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Revisiting Organ Donation – Voyage from Death, Donation, Transportation to Organ Transplantation

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ABSTRACT

The gap between the huge demand for organs and their inadequate supply is the issue of concern. Organ shortage is a global issue and deceased organ donation is the major sustainable way out. There are stringent criteria instituted for the retrieval, preservation, and transportation of donor organs. India slips to the 40th rank in the study of 69 countries in terms of the number of organ transplants per million population. However, the country has significant potential for deceased organ donation due to a higher proportion of fatal road traffic accidents. There are various programs, policy, legislation, organizations including observation of 'Organ Donation day' addressing organ donation. From the Transplantation of Human Organ Act to National Organ and Tissue Transplant Organization, each modality promotes organ donation & transplantation. There are various determinants of organ donation especially influencing the decision making for donation. It is the need of the hour to address wherein the process, and for what reason, potential donors fail to become actual donors. This article reviews and revisits the evolution of organ donation, the magnitude of the problem of inadequate organ donation, measures and services available to promote organ donation.

Key Words: Organ donation, Organ transplantation, Legislation, Transportation, Determinants, Deceased

BACKGROUND

Organ donation has evolved significantly from an experimental procedure to acceptable medical treatment for terminal illnesses. Despite these contemporary advances, globally there has been relatively slow progress in the supply of organs for transplantation.¹ In many countries, increasing the number of donors and thereby decreasing the waiting list for donor organs is an important subject on the health policy agenda as organ transplantation is an important, and sometimes even the only option to treat organ failures.² There are various determinants of organ donation especially influencing the decision making for donation. It is the need of the hour to address wherein the process, and for what reason, potential donors fail to become actual donors. This article reviews and revisits the evolution of organ donation, the magnitude of the problem of the shortage of organ donation, measures, and services available to promote organ donation.

DATA EXTRACTION

The data is extracted from PubMed, Web of Science, Google Scholar, and websites of WHO, Ministry of Health & Family

Welfare, Government of India and other websites related to organ donation, transplantation. The extracted information included statistics from various countries including India, the magnitude of the problem of inadequate organ donation, various programs, policy, legislation & organizations for the promotion of organ donation and transplantation.

PROBLEM BURDEN

Global silhouette

The WHO's global observatory on donation and transplantation data suggests that less than 10% of the world transplantation need is met. Organ donation can only result from around 1% to 2% of all deaths. Even these potential donors might not be willing to donate because of false perceptions, superstitions, and other factors. Fewer than 2000 of the 420,000 kidney transplants in the US since 1988 have been from altruistic living donors who didn't know the person getting their organ. About one third have been living donors who did. The rest of these transplants were from deceased organ donors. Among all the countries, Spain has the high-

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est rate of organ donation. The rate of donation in the US is about midway among nations that are tracked.³

Indian Scenario

India's organ donation rate in 2016 stood at an abysmal 0.8 persons/million population whereas other western countries like Spain, Croatia, US at 36, 32 and 26 per million, respectively.⁴ In India, every year nearly 5 lakh people die because of the non-availability of organs. Two lakh and 50,000 people die of liver and heart disease respectively. 1.5 lakh people require kidney transplantation, but it gets available to only 5000. Ten lakh people suffer from corneal blindness yet, less than a thousand transplantations from deceased donors are performed each year - an insignificant number compared to the statistics.⁵

There is a paucity of skilled manpower and facilities too in the country for transplantation. There are less than 100 kidney transplantation centres, less than 350 clinicians involved in transplantation. Thus, India slips to the 40th rank in the study of 69 countries in terms of the number of transplants per million population, with only three in a million getting the kidney in case of renal failure. The country's number has now come near to one, after revolving around 0.5 for many years. For India, the country with the second-largest population (over 1.3 billion) across the globe, the number of organ donations taking place is remarkably low.

