Role of Social Worker in Cadaver Organ Donation and Transplant Coordination- A Single Centre Experience

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Abstract Medical advances in the field of transplant immunology, surgical management and techniques of organ preservation have made the transplantation of human organs a viable approach for the treatment of end stage organ diseases. When vital organs like heart, lungs, liver, pancreas etc. suffer a functional damage that cannot be repaired by drugs or any kind of conventional surgical treatment, organ transplant is often the only solution to the problem. Procurement of human organs, however, has been the biggest challenge to the success of transplant programme in the country. Although the removal of human organs for therapeutic purposes has been legalized by the government, it has not yet received social sanction to facilitate cadaver transplant in our country. Professionally qualified social workers play a crucial role in procurement of human organs for transplantation. They coordinate the entire process of cadaver organ donation, undertake public education and awareness activities provide training and continuing education to hospital staff and carry out research studies on topics related to organ donation and transplantation. The paper discusses about the role and activities of the social worker in cadaver organ donation and transplantation coordination at a tertiary healthcare institute of the country.

Keywords Social Worker, Cadaver, Organ Donation, Transplantation

Introduction

Human Organ Transplantation is the field of medical sciences which, over the years, has rapidly developed beyond the imagination of mankind. Immunosuppressant drugs which increase compatibility between donated organs and their recipients and technologies for the preservation of organs outside the donor's body have been developed. These developments have offered opportunity for many patients suffering from life threatening diseases to resume a healthy and productive life. For renal failure patients, transplantation gives the opportunity to get rid of painful dialysis treatment

and lead a normal life. For heart and liver failure patients organ transplantation is the only chance of survival as there is no therapy like dialysis for such patients.

There can be no organ transplant without an organ donor. Organ donors can be living or cadaveric. Living donor can donate only a few organs namely one kidney, a portion of pancreas (as half of the pancreas is adequate for sustaining pancreatic functions) and a part of liver (as the few segments that are donated will regenerate after a period of time). On the other hand, a cadaveric donor can donate all vital organs such as heart, lungs, liver, kidneys, pancreas and tissues such as heart valves, eyes, bones etc.

There is an acute shortage of human organs for transplantation. As per experts, there is a requirement of 1-1.5 lakh kidneys but only 3500-4000 are transplanted. Similarly, 15000-20000 liver are required but only 500 are transplanted and 1 lakh corneas are required but only 25000 corneas are transplanted. The cruel irony, however, is that this shortage need not exist, even if a fraction of our population comes forward to serve the living by donating organs after death.

The government of India enacted Transplantation of Human Organs Act-1994 which legalized brain-death and regulated the removal, storage and transplantation of human organs for therapeutic purposes. The act was amended in the year 2011 wherein many new clauses were added to increase the rate of organ donation in the country. The law makes it mandatory to appoint a Transplant Coordinator in a hospital for coordinating all matters relating to removal or transplantation of human organs or tissues or both and for assisting the authority for removal of human organs in accordance with the provisions of the act. Professional social workers are performing the role of transplant coordinators in our country.

Methodology

Cadaver organ donation and transplant activity is very limited in our country. The deceased donation rate in our country is 0.05/million population which is very low as

compared to many other countries. Only a few states like Tamil Nadu, Andhra Pradesh, Maharashtra etc. are running structured cadaver transplant programmes which are based on an organ allocation system as per the centralized transplant waiting list. In other parts of the country, cadaver transplant activity is hospital or individual centre based. NGOs are also working to promote the noble cause of organ donation. In some hospitals doctors and nurses have been designated as TC to look into the cadaver transplant activity in addition to their routine medical duties, whereas in some big hospitals full time professional social workers have been trained to work as TC. They coordinate the cadaver donation and transplantation and keep other medical and para medical staff free to undertake their routine duties. NGOs have also employed social workers to promote the cause of organ donation. All India Institute of Medical Sciences, New Delhi is a premier public sector healthcare institute of the country having multi organ and tissue transplantation facilities. The paper attempts to understand and describe the role and activities of trained social worker in the cadaver organ donation and transplant programme of the hospital.

