

Living on a limb and a prayer

Gap in demand and supply, lack of awareness, absence of a streamlined process; organ donation in the country is rife with challenges

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When 21-year-old Abhishek Jogdandhar died in a motorbike accident, his family was willing to donate his organs but this to Chennai and Delhi failed to find a match, and his heart and lungs could not be donated. In June, two recipient families in Mumbai paid Rs 14.5 lakh for a charter plane to transfer a heart and lungs from Chandigarh in time.

In the meantime, three-year-old Aaradhya Mule in Mumbai waits for a heart. She has been on Fortis Hospital's waiting list since October 2016 but no organ has matched the requirement. "We went to register at a hospital in Chennai, but they couldn't do it without examining Aardhaya first, who was too weak to travel," said her mother, Pratibha Mule. Her parents have lost track of the number of times she has been in and out of hospitals. With multiple organ registries in different states, getting a heart can sometimes be a matter of pure luck.

At the time of donation, police officials are required to sign a No Objection Certificate (NOC). "They interact with the patient's family to ascertain if any malpractice was involved. They provide the NOC and later oversee the post-mortem," said a transplant coordinator at a leading private hospital in the city. On Wednesday, a police official in Nerul talked the father of a 19-year-old hospital brain dead patient out of donating his organs. The incident brought to the fore the complicated issues related to organ donation. "One needs to focus on awareness among the public. How they interact with the grieving family can at times lead to withdrawal of consent," adds the transplant coordinator who has overseen close to three dozen organ donations.

In the past few years, organ donation centres across Maharash-

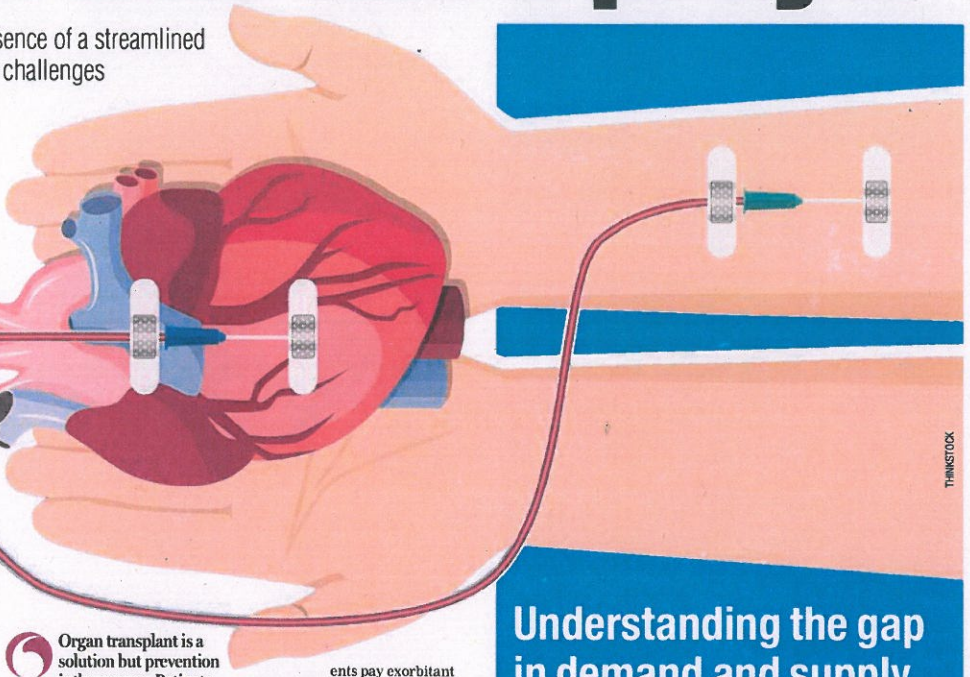
tra have seen a rise but with 3,200 people waiting for a kidney and nearly 200 for a liver in Mumbai alone, the gap between demand and supply is staggering.

The story of organ donation in the country is one of extremes. While on one hand, southern states lead the pack, routinely carrying out organ donations; north-eastern states are yet to see a single heart transplant.

Lack of a comprehensive registry
Dr Vimal Bhandari, Director National Organ and Tissue Transplant Organisation (NOTTO) said, "Every state has to register with us and show us their waiting list, but there are many states like Tamil Nadu who are yet to share their lists with us." NOTTO started functioning only recently and states with fully functional organ donation programmes have been resisting the sudden interference from the capital.

Most states are averse to providing lists of donors registered with individual hospitals to regional and state counterparts called ROTTO and SOTTO as there are a lot of unanswered questions about accountability. "We have created the programme painstakingly over so many years, and now Delhi wants to dictate terms to us," said a senior doctor, part of the Mumbai ZTCC (Zonal Transplant Coordination Committee).

Hospitals register with the four ZTCCs in the state that function as independent NGOs. A patient registered in a zone where organ donation programme is active stands a better chance of getting an organ.



