EXPLORATION INTO MEDICAL, LEGAL, SOCIAL AND ETHICAL ISSUES OF BRAIN STEM DEAD DONATION AND TRANSPLANTATION: A CASE STUDY OF NOTTO (NATIONAL ORGAN AND TISSUE TRANSPLANT ORGANIZATION)

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DECLARATION

I declare that the thesis entitled "EXPLORATION INTO MEDICAL, LEGAL, SOCIAL AND ETHICAL ISSUES OF BRAIN STEM DEAD DONATION AND TRANSPLANTATION: A CASE STUDY OF NOTTO (NATIONAL ORGAN AND TISSUE TRANSPLANT ORGANIZATION" is being submitted by me in partial fulfilment of the requirements of the award of the degree of **DOCTOR of PHILOSOPHY** of Jawaharlal Nehru University. This thesis has not been submitted for the award of any other degree of this university or any other university and is my original work.

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We recommend that the thesis be placed before the examiners for evaluation and consideration of the award of Degree of Doctor of Philosophy.

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CONTENTS

LIST OF ABBREVIATIONS	
AGT	Alanine Glyoxylate-amino Transferase
AIIMS	All India Institute of Medical Sciences
AORTA	Armed Forces Organ Retrieval and Transplant Authority
AP	Andhra Pradesh
AP View	Arterio-Posterior View
AST test	Aspartate Aminotransferase test
BSD	Brain Stem Death/Dead
BSDC	Brain Stem Death Committee
BP	Blood Pressure
BPL	Below Poverty Line
CASR	Centre of Advanced and Scientific Research
CCU	Cardiac Care Unit
CDC Test	Complement-Dependent Cytotoxicity test.
CGHS	Central Government Health Scheme
CHEB	Central Health Education Bureau
CPWD	Central Public Works Department.
CSR	Corporate Social Responsibility
CTAC	Cadaver Transplantation Advisory Committee
DAVP	Department of Audio Video Publicity
DBD	Donation after Brain Death
DCD	Donation after Circulatory Death
DDLT	Deceased Donor Liver Transplant
DGHS	Directorate General of Health Services
DTC	Donor Transplant Coordinators
EEG	Electroencephalography
EOS	Electronic Organ Sharing
ESRD	End Stage Renal Disease
FORTE	Foundation for Organ Transplant and Education
GB Pant hospital	Govind Ballabh Pant hospital
GFR	Glomerular filtration rate
GODT	Global Observatory on Donation and Transplant
GoI	Government of India
Hb	Haemoglobin
HBT	Heart Beat Transplants
HCV	Hepatitis C Virus
HLA Test	Human Leukocyte Antigen Test
HM & FW	Health, Medical & Family Welfare
HTA	Human Tissue Authority

ICU	Intensive Care Unit
ICMR	Indian Council of Medical Research
ID	Identity
IEC	Information Education and Communication
IGIMS	Indira Gandhi Institute of Medical Sciences
IITF	India International Trade Fair
ILBS	Institute of Liver and Biliary Sciences
ISOD	Indore Society for Organ Donation
ISTM	Institute of Secretariat Training and Management
IPGMER	Institute of Post-Graduate Medical Education and Research
KNOS	Kerala Network for Organ Sharing
LAMA	Left Against Medical Advice
LDLT	Living Donor Liver Transplant
MBBS	Bachelor of Medicine and Bachelor of Surgery
MELD	Model of End Stage Liver disease.
MGM	Mahatma Gandhi Memorial
MOHAN	Multiple Organ Harvesting Aid Network
MOHFW	Ministry of Health and Family Welfare
MOU	Memorandum of Understanding
MPH	Master’s in Public Health
MTS	Multi-Tasking Staff
NBCC	National Building Construction Corporation
NCR	National Capital Region
NGO	Non-Governmental Organization
NHBT	Non-Heart Beat Transplants
NHSBT	National Health Services Blood and Transplant
NIC	National Informatics Centre
NIMS	Nizam's Institute of Medical Sciences
NOTTO	National Organ and Tissue Transplant Organization
NOTP	National Organ Transplant Programme
NTOHC	Non-Transplant Organ Harvesting Centres
OPC	Organ Procurements Coordinators
OPD	Out Patient Department
OPTN	Organ Procurement Transplant Network
ORBO	Organ Retrieval Banking Organization
OTC	Organ transplant coordinators
OTDRC	Organ and Tissue Donation Cum Retrieval Coordinator
OTRC	Organ and Tissue Retrieval Coordinator
OTRH	Organ and Tissue Retrieval Hospital
OTTC	Organ and Tissue Transplant Coordinator

OTTH	Organ and Tissue Transplant Hospital
PA	Personal Assistant
PAC	Pre-Anaesthetic Check-up
PGI	Post-Graduate Institute
PGIMER	Post Graduate Institute of Medical Education and Research.
PH1	Primary Hyperoxaluria type1
PM	Prime Minister
pmp	per million population
PMSSY	Pradhan Mantri Swasthya Suraksha Yojana
PRA	Panel Reactive Antibodies.
RML Hospital	Ram Manohar Lohia Hospital
RNOS	Rajasthan Network for Organ Sharing
ROTTO	Regional Organ and Tissue Transplant Organization
SGOT	Serum Glutamic-Oxaloacetic Transaminase
SGPT	Serum Glutamic Pyruvic Transaminase
SJH	Safdarjung Hospital
SOP	Standard Operative Procedures
SOTTO	State Organ and Tissue Transplant Organization
THOA	Transplantation of Human Organs Act
THOT	Transplantation of Human Organs and Tissues
ToI	Times of India
TNOS	Tamil Nadu Network for Organ Sharing
TRANSTAN	Transplant Authority of Tamil Nadu
TSH	Thyroid Stimulating Hormone.
T3/T4	Level of thyroid hormones
TV	Television
UAGA	Uniform Anatomical Gift Act
UK	United Kingdom
UNOS	United Network of Organ Sharing
UP	Uttar Pradesh
US	United States
USA	United States of America
UTs	Union Territories
VMMC	Vardhman Mahavir Medical College
WHO	World Health Organization
ZTCC	Zonal Transplant Coordination Committee
ZTCK	Zonal Coordination Committee of Karnataka

LIST OF TABLES

CHAPTER 1

Introduction to Organ Donation and Transplantation

Organ donation means the gift of vital organs of human bodies for transplantation into sick people for treatment. These organs are liver, kidney, heart, pancreas, lung and small bowel. Occasionally these organs fail to function in human beings as a consequence of disease or injury. Organ transplant in such situations is the lifesaving treatment that necessitates donation of organs either from healthy individuals or from Brain Stem Dead (BSD) donors in India (Dar, 2014). The advancements in medical technology have made it possible to replace the diseased organ of an ailing person with a similar organ from a living donor or from a deceased donor for extending his life. The immunosuppressant drugs used for prevention of organ rejection has further given meaning to transplantation of organs by preventing rejection of transplanted organ in the recipient body and has saved the lives of many people in many parts of the globe (Dar and Kumar,2015). However, this has also increased the demand for organs all over the world, including India. The need for organs, on the one hand, has led to unethical practices in organ donation exploiting weak and powerless. And on the other hand, it has led to legal amendments in defining and redefining deaths to retrieve viable organs for transplantation (Dar,2015).

The need for organs for transplantation far exceeds their availability that challenges health authorities to restrain unethical practices. Many countries have developed their country-specific legal frameworks for the donation of organs and transplantation in human beings from living as well as deceased donors. Unfortunately, commercialisation of human organs, exploitation of poor and powerless, transplant tourism and trafficking in human organs remain unabated all over the world and India is no exception to it.

It was in 1991 only, World Health Organization (WHO) developed the guiding principles for organ donation and transplantation. These principles were developed after the World Health Assembly (WHA) voiced its deep concern in 1987 through WHA Resolution 40.13. Human organ trade activities were going on at the cost of human rights violations. World Health Organization (WHO) laid five guiding principles. These principles preferred deceased donor over living donors and genetically related to unrelated donors, banned commercial activities, introduced informed consent as preconditions in all cases and fair allocation and equitable access to organs from deceased donors (WHO, 1991). Following this organ donation from living as well as BSD donor was legalized in India through Transplantation of Human Organs Act In 1994(THOA ,1994).

Organ donation and transplantation is an evolving subject. The Istanbul Declaration in 2008 provided leadership and supported the growth of organ donation and transplantation programs ethically without any exploitations of human beings to prevent organ trafficking and transplant tourism all over the globe. About 135 professional bodies around the world endorsed this declaration (Istanbul declaration, 2008). Many countries started deceased donor organ transplant programmes. In India National Organ Transplant Programme (NOTP), a national programme on organ transplant started in 2009(Dar and Kumar, 2015).

World over several countries faced a number of issues and challenges in organ donation and transplantation irrespective of their country specific laws in place. At the World Health Assembly, these issues and challenges in organ transplantation were discussed, following which WHO framed 11 guiding principles. On May 21, 2010, the 63rd World Health Assembly (WHA) endorsed the eleven WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation. These guiding principles focus on (1) unambiguous definition and determination of death; (2) permission for deceased donor's donation; (3) consent from live donors; (4) protection of incompetent individuals and minors; (5) no trade activities for organs, tissues and cells; (6) promotion of philanthropic donation, no publicity or brokering;

(7) accountability on the origin of transplant; (8) reasonable professional fees; (9) distribution rules of organs, tissues and cells; (10) maintenance of safety, quality, efficacy of procedures and, (11) continuation of transparency and confidentiality (WHO,2010). In India, unethical practices in organ donation and transplantation remained unabated. These practices were exploitative for the poor and powerless. In response to all these global interventions, India modified Organ transplant laws. India took care of most of the principles laid down by WHO and amended the transplant Act of 1994 in 2011 (THO amended Act, 2011). This was later followed by gazette notification of amended rules also (THOT Rules 2014). National Organ and Tissue Transplant Organization (NOTTO) is a national level body that has been set up under NOTP; Directorate General of Health Services (DGHS), Government of India (GoI) in 2014. It is supposed to maintain a national database in organ transplantation activities for the whole of our country. The ethical, medical, legal and social issues of organ donations from Brain Stem Dead donors and their transplants remain unexplored in Indian context keeping in view the mandate of NOTTO.

Unlike, the USA that has the Uniform Anatomical Gift Act (UAGC -1968), there are many laws that direct donation of the body or its parts in India. Body donation is meant for educational and scientific purposes only and is governed by Anatomical Act introduced in 1949 (Ajita and Singh, 2007). The Transplantation of Human Organs Act (THOA) – 1994 focuses on organ donation from Brain Stem Dead donors and living donors for treatment purposes of patients requiring organ transplants. THO amended Act 2011 concentrates on tissue donation like corneas from eyes, skin, bones, ligaments, tendons and blood vessels as well (THO amended Act, 2011). Tissues like corneas of eyes give sight; skin helps in healing the fire and injured victims, ligaments and bones provide mechanical support for helpful movements of recipients. People and professionals do not understand the difference between body, tissue and organ donation in India (Dar, Dar and Kumar, 2016).

There is no standardized protocol in place to declare such deaths globally. In other words, there is great difference in the legal declaration and acceptance of these deaths that fascinatingly varies across the globe. For example, in China, the national protocol for deceased-organ donation identifies three categories of deaths. The first category means organ donation after the declaration of brain death; the second category means the donation of organs after circulatory death and the third category comprises of organ donation after brain death, followed by circulatory death (Huang et al. 2013). India so far has only Brain Stem Death criteria of deceased organ donation in place. However, cardiac death contributes minimal organs in comparison to donation after brain death /Brain Stem Death, globally.

Types of Organ Donors in the Context of THOA-1994 And THO Amended Act-2011

There are two types of organ donors like Living and deceased organ donors who donate organs for transplantation as per the laws of different countries. It is fascinating to know that human being born with two kidneys can survive with one after donating the other to a needy person. A living donor can also give a part of the liver that generally redevelops within three months in a donor. Living organ donors are healthy individuals who gift organs like a part of the liver, a part of the pancreas or one kidney to an ailing person for his treatment. Living organ donation is generally possible for organs like kidney or a part of the liver. In India Transplantation of Human Organs (Amendment) Act, 2011 (THO amendment Act,2011) paved the way for swap transplants among mismatched organ recipient and living donor pairs.

The precondition for a living donor is that he should donate organs out of affection and love, be above 18 years and should not be suffering from diseases like hepatitis, Human Immunodeficiency Virus, acute infection, uncontrolled high Blood Pressure, diabetes, cancer, psychiatric condition etc. As per the figures available with national organ transplant program (NOTP); Directorate General of Health Services (DGHS) for the year 2011, only 5,719 organ transplants were done both with living organ donors and BSD donors. The majority, i.e., 4795, were kidney transplants, 870 liver transplants and only 15 heart transplants (Dar and Kumar, 2015).

Types of Living Organ Donors: -

The living organ donors are either known or unknown donors. Known organ donors can either be 'Near relatives' or 'Other than near relatives. Unknown Organ Donors can be Non -altruistic, Quasi - altruistic donors or Purely Altruistic donors (Dar and Dar, 2015).

- **Known Organ Donors: -**

These living donors are known to the recipient. The THOT- Rules, 2014, permit organ donation and transplantation among near relatives like spouses, parents, grandchildren, grandparents and siblings only after approval by the "Competent Authority". They gift organs out of love without any coercion to save the life of their loved ones. However, the "Competent Authority" require several documents to authenticate such relationships like Ration card or Pan card or Aadhaar card or Birth certificates, Marriage certificates, Other relationship certificate from Tehsildar or, Sub-divisional Magistrate or Metropolitan Magistrate or Sarpanch, for proving identity and proof of residence, ensuring existence of relationship among Indians and foreign nationals etc. (THOT Rules 2014). The Director or Medical Superintendent or in-charge of a hospital is the "Competent Authority" that finds out whether the donor-recipient relationship is genuine and free of pressure or intimidation on the donor (Dar and Dar, 2015).

Organ donation by other than near relatives like cousins, aunts, uncles, friends etc. is also permitted but only after the approval by the "Authorization Committee" of either the organ transplant hospital or a "District Authorization Committee" or a "State Authorization Committee". A hospital accomplishing more than 25 transplant surgeries per annum can have a "Hospital Authorization Committee". In the year 2011, "other than near relatives" donated 1495 organs (Dar and Kumar, 2015).

The THOT Rules provides 11 forms for facilitating living organ donation and transplantation. The ''Authorization committees'' go through several documents for approving different types of living donations. The Committees meet at regular intervals to examine applications for organ transplantations with living donors and see to it that living donor is donating purely out of love for the recipient through personal interviews of the donor, recipient and their family members that are video-recorded. The Indian system is meticulous in approving such transplants because of the perceived threat of organ trading making committees feel suspicious even with genuine cases.

- **Unknown Organ Donors**: -

These donors are unknown having no previously existing love bond towards the recipient. Such donors could be of three types, like Purely Altruistic Organ Donors, Quasi - Altruistic Organ Donors and Non-altruistic organ donors, as explained below:

Purely Altruistic Organ Donors donate organs to strangers after coming across the appeals in print or electronic media. A few others gift organs to anyone on the waiting list and a few others are instrumental in initiating an organ donation domino chain (Dar and Dar, 2014). The Indian law does not permit altruistic or anonymous organ donors barring a few States, but some advanced nations like the USA and UK allow such charitable donation.

Quasi - Altruistic Organ Donor gifts an organ after getting a similar organ from a living donor or a deceased donor. In this case, the recipient is not only the organ recipient but an organ donor as well (Dar and Dar, 2015).

Non-Altruistic Organ Donors donate organ to strangers with an intention to help their own near and dear relative needing a transplant. In this category, the two-incompatible donor-recipient pairs enter into a contract of swapping donor organs. The previously unknown recipients and donors exchange donor organs only for receiving the best-matched organs in both cases (Dar,2015). Organs, if swapped between more than two donor-recipient incompatible pairs, are named as domino transplants.

Organ transplant activities in a State are governed by the 'Appropriate Authority" that issues licences for different organ transplants in health facilities. Established by the State Governments, it inspects the transplant health facility and grants them registration. It conducts regular inspection, carries out a fair investigation in case of any complaint, suspends or cancels registrations and renews the same after every five years. Transplantation of Human Organs Rules of 1995 contains only 13 forms (THO Rules, 1995) but THOT Rules-2014 includes 21 forms. There are four forms in THOT Rules -2014, two for applying for licences and third for issuing a certificate of registration and the fourth for the renewal of the same (THOT Rules, 2014).

Types of Deceased Organ Donors

Deceased donors are donors who donate organs or tissues or bodies after their death. Body and tissues are gifted after whole-body death when the heart stops beating. But organs can be given only after the declaration of Brain Stem Death in India when the heart continues to beat even after death declaration. The world over, the medical system is supposed to abide by the Dead Donor Rule for legal, medical and social acceptance of such donations. This rule makes it compulsory to declare death before donation (Sade, 2011). Such Death declaration ensures minimum damage to the organs for the benefit of the recipient as well as the transplant surgeons. Such deaths have been accorded medical and legal sanctions in many countries amidst unceasing debates concerning social and ethical aspects of these donations and transplants. There are mainly two types of deceased donors that are:

1. **Heart Beat Donors**
2. **Non-Heart Beat Donors**

The hearts of deceased donors are either beating or have stopped beating. The heart continues to beat in brain death/Brain Stem Dead donors only. In other words, there are two types of deceased donor transplants named Heart Beat Transplants (HBT)) and Non-Heart Beat Transplants (NHBT). The former means organ transplants with brain dead /Brain Stem Dead donor's organs. The latter means transplants with organs of those donors who might have suffered cardiac death / circulatory death. All these terms relating to deceased donation have different understandings, shades, and diagnostic procedures throughout the globe. These terms are perplexing to medical professionals also at times who interpret these terms differently. After the heart stops beating, none of the organs is mostly viable and medically acceptable for transplant. Organs donated by deceased donors or BSD donors is also called cadaver donation in India.

Regarding brain death or Brain Stem Death (BSD), it is a new medico-legal and neurological definition of death peppered with controversies all over the globe. It was in 1968, a new explanation of death called brain death was added to the medical system by Ad Hoc Committee of the Harvard Medical School in the United States. According to this Committee, brain death depicted that patient is in 'irreversible-coma'. Also, he is not receptive to any stimuli and has an absence of all cranial reflexes. In addition to it, there are no spontaneous respiratory efforts during three minutes once he is disconnected from the ventilator (1968). Its' main resolution, perhaps, was to propagate organ donation. Brain dead person is a dependent patient who is unconscious and breathing through a ventilator. One can feel his pulse, blood pressure and other signs of life. There is a loss of functioning of the brain and body is in the process of death and would soon stop working even if the ventilator is there. Ventilator prolongs the process of dying (Lori, 1999). And organ from such brain-dead donors can be retrieved before his heart comes to rest. However, this donation-transplant business continued to be dogged by some ethical and emotional issues. Organ donation by a Brain Stem Dead person was legalized in India (THOA-1994) in India based on the guiding principles of WHO framed in 1991. Brain Stem Dead donors are also called as cadaver donors or deceased donors in India (Dar and Kumar, 2015). A layperson can recount the concept of organ donation with the marriage of a daughter in Hindu religion by drawing comparisons between the two (Dar, 2017).

Again, there are broadly two ways of declaring brain death, i.e., brain death or Brain stem death. Brain death means the permanent absence of brain functions, i.e., total brain death as followed in the USA. Brain Stem Death, on the other hand, means the death of brain stem only as legalized in the UK and India. The investigations and processes for declaring either Brain Stem Death or brain death vary across the globe. In Brain Stem Death there is a possibility for patients to have some cortical electrical activity in brain that is not possible in case of whole-brain or brain death concept. In other words, Brain Stem Death is little problematic than the brain-death (Smith, 2012). Brain death declaration is helpful in organ donation and transplantation. Brain dead/BSD person seems alive because complex technological innovations sustain him. It helps him breathe, take fluids and other forms of nourishment besides excreting waste material from the body (Slomka, 1995). The concept of organ retrieval from a brain-dead person could be compared with evacuating possessions of a household that is on fire (Dar and Kumar, 2015).

In this thesis, organ donation and transplantation from Brain Stem Dead donors has been chosen to carry out a detailed study on its various issues. This study holds importance as none of the Central Government initiatives were taken from 1994 till 2009. All States and organ retrieval and transplant centers of the country were left on their own. They followed their system of diagnosis and declaration of Brain Stem Death; retrieval and distribution of organs from Brain Stem Dead donors as per their conveniences and preferences. In India, almost all States and Union territories have adopted this law. However, Jammu & Kashmir and Andhra Pradesh did not adopt THOA-1994 but have constituted their own laws on organ transplantation. Also, several networks like AORTA (Armed Forces Organ Retrieval and Transplant Authority); ZTCC (Zonal Transplant Coordination Committee); ORBO (Organ Retrieval Banking Organization); TNOS (Tamil Nadu Network of Organ Sharing) and FORTE (Foundation for Organ Transplants and Education) etc. had evolved. These networks were sharing organs of Brain Stem Dead donors for transplant within their network of hospitals. At times the recipients for various organs could not be found that led to wastage of organs. However, unlike in other countries, there was no national database for organ donation available in India.

CHAPTER 2

Review of Literature on Organ Donation and Transplantation

The review of literature is presented in the following sections. The first section gives an overview of organ donation and transplantation in various subheadings. It gives an introduction to global models, global situation and Indian scenario of organ donation and transplantation. It gives a brief history of organ donation from Brain Dead donors, describes global legal options for deceased donation, explains legal catalysts for opt-in legislation, highlights presumed consent or opt-out legislation and describes global current legislative demands for organ donation. It also highlights the issues and challenges to various types of organ donation and transplantation in India. The second part focuses mainly on the subject under study and gives an overview of organ donation from Brain Stem Dead (BSD) donors. It deals with professional perspectives, sociological perspectives, debates, dilemmas and ethical issues concerning BSD donors, society, professionals, donor families and recipients. The third section of the Chapter gives an overview of conceptual framework of the study revealing motivation of the study, rationale for the study, conceptualization of the problem, aim and purpose of the study, an overview of study design and outline of the Chapter organisation.

An Overview of Organ Donation and Transplantation: -

This part of the chapter gives us an overview of organ donation and transplantation from global and Indian perspectives. It reveals various legal, social, medical and ethical challenges and issues with such donation and transplantation.

Introduction to Global Models, Global Situation and Indian Scenario of Organ Donation and Transplantation: -

This part reveals various global models of organ donation and transplantation, transplantation situation as per the Global Observatory on Donation and Transplant

(GODT) maintained by World Health Organization and Indian situation of organ and tissue donation and transplantation including body donation.

Global Models of Organ Donation and Transplant

There are a few best models of organ donation and transplantation. While Iran gets regarded as the best model for living organ donation, Spain is the best for deceased organ donation. Spain enjoys the conversion rate of 80 to 85 % and WHO recommends its model for member countries too. The Iran model gets appreciated for its pro –donor (Larijani and Zahedi, 2007) pro-poor (Ghods, Ossareh and Khosravani, 2001), pro-patriotic and self- reliance in living organ donation (Ghods, Ossareh and Savaj 2000; Larijani and Zahedi, 2007).

The Spain Model operates with presumed consent and active detection of potential donors (Shroff, 2010). The transplant coordinators, the majority of whom are medical doctors, regularly visit emergency rooms and Intensive Care Units (ICU). They check the roster of patients and their status. Also, they follow up potential donors extensively and motivate their families to donate organs irrespective of presumed consent. Spain established a transplant co-ordination network in 1989 that supports Organ Transplant Coordinators in identifying potential organ donors (Dar, 2016).

Global Situation of Organ Donation and Transplantation

As per the data available with Global Observatory on Donation and Transplant (GODT) maintained by World Health Organization, there are only 77 countries that have deceased donation programme and 104 countries perform kidney transplantation. As per the statistics of 111 Member States on organ transplantation activities included in the GODT, there have been a total of 126,670 solid organ transplants in the year 2015, as shown in the table below:

Table 2.1: Global activity in organ transplantation during 2015

Type of organ transplant	**Total number of solid organ transplants done**	**Percentage**
Kidney	84347	66.59
Liver	27759	21.92
Heart	7023	5.54
Lung	5046	3.98
Pancreas	2299	1.82
Small Intestines	196	0.15
Total Organs Transplanted	126, 670	100%

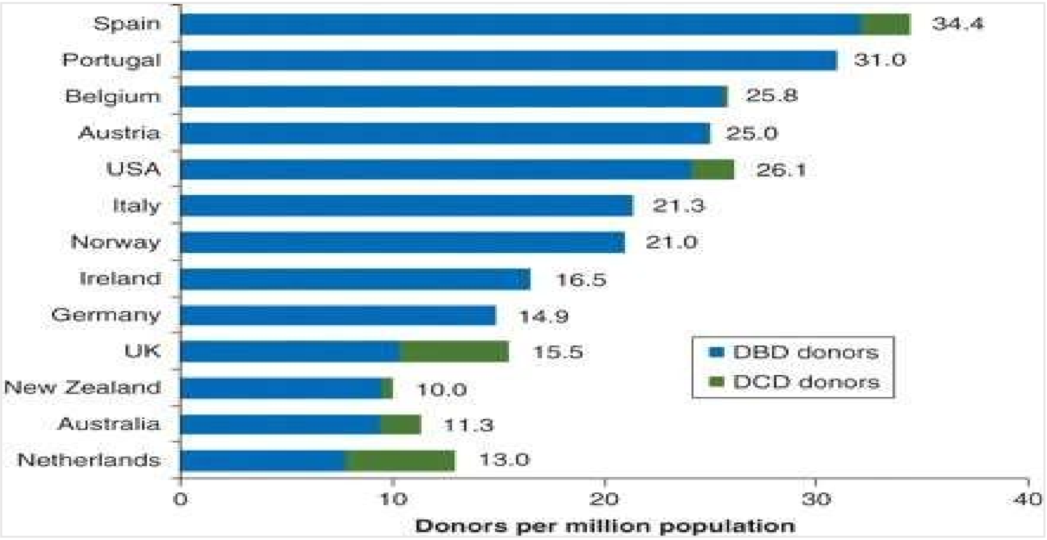
Source: - Adapted from Global Observatory on Donation and Transplantation (GODT), WHO (2015)

Table 2.1above reveals that kidney transplants done all over the world outnumber all other solid organ transplants. The majority of 66.59% organ transplants done in the world are Kidney transplants. Small intestine transplants are the least transplants done in the world, comprising only 0.15% of the total transplant operations as per Global Observatory of Donation and Transplant.

The deceased donor programme means Donation after Brain Death (DBD) and Donation after Cardiac Death (DCD). Donation after Brain Death (DBD) means a gift of organs from Brain Dead Donors/Brain Stem Dead donors depending on the legal framework of the various countries (Dar,2015). The rates of DBD and DCD are mentioned as donors per million populations.

The significant factor in deceased donation programme is many countries is the appointment of the hospital and national transplant coordinators like Spain (Matesanz and Miranda, 2002) and Croatia (Živčić-Ćosić et al. 2013). These coordinators are trained to counsel families to donate organs to needy people in need of organ transplants.

Figure 2.1 Display of international deceased donation rates per million population (pmp) including both Donation after Circulatory death (DCD) and Donation after Brain Death (DBD)



Source: - Murphy and Smith, (2012).

Figure 21 reveals the rates of DBD and DCD were different globally in 2009 and Spain is the best country in the world with 34.4 donors per million populations as per the courtesy of Transplant Procurement Management.

Introduction to Indian Scenario on Organ Donation from Brain Stem Dead Persons

The demand exceeds the supply of organs in India as is the case with all other countries too. India needs approximately two lakh organs every year. With an annual requirement of about 20000 livers and 150000 kidneys, only 500 livers and 3500 kidneys get transplanted (Shroff, 2009). However, organs are primarily donated by living donor (near and other than close relatives) only and very less from Brain Stem Dead donors. The first heart transplant surgery took place in the All India Institute of Medical Sciences, New Delhi in 1994 and the THOA is in place since February 4, 1995. This law legalized organ donation and transplantation of human organs from BSD donors for the treatment purposes only. This law was introduced into medical system with an intention to discourage commercial dealings of all kinds in human organs. But the law failed to popularize organ donation from BSD donors, and the primary source of organs are living donors.

As per a key person associated with National Organ Transplant Programme, almost all States and UTs have enacted this legislation. But two States like Jammu and Kashmir and Andhra Pradesh have their own laws in place. However, India does not have a national database for organ donation like USA or UK. United Network of Organ Sharing (UNOS,2010) and National Health Services Blood and Transplant (NHSBT,2010) are databases for the USA and UK, respectively.

In India, several networks are maintaining some database. These networks are also sharing the organs of Brain Stem Dead donors for transplant within the system of registered hospitals in their States or neighboring States depending on the topographical proximity (Dar, 2014). The laws neither deterred people from indulging in organ trade nor did it increase organ donation from Brain Stem Dead persons. Hence Transplantation of Human Organ amended Act (THO amended ACT,2011) was passed in 2011 with few amendments. The Transplantation of Human Organs and Tissues Rules 2014 (THOT Rules,2014) followed this amended Act.

Almost after a pause of 15 years, post THOA-1994, the National Organ Transplant Programme started in 2009. It was allocated a budget of Rs. 149.5 Crore during 12th Five-year Plan to promote BSD organ donation (Dar and Kumar,2015). However, this extensive lull by central Government, left States and private organizations on their own to develop their unguided mechanism of organ donation and transplantation. Later as per THO amendment Act 2011, it was mandated to establish National Human Organs and Tissues Removal and Storage Network and establish National Registry for Transplant. National Organ and Tissue Transplant Organization (NOTTO) started in 2014. It has initiated a process of picking up the pieces together in a bid to amalgamate the efforts of all stakeholders.

History of Organ Donation from Brain Dead Donors

Organs were retrieved from completely dead persons after their heart had stopped beating, but unfortunately, such donated organs failed to function in recipient bodies because in the process of death with no blood circulating in the body, these organs would deteriorate, which eventually led to their rejection in the body of recipients (Valko, 2002). This led to a significant setback for transplant surgeons. They felt that there is a need to declare the death a few steps ahead of the whole-body death to prevent such deterioration of the organs. Death, for them, is a process and not a solitary event. The focused move probably was not only to retrieve organs for the benefit of living persons but also to make it acceptable to people and professionals. The professionals in medicine faced another dilemma of prolonging the lives of patients by putting them on the life support of ventilators who were almost dead and had no chance of survival. They knew that they were delaying their process of death by a few hours to a few days. For them, it was a sheer wastage of medical technology and effort.

In 1959, two French physicians seeing patients hooked to ventilators, in a deep coma and dead for all practical purposes in Intensive Care Units of hospitals created a new term in the form of coma depasse (a state beyond coma). This idea gave a novel aspect to the field of transplant. In 1968, the Ad Hoc Committee in the Harvard Medical School at United Kingdom evolved a new definition of death in the form of brain death. Brain death means a patient is in ‘irreversible-coma' with an absence of all cranial reflexes and no spontaneous respiratory efforts during 3 minutes of disconnection from the ventilator (Adhoc Committee,1968).

The report of this ad hoc committee published in August without revealing the name of the author in 1968 in the Journal of American Medical Association is considered a groundbreaking article in the context of transplants. This Ad Hoc committee smoothed the way for organ transplants from the brain-dead donors. In fact, a brain-dead person is perceived as a cache of organs as well as tissues that could save seven to nine people and improve the lives of many others. However, political will, expertise, infrastructure available in various countries enabled majority of countries to move ahead in organ donation and transplantation through legislative system. With passage of time the legal mechanisms in various countries moved in the direction of legalizing organ donation from brain dead persons. Professionals envisaged that giving legal sanction for organ donation and transplant will put an end to the unethical practice of organ trading etc. However, this donation-transplant business continued to have some mindboggling emotional and ethical issues. For many of us, organ retrieval from brain dead cadavers means two times death for a donor (Lock, 2000), while others believe it as the kindest act (Green, 2007).

This new definition smoothed the way for organ donation but failed to get the required number of organs. As a result of this, many countries reintroduced abandoned cardiac death, also called Non-Heart Beat Transplants. Donation after Cardiac Death (DCD) is another form of deceased donation peppered with several ethical debates across the globe. In DCD, the patient who does not fit the brain death or Brain Stem Death criteria is shifted to the operation theatre after the permission of relatives. He is disconnected from the support of ventilator, and If his heart stops beating for 2-5 minutes within one hour, doctors declare him dead and retrieve organs immediately. If his heart does not stop beating within one hour, he is sent back to ICU. There, he is allowed to die naturally without reverting him on any life support system (Sade, 2011). In India, there are no clear-cut legal guidelines for withdrawing or withholding life support (Balakrishnan and Mani, 2005). Hence DCD of this kind is not done in India as on date. It is interesting to know that donation after cardiac death is divided into five categories as per Maastricht classification, and India like majority of other countries lacks uniform guidelines regarding the same. India requires national uniform guidelines through debates and discussions at the national level to address the ethical, legal and medical issues involved therein and arrive at a clear policy (Bardale, 2010). Introduction of cyclosporine, in 1980 was a significant achievement in organ donation and transplant and a significant milestone too. This immunosuppressant drug prevented the rejection of transplanted organs and helped in increasing survival rates of heart and liver transplants. It, in turn, also generated demand for an increasing number of organ transplants (Greenberg, 2001).

