ABSTRACT

Tamil Nadu has been at the forefront of medical care in the country. It was the first state in the country that started a living kidney transplant program. It is also the first state to successfully start the cadaver programme after the passing of the “Transplantation of Human Organ Act” of 1994 and in the last 5 years has formed a network between hospitals for organ sharing. From the year 2000 to 2006 an organ sharing network was started in Tamil Nadu and the facilitator of this programme has been a non-government organization called MOHAN (acronym for Multi Organ Harvesting Aid Network) Foundation. The organs shared during the period number over 460 organs in two regions (both Tamil Nadu and Hyderabad). In Tamil Nadu the shared organs have included 166 Kidneys, 24 livers, 6 hearts, and 180 eyes. In 2003 sharing network was initiated by MOHAN in Hyderabad and to some extent the Tamil Nadu model was duplicated with some success and 96 cadaver organs have been transplanted in the last 3 years. There are many advantages of organ sharing including the cost economics. At present there is a large pool of brain dead patients who could become potential organ donors in the major cities in India. Their organs are not being utilized for various support logistics. A multi-pronged strategy is required for the long term success of this program. These years in Tamil Nadu have been the years of learning, un-learning and relearning and the program today has matured slowly into what can perhaps be evolved as an Indian model. In all these years there have been various difficulties in its implementation and some of the key elements for the success of the program is the need to educate our own medical fraternity and seek their cooperation. The program requires trained counselors to be able to work in the intensive cares. The government’s support is pivotal if this program to provide benefit to the common man. MOHAN Foundation has accumulated considerable experience to be able to evolve a model to take this program to the national level and more so as it recently has been granted 100% tax exemption on all donations to form a countrywide network for organ sharing.

Organ Donation and Transplantation—The Chennai Experience in India

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TAMIL NADU over the years has been well known in India for offering advanced medical care. The first successful living transplant program in India was done at Christian Medical College Hospital 36 years ago on February 2, 1971. Following this, many more transplant programs were successfully started in Chennai and more recently at Combater, Madurai, and Trichy. The passing of the Transplantation of Human Organ Act in 1994 and its subsequent adoption by the state legislature of Tamil Nadu in May 1995 added a new dimension to the field of transplantation and heralded the onset of cadaver organ donation and multiorgan transplantation program in the state.

Three hospitals that prominently figured in the early years after the act was passed included Apollo Hospital and Sri Ramachandra Hospital from Chennai and All India Institute of Medical Sciences, New Delhi. Madras Medical Mission in Chennai was another hospital that had successfully done a number of heart transplants.1,2 Tamil Nadu had quite a few centers that started doing cadaver transplants

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and included Christian Medical College, Vellore and Kovai Medical Centre, Coimbatore, besides a number of hospitals in Chennai including Madras Medical College and Stanley Medical College Hospital. In a review in 1998 there were 80 kidney, 9 heart, 9 liver, and a single lung transplant had been undertaken in India.3

The Apollo Hospital and Sri Ramachandra Hospitals in their initial 4 years very successfully did cadaver kidney transplants, thanks to a couple of enthusiastic doctors who counseled the families of donors and took interest in the donation process. In fact both hospitals together were doing three to four cadaver transplants almost every month and their numbers soon increased to over 150 by the year 2000.4 In the month of October 1999 MOHAN (acronym for Multi Organ Harvesting Aid Network) Foundation a non-government organization that was doing public education for organ donation organized a memorial service to honor the cadaver organ donor families in Chennai. There was a surprising turnout of the deceased donor families at the function and almost 35 families with their relatives attended the function. This included an American family who flew in from USA for the memorial service of their mother who died in a road traffic accident in Chennai and donated all her organs. A survey conducted during this function indicated that the families showed dissatisfaction on how the organs were being utilized and lack of support network for the families following the organ donation process. However, none of the family members regretted having donated the organs of their loved ones to save another life. Soon after the function MOHAN Foundation added two further objectives to its organ donation mission. The first was formation of a counseling unit that could counsel the families for a period of 6 months to 1 year after the donation and the second was to try to form a network among hospitals doing cadaver organ transplants for better coordination of the donation activity.