Organ transplant is a solution but prevention is the answer. Patients shouldn't go to the stage where the only option left is a transplant.
Dr P Balaji, Tamil Nadu Cadaver Transplant Programme

Transporting organs
In Tamil Nadu, it is the government that overlooks organ distribution and organs are mostly absorbed in the state. In Maharashtra, the ZTCCs coordinate donation and distribution. Often recip-

ients pay exorbitant amounts to fly organs from places like Surat or Chandigarh. "Health is a state issue but it's important that organs be distributed fairly. At the moment we only have a rough idea of the waiting list but we need data to incorporate it in the national registry," said Dr Bhandari. The government hopes that NOTTO will help ease the distribution of organs.

Where are the organs?
The rate of India's organ donation, when compared to rest of the world, languishes at the bottom of the list. While Spain records the highest, 36 organ donations per million population, India has now come close to 1, after hovering around 0.5 for years.

"I am all for a national organ registry but we need to generate more organs. Kidneys and heart should ideally be absorbed in the same region since they last only for a few hours and to keep the costs low," said Dr Sunil Shroff, managing trustee of Chennai-based Mohan Foundation that works with governments and private players across the country to increase organ donations. Currently, only half a dozen states have active organ donation programmes. Most have no infrastructure, and a majority of patients in need of organs are on no registry at all.

"A heart transplant can cost anywhere from Rs 6 to 26 lakh, a kidney transplant Rs 2 to 8 lakh and liver transplant Rs 12 to 30 lakh," said Dr Shroff, stressing on the need to make it affordable to the common man. At the moment, close to 90 per cent of the hospitals are private, while government hospitals form a minority.

Prevention & awareness
"To improve the rate of organ donation, we need to first create awareness," said Dr P Balaji, member secretary, Tamil Nadu Cadaver Transplant Programme.

Tamil Nadu is the pioneer in organ donation. The programme, started in 2008, is overseen by the state government and there are over 1,000 organ donations in a year. It is now being mirrored by neighbouring states like Kerala and Andhra Pradesh.

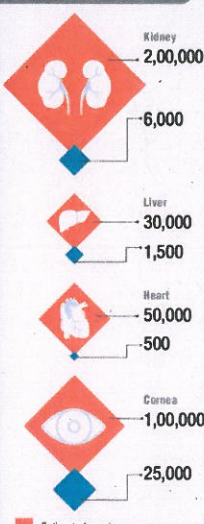
"Organ transplant is a last solution but prevention is the answer. Diabetes and hypertension must be brought under control. Patients should not go to the stage where the only option left is an organ transplant," added Dr Balaji.

Homegrown solutions
Models in tier-2 cities like Indore and Surat demonstrate how to carry out organ donations driven by community involvement.

Indore's divisional commissioner, Sanjay Dubey, who oversees eight districts in western Madhya Pradesh, made sure that the city has an online portal where donors can register themselves, hospitals can join and doctors can have access to the recipient list; a process that ensures transparency. While the number of permissions required has reduced, they have also

Understanding the gap in demand and supply

DONATION GAPS



WHO LOOKS AFTER DONATION?

NOTTO (National Organ and Tissue Transplant Organisation) under the Ministry of Health and Family Welfare (MoHFW) was set up in 2014 to oversee the process. Under it is the ROTTO (Regional Organ and Tissue Transplant Organisation) and SOTTO (State Organ and Tissue Transplant Organisation) but the structure is still in the process of being set up. It's the first step towards a national organ registry.

STATUS OF STATES

TAMIL NADU
One of the most successful programmes, the Tamil Nadu Cadaver Transplant Program has been active since 2008. The government oversees the distribution of organs while NGOs carry out awareness programmes.

KERALA

State-run Kerala Network for Organ Sharing (KNOS) tops the list in the country for the maximum organ donations in terms of per million population. The government oversees organ distribution.

MAHARASHTRA

Before NOTTO, most states followed their own pattern. Maharashtra has four regional ZTCC (Zonal Transplant Coordination Centres) in Mumbai, Pune, Aurangabad and Nagpur.

ORGAN HARVESTING

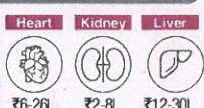
Living: Any person who is more than 18 years of age and is related to the recipient can donate organs after permission from competent authorities.

Cadaver: Any individual who has suffered brain death or cardiac death.

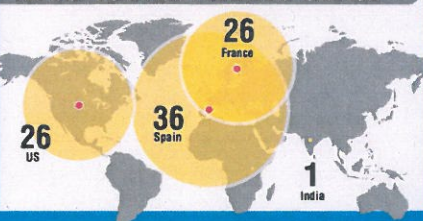
CHALLENGES

- Demand vs Supply gap
- High burden
- Poor infrastructure including shortage of surgeons
- Organ trading
- High cost
- Maintenance of standard in transplantation

TRANSPLANT COST



RATE OF DONATION PER MN POPULATION



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