

Analysis upon the Contribution of Social Worker in Organ Donation and Transplantation: Legal and Social Issues

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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.

Organ donation is a noble act and it gives the opportunity to save the life of others even after death. Even with the technological improvement and man power resources, there is a huge need for human organs for transplantation. There are lots of hurdles in carrying out the process of organ transplantation due to misconceptions and lack of awareness. To improve organ donation lawfully, the essential factors are creating awareness, clarifying myths and misconceptions, educating legal procedures and eliminating malpractices like organ trade. In all these areas, social workers have major role and this article focuses on procedures of organ transplant and specific roles of social workers in the field of Organ Transplantation.

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INTRODUCTION

Qualified social workers with Master of Social Work degrees are required by the Centers for Medicare & Medicaid Services to be part of the transplant center's multidisciplinary team. Social workers complete comprehensive psychosocial evaluations for all patients referred for transplant or live organ donation to determine if they meet psychosocial selection criteria.

CMS requires transplant centers to have written psychosocial and medical selection criteria to guide patient evaluation, acceptance for transplant or live donation, and waitlist maintenance. Centers are also required to have policies that address post-transplant discharge planning for transplant recipients and living donors. In addition to conducting psychosocial

evaluation for living donors, social workers also function as the Independent Living Donor Advocate in many transplant programs. However, social workers functioning as Independent Living Donor Advocates are prohibited by CMS from routine involvement with transplant candidates or recipients. As members of the multidisciplinary team, social workers collaborate closely with the transplant surgeon, transplant physician (i.e., nephrologist), registered nurse transplant coordinator, nutritionist, pharmacist, as well as the in-patient nursing and allied health staff caring for the transplant patient or living donor. Psychiatrists and clinical psychologist may also be a part of the team. Of course, the patient and family are critical members of the team as well.

It is important for the psychosocial evaluation to include *t* Social, personal, housing, vocational, financial, and environmental support and strengths

- ❖ Cultural and language factors
- ❖ Identified and confirmed post transplant caregivers
- ❖ Post transplant medication plan
- ❖ Coping abilities and strategies
- ❖ Understanding of the risks and benefits of transplantation or live kidney donation
- ❖ Ability to adhere to a treatment regimen, and
- ❖ Mental health history, including substance or alcohol use and/or abuse and how it may impact the success or failure of organ transplant or the safety" of the living donor.

The psychosocial patient selection criteria and psychosocial evaluation address psychosocial issues that affect patient and graft survival outcomes, similar to the medical patient selection criteria emphasis on the medical issues and how they affect patient and graft survival and outcomes. The National Transplant Act and CMS require transplant centers to operate in ways that maximize patient and graft survival and minimize "waste" of organs given the severe shortage of organs available for the 120,000 people on the national waiting list. CMS also requires centers to maximize transplant recipient living donor safety" and protection of their rights. Both transplant candidate/recipient and living donors receive services from qualified social workers and both receive psychosocial evaluations. Transplant social workers role and involvement with living donors is entirely separate for the social workers working with patients needing transplant.

At International level, the first successful living-related kidney transplant was led by Dr. Joseph Murray and Dr. David Hume at Brigham Hospital in Boston during the year 1954. A kidney was transplanted from Ronald Herrick into his identical twin, Richard. Live donation of parts of other organs were innovated in 1990s, later, there was a lot of growth took place in technology. During the year 2010, Spanish doctors conducted the world's first full face transplant for a man injured in a shooting accident.

In India, the first ever human kidney transplant performed was done at the King Edward Memorial Hospital at Bombay in May 1965, using a cadaver donor in a non-renal failure patient who had hyper-nephroma.

Even with the technological improvement and man power resources, there is a huge need for human organs for transplantation. The report by Times of India (2013) states that 500,000 people die because of non-availability of organs, 200,000 people die of liver disease, 50,000 people die from heart disease, 150,000 people await a kidney transplant but only 5,000 get. 1,000,000 lakh people suffer from corneal blindness and await transplant. The need far exceeds the supply of transplantable organs and it is a great concern of the Government.