Global Legal Options for Deceased Organ Donation

Globally different legal mechanisms have been geared to increase deceased organ donation rates in their respective countries depending upon their infrastructure and expertise in the field. Since the donation of organs is much less than the demand globally, it has become a more challenging and ever-demanding field for lawmakers also. While the focus of these laws is intended to facilitate more organ donation, these also tend to put pressures on people and professionals looped in organ donation (Dar, 2015). The rules promise a second lease of life to the potential recipients and fame, money and skill enhancement to professionals working in transplantation business. Innovations in scientific technology, improved surgical skills and introduction of effective immunosuppressant regimens have changed the scenario of organ donation and transplantation. It has been backed by social research also. The laws are routinely changed and amended to narrow the gap between the demand and the supply of organs globally.

Organ donation from deceased donors invokes additional attention because living organ donation does not offer a variety of organs. Also, living organ donation has a health threat to donors. On the other hand, the deceased donation from a single BSD donor can give life to 7-8 persons besides rewarding the transplantation professionals with social recognition and other benefits as mentioned above (Dar,2014). The donation of two lungs, single heart, whole liver, two kidneys, entire pancreas and intestines is possible only from a Brain Stem Dead donor in India. In other words, a deceased donor not only yields a more significant number of organs but a variety of organs too for a variety of transplant professionals. Organ donation, usually described as a gift of life from donor to recipient, is, in fact, a medical industry of multimillion-dollars (Sharp, 2000). Legislative mechanisms for organ donation and transplantation from deceased donors varies across the globe and get continuously modified with the sole intention of increasing organ donation rates from deceased donors. The two main legislation, i.e. opting -in or opting –out are operational all over the globe.

Opt-In Legislation and Opt-Out Legislation

In opt -in system of law, the person opts- in to be the organ donor during life by pledging to donate organs in national organ donor registers as is done in the UK, USA and India (Dar and Dar, 2014). Opt-in system is a family friendly and modest way of asking people to donate organs. People pledge to donate organs/tissues in organ donor registers like the UK (NHSBT, 2014) has 20 million, and USA has 100 million people (UNOS, 2011) as registered organ donors. Most of the nations started with the policy of voluntary "opting-in" for organ donation from deceased donors. But with escalating dissatisfaction over the insignificant number of organs attained in this way, several countries introduced "presumed consent".

In “Opt-out or presumed consent”, a potential donor is considered an organ donor and family consent is not required to retrieve organs if he has not legally documented his objection against organ donation. Columbia, France, Singapore, Belgium, Italy, Sweden, Norway and Spain are a few countries that adopted presumed consent. (Sheldon, Rachel and Stacey, 2005). This legislation is a misnomer and assumes that everybody has pledged to donate organs if legally registered will against organ donation is absent. This coercive option promises relief from obligations for professionals as well as the organ retrieval hospitals but removes sacredness of donating organs as ‘gifts of life’. It amounts to legalized robbery of biological assets as well.

Opt-in Legislation in India

A national level organization National Organ and Tissue Transplantation Organization (NOTTO) is registering donors in the national organ and tissue donor register. This organization is in the process of including the efforts of other networks also. Opt-in legislation requires an individual to fill a pledge form (Form 7 of THOT Rules) and give consent for organ and tissue donation. An individual can mention his choices for the donation of specific organs or tissues or both after death or Brain Stem Death. The individual submits the filled form to NOTTO, either online or offline (THOT Rules, 2014).

An introduction to National Organ and Tissue Donor Registry

National Organ and Tissue Donor Registry is an online register created to lessen the refusal rates. The register usually permits access to all the registered retrieval hospital. They, in turn, access the 'Will of the Donor' at the time of his BSD declaration/death, thereby facilitating organ and tissue donation as per laws and rules of a country.

Globally people pledge to donate body or its parts in their country-specific organ/body /tissue donor registers. According to the World Health Organization (WHO), globally, Road Traffic Accidents is the second main reason for deaths In India alone, about 1,30,000 road accidents happen annually in India (Krishnan, 2010) and the majority of such victims could be the potential organ donors as a result of severe head injuries.

India follows an opt-in mechanism of organ donation like the USA and provides two tools of opting in either through the opt-in register or making a will in driving license to be an organ donor.

Form 7 in THOT Rules 2014 is used for making a 'Will 'to donate organs and tissues. People can opt-in with different organ sharing networks and hospitals of the country that eventually must form a part of the National Organ and Tissue Donor Registry. Such pledges do not have legal standing. But it shows a path to the family when they come across a situation that requires their consent for organ and tissue donation of their relatives at the time of Brain Stem Death/death. In several studies, most of the donor families felt ethically obliged to fulfil the organ donation 'Will' of the deceased donor at death. On the other hand, majority of those families who declined their consent to donate organs were ignorant of the desire of the dead person (Tymstra et al. 1992; Martinez et al. 2008; Pearson et al. 1995).

People can Opt-in through driving licenses also in some cities like Bangalore, Mumbai and Pune register (Dash, 2013). This practice is followed in various developed nations as well, including the USA. But the family has a choice to refuse the "Organ Donation Will" of the person in India.

Challenges to National Organ and Tissue Donor Register in India

One of the challenges is the integration of data of various stakeholders with the National Organ and Tissue Donor Registry. People pledge to donate their organs with multiple organizations and hospitals. During 2013 more than 60000 people submitted their pledge forms with Times of India during their Indian organ donation awareness campaigns (August ToI, 2013) and is continuing every year. There is a great need to integrate data of all State and Union Territories in one standard register at NOTTO (Dar and Dar, 2014). There is a need for robust Information Education and Communication strategy about the modalities of the register. Family permission is a must for the donation of organs of a BSD donor. Hence, it calls upon people to initiate a discourse on death, Brain Stem Death (BSD), organ and tissue donation with family members. But IEC campaigns revealed family hesitation and superstitions associated with discussing death (Dar, 2015). UK and USA promote the Organ Donor Register with strong IEC movements by including celebrities in such efforts (NHSBT, 2012). These movements motivate people to contemplate, reason and talk about organ donation.

People hesitate to donate organs of their BSD donors. But do not mind getting organs from such donors if needed for transplants. Some countries appreciate organ donation will of the persons like Israel assigns an organ to the near relative of an organ donor (Jacob et al. 2010). Same is true with Japan (Aita, 2011). NOTTO has to decide whether such reciprocity could be encouraged in India as well.

There is a great need to build in the faith of the people and maintain it. BSD is not understood by people at ease. It is essential not to trap people in the donation of organs without making them understand this form of death. Let there be an informed choice. Let professionals speak honestly divulging whole truth about this definition of death and organ donation processes (Manning, 2013) before forcing them to pledge organs.

Legal Catalysts for Opt-in Legislation –

The opt-in law is not of much help when it comes to making organs available for recipients. The entire system works towards building legislative pressures either on the donor, donor families or professionals to facilitate deceased donation. On the one hand, several catalytic legal options hold great promises to recipients and transplantation community. But, on the other hand, same catalytic variants exert tremendous pressures on people and professionals without whom donation cannot occur. Some of the catalytic options are: -

1. Mandatory choice in driving licenses
2. Mandatory transplant coordinator
3. Mandatory declaration of brain death
4. Mandatory request for organ donation

Mandated choice in driving licenses

In some countries, it is mandatory to give an option either to be an organ donor or not, in pan cards, driving licenses or identity cards as per the policy of a country. Individuals can also choose to be indecisive. However, people in Virginia and Texas did not take this mandated choice favorably (Laurance, 2009). India also proposes to use this mandated choice strategy while issuing driving licenses (Dar and Dar, 2015). The aim is to focus on the target population of drivers who might become the victims of Road Traffic Accidents and potential organ donors.

Mandatory Organ Transplant Coordinators

In the US, the centers for Medicaid and Medicare Services made it mandatory to employ well-trained " Organ Transplant Coordinators/ Requestors " who could appeal the donor families for organ donation (UNOS,2008). India has also made it mandatory for registered transplant hospitals to recruit an Organ Transplant Coordinator for motivating families to donate organs as per THO amendment Act of 2011.

Mandatory Brain Death Declaration

A few states like Tamil Nadu and Kerala have made it mandatory to certify patients in ICU's as Brain Stem Dead (Umesh, 2012). The declaration of Brain Stem Death benefits private hospitals only and India needs to be cautious with this option given to understand that 44% of surgeries are done unnecessarily in India (Iyer, 2015). Doctors prescribe needless investigations and procedures and take kickbacks for referrals (Nundy, 2014). About 78 per cent of doctors admitted indulging in unethical practices under pressures from hospital management for generating profits (Nagarajan, 2015).

Mandatory Request for Organ Donation

With this option in place, it is mandatory to request the families of potential donors for organ donation. Like the US, India too introduced this option in 2014 (THOT Rules, 2014). People usually don't accept Brain Stem Death as death and professional are also hesitant to ask relatives to donate organs. A study on 78 bereaved people whose relatives had died following accidents in ICUs revealed that 72.9% would not have minded if asked for organ donation (Wellesley, Glucksman and Crouch, 1997).

Presumed Consent or Opt-Out Legislation is in Demand in India: Points to Ponder over

India is subtly pressurized to shift to opt-out option or presumed consent. Several countries claim to have amplified organ donor rates with this option. But presumed consent alone cannot do wonders with organ donation rates. Other factors like infrastructure availability for retrieval of organs, transplantation services, trained workforce, health care investments, public and professional attitude to organ donation are equally important (Amber et al. 2009).

Concept of Presumed Consent System, Ethical Challenges and the Anticipated Outcomes

Presumed consent presumes that everybody has pledged to donate organs if he has not registered his will against it. Aghast with low acceptance of brain death and increased refusal rates by families. this option serves the purpose of increasing organ transplant rates in a country (Dar, 2016). Presumed consent promises an authority and proprietorship of organs and tissues of brain-dead donors. India wanted to introduce presumed consent way back in 2008 after our Health Minister visited a few countries, including Spain. He got motivated and thought of replacing the opt-in system with presumed consent system in India. He conceptualized to introduce it through Organ Retrieval Banking Organizations (ORBOs) first for eye donation and later for organs (Datt, 2008). But it did not materialize in due course of time.

We need to be cautious with this option as organ donation cannot be viewed in isolation. It is linked with the new definition of death neither explained to people nor understood by them. We cannot presume that everyone has understood this death, i.e., BSD and have no objection to organ donation. Not only are there many types of tissues and organs in the body, but there are several types of deaths as well (Dar, 2015). It is not ethical to introduce this option in India as 33% of the people are living below poverty; there are gross social and economic stratification and uneven distribution of resources (Dar,2016). This option, if introduced, would favor transplant tourism, help the rich and exploit the poor only as transplant surgeries are not within the reach of ordinary people in India.

The media and professionals both take us to fool's paradise by boasting of saving lacks of people through organ donation. The same is contrary to the exiting truth with transplant data accumulated worldwide. Only 117,700 organ transplant surgeries took place in 2016 (GODT, 2016). In other words, even if we pool all the global resources together and place them in India, we may not be in a position to save lakhs of people. With this option in place, only a few shall benefit of these surgeries.

We cannot compete with Spain as it is a developed small country with 46,507,760 inhabitants (Cifras de Población a 1 de enero de, 2014). Besides, it has 77% Catholic Christians (Religion in Spain,2014) who support organ donation (Miranda et al. 1999). On the other hand, India is a developing country with 210,854,977 inhabitants, has multiple cultures with 79.80% Hindus (Our Census Our Future, 2011) with diverse views on organ donation (Shroff et al. 2003).

The transplant legislative mechanism operationalized in 1979 for Spain and in1994 for India. Spain initiated the organ transplant program way back in 1989 and India started late in 2009 only. NOTTO established only in 2014. Also, annual financial investment on organ donation programme is much more in Spain in comparison to India (Dar, 2016; NOTP Cell, 2015; Miranda et al. 1999).

Spanish public health services win laurels across the world (Health care system in Spain expatica, 2015) whereas it is abysmally weak and unreliable in India (Jesani and Nandraj,1994; Chandra et al. 2012). Besides the availability of an adequate number of Spanish ICU beds (Forsythe, 2013) in comparison to an abysmally low number in India (Yeolekar and Mehta, 2008; Jayaram and Ramakrishnan, 2008) paves the way for increased organ donation rates in Spain not possible in India. Adequate infrastructure and rigorous identification of potential organ donors in ICUs are believed to be responsible for increased organ donation rates from 14.3 pmp to 35.1 pmp from 1989-1998 in Spain and not the presumed consent (Simini, 2000). Building such infrastructure shall take time in India (Dar, 2016). In India, some patients die waiting for their turn for transplant surgeries. These patients suffer even when they have willing living organ donors revealing a shortage of human resources and infrastructure for such transplant surgeries (Financial Express, 2015).

Studies reveal organ donation rates decreased in Chile (IRODaT- 2014), failed to make its impact in developing countries (Tumin, Tafran and Mutalib, 2015), failed to increase in Sweden and a few countries like Brazil and France witnessed a hostile atmosphere after presumed consent system (Bramhall,2011). On the other hand, the USA relishes a high donation rate with the opt-in system only (Sheldon, Rachel and Stacey, 2005).

If India introduces this option, there are chances of creating a hostile environment the way it happened with "forced sterilization" for family planning program during 1976-77 (Park, 2009). India needs to focus on other crucial subjects accountable for increasing organ donation rates and not on presumed consent (Amber et al .2009).

Global Current Legislative Demands for Organ Donation

Worldwide, the supply of organs has failed to meet the demand, and the increasing demand for various kinds of organ transplants is not possible by living organ donors alone. This gap in demand and supply has resulted in increasing pressures on donation of organs from deceased donors by roping in legislative mechanisms and establishing new policies and laws.

The latest in the pipeline is an abandonment of Dead Donor Rule (DDR) that is discussed globally in the current scenario (Robert, Franklin and Scott, 2013; Nair-Collins, Sydney and Angelina, 2014). They suggest abandonment of DDR and creation of a different kind of "Individual Will" that could help in the retrieval of organs even before the declaration of death. Such a decree could prohibit life-sustaining therapy, focus on the donation of organs and not on the announcement of death. They propagate that DDR is not in the interest of the donor who has to be declared dead before the donation of organs. It does not matter to a donor if he is declared dead before or after the donation of organs (Thomas and Matt, 2011). The pieces of evidence reveal support to organ transplant recipients and not to organ donors.

Some specified tests called “Apnoea Test” as per THOA-1994 are mandatory for declaration of BSD in India twice at a gap of 6 hours minimum. Professionals expect India to follow the procedure of the UK, where the difference between the two diagnostic procedures is flexible (Seth et al. 2009).

Issues and Challenges to Organ Donation in India

There are some common issues and problems to organ donation and transplantation in case of both living and BSD organ donation, while a few are unique to both in isolation.

Issues and Challenges Common to Living and Brain Stem Dead Donors in India

Some issues and challenges common to both living and Brain Stem Dead donors are:

- **Meeting the ever-increasing demand for organ transplantation**

India is a diabetic capital of the world, with 41 million people suffering from diabetes (Joshi and Parikh,2007). Also, most of the rural adults and urban adults are hypertensive (Raghupathy et al. 2014). These two killer diseases are enough to increase organ failure rates in India. There is a need to give equal attention to both living and BSD organ donation. It requires importance like other countries where deceased donor rates, as well as living donor rates, are high (IRODaT ,2014). The demand for organs is more in comparison to its supply in India (Dar and Kumar, 2015).

- **Nationwide adoption of THOA- 2011 and THOT-Rules 2014**

Health is a State subject. THO amended Act -2011 and THOT Rules -2014 has to be adopted by all States to ease the processes of living organ donation and permit swap transplants nationwide among living donor-recipient incompatible pairs. It was an arduous task for NOTP to persuade States to do so. However, recently in 2019, a key person in NOTP revealed that 26 States have adopted this Act and Rules as well.

- **Infrastructural and workforce issues in Government sector**

There are approximately 301 organ transplant hospitals in India and majority of these hospitals are private (**Umesh, 2017**). Infrastructure and workforce in Govt. hospitals are inadequate and private hospitals perform 90% of transplant surgeries. People die waiting for organ transplant surgeries in hospitals even when they have a living donor to donate organ (**Financial Express-2015).**

- **Unregulated exuberant costs of transplant surgeries**

The unregulated high-priced transplant surgeries are beyond the reach of ordinary people in India. The costs of these surgeries for a CGHS employee **(Government of India, 2013)** and others varies tremendously **(ORGAN India, 2014).** There is a great necessity to address this issue and control the cost of these surgeries. Ministry of Health and Family Welfare must regulate the prices of these surgeries in private hospitals for ordinary uninsured people as well.

- **Post-transplant costs and follow-up care**

It is only the rich who can afford post-transplant costs of surgeries. A recipient requires lifelong immunosuppressants without a single day pause for preventing rejection of the transplanted organ, that is not within reach of an ordinary person **(Dar and Dar,2015).** The cost of immunosuppressant and follow-up care is a costly affair for an ordinary person. However, National Organ Transplant Program (NOTP) is working out the modalities for incurring the cost for immunosuppressants for poor patients (**Dar and Kumar**, **2015**).

- **Prevention of donor and recipients' manipulations by private hospitals**

The doctors prefer to give selective information about the costs and risks associated with such surgeries for financial gains. In some cases, both the donors and recipients receive incomplete information that needs to be taken care of by the Government **(Srinivas, 2005).**

- **Altruistic organ donation from living and BSD donors**

Legally people donate organs altruistically without any commercial angle or exchange of money or coercion or anticipating anything in return for the organ. Altruistic gift of an organ to someone in need provides a sense of gratification to the donor (Meran, 2002). Incidentally, the concept of altruism meant different things to professional in a study on transplant physicians (Fortin et al.2010). Reg Green's two books divulging the importance of donating organs altruistically (Green, 1999; Green, 2007) have done marvels on this subject.

India has been very vigilant about introducing living altruistic organ donors at the national level. Among living donors, there are two types of philanthropic organ donors like Living Directed Altruistic Organ Donor and Living Non-Directed Altruistic Organ Donor. Similarly, among deceased donors, the two types of donors are Deceased Directed Altruistic Organ Donor and Deceased Non- Directed Altruistic Organ Donor (Dar and Dar,2014). The studies reveal that people donate organs during life because of spiritual belief and not out of coercion (Henderson et al. 2003).

Altruistic donors consider such donations nothing more than blood donations as revealed in a study (Briggs, 2013). A Living Directed Altruistic Organ Donor gives his organ directly to the stranger. But Living Non-Directed Altruistic Organ Donor enters into a domino chain and makes several transplants possible among incompatible donor-recipient pairs (Rees et al. 2009). Such altruistic donors are allowed in the UK (NHSBT, 2014) and also in the USA (Veale, 2013).

Regarding deceased organ donation, the relatives of BSD donor donate organs without knowing the recipients to help them live longer. It also gives meaning to the lives of donor families (Green, 1999). Israel and Japan have modified their laws.

Both these countries reciprocate to donor families by giving priority to first-degree relatives in organ allocation. (Jacob et al. 2010; Aita-2011). Regarding Deceased Non- Directed Altruistic Organ, USA allows organ allocation of one organ only to a person as wished by the donor family. But all other donor organs go to others in the waiting list (OPTN, 2009). Some people prefer to give donor organs to the people of their choice; sometimes, that is acknowledged and permitted too (Mishra, 2013; Wilkinson, 2003).

Issues and Challenges Specific to Living Organ Donation

Living organ donation and transplantation faces unique issues and challenges as discussed below: -

- **Unavailability of Wide-Ranging Living Organ Donation and Transplantation Data**

Living organ donors are unable to evaluate the risks of organ donation primarily due to unavailability of complete data on living organ donation and transplantation (Kumar and Mattoo, 2015). The absence of a nationwide donor follow-up registry is a barrier to understand the nuances of living organ donation and people donate organs without knowing the repercussions of the same to their future lives.

- **Gender Issues**

Worldwide females shoulder the burden of donating organs during life. The annual data presented over decades by OPTN in 2010 (UNOS,2010) and National Health Services Blood and Transplant of the United Kingdom (NHSBT,2010) revealed an interesting trend of female living donors outnumbering males every year. About 80% of living organ donors in India are females (Shakeel, 2009). Data revelation by NOTTO also reveals that the majority of organ recipients were males (NOTTO,2015). There are soft pressures on female donors to donate organ usually for male members. Females are supposed to satisfy the belongingness needs of its family members (Kremer and Claudia, 2013) and giving an organ is one of the ways to do so. Media glamorizes female living organ donors, thus motivating more to do so

(ToI, 2012; Trivedi, 2015; dnaindia, 2007;). But when it comes to BSD donors worldwide, the number of male donors outnumber females as a single BSD donor can contribute many organs (Ikels, 1997).

- **Issues with "Authorization Committees"**

A few issues with "Authorization Committees" are delays in scrutinizing applications, overcautious health system resulting from an abuse of organ donation laws by people and professionals alike. According to a report by NITI Aayog, India relishes 18 % of the global tourist market and medical tourism is the primary source of revenue. Tourists from Bangladesh, Afghanistan, Yemen, Maldives, Iraq, Uzbekistan and Sudan come for various medical problems that include organ transplant surgeries also (Bhargava,2018).

Unfortunately, the "Authorization committees" do not scrutinize the applications regularly causing anguish among Indians and foreign recipients and their caretakers. At times people from India prefer to go abroad like Egypt (ToI,2017) to overcome such hassles. These committees also act overcautiously (MOHFW, GoI, 2011) because of organ trade rackets (Shroff.2009), misuse of technology and use of fake documents etc. (Dar and Dar,2015). These committees face the dilemma of causing death if they follow stringent rules or irresponsible if they favor recipients (Andhale, 2015).

- **Issues with living donor's life**

Organ donation by living donors is not without threat to the donor. A few of the donors have lost their lives after the donation of organs; a few needed a transplant themselves within a few years after a gift of their organ (Deborah, 2015). Absence of insurance cover to living donors complicates their future life in some cases (Dar and Dar,2015). This issue needs redressal.

- **Challenge to run swap and domino chains**

Swapping donors have given new hope to incompatible donor-recipient pairs. There are various types of swap and domino transplants (Dar, 2015). Swapping donor organs to get the most compatible organ has solved the problem of most blood group mismatched and tissue type mismatched donor-recipient pairs. There is an urgent need to initiate swap registries and run domino chains at SOTTO, ROTTO and NOTTO as other countries do.

Issues and Challenges Specific to Brain Stem Dead Donation

Organ donation from Brain Stem Dead donors is peppered with numerous challenges that are discussed below; -

- **Brain Stem Death not acknowledged as death**

Brain Stem Death is not considered and accepted as real death by the relatives (Dar and Kumar, 2015). It is because most of the visual signs of life are intact when counsellors approach relatives of a BSD donor for organ donation. Relatives express anger, feel suspicious of motives of the counsellors and suspect organ trade rackets of the hospital. In most countries, Organ Transplant Coordinator (OTC) motivate families to donate organs. Similarly, in India, Transplantation of Human Organs (amended) Act, 2011(THO amended Act, 2011) has made it mandatory to have trained Organ Transplant Coordinator (OTC) in each transplant health facility.

- **Challenges of the National Organ Transplant Programme (NOTP) to Manage BSD Donation Nationwide**

There are various challenges to the National Organ Transplant Programme. These are establishing National Organ Donor Registry (Dar and Dar, 2014), developing Standard Operative Procedure for declaration of BSD, management of BSD donors, establishing organizations like SOTTOs and ROTTOs, uniting organization(Dar, 2014) through electronic linkages, evolving transparent organ allocation and sharing mechanism, coordinating team efforts for packing, transportation and transplantation of retrieved organs and initiating regular auditing system of recovered organs(Dar and Kumar, 2015). Organs require timely transplantation. Chennai and many other States have roped in the police force for doing this job effectively by creating need-based green corridors for transportation of organs within a State or national networking hospitals (Sampath, 2014).

- **Lack of awareness and incentives for BSD donor families**

There is a tremendous lack of awareness about Brain Stem Death among professionals as well as people (Dar and Adhish, 2014). There is a need to create awareness among both, giving accurate information without the intention of trapping people in organ donation (Dar, 2015). Donation of organs by the families of BSD donors has no incentives attached to such acts that are responsible for low acceptance rates. Donor families don't get anything out of such selfless acts. Even the identity of recipients is deliberately kept hidden from them. Reg Green met all recipients of his donor son and felt overwhelmed after meeting them (Green, 1999). Revealing recipient identities to donor families could convert their grief into joy.

An Overview of Organ Donation from Brain Stem Dead Donors

This part of the Chapter gives an overview of professional and sociological perspectives regarding BSD donation. It discusses debates, dilemmas and ethical issues that concern BSD donors, professionals, society, families of donors and recipients about organ donation from BSD donors.

Professional Perspectives on Brain Stem Dead Donors

Organ donation from Brain Stem Dead donors reveals not only confusions but a lack of acceptance too among professionals treating the patients. Most of the research articles reveal such dilemmas since its inception into the medical system.

Professionals lack understanding about this definition of death (Akgun et al. 2003). A few studies revealed an absence of consensus among professionals on this definition of death worldwide (Haupt and Rudolf, 1999; Evans and Potts, 2002). Besides this, there are variations in criteria for declaring a person brain dead ranging from Brain Stem Death to complete brain death (Long, Magi and Julia, 2008). Once a person is acknowledged a possible organ donor, it necessitates a change of commitments from the individual to the package of life-saving organs. Treating doctor faces an ethical dilemma between safeguarding organs for recovery of viable organs or preserving the brain. This procedure (Martyn, Richard and Leo, 1988) requires the physician to begin transferring commitment from the patient under his care to the organ recipients under the supervision of others. There is professional variation in opinions also who either don't believe in this form of death or support such deaths for organ transplants mainly. Some even hesitate to ask relatives for organ donation from their BSD donor. To avoid such apprehensions most of the countries including India have introduced OTCs who are specially trained to ask families to donate organs (NHSBT, 2011; Dar, 2014). Several studies done abroad among Australian Intensive Care Nurses (White, 2007) professionals in major hospitals in Korea and other countries (Ran, Iliott and Hyde, 2004; Youngner et al. 1989) revealed an utter absence of agreement on this definition and acceptance of death.

Amidst this confusion over death and life sometimes a few movements of BSD donors complicate such situations further for the professional as well as the family members. Many studies reported that there are spontaneous reflex movements prompted by the mere touch of these donors (Dosemeci et al. 2004; Paul 2001; Spittler et al. 2000; Saposnik, Basile and Young, 2009). The most astonishing movements are the 'Lazarus sign' (Paul et al. 2005; Arkellinglis,2014)). The studies reveal two extremes of professional perception one believing in such movements arising from spinal reflexes and not from the brain and others considering these movements as signs of life (White, 2007).

Further a number of studies done abroad among nursing professionals (Akgun et al. 2003; Chung, 2008) revealed lack of trust on medical professionals that prevented many from pledging to donate organs. In India, very few studies have been done on organ donation from brain dead donors. The studies done earlier have focussed on understanding the perspectives of professional students on eye donation specifically. In a study conducted among medical students, 87.8% were willing to donate eyes (Dhaliwal,2002). Another study carried out on 188 nursing students revealed adequate awareness about eye donations and inclination of the majority of students to donate eyes after death (Gupta et al. 2009). Regarding a few studies done on organ donation and brain death, professional students revealed lack of knowledge about the concept of brain death and organ donation who otherwise were motivated individuals having a positive attitude towards organ donation (Mishra, Vij and Sharma, 2004; Bapat, Kedlaya, and Gokulnath, 2010).

Sociological Perspectives for Organ Donation from Brain Stem Dead Donors

The review of the literature revealed that some people are willing to donate organs. Some people willing to donate organs have neither signed donor cards nor expressed their wish to their relatives. A few have already given their relative's organs, and a few others have refused to do so. Also a few have received such donated organs. Perspectives of all these people vary.

Perspective of Donor Families

An analysis of the interviews done with seven organ donor families (Pelletier, 1993) revealed that the donor families went through three different coping phases while choosing to donate organs. i.e., the anticipation phase, the confrontation phase and post confrontation phase. During the anticipation phase, they anticipated a miracle to happen that could save their donor. During the confrontation phase, they confronted brain death, overcame their disbelief and shock by granting permission to donate organs. And later they grieved the loss of their loved one in the post-confrontation stage.

Various studies done on donor families revealed their perspectives. In one study of 6 donor families, a few families felt morally obliged to respect the expressed will of the person for organ donation. A few felt the donor would have wished it knowing that he was a very helping person, a few wanted to save lives and wanted him to live in others (Martinez et al, 2008). Family consent to donate organs was influenced in most studies by the “Organ Donation Will” of the deceased donor. An availability of organ donor card in possession of the donor at death paved the way for organ donation. The expressed will of the donor played a significant role and offered direction to the family while consenting to donate organs in several other studies also (Tymstra et al.1992; Haddow,2005; Simmons., Klein and Simmons. 1987; Pearson et al.1995; Jacoby, Breitkopf and Pease, 2005). In a study on 49 donor families, a few donor families wanted to add something constructive to death. A few felt that it would help recipients in leading better lives. A few knew that the donor had expressed the wish to donate organs during life and felt morally responsible for respecting the will. For a few others, it allowed the donor to continue living in someone else (Savaria, Rovelli and Schweixer, 1990)

Perspective of Families who Refuse Organ Donation of BSD Donors

Almost all countries are trying to reduce refusal rates. Countries globally have different conversion rates the best being Spain with 85% conversion rate. Organ donation linked with brain death is debated globally for its unacceptance as a form of death. When relatives see the evidence of life in the donor, they feel he is still alive, they harbour abundant doubts against the hospital and refuse organ removal (Paul, 2005). In a study (Jacoby, Breitkopf and Pease, 2005), the families who refused consent to donate organs expressed insufficient time to decide on the donation of organs while coping with the crisis of death. In another study, the main blockades of organ donation among a sample of 22 individuals of a local Sikh community in the United Kingdom were disfigurement and apprehensions related to methodological aspects of the transplantation procedure (Exley et al.1996). However, a study reported (Wellesley, Glucksman and Crouch, 1997) that the majority of relatives do not mind being asked for consent for organ retrieval from their dead donor relatives.

Perspective of Registered and Non -Registered Donors

People all over the globe have registered themselves for organ donation where the opt-in system is the governing law. Similarly, people who do not wish to donate organs, opt- out of such wish where presumed consent is the law. People carry donor cards. Three Focus Group Discussions (FGDs) on health professionals in South Carolina revealed distrust on the medical community, the main barrier to organ donation (Shilling et al. 2006). Similarly, in another survey of 1253 subjects, African Americans conveyed greater distrust and partiality of the system (Siminoff, Christopher and Said, 2006).

A survey of the 5008 people during 1995-96 revealed that the brain death concept was new to the majority of people and only 50% were willing to donate organs in comparison to 72% who were ready to give eyes (Shroff et al. 2003). A study conducted in Delhi hospitals unveiled a lack of awareness amongst the public; the primary reason for the poor performance of the Organ Transplant program (Mishra, Vij and Sharma, 2004).

Debates, Dilemmas and Issues about Organ Donation from Brain Stem Dead Donors

Organ donation continues to be peppered with contradictions, dilemmas and unanswered ethical questions for all the stakeholders. Brain death lacks understanding and acceptance by common people. While some people believe in this type of death (Dosemeci et al. 2004), others do not (Slomka, 1995). Some believe that “Apnoea Test” done for declaration of brain death is not required for the therapeutic purpose of the person but for pronouncing death for organ retrieval. The same is not in the interest of the person and maybe anti-therapeutic for the patient himself (Valko, 2005; Joffe, 2006).

Further, the family of the BSD donor do not benefit in any way after organ donation (Peters, 1991). They must donate altruistically to strangers. But altruism is not required in the private health system which charges exorbitantly from recipients. They even do not reveal the cost of such surgical operations (ORGAN India,2014).

Also, the individuals get partial instructions; are lured and trapped into pledging to donate organs. The individuals sign donor cards in good faith without knowing the nuances of such death like BSD. The families of such uninformed individuals, in a few cases, are trapped into the donation of organs by giving a plea that their donor had pledged to donate organs (Manning, 2013). Bollywood actors roped into the cause of organ donation also support organ donation without understanding it fully. However, they too recommend making the process transparent and known to the public and ensuring the dignity of the donor body (Gupta,2013).

The donor body makes some movements even after the person is declared brain dead (Saposnik, Basile and Young, 2009). These unexpected movements of a dead body create suspicion about the death of their family member who believe the person is alive. Also, there are some stories when the person whom doctors wanted to donate organs are living today after their families declined to donate organs (Hoffman, 2012).

There are professional pressures to shift to a presumed consent system for a free flow of organs (ORGAN India, 2014). However, the same may not be appealing to people who could be trapped by professionals in the donation of organs. The predominant exploitation of people in health care facilities and lack of trust in professionals (Berger, 2014) does not support such a draconian move. Government has to be alert to such exorbitant transplant surgeries that are primarily done in private hospitals and are not within reach of people at large.

Even when a family decides to donate organs of their BSD donor, they face post mortem issues. It is because the forensic doctors are generally busy professionals that delay the process of organ donation (Iyer, 2013).

Besides, the recipient information is kept confidential and not revealed to BSD donor families. Donor families want to know the recipients to see how their donor is living in others. Surprisingly these barriers are breaking down in the USA and donor families find their recipients in many events organized for donors and recipients (Transplant Games of USA, 2014). People believe in donating organs of their relatives to give life to others. Some put certain conditions before donating several organs. Most of the time, such requests like donating to their needy relatives, same religion person etc. are not paid any heed usually. That eventually does not go well with people (Dar and Dar, 2014). Unregulated market further (ORGAN India-2014) adds to the woes of donor families and the recipients equally.

