

Organ Donation and Transplantation in India: The Role of a Medical Social Worker in a Hospital Setting

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Abstract

Organ donation and transplantation is a relevant area which requires more deliberation and action. The increased organ trafficking in the field of organ donation and transplantation has made the role of a medical social worker crucial. Apart from the legal workup and counselling, the medical social worker also plays an important role in the areas of administration, assessment, intervention and evaluation within the legal aspect of the healthcare system. This article highlights the different roles of the medical social worker in the healthcare system, along with the legal process of organ donation and transplant in India with the support of three case studies. The article also throws a light on the need to have continuous training and value-added programmes for medical social workers to keep them up to date.

Keywords

medical social worker, organ donation, organ transplantation

Introduction

Organ donation involves the transplantation of a human organ or tissue from a living or deceased person to be used for another person. The person who donates is called the donor and the person who receives is the recipient. This noble act provides an opportunity for those suffering from organ failure to lead a normal life. It is the only therapy for a patient with heart, liver or lung failure. Although patients suffering from kidney failure

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have an option of dialysis, transplantation gives them a better quality of life. But for the patients who are suffering from heart failure or lung failure the only option is an organ transplant. Hence, organ transplantation is considered as the best option in medical science for the patients who are suffering from organ failure. But there is huge gap between the demand and supply. According to the Global Observatory Data (WHO-ONT, 2021) the organ donation rates in India are 0.25 per million population in 2020 which is only a fraction of the number when compared to Spain (37.97/million population) and the USA (38.03/million population). There is a huge potential for deceased organ donation in India. The living organ donation has its own limitations as this is only possible with kidneys and livers. The patients who are suffering with heart, lungs or pancreas problems may die waiting for an organ transplant. In living donor transplants, the poor are exploited by the rich. Thus the streamlining of the entire process of human organ donation and transplantation is important and the Government of India has enacted the law. This paper explores the role of the medical social worker in organ donation and transplantation with the support of three case studies. The paper stresses the relevance of knowledge, skills and attitude the professional must possess in terms of laws and procedures concerning the organ donation and transplantation which may help the academicians, practitioners and researchers to improve in their respective domains.

The Transplantation of Human Organ (THO) in India was passed in 1994. The purpose of the Act is to provide the regulations for the removal, storage and transplantation of human organs and for the therapeutic purposes. It is also for the prevention of commercial dealings in human organs and for the matters concerned therewith or incidental thereto (GOI, 1994). The Act was initiated at the request of the governments of Maharashtra, Himachal Pradesh and Goa (they therefore adopted it by default) and was subsequently adopted by all States in India except Andhra Pradesh and Jammu and Kashmir.

An amendment to the Act was proposed by the states of Goa, Himachal Pradesh and West Bengal in 2009 to address the inadequacies in the efficacy, relevance and impact of the Act. This was subsequently amended in 2011 and in 2014, when The Human Organ and Tissue Transplantation Rules (THOTA) came into force (Ministry of Health and Family Welfare, 2014). As health is a State subject, it depends upon the State whether or not to accept this new amendment. The law has also mandated the role of a transplant coordinator in all the hospitals doing transplants as well as the

non-transplant retrieval centres. Thus the role of the medical social worker is important in the field of organ donation and transplantation

Types of Organ Donation

Living Donor

In living donation, the donors are classified as near-related donor and other than near-related donor. Near-related donors include parents, siblings, spouses and children. In the recent 2014 rules, grandparents and grandchildren above 18 years of age have also been included on the list of near-related donors. All donors except those defined under near-related donors come under this category. Permission in such cases is granted only by the authorisation committee which is a regulatory body as per the law. This category is the most controversial as there is the possibility of a monetary transaction in the case of a donation from a poor person to a rich recipient where the latter can coerce the poor donor to donate his/her organ against his/her will in order to get some cash/kind in exchange. The act has made several provisions to avoid organ trading. The authorisation committee interviews the recipient and the donor separately to:

1. Evaluate the commercialisation in organ donation.
2. Understand the motivation behind the donation.
3. Examine the documentary evidence to prove the claimed relationship.
4. Evaluate that there is no middleman or tout involved in this donation.
5. Evaluate the financial status of the donor and the recipient to avoid organ trafficking and
6. Ensure the mental stability of the donor in taking the decision of organ donation.

The limitation in living organ donation is that one donor can save only one person.

Deceased Donor

This is another source of organ donation. Deceased donation can be after either brain death or after cardiac death.