Organ donation in India has a relatively short history compared to the developed world. A closer look at donation patterns across the country reveals that deceased donation is largely driven by hospitals with active transplant programmes. This could be an area for India to explore to increase the donor pool. Whilst we must continuously strive towards increasing donation rates, we must not lose sight of this big picture. In India, there is significant potential for deceased donation due to the large proportion of fatal road traffic accidents. Over 50% of brain death involves young people with head injury due to road traffic accidents. With adequate systems in place, people succumbing to accident-prone injuries could meet a major portion of the demand.⁶

RELATION BETWEEN BRAIN DEATH AND DONATION

Brain death is characterised by an irreversible loss of consciousness and the absence of brain stem reflexes. Using artificial technology, the body organs can be kept alive, even after brain death. Vital organs can be donated only if death occurs in the hospital. In case of cardiac death, organs that can be donated are cornea, bones, ligaments, veins, heart valves, blood, platelets and stem cells.

Deceased organ donation

For patients who have not registered to donate, the organization educates families about the donation process and seeks their consent on the patient's behalf.

Living organ donor program

Live donations impose risks to donors which include infection, bleeding, pain and even death. It also affects their quality of life and daily day to day activities. Organ donation after death suffices the need for organs then the need for living beings to donate will be minimal and they will not be compelled to donate. There are a lot of ethical issues related to living organ donation.

Determinants of organ donation

In a systematic review by Irving et al.⁷ out of the qualitative literature on 'Factors that influence the decision to be an organ donor', studies that explored community attitudes towards living and deceased solid organ donation (heart, liver, kidney, and lung) using qualitative data through focus groups or interviews were included. The review highlighted that seemingly intractable factors, such as religion and culture, are often tied in with more complex issues such as a distrust of the medical system, misunderstandings about religious stances and ignorance about the donation process. Similarly, various community based studies^{8,9} showed opposition from family, fear and concern as some of the key barriers for organ donation.

The foremost necessary facilitators were the thought that organ donation would save someone's life and a sense of improved immunity. Education, occupation, marital status, socio-economic status were also found to be determinants of intention to gift organ.

PROGRAMS, POLICY, LEGISLATION & ORGANIZATIONS ADDRESSING ORGAN DONATION

National Organ Transplant Program¹⁰

The various activities under the program are preventive, health education, curative, surveillance and research, training, etc. It also includes the initiatives required to enhance the role of organ retrieval banking organization. The programs stated that there are improved facilities for organ transplantation throughout India, establish a network for equitable distribution of retrieved deceased organs, increase organ availability through a change in attitude and facilitating the retrieval of deceased organs, building up human resource like training required manpower.

Legislation¹¹

Transplantation of Human Organ Bill was introduced in the Lok Sabha on 20th August 1992. Transplantation of Human Organ Act (THOA) was passed in 1994. This is the primary

legislation related to organ donation and transplantation in India. Before the introduction of this act, the regulations for organ donation and transplantation in India were non-existent and malpractices were rampant. The amendment to the act was passed by the parliament in 2011, and the rules were notified in 2014 as the Transplantation of Human Organs and Tissue Rules – 2014.

National Organ and Tissue Transplant Organization (NOTTO)¹²

It is a national level organization set up under the Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India. It has the following two divisions:

- a) **National human organ and tissue removal and storage network-** This has been mandated as per the THOA 2011. The division of the NOTTO is the nodal networking agency and network for procurement allocation and distribution of organs and tissues in Delhi.

The national network division of NOTTO would function as the apex centre for all Indian activities of coordination and networking for procurement and distribution and registry of organs and tissues donation and transplantation in the country.

- b) **National biomaterial centre / National tissue bank-** The THOA act 2011 has included the component of tissue donation and registration of tissue banks. The objective of the centre is to fill up the gap between 'Demand' and 'Supply' as well as promote 'Quality Assurance' in the availability of various tissues so that demands of tissue transplantation including activities for procurement, storage and distribution of biomaterials can be fulfilled.