To improve organ donation lawfully, the essential factor are creating awareness, clarifying myths and misconception, educating on legal procedures, eliminating malpractices like organ trade. In all these areas, social workers have major role and this article focuses on procedures of organ transplant and specific roles of social worker in the field of Organ Transplantation.

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.

ISSUES AND CHALLENGES IN ORGAN TRANSPLANTATION

Organ donation is a noble act and it gives the opportunity to save the life of others even after death. The term organ transplant refers to the transplantation of an organ from one body to another. The person who receives the organ is the recipient and one who gives is called the donor. This procedure is undertaken for the replacement of the damaged organ in the body of the recipient with the working organ from the body of the donor. The organ donor can be a deceased or alive.

There are lots of hurdles in carrying out the process of organ transplantation. People have lot of doubts about organ donation like is it acceptable by religion, caring of the donor during emergency, organs to be donated, eligibility for donation, age for donation, does the body disfigures after donation, who will take care of donation cost, financial status of the recipient etc.,

Apart from heart, liver, kidney and other organs like lungs, intestines, pancreas, and tissues can be donated including eyes, skin, bone, heart valves and tendons. If a person is waiting for transplantation, his severity of the illness will be counted and not the financial status. Regarding the eligibility for donation, all are eligible irrespective of their age and medical history. World's youngest organ donor was a baby with anencephaly, born in 2015, who lived for only 100 minutes and donated his kidney to an adult with renal failure (Kat Lay, 2015). Medical condition at the time of death will determine the status of donation.

The major concern of the donor's family is disfiguring after organ donation. Organs are removed surgically and there is no change in the appearance of the donor's body. None of the religion is against organ donation and admits it as a form of charity.

LEGAL AND SOCIAL ISSUES

CURRENT LAWS -

Organ donation laws at the state and federal levels exist for two primary purposes. The first purpose of organ donation laws is to help ensure a safe and fair organ donation collection and distribution practice. The

second type of organ donation laws have been enacted to widen the pool of potential donors in an effort to increase the number of organs available for transplant.

National Organ Transplant Act of 1984 - The goal of the National Organ Transplant Act (NOTA) was to address the problems of organ shortage and improve the collection and distribution of organs nationwide. It was passed by the United States Congress in 1984.

- Established the United Network for Organ Sharing (UNOS) to maintain a nationwide computer registry of all patients who need organs.
- Established the Organ Procurement and Transplant Network (OPTN) – OPTN keeps a national registry of patients and organs and matches organs with patients.
- Established the Task Force on Organ Transplantation.
- Banned the purchase or sale of organs or tissues.

Consolidated Omnibus Reconciliation Act of 1986–

The Consolidated Omnibus Reconciliation Act (COBRA), passed by the United States Congress in 1986, primarily addressed health benefits and health insurance coverage. Regulations concerning organ transplantation and allocation were written into the COBRA reforms:

- Requires hospitals to establish a relationship with a federally mandated Organ Procurement Organization. The Act also includes the instruction that Organ Procurement Organizations must work with hospitals to coordinate transplants at the local level.
- This act forced all hospitals receiving Medicare or Medicaid funding to enact a "required request" policy. A required request policy ensures that all families of potential donors are told about organ donation and their right to decline donation.

Uniform Anatomical Gift Act - The Uniform Anatomical Gift Act is a set of model regulations and laws concerning organ donation that all 50 states have passed in some measure. There have been many revisions to the Act.

- 1968 – The passage of the Uniform Anatomical Gift Act in the United States Congress allows people to donate their organs.
- 1972 – The Uniform Donor Card is passed as a legal document in all 50 states, allowing anyone over 18 to donate their organs.

