**Cadaveric Organ donation in India and Policy Dilemma : Reflection from Households of a donors family**

Researchers and academician often debated very few cadaveric organ donations in India for various reasons.1 Organ transplantation in India has a relatively short history compared to the developed world. India’s conceptual, academic and scientific contribution to this specialty has been limited even as it has been at the epicenter of one of the biggest ethical controversies concerning transplantation. 2, 3 In-spite of a through literature search by authors, no academic documentation either in from of qualitative, narratives or documented case study to reflect on the perspective of the of the household members for organ donation of family members in India could not be located. Presented here is the case study on Policy dilemma on cadaveric organ donation in India from the perspective of household members of donor family declared brain dead by panel of doctors.

A 46 years old male was admitted to a well-known, reputed corporate hospital of Central India. He presented with a brief history of 24 hours of stroke, initial MRI suggested Brain stem infarct involving both cerebellum. He later developed had bradycardia and hypotension following which the he was put on ventilator. The follow up CT scan after 24 hours suggested further deterioration of the condition with no pupillary reflexes and any further evidence of brain activity. On suggestion of no further improvement in the condition and inevitable brain death of the patient, as a well-informed, educated and social family members decided to donate the organs assuming it a good will gesture to the society. The decision was facilitated by the members from medical fraternity in family. Few members and friends of the family were briefly aware about legislation called the Transplantation of Human Organ Act (HOTA) in India to streamline organ donation and transplantation activities facilitated the decision.4

It is worth mentioning here that there is a substantial population in India needing the benefits of transplantation, but still it is not available to a large proportion of India’s population needing them. Many patients with end stage renal disease are on long-term dialysis and lead a very poor quality of life.1 even dialysis facilities are limited, expensive and inaccessible. More than 90% of patients in South Asia die within months of diagnosis because they cannot afford treatment.3 It has been estimated that only 2.5% of patients with end stage renal disease in India actually end up getting a transplant.3

As soon as the brain death of the patient was declared at the corporate hospital and communicated to the family, members of the family started discussing about the possibility of organ donation. The decision for willingness to donate the organs was conveyed by the family to the hospital authorities at around 8.00 AM. However, hospital authorities shared the inability for transplant as the center is not recognized by the authorities as per THO, but informed the family about nearest center registered under the act with in city for transplants. The recognized center was another for profit multi-specialty hospital situated about 15 KMs from the hospital where the patient was admitted. Hospital administrators also provided the necessary contacts of the persons who might facilitate organ transplant, avoiding making a direct contact, which they could have easily facilitated. The grieved family and their family friends contacted nodal centers but had to face loads of difficulties in answering to the technical and difficult queries regarding the chronology of events, status of patients , status of organs and so on so forth, which could have easily being answered by the staff of the hospital where patient was admitted. Entire saga of so call smooth procedure of cadaveric Organ donation now seemed to be a trick, tiring and harassing procedure. For a successful transplant it is mandatory that the decision and action for organ donation should be very quick but on other hand as a social norm and as per the Hindu mythology the funeral or “anthiyesti” should be performed as early as possible preferably before the sun set and within the day of death.5 The social pressure was mounting rapidly on the family of the deceased, the more unexpected and sudden was the death, there was greater the bereavement and commotion. Further to avoid any social pressure on the family/ household and to ensure the donation, family friends tried to relieve the anxiety and panic. They wished the last rites should be performed on time .But no one either at the nodal center or hospital where the patient was admitted were able to provide a rough estimate of the time that would be required.

However with a heavy heart family communicated the hospital administrators communicated to shift the body to the nearest recognized center by Government of India for organ harvesting and possibility of organ transplant. But the family was insisted to pay total amount of expenses and an overdraft amount by 10% in spite the patient being covered by “so called cash less” Medi-claim by a reputed insurance company in India.6, 7 The hospital ensured that the patient is not certified as Discharge on Request (DOR) rather discharged the patient under Leave Against Medical Advice (LAMA), the reason cited was the THO doesn’t have any clause for discharge on request. The hospital where the patient was admitted feared the as their center was not a registered hospital for transplant and TPA can create a problem in final settlement of bill,7 authorities were not ready to provide DOR, in-spite of being fully aware about the noble cause for which family and knowledge about Medi-claim and TPAM claim procedures. But the committed family members ensured the payment and passing timely intimation to the registered hospital so that they can arrange for the possible recipient. All the files were scanned and necessary information like blood group, history of present illness and personal history and relevant clinical history were communicated.

The corporate hospital arranged an Ambulance with facility of ventilator on request of the household as the nodal center for renal transplant denied the same due to shortage of such ventilator equipped Ambulance. But before arranging the Ambulance the corporate hospital where the patient was admitted ensured the charges to be deducted in advance against the use of ventilator equipped ambulance.

