solid organs is being attempted in increasing numbers in India. Simultaneously with the introduction of a specific act called the Human Organ Transplant Act (HOTA) in 1995, the way has also been paved for performing 'cadaver' transplants from 'brain dead' patients. The Act, which was partially a response to the public outcry about the 'organ trade' in the early 90's, is also meant to monitor organ trading. Reports from the field indicate that the act has not really succeeded in achieving its main objectives viz: to promote cadaver transplantation and to curb trading in organs.

As a journal trying to raise discussion relating to the ethical practice of medicine in India we have in the past carried articles on various aspects of transplantation ethics. We thought that this was an opportune time to revisit some of the ethical controversies in this collection of articles.

### Historical evolution

Mythology is not medical history but many religious texts are replete with stories and figures where human organs are replaced by animal ones. The 'miracle' of Saint Cosmos and Saint Damien from Christian mythology as described in the 'Lives of the Saints' needs mention at least for the bizarre similarity it has to modern transplantation in more than one way. Saint Cosmos and Damien were called upon to treat a priest afflicted by a cancer of his leg and the two saints went to the nearest graveyard where an 'Ethiopian' had just been buried, took off his leg and used it to replace the priest's leg.

The British surgeon John Hunter in the late 18th century successfully transplanted a human tooth on to a hen's comb and thus made some of the first scientific attempts at animal transplantation. However it was really in the 20th century

that transplantation caught the fancy of the medical fraternity and became a reality. The first attempt at human solid organ transplantation was made by a Russian Surgeon, Voronoy who unsuccessfully transplanted a kidney from a cadaver into the thigh of a patient suffering from renal failure. Surgeons in Boston first successfully transplanted the human kidney in 1946 between two identical twins. This was followed by the liver in 1963 and the heart in 1967. Today, many other organs including the lung, pancreas and intestines are also being transplanted with varying degrees of success. Transplantation of organs like the kidney, liver, and heart is no longer regarded as experimental but an established therapy by the W.H.O.<sup>1</sup> and around 50,000 such transplants are being annually performed.

The kidney, being a paired organ can be removed from a living person, whereas the heart and the liver have to be removed from dead individuals. In the initial stages, removing organs from an individual who was "dead" as per our classic understanding of death i.e. when the heart had stopped was attempted. This was largely unsuccessful since for an organ to be viable it had to be removed within minutes of cessation of heartbeat, which was an impractical proposition. This is unlike the 'cornea' or the eye, which remains viable for a few hours and hence can be removed after some time has elapsed after death. In the last three decades, the concept of "brain death" i.e. a state where the brain is irreversibly damaged but the heart is beating came into being in the Western world. 'Death' as we understood it over the years was redefined. 'Brain Death' represents a state of irreversible damage to the brain which over a period of time (12 to 36 hours) inevitably leads to stoppage of the heart (cardiac arrest). This is typically seen in patients with severe head injury, massive stroke, brain tumors, brain hypoxia, and as a complication of neurosurgery. Such brain dead individuals or "heart beating donors" are in intensive care units (I.C.U's) on artificial respiration and removal of organs from them is performed as an operative procedure. Almost all transplants in the developed world are now done in this fashion.

French physicians first described the concept of brain death in 1959, before the era of organ transplantation. However it was then legalized and popularized due to its implications for organ transplantation. Till recently 47 countries in the world had accepted "brain death" as a legal concept and 39 countries had enacted specific laws on organ transplantation.<sup>2</sup>

The form and method of obtaining consent for removal of organs from brain dead individuals has varied. Generally, two forms of consent have been practised. The commonest form of consent is "informed consent" in which close family members agree to donate organs of the deceased after "brain death". This involves the treating doctor motivating the family for organ donation after "brain death" has been certified. Even in the West, doctors have been observed to be reluctant to do so for the fear of inviting the wrath of

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*Dr Sanjay Nagral, . Email: nagral@bom3.vsnl.net.in*

family members in an emotionally charged situation and only about 30 to 40 per cent of families actually give consent. The other form of consent is called “presumed consent”. This grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available in the absence of objection from the deceased in his or her lifetime or family members. Presumed consent places the burden of opting out of organ donation on those who object to this procedure. This system has been legalised in European countries like Austria, Belgium, Denmark, Finland and France. Vijay Rajput in an article in this issue (ref) examines presumed consent in detail.