Conditional donation is not permitted that does not go well with people (Dar and Dar, 2014). Lack of incentives for donor families post donation, lack of men and wherewithal, unaffordable costs for transplant surgeries are some critical deterrents to the gift of organs from BSD donors (Dar, 2014).

Ethical Issues Concerning Donors, Society, Professionals, Donor Families and Recipients

There are various ethical issues concerning BSD donors from the perspectives of donors, society, professionals, donor families and recipients that are as follows: -

Ethical Issues Concerning Donors

The process of organ donation-transplanting spins around a person who is at the compassion of others. His organs are considered as waste if not donated. Also, brain death is compared with a total death to make therapeutic use of his organs for the recipient bodies and earn money as well. It questions the ethics of organ donation after the declaration of BSD. Is the person declared BSD, dead or alive? Opponents believe that brain dead persons are not entirely deceased persons (Slomka,1995; Youngner et al. 1989; Haupt and Rudolf, 1999; Evans and Potts, 2002). However, others, who, possibly, are a majority, wholeheartedly accept that brain dead persons are entirely dead persons (Paul 2001; Dosemeci et al .2004).

Also, the present laws seem to be skewed against the donor and biased in favour of the recipient. Even the tests that enable doctors to declare someone brain dead hamper with the treatment to the potential donor. Most of the tests, especially the "Apnoea Test" (Valko-2002), does not help the donor in any way, but instead, it aggravates the patient's condition (Joffe, 2006).

The ethical issue here is that existing laws treat organs of the brain-dead person as a commodity for the use of recipients. Also, publicity materials available on the topic do not hesitate to treat organs as a commodity as these quote religious verses to support the donation.

Ethical Issues Concerning Society

Organ transplant, it seems, has given us the liberty to have an eye on organs of females, family members or strangers during life. We have also started viewing a brain-dead patient a treasure of organs for financial gains. The foundation of organ donation rests on altruism primarily that is not enough to eradicate waiting list of transplant recipients. Also, altruism is a must for BSD donor family only and has failed to percolate down to the entire system. Most of the hospitals in the garb of life-saving ventures are interested more in money-making ventures through organ donation and transplantation. They do not hesitate to charge recipients exorbitantly and trap donor families as well. There is no regulation on the costs of organ transplantation and as such transplants are not within reach of everyone requiring it.

In India, the Government is subtly pressurised to make changes in the existing laws and give sanction to the concept of presumed consent. This move would trap poor people and undermine the idea of donation as a gift. The legal option will, no doubt, benefit the rich in India and foreigners also. Also, presumed consent can make India a hub of transplant tourism. In Nov.2010, Director General of Health Services (DGHS) appraised the gathering on Indian organ donation day that hospitals in the country draw a substantial number of overseas patients for transplant. He said that medical tourism is growing every year, and by 2012, it is going to be a 2-billion-dollar industry in India. However, these surgeries are not within the financial reach of the majority of terminally-ill patients of India. A kidney transplant costs about Rs 3-4 lakh, (Singh, 2009) with a lifetime monthly post-operative care costing at least Rs10, 000. The presumed consent thus could give a boost to transplant tourism and eventually may lead to human exploitation. Studies have established a clear hierarchy between the donors and the recipients – the former are usually poor and impoverished, and the recipients are wealthy foreigners (Delmonico, 2009).

Ethical Issues Concerning Professionals

The medical professional, usually a Neurologist, experiences professional pressure from the transplant physicians for declaration of brain death for a potential donor under his care.

Further, worldwide, the diagnostic procedure of brain death varies among countries. It lacks consensus at the international level (Haupt and Rudolf 1999; Evans and Potts, 2002). The different standards for identification and declaration procedure of brain death make it confusing for everyone. Interestingly, some countries depend on Brain Stem Death (Long, Magi and Julia, 2008) criteria for death declaration while others on brain death. The variation in diagnostic procedures globally are the subject of intense global debate.

It raises a vital issue for professionals. The very first step of declaring a person brain dead necessitates a medical professional shift his devotions from the individual to the package of life-saving organs for at least seven persons (Martyn, Richard and Leo, 1988). All this creates an ethical dilemma among treating professional.

Ethical Issues Concerning Families of Donors

Even for the BSD donor families, it is not an easy mission to decide in favour of organ donation in the presence of the 'expressed will' of their donor. Was he aware of the concept of brain dead at the time of signing the donor card is an issue that may haunt the donor family? The donor or his family don't get adequate explanations on BSD concept, its linkage with organ donation and retrieval processes of organs etc. In most of the case, the donors get incomplete or choosy information that lures them into organ donation that could be confirmed from the online donor card forms.

The most sarcastic part of the story is that their consent is not required for conducting tests, especially the “Apnoea Test”. Interestingly this test is meant for declaration of death only and not for treatment purposes of the donor.

Another mockery of the situation is that under the existing law, the sale of donated organs by the donor families is illegal, but profitable activity at other levels is not. All those involved in the process like surgeons, coordinators, physicians, social workers, hospitals, etc. are benefitted. Regrettably, the BSD donor family does not accomplish anything (Peters, 1991). It surely is discriminating and indifferent and may breed public suspicion of the system.

Ethical Issues Concerning Recipients

There are many ethical debates as to who should be allocated the organs. Should organ allocation be based on maximum matching/ similar age group / similar sex? Should people of all age groups be given importance etc.?

Further, a recipient who gets the lifesaving organ has to take anti-rejection drugs for the rest of his or her life after transplant surgeries. He is also under the constant threat of body rejection of the transplanted organ. To sustain such organs immunosuppressants at the cost of 10000-12000 rupees per month (Singh, 2009) are to be taken by each recipient, which makes it outside the reach of poor people. Further, lifelong intake of immunosuppressants reduces the immunity of recipients to fight infections and increases their susceptibility towards multiple infections and cancers. As a result, the recipient may face many illnesses for one chronic condition.

Donor Recipient Identity and Formation of New Kinship Ties

Worldwide donor-recipient identity is kept confidential. Wherever donor families have come across the recipients, new relations emerged, and recipients celebrated their rebirths with them. Going through the literature, three types of recipient identities are possible. One is directly-revealed identity; the second is indirectly-revealed identity, and the third is a secret identity. Globally, the rules that forbid donor-recipient contact are getting flouted. Social media print and electronic media have come to the rescue of donor-recipient mingling. Recipients are finding their donor families quickly now and vice versa. In the US, the hosting of Transplant Games provides a favourable opportunity for searching, mingling and socialization of donors and recipients, thereby making new kinship relations possible (Transplant Games of USA,2014).

Anthropologists believe that human bodies have become commodities in fragments or as a whole. Such commodification involves massive monetary exchanges that are camouflaged as something in the attire of love, kindness, altruism, the gift of life etc. Anthropologist Scheper-Hughes maintains the "organ watch repository" on organ donors and recipients. It speaks volumes about the commodification of the body and its parts (Scheper-Hughes,2001). Cohan also highlights the commodification of body organs. Cohen believes that there is intentional manipulation of information, factual information is hidden, and kidney scandals are highlighted especially by the new authorities. Cohan warns of medical brokers influencing donation of organs and expresses deep concern with the degradation of publicity ethics (Cohen, 1999).

An Overview of conceptual framework of the study:

This part of the Chapter gives an overview of conceptual framework of the research study and apprises about various research questions and objectives of the study.

Motivation for the Study

The researcher's own work experience at Central Health Education Bureau (CHEB) motivated the research work. It is an apex organisation that is involved in Information Education Communication (IEC) activities of various national health programmes of the Government of India. It was way back in 2007, in CHEB, a meeting involving Organ Retrieval and Banking Organization (ORBO) officials and eminent transplant surgeons was called prior to initiation of NOTP and researcher was assigned the job of a member secretary. While interacting with the surgeons, the researcher came to know that a part of the liver can be donated by a living person for the first time. It was interesting to know that unlike one kidney donation by a living donor, only a part of the liver is donated by a living donor as an individual has only one liver and cannot survive without it. It was also interesting to know that the liver has the potential to regenerate in living donors within 3-4 months. With this new revelation, the researcher felt interested in the subject. Later, very often, the researcher came across the news of organ transplantation with organs of a brain-dead donor. Having worked in hospitals as a student, the researcher knew about brain death, and patients hooked to a ventilator but could not link such deaths with the donation of organs. A person on a ventilator was not a dead person to the researcher but a person in the process of dying having no hope to survive long. When are the organs retrieved from such persons who are on a ventilator was a question that haunted her? The researcher reviewed a lot of literature to find an answer to this question. One unanswered question led to so many other questions, and so on. While finding an answer to one question, the researcher came across many other related questions. This topic was not only unexplored but unfamiliar to people and medical professionals as well. The researcher developed a passion for this topic and decided to explore the issues related to BSD donation and transplantation.

Rationale for The Study

There is a need for organ donation, as many people are dying due to the failure of organs. A Brain Stem Dead donor gives life to many people through the gift of his two kidneys, liver and heart in India. Globally, in most of the countries, it is legal to donate organs like kidney and liver by living donors, but it is not without threat to the living donor (Dar, 2014; Dar, 2015). A new definition of death called brain death has been constituted to pave the way for the transplantation of several viable organs. However, in India, this death is linked with organ donation only at present. The ethical, medical, legal and social issues of such organ donation and transplantation are unexplored from the perspective of people and professionals in India.

The Government does not know much regarding the processes of organ donation from Brain Stem Dead donors. The national initiatives by Government of India started late in 2009 with the initiation of the National Organ Transplant Programme (NOTP) after a gap of about 15 years when Transplantation of Human Organs Act got legalized in 1994. This law permitted organ donation from Brain Stem Dead donors from 1994 onwards. Later every State followed own processes of organ donation and transplantation. Also, a national level organization called National Organ and Tissue Transplant Organization (NOTTO) started taking the nationwide reins of transplantation in 2014 in response to THO amended Act of 2011. NOTTO is constituted to lead the country but learns simultaneously. It needs to take stock of the situation given to understand that private hospitals do most of such transplants. Most of these hospitals are interested in commercial gains mainly, and organ transplantation involves huge investments by recipients. Understanding the perspectives of people and professionals may help in understanding the processes of organ donation from Brain Stem Dead donors and transplantation of these viable organs. In turn, this will help the researcher in giving feedback to the National Organ and Tissue Transplant Organization (NOTTO) to take suitable measures within their jurisdiction. The data collected in the study shall be helpful to NOTTO in taking corrective actions wherever required. The study shall help in understanding the perspective of people and professionals. It shall bring in coordination for developing an effective programme on National Organ Transplant. The study shall help in identifying gaps for corrective measures wherever required. The study shall try to bring in focus the issues about donor and recipients that need rectification by Government of India. The findings of the study can be helpful in future policy formation. The narratives of respondents could be used to develop useful IEC messages.

Conceptualization of the Problem

The review of literature throws light on the increasing need for organ donation and transplantation all over the globe. The study also throws light on various issues concerning organ donation from living as well as brain dead donors. Brain death, a new definition of death, is not understood by people as well as professionals. Organ transplantation professional bodies are optimistic about this new definition. They believe that it can reduce organ shortage and relieve poor people of exploitation. Legal sanction accorded to organ donation from Brain Stem Dead Donors raises questions because of its selective social and medical acceptance in India.

There are several intrinsically related ethical, medical, legal and social issues with Brain Stem Death declaration. None of these issues has been studied together in India.

Social issue in the context of brain death are psychological, religious and social domains of altruism; reincarnation and mutilation issue of donors; denial of donor-recipient identity or denial of new kinship relation between donor family and the recipients; financial, socio-cultural and patriarchal domain of gender issue; lack of social, economic or health-related incentives to donor families and belief in altruism without any encouragement. None of these issues has been investigated in Indian context from the perspective of people and professionals together. It could have thrown light on such vital matters influencing conversion and refusal rates of organ donation from Brain Stem Dead donors in India.

Legal Issues in the context of Brain Stem Death are acceptability of current legal options like opt-in system, an opt-out legal system of organ retrieval, incentives for all except donor families, the legal standing of donor cards and rights of foreigners on Brain Stem Dead donors' organs.

Medical issues in the context of brain death relate to the processes of BSD declaration, choice of recipients for BSD donor organs, rejection of donated organs by recipients, the overall health of recipients, medical costs and availability of immunosuppressants.

Some issues concern all. People and professionals equate organ donation from brain dead persons with the management of solid waste. Declaration of brain death is an issue debated worldwide. It shall be studied from the perspective of professionals and people as well. Criteria used for Brain Stem Death, professional pressures for BSD declaration, the involvement of relatives in declaring brain death shall be explored through interviews and observations. The issue of fragmentation from a unified individual to a bundle of organs shall be studied from the perspective of professionals and people as well.

Psychological religious and social domains of altruism need exploration. Further, there is no incentive given to the BSD donor families in India, no matter how poor they are. They may also have sold their property with the hope of saving their patient. The organs of BSD donors go to several patients of Indian as well as foreign origin. Perspectives of people and professionals on donor issues need to be studied.

The current study will look at the medical issues concerning BSD donors, knowledge and understanding of brain death by the donor card holders as well as non-donor card holders. It shall also look at the diagnosis of brain death and the involvement of relatives in the declaration of brain death. It is not a legal binding to allow a person to pledge organs only after giving full information regarding this new definition of death, and the processes involved in such donation. Many a time, a person signs the donor card misinterpreting brain death with total body death. At the same time, people do not sign donor cards mistaking brain death with the permanent vegetative state. The understanding of brain death from the donor card holders and non- donor card holders shall be studied. The current study will look at the opinion on involvement and non-involvement of relatives in diagnostic processes by the doctors, which is not binding on him. The issues like opt-in and opt -out system, the legal standing of organ donor card holders in addition to the social problems with regards to the extensive list of relatives; hierarchical and consensus issues of BSD donor families both from the perspectives of people and professionals shall be explored not done so far in India.

Gender issues shall also be the focus of this study. The study shall explore self-imposed or socially-imposed pressures built on females to donate organs for prolonging the lives of their relatives.

Rejection of donated organs is one of the significant issues of cadaver donation. The study shall explore the knowledge, understanding and apprehensions associated with such rejection. It shall also look at the physical, social, psychological, financial and spiritual domains of organ recipients. The transplant and post-transplant costs that sustain transplanted organs shall be explored from recipients' and professionals.

The current study will look at the issues concerning immune-suppressants from the records of the hospitalized patients and recipients coming for follow-up after organ transplant.

There is yet another issue concerning both donor and recipient that is donor-recipient identity. The study shall explore this issue from BSD donor families, recipients, people and professionals as well. This issue shall also be studied from families who refuse organ donation of their BSD donors. From the recipients' and donor families, it shall be explored whether they made any effort to know their BSD donor families and recipients, respectively. And if so what kind of relations have developed. This kind of data shall also be assessed from transplant coordinators too. The experiences and viewpoints of the transplant coordinator shall also be studied.

Matching of donor blood groups and HLA (Human Leukocyte Antigen) of the donor with that of the recipient a critical factor in organ transplant is another issue which this study will look at from the perspectives of all those, directly and indirectly, involved in it. Participant observation in this area shall widen the practical and medical feasibility aspects of this area.

Therefore, in this framework, this research work aims to explore the medical, legal, social and ethical issues of organ donation from Brain Stem Dead donors in India.

Aim and Purpose of the Study

The broad objective of the study was to explore the ethical, medical, legal and social issues of organ donation and transplantation from Brain Stem Dead donors through a case study of National Organ and Tissue Transplant Organization (NOTTO). Under this broad objective, the study aimed to explore these issues from the perspectives of individual BSD donor families, professionals involved in care of donors and recipients, organ recipients (kidney, liver and heart recipients only), relatives of recipients of organs, the society who either chose to fill form 7 of THOT Rules 2014 for donation of organs or refused to do so in well- organized awareness programmes conducted by a National Organ and Tissue Transplant Organization (NOTTO). To achieve the purpose of the study as mentioned above several research questions were developed that are as follows: -

Research Questions:

Several research questions are developed to achieve the purpose as mentioned above. These are as follows: -

1. What are the perspectives of families and professionals in the context of conversion and refusal rates of organ donation from Brain Stem Dead donors?
2. What are significant issues related to recipients of kidney, liver and heart in the context of organ donation from Brain Stem Dead donors?
3. What are the perspectives of people who intend to donate organs by filling form 7 of THOT Rules in mass awareness campaigns on organ donation from Brain Stem Dead donors?
4. What are the perspectives of people who do not intend to donate organs in mass awareness campaigns on organ donation from Brain Stem Dead donors?

Objectives of the study: -

- To understand the perspectives of families and professionals in context of conversion and refusal rates of BSD donation.
- To explore recipient centric issues of cadaver donation.
- To study the perspectives of people who intend to donate organs by filling form 7 of THOT Rules in mass awareness campaigns.
- To study the perspectives of people who do not intend to donate organs by not filling form 7 of THOT Rules in mass awareness campaigns.

Overview of Study Design

In this Study, mixed methods were employed to have an in-depth understanding of the problem under study. This method uses both quantitative and qualitative methods of data collection and analysis. The separate results of two data sets are amalgamated for the meaningful interpretation of data. Both quantitative and qualitative research method was intentionally used to elicit information from the respondents on different issues and get in-depth insights into various concerns of organ donation and transplantation mainly in the context of BSD. The data collection started from July 2015 to December 2018. The three main types of mixed methods used were observational methods, case-study method and survey method. A total of 144 sample size was chosen to get insights into various issues of organ donation and transplantation. This included 14 Donor Families who had donated organs of their Brain Stem Dead (BSD) donors, 40 Recipients of organs (kidney, liver and heart only) along with their relatives in a few cases, 20 Organ Transplant Coordinators (OTC),10 Key persons associated with NOTTO, 30 Organ donor card holders who had pledged to donate organs and 30 Non-organ donor card holders who had not pledged to donate organs in well-organised awareness programmes conducted by NOTTO. The quantitative data was processed using excel sheets and data was analysing through tables and graphs. The qualitative data was presented by drawing themes, sub-themes and using descriptive and interpretative analytical approach.

Outline of the Chapter Organisation

This thesis comprises of thirteen chapters, including this chapter.

Chapter two is a review of the literature on organ donation and transplantation. This Chapter presents the global and Indian scenario of organ donation and transplantation. It discusses issues, professional perspectives, people's perspectives, debates and dilemmas about organ donation from Brain Stem Dead donors. It gives an overview of conceptual framework of the study.

Chapter three presents the research methodology. This Chapter gives a brief description of the rationale for choosing mixed research design for the study, study setting, pilot study, study design, sample and sampling technique, development of tools, data collection procedure and permission sought for doing research, data validation and data triangulation, data management and analysis, ethics of research: informed consent & maintaining confidentiality and limitations of the study.

Chapter four presents the National Organ and Tissue Transplant Organization (NOTTO) and other institutions**.** This Chapter gives an overview of National Organ and Tissue Transplant Organization (NOTTO) concerning NOTP and reveals the Indian scenario before its establishment. This Chapter highlights the struggles of initial years of NOTTO to establish linkages and portrays the current status of NOTTO.

Chapter five describes the historical genesis of Organ Transplant Coordinators (OTCs) in India and reveals perspectives of OTCs towards the donation of organs from BSD donors. The Chapter explains various milestones in Training OTCs in India before the establishment of NOTTO. An in-depth case report of a BSD donation highlights the intricacies of organ donation from BSD donors. The findings of the study on 20 Organ Transplant Coordinators (OTCs) reveals the various medical, legal, ethical and social issues of organ donation from BSD donors.

Chapter six presents the perspectives of BSD donor families. The Chapter deals with pre-donation perspectives of 14 BSD donor families. It gives an account of understanding of BSD, reasons for donating organs and preconditions posed by them before giving consent. It explains social influences and impediments on their decision-making processes, and the role played by organ sharing networks. This Chapter also provides an account of their post donation expectations and management of problems encountered by them.

Chapter seven presents the perspective of 30 kidney recipients and explains various issues and challenges faced by them during multiple stages of the disease and treatment.

Chapter eight presents the intra and interfamily influences of kidney transplantation. This chapter reveals sufferings, support, compulsions, conflicts, apprehensions and anticipations of family members in the context of organ donation and transplantation.

Chapter nine presents the perspectives of liver and heart recipients. This Chapter deals with the issues of seven (7) liver and three (3) heart recipients and discusses the cause of liver and heart disease and treatment-seeking behavior of recipients. This Chapter brings into focus the problems associated with BSD donor availability, family support and sufferings, financial investments, post-transplant care including adjustments with drugs, post-transplant problems and hospital episodes.

Chapter ten reveals gender inequalities associated with kidney and liver donation and transplantation. This Chapter also explains common issues with kidney, liver and heart transplant recipients.

Chapter eleven presents the perspectives of organ donor card holders who had pledged to donate organs in well-organised awareness programmes conducted by

NOTTO. This Chapter gives an understanding of the perspectives of 30 organ donor card holders towards donation, reveals their knowledge about the subject and elicits their opinion about specific issues of organ donation and transplantation. This Chapter explains the findings of FGDs on two issues, i.e., “presumed consent” and “revealing recipient identity” to donor families and vice versa” in the context of Brain Stem Death.

Chapter twelve presents the perspectives of non-organ donor card holders who had not pledged to donate organs in well-organised awareness programmes conducted by NOTTO. This Chapter gives an understanding of the perspectives of 30 non-organ donor card holders towards donation, reveals their knowledge about the subject and elicits their opinion about specific issues of organ donation and transplantation. The Chapter also explains the findings of FGDs on three issues, i.e., “trust on medical fraternity”, “the inclusion of incentives for organ donors” and “acceptance of brain death as a form of death”.

Chapter thirteen is the discussion and conclusion Chapter. This Chapter brings together the significant findings of all the above nine chapters from Chapter 4 to Chapter 12. These findings are analyzed within the analytic framework developed for the study. This Chapter explains the implications of research at a policy level at NOTTO and gives recommendations.

CHAPTER 3

Research Methodology

This Chapter describes the methodology used to achieve the main objectives of the study and gives a brief description of various steps undertaken by the researcher for conducting this study. The main aim of study was to explore the medical, social, legal and ethical issues of organ donation and transplantation from Brain Stem Dead (BSD) donors through a case study of National Organ and Tissue Transplant Organization (NOTTO) by studying the perspectives of professionals and people directly or indirectly involved with organ donation and transplantation. This study used a mixed method research design for the collection of data. This design uses both quantitative and qualitative methods for data collection and data analysis. The quantitative research method was employed to measure specific constructs and draw comparisons. And the qualitative research method was used to obtain in-depth information from various categories of respondents on medical, social, legal and ethical issues of organ donation and transplantation from Brain Stem Dead (BSD) donors. This Chapter gives a brief description of the Rationale for choosing a mixed research design for the study and the Study setting. This Chapter describes Pilot study, Study design, Sample and sampling technique, Development of tools, Data collection procedure and permission sought for doing research, Data validation and data triangulation, Data management and analysis, Ethics of research: Informed consent and maintaining confidentiality and Limitations of the study.

Rationale for Choosing a Mixed Method Research Design for the Study

In this study, a mixed-method research design was adopted to get a better understanding of the research problem under investigation. Mixed methods systematically blend quantitative data with qualitative data within a single investigation during the same timeframe (Creswell et al. 2003). This kind of mixing helps in a synergistic and comprehensive analysis of qualitative data with that of quantitative data (Moghaddam, Walker and Hare, 2003). This method amalgamates the strengths of various approaches and weakens the weaknesses of individual procedures. While qualitative research has some advantages, it has its flaws too, and the same holds for quantitative analysis. The understanding of a research problem strengthens when both approaches are adopted together. The quantitative approach has the strength to measure a specific construct accurately, draw comparisons and determine the association between variables, but it has weakness of decontextualization of an event or problem. Quantitative approach disconnects evidence from its original “real-life” setting and dampens comprehension of a problem under study (Moghaddam Walker and Hare, 2003).

In contrast, the qualitative approach studies a phenomenon holistically. This method adopts a fully contextualized approach (Guba and Lincoln, 1994). It gives detailed accounts of human experiences integrated with individual emotions, beliefs, and behaviours (Gelo, Braakman and Benetka, 2008). Qualitative research comprehends complex individual, familial and cultural experiences that are not possible with quantitative measurements (Plano et al. 2008).

The study employed a Concurrent Triangulation Design, a form of mixed methods to have an in-depth knowledge of the problem under study. Mixed methods compare quantitative and qualitative data, reflect participants’ point of view, nurtures scholarly interaction, permits methodological flexibility, collects wide-ranging rich data, strengthens the rigour, and enriches the analysis and findings of any research (Wisdom et al. 2012).

This design usually involves the simultaneous, but separate, compilation and analysis of quantitative and qualitative data for better understanding of the research problem. The two sets of data are amalgamated for useful interpretation of data, as shown in Figure 3.1 below:

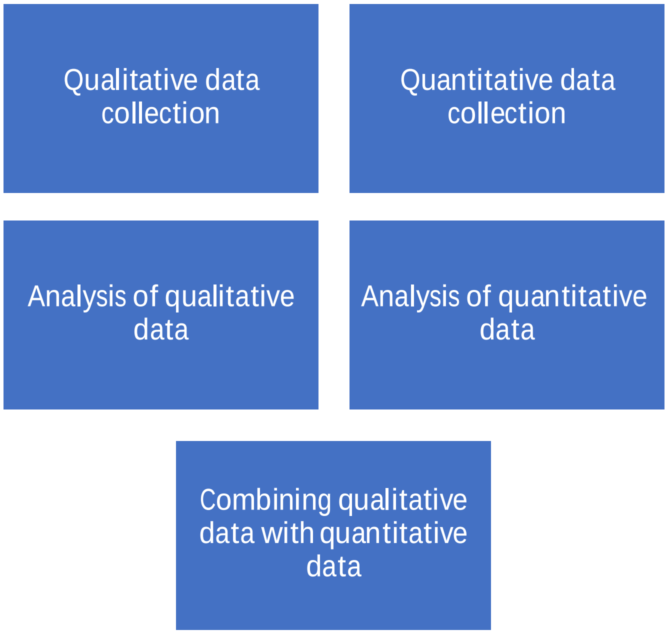


Figure 3.1 Showing concurrent triangulation design used in the study

Study Setting

The study was conducted in NOTTO an apex level organization in the country for organ donation and transplantation.

Table3.1 Showing settings used for interviewing various types of respondents (N=144)

Type of Respondents	Interview setting
Donor Families	ISTM premises and Constitutional club in Delhi
Kidney, Liver and Heart Recipients	SJH, GB Pant hospital, Residential Places in Delhi
Organ Transplant Coordinators	NOTTO, Gurugram Hotel, Hospitals in Delhi and NCR, IITF, CHEB and Residence of the researcher
Key Professionals associated with NOTTO	NOTTO, Govt and Private Hospitals under NOTTO in Delhi and NCR, NGO offices in Delhi and Gurugram
Organ Donor Card Holders	NOTTO, DGHS, Colleges of Delhi University, Nursing School
Non-Donor Card Holders	NOTTO, DGHS. Colleges of Delhi University, Nursing School

Table 3.1 reveals that the interviews and questionnaires were administered at various places like, Institute of Secretariat Training and Management (ISTM) premises, Safdarjung Hospital (SJH), India International Trade Fair (IITF), Central Health Education Bureau (CHEB), Directorate General of Health Services (DGHS), Non-Governmental Organizations (NGO), Residential Places, Private Hospitals, Constitutional club and a few selected Colleges of Delhi University etc. A detailed description of NOTTO is revealed in Chapter 4.

Rationale for Choosing NOTTO

National Organ and Tissue Transplant Organization (NOTTO) is a national level organization that has started functioning from 2014 only in accordance with the Transplantation of Human Organs amended Act of 2011. This apex level Government organization started working to bring in transparency in organ donation and transplantation. NOTTO had to lead and learn simultaneously about the various processes followed in organ donation and transplantation all over the country. It needed to take stock of the situation as such transplants are done in private hospitals mostly who are primarily interested in commercial gains. Organ transplantation involves huge investments by recipients also. It was thought that understanding the perspectives of people and professionals regarding processes of organ donation and transplantation will help the researcher. She, in turn, shall give feedback to the National Organ and Tissue Transplant Organization (NOTTO) to take suitable measures within its jurisdiction. The data collected in the study shall be helpful to NOTTO in taking corrective actions wherever required. The study shall help in identifying gaps for corrective measures wherever needed and help in addressing professional issues in addition to donor and recipient issues. The findings of the study could help in future policy formation. The narratives of respondents could be used to develop useful IEC messages.

Pilot Study

A pilot study was conducted only after approval to conduct the study was granted by NOTTO. Two respondents in each category were interviewed to assess the feasibility of research methods, tools and research study. Based on the findings of the pilot study, tools like interview schedules, questionnaires, interview guides were modified. Some changes in the data collection process were also done in the final research.

The use of audio recording caused hesitation among respondents during the pilot study, and the idea of sound recording was given up in the final study. Instead, field notes and diaries were used to capture the narratives of the respondents in the final study.

NOTTO invited BSD donor families from all over the country for felicitations on Indian Organ Donation Day every year. During the pilot study, the researcher found that interviewing BSD donor family needs to be initiated a few days earlier. The researcher found it challenging to develop a rapport with them during their short visit to Delhi. Hence, during the final study, a rapport building process with BSD donor families was initiated a few days earlier telephonically. NOTTO provided the phone numbers a few days earlier. The convenient day, time and place for the meeting were prefixed for Delhi on the telephone. Interviews were carried out at various locations in Delhi after mutual consultations during their short stay at Delhi for felicitations on organ donation day.

During the pilot study, telephonic interviews were not found feasible because of network and communication problems. Hence it was decided to prefer face to face interviews in most of the cases.

It was also found, during the pilot study, that it won't be feasible to interview recipients in Ram Manohar Lohia (RML) Hospital. There was a space crunch in that hospital. The condition of doctors managing OPD patients in a tiny room was pathetic there.

During the pilot study, direct observation of the procedure of declaration of death (BSD) and interviewing families who had refused to donate organs of their BSD donors were not found feasible. Such observation and interactions were not permitted.

Study Design

It is a mixed study design that consists of six sub-studies. First is the study of NOTTO and other organizations. Second is the study of Organ Transplant Coordinators. The third is the study of BSD donor families who had consented to donate organs of their BSD relatives. Fourth is the study of recipients. The fifth is the study of people who had pledged to donate organs during well-organized awareness programmes conducted by NOTTO. And sixth is the study of people who had not pledged to donate organs during well-organized awareness programmes undertaken by NOTTO. Both quantitative and qualitative research methods were used to elicit information from the respondents and get in-depth insights into various issues of organ donation and transplantation, mainly in the context of BSD. The three main methods used were observational methods, case-study method and survey method.

Observational Method: Observational method is a social research method. It involves observation of phenomena directly in its natural setting (Walliman, 2011). The various types of observation techniques used were: -

Participant Observation: - Participant observation involves the researcher's engrossment in a variety of activities over an extended period. It includes observing the respondents in a natural setting, participation in their actions to have a better understanding of behaviours, clarifying research findings through formal interviews and informal conversations. It also requires organized, structured field notes on the part of the researcher to help in the development of a narrative that explains various aspects to the researcher (Kawulich, BB. 2005).

The researcher is working in Central Health Education Bureau (CHEB). It is a central Government institution in India concerned with health education and health promotion activities among public and professionals on various programmes of MOHFW. It was involved in developing IEC strategy on NOTP in 2010 in which the researcher played a very crucial role. A few awareness programmes were conducted at India International Trade Fair (IITF) on organ donation and transplantation regularly from 2012 for 14 days in November. The researcher took the great initiative to initiate this activity officially by convincing NOTP nodal officer and Director CHEB as well. For the year 2013, before IITF-2013, the researcher prepared a game named "Tombola on organ donation and Transplantation" an innovative way of health communication (Dar, 2015). The content of the game was submitted to five experts in the field for content validity, including PhD guides and NOTP Programme officer. The researcher merged their recommendations in the game. The nodal officer of NOTP announced this innovative game in Lok Sabha Television Channel before its usage at Health Pavilion in IITF-2013. The game was appreciated by all (Annexure 3.1). Following this, the researcher was called on various occasions by NOTP and NOTTO for creating awareness through this innovative game. There is a mention of this innovative approach of health communication in the annual report of Ministry of Health and Family Welfare during 2013-14 as well (GoI,2014, p.306). "Tombola on organ donation and Transplantation" was prepared to stimulate, sensitize and motivate people as well as professionals towards the issue. The game was mathematical, scientific, entertaining, and incentive-based. It helped people to participate actively and speak out from their hearts. This game helped in getting across the messages in an enjoyable manner (Dar,2015).

The researcher opted for pretesting the single Form 5 of Draft Transplantation of Human Organs and Tissue Rules (THOT Rules) out of 24 forms of the same rules through a proper official channel (Annexure 3.2). THOT Rules were placed on the

Ministry of Health and Family Welfare website in the year 2013 for the public to give feedback. The researcher chose Form 5 purposefully as she felt a need to modify the same. This form held importance for her organization, too, as this form had its importance in awareness programs for public and professionals. This form was the only form that could come under the domain of her organization.

Interestingly there was no mention of Brain Stem Death in the Form 5 depicting limited knowledge of health professionals in MOHFW (Annexure 3.3). The findings of pre-test done on 200 professional students were submitted officially by the researcher to the nodal officer of the National Organ Transplant Program (NOTP). The nodal officer incorporated the results in this form that later became the form 7 of THOT Rules 2014(Annexure 3.4). Fortunately, Brain Stem Death was linked with organ donation in Form 7 after the researcher's interventions and feedback (Annexure 3.5).