Necessary documents were provided to the family members and on hired ventilator equipped ambulance the patient was shifted to the center recognized for organ transplantation and harvesting. On reaching the nodal center, the grieved family was again tortured mentally for asking the patient to be re admitted to the nodal center as fresh case and was asked to get a new indoor admission slip, in spite of being aware, the residents and duty doctors wasted huge amount of time in taking the history of sequence of events which they could have easily noted from the discharge summary report of previous hospital. And after an hour the patient was admitted to the ICU. Except for the head of the transplantation unit for obvious reasons none of the staff seemed to be active and proactive. On requesting for an early initiation of the procedure for organ harvesting, the family came across a very tedious process laid by government under THO. Number of forms needed to be filled up, nodal center insisted the presence of at least two-three blood relatives preferably wife or father of the deceased to sign and vouch for the pledge to organ donation and certify no objection for the process. On inquiring about extra-ordinary delay in initiating the process and delays the family was informed that the new act amendment of GOI makes mandatory that the process should be under the supervision of SIX member committee (page 7 of HOTA), and as one of the committee member is busy in some other administrative work possibly in the board meeting of the nodal center. It was very evident from the amount of time the nodal center was taking in spite of having prior information, that there are other priorities to the committee members rather than only being a member of central committees but because of the norms laid by the government of India, they have undertaken additional responsibilities. Few of the committee members are so senior and possibly must be having more than one responsibility. More so the cadaveric organ donation is so rare phenomenon that they lack the sensitivity and empathy towards this noble cause. It is surely a matter of more in-depth research if the committee members have ever been trained or sensitized for counseling on cadaveric or organ donation per se. It was pretty evident from the fact that in the history of the entire city only 6 cadaveric renal transplants were done and the last cadaveric renal donation was done only about 2 years back at the nodal center, although the information needs to be verified.

One more tricky condition the family had to face was absence of any clear cut guidelines of Organ allocation policies for deceased donor organs in India. Later on after an in-depth review of articles, policies on organ donation, it was revealed that organ allocation policies differ from state to state within India. Although there is an attempt to centralize the activity by the formation of a national Organ and Tissue Transplant Organization (NOTTO) under the Ministry of Health and Family Welfare and one of the stated objectives of this organization is to evolve a national network for organ sharing but it might take years for this to happen. Given that India is a large and diverse country with regional variations and aspirations, a centralized approach may not be appropriate, and the states must be allowed flexibility in approach as long as they meet basic ethical requirements. The family also came across the bitter truth of no unanimity on whether the organs should be allocated based on severity of disease, waiting period or on an institutional rotation in the nodal center. Unfortunately, THOA laid down elaborate criteria on who can donate organs, but did not elaborate on how the donated organs would be distributed. Conceptually, donated organs do not belong to the hospital or the city where the donor’s death took place; all altruistic donations belong to society as a whole. But the family was helplessly observing, witnessing the entire fancies and wimps of consultants negotiating amongst themselves on how and to whom the organ should be transplanted without being aware of the fact the someone has lost their very near and dear ones. It was clearly a case of breaching the trust placed in the institute of organ donation by donor families.

HOTA also doesn’t have any provision of dedicated counselor at the nodal center for sharing the guidelines and essentials procedure approximate time needed for transplant.

The family who decided for the organ donation had to pass through the trauma for more than 10 hours and were not clear about the duration of time till which the process is going to end and finally broke down, begging to the hospital management to give them back the body of deceased even without donation. There was no one to console them or to reply to tier queries and the trauma continued. After a long wait after the body was shifted in the OT for organ harvesting, and almost after 8-10 hrs. of mental agony of losing someone, family was informed about successful process of organ harvesting. The family was hopeful that they will get back the body but then they were informed that the corneal donation is in process and might take an hour more. The family failed to understand why the process could not be done simultaneously or the process should have initiated simultaneously. Unfortunately HOTA doesn’t have clear cut guidelines on simultaneous organ donation. After the organ donation process was over and the family thought that the process is over and the last social rites could be performed at home. The body was again shifted to the ICU citing that the necessary life support will be withdrawn and only after one hour the final death certificate be issued.

No assistance was provided from the hospital management to arrange for a designated vehicle to drop the body of the deceased who had done a great service to the society and mankind by donating the organ, instead the family was asked to deposit money for the vehicle and ensure that it is available by booking the vehicle on special charges. By the time the patience of the family was lost and they were ready to pay any charge for getting back body of their beloved one so that social rites can be performed on time.

Issues that emerge out from the present case study are as follows:

1. Tertiary care including Organ harvesting and organ donation in India is dominated by the private sector to be more precise corporate multi-specialty for profit hospitals.1 this domination is even more for organ transplantation. Transplant programmes in government is restricted only to corneal transplantation.1
2. There is no written mechanism for organ allocation hence in majority of transplant following deceased organ donation cases it’s the rich who is benefitted most as they can afford the private for profit corporate hospitals. Such scenario requires more political will and clear cut guidelines for mandatory allocation of the organs ensuring that proportion of organs are allocated to for public sector institutions. But this also will required developing transplant facility in the public hospitals, which presently is largely lacking.
3. Present act HOTA in India requires greater deliberation and debate to ensure social and cultural acceptance, and strict substantive regulatory mechanisms.
4. There has been much discussion in the recent transplant ethics discourse on offering some form of incentive to families of deceased donors.8 This is being tested in countries like China, and there have been calls by Western ethicists to consider limited incentives like payment of funeral expenses to donor families.8, 9 This has not as yet entered the realm of policy in India. But as a token of gesture incentives like waiver of fees either partial or full, free transport availability to drop back the body after organ donation can be practiced. Such incentive should be mandatory as the recipient and the hospital performing the transplant are beneficiaries of the donation, and the hospital charges full amount ranging from few lakhs to undisclosed amount, it can be argued that there is no reason why the act should not be acknowledged the donor, donor family and compensate them at least socially if not financially.
5. There is an urgent need to have a dedicated post of counselor to assist the family in coping up with the mental trauma and agony.
6. There is a need for easing the process of organ donation and few of its useless essentials like SIX member committee, lots and loads of paper work.
7. Lastly more such case studies should come in open that also talks about the flip of so called media hype of pushing for organ donation.

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