In spite of many measures to promote organ donation, the discrepancy between “demand” and “supply” of organs continues to grow. In 1994, around 3000 patients waiting for an organ died in the U.S.A.. As more and more patients are put on transplant waiting lists the desperation to look for methods to increase the ‘supply’ of organs has increased. Transplant surgeons have resorted to the use of organs from animal species in a process called xenotransplantation. So far kidneys, livers and hearts have been transplanted from non-human primates commonly the baboon to man. Besides raising animal rights issues, there have been ethical objections to the purely “experimental” nature of such procedures where the patients were made “guinea pigs”. These issues are discussed in detail by Vijay Rajput’s (ref)

Once consent for removal of organs has been obtained from relatives of brain dead patients, intimation is given to networks, which coordinate transplant programs between various centers. The organs are distributed based on a ‘waiting list’ where recipients are prioritized. With organs being in short supply there is a scope for considerations like money, influence, race and nationality creeping into the distribution system. In choosing the recipient, another debate that has raged for a long time is whether to transplant the sickest patients since they need the organ most but also have the poorest chance of

survival or to transplant relatively healthy patients in whom the result is better and hence the organ is utilised better. In patients with diseases resulting from addictions, e.g. liver disease due to alcoholism, it has been debated whether a transplant should be performed at all since the disease has been brought on by an addiction and there is a chance that the patient could go back to the same addiction. In general, the question has been raised whether given the shortage of organs the medical profession should sit on moral judgment about diseases that are preventable or should it purely go by the medical merit of the case.

### Transplantation and religious beliefs

Transplantation has thrown up peculiar and complicated religious and moral questions. For example if a heart is removed from a cadaver, does it mean that it is now devoid of a “soul”? Also, will removal of organs in any way affect the process of “rebirth”? Both Roman Catholics and Protestants tend to support organ donation believing that God’s power to resurrect the body will not be thwarted by prior disposal of its parts. Jewish law prohibits deriving benefit from mutilating or delaying the burial of a corpse but this prohibition can be overridden to save a life. The Islamic Organization of Medical Sciences passed a resolution many years back recognizing brain death<sup>2</sup> and many Islamic countries are now performing cadaver transplants. The only big religious group, which till recently opposed the idea of brain death, is the Shintos in Japan. Thus Japan, a country otherwise extremely advanced medically was unable to start cadaveric transplantation of organs till recently when the Japanese Parliament gave a go ahead. Swami Lokeshwarananda of the Ramkrishna Mission is reported to have said in a seminar in 1988 that Hindu and Vedic scholars accept the concept of brain death<sup>2</sup>. The concept of “giving” or “daan” is ingrained in Hindu thought and therefore there seems to be no major religious objection to the act of organ donation. Activists of organisations involved in mobilizing people for organ donation report that

they have received hundreds of inquiries from citizens desiring to donate their body/organs after death. The eye donation movement in India has never faced any significant religious resistance. A survey by the Tata Institute of Social Sciences in Bombay revealed that the majority of respondents irrespective of religious and economic status were in favor of organ donation.<sup>2</sup>

### The Indian scenario

In India a majority of patients with end stage disease of potentially transplantable organs presently die of their disease. In the case of kidney failure some are on long-term dialysis an alternative inferior to transplantation. Till the passage of HOTA there was no comprehensive legislation regulating the removal of human organs. In 1991, the Central government constituted a committee to prepare a report, which could form a basis for all India legislation. Although the main terms of reference of the committee were concerned with “brain death”, it also recommended that trading in human organs be made a punishable offense. The Transplantation of Human Organs Transplant Act was thus passed by parliament in 1994. The act legalizes ‘brain death’ making removal of organs permissible after proper consent. The first few hundred such cadaver transplants have been performed mainly in the metros in the last 2 to 3 years but the activity in the field is well below what was expected or what is needed.

