

# Challenges in Organ Transplantation -An Indian Scenario

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## Abstract

Until recently, financial incentive was the prime motivation in transplantation of kidneys from nonrelated living donors in India. Prior to the Human Organ Transplantation Act of 1994, it was legal in all states of India to purchase and merchandise organs, eliminating the opportunity for black markets currently created by the enormous demand for organs. Despite the Transplantation of Human Organ Act passed in Indian Parliament in 1994, cadaver liver and/or kidney transplant are infrequently performed (in a few private hospitals) in our country compared to living donor liver or kidney transplant. The need for performing more cadaver liver and/or kidney transplants in private and public hospitals is obvious. Immediate measures which should be taken to facilitate more cadaver organ transplant both in private and public hospitals are suggested. This article reveals attitudes and beliefs about organ donation in India from the perspectives of the public. Mistrust of the medical profession and concerns about illegal buying and selling of organs were some major issues in organ donation. Additional issues were the need for public education, advertisement, and role models to promote organ donation in India.

**Keywords:** Organ Donation; Challenges; Public Education; Brain Death; Organ Transplantation.

## Introduction

Organ transplantation has achieved a state of preferred therapeutic option for patients with end-stage organ failure, in the western world. Cadaver donors form the largest pool of organs, approaching 95% and 70% in Europe and USA, respectively. However, the predominant limitation to broader application of clinical transplantation is the inadequate number of donor organs available.

In a developing country like ours, slow growth of organ transplantation is due to high costs involved, lack of facilities in government hospitals, non-availability of a suitable donor from the family and lack of well-developed cadaver programme. Since the passage of THO (Transplantation of Human Organ) Act by the Indian parliament in 1994, cadaver organ transplants have been performed so far, with acceptable results. It is estimated that every year, 3500 kidney transplants are being performed in our

country, out of which not less than 2% are from cadaver donors with sporadic reports of transplantation of other organs. There is a large pool of cadaver donors available in our country and if this is mobilized, there will not be any need to undertake living organ donation. This alone will stop unethical transplants involving commerce.

*Challenges in Organ Transplantation –Indian Scenario* [2,7]

### Systemic Issues

- In spite of periodic amendments to the Organ Transplant Act in the recent past, there has not been a significant change or increase in the overall donation numbers or to the establishment of a donation system within the country (apart from a few states).
- In the case of living organ donations (from a living donor to a recipient), if the donor is not related to the patient, the transplant needs to be approved by a state-level committee or hospital committee, including government officials. Naturally these requirements lead to delays in the whole process.
- In the case of deceased organ donations, few hospitals declare brain deaths and people are

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not in place to counsel families, both of which lead to a poor conversion rate. Brain death as a form of death is not widely understood or recognized by the public. Also there is hesitation on the part of the medical fraternity to certify brain death. This has to change if the organ donation rates have to be increased.

#### *Infrastructural and Skilled Personnel Problems*

Few hospitals are equipped in terms of the required personnel (qualified doctors and trained transplant coordinators) and equipment to conduct a successful transplant.

- Ventilators for maintaining brain dead persons are not available everywhere. Limited facilities for transport of donated organs aggravate the situation. Very few specialized private hospitals can boast of standard infrastructure for carrying out a smooth organ transplant process. The situation worsens in case of public hospitals, which account for witnessing majority of such cases.
- Lack of training for intensive-care unit personnel to maintain brain dead person, is also a constraint according to a number of doctors surveyed in our study.
- A big percentage of medical professionals are unaware of the process as a whole and about the idea of brain death since it is not part of their formal education curriculum.

#### *Lack of Awareness, Religious and Other Issues*

- Lack of awareness remains one of the leading reasons for such low organ donation rates in India. There are no structured/focused awareness initiatives or drives to help people understand the what, why or how of organ donation. While some NGO's are making efforts, these are at best – drops in the ocean.
- It is a usual refrain that people in India do not sign up for organ donation, but in reality there are hardly any platforms available for 'sign up'. Most people have never been offered this opportunity in their life time. Many don't know where to go even if they are aware and willing.
- Religious beliefs also may be a reason why families do not agree to deceased organ donation. The idea of charity and perceptions about donation varies from one community to another. The religious mindset together with the unpleasant experiences in the health sector faced

by people is detrimental to the improvement of the organ transplant scenario in India.