A meeting of hospitals that were doing cadaver transplants was called and common issues related to the cadaver program were discussed. It was at that meeting that an initial network group was formed to work out the possibility of sharing organs between different hospitals as and when a cadaver organ donor was available. Five hospitals formed the initial group, which included Apollo Hospital, Sri Ramachandra Hospital, Sundaram Medical Foundation, Madras Medical Mission, all from Chennai and Christian Medical College from Vellore. A simple draft document was signed agreeing to the principles of sharing by all the members who were present at the meeting. This became the memorandum of understanding for the group working together. A trial period of 6 months to 1 year was given to test the commitment of the group to the cause of organ donation. The group was called “Initiative to Network for Organ Sharing” (INOS).4 The group has since then met almost every month and has held more than 40 meetings of its members to help with streamlining of the cadaver organ donation and transplant process and to strategize a future course of action. All the problems are discussed honestly and a consensus course of action is drawn out. The short-term results of all cadaver graft outcomes are also discussed. The group strategizes on how to standardize retrieval and perfusion techniques, improve organ donation rates and transplant outcomes and over the years has accumulated considerable amount of expertise on a workable Indian cadaver model for the country.

In March 2003 at the request of few social activists and doctors it started its unit in Hyderabad. From 2003 to 2006 it had shared 96 organs in the state of Andhra Pradesh and these have included 37 kidneys, 20 livers, 3 hearts, and 36 corneas. Hospitals that have benefited from the cadaver donation program in Hyderabad have included Nizam Institute of Medical Science, Global Hospital, LV Prasad Institute of Medical Sciences, Medwin Hospital, Kamineni Hospital, Apollo Hospital, Care Hospital, Mediciti Hospital, and Care Banjara Hospital.

STRUCTURE AND FUNCTIONING OF MOHAN (MULTI ORGAN HARVESTING AID NETWORK) FOUNDATION

MOHAN Foundation was formed to be a facilitator of cadaver organ donation and transplant programme in the country in 1997 and has tackled various issues related to the field. There are nine trustees from medical and nonmedical background. The focus of the Foundation is aimed at working as a “Support Group for Patients, Physician & Public.” It is a registered nongovernment organization which besides having 80G income tax exemption, has recently been granted a 100% income tax exemption for creating a countrywide network for organ donation and transplantations. Donation up to Rs. 19.7 million is exempt for a period of 3 years for formation of this network. Besides facilitating the networking group for organ sharing and counseling of families, it also runs a kidney patient support group and has a quarterly national publication called “Indian Transplant Newsletter.” Over the years it has distributed over 200,000 organ donor cards in various Indian languages, leaflets on organ donation, conducted brain death symposium in ICUs of major cities and published its own manual on “Brain death and Cadaver Organ Donation.”

NETWORKING AND SHARING OF ORGANS AND ITS ADVANTAGES

Making a sharing network has considerable theoretical and practical advantages.

1. Larger pool with better matched organs. Organs especially kidneys are not wasted as there is a larger pool of recipients.
2. Cost economics. Sharing results in lesser overall costs in maintenance of donor and retrieval surgery costs especially when it involves using expensive perfusion fluids.
3. Avoids organ wastage. Most hospitals in network have expertise for kidney transplants. Sharing ensures or-
gans such as liver and heart are also utilized by other hospitals in the network.

3. **Standardizing retrieval protocols and perfusion techniques.** Sharing helps in standardizing retrieval protocols and perfusion techniques. On three occasions livers have been retrieved by the team from CMC Hospital either from Chennai hospitals or from their own hospital and shipped to another location in the country.

4. **Sharing of expertise and staff between hospital.** Within the group on two occasions it has happened that the transplant surgeon was on leave and the surgeon from one of the sharing hospitals either retrieved the organ or transplanted it.

5. **Family’s perspective.** Sharing helps in keeping the family more convinced that their decision helps the society at large by helping out many suffering patients It has generally been observed that there is less apprehension in the minds of donor families when they are informed that the organs would be shared between different hospitals.

6. **Protecting the programme from scandals.** Sharing of organs to a great extent dispels public misgivings about commerce and organ donation. Sharing indirectly protects the programme from possible backlash and scandals. We have sometimes observed that although the head of the family graciously agrees to organ donation; the other family members are less supportive of the donation process and can often become an obstacle and are sometimes very demanding. These members often try and find faults with the doctors and hospital and can even threaten the doctors and hospitals of punitive action. The delay spent after brain death declaration and consent from the family for donation and the time of actual handing over of the body to the family can be anything from 12 to 24 hours. This is a very testing time for the transplant coordinators. On a few occasions it is during this time that the family head changes their mind or makes demands from the hospital for donation. Money has often been demanded. On five occasions the donation has been abandoned for this reason at the very last moment. The public’s perception on kidneys donation in India is usually related to commerce. This on many occasions has been a hindrance in successfully counseling the family.