Donation after brain death

The concept of brain death was legalised in India in 1994. Brain death is defined as the cessation of all activities of the brain stem and it is a clinical diagnosis. It is generally declared in patients who are on a ventilator and a

Glasgow Coma Score (GCS) of 3/15. GCS is a scale which assesses the patient according to three aspects of responsiveness: eye-opening, motor and verbal responses. The brain death declaration is done by a panel of four doctors who do a series of tests to assess the patient's reflexes and efforts to breathe by himself/herself. This test is repeated after a minimum time gap of six hours by the same panel of doctors. The patient is declared brain dead if he/she fails to respond to all the tests in both the sets. The advantage of this kind of donation is that one organ donor can save at least nine lives by donating the heart, lungs, liver, kidneys, pancreas, bowel, intestine, hands and corneas.

Donation after cardiac death:

This is when the organ donation takes place once the heart stops beating. Tissues such as corneas, skin, bones and tendons can be donated. In India, only a few transplant centres like the Post Graduate Institute of Medical Education & Research, Chandigarh is doing kidney transplants after cardiac death.

The Process of Organ Donation in India

As per the Transplantation of Human Organs Act 1994, once the patient is declared as dead, the doctor in the ICU/ transplant coordinator/ counsellor speak to the family of the deceased about the opportunity to donate organs to save several lives. The option of organ donation is only given once the family accepts the death of their loved one. If the family is willing for the organ donation to take place, the consent is signed and the allocation centre of the State Organ and Tissue Transplantation Organization/ Regional Organ and Tissue Transplantation Organization / National Organ and Tissue Transplantation Organization is informed as per the State protocol. The allocation of the organs is done by the allocation centre as per the priority on the waiting list. The major challenges faced in deceased organ donation are the lack of acceptance about brain death, organ donation and lack of brain death declaration by the hospitals.

In living donation, the medical social worker educates the patient on the need of the organ replacement therapy and helps to map the living donors from the family. If the donor agrees to donate the organ after understanding the outcome after donation and the life after donation, the transplant coordinator proceeds with the documentation to prove the relationship between the donor and the recipient and to seek the approval from the authorised approving committee for the organ transplant with

the respective donor. The challenges faced by the transplant coordinators are in identifying fraudulent organ donors (Mathew, 2018).

The Human Organ and Tissue Transplantation Rules 2014 have made it mandatory to appoint a transplant coordinator in a hospital for all matters relating to the removal or transplantation of human organs and tissues or both and for assisting the authority for the removal of human organs in accordance with the provisions of the Act. The Transplantation of Human Organs and Tissues Rules, 2014 defines the qualification and the role of a transplant coordinator as a graduate of any recognised system of medicine or nurse or a Bachelor's degree in any subject and preferably a Master's degree in Social Work, Psychiatry, Social Sciences or Public Health. The transplant coordinator is a person who counsels and encourages the family members of the deceased to donate human organs or tissue including eyes or corneas and coordinates the activities related to organ donation and transplantation. India has very structured training programmes conducted by the National Organ and Tissue Transplantation Organisation and by various NGOs like the Multi Organ Harvesting and Aid Network Foundation.

The Role of Medical Social Workers in Organ Donation

Given below are three case studies for a better understanding of the role of a medical social worker as the transplant coordinator.

Case 1

Mrs. X came to the Out Patient Department with chronic kidney disease, with Mr. AB as the donor. Both of them were accompanied by three men, of which one was claiming to be their brother-in-law and the others as Mr. AB's friends. During the interrogative session, Mrs. X mentioned that theirs was a love marriage, she had three abortions and none of the family members were on good terms with them.

In the meanwhile, until the surgery could be organised, Mrs. X was advised to undergo dialysis in the transplant centre. They were also asked to produce documents such as the voter identification card, marriage certificate, ration card and bank account passbook for the joint account they claimed to have. During verification, the transplant coordinator had doubts about the marriage certificate and the voter identification card of the donor. The coordinator asked them to produce their album of marriage photographs and old family photographs.

The patient took a week to get the photographs. Meanwhile, the

transplant coordinator noticed that whenever Mrs. X came for dialysis, she was accompanied by another man who was not introduced to the transplant team. When the transplant coordinator enquired about this man, she was told that he was her husband's friend. The doubts of the transplant coordinator became stronger. When the photographs were produced, the transplant coordinator noticed in the marriage photograph a fistula (access to undergo dialysis) on Mrs. X's left arm. Keeping that in mind, she enquired about the marriage details such as date of the marriage, date of diagnosis of the kidney failure and the date of the AV fistula creation. The transplant coordinator learned from Mrs. X and Mr. AB that their marriage was 10 years old and Mrs. X was diagnosed with kidney failure six months and the fistula was also created at the same time. When the transplant coordinator questioned the mismatch of the documents provided and the details given by Mrs. X, Mr. AB and the people accompanying them confessed that Mr. AB was not her husband, but had agreed to donate one of his kidneys to Mrs. X.