Results and Discussions

All India Institute of Medical Sciences is the largest tertiary healthcare institute situated in the capital region of the country. The institute has facilities for heart transplantation, kidney transplantation, liver transplantation, pancreas transplantation, cornea transplantation and banking, heart valve transplantation and banking and bone transplantation and banking. Organ Retrieval Banking Organization (ORBO) is the organ donation and transplant coordination facility which has been set up in Cardio-thoracic Sciences Centre with a purpose of encouraging organ donation, fair and equitable distribution and optimum utilization of human organs. This organization maintains donor registry, coordinates the entire process from procurement of human organs and tissues to the transplantation and conducts awareness generation, training and research activities in the area of organ donation and transplantation. For the purpose of organ sharing and increased donor pool ORBO has established a network with major hospitals where transplant activities are carried out. Organs procured at AIIMS and other hospitals are shared through this network. There are three Medical Social Service Officers (MSSO) having Master's degree in social work to coordinate cadaver donation and transplantation round the clock and promote organ donation. The activities of MSSO are:

Procurement of Cadaver Organ and Transplant Coordination

Identification of Potential Donor

The MSSO visits the critical care areas of the hospital (I.C.U.s, Emergency, Wards), maintains interaction and build

up rapport with medical and para medical staff to identify potential donors. Most of the potential donors are identified from neurosurgical ICUs, Trauma Centre and Emergency areas.

Brain-death Certification

The hospital has constituted brain death committee. Once a potential brain dead donor is identified, MSSO contacts the panel of experts who clinically examine the potential donor twice at an interval of 6-8 hours to certify brain-death as per the law.

Grief Counseling and Motivation for Organ Donation

Grief is the most painful of all human experiences. MSSO helps the family members understand the process and phases of grief. He along with treating doctor approaches the relatives of the potential donor at regular intervals to make a request and build up motivation for organ donation. Complete information about the condition of the donor, brain death, possibility and procedures involved in organ donation is provided. While giving an option for organ donation, MSSO remains genuine, empathetic and non judgmental. Though back up arguments are extensively used to convince the family for organ donation, yet, the right to self determination of the attendants is always accepted. Counselling and communication techniques such as listening, observation, exploration, ventilation, informing, logical discussions etc. are extensively used.

Obtaining Consent

In case relatives agree for organ donation, MSSO obtains written consent or authorization for retrieval of organs on the format as prescribed in the legislation.

Screening of Potential Donor

Screening of potential donor is very important to rule out malignancy or infection that could be transmitted to the recipient. Therefore, MSSO goes through the case records to ascertain cause of death and medical and social history of the donor and organizes clinical investigations (x-ray, ultrasound, echocardiography, anti-HIV, HbsAg etc.) required for the assessment of the donor.

Maintenance of Potential Donor

To procure viable organs in a healthy condition the potential donor should be treated and maintained correctly. Brain-dead donors need a strict monitoring and periodical analysis of various clinical parameters such as ECG, AP, CVP, Electrolytes etc. which is facilitated by the social worker with the help of other hospital staff such as treating physician, anesthetist, nursing staff, transplant teams etc.

Medico-legal Formalities

Most of the brain-dead patients are victims of road traffic accident and become medico-legal cases. In such cases, the custody of deceased body rests with the police till the post-mortem is completed. MSSO coordinate s with local

police and forensic expert of the hospital to obtain NOC for organ retrieval in medico-legal cases.

Coordination with Transplant Teams

Depending upon the number of organs and tissues to be harvested, MSSO informs about the availability of potential donor, time and place of organ retrieval to different transplant teams like heart transplant team, liver transplant team, kidney transplant team, eye bank, bone bank etc. and nodal officers in other hospitals if an organ is to be shared and thus facilitate retrieval of cadaver organs and tissues.