- An assurance about the system that these organs will be utilized for good and not be a commoditized in the organ market may encourage organ pledges. The idea of a commodity and charity are viewed as distinct and the donor/donors family would not want their charity to be a monetary gain for someone else.

#### *Lack of a Centralized Registry for Organ Donation Unlike Other Countries*

India does not have any centralized system in place to enable/assist donors or medical institutions. There is no centralized list of potential recipients being available to different hospitals so that organs could reach the right people in time. Apart from a few states, there is no sharing protocol in place in the rest of India. This leads to unethical and unhealthy practices. Further, it leads to wastage of organs which is a shame when a family has taken this courageous decision to donate.

#### *Expectation of the Possibility of Organ Rejection*

Certain studies reveal that technically there is always a possibility that the patient might face a rejection, wherein the body fights off the newly implanted organ even if the surgery goes well. Rejection is harmful to transplant success because the body fights off the new organ as if it were a virus or bacteria akin to any other harmful foreign invader. The immune system makes proteins called anti-bodies that go to the transplanted organ and try to kill it.

In order to hold back the antibodies that threaten the new organ, transplant patients have to take powerful additional immunosuppressant drugs to keep the level of antibodies down, low enough to allow for the organ to integrate into the body.

In India where health services are seemingly expensive for the average person, the ability to afford a transplant operation is beyond the common man's means, especially at a private hospital. The added risk that the organ may not benefit the patient is a negative add-on. Therefore, a majority of patient and patient parties back out due to the uncertainty quotient clubbed with the amount of financial drain out it leads to. This is also in certain ways connected to the fact that health insurance in India still does not have a good enough reach. Most people are not even aware of how they could arrange funds. Cumulatively, it leads to discouragements in a number of ways.

### *Organ Wastage in India*

Medical Science has made tremendous progress in recent times in the field of transplant surgeries and operations, with organ donation from one person after brain death capable of saving up to 9 lives and improving the lives of many others.

However, due to the prevalence of myths surrounding brain death and the lack of awareness in India, majority of people do not take up this noble cause for the benefit of others.

According to medical practitioners, kidney, a part of the lung, a part of the liver, blood and bone marrow can easily be transplanted while the person is alive. But in deceased organ donations (after brain death), more organs and tissues such as the heart, pancreas and cornea can be transplanted if the patient is on the ventilator till the organs are extracted.

#### *Following Statistics are Alarming in the Indian Context [8]*

- The total number of brain deaths due to accidents is nearly 1.5 lakhs annually. Other causes of brain death such as sub-arachnoids' hemorrhage and brain tumors would potentially add more numbers.
- There is a need of 2 lakh kidneys, 50,000 hearts and 50,000 livers for transplantation every year. Even if 5-10% of all brain deaths are harvested properly for organ donation, technically there would be no requirement for a living person to donate organs.
- One person dies of kidney failure every 5 minutes. This amounts to roughly 290 deaths every day due to kidney failure. These numbers suggest that with adequate systems in place, people succumbing to accident-prone injuries could meet a major portion of the demand.

In light of the number of brain deaths that probably take place every year; the number of donations in comparison are abysmally low. This is because most brain death cases go unrecognized and therefore uncertified. This wastage could be prevented by mandating certification of brain death. In addition, hospitals need to have well-trained personnel who can effectively identify, certify and maintain brain dead patients for organ retrieval to take place. Trained transplant coordinators are an absolute must to counsel families in grief and help them to think about organ donation to save other peoples' lives.

The situation of organ wastage is the most severe in case of hearts. In a recent study[1] conducted in January 2013, it was found that only 17% of hearts received were used by surgeons in the state of Tamil

Nadu in 2012, according to Tamil Nadu organ transplant registry Convener Dr. J. Amalorpavanathan. The registry received organs from 306 brain dead patients and allotted them to different hospitals based on a waiting list. While 280 livers and 563 kidneys were retrieved for transplant, only 52 hearts and 13 lungs were harvested. The reason for the same was poor coordination among transplant surgeons causing delay in retrieval.