The transplant coordinator successfully prevented a paid donation as it was proved that the man who was accompanying Mrs. X for every dialysis was her real husband and they had three children. Mr. AB proved to be a commercial donor.

Case 2

Mr. Y was declared brain dead and the family members were informed about the status of the patient. The transplant coordinator was involved in the process of counselling the family of the deceased. The patient's family had gone through the different stages of grief and the transplant coordinator had done several sessions of counselling until the family of the deceased accepted the fact. The daughter of the deceased came to listen to the further proceedings after the declaration of the brain death and the transplant coordinator explained to the family about the options of organ donation such as heart, liver, kidneys and eyes. Initially the few family members started blaming the hospital and the system. The transplant coordinator continued to counsel them until they decided upon organ donation. The family members were motivated to donate the heart mainly after understanding that their mother's heart would continue to beat in somebody else's body. The transplant coordinator counselled and motivated them to also donate the rest of the organs like the liver and kidneys. The family had denied donating eyes, keeping their emotions in place. When the written consent was signed by the family members of the deceased, the

transplant coordinator informed the hospital authorities and the treating team about the allocation centre (independent centre where the allocation of the organ takes place as per the priority of the patients who are waiting for a transplant on the State/ national waiting list) and the wishes of the family regarding organ donation. The transplant coordinator liaised with the allocation centre and the recipient centre (hospital where organ recipients are admitted) as per the instruction of the allocation centre and was the sole point of contact until the donation happened. The major challenge faced by the transplant coordinator in this organ donation was coordinating with the treating team.

Case 3

Mr. S was accompanied by an old transplant patient and visited the transplant coordinator to undergo a transplant with his wife as the prospective donor. The wife of Mr. S was not present at the hospital during his initial visits. The documents to prove the marital relationship between the donor and Mr. S were initially provided and then the donor was present for the interrogation.

As part of the protocol to understand the depth of the relationship between Mr. S and his wife, the transplant coordinator interrogated Mr. S. He claimed that their marriage was 20 years old and they did not have children as his wife was suffering from polycystic ovarian disease (a hormonal disorder). Mr. S is a management graduate and speaks fluent English and has an affluent outfit. He also mentioned that ever since he was married, he was on business tours and his wife took care of his parents in Delhi. Based on the interrogation, the transplant coordinator had asked for the passport, voter identification card and Aadhar card. The transplant coordinator requested Mr. S to bring his wife (donor) in order to understand her motivation in donating an organ.

The wife of the Mr. S came to the hospital after a couple of days to visit the transplant coordinator. The first impression was shocking for the transplant coordinator. The wife of Mr. S was not able to speak her name properly nor was she able to speak any language other than her native language (a very rural Punjabi) although she had been living in Delhi for the last 20 years. The transplant coordinator also realised that the wife of Mr. S was not even able to spell out the names of her husband, parents-in-law or his siblings. She was not aware of his likes and dislikes, hobbies,

duration of the disease, nature of the disease, or treatment advised for Mr. S. When the transplant coordinator discussed her concerns in carrying out the transplant process with his wife as the donor, Mr. S claimed that she was nervous as she was coming out of the house for the first time and had never before faced such a situation. Mr. S also requested for one more trial after a couple of days. The transplant coordinator agreed to the request and gave a future date for the interrogation.

After a couple of weeks, the wife of Mr. S returned to the office of the transplant coordinator. This time the transplant coordinator was shocked at the outfit of the wife who arrived in an ill-fitting modern dress, with streaked hair and her nails done. During this interrogation, the transplant coordinator asked a different set of questions from the previous session. The wife of Mr. S replied to the transplant coordinator by saying that “I can answer only the questions which you have asked last visit. I am not prepared to answer new questions and also I am an illiterate.” The transplant coordinator discussed the interrogation session with Mr. S and the transplant team and refused to perform the transplant in that hospital.

The documents which were produced by Mr. S like a passport mentioning the name of the spouse and Aadhar card mentioning the name of the husband were all found to be original. The transplant coordinator found that the person representing Mr. S’s wife was a fake.

The above-mentioned cases establish the roles played by the medical social workers in the context of both living and deceased donor transplants. In India, the medical social workers play multiple roles with regard to the procurement of organ donation and transplant coordination (Mukesh, 2013). The specific roles are discussed briefly in the following section.