MEDICARE Conditions of Participation –

Medicare developed five incentive policies in 1998 to encourage organ donation and organ procurement in participating hospitals. They are printed on the International Association for Organ Donation website:

- “The hospital must notify the organ procurement agency of every death occurring in their facility.
- All hospital personnel providing the option of donation to families will be trained by the organ procurement agency.
- The Hospital will have a written agreement to work with organ, tissue and eye banks.
- The hospital will acknowledge that screening for potential donors will be conducted by the appropriate recovery agency.
- The hospital will work in conjunction with recovery agency to conduct record reviews to determine the donation potential of individual facilities.”

First Person Consent Laws - In the 1990's, states began to pass first person consent laws. These laws require hospitals and organ procurement organizations to follow a patient's organ donation wishes as indicated on their driver's license or in a health care directive. Where the laws are enacted, the hospital and the organ procurement organization has a legal right to follow a deceased person's written organ donation wishes and does not require them to approach the deceased person's family for permission to remove the organs.

Some advocacy organizations suggest that as many as 2/3 of people who sign organ donation consent forms do not have their wishes honored when they die. This is because when families are approached for consent to remove the organs, they do not give it. The first person consent laws attempt to eliminate the discrepancies between a person's organ donation wishes and family consent by putting the patient's decisions above the decisions of their family. This practice supports and acknowledges autonomy. Autonomy is the right to make decisions for oneself and to practice self-determination and self-governance. Many Americans value autonomy very

highly and consider selfdetermination a fundamental right.

THE IMPACT OF TRANSPLANTATION -

Receiving an organ donated from a living or deceased donor is a life changing event. Organ donation impacts a staggering number of people and the stories of how organ transplantation has affected someone's life are often collected to be shared with others. You can read about the impact of organ transplantation in the following resources:

- The United Network for Organ Sharing website has stories of donors and recipients. <http://www.transplantliving.org/patientProfile.asp>
- TransWeb.org is a website “...all about transplantation and donation.” They have recipient and donor stories on their website under the heading “Real People.” www.transweb.org
- Dick A. Hawkin's Liver Transplant is a web page published by a man who received a liver transplant. It tells his story. There are several similar pages out there published by people who wish to share their experiences. This particular website is located at www.sadiehawkins.com/liver.htm

ROLE OF SOCIAL WORKERS

Organ transplantation consists of multi disciplinary team and it includes transplant surgeon, transplant physician (i.e. nephrologists) registered nurse transplant coordinator, nutritionist, pharmacist, as well as the in-patient nursing and allied health staff. Psychiatrists and clinical psychologist may also be a part of the team. As members, social workers collaborate closely with them and caring the transplant patient or living donor.

Organ transplantation requires an invasive surgical procedure that has both physical and psychological implications. Social workers play a vital role in dealing the psycho social issues of donors and recipient family. They act as a liaison between the receiver, donor and the medical team.

They are with the transplant patients and living donors throughout the transplant donation process. Their job is a challenging one, both at the transplant center and at the community. At the transplant centers, social workers engage in dealing psychosocial issues of the patients. They do pre-evaluation, guide them, make them to accept for transplant or live donation, will get informed consent, engage in transplant and living donor selection, hospital discharge planning and follow up. They also maintain wait list and do referral services

to hospitals and community resources. They coordinate the delivery of the organs in time to the transplant center.

In the pre evaluation they discuss with the patients on their social, personal, housing, vocational, financial and environmental support and strengths, Cultural and language factors, post transplant caregivers and medication plan, Coping abilities and strategies, Understanding of the risks and benefits of transplantation or live kidney donation, Ability to adhere to a treatment regimen and Mental health history, including substance or alcohol use and/or abuse and how it may impact the success or failure of organ transplant or the safety of the living donor. After psycho social evaluation, Social workers are also involved in getting informed consent from patients.

SOCIAL AND RELIGIOUS CONSIDERATIONS REGARDING ORGAN TRANSPLANTATION

The shortage of organs for transplantation makes it important to understand why some oppose organ donation . There are many reasons why certain populations are less likely to consent to organ donations. Among these reasons, both social and religious issues play an important role, especially in a multiethnic, multicultural and multireligious community like Malaysia. It had been reported that the formal position of a religion to organ donation and transplant play an important factor in persuading the community regarding organ transplant.