#### *Government Bodies Involved in Organ Donation and Transplantation Policies*

According to the Indian law, Organ Transplantation is a State subject and is under the direct control of the respective State Governments. However, the Union Health Ministry is responsible for making amendments to the Transplantation of Human Organs Act, so that the organ transplantation system in the country runs effectively.

#### *Central Government*

In case of the Central Government, the Ministry of Health and Family Welfare is the body looking at decisions related to the organ transplantation processes in the country. The Ministry comprises of four departments, each headed by a Secretary, out of which the Department of Health & Family Welfare is responsible for taking actions related to organ donation and transplantation. In addition, there is the Directorate General of Health Services (DGHS) which is the attached office of DH&FW. It renders technical advice on all medical and public health matters and is involved in implementation of various health services. The ministry as reported has been contemplating on measures such as 50% discount on second class railway tickets, provision of lifelong free medical test and care in the hospital where the organ has been donated.

#### *Role of Non-Government Organizations & Other Groups [2]*

##### *MOHAN Foundation*

MOHAN (Multi Organ Harvesting Aid Network) is one of the front-running NGOs promoting and taking up the cause of organ donation in India, especially in the case of deceased donors. The organization believes that the shortage of organs can be overcome if the plans are executed properly.

MOHAN foundation has taken up state-by-state implementation of the organ transplant awareness

initiatives, starting with the southern parts of the country. The organization has had significant success because of the wide-scale awareness created by the organization. They were responsible for distribution of donor cards and MOHAN foundation has sent its recommendations to both the central and the state governments. These recommendations are as follows:

1. Making it compulsory for the hospital staff to ask for organs in case of brain death.
2. Provide an Organ donation clause in the driver's license cards.
3. Conducting Post-Mortem Examination during the same time as Organ Retrieval Surgery to avoid unnecessary delays.
4. To reduce the hassle of transporting the donors from hospitals where organs can be retrieved to hospitals where they can be transplanted.
5. Making it compulsory to appoint Transplant Coordinators in the ICUs of hospitals.

#### *AORTA (Armed Forces Organ Retrieval and Transplantation Authority)*

AORTA or the Armed Forces Organ Retrieval and Transplantation Authority have been actively pursuing the cause of Organ Donation, Retrieval and Transplantation in the country. They had organized an extensive drive to promote deceased organ donation in India. During the drive, information was disseminated on brain death and organ donation through various lectures, posters, billboards and extensive coverage via local and national newspapers and periodicals in the country. Some of the steps taken up by AORTA are as follows:

1. Establishing organ donor registry at the hospitals
2. Issuing donor cards to the individuals to help them pledge organs in case of brain death
3. Conducting organ pledging ceremonies involving prominent personalities (including movie stars and athletes)
4. Honoring families of organ donors to spread the message of organ donation

#### *Many Firsts have been Achieved through the Initiatives Taken by AORTA*

1. For the first time in India, a liver was flown from New Delhi in the north to Hyderabad in the south and transplanted, thereby diminishing geographical boundaries with regards to organ transplantation.

2. Kidneys were transported by air from New Delhi to Mumbai, Pune, Lucknow and Bangalore.

AORTA argued that the previously held concerns about social and religious beliefs as a cause for lack of organ donation in India were found to be untrue contrary to what the existing argument is.

3. ORBO (Organ Retrieval Banking Organization) by AIIMS

ORBO has been setup by the All India Institute of Medical Sciences (AIIMS) Delhi with the purpose of encouraging organ donations across the country. It aims to achieve fair and equitable distribution and utilization of organs. ORBO is concerned with the following primary activities:

- a. Maintaining donor registration
- b. Coordination from procurement of organs to transplantation
- c. Dissemination of information to all the concerned hospitals in the network
- d. Creating awareness about organ donation and transplantation
- e. Organizing promotional activities directed towards helping the cause of organ donation

ORBO has established a network of 20 hospitals (8 Government and 12 Private) in the NCR(National Capital Region) region and is now moving towards expansion of the same, with both national and international groups on the agenda. Each of the participating hospitals has the infrastructural support from ORBO. An officer from the hospital is also nominated as a nodal officer to coordinate with ORBO.

