

Why our cadaver donation programme doesn't work

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Six years since the passing of the Transplantation of Human Organs Act, 1994, recognising brain death, only 28 cadaver kidneys have been transplanted in Mumbai. Why is our cadaver organ transplant programme in such a sorry state?

The definition of death

Most doctors are uncomfortable with the idea of declaring brain death and hesitate to explain it to deceased patients' families, preferring to wait till cardiac arrest occurs. This is a disservice to those needing organ transplants.

Further, the definition of brain death is specified only in the context of the transplant law. Doctors often interpret this to mean that brain death should be declared only if the deceased's organs will be donated. If not, the person is continued on 'life support' till cardiac asystole. This creates confusion and stress. For example, a family was told that their loved one was no more, and then asked if they would like to donate her organs. When they decided not to donate, they were told the body could not be taken immediately; they were legally required to wait for cardiac arrest to occur. This made them wonder whether the brain death diagnosis was correct, and reinforced their decision against donation.

System flaws

Cadaver transplants have not been promoted by the medical profession. Doctors not directly connected with transplantation programmes have often advised against organ donation, even when families inquire about the procedure. This broadcasts their lack of faith in the medical system. Some nephrologists agree to transplant from unrelated living donors instead of suggesting that the patient register for a cadaver kidney. Finally, hospital authorities ignore instructions to report brain death cases.

Efforts to promote cadaver organ transplants have also back-fired because of doctors' thoughtlessness. It is important to give the family time to come to terms with their loved one's death before suggesting organ donation, but doctors are known to tell the family about the death and ask them to consider organ donation in the same breath.

Some donor families have wrongly been billed for the donation process. Such lapses harm the programme.

The time involved in the organ donation process can be a deterrent, especially in medico-legal cases. A patient was admitted for cerebral trauma following an accident, and declared brain dead. Before the organs could be retrieved the body had to be taken to the police station and then for post mortem. Couldn't post mortems be avoided when the cause of death is not controversial? Could postmortems for patients of donor families be done on a priority basis?

Some families ask for monetary compensation or waiving of hospital charges as a condition to donation. Such

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incentives could help increase donations. In Spain (with the highest rate of organ donors), the government meets donors' funeral expenses.

Public awareness

Public awareness of brain death and organ donation is low, and most families are exposed to the idea for the first time when a loved one is declared brain dead — a difficult time to discuss consent to donation. The problem is compounded by public suspicion of kidney transplant racketeers.

In India, the extended family is involved in important decisions, and may overrule the immediate family's agreement to donation. Some common misconceptions to be tackled are: organ donation is against one's religion, it will cause the family further pain, or the system of organ allocation is biased.

Donors' relatives have been grateful for the opportunity to donate their loved one's organs. Those not given the opportunity have regretted that their loss was not mitigated by something good out of the tragedy. Everyone in this position should receive comprehensible information to make an informed decision on the matter.

Recipients' reservations

Most patients needing transplantation are unaware of the option. Renal failure patients are rarely aware of the possibility of a cadaver-kidney transplant; they are usually looking for a living donor. Other organ failure patients are dying because no treatment options exist. For those who do register for a transplant, the uncertainties of waiting for an organ can be emotionally sapping. Then, some cannot afford the cost of surgery and post-transplant drugs to be taken lifelong. Patients registered for a cadaver kidney have been forced to decline when a kidney became available because they could not raise the money. Planning is necessary; charitable trusts offer financial help for medical treatment, the government can reduce drug costs, and early enrollment to health insurance schemes can make this treatment accessible to a greater percentage of patients.

In Mumbai there have been no cadaver transplants of organs other than kidneys. So patients needing other organs fear being 'guinea pigs' and hesitate to register for a transplant. They shop around for advice and resort to alternative therapies, in the bargain losing money and sometimes their lives. On the rare occasion when a donor organ is available, potential recipients are not on record. In one case a liver retrieved in Mumbai was used for a patient in Delhi.

We need a body to monitor organ demand and supply, with a transparent protocol for putting patients on the waiting list and distributing organs. This will require support from doctors who identify donors and those who transplant organs, from families who donate organs and from patients waiting for organs. It will work only if people know that it is impartial and in society's interest.