Specific Roles of Medical Social Workers

Deceased Donor Transplant

Identification of a potential donor

The medical social worker visits the critical areas of the hospital like the intensive care unit and emergency area or trauma centre to build a rapport with the medical and paramedical staff to identify the potential organ donors. The legal formalities need to be followed and the family members need to be convinced. The task is challenging as the family will be in a state of crisis and trauma.

Certification of brain death

Once the potential brain death patient is identified, the medical social

worker coordinates with the brain death committee in consultation with the primary treating physician and the head of the hospital. The medical social worker helps the family members to understand the concept of brain death and gives support to the grieving family.

Grief counselling and motivating the family for organ donation

Grief is the most painful experience. The family of the deceased person will undergo the different stages of grief such as denial, anger, bargaining, depression and acceptance. The medical social worker along with the treating doctor or the doctor in the hospital approaches the family at regular intervals. Once the family reaches a level of depression or acceptance, the medical social worker approaches the family with the option of organ donation. While counselling the grieving family, the medical social worker remains genuine, empathetic and non-judgmental, at the same time needing to use counselling and communication techniques such as listening, observation, exploration, ventilation, passing the right information and logical discussions to see that the information is appropriately communicated.

Seeking consent for organ donation

Once the family agrees to organ donation, the medical social worker is responsible for obtaining written consent for the retrieval of the organs in the format prescribed by the law. This is mandatory as there have been occasions where the spouse/care giver was later forced to change the decision on the compulsion of the relatives and file a case against the hospital.

Screening of the potential donor

Screening is done to rule out malignancy and infection that can be transmitted to the recipient through transplantation. The medical social worker goes through the case records to ascertain the cause of death and the medical and social history of the potential donor so as to understand the eligibility. In a living donor transplant, the transplant coordinator is responsible for proving the relationship of the donor and the recipient by the documentation and witnesses the DNA typing test to medically prove the relationship. The coordinator also does the pre-transplant counselling which explains the advantages and disadvantages of undergoing a transplant, motivates patients and facilitates the medical screening of the patient and the donor.

Informing the allocation centre

Once the eligibility of the donor is confirmed, the medical social worker informs the allocation centre as per the State and the hospital policy about the availability and the willingness of the family to donate organs. The medical records of the eligible donor are shared with the allocation centre, so that they allocation centre can share them with the recipient centre (the hospital where the recipients are admitted).

Medico-legal formalities

Some of the brain-dead donors are either the victims of road traffic accidents or suicides, and they are registered as medico-legal cases by the hospital where the patient is admitted. In such cases, the custody of the dead body lies with the police until the post-mortem takes place. The medical social worker needs to obtain a No Objection document from the Department of Police and Forensics in order to carry on with organ retrieval.

Coordination with the transplant team

Social workers are responsible for being in regular touch with the transplant team for the smooth functioning of the retrieval of organs. It is also the responsibility of the medical social worker to coordinate the retrieval timing, facilitate the transportation of the organs and the operating theatre team.

Support to the donor family

The medical social worker represents the hospital and in the entire process of procurement of organs and transplantation provides the support throughout to the grieving family and helps them to cope with their loss.

Psycho social support to patients waiting for a transplant

When the patients are informed about their organ failure and the need for a transplant by the treating doctor, they undergo mixed emotional reactions like shock, disbelief, anger at the self and loved ones and depression. The medical social worker educates and counsels the family and the patient about the nature of the disease and the ray of hope for the future

Living Donor Transplant***Assessment of motivation in living donation***

The exploitation of the poor is taking place in India when it comes to organ donation. In order to avoid that, the medical social worker assesses

the motivation behind the donation of an organ such as a kidney or liver by a living donor.

Verification of the documents

The medical social worker assesses the donor and the recipient from the time they are introduced by the transplant physician. The assessment is done according to their appearance and body language after the initial introduction and pleasantries by the medical social worker with the donor recipient and their family members. They are called in separately for the interrogation session to understand the depth of the relationship and motivation to donate the organ. In the case of organ trading, the suspicion starts at this point.

These separate sessions could cover the following:

- I. Understanding the educational background of the donor and the recipient
- II. A thorough interrogation in a casual and friendly manner around the following areas could be helpful:
 - i. Details and names of other family members and their relationship
 - ii. The house in which all of them are staying, living together or separately.
 - iii. Details of servants, drivers etc that they employ.
 - iv. What do they enjoy the most - hobbies, sports etc.
 - v. At which school did they study? Grades in school/ college?
 - vi. What was their desired profession?
 - vii. Who is their favourite star, politician etc.?