The researcher was invited for various meetings held at NOTTO as a member of the working group. NOTTO appreciated her keen interest in this programme. Senior officials of DGHS like Deputy Director General, Director NOTTO, and Advisor to the Government of India for organ transplant and National Informatics Centre officials etc. attended these meetings. The researcher was a part of all working group meetings of NOTTO from Jan 2015 to August 2015. She had to discontinue the same unwillingly because of official pressures. It was because her organization felt it is leading to the researcher's growth and not to the growth of CHEB as communicated to the researcher.

During this period researcher helped NOTTO to develop a draft for requesting relatives to cooperate with professionals when asked for organ donation in Intensive Care Units (Annexure 3.6). This Information Education and Communication message (IEC) message was produced for the promotion of cadaver organ, and tissue donation. It was required for Display Boards outside the Intensive Care Units and at strategic locations in the hospital. The display board mentions that “Law requires the doctor on duty/transplant coordinator /counsellor to make a request for organ donation from family members of Brain Stem Dead persons". The material for display board was later shared with all transplant hospitals in Delhi. It was required as Organ Transplant Coordinators were shunned by relatives of BSD donors when they were asked for organ donation. OTCs communicated this problem in various meetings held at NOTTO. It may be essential to mention that amidst reservation by transplant community Brain Stem Death was incorporated in the request display boards as suggested by the researcher.

As per the request of higher officials of MOHFW, the researcher participated in organ donation awareness activities on the closing ceremony of a Cricket match organized by MOHFW on 15th January 2016, at Karnail Singh stadium.

The researcher was not allowed by CHEB authority to go to NOTTO after August 2015, but researcher preferred to go on Saturdays, which were her off days. The researcher was accepted by NOTTO very well and was already a part of that culture.

NOTTO also organized Organ donation awareness programmes for officers/officials of MOHFW from 17th-19th February 2016. And researcher had an opportunity to interact with people and professionals and observe the events that occurred during such interactive sessions.

As a result of such participation, the researcher was observing the phenomena directly in its natural setting. And all-important recordings were noted during such participation in research notes and dairy.

Direct Observation: - Direct observational method was also used by the researcher on many occasions while attending training programmes and conducting interviews. The researcher made relevant records of participant interactions in natural environments like trainer-trainee interactions, OTC to OTC interaction, living donor to living donor interactions, family interactions of recipient families, official interaction etc. Researcher being Health Education Officer, working in the Ministry of Health had an opportunity to be a part of NOTP. The researcher was called for many meetings held at NOTTO to work on various issues on organ donation and transplantation.

Case Study Method

Case study research methodology was used to get an in-depth understanding of the various issues related to organ donation and transplantation from the perspective of people and professionals, especially in context of organ donation from Brain Stem Dead donors and organ transplantation. With the excellent cooperation of respondents, the researcher conducted three in-depth case studies. These three case studies revealed the underlying gender issues, the emergence of a socially gratifying relationship between a BSD donor family and organ recipient and the processes of organ donation from a Brain Stem Dead donor.

Survey Method

Different methods of data collection provide an opportunity to account for similarity and complementarily of information collected (Greene and McClintock, 1985). Survey method of research was also used by administering pre-designed and validated, questionnaires and interview guides as follows: -

Questionnaires: -The researcher administered semi-structured questionnaires to Organ Transplant Coordinators to understand their perspectives. Perspectives of Organ donor card holders and Non-organ donor card holders were also assessed by administering questionnaires after well-organized awareness programmes organized by NOTTO. The questionnaires were followed by telephonic interviews in some cases.

In-Depth Interviews: -The researcher conducted in-depth interviews with the transplant coordinators, NOTTO officials, relatives of donors and recipients to develop deeper insights into various debatable issues from their perspectives. These interviews helped in getting rich qualitative information.

Personal Interviews through Semi-Structured Interview Guides:

Semi-structured interviews are suitable for quantitative data collection (Williman, 2001). Semi-structured, preapproved, pretested and modified Interview Guides were administered to recipients, Brain Stem Dead donor families and Key professionals working with NOTTO. The purpose was to elicit relevant information and explore unknown issues. The researcher preferred Interview Guides for an in-depth understanding of various aspects of organ donations and transplantation. These interview guides helped the researcher to do intensive interviews on specific issues that necessitated more significant insights from the perspectives of different categories of professionals and people.

Telephonic Interview/ Conversations: - The researcher interacted with all groups of respondents on the telephone. BSD donor families, recipients, relatives of recipients, living donors of interviewed recipients, OTCs, Key professionals associated with NOTTO, Organ Donor Card Holders and Non-organ Donor Card Holders. In some of the cases, the telephonic conversation was done to get the respondents acquainted with the researcher and enable them to know the purpose of research and set the ball rolling for personal interviews. The intention behind many telephonic interactions was to maintain the accuracy of data too. The telephonic interviews were also conducted with relatives of recipients like living donors who could not be interviewed personally and could throw light on issues under research. Telephonic Interviews were also conducted with those Organ Transplant Coordinators, NGO coordinators who had helped BSD donor families and recipients of this study. These NGOs and OTCs had provided financial help for treatment to transplant recipients and helped the BSD donor families in bearing the loss, respectively.

Unstructured Interviews: - Unstructured interview were conducted with eight key officials that belonged to NOTP, NOTTO and NGOs associated with NOTTO. These interviews were carried out with Organ allocation consultant of NOTTO, IEC consultant of NOTTO, Nodal officer for NOTP, Web designer of NOTTO, Director NOTTO, Incharge of an NGO having its base in Delhi, In charge of an NGO having its base in Gurugram and Data entry operator of NOTTO to explore the broader issues of the study and understand the problems faced by NOTP and NOTTO. These unstructured interviews were held as per their area of expertise. Their inputs helped the researcher in the formation and conceptualization of Chapter 4.

Informal and Formal Discussions: - The researcher conducted both formal and informal discussions with the personnel associated with NOTP and NOTTO on many occasions during the study period. Informal discussions were held with other categories of respondents, also on various issues during the study period.

Focussed Group Discussions: -The researcher conducted Focused Group Discussions on various conceptualized issues like presumed consent as a legal option, revealing recipient identities to BSD donor families and vice-versa, trust on medical fraternity, incentives for donor families, and acceptance of brain death as a form of death. These FGD's were done with organ donor and non-organ donor card holders. Permission from the organizational head was sought before proceeding with these FGDs. The in-charge of the Organizations allotted the place and time.

Table 3.2 Data collection tools /methods used for various types of respondents (N=144)

Type of tools used / Type of respondents	Number of respondents administered Interview Guide	Number of respondents administered Questionnaires	Unstructured interviews	Total FGDs
BSD Donor Families	14			
Recipients	40			
OTC		20		
Key persons associated with NOTP &NOTTO	2		8	
Organ Donor Card Holders		30		5*
Non-Organ Donor Card Holders		30		
Total	56	80	8	

Table 3.2 reveals that a total of 56 respondents in the study were administered interview guides, 80 respondents were administered questionnaires, and

unstructured interviews were conducted with eight respondents. Regarding 5* FGDs done with Organ Donor Card Holders and Non-Organ Donor Card Holders, the number of respondents varied in each FGD as discussed in Chapter 11 and Chapter12.

Sample and Sampling Technique

A total of 144 sample size was chosen to get insights into various issues of organ donation and transplantation.

Criteria for Sample Selection

- Only adults above the age of 18 years were the study subjects.
- Only willing respondents were part of this study.
- Tissue donor families (families who had donated tissues like eye /skin only) and tissue recipients were excluded.
- Only those respondents who had some association with NOTTO were the study subjects.

Sampling Technique

Only two types of sampling techniques like Simple Random and Purposive Sampling techniques were adopted for the study. When the whole population is accessible, and the investigator has a list of all subjects called the "sampling frame", a simple random sampling method can be chosen. A random sample is drawn from the sampling frame using the lottery method that represents the target population (Elfil and Negida, 2017). Only 88 respondents were chosen through a simple random sampling method. These respondents were 30 organ donor card holders, 30 non-organ donor cardholders and 28 kidney recipients as it was possible to do so with such respondents only.

Study respondents are selected using a purposive sample to ensure productive and wide-ranging information. The purposive sample allows the selection of respondents with varied background having different experiences with health care services.

Purposive sample enriches the nature of data collection (Patton, 2002). Hence, for the rest of the 56 respondents' purposive sample was used. The 56 respondents included 14 BSD donor families, two (2) kidney recipients, seven (7) liver recipients, three (3) heart recipients, 20 Organ Transplant Coordinators and 10 Key persons associated with NOTTO.

Table 3.3 Sampling technique used for various types of respondents (N=144)

TYPE OF RESPONDENTS	NUMBER	SAMPLING TECHNIQUE
BSD organ donor Families	15	Purposive Sample
Recipients	40	Purposive and Simple Random Sample
Organ transplant coordinators (OTCs)	20	Purposive Sample
key persons associated with NOTTO	10	Purposive Sample
organ donor card holders	30	Simple Random Sample
Non-organ donor respondents	30	Simple Random Sample

Table 3.3 gives an overview of sampling techniques used for various types of respondents.

Sources of Data Collection

The two significant sources of information of this study were the documentary source and field data.

Documentary Source

Both online and offline data maintained by NOTTO and NOTP formed a part of this study. General data was gathered from NOTTO. Records maintained by NOTTO regarding hospitals registered with it, transplant waiting list of patients of a few Delhi and NCR hospitals, list of Organ Transplant Coordinators, BSD organ donor families, recipients etc. were provided by NOTTO as and when requested by the researcher. The researcher was offered most of the documents at ease without any hesitation by NOTTO and NOTP officials.

The researcher studied the case files of the recipients' wherever possible to understand the medical histories, diagnostic and therapeutic measures taken for them. Documentary source helped the researcher in proceeding ahead in research and understanding the subject in details.

Field Data

The researcher did the field study and collected data from the field through a variety of tools based on direct or indirect observation. Direct observation enabled the researcher to understand the nuances of organ donation and transplantation and helped her in recording the events first hand. Indirect observation through interviews, questionnaires, in-depth interviews enabled her to understand the perspectives of people and professionals. The field diary and field notes were used to collect relevant information.

Development of Tools

Based on the framework developed for the study, the researcher developed various tools for people and professionals.

Content Validity

The questionnaires and interview guides were submitted to three experts working in the field of public health besides getting their approval from the guides. Experts were selected based on their experience in organ donation and transplantation.

Description of Tools

This section gives a brief description of various research tools.

- **Interview Guide for Brain Stem Dead Donor Family**

The interview guide for BSD donor family comprised of two parts. The first part elicited background information about the Brain Stem Dead donor whose organs were donated by the donor family.

The second part of the interview guide comprised of 17 items that could elicit information regarding brief history of hospitalization of Brain Stem Dead donor, history of declaration of brain death/Brain Stem Death and organ donation, family involvement in process of donation, understanding of brain death/Brain Stem Death by the interviewee, description about organs donated and transplanted, main reasons for donating relative's organs, consensus issue within family , issue with getting permission for organ donation from police or from forensic experts etc, issue with the hospital, issue with getting back dead body after organ donation (timings, body dignity, packing's etc.), their feelings regarding donation of organs , reaction of relatives at home after getting dead body, any regrets of the decision of donation, knowledge about the recipients ,felicitations received after donation and their message to the people**(Annexure 3.7)**.

- **Interview Guide for Recipient Family/ Recipient**

The interview guide for recipient family/ recipient comprised of total 18 items; the first two items could reveal background information about the recipient of kidney, liver and heart. The remaining 16 items elicited information regarding brief history of recipient's health and disease , history of dialysis, problems faced by individual and family during dialysis, treatment taken for the disease, exploring living donors within family , attempts made to find a living donor outside family, the date and processes of organ transplantation, financial implications , family support and sufferings, the life of recipient post-transplant, any effect on occupation, any episode of hospitalization post-transplant, any episode of organ rejection , any other disease which erupted after organ transplant and life after the transplant surgery(Annexure 3.8).

- **Interview Guide for Key Persons Associated with NOTTO**

Two interview guides pre-approved by research supervisors were administered to eminent personnel who were responsible for the initiation of OTC training programmes in the country prior to establishment of NOTTO (Annexure 3.9).

- **Questionnaire for Organ Transplant Coordinators**

Questionnaire for Organ Transplant Coordinators comprised of three parts. The first part was to get socio-demographic information about OTCs. The second part consists of 9 questions that could depict perspectives of OTCs towards the donation. Third part comprised of 33 main questions that could reveal their knowledge, experiences, practices and opinions about organ donation and transplantation with particular focus on Brain Stem Dead donation (Annexure 3.10).

- **Questionnaire for Organ Donor Card Holders Who Had Pledged to Donate Organs in Well-Organized Awareness Programmes Conducted by NOTTO**

The questionnaire for people who had pledged to donate organs comprised of four parts (Annexure 3.11). The first part dealt with socio-demographic information and information regarding organs/tissues pledged in form 7 of THOT Rules in well-organized awareness programmes conducted by NOTTO. The second part comprised of 3 knowledge-based items that could reveal their knowledge regarding organ donation and transplantation. The first question was to see their basic understanding of who can donate organs in India. The second question comprised of 11 sub-questions in the context of their understanding about Brain Stem Death and third question consists of 9 items regarding various aspects of organ donation and transplantation. A scoring key for question 2&3 was developed (Annexure 3.12). An individual could score max marks of 20. Only one mark was assigned to an item for each right answer and zero mark for the wrong answer. Third part had ten items depicting their perspectives towards the donation. Fourth part carried 13 items eliciting opinions of the respondents to various aspects of organ donation and transplantation. The last question of this part was to reveal their reason for filling form 7 of THOT Rules and making a pledge to donate organs (Annexure 3.11).

- **Questionnaire for Non-Organ Donor Card Holders Who Had Not Pledged to Donate Organs in Well-Organized Awareness Programmes Conducted by NOTTO**

The questionnaire for non-organ donor card holders was similar to the questionnaire for organ donor card holders as described above. The only dissimilarity in the two questionnaires was the last question. In this questionnaire, non-organ donor card holders were required to give the reason for not filling form 7 of THOT Rules for organ donation (Annexure 3.13). The scoring key for question 2 and 3 on knowledge-based items was also same as that of the organ donor card holders (Annexure 3.12).

Data Collection Procedure and Permission Sought for Doing Research

After completing MPH, the researcher qualified for PhD enrolment in the same university. She decided to conduct the study at Armed Forces Organ Retrieval and Transplant Authority (AORTA) that had a good conversion rate of BSD donation. Before submission of the synopsis, the researcher interacted with AORTA officials several times for seeking their concurrence for conducting the study on organ donation from BSD donors. AORTA expressed willingness and cooperation but placed two preconditions for granting official permission. The first precondition was, the consent will be given after the synopsis is approved and second, was that the request for conducting this study should come from Govt. Organization and not from JNU. With a positive mind, research submitted her synopsis deciding to conduct her study at AORTA. Her PhD synopsis was approved in 2012. The researcher could persuade Director CHEB to write a letter to AORTA in this regard (Annexure 3.14). Without assigning any reason for refusal, the permission was officially declined (Annexure 3.15). The researcher approached DGHS, GoI and persuaded him to write a letter to AORTA for permitting to conduct the study. Interestingly DGHS was the Chairperson of AORTA as per the records of AORTA handed over to the researcher during her initial visits. Unfortunately, permission to conduct the study at AORTA even after two request letters by DGHS, persistent requests and follow up by the researcher for more than two years was not granted (Annexures 3.16 & 3.17). AORTA chose not to respond to the letters from DGHS. Eventually, researcher informally requested NOTTO authorities to permit her to do the study at NOTTO, and fortunately, they accepted such request. As a result, JNU authorities were formally asked to allow the researcher to change the study area from AORTA (Armed Forces Organ Retrieval and Transplant Authority) to NOTTO (National Organ and Tissue Transplant Organization). They honoured the request. JNU authorities sent a formal request letter dated 1st May 2015 to allow the researcher to conduct the study at NOTTO to NOTTO (Annexure 3.18). An official letter by Director NOTTO dated 8th May 2015 communicated the formal permission to do the research (Annexure 3.19). A number of key terms and words were used for the operational purposes of the current study (Annexure 3.20).

While NOTTO was in its initial stages of establishment, it had no data of its own. It had to collect and compile data from different organ and tissue transplant centres and networks all over the country. It had to develop three online registries that are Pledge Registry, Transplant Registry and Donor Follow up Registry.

The researcher collected data from July 2015 onwards to December 2018. The researcher had no alternative except to wait for the events that had to be organized by NOTTO. The researcher had to keep in touch with NOTTO officials to inquire about the events held by them. Their support helped her to plan leave for such events like Indian Organ Donation Days and well-organized awareness programmes. The researcher collected data taking leave from the office from time to time. The researcher had to keep everything going like the demands at home, demands at office and requirements of research itself. The researcher could always feel research on the top priority that was giving her strength whenever she moved forward in research.

Study of Organ Transplant Coordinators (OTCs)

Organ Transplant Coordinators are the key to the success of BSD organ donation in India. Using interview guides, the researcher interviewed two Key professionals of a well-recognised Foundation associated with NOTTO. The Foundation had started OTC training programmes in India way back in 2009 before NOTTO. Their inputs were vital as they were responsible for the inception of Organ Transplant Coordinators training courses in India. They were the leading trainers in NOTTO initiated OTC training programmes as well. The interviews were prefixed through email and telephonic conversations and were held in 2016. The meetings were held in a private hospital and a Gurugram hotel. Both of them had a short visit from Chennai for one of the NOTTO supported Organ Transplant Coordinators training programmes. This training programme was conducted in one of the private organ transplant hospitals in Gurugram.

The researcher took permission from the head of NOTTO to administer questionnaires to Organ Transplant Coordinators (OTCs). The questionnaire used in the study was given to two experts in public health and guides too for content validity. After making modifications, the questionnaire was pretested on two transplant coordinators working in a well-known NGO at Gurugram. The modified questionnaire was administered to 20 OTCs during the second OTC training programme conducted at NOTTO in 2015. These OTCs were working in six private and four Government hospitals in Delhi and NCR hospitals. These transplant coordinators were made to explain specific issues in detail through telephonic interviews whenever required.

Some OTCs who were working in various organ sharing networks of India were also interviewed on specific aspects of organ donation and transplantation. Some of the transplant coordinators were not willing to elaborate on particular issues because of their own perceived threats while a few did not mind to reveal the facts in details.

Also, a few transplant coordinators who were not willing to be administered questionnaire had no problem when it came to informal discussions. They discussed their issues and narrated a few stories of donor families. Their inputs have become a part of Chapter 5.

The two Organ Transplant Coordinators invited from a reputed NGO for mass awareness programmes during IITF -2014 conducted by NOTP and CHEB together shared a lot of information with the researcher that is included in the findings.

Also, one Organ Transplant Coordinator volunteered to come to the researcher's residence and shared her experiences through an in-depth case study. This case study helped the researcher in understanding the nuances of organ donation and transplantation from Brain Stem Dead donors in details.

From 2015 onwards, the researcher attended five days of Organ Transplant Coordinators training programme four times during the study period, twice in NOTTO and twice in a private hospital. The researcher did Informal and Formal discussions in these training programmes with transplant coordinators and had two sessions of her innovative game "Tombola on organ donation and transplantation" on two occasions. The researcher held several formal discussions and deliberations in these training programmes with the participants. Recording of the trainer-trainee interactions in such training programmes has been incorporated to add value to this study.

All deliberations mentioned above were helpful in the formation of Chapter 5 on "Historical Genesis of OTCs in India and perspectives of OTCs towards the donation of organs from BSD donors".

Study of BSD Organ Donor Families

Structured interview guide prepared by the researcher and approved by guides, was administered to 14 BSD donor families. In the beginning, the donor families were approached on the phone. The researcher introduced herself to the donor family members, explained the purpose of the study and took verbal consent to carry the interview in advance. The researcher made telephonic clarifications and held informal and formal discussions with these donor families.

NOTP had been observing Indian organ donation day in November every year from 2010 onwards. NOTTO initiated the process of inviting BSD donor families from States and UT’s from 2015 onwards. The Indian organ donation day was observed on 30th November and 27th November during 2016 and 2017 respectively, and a few

BSD donor families were invited for felicitation also. Each State and UT was asked to send two nominations for best hospitals and two nominations of organ and tissue donor families. During 2016 and 2017 too, the researcher was provided with a list of 10-12 nominees of donor families of various States and UT's a few days in advance of the Indian organ donation day. NOTTO permitted to conduct interviews with these BSD donor families. The stay of these donor families was arranged in ISTM premises hostel during 2016 and 2017.

The interviews could be carried out with only four donor families in ISTM premises hostel on 29th November 2016 as the remaining families were out on sightseeing activities. Due to the shortage of time, more interviews could not be held. The felicitation event was organized at Constitution Club of India on 30th November 2016 in the presence of Union Minister of Health, Mr. J.P.Nadda. The remaining ten interviews were carried out on 26th and 27th November 2017 again at ISTM premises and Constitutional club respectively. The BSD donor family members had donated organs and tissues of their Brain Stem Dead donor during three years from 2015-2017.A total number of three, four and seven BSD donor families had donated organs during 2015, 2016 and 2017 respectively. Relatives who had donated tissues only like skin, bones and eyes were excluded from the study. The researcher came across two such families who were told to be organ donor families but were tissue donor families.

The interviews were carried out in the Hindi language with relatives who could speak this language. The interviews were carried out in English with relatives representing donors from southern States like Kerala and Tamil Nadu as they were unable to understand Hindi. None of the relatives refused to get interviewed. Although interviews were carried out with one family member only but the reactions and unique inputs of the other family member present at the time of the meeting have also been incorporated.

Study of Organ Recipients

The interviews were carried out with Kidney, liver and heart recipients using pre-approved interview guides. In-depth interviews, formal and informal discussions were also held with these organ recipients and their family members. The researcher approached a few transplant hospitals for conducting interviews through NOTTO Director. The two private hospitals showed inclination in the beginning but eventually declined to offer any help. However, they guided the researcher to get access to their recipients through the recipient waiting list shared by them with NOTTO. The only hospital that officially consented to help the researcher was SJH, that is a Government hospital. The researcher interviewed 40 recipients as depicted in Table 3.4 below.

Table 3.4 Number and type of organ recipients interviewed (N=40)

Type of Recipients Interviewed	Number	Percentage
Kidney Recipients	30	75%
Liver Recipients	7	17.5%
Heart Recipients	3	7.5%

Table 3.4 reveals that majority, i.e., 30(75%) kidney recipients were interviewed by the researcher followed by liver and heart recipients.

- **Kidney Recipients**

A total of 28 recipients (End Stage Kidney Failure) were interviewed using interview guides. In many cases, the researcher talked to these recipients telephonically as well. In some cases, the relatives of the same recipient were also contacted and interviewed. These interviews helped in getting insights from their perspectives as well. However, the conversation with the recipient through an interview guide along with his/her relative's inputs has been taken as one recipient or one recipient case study only in this study.

It is essential to mention that SJH started kidney transplant from 2014 only. The head of the nephrology department SJH gave consent to conduct interviews on every Wednesday in one of the rooms in his department in June 2017. Two NOTTO recruited Organ Transplant Coordinators shared this room as well. The researcher took leave from the office on various Wednesdays, the outpatient day and interviewed the recipients and their relatives. These recipients were either waiting for a transplant or had been transplanted kidneys. Some of them had registered for cadaver donor kidney while a few were in the process of getting the transplant operation done with living kidney donation.

The researcher explained the purpose of the interview in details and took verbal consent from the recipients and their relatives. Recipients were randomly selected. The researcher interviewed only those recipients who were willing to devote half an hour time without any inconvenience or any delay to their investigations and medical care. Relatives and recipients shared information without any hesitation after knowing the purpose of the interview.

A total number of 3-4 kidney recipients were randomly selected on every Wednesday in 2017 and interviewed for half an hour or more. The researcher had an opportunity to observe the interactions of relatives with recipients and also among living donors. That has been amalgamated in the Chapters focusing on recipient issues.

An in-depth case study was done with Ms. Mitta who was the spouse of one of the kidney transplant recipients. Her husband was transplanted a kidney of a BSD donor in a well-reputed autonomous hospital at Delhi long back in 1994. This in-depth study helped the researcher to identify gender issues ingrained into organ donation and transplantation. This story was necessary for the researcher as the respondent had married a person knowing that he was suffering from kidney failure. Also, her husband had lived for 18 years after a BSD donor kidney transplant. She had volunteered to come to the researcher's residence to share her story for a whole day after attending an OTC training programme at NOTTO.

Another in-depth case study was done with Ms Pitta. The researcher came to know about this recipient through one of the BSD donor families interviewed by her. The donor and recipient families had developed gratifying relationships. This kidney recipient was from Indore and was purposefully interviewed to get insights into donor-recipient identities and establishment of biosocial relationships.

In a nutshell, the 28 interviewed kidney recipients/ relatives were from Government hospital at Delhi, one from the autonomous hospital at Delhi and one from the private hospital of Indore. Except for one telephonic interview conducted with the lone kidney recipient from Indore, all 29 interviews were carried out in person with kidneys recipients/relatives.

- **Liver Recipients**

NOTTO itself was in the process of getting access to data and persuading hospitals to get registered with it. Hence, it was not possible for the researcher to get access to transplant recipients at ease. The researcher interviewed seven liver transplant recipients /their relatives that were either waiting for a transplant or had been transplanted liver. During the initial period when NOTTO was in the process of registering hospitals, one recipient of a Govt hospital was contacted for an interview by the researcher. She was reached only after seeking permission from the Liver Transplant Surgeon through NOTTO authority. The recipient willingly shared her story on several occasions and visited the researcher many times uninvited. The researcher also visited her in her residence once. It is interesting to note that our Prime minister had talked about this recipient only in his radio talk titled "Mann Ki Baat” in 2015.

Another liver transplant recipient invited in one of the NOTTO supported Organ Transplant Coordinators training programme was also interviewed.

One relative of multi-organ transplant (two kidneys and one liver) of a private hospital was also interviewed. This recipient was traced by one of the BSD donor families interviewed by the researcher. In short, three liver transplant recipients were interviewed outside the waiting list of liver transplant recipients provided by NOTTO to the researcher.

In 2017 a waitlist of 30 random transplant recipients registered with Delhi and NCR hospitals was provided by NOTTO to the researcher on request. The researcher could interview only four recipients telephonically. The waiting list provided by

NOTTO had recipients outside Delhi and NCR indicating recipients registered in Delhi and NCR hospitals were from different parts of the country.

NOTTO has been complaining of data not being shared by the hospitals. The researcher brought many other facts in focus related to the same issue through this research. A few phone numbers of the recipients given by the hospitals were non-existent. Some of the recipients were without any phone numbers, and one recipient was registered twice by the same hospital, only the date of registration was different. Some of the recipients who were waiting had already died or had been transplanted liver as per the NOTTO waitlisted recipients.

So eventually, only two interviews were conducted in person, and the rest five interviews were conducted telephonically with liver recipients.

- **Heart Recipients**

Out of the three recipients who had got heart transplants done, there was direct interaction with two heart recipients. One of the recipients was paid a visit to her home after taking an appointment with her. She had got a heart transplant done three and a half year back in Chennai from a BSD male donor. She was feeling great and had forgotten about heart transplant at the time of interview. She was on follow up care in one of the private hospitals registered with NOTTO. In fact, at the time of the meeting, she was moving here and there without any problem at all. She was getting a truck full of flower pots offloaded. She even had a cup of coffee with the researcher during interactions. Telephonic interviews were carried out with other two heart transplant recipients.

Study of Key Persons Associated With NOTTO

To study the critical issues related to OTCs, NOTTO and NOTP, the researcher interviewed ten Key personnel. Preapproved interview guides were used to elicit information from two key personnel associated with OTCs training programmes. The researcher held the unstructured interviews with eight Key staff related to different aspects of NOTTO and NOTP. All these key persons were directly or indirectly related to NOTTO. Informal and formal discussions with such officials were held on many occasions. These discussions were held in person and telephonically, too, during the study period.

Study of Organ Donor Card Holders

NOTTO conducted several well-organized awareness programmes. One such programme was organized in DGHS for officers/officials of MOHFW from 17th-19th February 2016 and another for Delhi University students in the year 2017. Non-organ donor card holders were more in number in each of the awareness programmes while organ donor card holders were almost negligible in each such programme. A total of 40 organ donor card holders could consent to be a part of the study in many awareness programmes from 2016-2017. Out of 40 such filled questionnaires, a total of 30 questionnaires were selected randomly for the study of organ donors.

Study of Non-Organ Donor Card Holders

In above mentioned NOTTO organized awareness programmes during 2016 and 2017, the researcher administered a total of 140 questionnaires to non-organ donor card holders. These questionnaires were administered mostly in classrooms of three different institutions at Delhi. A few questionnaires were administered in office settings at DGHS also. The researcher randomly selected 30 completed questionnaires among 140 filled questionnaires for the study.

Data Validation and Data Triangulation

At the end of each interview, the summary of the interview notes was presented to the respondents to maintain facts and avoid personal bias. Data validation was either done immediately at the time of the interview or within 24 hours. All the respondents, including BPL cardholders of this study, had a mobile phone with them that ensured secure communications. They did share their numbers with the researcher without any hesitation.

Data Management and Analysis

The quantitative data, in many cases, is usually presented in a Table depicting frequency distribution (Walliman, 2011). Quantitative data collected in the study has been analysed and shown in Tables and Figures. The Qualitative data presentation was done by clustering the findings into themes and subthemes. The qualitative data has been merged with quantitative data.

Documentation and editing of data collected is the prerequisite of data analysis of qualitative research. Recording data, editing (transcription), and constructing a new reality are three main steps of data documentation (Flick, 2009). In the present study field notes and research diary was used to collect data. Using the voice recorder was not accepted by professionals as they were reluctant to do so. Voice recorder used with other respondents like recipients, families and people was found to be obstructing the conversation. The researcher also felt that respondents were conscious not to speak out from their heart. Interviews were carried in the Hindi language mainly. The researcher made a small paragraph at the end of each conversation, indicating the environment in which the meeting took place. It also included the nature of cooperation or hostility encountered from the interviewee, the issues which interviewee felt close to his or her heart and other related information. After each interview researcher jotted down the notes in the interview guide. Any missing data from the interview was obtained through telephonic conversation later with the interviewee. The interview data were transcribed in Hindi and translated to English. Transcribing every bit of data is not required. Transcribing limited and necessary data to answer the research questions is more reasonable. Transcribing data precisely and in detail, consumes a lot of time which could be used in their interpretation instead (Strauss,1987). Data collection and data analysis was undertaken simultaneously.

Ethics of Research: Informed Consent and Maintaining Confidentiality

Necessary consent was taken from the concerned officials and institutions to conduct the study. The participants were made to understand the study purpose and its outcome. Before administration of tools, verbal consent was ensured from all the participants in the study. All the participants who volunteered to be the part of the study were given assurance of confidentiality, privacy and anonymity. They were informed about their right to withdraw if they are not interested in continuing with the conversation. The names of the participants have been kept anonymous by giving fictitious names to them in the study.

Limitations

The study is limited to verbal and written responses only and lacks observation of actual and crucial events concerning diagnosis and declaration of Brain Stem Deaths, the process of request for organ donation and reactions of BSD donor families in hospitals etc. The private hospitals did not allow the researcher to conduct interviews with donor families or with their recipients. Hence, the researcher had to be happy with selective data made available to the researcher. As proposed in the synopsis, the interviews could not be carried out with those BSD donor families who had refused to donate organs when confronted with a request for organ donation by OTCs. That could have thrown light on refusal rates and helped the researcher in understanding the perspective of families who refused organ donation. Such interviews could have been beneficial to understand the intricacy of refusal of organ donation from BSD donors. NOTTO did not show any interest so far to make it mandatory for hospitals to report refusal cases. The study is limited to the study of new cases only who registered with NOTTO after 2014. As a result, the perspective of recipients who have been transplanted organs long back before the establishment of NOTTO could not be obtained. NOTTO is registering current cases only and shall have no data of previous cases in coming years also. Hence, this study could not explore the long-term effects of organ donation on living donors and organ transplant on the recipients.

Summary: -This Chapter describes the details of the research methodology of the researcher's research work. It is an exploratory study to explore the medical, social, legal and ethical issues of organ donation and transplantation from Brain Stem Dead donors through a case study on NOTTO by studying the perspectives of professional and people directly or indirectly involved with organ donation and transplantation. In this study, mixed methods were employed to have an in-depth understanding of the problem under investigation. The researcher adopted both qualitative and quantitative methods of data collection in the study. After giving the rationale for choosing this type of mixed methods, the study setting is described. Chapter 4 explains the study setting in details. The two significant sources of information were the documentary source and field data collected by the researcher. The researcher used different data collection methods like observation method, case study method and survey methods. The tools used were interview guides, questionnaires, FGD, telephonic conversation, in-depth interviews, informal and formal discussions. The total sample size was 144 respondents. The study employed only two types of sampling techniques. Simple Random sampling method was used for only 88 respondents that are organ donor cardholders (30); non-organ donor cardholders (30) and kidney recipients (28). For the rest 56 respondents, the purposive sample was adopted. These include Donor Families (14); recipients (12) viz., kidney recipients (2), liver recipients (7) and heart recipients (3); Organ transplant coordinators (20) and Key persons associated with NOTTO (10). The data was collected from July 2015 to December 2018, although informal discussions had started immediately after approval of synopsis. Qualitative data presentation was done by clustering the findings into themes and subthemes. The qualitative data were analysed using excel sheets and presented with frequency tables and charts. The two data sets, qualitative and quantitative data, were amalgamated wherever required. All the findings are organized into various chapters from Chapter 4 to Chapter 13.