#### *Recommendations – Future Strategy & Action Plan [1,3]*

##### *Large-Scale Awareness Building*

It is only through awareness programmes that the number of deceased donations can be increased. What is needed is a large scale campaign which only the government can undertake or fund. Clear messaging by the government will also add credibility to the cause. In fact all messaging in public places and hospitals in the form of standees, video spots etc. have to have the government logo along with that hospital in order to increase people's trust.

Large-scale advertising campaigns should aim to educate people about benefits of organ donation, clearing all prevalent myths and misconceptions. The concept of brain death needs to be adequately dealt with so that organs of the deceased which can be retrieved and utilized and do not go waste.

*Positive Messaging on Organ Donation Can Be Done Using The Following Mediums*

- Advertising campaigns across all media (TV, Print, Radio, In-cinema ads)
- Social Media
- Celebrity endorsements
- Theater & Street Plays Events to promote organ donation (Marathons, Concerts etc.)
- On-ground awareness drives at Schools, Colleges, Corporate offices, Clubs etc.

*Setting Up of A National Registry and A Centrally Managed Organ Donor-Recipient Network*

A central organ sharing registry or a recipient registry is an absolute must, so that donated organs can be shared in a fair and transparent manner. This has already been initiated in the Transplantation of Human Organs Act, which has made a provision for the same. However there is no such system yet. Apart from a few states, there are no sharing protocols in place. This leads to unethical and unhealthy practices. Further, it leads to wastage of organs which is a shame when a family has taken a courageous decision to donate. The sharing of cost between hospitals also has to be clearly defined.

This system however will not work in the current scenario with seemingly unhealthy and negative attitudes amongst the various stakeholders. There needs to be a spirit of cooperation, sharing and the willingness to adopt from successful practices in other parts of the country. The concerned agencies would be recommended to look into the practices and policy measures undertaken by the states such as Tamil Nadu and Maharashtra. This could enable them to build a model that could be implemented in other parts of the country as well.

*Make Brain Death Declaration Mandatory*

Making the declaration of brain death mandatory will increase instances of organ donation. It will help facilitate a discussion between the doctor/physicians and the relatives about brain death and organ donations. It would help Transplant Coordinators and personnel from other Departments to intervene and convince the relatives about organ donation.

*Recognizing the Pivotal Role of the Transplant Coordinator in the Organ Donation/Transplant Process*

It is imperative to understand and acknowledge the pivotal role that the Transplant coordinator plays

in the entire process of organ donation and transplantation. It is only when that the hospital is able to establish a personal rapport with the patient and the patient's relatives, can they create a precondition necessary to establish talk regarding organ donation later on. The role of the Transplant Coordinator is to reach out to potential donor families and explain to them the need and importance of the act of donation. His/her task would be to facilitate and enable the retrieval of the organ from the deceased patient's body in a smooth and quick manner so the organ does not go waste.

An increased number of Transplant Coordinators would help in creating awareness and also help in counseling the relatives to manage the system of organ donation. Higher numbers of Transplant Coordinators are required in a public set-up as the amount of patients there are significantly higher.

*Improve Infrastructure within Public Hospitals for Transplantation*

Transplantation as a service should be readily available in all Government hospitals as the majority of patients go there for treatment and many cannot afford treatment at private hospitals. The Government also needs to take the necessary steps to improve the infrastructural set-up at all public hospitals to store/transport organs and train the hospital staff/personnel for organ transplantation procedures and on the subject of brain death, and how to increase awareness regarding the same.

*Non-Transplant Hospitals Need to Be Involved in Organ Retrieval*

These medical centers (which have ICU's but are not transplant centers) are crucial because a lot of accident victims are brought here for treatment. They should be geared up for brain death declaration. They need to be given an incentive to be participants in organ retrieval, and a system has to be worked out wherein they are compensated adequately for their active involvement in the Organ Donation programme.