Policy for organ donation

a) Opt-in or Opt-out policy

Several countries, including the Republic of Ireland & Germany, have plumped for an 'Opt in' policy. According to this kind of scheme, people are placed in an organ donor register if they take active steps to have their name added to the list.

In contrast, the other countries like Singapore, Spain, have adopted a slightly more radical 'Opt out' policy. As per the scheme, mandatorily every eligible adult is auto-registered in an organ donation register. If any individual does not wish his/her organs to be donated after death, then he/she has to complete official formalities for removal of his/her names from the registry.

b) Mandated choice policy

Several states in the USA, most notably Texas and California have experimented with another kind of policy termed as

'Mandated Choice policy', which tries to seek every adult citizen for declaring their views about organ donation. Often newly qualified drivers are asked to declare their preference as a condition of being giving their driving license.

World Organ Donation Day

August 13th is observed as 'World Organ Donation Day' every year with the purpose to remove the taboo and promote organ donation for those who require them as lakhs of people die each year because of organ failure. These precious lives can be saved only if healthy volunteers could go ahead with donating their organs. Donation of organs like liver, kidney, heart, intestine, lungs, pancreas, bones, veins, skin, etc. can be life-changing for thousands of people in need, all across the world.

Zonal transplant coordination committee(ZTCC)¹³

ZTCC is a not-for-profit, government organization that started to promote organ donation. It works with the objectives like promoting cadaver transplant and fair distribution of organs, reaching out to every needy waiting recipient as per government guidelines, creation of transplant registry and maintaining an organ-specific waiting list of recipients, improving awareness about organ donation.

Transplant Coordinator is a person appointed by the hospital for coordinating all the matters related to removal or transplantation of human organ or tissues or both and for assisting the authority for removal of human organs following the provision of section 3.

Transplant coordinators play a crucial role in the achievement of any organ donation and transplantation. The THOA has made transplant coordinators nomination mandatory before a hospital is registered as a transplant centre. Hence, such a training programme on transplant coordinator is required which will enable to enhance the counselling and coordination skill & other needed competency of the coordinators.

MOHAN Foundation- Key NGO working in the field of organ donation

Mohan foundation i.e. Multi-Organ Harvesting and aid Network is a not for profit non-governmental organization that started to promote organ donation in 1997 in Chennai. It has branches in several cities of India. It is started by the like-minded and concerned medical and non-medical professionals committed to increasing the reach of transplantation of human organs act. Its mission is to ensure that every Indian who is suffering from end-stage organ failure be provided with the 'gift of life through a lifesaving organ.'¹⁴

Green corridors

It refers to a special road route that facilitates the transportation of harvested organs meant for transplantation to the

desired hospitals. The street signals are manually operated to avoid stoppage at red lights and to divert the traffic to ensure rapid transportation of the desired organ. There are many recent instances in India where organs were transported in time using this facility.¹⁵

Tissue banks

Tissue banking is the process in which biomedical tissue is stored under cryogenic conditions to be used later when the need arises. Several tissue banks have been established in India in recent times, which help in storing tissues such as the cornea, skin, heart valves, bones and tendons for later use. These centres help in preventing tissue wastage to a great extent.¹⁵

Green Ribbon

It symbolizes hope for those who are waiting for a second chance at life through organ transplantation. It reminds of the individuals who have died waiting for a life-saving transplant. It also takes into cognizance the contribution of donors and their families for bestowing the greatest gift, the gift of life to the needy.

CONCLUSION

Thus, globally and nationally, there is a need to strengthen the promotion of organ donation since there is an acute mismatch between the organs donated and people in the queue for transplantation. It points towards the need to assess the awareness and willingness of the community for organ donation. Because if people will be aware of when and how they can donate organs, will donations happen.

Efforts must be undertaken to motivate the people of the community by large scale information dissemination. In addition, eradication of the misconceptions that continue to overshadow reason and hamper the spread of an action saving many lives is also crucial.

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