CHAPTER 4

National Organ and Tissue Transplant Organization (NOTTO) and Other Institutions

This Chapter gives an overview of National Organ and Tissue Transplant Organization (NOTTO) and its sister concerns. It has been developed with the help of interviews, formal and informal discussions, excel sheet data and PowerPoint presentations shared by NOTTO officials on several formal and non-formal occasions with the researcher. A few officials did not mind visiting the researcher's place of residence to share their experiences and provide the most valuable inputs towards the development of this chapter. NOTTO website data, telephonic interaction with senior level officials whenever in confusion, WhatsApp interactions on NOTTO group, communication with different networking authorities has also helped the researcher in the full development of this chapter. This Chapter is divided into six major subsets giving an overview of National Organ and Tissue Transplant Organization (NOTTO) in relation to National Organ Transplant Programme (NOTP), Indian scenario before its establishment, persistent political support enjoyed by NOTTO, arduous task of establishing linkages all over the country, struggles of initial years of NOTTO and current status of NOTTO.

An Overview of National Organ and Tissue Transplant Organization (NOTTO)

National Organ and Tissue Transplant Organization (NOTTO) established in 2014 is an apex organization in India. It is entrusted with the responsibility of building a well-established network for obtaining, allocation and distribution of tissues and organs for transplantation in the country. It has been established within the vision of NOTP (National Organ Transplant Programme) in India.

National Organ Transplant Programme (NOTP) In India –An Update

National Organ Transplant Programme was initiated in India in 2009 almost 15 years after passing Transplantation of Human Organ Act (THOA) in 1994 with a budget allocation of Rs. 149.5 Crore during 12th Five-year Plan **(NOTP Cell, 2015).** It was aimed to improve the rate of organ transplantation for needy citizens of our country by promoting the donation of organs from Brain Stem Dead donors mainly. The shortage of organs is practically a global problem and India is no exception to it. There aren't enough organs for transplantation available for people needing organ transplants. Most of the Road Traffic Accidents with hazardous head injuries could be the potential Brain Stem Dead (BSD) donors. Most of such cases have a chance to be declared BSD for organ retrieval and transplantation.

Situation of Organs Transplantation in India

There is a vast gap between the need for organ transplants in comparison to the availability of organs in India. As per a crucial senior person in DGHS, it has been found that every year, about 2 lakh people suffer from kidney failure, but only about 6000 -7000 kidney transplants are performed. Similarly, against a need for 25000 liver transplants every year, only 1200 are done. Also, only 50 heart transplants are done in one year as against the requirement of 50000 every year in India.

The Legal Framework of Organ Donation and Transplantation in India

Transplantation of Human Organs Act (THOA) was endorsed in1994. It offered a system of recovery, storage and transplantation of human organs for treatment purposes and discouragement of commercial transactions in human organs. THOA - 1994 has been accepted and adopted by all States, but Andhra Pradesh and J&K are the exceptions to it. They have framed their State-specific laws of organ donation and transplantation. Under THOA,1994 sources of the organs could be:

1. ‘Near Relatives’ like parents, children, siblings and spouse.
2. ‘Other than near relatives’ like uncles, aunts, cousins, friends etc. However, such living donors can donate after they prove their love and attachment with the recipients to the “Authorization Committee”. They also have to

show that they are doing so without any element of coercion or commercial intentions.

3. Brain Stem Dead donor also called deceased donors: they are usually the victims of Road Traffic Accident with severe head injuries.

This Act was later amended in 2011 as Transplantation of Human Organs (Amendment) Act- 2011 that was followed by the Transplantation of Human Organs and Tissues Rules (THOT Rules) in 2014. Some of the crucial amendments in the context of Brain Stem Dead donation and living donation under the (Amendment) Act 2011 and corresponding THOT Rules are as under:

Provisions for Organ Donation from Brain Stem Dead Donors as per THO (Amendment) Act 2011 and THOT Rules 2014

It has the provision for the formation of National Human Organs and Tissues Removal and Storage Network and electronic National Registry for Transplant. The other clauses are the inclusion of Tissue retrieval, and establishment of "Tissue Banks".

For deceased donors, it has provided an option for registering "Organ Retrieval Centres' for retrieval of organs. It has eased the Composition of Brain death certification board. An anaesthetist or intensivist can become a board member if Neurophysician or neurosurgeon is not available. However; they should not be members of any transplant team. It is mandatory for organ transplant hospitals to have 'Transplant Coordinator'. It is mandatory to request relatives of potential donors to donate organs in ICUs. Further, an 'Advisory Committee' has to be formed to render support and guidance to the 'Appropriate Authority'.

Provisions for Living Organ Donation as per THO(Amendment) ACT 2011 and THOT Rules 2014.

The definition of 'Near relatives' has been stretched to include grandchildren and grandparents and swap transplants permitted. A trained technician can do enucleation of corneas. It has introduced higher penalties to prevent organ trading.

It has the provision of protection of vulnerable and poor. Besides, it recommends greater caution for foreigners and minors. The Act prohibits living organ donation from mentally challenged persons.

The National Organ Transplant Programme under Directorate General of Health Services, Government of India is carrying out the activities as per the amendment Act. It is promoting organ donation from deceased persons. However, the programme faces several issues and challenges while promoting organ donation and transplantation.

Issues and Challenges to National Organ Transplant Programme (NOTP): - It has to meet the challenge of fulfilling the demand for organ donation in the face of less supply of the same. The Government organ transplantation Infrastructure is inadequate. People and professionals, both lack understanding and knowledge about the concept of Brain Stem Death, and BSD Certification is abysmally low. A well-systematized system is absent for organ procurement from Brain Stem Dead donors. It has to set Standard Operative Procedures (SOPs) in organ and tissue donation, retrievals and transplantation. It has to do its best to prevent and control commercial activities in organ transplants nationwide. The high cost of these transplant surgeries is not within reach of poor and uninsured people, and it faces the challenge to regulate the expenses in Non- Govt. Sector.

Objectives of National Organ Transplant Programme: -

- To establish a system of organ and tissue procurement, sharing & distribution in the country.
- To monitor organ and tissue transplant services all over the country and bring about programme rectifications/ changes each and every time needed.
- To encourage deceased organ and tissue donation and transplantation in the nation.
- To train the workforce required for organ and tissue donation and transplantation.
- To shield the vulnerable people from organ trafficking.

Strategies of National Organ Transplant Programme: -

- To create a proper infrastructure for implementation of the National Organ Transplant Program.
- Develop Networking for organ and tissue donation and transplantation.
- Develop a national registry for organ donation and transplantation.
- Capacity building of human resources for coordination, retrieval and transplantation of organs and tissues and to train required manpower for retrieval of organ/tissue and transplantation.
- Advocacy for promoting deceased organ and tissue donation and conducting IEC for bringing awareness among the general public and professionals.
- Follow the “opt-in” system of deceased organ/tissue donation – where individuals are asked to register their willingness to be a donor after death.

National Organs and Tissue Transplant Organization (NOTTO): An Introduction

As per THO amendment Act 2011, it was recommended to establish National Human Organs and Tissues Removal and Storage Network along with National Registry for Transplantation of organs. As a result, a national level organization started in the name of National Organ and Tissue Transplant Organization (NOTTO) in 2014 within the vision of NOTP (National Organ Transplant Programme) as per the Transplantation of Human Organs (Amendment) Act 2011. NOTTO aims to build up a well-established network for procurement, allocation and distribution of organ and tissue donation and transplantation in the country.

Location of the Premises of NOTTO

NOTTO as an organization occupies 4th and 5th floor of pathology department of ICMR building in the campus of SJH at New Delhi. The premise was constructed with the budget of Safdarjung hospital that is a Government hospital in Delhi under DGHS, MOHFW. From 2014 this organization is in the process of picking up the pieces together and trying to amalgamate efforts of various stakeholders who had been working in the area of organ donation and transplantation.

There were no specific national organ donation and transplantation guidelines until 2014. It was envisaged that NOTTO would develop various procedural and personnel guidelines for organ donation and transplantation with the help of its technical expert advisory groups. Besides, NOTTO had to initiate liaising activity with transplant centres all over the country, identify training centres for conducting training and establish a 24-hour helpline as a part of IEC. The mandate of NOTTO envisaged is as follows: -

Development of Procedural and Personnel Guidelines: -

NOTTO had to develop procedural guidelines for the following: -

- Diagnosis & certification of Brain Stem Death in adult, children and infant.
- Donor management, including pediatric donor management, donor screening, donor investigation, general nursing care.
- Transplant coordinators and their role.
- Information for anesthetist on the management of the multi-organ donor, preoperative donor management, donor procedure, surgical outline, post-operative care etc.
- Information for operating theatre staff on procurement, general theatre requirements, staff specific theatre requirements, preliminary dissection, organ-specific requirements for removal of kidney, lungs, liver, heart, pancreas, intestine and tissue-specific requirements for heart valve / cornea or whole eye / bone /skin donation etc.

Liaising Activities with Transplant Centres

- It was envisaged that NOTTO shall compile and prepare a list of organ and tissue transplantation centers of all States/UTs and analyze such data on a monthly/quarterly basis.
- It shall coordinate the organ and tissue transplant centers of Delhi NCR region for which it will prepare a list of Brain Stem Death Committees of Registered Transplant and Retrieval hospitals and selected trauma centers of Delhi & NCR Region so that a model networking of organ procurement and allocation system is developed in Delhi & NCR region.

- It shall conduct an annual half-yearly meeting with ROTTOs, SOTTOs, Tissue banks and Trauma centers.
- It shall monitor NOTP and prepare program evaluation proposal after 3 years of implementation.

Capacity Building Activities of NOTTO

- It shall conduct orientation training of various categories of staff and selected persons from the general public with the help of identified training institutes.
- With the help of appropriately identified institutions, it shall do the following: -
  - I. It shall conduct a national workshop for finalization of standard training curriculum for different categories of staff under NOTP.
  - II. It will develop a training manual for the staff & SOPs for the laboratory staff.
  - III. Identify the centers capable of doing State of the art training for following categories of staff namely Organ and Tissue Transplant Coordinators (OTTCs)/ Organ and Tissue Retrieval Coordinators (OTRCs), State Nodal Officers, NOTTO/ROTTO/SOTTO Program Managers & Consultants for Transplant networking organizations and tissue banks.
  - IV. Conduct orientation training of Transplant Program Managers from each registered organ/ tissue hospital.
  - V. Will advertise expression of interest for the development of IEC campaign material for NOTP.

People-Centric Activities of NOTTO

A 24-hour helpline has been established to address the queries of people. Besides National Organ and Tissue Transplant Organization (NOTTO), development of Regional Organ and Tissue Transplant Organizations (ROTTOs) and State Organ and

Tissue Transplant Organizations (SOTTOs) at regional and State levels are also in process.

NOTTO Manpower as on July 2018

NOTTO is majorly run by contractual employees who are always in a fix whether they would be able to continue job given to understand that such contractual jobs don't guarantee them lifelong security. Only the Director and Joint Director are permanent posts rest everyone holds contractual positions that are usually renewed after one year. The total number of contractual employees with their salaries are listed below:

I. **Director NOTTO -**Permanent Post
II. **Joint Director: -** Permanent Post
III. **Consultant Coordinator**- appointed for a consolidated salary of Rs. 60000 per month.
IV. **Consultant IEC** - appointed for a consolidated salary of Rs. 50000 per month
V. **Administrative Officer**- appointed for a consolidated salary of Rs. 50000 per month
VI. **Accounts Officer** - appointed for a consolidated salary of Rs. 50000 per month
VII. **PA to Director** - appointed for a consolidated salary of Rs. 30000 per month
VIII. **Tele Counsellors** – are 6 in number for and appointed for a consolidated salary of Rs. 20000 per month
IX. **Data Entry Operators** - are 10 in number appointed for a consolidated salary of Rs. 15000- 20000 per month
X. **MTS** are 3 in number, for a consolidated salary of Rs. 10000-12000 per month

Six Tele- counsellors are provided by the National Blindness Control Programme. Some sort of inter- programme convergence can be seen in the recruitment of these counsellors. They counsel the grieving families and motivate them to donate tissues as well as organs.


HIERARCHY

MoHFW

DGHS

NOTP

NOTTO

ROTTO

SOTTO

Figure 4.1 Depicts the hierarchy of NOTTO

Indian Scenario Prior to Establishment of NOTP and NOTTO

In the absence of national guidelines, every organization involved in organ donation and transplantation was free to follow any guideline and organ sharing procedure as per their preferences and conveniences. About 15 years lull by central Government from 1994 to 2009 without any national actions towards this endeavour, left all States and private organizations on their own. As a result, different organizations, private sector, NGOs, Societies also emerged. They tried to move ahead at their own pace within their comfort zones to increase organ donation for transplantation without any directions from the central Government. Several networks of organ sharing also evolved. With no centralized waiting list of transplant recipients, these networks developed their own methods and strategy of organs sharing arrangements. And all hospitals had their waiting list of patients waiting for organ transplants. The transplant of donated organs from a BSD donor was possible within their developed network of registered transplant hospitals within their States or neighbouring States depending on the geographical proximity (Dar, 2014). As reported, several organs could not find recipient resulting in loss of precious biological assets. When the National Organ Transplant Programme started, it had no choice except to pick up the pieces together and take a leadership role in the country. In the absence of expertise in the field, it had the dual responsibility of leading and learning simultaneously.

Media supported this cause vehemently. Times of India, a national newspaper took a week-long initiative from 2013 onwards to promote organ donation. Times of India, along with NGOs like Multiple Organ Harvesting Aid Network (MOHAN) foundation and corporate sector, encouraged people to pledge to donate organs. The campaigns touched the hearts of people. Many other organizations like Shantanu, Gift of Life, Armed Forces Organ Retrieval and Transplant Authority (AORTA), Organ Retrieval and Banking Organization (ORBO), Dadichi Deh Dan Samiti etc. made efforts to motivate people to pledge their organs, tissues and even bodies. The Indian Society of Nephrology, The Transplantation Society, Indian Liver Foundation, The Indian Society of Organ Transplantation etc. evolved and worked towards this cause. These organizations took their initiatives to create awareness, develop guidelines, and develop sharing and allocation policies to meet the demand for organ transplantation.

Persistent Political Support: A Great Encouragement for NOTTO

NOTTO was one of the institutions within DGHS that received a lot of encouragement from Ministers in the Ministry of Health and Family Welfare from time to time. NOTTO enjoyed great political support right from its inception.

Radio Talk by Prime Minister Narendra Modi in “Mann Ki Baat”: A Significant Boost to NOTTO Activities

Organ donation gained political will and support vehemently. Our Prime Minister Mr. Narendra Modi touched the issue of organ donation wholeheartedly in his radio talk "Mann Ki Baat" program in October and also in November 2015. He highlighted the role of NOTTO in organ donation and transplantation and encouraged people to come forward to donate organs. He made a special mention about a mantra "Tyen Tayjen Bunjitha" (Meaning sacrificing gives peace). He requested people to further the cause of organ donation. Following repeated talks of our PM, the number of calls at NOTTO increased tremendously, as depicted in Figure 4.2.

Figure 4.2 Number of calls received by NOTTO before and after "Mann ki Baat" by Prime Minister in October 2015

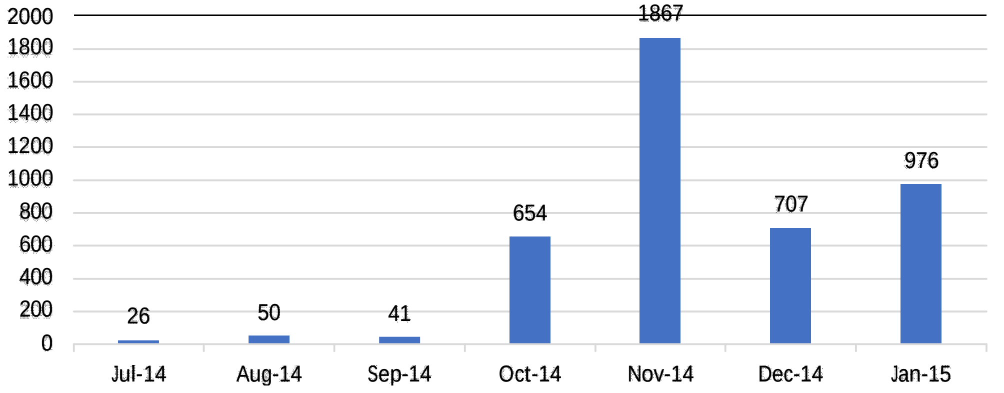


Figure 4.2 reveals the increase in number of calls received by NOTTO after ***"Mann Kee Baat"*** by our Prime Minister in 2015**(Source: NOTTO data).**

Political Encouragements on Observation of Indian Organ Donation Day

From 2015 to 2017 the Health Ministers of Government of India were a part of Indian Organ Donation Day observations without any failure. Special attention was given to NOTTO by all ministers in Health and Family Welfare Departments. They would deliver speeches among big gatherings for motivating people to donate organs. This day was a day that brought all States and UTs at one platform. NGOs, transplant coordinators, donor families from all States and UTs were also invited to this event. State ministers of well-performing States were felicitated. The salutations of States, hospitals, donor families, transplant coordinators were a part of this event. This event was a rapport building event with all stakeholders in the country.

India's first National Biomaterial Centre established at 5th floor at NOTTO office was inaugurated by Honorable Minister of State MOHFW, Ms Anupriya Patel on 22nd November 2017. It has well equipped four tissue banks that can store tissues like cornea, skin, bones and heart valves. The banks can store these tissues for extended periods up to five years for transplantation like skin, bones and heart valves.

Establishing Linkages All Over the Country: An Arduous Task for NOTTO

NOTTO had to make its presence felt all over the country. It was a daunting task after a complete absence of central Government initiatives and a centralized network for a long duration of 19 years.

NOTTO Networking Obligations: An Overview

NOTTO had a hectic task to bring all organizations together for developing a national database of organ and tissue transplant activities all over the country.

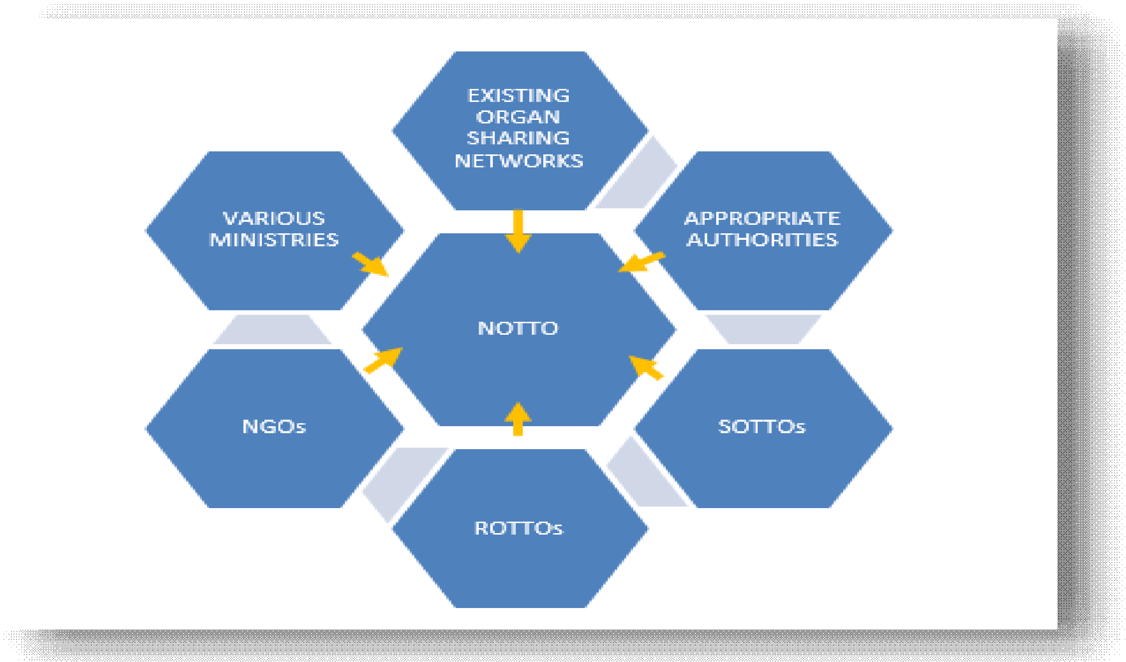


Figure 4.3 Showing Networking Requirements of NOTTO

Figure 4.3 reveals that NOTTO had to develop linkages with "Appropriate Authorities" of the States, existing States organ sharing networks, SOTTOs, ROTTOs, NGOs and various ministries in the country. The same is discussed in this section of the chapter.

When NOTTO established, it was envisaged that it would have to coordinate transplant activities in the country through five Regional level organizations. The regional level organizations were planned in PGI Chandigarh, Guwahati Medical College, IPGMER, Calcutta, Government Medical College Chennai and King Edward Memorial Hospital Mumbai. These regional institutions, in turn, are supposed to coordinate with State level SOTTOs. It was planned to develop SOTTOs in six AIIMS like institutions established under PMSSY in Bhopal, Jodhpur, Rishikesh, Bihar, Bhubaneshwar and Raipur, as shown in Figure 4.4.

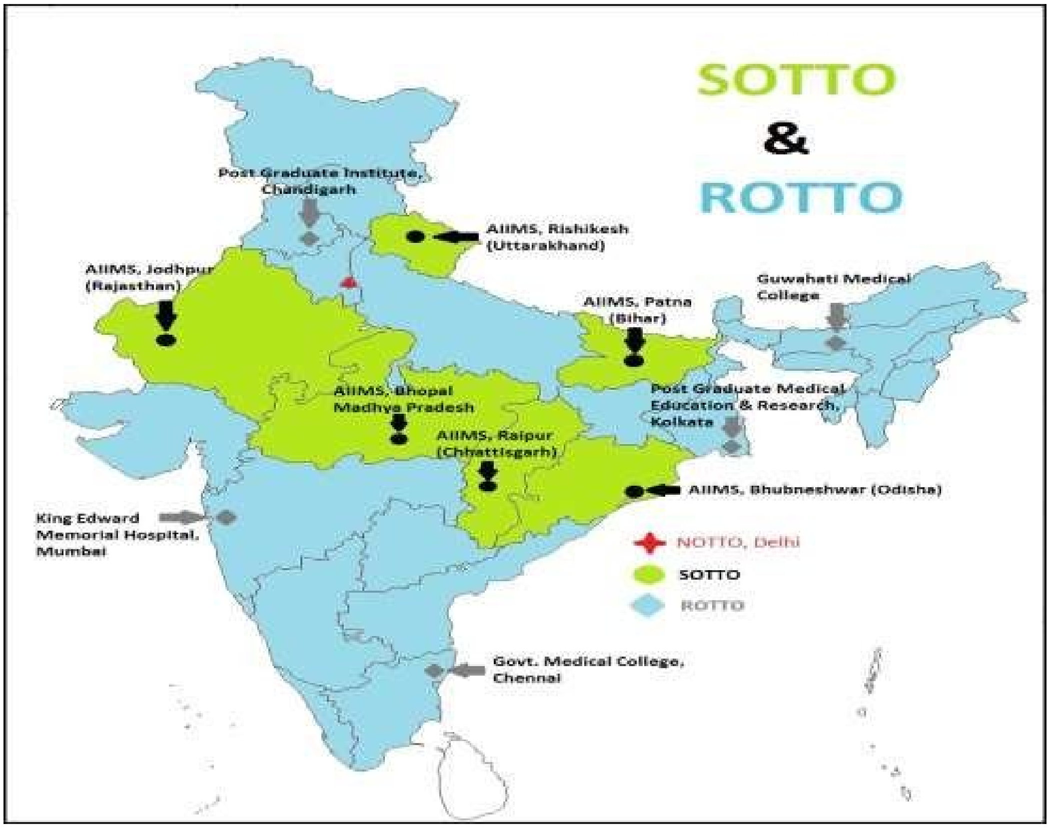


Figure 4.4 Distribution of Regional Level (ROTTOs) and State Level networking Organizations (SOTTOs) in relation to NOTTO as proposed by NOTP.

Not only this NOTTO is accountable to NOTP, and all files route through NOTP for financial approvals that have been difficult at times. NOTTO curtails its expenses when made to do so by NOTP that is not liked by NOTTO officials in many instances. NOTTO is also accountable to Global Observatory for making the country level data available to it.

Establishing Linkages with “Appropriate Authorities” of States and UTs

As per the information shared by NOTTO, all the States and Union Territories had their “Appropriate Authorities” that were involved in organ donation and transplantation activities. The States where organ transplant activities were not taking place, in those States also the “Appropriate Authorities” were nominated. As per THO amendment Act 2011, the Central Government had to appoint one or more officers as “Appropriate Authorities” for each of the Union Territories for this Act and the State Government also had to appoint one or more officers as “Appropriate Authorities” for this Act.

As per a key person, State Health Secretaries are the nominated officers for "Appropriate Authorities" in most of the States by default. In a few States only, it is the Director of Health Services or Director of Medical Education.

The list of hospitals doing transplant surgeries was shared by "Appropriate Authorities" with NOTTO. NOTTO had to make tireless efforts contacting these "Appropriate Authorities" by sending repeated reminders and maintaining perseverance even after many fruitless efforts in some instances.

The various functions of "Appropriate Authorities" are, to grant registration for 5 years, to renew the same after 5 years, suspend or cancel registration, enforce standards for removal, storage or transplantation of any human organ and tissue Banks engaged in recovery, screening, testing, processing, storage and distribution of tissues.

The "Appropriate Authority" has all the powers of a civil court to perform its functions effectively.

To grab the attention of State Health Secretaries, Director Health Services and other stakeholders, one Day National Advocacy Conference was conducted on 27th March 2015. On this occasion, Operational Guidelines of National Organ and Tissue Transplant Program for its implementation depicting the role of various stakeholders was also released at VMMC, SJH; New Delhi.

Networking with Existing Organ Sharing Networks

Several networking organizations for organ sharing had established themselves in absences of State or Central initiatives in many States of the country and NOTTO had to establish linkages with them. These were Zonal Transplant Coordination Committee (ZTCC) in Maharashtra, Tamil Nadu Network for Organ Sharing (TNOS) in Tamil Nadu, Kerala Network for Organ Sharing (KNOS) in Kerala etc. The Registered Societies, NGOs, etc. operated these networks. When Government machinery of States and Centre took the command of organ donation and transplantation, some of these networks dissolved and new State Government owned networks established. While some NGOs/Societies operating previous networks got protection from State Government like TNOS, few others faced an axe also like ZTCC and ZCCK. The equations varied from one State to another. A few of these networks for NOTTO networking are: -

Zonal Transplant Coordination Committee (ZTCC)

In Maharashtra, a Non-Governmental organization, the Zonal Transplantation Coordination Centre (ZTCC) was established in 1996. It is involved in all the processes of organ donation, retrieval, transportation and transplantation of organs. This committee contains a team of surgeons, members of NGOs, etc. The ZTCC has its offices in Pune, Mumbai, Nagpur, and Aurangabad. The cadaver organ donation in Maharashtra picked up very well in the last few years. Maharashtra supported NOTTO in all possible ways as communicated to the researcher by officials at NOTTO.

Figure4.5 Year of establishment of Organ Sharing Networks in India

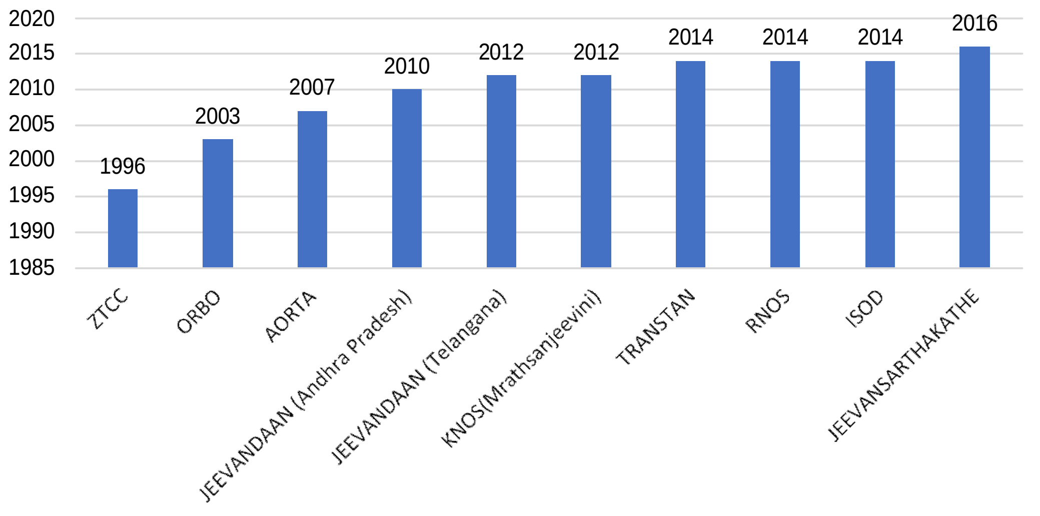


Figure 4.5 reveals the year of establishment of organ sharing networks in India. ZTCC is the oldest and ‘Jeevansarthakathe’ the newest network of organ sharing established in 1996 and 2016, respectively.

Indore Society for Organ Donation (ISOD)

The State of Madhya Pradesh lacked an efficient mechanism of organ donation that led to the formation of a society headed by Divisional Commissioner, Indore. This society registered in 2014-15. As on date, it has 15 organ and tissue transplant hospital registered with it. This society is in the process of launching a full-fledged website to rope in all stakeholders in organ and tissue donation and transplantation. Its website has the provision of hospital and NGO registration. It maintains the wait list of recipients and provides links to NOTTO also. Is has been instrumental in using organs within its State hospitals and has shared organs with hospitals of other States in close coordination with NOTTO.

It has distributed BSD donor organs to different State from 2015 to 18th September 2017. Eighteen cadaveric hearts shifted to various States after establishing green corridors and airlifting hearts to Delhi (5), Haryana (1), MP (11) and Maharashtra (1) from 2015 to 18th September 2017. Similarly, 23 cadaveric livers had been shared with these States during the same period Delhi (7), Haryana (4), MP (11) and

Maharashtra (1). The society is functioning to get the Heart & Liver transplant done in Indore itself and is cooperating very well with NOTTO as per a key person associated with it.

JEEVANDAAN Cadaver Transplant Programme -Telangana

'Jeevandan' is a Government run organ donation and transplantation scheme in Telangana, established in 2012. It addresses the various issues relating to organ donation and transplantation in Telangana.

'Jeevandaan' has 25 registered hospitals for organ transplant, 24 hospitals are registered for a kidney transplant, 11 for liver transplants, 13 for heart transplants, 5 for pancreas transplants and 2 for lung transplants as per the latest records available with NOTTO.

The Nizam's Institute of Medical Sciences (NIMS) is designated as the "Appropriate Authority for Cadaver Transplantation (AACT)".

Figure 4.6 State-wise distribution of Organ Sharing Networks in India

Telangana and Andhra Pradesh divide can be seen in organ sharing as well. It was reported in the beginning when the State of Andhra Pradesh got bifurcated, Telangana got many hospitals but was also in need of more organs like liver and heart. On the other hand, AP had mostly kidney transplant hospitals and could share the liver and hearts with Telangana but was reluctant to do so after the State got bifurcated.

‘JEEVANDAN’ Andhra Pradesh

One networking organization called 'Jeevandan' formed in 2010 as per a Government order. At that time Telangana was not a separate entity but part and parcel of Andhra Pradesh. But when Andhra Pradesh got bifurcated into two States in 2014, the equations changed between Telangana and Andhra Pradesh, the boundaries got distributed so did the hospitals. The transplant hospitals got distributed between the two States. NIMS, Hyderabad, Osmania Medical College, Hyderabad and Gandhi Medical College, Secunderabad were in the State of Telangana. Because of the above, certain amendments were made to existing rules and it was contemplated to replace "NIMS, Hyderabad" with Dr NTR University of Health Sciences, Andhra Pradesh Vijayawada to serve the purpose of 'Jeevandaan'at AP. Accordingly, NIMS, Hyderabad is the office for 'Jeevandan Telangana' and Dr NTR University of Health Sciences, Andhra Pradesh, Vijayawada is the office for 'Jeevandan' Andhra Pradesh. There are 33 transplant hospitals in Andhra Pradesh, and four hospitals are Non-Transplant Organ Harvesting Centres (NTOHC). All 33 organ transplant hospitals are kidney transplant hospitals. Out of these 33 kidney transplant hospitals, 7 are performing liver, 4 are performing heart and 3 are performing lung transplants also.

Zonal Coordination Committee of Karnataka (ZCCK) / JEEVASARTHAKATHE

Zonal Coordination Committee of Karnataka for Transplantation (ZCCK) had been a nodal organization for organ sharing in Karnataka till 2016 November officially. It had 34 hospitals in its network. In order to improve cadaveric organ donation in the State, the Government of Karnataka in November 2016 set up 'Jeevasarthakathe' that shall work on the lines of 'TRANSTAN' (Transplant Authority of Tamil Nadu), 'Jeevandan', and 'Mrithasanjeevani' that are three different transplant authorities in Tamil Nadu, Telangana and Kerala respectively. 'Jeevasarthakathe' society geared to set up a State Organ and Tissue Transplantation Organisation (SOTTO) in Karnataka, as mandated by the National Organ and Tissue Transplantation Organisation (NOTTO).