Donor Family Support

Social worker represents the hospital, the recipients and is doorway through which the family has access to the deceased memory. In this entire process of organ and tissue procurement and in future, MSSO provides throughout support and consolation to the donor family relieving their grief and sufferings.

Maintaining Records

After the organs are transplanted, MSSO keeps track of the transplant recipients and maintains complete record of donation-transplantation coordination process.

Apart from organ donation in brain-death, MSSO also coordinates tissue donation calls in cardiac death from mortuary and outside community. 1260 organs and tissues have been procured and allocated to hospitals for transplantation. 113 whole body donations have also been coordinated to facilitate medical education which has fulfilled the requirement of the hospital.

Psycho-social Support to Waiting Patients

MSSO maintains waiting list of heart transplant recipients. When the patients and the family are informed about the need of heart transplantation, they undergo variety of mixed emotional reactions such as shock, disbelief, anger etc. MSSO counsels the patient and the family to reach the stage of acceptance and achieve positive reaction for taking proper treatment. He provides information about heart failure and transplant, adherence to treatment regime and follow-up. He also coordinates admissions, work-up and transplantation of these patients as and when required and coordinates in fund raising for poor patients with the help of government and charitable organizations.

Awareness Generation and Public Education

Familiarity with the significance, process and healthcare importance of transplantation is an essential factor for people to come forward for the cause of organ donation. In our country there is a lack of awareness in society about brain-death and organ donation. Even if people are aware and willing to donate organs they do not know the procedures involved in cadaver donations. MSSO has participated in developing the following IEC material:

Brochures

Posters

Handbills

Donor form and card

Electronic display boards

Big hoardings

Website

Motivational book having stories of organ donors and recipients

MSSO has actively organized numerous public education activities (awareness-cum-pledge camps, lectures, presentations, poster competitions, slogan competitions on organ donation etc.) in hospitals, schools, colleges, academic institutions, NGOs and other government and private organizations to create awareness and sensitize people about organ donation and transplantation. 21000 secondary and senior secondary students and teachers of schools around the hospitals have been sensitized about the noble cause of organ donation. He also runs the helpline to answer public queries and coordinate organ donation at anytime. The awareness activities have resulted in the enrolment of more than 20000 donors in brain death donor registry of ORBO which is the first active brain death donor registry of any public sector organization in the country.

Orientation and Training

Orientation and training of medical and para medical staff of the hospital regarding organ donation and transplantation is again an important factor in cadaver donations. Although many of them are aware about the need of scarce resources, yet, there is often a resistance because doctors, nurses and other staff are not familiar with brain death, family consent and organ procurement practices. To overcome this problem, MSSO has organized orientation, training and continuing education of healthcare personnel (doctors, nurses, grief counselors, transplant coordinators etc.) of AIIMS and other hospitals and other stake holders such as Police about process and issues in cadaver organ donation and transplantation.

Other Activities

In addition to this, trained social worker has participated and undertook the following activities.

- Developed guidelines and standard operating procedures to facilitate cadaver donations in MLCs and Non MLCs.
- Organized donor honor programmes.
- Organized consultations to develop standard guidelines and formats on various aspects of organ and tissue donation such as screening, retrieval, tracking etc.
- Conducted research studies on the issues related to organ donation and transplantation.
- Assisted the hospital authorities in registration and renewal of registration for different organ transplants.
- Update brain death committee
- Official correspondence related to organ donation and transplantation.

Conclusion

Trained social worker functions like axis of the wheel of multidisciplinary cadaver donor transplant team and plays an important role at every stage of cadaver organ donation and transplantation. As coordinator of organ donation and transplantation, he organizes organ donation process which includes legal and clinical aspects of organ donation, family support, coordination of retrieval/transplant teams, follow up of donor and recipient. He undertakes hospital and community education about organ donation and transplantation. He is involved in research and provides administrative support to the hospital authority to facilitate cadaver organ donation and transplantation programme of the hospital.

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