7. **Protects programme form legal problems.** On one occasion a husband threatened the hospital and sent a lawyer’s notice accusing the hospital of making money out of the donation and transplant process. A detailed reply by the hospital administrator about how all the organs had been sent out of the hospital and shared between different hospitals pacified the husband.

**PROBLEMS FACED BY THE ORGAN SHARING GROUP**

1. **Non-availability of recipients.** There have been occasions when despite the large number of patients on the waiting list, no organ is available for transplant at that time. On a few occasions the group has invited other public and government hospitals to join the group. However, this has not happened. Currently to avoid wastage of organs the group gives away the organ to any taker—either to hospitals outside the group or to hospitals outside the state.

2. **Wastage of organs.** Almost 6 kidneys have been wasted in the last 5 years for various reasons some of them were avoidable. These have included:
   - Poor retrieval technique (2)
   - No blood for cross match after the first recipient had cross match positive test (2)
   - Poor packing of organs (2)

All these wastages happened in the first 15 donations. However, for the last 3 years this has not happened.

3. **Shifting unstable cadaver donors bodies and losing organs.** On three occasions the hemodynamically unstable donors have had a cardiac arrest during shifting either from one hospital; to another or during shifting from the ward to operating rooms. Three donors have thus been lost in the process.

4. **Postmortem difficulties.** In medico-legal cases it is essential for the cadaver to undergo a postmortem after the organ retrieval surgery. It results in at least 12 to 24 hours delay in handing over the body to relatives. This is very traumatic to the families and leads to more emotional stress, more dissatisfaction with hospital authorities. Sometimes the police do not understand the concept of brain death declaration and its certification and if the forensic expert is not informed about the process of organ donation, they judge that the donated organ has been surgically removed without consent and this causes further delays with the postmortem reports.

5. **Difficulty in getting neuro-expert for brain death certification.** The empanelled neurologist and neurosurgeons that are certified by the government for declaring a patient brain- death are government employed doctors from different medical colleges in the city. Their numbers are limited and it can be extremely difficult to get them to come twice for the brain death certification process. If the hospital is some distance from the city, this can be even more difficult. Most of them come only out of a personal relationship with the some colleague of hospital. At present there is no compensation for them. There have been six occasions when a dozen neuro-specialists for certification have been contacted without success at one of the group hospitals. This delay in certification can make the donor even more unstable.
6. **Family hostilities and legal threats.** The emotional upheaval of death is the most difficult to overcome and in this condition accepting the notion of organ donation by the relatives can be understandably very difficult. However as mentioned previously it is the hostile reaction from the some members of medical profession and the general public that can be a more daunting task to tackle. The whole process was described by some as “neo-cannibalism” way back in 1966 by Prof Karanjavalla when he described the very first cadaver donation of kidney with which he was involved way back in 1966. This was a setback for the cadaver programme for not only in Mumbai but also the rest of the country. On four occasions the hospital, doctors and MOHAN Foundation counselors have had the wrath of the family members and the medical profession after the donation process was successfully undertaken. In most instances when the situation is investigated the reason has been mistrust, communication problem, or something very trivial that triggers of an emotional storm.

7. **Lack of trained personnel and counselors.** This seems to be a major problem facing the cadaver organ donation programme. Despite advertisement in the media getting a trained medical grief counselor to counsel the families is difficult. Majority of the medical social workers at present opt to work for organization related to the AIDS programme as this is a well funded internationally supported programme with lucrative salaries. There is at present an “AIDS divide” resulting in shortage of staff in many nongovernment organizations in the country. This situation makes it difficult to train able staff who can help take this programme forward.

8. **The government’s role and support.** Despite repeated letters to the state health department and health secretariat there has been no response for formulating guidelines to help with the cadaver program. On repeated occasions the officials have been explained about the difficulties related to cadaver donation process and urgent need to streamline some of its activities.