(This list should be of at least 20 questions and a select 5 to 10 should be asked and it should be different for each pair)
- III. Income details of the recipient, donor and other family members.
- IV. Is there affection and attachment between the family members?
- V. The reason for donation and the motive behind the decision to be assessed before taking them further for any psychological evaluation.

The medical social worker takes special care to corroborate and cross verify the details as given by the donor, the recipient and other family members, to judge the accuracy of the data as provided by the various sources. This will then give adequate information for understanding whether the donation is between legally valid pairs (donor-recipient), or is a commercial deal. After the session, documents that include a voter identification card, Aadhar card, ration card, marriage certificate if applicable,

Permanent Account Number card, passport, driving license or any other valid documents should be verified. If the medical social worker is not satisfied with the documents provided by the donor and the recipient, she /he can ask for a photo album, birth certificate, verification letter from the police, bank account details, insurance details or property details. The medical social worker correlates the details mentioned in the documents and those provided at the time of interviews. The scrutiny does not end with the first visit, it is a continuous process. If the transplant coordinator has any suspicions after the verification of the documents, the transplant team is informed about the findings and recommends a DNA test by a National Accreditation Board for Testing and Calibration Laboratories accredited laboratory. After the thorough verification shows that the details are correct, the case is referred for medical and legal workups.

Facilitating the medical workup and the legal workup

In a living donor transplant, the donor and the recipient undergo various tests to ascertain the fitness of the donor to donate and the recipient to receive an organ. The medical social worker plays a major role in facilitating the tests and coordinates the patient-donor and the transplant team. The law mentions a detailed legal workup for the living donor transplant compared to the deceased donor transplant. It is the medical social worker who does the initial assessment of the donor such as the reason behind the donation, education and financial status. The medical social worker facilitates the legal workup based on the claimed relationship between the patient and the donor and forwards the file for approval to the relevant authority. The patient is given the date of the transplant only after the authority approves the file.

Organising and coordinating with the Approval Committee

The medical social worker submits the legal file of the respective patient and the donor in front of the approving committee as per the claimed relationship. Once the committee has scrutinised the file, the donor and the recipient are interviewed separately and this authority provides the approval to go ahead with the transplant with that particular donor.

Coordination with the transplant team

Once the approval is given by the approving authority, the medical social worker is responsible for coordinating with the transplant team in providing

the date for the transplant and for the smooth admission formalities and the organ transplantation.

Fund generation

The medical social worker assists the poor patients to seek funds for the transplant and further medications with help of crowd funding, government and charitable organisations.

General Role of a Medical Social Worker in Organ Donation and Transplantation

Patient education and follow-up

The medical social worker educates the patient and the donor about the post-transplant care of the new organ at home and the importance of having regular follow-ups. The medical social worker is also responsible for reminding the patient if they miss an appointment for the follow-up.

Maintaining the data, research and publication

The medical social worker maintains the records of the donors (organ and tissue) whether living or deceased and the organ recipients, which is shared periodically with the transplant authority of the State. Based on the data, it is also very important to do the research and publication which in turn will improve the number of organ donations.

Awareness generation and public education

It is difficult for the family to take a decision to donate organs after the declaration of death. Familiarity with the significance of organ donation and the process and importance of organ donation is an essential factor in encouraging people to come forward to support this noble cause. In India there is lack of awareness about brain death and organ donation. The medical social worker plays a role in creating awareness through information, education and communication materials like brochures, posters, pledge forms and awareness talks.

Considering the myriad of roles of a medical social worker, it is important to have the qualities of an administrator, researcher, counsellor and advocate. There needs to be continuous training and value-added programmes where the organ and transplant coordinators are updated on legal systems and the competencies discussed in this paper.

Conclusion

Medical social workers function as the key personnel in the multidisciplinary team in a multi organ transplant programme whether it is a living or a deceased donor. The medical social worker is part of the clinical and legal aspects of organ donation, family support, assessment of the motivation behind the living donation, socio-economic assessment, socio-cultural assessment, coordination between the transplant team and the allocation team and follow-up of the donor and the recipient. The medical social worker undertakes hospital and community education about organ donation and transplantation. He/she is involved in research and provides administrative support to the hospital authorities in organ donation and transplantation programmes. Networking systems like The Network and Alliance of Transplant Coordinators, the Indian Association for Transplant Coordination and the Indian Society of Organ Transplant work to improve organ donation and transplantation in India.

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