Following the establishment of this new society, the former Zonal Coordination Committee of Karnataka for transplantation (ZCCK), which was run by a group of like-minded doctors from private hospitals, has ceased to exist.

Transplant Authority of Tamil Nadu / 'TRANTAN'

In response to undesirable Kidney scams revealed in tsunami settlements, Cadaver Transplant Program was initiated on 16.09.2008. MOHAN Foundation contributed a lot to Cadaver Transplant Program through Tamil Nadu Network of Organ Sharing (TNOS). But Transplant Authority of Tamil Nadu i.e., 'TRANSTAN'; a registered society, was formed on 12.12.2014 under the Chairmanship of the Honourable Chief Minister of Tamil Nadu. It functions as State Organ and Tissue Transplant Organization (SOTTO) for the State of Tamil Nadu and Regional Organ and Tissue Transplant Organization (ROTTO) for neighbouring States. It is delegated with the coordination and management of the entire range of organ and tissue transplant activities. Its office is situated at Government Multi Super Speciality Hospital Omandurar Government Estate, Chennai. It has 62 hospitals registered with it as per the latest records available with NOTTO.

Kerala Network for Organ Sharing (KNOS)

The “Mrithasanjeevini programme” a Deceased Donor Organ Transplantation Program started in Kerala in 2012 through State Government initiative It has established an online Transplant Registry called Kerala Network for Organ Sharing (KNOS). It has roped in private hospitals as well and is promoting deceased organ donation and transplantation on similar lines as that of Tamil Nadu.

Rajasthan Network for Organ Sharing (RNOS)

To increase the organ donation rate in the State, the Department of Health and Family Welfare in Rajasthan has engaged itself in promoting deceased organ donation and transplantation through Rajasthan Network for Organ Sharing (RNOS) in 2014. Impressed with the cadaver donor programme in the States of Tamil Nadu and Kerala it is in the process of evolving an effective State cadaver donation programme on similar lines.

Armed Forces Organ Retrieval and Transplant Authority (AORTA) -2007

The organ donation initiatives in the Armed Forces initiated in April 2007. It is being coordinated by Armed Forces Organ Retrieval and Transplantation Authority (AORTA) in Army hospital (R&R) under the aegis of Office of the Director General Armed Forces Medical Services (DGAFMS). AORTA owes its success to a team of about forty officials comprising of doctors and paramedics. They were sent to the United Kingdom to get acquainted with all aspects of transplantation and organ donation who later started AORTA as per the information shared by a key person in DGHS.

Organ Retrieval Banking Organization (ORBO): -Organ Retrieval Banking Organization is part and parcel of All India Institute of Medical Sciences (AIIMS), New Delhi. It was established in 2003 as reported by a very senior officer at ORBO. It was built with a purpose to improve BSD organ donation rates in India by creating awareness, developing linkages with organ transplant hospitals in the country. However, with the establishment of NOTTO, its role is limited to AIIMS only now.

Northern and Southern Divide in Networking and Getting Data

As per the data shared by NOTTO with the researcher, there were 231 hospitals registered with various organ sharing networks of 8 States, as shown in the Table below. But only 95 hospitals had registered with NOTTO till 6.9.2017.

Table4.1 Gaps between numbers of organ transplant hospitals registered with NOTTO in comparison to their registration with State level organ sharing networks as on 6.9.2017

State	Organ Sharing and Transplant Networks	Total Registered Hospitals with State organ sharing networks	Registered Hospitals with NOTTO	Percentage gap of registration with NOTTO
Andhra Pradesh	Jeevandan	*33+4(*NTOHC)	0	100%
Telangana	Jeevandan	26	1	96.16%
Karnataka	ZCCK	34	7	79.41%
Tamil Nadu	TRANSTAN (TNOS)	62	16	74.19%
Kerala	KNOS	26	16	38.46%
Rajasthan	RNOS	9	6	33.33%
Madya Pradesh	ISOD*(Indore)	7	11	0%*
Maharashtra	ZTCC* * (Mumbai)	30	38	0%**

ZTCC* *(Mumbai mainly) and ISOD*(Indore only)

Table 4.1 reveals gaps between numbers of organ transplant hospitals registered with NOTTO in comparison to their registration with State level organ sharing networks as on 6.9.2017. Regarding 0%*gap of Madhya Pradesh in the Table, it is important to mention that ISOD caters to Indore only leaving rest of the State.

Also, regarding the 0%** gap of Maharashtra, the researcher analysed that there were 30 hospitals in ZTCC Bombay, but only 14 organ transplant hospitals had registered with NOTTO. Also, there are some hospitals registered with NOTTO, but not with ZTCC that could be because those hospitals belong to ZTCC networks of Pune, Aurangabad and Nagpur.

There were huge gaps between the number of organ transplant hospitals from the Southern States like Telangana (100%), Andhra Pradesh (96.16%), Karnataka (79.41%), Tamil Nadu (74.19%) and Kerala (38.46%.) that got registered with

NOTTO. There are either no gaps or less gaps in the registration of hospitals with NOTTO when it comes to the northern part of India as on 6.9.2017.

Also, the southern States have a higher number of hospitals registered with their respective organ sharing networks in comparison to northern States.

As per the key personnel at NOTTO, 'TRANSTAN' in Tamil Nadu has Tamil Nadu Network of Organ Sharing (TNOS). Similarly, Rajasthan has Rajasthan Network of Organ Sharing (RNOS), and Kerala has Kerala Network of Organ Sharing (KNOS). All these networks are using the software of MOHAN Foundation, which is 20 years old software. It is not possible for that software to be compatible with NOTTO software as there have been more significant changes in organ donation and transplantation field. Instead of making NOTTO website compatible with these networks, there is a need to have their software compatible with NOTTO software as reported by concerned officials of NOTTO.

Establishing Linkages with Regional Organ and Tissue Transplant Organizations (ROTTOs)

NOTTO needs to maintain linkages with proposed ROTTOs at regional level primarily for monitoring transplantation activities and maintaining consolidated databank. NOTTO, in turn, shall circulate pertinent information to all stakeholders, assist in management of data also. NOTTO shall provide consultancy services on all the aspects of donation and transplantation both in legal areas and non-legal areas. It shall also coordinate/organize training for Health Professionals in the region. Such linkages could help in better Co-ordination for the procurement of organs and tissues.

Functions of Regional Organ and Tissue Transplant Organization (ROTTO):

- All Regional Organ and Tissue Transplant Organizations (ROTTO) shall develop their office under NOTP.

- Will network with registered organ and tissue retrieval and transplant hospitals, retrieval medical colleges, transplant centers & registered organ/tissue retrieval trauma centers of the region for organ and tissue donation and transplantation.
- Shall network with establishments for donor pledging as well.
- Identify organ retrieval teams for each major hospital & get these hospitals registered for organ and tissue retrievals.
- Make a list of Transplant coordinators of all transplant hospitals & retrieval centers, their surgeons/ other specialists.
- Identify staff who need training for their specific jobs like organ & tissue donation/ retrievals/ organ transplant/ maintenance of tissue banks and arrange their training.
- Prepare the Brain Stem Death Committee (BSDC) of each Organ and Tissue Transplant Hospital (OTTH) & Organ and Tissue Retrieval Hospital (OTRH). Besides ROTTO will encourage them for conducting training on BSD certification, donor maintenance etc.
- Prepare educational material for different levels of health professionals.
- Conduct short orientation and sensitization training for doctors, PG & UG students, lab technicians, nurses, health educators etc.
- Develop standard syllabus and duration for the training of Organ and Tissue Transplant Coordinators (OTTCs) & Organ Transplant and Retrieval Coordinators (OTRCs).
- Conduct IEC activities for general public/relatives of ICU patients.
- Display attractive posters, audiovisual message on organ transplant.
- Conduct advocacy campaign.
- Support eye banks of National Programme for the Control of Blindness. The facility of storage of eye/ cornea will be housed at NOTTO Tissue Bank as well as ROTTO tissue banks.

Table 4.2 Proposed organizations for ROTTOs in various States for networking with various States and UT's

Proposed organization for ROTTO	**State or UT for ROTTO**	**States and UT's under proposed ROTTO**
Seth GS medical college and KEM Hospital.	Mumbai (Maharashtra).	Chhattisgarh, Gujarat, Goa, Daman, Diu, Dadar and Nagar haveli, M.P and Maharashtra.
Govt. Multispecialty Hospital, Omnadurar.	Chennai (Tamil Nadu).	Andhra Pradesh, Andaman and Nicobar Islands, Lakshadweep, Kerala, Karnataka, Pondicherry, Tamil Nadu and Telangana.
Institute of Post Graduate Medical Education and Research.	Kolkata (West Bengal).	Bihar, Jharkhand, Orissa, Sikkim and West Bengal.
PGIMER Chandigarh.	UT of Chandigarh.	Chandigarh, Haryana, HP, J &K, Punjab, Rajasthan, Uttar Pradesh and Uttarakhand.
Guwahati Medical College.	Assam.	Assam, Arunachal Pradesh, Meghalaya, Mizoram, Manipur, Nagaland and Tripura.
NOTTO.	Delhi and NCR.	Delhi, a part of Haryana and a part of Uttar Pradesh.

Table 4.2 reveals the five proposed ROTTOs in the country along with the various States and UT's proposed to be networking with designated ROTTOs **(Source: -NOTP Cell,2015).**

Issues and Challenges of ROTTOs

As per the information received, out of five ROTTO's only three ROTTO's are functional. Kolkata and Guwahati ROTTO's are not working (as per the interview carried out with a contractual employee in 2018). Chennai is self-sufficient with multiple transplant hospitals and hardly considers NOTTO for sharing of organs. Mumbai and Chandigarh have shown loyalty towards NOTTO for sharing of organs.

The Government-run Regional Organ and Tissue Transplant Organisation (ROTTO) monitors the cadaver organ transplant programmes in western and central India and operates from KEM Hospital, at Mumbai, Parel. It may eventually dismantle State based NGO-run Zonal Transplant Coordination Committee (ZTCC). This ROTTO is coordinating organ transplants between various States like Maharashtra, Gujarat, Goa, Madhya Pradesh, Chhattisgarh and Union Territories like Daman, Diu, Dadra and Nagar Haveli. The KEM Hospital centre has been provided funds by the Centre. It is proposed to dissolve ZTCC after Govt. owned ROTTO stands on its feet. Eventually, ROTTO will facilitate organ transplants within the neighbouring States. Some members of ZTCC may become a part of the ROTTO team.

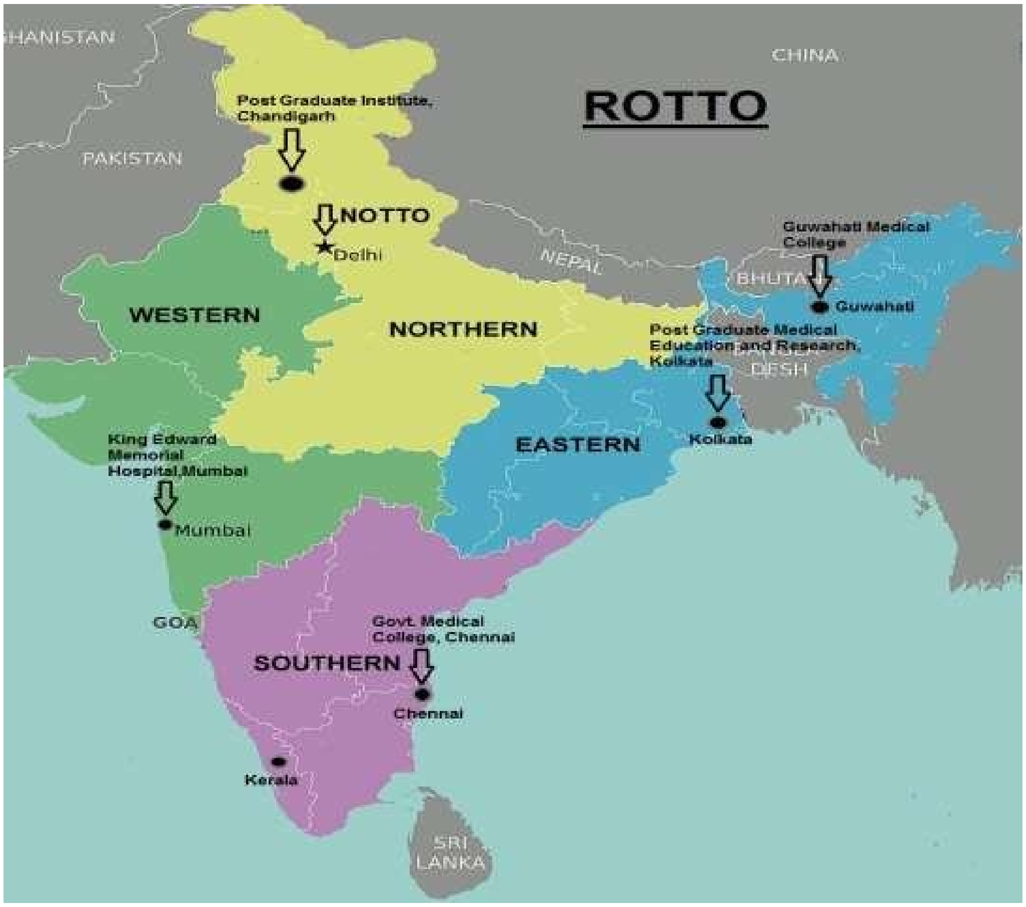


Figure 4.7 Proposed ROTTOs in the country

Establishing Linkages with State Organ and Tissue Transplant Organizations (SOTTOs):

Pradhan Mantri Swasthya Suraksha Yojana (PMSSY) announced in 2003, contemplated of setting up 6 AIIMS-like institutions in 6 States at Patna, Raipur, Bhopal, Bhubaneswar, Jodhpur and Rishikesh at an estimated cost of 840 crores of rupees per AIIMS.

Figure 4.8 Proposed six SOTTOs in the country in AIIMS like institutions

It has been proposed to establish State level organ donation and transplant organizations in the name of State Organ and Tissue Transplant Organizations (SOTTO) in above mentioned 6 AIIMS like institutes. One SOTTO each at Jodhpur in Rajasthan, Raipur in Chhattisgarh, Bhubaneshwar in Orissa, Rishikesh in Uttaranchal, Patna in Bihar, and Bhopal in Madhya Pradesh as shown in Figure 4.8.

Functions of State Organ and Tissue Transplant Organizations (SOTTOs):

The SOTTO will do activities like ROTTO in the respective State and take help of nearest tissue banks of the ROTTO/NOTTO. It will send regular reports in the specified format to the ROTTO & NOTTO. SOTTO will also coordinate with all the eye banks and other registered tissue banks and other stakeholders in the State e.g.

Organ and Tissue Transplant Hospitals (OTTHs), Organ and Tissue Retrieval Hospitals (OTRHs), Medical Colleges, Trauma centres and Hospitals with ICU.

Issues and Challenges in Getting Proposed SOTTOs Established

Proposed AIIMS like institutions are still in the process of getting established in some States. Creating SOTTOs is a dream that may not come true very early.

As reported, there are a lot of conflicts in some States as AIIMS like institutions are going to be autonomous bodies far from the control of State Govt. machinery. And a few well-established Govt. Hospitals in many States are doing transplant surgeries. Such Government hospitals want reins of SOTTOs in their hands. At present NOTP has received many proposals for the establishment of different SOTTOs at Indore, Patna, Rajasthan and UP and are in the process of getting established also. As per reports by a senior level officer, one SOTTO is going to get organized at MGM College at Indore instead of at Bhopal AIIMS as was earlier proposed. In this case, Bhopal AIIMS must be de-notified.

Similarly, another proposal from Jaipur for establishing SOTTO in Rajasthan has come that may lead to de-notification of AIIMS Jodhpur. Similarly, from Uttar Pradesh, a plan for creating SOTTO at Sanjay Gandhi Postgraduate Institute of Medical Sciences in Lucknow has come. Likewise, Indira Gandhi Institute of Medical Sciences (IGIMS), at Patna is trying hard leaving no stone unturned in a bid to establish SOTTO within it and get AIIMS Patna de-notified. All these processes of developing SOTTOs are going on as reported by a senior level DGHS official.

Establishing Working Relationships with NGOs Working in This Area

Several NGOs are working all over the country towards organ donation and Transplantation. These are MOHAN foundation, Narmada Kidney Foundation, Shine India Foundation, Muskaan Group, Shrimad Rajcharya: Love and Care, Apex Kidney Foundation, Zublee Foundation, A Million Pledges, Dadichi Deh Dan Samiti, etc. Establishing networking relationships was an essential mandate of NOTTO but a sensitive area too. ‘ORGAN India’ an NGO organized two Conclaves and involved

NOTTO and NOTP too. The collaborative Conclave provided a platform for bringing together all the NGOs working on different aspects of organ donation and transplantation. The first Conclave was organized on December 1, 2016, and second on November 28, 2017. The second Conclave was conducted in the premises of NOTTO and had about 50 representatives from various NGOs, and the researcher was also a part of that Conclave. Through this Conclave, various organizations came together and discussed their plans of action, challenges and issues faced by them that required redressal by NOTTO.

NOTTO Wanted NGOs to Focus On: -

- Increasing organ retrieval rate in India as there were limited organ retrievals done in 2017.
- Arranging Funds for BSD donor families by creating a corpus of funds by the Government of India where organ recipients may also contribute for providing financial support to family/ spouse/children of donor.
- Arranging special Insurance Schemes for BSD donor families for education or livelihood of the donor family.
- Providing incentives for individuals engaged in the process of organ donation like doctors, nurses, coordinators who make organ donation and transplant possible.
- Increasing registration of hospitals with NOTTO.
- Setting up regional tissue banks especially for skin and bones that are missing all over the country.
- Promoting body donation also.
- Organizing collaborative Conclave every six months.

Success Post Collaborative Conclave

- The online collaborative portal was launched; however, this portal was non-functional as this domain had expired on 5/25/2018 and is pending renewal or deletion.

- Helped in network building.
- School curriculum also introduced organ donation.

Agenda of Second Collaborative Conclave

- One universal design of donor cards to be issued by all agencies as there were different cards issued by various agencies.
- Should there be physical donor card or an e-card? Can NGO charge to send donor cards to make up the cost?
- Notification of November 27 as organ donation day by the Government.
- Funding for NGOs-financial support from NOTTO &Govt of India. Ways and methods to be evolved. How to apply?
- NOTTO website to update NGO page and operate it. Formal accreditation of NGOs on the NOTTO website.
- NOTTO to update SOTTOs and ROTTOs.
- Include a Chapter on organ donation among medical students.
- Building awareness among school children-lobby for one Chapter on organ donation in school books (NGOs to offer their expertise).
- Swap registry at the national level, a national database for swap transplants and merging of the cadaveric programme with swap programme.
- Organ transplants are taking place, but there is no mechanism to follow transplant patients to determine success rates. The same was asked to be made available to the public.
- Identifying and setting up protocols for non-transplant centers that are missing as on date.
- A lot of donor families are devastated due to the death of the person whose organs give life. An urgent need to provide help to donor family through CSR funds, NGOs and Governments was suggested.
- NOTTO was requested to be maintain Body donation registry also.

- Indian Medical Association to be roped in for supporting organ donation in a big way.
- Using new age communication tools, social media and other media to promote organ donation.
- NOTTO to write the film chamber of commerce and issue a directive to show a clip-on organ donation before every movie.

Establishing Inter-Ministerial Linkages

It was felt that involving other ministries shall go a long way in making a useful dent on organ donation and transplantation.

Inter-Ministerial Networking for Organ and Tissue Donation and Transplantation: - NOTTO understood that organ donation and transplantation is not only the responsibility of the Ministry of Health but requires the consolidated efforts of all other ministries. In this regard, the inter-ministerial committee to coordinate all activities related to the promotion of organ donation in the country was constituted, and the first meeting was held on 18.2.2016. Based on the minutes of meeting numbering S.12011/44/2015-MG/MS, dated 23.3.2015, following miniseries were roped in together for different inputs within their domain that could smoothen organ donation and transplantation in the country: -

1 Ministry of Human Resource Development: Department of School Education & Higher Education,
2 Ministry of Home Affairs
3 Ministry of Communications and Information Technology
4 Ministry of Women and Child Development
5 Ministry of Road Transport and Highways
6 Ministry of Information and Broadcasting
7 Ministry of Corporate Affairs
8 Ministry of Urban Development and CPWD
9 Ministry of Civil Aviation

10 Ministry of Skill Development and Entrepreneurship
11 Ministry of Railways
12 Ministry of Law & Justice
13 Ministry of Social Justice and Empowerment

Railways, road transport and civil aviation ministries were requested for offering travel **Concessions** to first degree relatives of BSD donors, transplant recipient and living donors. These ministries were also roped in to facilitate **Transportation** of BSD donor organs to various transplant hospitals of the country. **Financial support**, like Incentives to donor families and providing free treatment to poor transplant patients, was also sought from few ministries. Ministries were requested for **Social Support** to consider Living Donor' and 'Transplant Recipient' healthy after donation/ transplantation, arrange BSD donor’s funeral with dignity, provide support for dependent female patients (abandoned / destitute and children suffering due to End Stage Organ Failure of parents). The legal department was asked for **Legal support** for making post-mortem rules easy, ensure guidance and quick redressal of new issues, try all cases related to organ transplant under THOT Amended Act and no other Act. However, IEC was the core component of the support sought from all ministries, as shown in Figure 4.9 below.

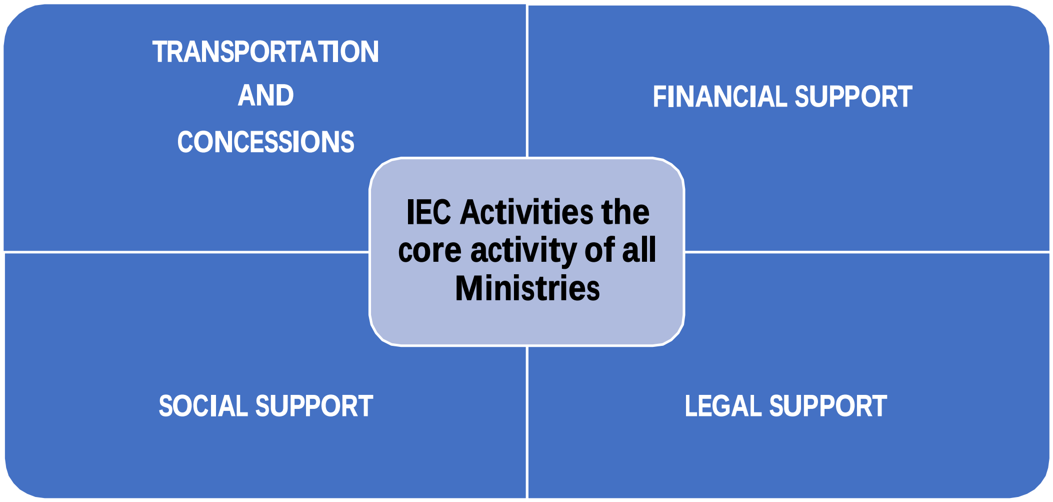


Figure 4.9 Diagrammatic representation of inter-ministerial support sought by NOTTO

Common Activities Proposed to Be Undertaken by All Ministries

The common activities proposed for all ministries focused on IEC activities. The main aim of these IEC activities was to rope in more people for pledging to donate organs & tissues and make them understand the importance of organ donation. The proposed activities are: -

- Information, Education and Communication (IEC)activities to promote organ donation.
- Information about organ donation may be put up on the website of all ministries.
- Link of NOTTO on the homepage of websites of all ministries.
- Encouraging officials to pledge to donate organs.
- Honoring organ donors.
- Non-Governmental organizations working with various departments to be sensitized on organ donation.
- Display organ donation slogans in various forms / documents /forms/ letter pads etc.
- Inclusion of donor status on all departmental ID and Smart Cards.
- Red Cross / Rotary/ Lions/ MOHAN Foundation/ Organ India and other NGOs to be involved in the promotion of organ donation.
- Organ donation promotion activities to be undertaken during national and international conferences. Ministry of Health shall provide expertise for the same.
- A punchline about organ donation may be printed on all official communications by the Ministries.

Besides, ministry specific actions proposed in the meeting are as follows: -

Ministry of Human Resource Development, Department of School Education & Higher Education

- Focus on Health promotion and prevention of organ failures.
- Inclusion of Organ donation and transplantation in the academic curriculum.
- Provide Organ donation and transplant Information on the HRD website.

- Distribute End stage Organ Failure and Organ transplant pamphlet in all educational institution at all levels.
- Do In-service update of teachers about organ donation and transplantation.
- Observe Indian Organ Donation day on 27th November in each school/ college/ university.
- Thematic activities about Organ Donation shall be undertaken during any Programme celebration.
- Organize State level / National level competitions.

Ministry of Home Affairs – Police/Custom

- Support and cooperate with providing Green Corridor during the transport of organs.
- Promptly handle Medico-Legal Cases and those related to the unclaimed body for organ donation.
- Sensitize Police Personnel about Organ Donation.
- Safety of transplant professionals by police.

Ministry of Communications and Information Technology

- Develop Stamp on organ donation.
- Provide messages on Post Cards / Inland letter cards / envelopes.
- Preparation of Mobile application for organ donation awareness.
- Use of Social Media.
- Organ donation messages while the telephone is getting connected.
- Inclusion of slogan on Organ Donation on all kinds of bills of MTNL & BSNL etc.
- Primetime use of media for spreading the message.

Ministry of Information and Broadcasting

- Services of Press Information Bureau to be utilized.

- Background material, including success stories to be given well in advance to PIB so that they can make use of that material for information dissemination at regular intervals.
- All India Radio talks and all DAVP related activities including the broadcasting of audio spots, telecasting video spots on TV Channels, displaying organ donation messages through slides in cineplex/ multiplex.
- Involvement of song and drama division and field publicity division for promotion of organ donation.
- Conducting media sensitization workshops.
- Skits / Plays / Competition / Messages / Debates by Door darshan, DAVP etc.
- Regular information about organ failure and organ transplantation in print and electronic media.
- Display of Organ Donation message in Digital display Boards at places like ITO/ Akshardham / Delhi Cantonment / Inter – State Bus Terminal / local bus stands and Stadia etc.

Ministry of Women and Child Development

- Support for dependent female patients (abandoned / destitute and children suffering due to End Stage Organ Failure of parents).
- Leave for Living Donor working women.
- Awareness about Organ Donation in Anganwadi centers/ Mahila Mandals / panchayats.

Ministry of Law & Justice

- Short/ Quick redressal and guidance on new issues
- Cases related to organ transplant to be tried under the THOT Amended Act and no other Act.
- Making post-mortem rules easy and operable concerning organ transplantation in consultation with MOHFW.

Ministry of Social Justice and Empowerment

- Financial support for poor Transplant patients.
- Incentives to donor families.
- Living Donor to be considered healthy after the donation of organ and should not be made unfit for the job.
- Transplant recipient not to be considered unfit in consultation with DOPT.
- Arrangement for Deceased Organ Donor's Funeral with Dignity.

Ministry of Road Transport and Highways

- Arranging a green corridor for transportation of organs.
- Supporting the cause by making the option for Organ pledging on the driving license.
- Organ transportation should be made free between States.
- Tracking system / Transplant vehicles to have special beacons.
- Display about Organ Donation message on highway hoardings.
- Travel concession incentives to first degree relatives of deceased donors and the recipient and living donor for transplant and follow up.

Ministry of Civil Aviation

- Sensitization of staff for early takeoff / exit of the organs (Box) with persons carrying it.
- Complimentary professionals and organ (Box) air transfer in the time of requirement.
- Concession on the basic fare for first degree relatives of the deceased donor.
- Standardized box carrying donor organ to be identifiable by aviation staff.

Ministry of Skill Development and Entrepreneurship

- Skill development of professional/ ancillary support staff for transplant & trauma centers.
- Support in capacity building for setting up stand-alone dialysis centers/ dialysis machines production/ and other material.

- Employment related to the skill development of poor transplant recipients for their own and family living.

Ministry of Railways

- Railway concession for recipient and donor for transplant and its follow-up.
- Railway pass for a first-degree relative (s) of deceased donor.
- Display about Organ Donation message on Screens at platforms/trains.
- Promotional messages about Organ Donation on all kind of tickets and eatable packages (Like Tea Cup, water bottle etc.).

Ministry of Corporate Affairs

- Promotion of organ donation may be added in the list of Corporate Social Responsibility through Ministry of corporate affairs.

Ministry of Urban Development and CPWD

- Display of boards about organ donation and information through all local self-Government bodies in their respective areas and on central Government buildings by CPWD.

Struggles of Initial Years of NOTTO

When NOTTO took over, it had a few initial years of struggle. It had to develop working relationships with multiple organizations, establish linkages and develop website etc. It faced a lot of challenges and issues in doing so.

The Initial Focus of NOTTO: Website Development with Teething Problems

NOTTO is a national organ and tissue donation and transplantation network like that of NHSBT in UK or UNOS in the USA. The budget of Safdarjung Hospital (SJH) helped in building its premises, and NOTP budget helped in the purchase of its furniture (as told by one of the senior officers associated with the programme). It is an apex organization under DGHS, MOHFW and occupies the 4th and 5th floor of pathology department of ICMR building in the campus of SJH.

As an organization, it must keep everyone pleased. It is situated within the campus of SJH and is under the financial control of Medical Superintendent of SJH. It is supposed to work under the guidance of DGHS in Ministry of Health and Family Welfare. And it occupies space in ICMR building. It cannot ignore anyone like SJH, DGHS or ICMR. Pleasing every organizational head was not that easy as every organization felt it contributed more to its formation.

Many times, the files did not move; there were issues of ego and ownership. NOTTO as a body wanted to breathe on its own and get rid of the shackles of its multiple owners. Senior members of NOTTO contemplated to form it into a Society several times during discussions in the presence of the researcher. It had to take a leadership role in the country when some States had moved ahead and were performing very well in the deceased organ donation programme. Some States, on the other hand, were much behind, and some States had yet to start organ transplantation services. It had a significant challenge to learn and lead simultaneously. The transplant surgeons of very high caliber were ready to help this organization to move ahead. It had to consolidate the effort of multiple actors who were involved in organ donation and transplantation.

It chose to move in small steps. The website that is the face of any organization had to be developed first. National Informatics Centre was made responsible for the development of the website in phases. One of the mandates of NOTTO is to connect organ and tissue retrieval and transplant organizations all over the country through ROTTO and SOTTO's of the country with financial support from NOTP. It contemplated of registering hospitals of Delhi and NCR first.

From 1994 after THOA-1994 till 2014 there was no national-level network in India although ORBO in AIIMS was supposed to create the same. During 2007 it was envisaged that there would be ten ORBO's in the county, but ORBO is a part of AIIMS. AIIMS is an autonomous organization and does not allow interference of

DGHS; MOHFW. DGHS officials interacted with the head of AIIMS to enable it to establish ORBO into a national network. But it was reported that AIIMS faced space crunch within its campus for building a national network (as per a very senior level DGHS officer who was interviewed by the researcher). As a result, it was found imperative to set up NOTTO a national level organization in the country directly under the supervision of DGHS, MOHFW. That eliminated the dual problem of space crunch and easy management and monitoring by DGHS. At the regional level five ROTTOs and State level ten SOTTOs had to develop strong linkages with NOTTO. SOTTO must carry out similar functions at State level. ROTTO must compile data and monitor the same at the regional level as per amendments of Transplantation of Human Organs (Amendment) Act 2011.

NOTTO aims to build up a well-established network for procurement, allocation and distribution of organ and tissue donation and transplantation in the country.

One of the tools to achieve its goal is to build up a vivacious NOTTO website. Well developed software at national level networking is possible only with close linkages with ROTTOs and SOTTOs. One platform to work for all the end users of the country is the website. The Prime Minister's speech in October and November 2015 focusing mainly on organ donation and transplantation put more pressure on it to achieve this goal.

As reported by the website developer, there are three key players in the formation of the website. They are client, development team and end users. They must be actively involved for the development of any software. The same holds for NOTTO. The three players involved in this work are-

1) Client (whose vision it is) like DGHS, MOHFW and NOTP

2) Development team (who are going to develop it like National Informatics Centre and contractual employees of NOTTO.

3) End-user (who are going to work on it in actuality) like doctors, Organ and Tissue Retrieval and Transplant Organizations, ROTTOs, SOTTOs, Organ

and Tissue Transplant Coordinators, transplant teams like liver transplant surgeons, heart transplant surgeons, eye Banks, Tissue Banks etc.

NOTTO faced many teething problems in the development of its website as reported by website manager and other officials on various occasions in interviews, discussions and face to face interactions. A few are listed below: -

Unique Programme: -National Organ Transplant Programme was a new programme and had no resemblance with any other national health programmes. The website demands of this programme were very intricate. These demands were not within the comprehension power of officials who had been working in other National Health Programmes in DGHS/Ministry of Health and Family Welfare.

Lack of Data: -NOTTO did not have any data and had to start from scratch. It required a list of organ transplant hospitals working in the country when it began. Hospitals had to be identified first through networks and licensing authorities of various States. All this required cooperation of States, Appropriate Authorities, and Organ Sharing Networks, private hospitals and Government Hospitals. The website data was dependent on the data that had to be shared by all hospitals of the country involved in organ and tissue donation and transplant. It was made possible by making daily calls, sending letters and reminders several times. As a result, by 12 .2.2016, about 20 hospitals got registered with NOTTO.