9. **Limited Resources.** The programme lacks adequate funding for popularizing the cause of organ donation. The television media was found to be the most effective for propagating the cause. However, the costs are phenomenal and most of the prime time is dictated by popular drama serials. No public message film is broadcast free and even the government channel demand money to put it on the air. The costs are prohibitive and cannot be sustained consistently by any non-government organization unless it is well funded.

10. **Identifying the family member for organ donation.** The decision maker in an Indian family is typically a senior male member. However on two occasions when the head of the family was brain dead and we had problem with certification process. On both the occasions the wife who signed the consent document was found later to be not the legal wife of the person, and on both the occasion the donation had to be aborted because the legal wife could not be contacted.

**FUTURE COURSE OF ACTION TO FACILITATE CADAVER ORGAN DONATION**

To succeed with cadaver organ donation program a multi-pronged strategy is required. Most of these issues are interlinked. From our experience in Tamil Nadu we have made the following recommendations for the success of this program. Some of these recommendations have been sent to the state government.

1. **Education of medical fraternity.** Besides the general public the medical fraternity needs to also be educated about brain death and the donation process. They need to believe in the cause and, if necessary, go an extra yard to help out. On ten occasions MOHAN Foundation counselors have received calls from intensive care staff (ICU) for organ donation after the patient has been disconnected from the ventilator by ICU staff and doctors. This shows the ignorance of the ICU staff about the process of donating solid organs. Having said this, however, there have also been some exemplary examples of organ donation, and at least on four occasions the doctor’s have themselves voluntarily opted for organ donation of their father, mother, brother and son when they were declared brain dead.

2. **Consent of relatives for organ donation.** This is one of the key elements for success of the program. All hospitals with infra-structural support to undertake transplants, should have a dedicated ICU staff who can work as a transplant coordinator. This is essentially to identify brain death and to build a rapport with the family members to ask for organs. There are at present very few trained dedicated co-coordinators in the country. Taking the consent is by far the most difficult job in the whole organ donation field and the success or failure of programs depends on such people. The public campaigns on organ donation go a long way in presensitizing the community about the possibility of organ donation in event of natural death or brain death. In Chennai where successful cadaver organ donation has happened more frequently then other cities, in eight instances in the last two years the families have come forward for organ donation when they were told that their relative was dead and being kept ventilated on the machine. This to some extent maybe attributed to publicizing the organ donation cause in the city by distribution of organ donor cards and running a campaign on television with a famous film personality by MOHAN Foundation.
3. **Public perception of organ donation and transplantation.** Organ donation and transplantation in India is not a new concept. The Indian mythology has many such examples and the most famous is that of Ganesha with the elephant’s head on the human body. When Daksha, the famous sage, was beheaded, a goat’s head was used. Story from South Kannapa the archer on Eye donation. Hence the Indian public does have some notion about the process. Surveys from 1995 of over 5000 people had shown that almost 72% accepted eye donation and were willing to carry a donor card.

4. **Government’s role in facilitating the cadaver program.**
The state governments have a pivotal role to play to make this programme a success. Some of the key recommendations made by the MOHAN Foundation in the past to both the Tamil Nadu Government and the central Government include the following:

a. “Required Request Law” that would make it compulsory for hospital staff to ask for organs in the event of ‘brain death.

b. “Mandated Choice” of “Organ Donation Clause” on Driving licenses issued by the Transport authorities in Tamil Nadu. Currently the application form and driving license in some of the States does have the blood group on the driving license.

c. Conducting the “Postmortem Examination During The Same Time As Organ Retrieval Surgery In A Medico-Legal Case.”

d. Delinking Hospitals Where Organs Can Be Retrieved From Hospitals where they can actually be transplanted. Moving bodies from one hospital that is not approved to another that is approved, limits the scope of number of brain death patients that is made available, difficult in brain death situation and most important traumatic to relatives of the patient.

e. Having a Rota of Government appointed “Neurosurgeons and Neurologist” available to hospitals to certify Brain death in Tamil Nadu.

Despite the many problems in implementation of this program in India a start has been made and the first hurdles have been crossed. There is potentially a large pool of brain-dead patients that are not being utilized especially from government hospitals. Education of the medical fraternity and the public and some help from the government machinery can help in bridging the gap between demand and supply of the organs quite comfortably in not only Tamil Nadu but most states in the country. A successful program has the potential not only to meet our own demands but also help out neighboring countries that sometimes looks towards India for their healthcare needs.

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