The government will have to provide all the facilities (or monetary incentives) to ensure that brain deaths are identified in these hospitals and organs retrieved.

*Sensitizing Police Personnel and Forensic Experts*

Sensitization of police personnel and the forensic experts has to be taken up on a war footing to make all medico-legal cases smooth. Most brain death cases are accident cases and therefore medico legal cases.

They usually are difficult to handle as they do not get cooperation from these quarters. We can recognize and highlight some police people who have been cooperative.

#### *Provision of More Opportunities for Donor Pledges*

Provide the public with organ donor intent forms and brochures while issuing driving licenses, Aadhar cards and college ID cards, so they can choose to express their intent on the cards.

#### *Emulate Successful Practices from Other States*

States such as Tamil Nadu for instance have recorded an 80% conversion rate when it comes to donating the organs of one kin. Through a motivated network of doctors who declare brain death, personnel who maintain the deceased on life support, and transplant coordinators who convince the near relatives of the patient, the state has a record organ donation which is 15 times the national average. An important step in this direction was the creation of a network of hospitals for sharing organs.

The Maharashtra government made it compulsory for all non-transplant hospitals equipped with an ICU and operation theatre to retrieve organs for harvesting and made it mandatory for them to officially identify brain dead patients.

#### *Recent Initiatives for Creating Awareness about Organ Donation in India*

##### *Promotion and Awareness by Famous Personalities/ Ambassadors*

- Actress and Former Miss World Aishwarya Rai Bachchan has promoted eye donation for a long time through various channels including print media, television advertisements and through events organized by the medical fraternity.
- Actors Aamir Khan and his wife Kiran Rao have pledged to donate his organs. Priyanka Chopra has also pledged to donate her organs.
- Sports celebrities like Kapil Dev and Gautam Gambhir have also pledged their organs.

Considering the fact that public figures have the potential to attract media coverage, social causes when promoted by celebrities have proven to have greater reach than a regular event. The personalities themselves hold immense brand value and the cause he/she upholds also becomes an attribute of their overall value.

##### *Student/College Initiatives towards Creating Awareness*

- More than 1,500 students of Shivaji College, Delhi University, organized a walk around their campus in early September, 2013, creating awareness about importance of organ donation by holding placards and banners[3].
- Faculty members of BMS department of Western College in Mumbai set an example for the students by donating their organs and initiating the same leading to 150 students coming forward for the cause in August, 2013[4].

Increasing involvement of National Media in awareness campaigns Times of India ran a campaign on organ donation, garnering more than 50,000 organ donation pledges in August, 2013. This included 1,000 CRPF Jawans, a large number of students and elderly people[5].

##### *Pledging Donation through Driving Licenses*

The Road Transport and Highways Ministry[6] is formulating a norm to include the provision of pledging organs through application forms used for obtaining a driver's license. This drive has already been implemented in cities like Bangalore, Mumbai and Pune; and other cities will follow soon.

The success of the program can be judged by the fact that organ donation pledging went up by 40 times in the first ten months of its launch in the pilot cities, thereby accomplishing the dual goals of creating awareness and increasing the number of potential organ donations. This initiative has now been taken up by the Central Road Transport and Highways Ministry for implementation across the country.

## **Conclusion**

In recent years, transplantation has assumed an important role in the treatment of patients with end-stage organ failure. With the passage of Transplantation of Human Organ Act by the Indian parliament, transplantation of organs from brain dead donors has become a reality. Although there are many issues in success of cadaver programme, the following measures can help in solving non-medical problems in organ transplantation in India:

1. Reducing the shortage of organs by promoting deceased organ donation with presumed consent and by educating the public.
2. Reducing the problem of finances by bringing in insurance, roping in philanthropists, getting some government help and requesting

pharmaceutical companies to reduce the cost of medicines.

3. Strict policing for illegal transplants and punishment of all the persons involved. It is time that the medical fraternity took a strong stand on this issue and started promoting the concepts of brain death and deceased organ donation

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