On the other hand, the Act also seeks to regulate non-related live donation of organs and makes commercial trading an offense. It makes it mandatory for institutions conducting transplants to register with an authority appointed by the State government. This authority will also enforce standards, investigate complaints and inspect the hospitals regularly to monitor quality. All persons associated in any way with hospitals conducting transplants without the proper registration are liable for punishment. Thus, it is probably for the first time that an external body has been given legal

powers to scrutinise and monitor the activities of medical institutions.

The Act also lays down criteria for determining brain death. Many safeguards against misuse have been built in the rules. The brain death tests must be performed by four individuals together none of whom has anything to do with the transplant and this must be done twice, with a minimum gap of 6 hours. Such brain death can be declared only in institutions recognised by state appropriate authority. The written consent can be obtained only from a close relative.

There are problems peculiar to the Indian situation that have already come up in the practice of cadaveric transplantation. Firstly the Act links 'brain death' and 'transplantation', which as Sunil Pandya and Harsha Deshmukh state in their articles (**ref**) is a fundamental flaw. The diagnosis of brain death is made in ICU's where the facilities for keeping a brain dead patient's organs working with mechanical ventilation, cardiac support and intensive monitoring exist. Such ICUs are few and are a part only of big hospitals in major cities. They are usually overloaded, understaffed and lack a central command structure. Given this situation, brain dead patients have traditionally been given low priority and treated with "benign neglect". When such patients become donors, they would require the attention like any other patient to keep the organs viable till they are removed. This would require a major attitudinal change and could be resented by an already overburdened staff. When other, salvageable patients often lack the required medical attention, is it ethical to lavish such care on the dead? Harsha Deshmukh, a transplant coordinator involved in the early cadaver transplants in Mumbai in a view from the field puts forth some of the practical problems (**ref**) that are being already experienced.

### 'Rewarded gifting': the unrelated donor

The 'Indian kidney bazaar' has been a subject of much discussion and three of the articles in this issue focus on this controversy. For a long time an

organized network of doctors and middlemen lured people in desperate need of money into 'donating' their kidneys, which were transplanted into the wealthy, including a large number of Arab patients. These operations were often performed in sleazy nursing homes with little respect for basic transplant principles. With the passage of the HOTA much of this activity died down. The discovery of an organized racket in NOIDA on the outskirts of Delhi a few years back showed that probably the racket has now moved from the metros to smaller places. In what many believe is a major loophole the HOTA allow for donation from a non-related person as long as the intentions of such a donation are scrutinized by committee in every state. It is now common knowledge that the number of such 'altruistic' donations forms a significant percentage of transplants. As Dr MK Mani from Chennai puts it in a recent article <sup>3</sup>'Dozens of slum dwellers from Chennai have this great and transcending love for millionaires from Kanpur or Calcutta, whom they could not have met more than a few weeks earlier. Truly this is love at first sight'.

A certain new line of argument from Western philosophers in favor of 'organ selling' supported by some from the International Transplant Community has appeared in the last few years. We carry two pieces which more than adequately convey the gist of this argument and a response from India. The question that is likely to be asked time and again however is what are the options for a patient who desperately requires an organ transplant for survival but does not have a close relative to donate the same or does not get a cadaver organ?

Finally, transplantation is a costly affair and this poses an ethical dilemma in itself. In addition to the cost of the procedure which runs into lakhs of rupees the patient has to bear a life long recurring cost of Rs.7000 to 8000 per month for immunosuppressive medication. The idea of equity in health care, which now rightfully occupies an important place in ethics, assumes a rather stark dimension in the field of transplantation. For the common man who is caught in the pincer of an ill equipped and

crumbling public sector and a costly private sector transplantation is in reality a very distant dream.

### Conclusions

This review has attempted to discuss some of the historical aspects as well as the areas of debate in the field of organ transplantation and some of the areas are detailed in the accompanying articles. An effort has been made to emphasise the Indian scenario. With the passage of time and advances in the field many more areas for ethical debate are likely to emerge.

Given the events of the last few decades it is a sad reality that at least in this country organ transplantation has come to be associated more with commerce than science and healing. For those who desire to provide the benefits of this advance in medical science to people at large in an ethical and equitable fashion, it is indeed going to be a daunting challenge to try and change this state of affairs

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