Lack of Vision and Understanding: -It was admitted even by top officials that vision of developing website was lacking. In the process of its development, someone quoted that "Blind leads blind "referring to the medical professional of NOTTO on one side and website developers on the other side. There had been a lack of understanding in both ways. The medical professionals working in this programme lacked understanding about software development, and National Informatics Centre software development Team could not comprehend the medical demands. In the absence of a blueprint of website development, the process was complicated further.

Model of The Website Was Missing: - When the web portal initiated, there were neither clear requirements nor the vision of developing the same. Besides, the website was developed in a hush-hush manner in response to a court case by a person verses DGHS. It was going on from 2012 onwards in the high court. The court case hearing of the same case was scheduled in May 2016 and DGHS had to reveal the progress of NOTTO web portal. In a nutshell, Model of the website and clarity was missing.

Lack of Vision to Address Language Issues: - India is a country having different languages in States. A vision to have robust software to convert one language into another could have solved many problems of language issues. Primarily NOTTO was not able to identify organizations, and when identified, they had reservations to share data. Even when they shared the data, the language barriers came forth. For example, in many States "Pledge Forms" had been filled up in languages like in Malayalam by Kidney Federation of India.

Similarly, Gandarpan shared "Pledge Forms", but they are in the Bengali language. Translation of each form was a costly affair. Robust software to convert one language into another could have solved the problem.

Predominant Clinical Demands and Lack of Expertise: - The website needed inputs from clinicians from varied specialities like gastroenterology, cardiology, plastic surgeons, eye surgeons etc. The expertise of diverse clinicians was not readily available from public hospitals. Public hospitals lagged far behind both in infrastructure and expertise. Hence, this not only required identification of clinicians but their cooperation and reaching a consensus as well that was at times difficult.

Developing Guidelines and Standard Operative Procedures (SOPs) for Various Procedures of Organ Donation and Transplantation.

When NOTTO took over the reins of organ donation and transplantation, several guidelines along with SOPs had to be developed. Allocation policies for retrieved organs from Brain Stem Dead donors were framed within a short period, with the expert opinion of Adviser to GoI, NOTP officials and other experts working in this area.

Following are available on NOTTO website.

- Allocation criteria for corneas.
- Allocation criteria for heart, lung & heart-lung.
- Allocation criteria for deceased donor liver transplantation in Delhi/NCR.
- Allocation criteria for a deceased donor kidney transplant (guidelines).

National and International Networking Activities

NOTTO undertook several activities to make its presence felt by others who had already established themselves and who were left behind. Some of its worth mentioning major activities are: -

Organizing Conference:

One Day National Advocacy Conference was conducted on 27th March 2015 for sensitization of State Health Secretaries, Director Health Services and other Stakeholders on NOTP.

Launch of National Organ & Tissue Transplant Registry and Observance of Indian Organ Donation Day

On 27th November 2015, 6th Indian Organ Donation Day was observed with various activities like the launch of National Organ & Tissue Transplant Registry, felicitation of the families of the donors, technical sessions and religious discussion etc.

Organized National Retrieval Workshop for Surgeons

NOTTO organized National Retrieval Workshop for Surgeons at M.S Ramaiah Advanced Learning Centre, Bengaluru on 23rd and 24th March 2017 and trained 36 surgeons across India on Cadaver Models with hands-on experiences.

Sensitization Workshop for ICU Experts

NOTTO organized a sensitization workshop for ICU experts and senior nurses. More than 10 ICU workshops have been conducted all over India.

Transplant Coordinator Training Programs for Various States and UTs

Approximately 1200 transplant coordinators have been trained from all over India under the aegis of NOTTO.

India-Spain MOU

1st India-Spain meeting under India-Spain MOU was conducted on 28th July 2017 on Organ Donation Procurement and Management.

Public and Professional Engagements Through Competitions at The National Level

Several competitions were organized by NOTTO from 2014 onwards to involve public and professional engagements on organ donation and transplantation.

Poster Cum Slogan Competition

A Poster cum Slogan Competition was organized by NOTTO on 17th June 2015 in collaboration with Department of Community Health, Vardhman Mahavir Medical College on the Topic "Deceased Organ Donation" with special focus on "Brain Stem Death" & "Organ Donation Pledge"**.** The participants invited were doctors, nurses, medical students & paramedical staff.

National Level Competition

A national level competition was organized by NOTTO via “At My GOV Portal” from 11th to 30th October 2015 for Creation of Logo, Background of Donor Card & Slogan Writing on Organ donation.

Movie Making Competition

On 31st January 2016, a “Movie Making Competition on Organ Donation” was organized by NOTTO in collaboration with VMMC. Five Teams from different Medical colleges of India participated in the competition.

Exhibition at VAMSCON 2016: -

An exhibition by National Organ & Tissue Transplant Organization (NOTTO), in collaboration with (VMMC Annual Medical Students’ Conference) VAMSCON 2016 was organized to create awareness among medical and nursing students.

With a concept of giving a feeling of Superhero to the people who would pledge to donate organs, a Photobooth was set up for pledgers. Every day quiz contest was organized for the students who visited the stall at the exhibition. Winners were awarded a token of the prize in form of NOTTO's Calendar.

Arranging Cricket Tournaments for Public Awareness

During 2015-2016, a health cricket tournament was planned by MOHFW for the promotion of Organ Donation. On each day at least two sessions of an innovative game prepared by the researcher that is “**Tombola on organ donation and transplantation**" were conducted to create awareness among the public. Quiz competitions were also organized, and winners were awarded a token of the prize. The final match of this cricket tournament was played on 15th January 2016. A heart touching skit/street play on Organ Donation was performed during the valedictory function by the cultural group of Vardhman Mahavir Medical College on Organ Donation, which was appreciated wholeheartedly by all dignitaries, spectators & participants.

College Level Competitions

NOTTO organized various competitions for promotion of Organ Donation in several colleges in Delhi in collaboration with Shri Ram College of Commerce, Delhi

University on 1st to 2nd November 2017. Many colleges participated in these competitions.

Conducting Major IEC Activities

NOTTO conducted several IEC activities in collaboration with many other organizations in the country. A few of the significant events from 2014 onwards are: -

Two Weeks Awareness Activities at India International Trade Fair -2014

Awareness activities through Health Talks, Counselling sessions and an interactive game **"Tombola on organ donation and transplantation"** prepared by the researcher were conducted at India International Trade Fair (IITF) from 14 to 27 November 2014 in association with CHEB at the main outdoor stage of Health Pavilion. Quiz contests, Panel Discussions and Role plays were also a part of this awareness activity. It was the first public awareness activity of NOTTO funded by CHEB and conducted at a significant platform in IITF-2014 because of the researcher's motivation and active participation.

SMS Messages

Motivational Messages were dissemination among the public through Mobile SMS in all States & UTs of India from 20th to 26th November 2015.

Accepting Invitations for Awareness Sessions

At many instances, NOTTO was invited to take sessions in awareness programmes conducted by other organizations. NOTTO would always accept such requests.

Well -Organized Organ Donation Awareness Programmes Conducted From 17th to 19th February 2016

A well- organized awareness programme was organized at Nirman Bhawan, New Delhi, to sensitize the officials/officers of Ministry of Health & Family Welfare, GoI. Total of 229 Participants attended this awareness programme over a period of three-day, but very few pledged to donate their organs. With a concept to attract people, a Superhero Photobooth was set up for pledgers. It was a well-organized awareness programme of half-day duration. One-hour session on brain death, organ donation and transplantation, video clips on diagnostic procedures, discussions, answering queries and distribution of NOTTO prepared IEC material were a part of this programme. Very informative question-answer sessions followed these activities attended by many specialists in the organ transplantation field.

On 23rd March 2016, an orientation programme on Organ Donation was conducted by National Organ & Tissue Transplant Organisation (NOTTO) in Conference hall for a group of 70 students from Rufaida College of Nursing, Jamia Hamdard University.

On 5th April 2016, an awareness session was organized by NOTTO to sensitize senior officers of National Building Construction Corporation at NBCC Lodhi Road.

For the year 2017, NOTTO, along with other organizations, conducted well - organized awareness programmes in academic institutions and professional Medical & Nursing institutions in Delhi. These programmes were organized on a similar pattern as done for officials/officers of the Ministry of Health & Family Welfare, GoI, mentioned above. In this event, multiple open competitions were organized on the theme of Organ Donation like Quiz Competitions, Rangoli Competitions, face painting competitions, poster making competitions, role plays etc. Students were made aware of organ donation by lecture methods, question-answer session, distribution of materials followed by their participation in competitions.

Current Status of NOTTO

This part of the Chapter is divided into seven subsets. These reveal glimpses of nationwide NOTTO registered organ and tissue donation and transplant hospitals, Status of Delhi and NCR registered hospitals under NOTTO, Country-level three years (2015-17) deceased donor data available with NOTTO, Organ sharing and allocation through NOTTO: Issues & challenges, Status of Organ and Tissue Donor Register, Status of Organ Transplant Registry and Status of Donor Follow -Up Registry

Glimpses of Nationwide Organ and Tissue Donation and Transplant Hospitals Registered with NOTTO till 6.9.2017

As per the data shared by NOTTO on 6.9.2017, a total number of 199 Hospitals / Health Facilities from 16 States and 4 UT's had registered with NOTTO.

Figure 4.10 Type of transplant health facilities Registered with NOTTO(N=199)

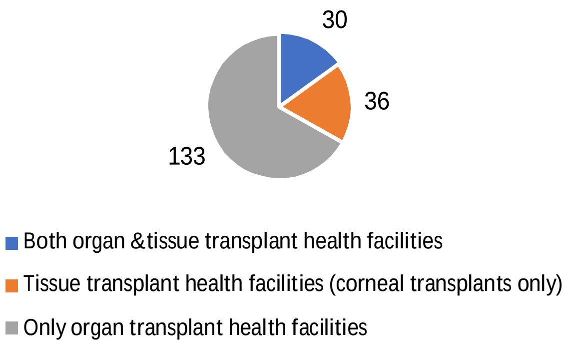


Figure 4.10 depicts that most of the hospitals registered with NOTTO, i.e., 133 were organ transplant hospitals doing organ transplants only, 30 were doing both organ and tissue Transplants and 36 were involved in tissue transplant only that is corneal transplants.

Table 4.3 Number and percentage of Organ Transplants Hospitals Registered with NOTTO as on 6.9.2017 (N=163)

Type of Organ Transplants done	**Number of Hospitals registered with NOTTO**	**Percentage of Hospitals**
Kidney Transplants	159	(97.54%)
Liver transplant	62	(38.03%)
Heart Transplants	34	(20.85%)
Lung Transplants	20	(12.26%)
Pancreas Transplants	13	(7.97%)
Intestine Transplants	7	(4.28%)

Table 4.3 reveals that among 163 organ transplant hospitals registered with NOTTO, majority of the hospitals 159 (97.54%) were kidney transplant hospitals followed by

62(38.03%) liver transplant hospitals and 34(20.85%) heart transplant hospitals. Some of the hospitals were doing more than one type of organ transplants

Table 4.4 Type of Hospitals/health facilities Registered with NOTTO for various tissue retrieval and transplant as on 6.9.2017 (N=66)

Type of Tissue	**Both Organ and Tissue Transplant Hospitals**	**Tissue Transplant Hospital/ Health Facilities only**	**Total**
Cornea	30	36	66(100%)
Heart valves	4	0	4(6.06%)
Cartilage	1	0	1(1.51%)
Blood Vessels	1	0	1(1.51%)

Table 4.4 reveals that there were 66 tissue transplant hospital/ health facilities that had registered for tissue transplant and all 66(100 %) tissue transplant health facilities were involved in corneal retrieval and transplants. There were 4(6.06%) centres involved in the retrieval of heart valves and 1(1.51%) each for cartilage and blood vessel retrieval and transplants.

Table 4.5 State wise distribution of NOTTO Registered organ transplant hospitals (N=199)

STATE AND UT'S OF INDIA	TOTAL REGISTERED HOSPITALS	KIDNEY	LIVER	HEART	PANCREAS	LUNGS	INTESTINES
Haryana	6	5	2	1	1	1	1
Gujarat	5	5	2	1	0		
Goa (UT)	1	1	0	0	0		
Delhi (UT)	37	25	11	7	2	2	2
Chandigarh (UT)	1	1	1	1	1	1	
Bihar	1	1	0	0			
Assam	3	2	1	0			
Karnataka	7	7	1	0			
Kerala	16	15	8	9	3	6	2
Madya Pradesh	14	11	7	2			
Maharashtra	38	38	16	8	4	5	1
Manipur	1	1	0	0			
Puducherry (UT)	2	2	1				
Punjab	23	10	3	0			
Rajasthan	6	4	1				
Tamil Nadu	16	16	3	3	1	3	
Telangana	1	1	1	1	1	1	1
Uttar Pradesh	12	7	3	1		1	
Uttarakhand	2	0	0	0			
West Bengal	7	7	1				
Total	199	159	62	34	13	20	7

Table 4.5 reveals the State wise distribution of 199 NOTTO registered organ transplant hospitals that included 16 States and 4 UTs.

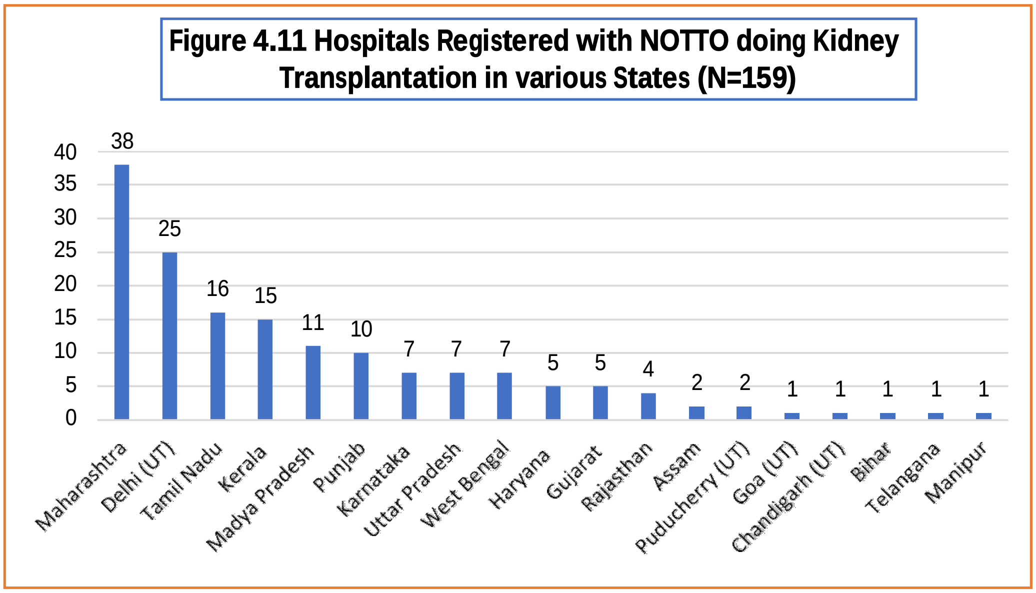


Figure 4.11 Hospitals Registered with NOTTO doing Kidney Transplantation in various States (N=159)

Figure 4.11 reveals that out of 159 NOTTO registered kidney transplant hospitals majority, i.e., 38 were registered by Maharashtra.

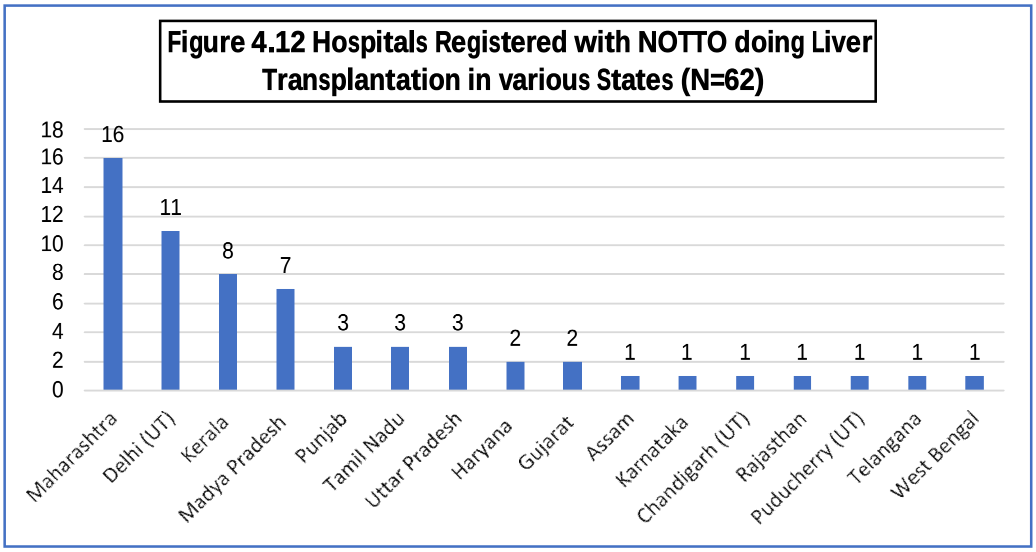


Figure 4.12 Hospitals Registered with NOTTO doing Liver Transplantation in various States (N=62)

Figure 4.12 reveals that out of 62 NOTTO registered liver transplant hospitals most of the hospitals numbering 16 were registered by Maharashtra.

Figure 4.13 Hospitals Registered with NOTTO doing Heart Transplantation in various States (N=34)

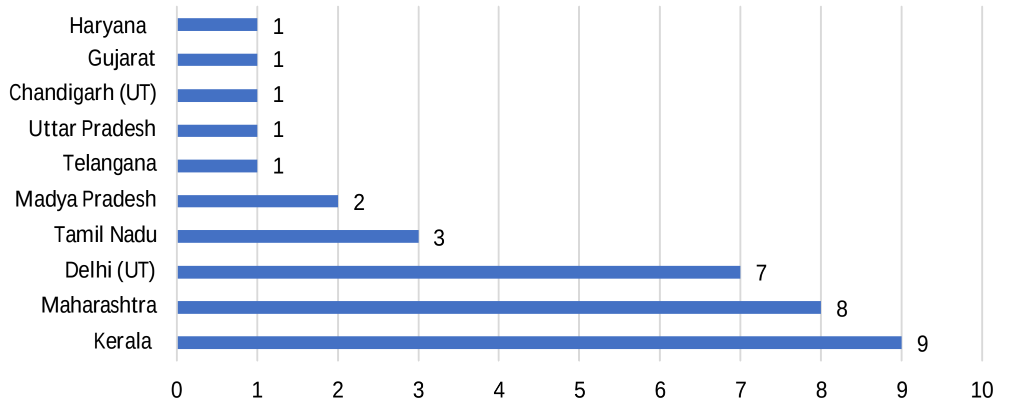


Figure 4.13 reveals that out of 34 NOTTO registered heart transplant hospitals most of the hospitals numbering 9 were registered by Maharashtra.

Figure 4.14 Hospitals registered with NOTTO doing Pancreas Transplantation in various States(N=13)

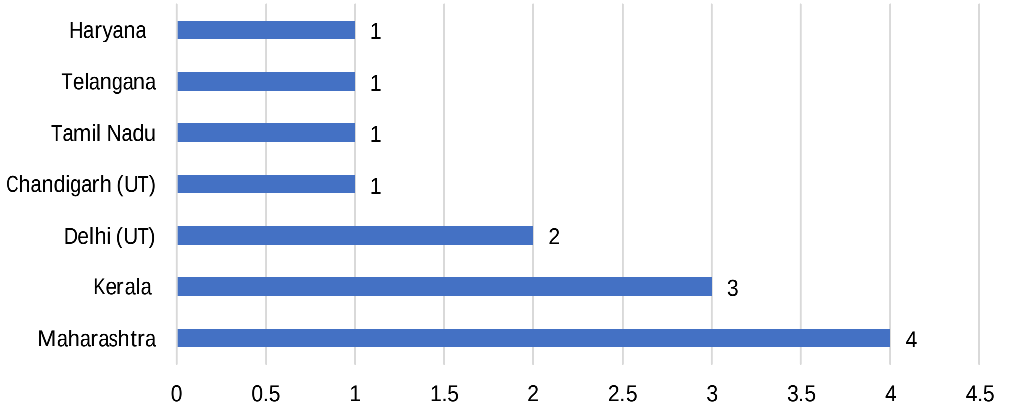


Figure 4.14 reveals that out of 13 NOTTO registered pancreas transplant hospitals majority, i.e., 4 were registered by Maharashtra.

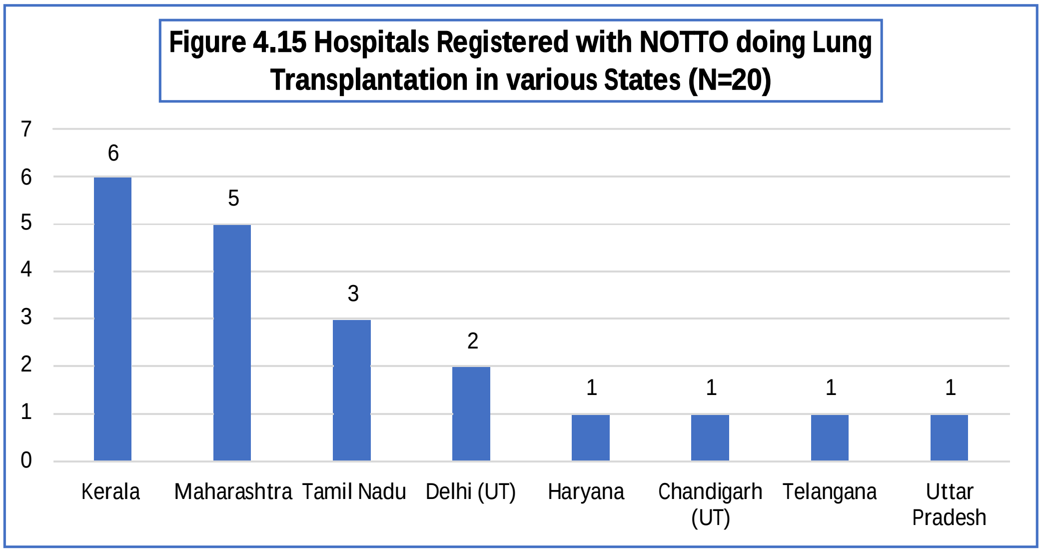


Figure 4.15 Hospitals Registered with NOTTO doing Lung Transplantation in various States (N=20)

Figure 4.15 reveals that out of 20 NOTTO registered lung transplant hospitals majority, i.e., 6 were registered by Maharashtra.

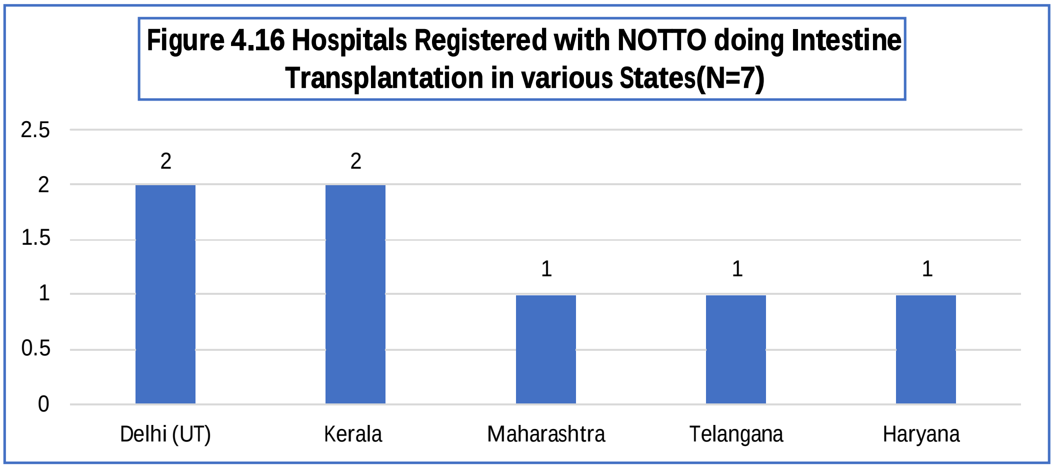


Figure 4.16 Hospitals Registered with NOTTO doing Intestine Transplantation in various States(N=7)

Figure 4.16 reveals that there were very only seven (7) NOTTO registered intestine transplant hospitals with two (2) hospitals in Delhi and two (2) in Kerala.

Status of Delhi and NCR Hospitals Registered With NOTTO

As per the mandate, it was the first and foremost duty of NOTTO to start networking activities initially with all the “Appropriate Authority” licensed hospitals in Delhi and NCR Region as per the objectives mentioned earlier in this chapter. The tireless work done by NOTP and NOTTO could bring 40 hospitals together in Delhi and NCR Region as reported by NOTTO officials in June 2018. The scenario of these hospitals reveals the situation in Delhi and NCR Region.

Figure 4.17 Type of NOTTO Registered hospitals in Delhi & NCR along with the type of organ transplants done (N=40)

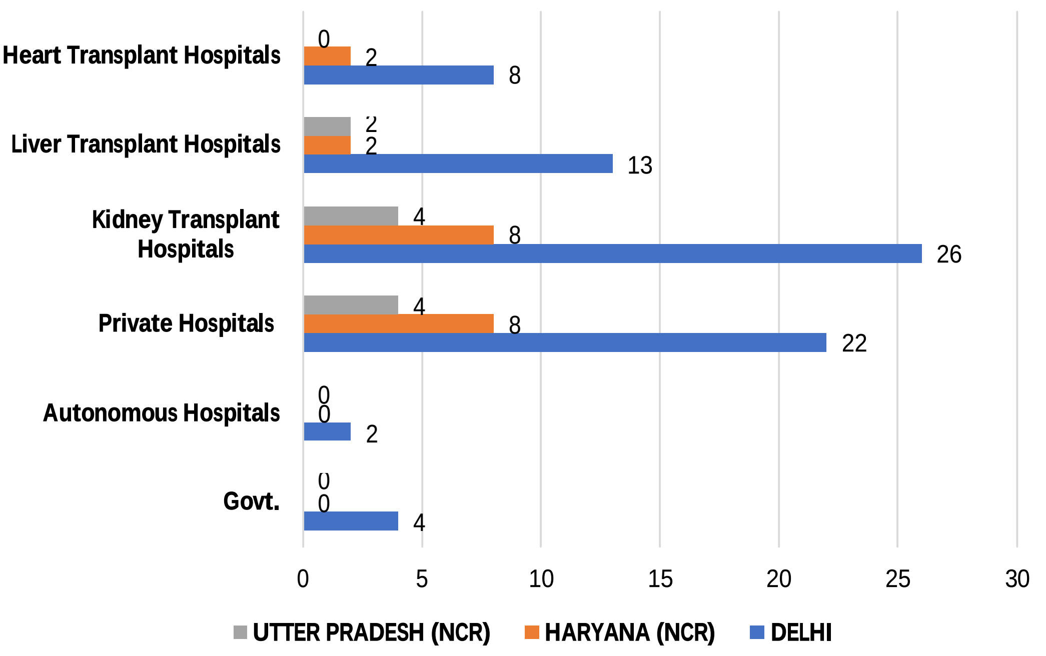


Figure 4.17 reveals the status of 40 NOTTO registered hospitals in Delhi and NCR. There are four (4) Government hospitals and two (2) autonomous hospitals in Delhi only and none in NCR. On the other hand, there are 22 private hospitals in Delhi, 8 in Haryana (NCR)and 4 in UP(NCR). The number of kidney transplant hospitals in Delhi and NCR are more in number as compared to liver and heart transplants.

Table 4.6 Organ transplant services provided by NOTTO Registered Autonomous and Government hospitals of Delhi as on June 2018 (N=6)

NOTTO Registered Organ Transplant Hospitals	Autonomous Hospital	Govt. Hospital	Kidney Transplants	Liver Transplants	Heart Transplants
AIIMS	✓		✓	✓	✓
ILBS	✓		✓	✓	
PGIMER, RML Hospital		✓	✓		✓
GB Pant Hospital		✓		✓	
Safdarjung Hospital		✓	✓		
Army Hospital		✓	✓	✓	
Total	2	4	5	4	2

Table 4.6 reveals that there are total four (4) Government organ transplant hospitals and two (2) autonomous organizations, i.e., AIIMS (under Central Govt.) and ILBS under Delhi Govt. Also, five (5) hospitals were doing kidney transplants and four (4) liver transplants. There were only two institutions that were doing heart transplants.

Table 4.7 Organ transplant services provided by NOTTO Registered hospitals in Haryana under NCR as on 2018 June (N=8)

Name of Private Hospitals	**Place in Haryana**	**Kidney Transplants**	**Liver Transplants**	**Heart Transplants**
Fortis Hospital HUDA	Gurugram	✓	✓	✓
Medanta Hospital	Gurugram	✓	✓	✓
Asian Institute	Faridabad	✓		
Alchemist Hospital	Gurugram	✓		
Artemis Hospital	Gurugram	✓		
Columbia Asian Hospital	Gurugram	✓		
Paras Hospital	Gurugram	✓		
Metro Heart and Super Speciality Hospital	Faridabad	✓		
Total hospitals in Haryana NCR Region		8	2	2

Table 4.7 reveals that all eight (8) hospitals in Haryana under NCR Region are private hospitals and all the hospitals registered in Haryana are in NCR Region as per the data available with NOTTO as on June 2018. As per the table, all eight (8) hospitals in Haryana are doing kidney transplants, and only two (2) hospitals are doing liver, and two (2) heart transplants also.

Table 4.8 Organ transplant services provided by NOTTO Registered private hospitals in Delhi as on 2018 June (N=22)

Private Hospitals /Health Facility	**Kidney Transplants**	**Liver Transplants**	**Heart Transplants**
Batra Hospital and Medical Research Centre	✓		
Dharamshala Narayana Super speciality Hospital	✓		
BLK Hosp.	✓	✓	✓
Fortis Escorts Heart Institute, Okhla	✓	✓	✓
Fortis Flight Lt Rajan Dhall Hospital, Vasant Kunj,	✓		
Fortis Hospital, Shalimar Bagh	✓		
Indraprastha Apollo Hospital; Sarita Vihar	✓	✓	✓
Jaipur Golden Hospital	✓		
Maharaja Agrasen Hospital	✓		
Max Super Speciality, Patparganj	✓		
Max Hospital Saket	✓	✓	✓
Max Smart Super Speciality Hospital, Saket	✓	✓	✓
Max Super Speciality Hospital, Shalimar Bagh	✓		
Moolchand Hospital	✓		
Primus Super Speciality Hospital	✓		
Pushpawati Singhania Research Institute	✓	✓	
Rockland Hospital	✓		
Rajiv Gandhi Cancer Institute and Research Centre		✓	
Sir Ganga Ram Hospital	✓	✓	✓
Saroj Super Speciality Hospital, Rohini	✓	✓	
Sri Balaji Action Medical Institute	✓		
St Stephens Hospital	✓		
Total	21	9	6

Table 4.8 reveals a total of 22 private organ transplant hospitals in Delhi. Also, 21 hospitals are doing kidney transplants, and nine (9) private hospitals are doing liver transplants. There are only six (6) hospitals that are doing heart transplants.

Table 4.9 Organ transplant services provided by NOTTO Registered hospitals under NCR of Uttar Pradesh as on 2018 June (N=4)

Name of Hospitals	**Private Hospital**	**NCR region of Uttar Pradesh**	**Kidney Transplants**	**Liver Transplants**
Max Hospital Ltd.	✓	Ghaziabad	✓	
Fortis Hospital	✓	Noida	✓	✓
Jaypee Hospital	✓	Noida	✓	✓
Metro Hospital and Heart Institute	✓	Noida	✓	
Total hospitals	4		4	2

Table 4.9reveals that there are four (4) hospitals in Uttar Pradesh under NCR Region, all are private hospitals, all four (4) hospitals are doing kidney transplants, and only two (2) hospitals are doing liver transplants also. But none of the four (4) hospitals is doing heart transplants.

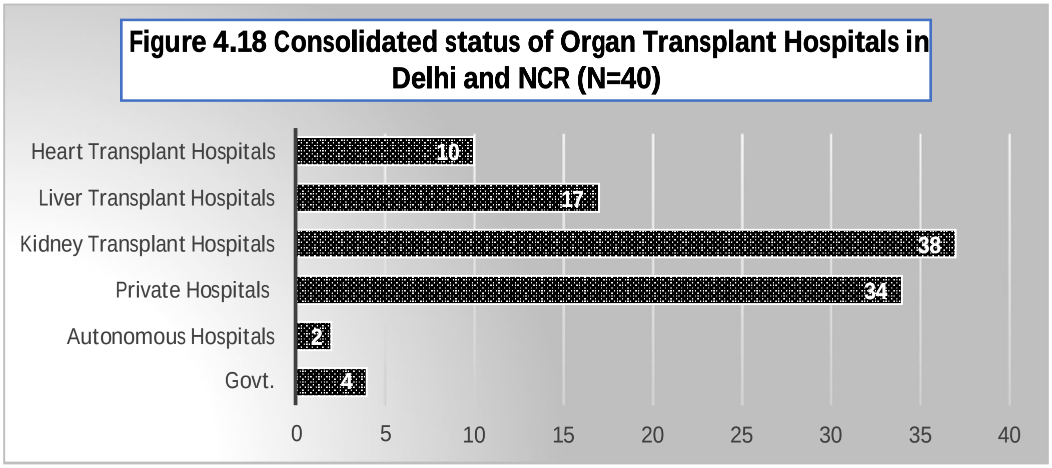


Figure 4.18 Consolidated status of Organ Transplant Hospitals in Delhi and NCR (N=40)

Figure 4.18 reveals that there are 4 Government hospitals only in comparison to 34 (85%) Private Hospitals in Delhi and NCR region. The total kidney transplant hospitals that are 38 in number outnumber 17 liver and ten (10) heart transplant hospitals if added together.