Social issues -Many social issues need to be considered when promoting organ transplant in the community. Some of these issues are misconceptions that need to be addressed individually.

The first misconception that needs to be collected is the perception that the body of the donor would be mutilated and treated badly. This is not so. as the organs would be removed surgically in a routine operation. Organ donation does not disfigure the body or change the way it look in the casket and normal funeral arrangement would be possible.

The second misconception is the wony that even if the person wanted to donate one organ, that other organs would also be taken. This wony can be collected by informing the patient that only organs specified for donation will be taken from the body. The third misconception is the wony that if a person was involved in an accident, that the doctors would not save his life if they knew that he was a donor. This fact is totally incoect as the doctors at the accident unit are different fr om those in the transplant team. The organ procurement team would only be notified after all lifesaving efforts had failed and after death had

been detennined. and after the family had consented to organ donation. The fourth misconception is the wony that a person's religion do not approve donation.

Generally, all organized religions support organ donation as it is typically considered a generous act: however this aspect will be discussed in more detail below. The fifth misconception reported was whether a person was the right age for donation. It was reported that age do not form a barrier for organ donation, as organs can be donated from someone as young as a newborn. However, transplant teams generally consider the age limit for tissue donation as 70 years old.

Religious considerations -In this report, the author wishes to discuss the religious perspective of the 3 main religion in Malaysia: Islamic view. Confucianism and Christianity. The views of Buddhist and Taoist will be briefly addressed.

i). Islamic perspective - There is a striking variability in attitudes towards transplantation throughout the Muslim world. The practice of organ donation and transplant is sanctioned in Saudi Arabia and Iran but unclear in Turkey in contrast, almost half of Arab Bedouins believe that Islam prohibits organ donation. Majority of Muslim scholars (both Sunni and Shia) promote the importance of saving human life, based on the teachings of Prophet Muhammad who encouraged his followers to seek medical attention when ill. and hence allow organ transplantation. However, there is no unanimous support for this view. This variability in attitude towards organ donation is thought to be due to the variable opinions of individual religious leaders and Muslim scholars, who had variable knowledge regarding organ transplant

(ii). Confucianism, Buddhist and Taoist perspective - It has been reported that persons of Chinese ethnic origin, due to the influence of Confucianism values. Buddhist. Taoist and other spiritual beliefs do not support the thought or organ donation as they associate an intact dead body with respect for ancestors or nature. In particular, in Confucianism, the concept of 'filial piety' dictated that individuals should return their bodies in the same condition that they received from their parents, out of respect for their ancestors. It is therefore wrong to return a person's body not intact by removing organs from it³⁸. However, if they do decide to donate their organs after their death, the priority is to

close relatives, and then in descending order, distant relatives, people from their home country (other Chinese ethnic group) and then only to strangers. This 'negotiable' willingness to donate has enormous implications, where transplant specialist can use it as a strategy to increase organ donation rates among Chinese community. As for the Buddhist, they believe that the dying process takes several hours, and the Taoist believes that organs have one to one relationship with nature.

- (iii). Christianity perspective - As for Christianity, the main branches of Christianity: i.e. Catholics and Protestants support and encourage organ transplant. Christians look at Jesus Christ, whose life was one of self-giving as guidance. Pope John Paul II, the recently deceased Pope had repeatedly advocated organ donation and organ transplant as a 'service of life'. However, in order to prevent conflict, it was suggested that the freedom of the prospective donor should be respected, and that the physician who determines death should not be a member of the transplant team.

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 -

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.

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.

In the current scenario, awareness on organ transplantation is very essential to increase organ donation to save the life of the needy patients and to control organ trading which is legally punishable. Social workers have the major role in all these areas and they need to be trained at the field level. They need exposure in handling the psycho social issues related to donors and his families, specific roles in the multi disciplinary team and enlarging community participation. For successful delivery of these responsibilities, they have to be placed in agencies working for organ transplantation for field work and block placement.

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