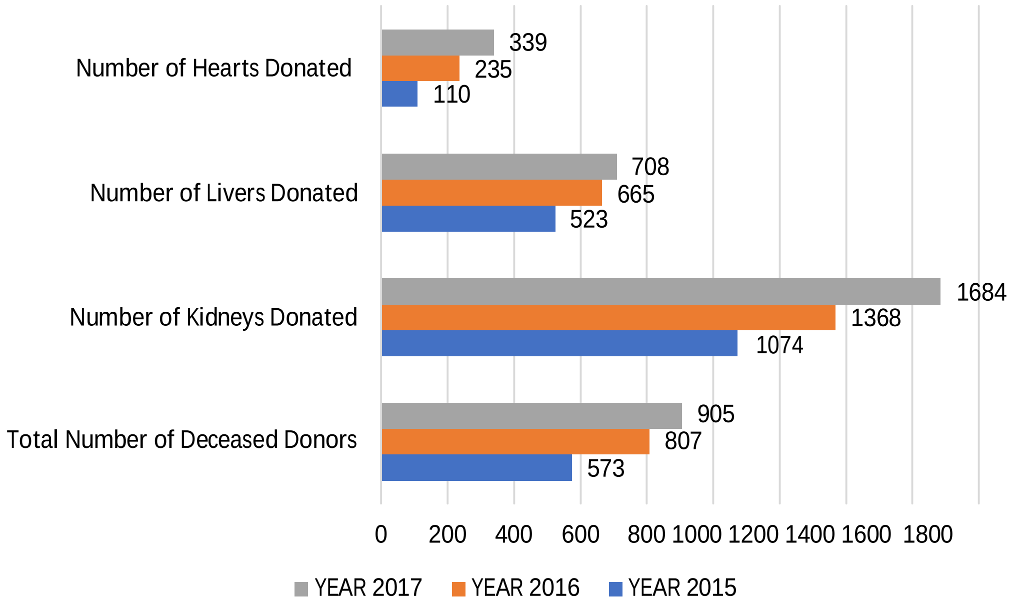
In a nutshell, there are 40 hospitals in Delhi and NCR who have shared data on organ donation and transplantation with NOTTO and have got their hospitals registered with NOTTO. Out of 28 registered hospitals in Delhi, there are only 4 Government hospitals and two (2) autonomous hospitals. Only three Govt. hospitals are directly under the control of NOTTO here in comparison to 34 private hospitals as AORTA is governed by different armed forces rules. AORTA shares organs with NOTTO but is not bound to do so as per Rules (THOA Rules -1995).

Out of 40 hospitals in Delhi and NCR region, four hospitals belong to the neighbouring area of UP and eight (8) hospitals belong to the neighbouring area of Haryana State. However, in NCR region all the 12 hospitals comprising a part of Haryana and part of Uttar Pradesh are private hospitals.

Country Level Three Years (2015-17) Deceased Donor Data Available With NOTTO

Insistent written communications, engagement of NOTTO Director with officials of various States and UTs through tours, developing and building rapport, inviting States on Indian organ donation day and felicitating well performing States, their officials and families of deceased donors motivated States to share data with NOTTO. Glimpses of the data shared by NOTTO officials with the researcher are presented in the following tables and figures: -

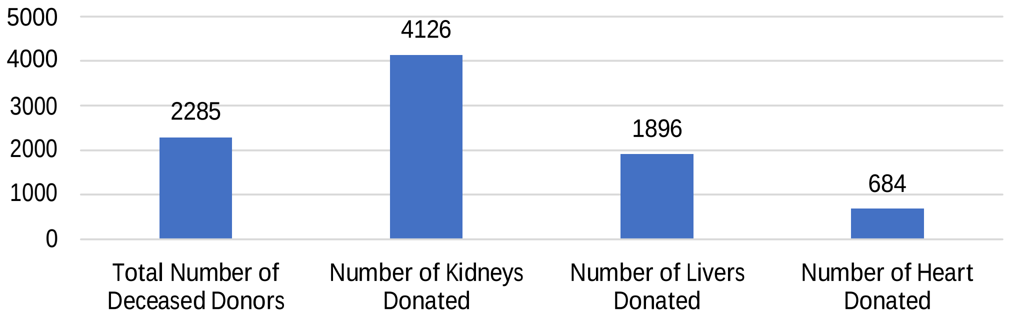
Figure 4.19 National BSD donor data available with NOTTO from the year 2015-2017



Source: NOTTO

There has been a steady increase in organ donation from BSD donors all over the country, as depicted in Figure 4.19.

Figure 4.20 Total number of BSD donors with number of Kidneys, Livers and Hearts donated in India from the year 2015-17



Source: NOTTO

Figure 4.20 reveals that the number of liver and heart donations were very less in comparison to the number of BSD donors depicting underutilization of these organs that is not the case with kidney transplants.

Table 4.10 State-wise data of BSD donors and organs donated for the year 2017

States and UTs	Total Donors	Kidneys Donated	Liver Donated	Heart Donated	Lungs Donated	Pancreas Donated
Tamil Nadu	**176**	**318**	**152**	**112**	**87**	**4**
Maharashtra	**170**	**320**	**125**	**55**	**1**	**2**
Telangana	**150**	**292**	**143**	**42**	**2**	**1**
Karnataka	**87**	**166**	**56**	**27**	**0**	**0**
Gujarat	**85**	**162**	**68**	**12**	**0**	**0**
Chandigarh	**44**	**82**	**20**	**12**	**4**	**3**
Madhya Pradesh	**38**	**68**	**23**	**10**	**0**	**0**
Andhra Pradesh	**34**	**62**	**29**	**16**	**25**	**0**
Delhi	**33**	**60**	**24**	**14**	**0**	**0**
Rajasthan	**28**	**50**	**26**	**16**	**1**	**1**
Kerala	**26**	**46**	**19**	**8**	**5**	**3**
Puducherry	**15**	**28**	**6**	**5**	**0**	**0**
Haryana	**12**	**18**	**12**	**8**	**0**	**0**
Uttar Pradesh	**7**	**12**	**5**	**2**	**0**	**0**
Total	**905**	**1684**	**708**	**339**	**125**	**14**

Table 4.10 above depicts that Tamil Nadu had maximum BSD organ donors, and Uttar Pradesh had the least BSD organ donors in the country during the year 2017.

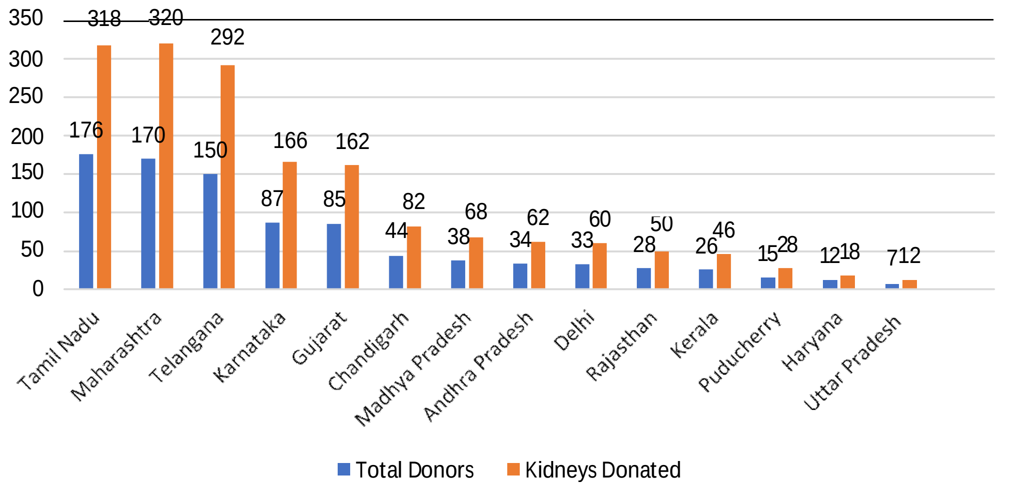


Figure 4.21 State-wise number of BSD donors with number of Kidneys donated for the year 2017

Figure 4.21 depicts that Tamil Nadu had maximum BSD organ donors numbering 176 with 318 kidney donations in comparison to 7 donors with 12 kidney donations in Uttar Pradesh. Delhi also is lacking in organ donation from BSD donors in the country having contributed only 60 kidneys from 33 deceased donors during the year 2017.

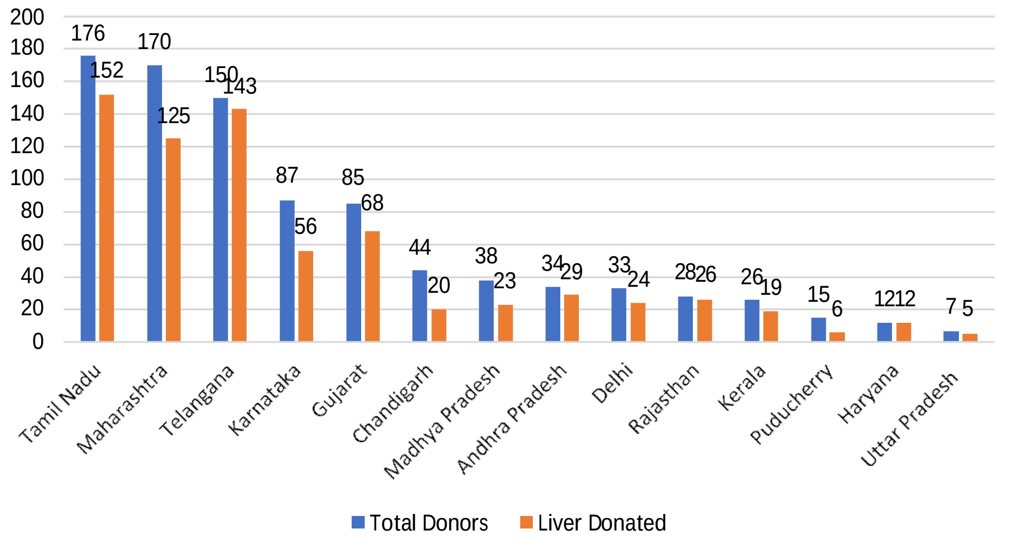


Figure 4.22 State-wise number of BSD donors with number of Livers donated for the year 2017

Figure 4.22 depicts that Tamil Nadu had maximum BSD organ donors numbering 176 with 152 liver donations in comparison to 7 donors with 5 kidney donations in Uttar Pradesh. Delhi also is lacking in liver donation from BSD donors in the country have contributed only 24 livers from 33 deceased donors during the year 2017.

Figure 4.23 State-wise comparison of BSD donors and Hearts donated for the year 2017

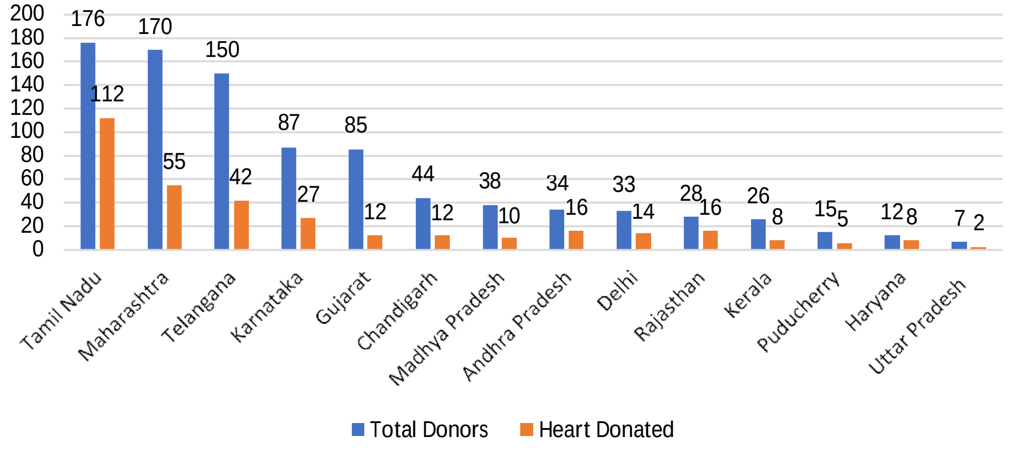


Figure 4.23 depicts that Tamil Nadu had maximum BSD organ donors numbering 176 with 112 heart donations in comparison to 7 donors with two heart donations in Uttar Pradesh. Delhi also is lacking in heart donation from BSD donors in the country having contributed only 14 hearts from 33 BSD donors during the year 2017.

Figure 4.24 State-wise number Of BSD donor Lungs donated for the year 2017 (N=125)

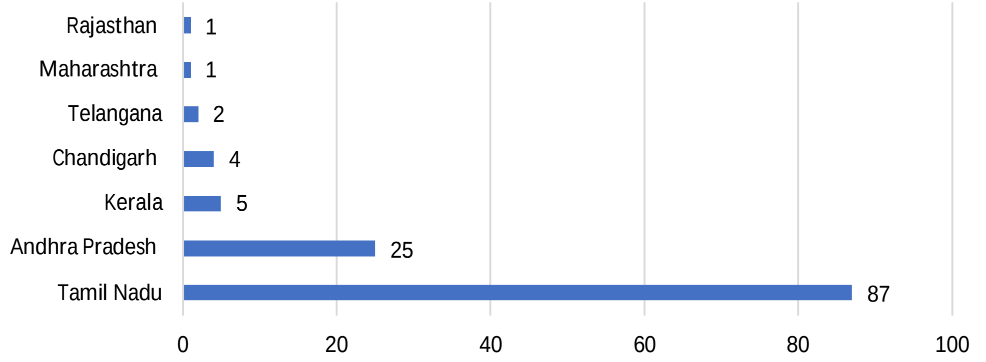


Figure 4.24 depicts that Tamil Nadu had maximum BSD lung donation numbering 87, followed by Andhra Pradesh that contributed 25 lungs from the BSD donors during

the year 2017. Very few States have lung transplant activities going on in their States as depicted in the figure.

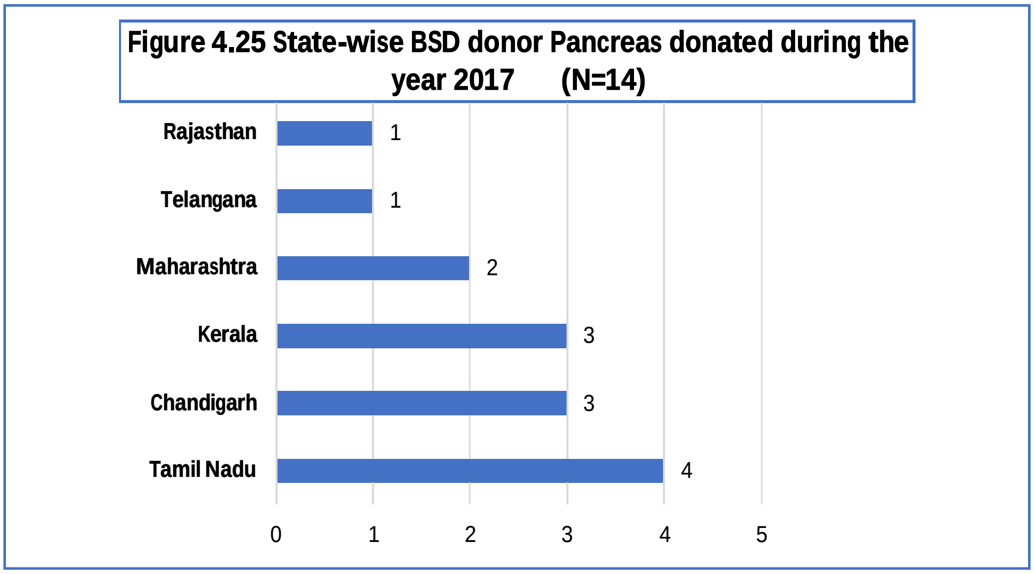


Figure 4.25 depicts that Tamil Nadu had only four and Rajasthan had only one pancreas donation from the BSD donors during the year 2017. Very few States have pancreas transplant activities going on in their States.

Organ Sharing and Allocation Through NOTTO for The Year 2016: Issues and Challenges

One of the most critical functions of NOTTO has been the allocation of organs. NOTTO, by the year 2016, had registered several hospitals of various States and Union Territories. There had been the initial reluctance of hospitals and States to share organs with NOTTO but over a period with continuous follow up by NOTTO authorities, hospitals registered themselves with NOTTO. As reported by a key person involved in organ sharing, there were no Indian patients with blood group AB and hearts of BSD donors with this blood group AB were allocated to foreigners, usually. Most of the heart transplant happen in Bombay and Chennai.

ROTA system of allocation of organs meaning the rotational system of organ allocation is followed for all the organs as on date. This system shall later move to digitalization mode of distribution for kidney only (as reported in June 2018). In the ROTA system, organs are allocated on a rotational basis among hospitals.

The Resistance of State Hospitals to Register With NOTTO

There has been a high resistance of hospitals to register with NOTTO. NOTTO was considered a big fish, trying to prey on all small fish. It was said by a very reputed medical professional working in a private hospital during one of the meetings attended by the researcher. There were apprehensions with such registrations, and each hospital would weigh the pros and cons of such registration. They had several questions like Why register? What are the benefits? What are the harms? What will happen if we don't register? NOTTO is not the licensing authority and has no right to issue, renew or cancel licenses for transplant surgeries all over the country. It is to mention here that hospitals get licenses from "State Appropriate Authorities" for conducting different transplant surgeries.

NOTTO Perceived as A Threat to The Autonomy That Was Enjoyed by Groups of Branded Hospitals

NOTTO was perceived as a threat to the autonomy that was enjoyed by hospitals all over the country until 2014. The presence of NOTTO and its demand for bringing in transparent data sharing mechanisms was fetching them an aura of insecure and indulgent environment. For example, there were some groups of branded hospitals who had been sharing the BSD donor organs among their own branded hospitals. The same was not possible after registering with NOTTO as organ allocation had to be done as per the allocation policy of NOTTO. It took time for hospitals to register with NOTTO in the initial stage. After registering with NOTTO, data of donor and recipients was not shared to the extent as required by the national level organization NOTTO.

Initial Focus on Registration With NOTTO

However, from 2015 onwards different States and UT's took NOTTO in confidence first for registering their hospitals with NOTTO and later for sharing of organs. As per the reports, 80 organs were shared up to 26th Nov 2017 for the year 2017. In a nutshell, a total of 165 allocations of organs were coordinated by NOTTO as per the slides presented by NOTTO official on 7th organ donation day on 27.11.2017 that were shared with the researcher.

Figure 4.26 Summary of reported data by NOTTO for the year 2016

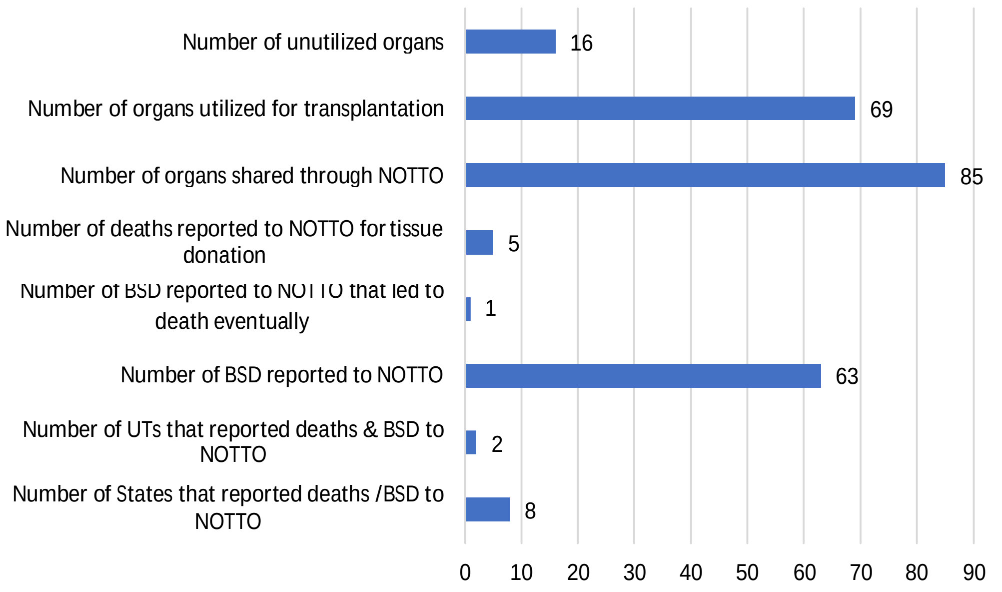


Figure 4.26 reveals that there were 8 States and 2 Union Territories that shared organs through NOTTO. A total of 63 Brain Stem Deaths and five (5) cardiac death were reported to NOTTO. Only 85 organs were shared, with 69 organs getting utilized and 16 organs not getting used eventually in 2016.

Figure 4.27 State-wise number of Brain Stem Deaths reported to NOTTO for organ allocation in 2016 (N=64)

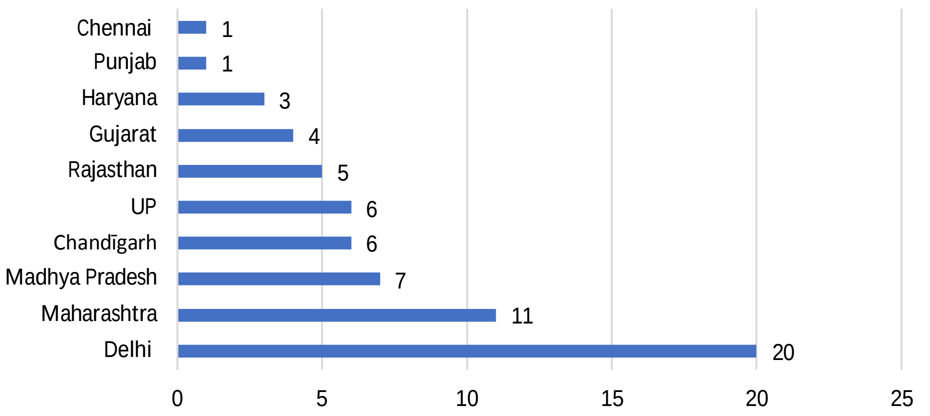


Figure 4.27 reveals that majority of Brain Stem Deaths were reported by Delhi 20 followed by Maharashtra 11 and Madhya Pradesh 7 for allocation of organs through NOTTO. Chennai shared the least i.e., only one (1) organ with NOTTO.

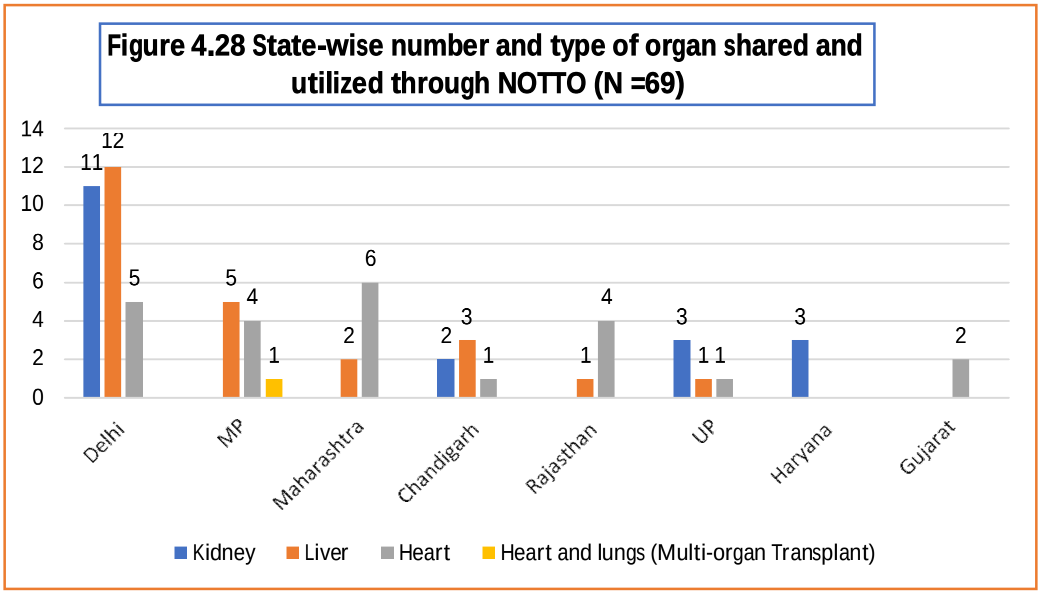


Figure 4.28 State-wise number and type of organ shared and utilized through NOTTO (N =69)

Figure 4.28 reveals that Delhi shared maximum organs through NOTTO followed by MP and Maharashtra. Sharing of hearts can be seen more as compared to other organs. In one case of multi-organ transplant, three organs that are one heart along with two lungs together was shared with NOTTO by one of the hospitals from MP.

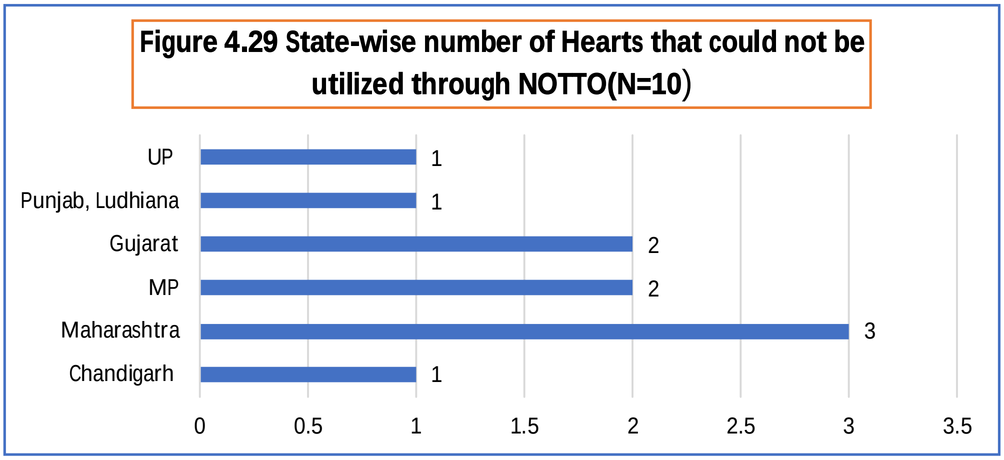


Figure 4.29 State-wise number of Hearts that could not be utilized through NOTTO(N=10)

Figure 4.29 reveals that three hearts shared by Maharashtra could not find recipients. A total of 10 hearts shared by 6 States with NOTTO remained unutilized.

Figure 4.30 State wise Heart and two Lungs together shared through NOTTO that could not be utilized(N=2)

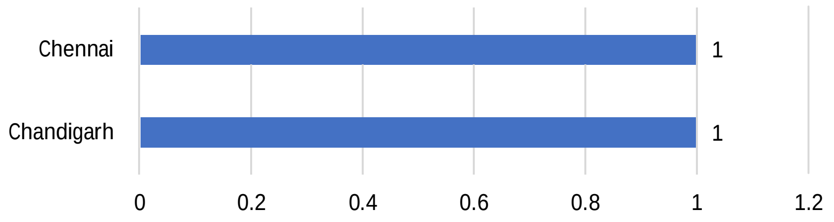


Figure 4.30 reveals that three organs together that are one Heart and Two Lungs from each of the two States Chennai and Chandigarh could not be transplanted. Their transplantation could not materialize due to unavoidable circumstances like non-availability of the recipient, mismatch with the recipient, loss of time due to certain unavoidable circumstances, unavailability of charter planes to carry organ from one State to other etc.

In short, from Figure 4.29 and Figure 4.30, it can be concluded that out of 16 organs that remained unutilized through NOTTO, majority of organs were hearts numbering 12 followed by four (4) lungs.

Figure 4.31 Distribution of BSD donors by sex as recorded by NOTTO during 2016 (N=63)

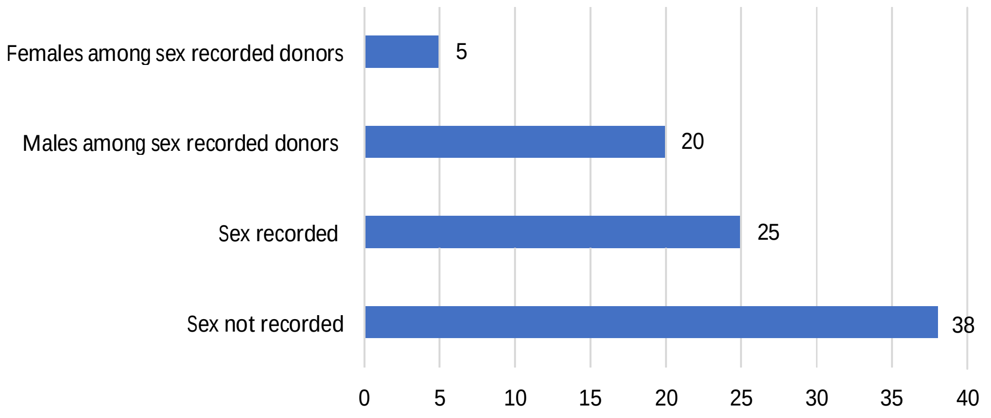


Figure 4.31 reveals that sex of most donors i.e., 38 was not recorded in the reports of NOTTO. Out of the remaining 25 donors 20 were males in comparison to 5 females.

Figure 4.32 Age wise distribution of BSD donors reported by NOTTO during 2016(N=63)

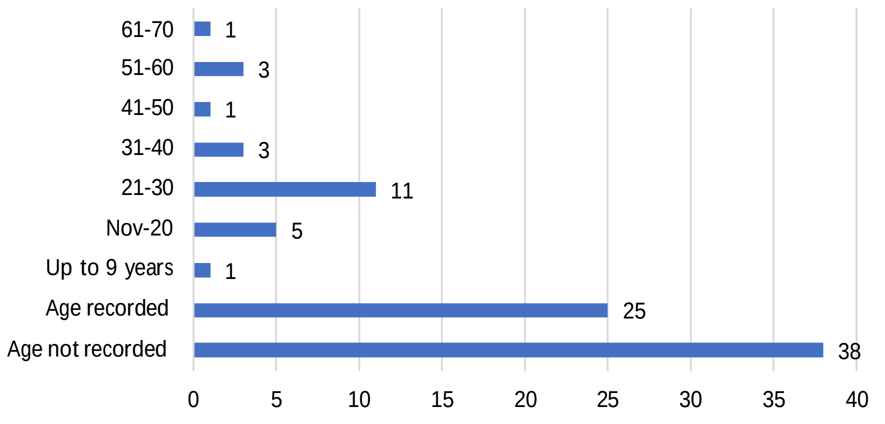


Figure 4.32 reveals that the age of most donors, i.e., 38 was not recorded in the reports of NOTTO. Out of the remaining 25 donors whose age was recorded most donors, i.e., 11 were in the age group of 21-30 years.

Rotational System of Organ Allocation Was Faced with Many Challenges –

NOTTO faced a lot of issues and challenges with rotational system of organ allocation as reported by a key person of NOTTO who was actively involved in allocation of organs for a period of almost two years. These challenges are as follows: --

Time the biggest challenge

When a brain-dead donor becomes available, NOTTO receives a call. As per rotation, it informs the respective hospital about the place of availability of organ along with other information. Hospital gears up to arrange for retrieval of the organ and receive the same for transplantation. It calls 3-4 patients with the same blood group and gets their cross matching done. Crossmatching takes 3-4 hours. If the crossmatch is positive, then the kidney is not transplanted. The best-matched recipient is the luckiest among other recipients to receive the organ. Meanwhile, the retrieval team proceeds to retrieve the organ.

In case all the recipients called in the hospital are not the best match the hospital says “no” to organ transplant, and NOTTO calls another hospital and repeats the process. All this takes time and keeps everyone on toes and full of tensions.

Challenge for recipients to reach the hospital for transplant

Recipients are called from home and are required to make arrangement for money and reach the hospital for transplant within a short period. They need to be physically and medically fit to get the transplant done. The procedure involves the psychological readiness of the recipient as well. Many patients are not able to reach the hospital because of the long distance from home to transplant hospital, unavailability of decision makers at home, financial constraints etc. The common excuses given by people are ***"Ghar Par Koi Nahee Hai"(***Meaning there is no one at home), ***“Kaun Saath Aayega"*** (Meaning who will come with me), "***Relation Ko Bulaoonga***"(Meaning I will call relatives),*"**Baccho Ko Kaha Rahkooonga**"*(Meaning where to keep my children) etc.

Challenge to maintain donor

The brain-dead donor sometimes crashes before the retrieval of organs. Sometimes, this leads to wastage of money incurred on air travel by the recipient hospital. In one case, the recipient hospital's surgical team reached the transplant hospital and returned without an organ due to donor crash.

Challenge to get a viable organ after putting a lot of efforts

Donor organ is also found unsuitable once the retrieval team reaches the hospital for retrieval of organs. In one case, the nodular liver was rejected by the retrieval team after reaching the hospital for liver retrieval.

Financial investment required to retrieve organs

Commercial flights are used to fetch the organ allocated to the hospital. DG Civil Aviation has instructed all flight operators to carry the retrieved organ, but they expect an escort along with the organ. Priority clearance is given without scanner. The transplant team of the transplant centre that is allocated an organ first goes to the retrieval centre to retrieve organs and fetches it to the transplant centre. It requires investments in terms of money and human resources, as well.

Challenge to maintain communication with various hospitals

NOTTO official responsible for allocation of organs usually makes at least 50 calls. In some cases, there could be 200 calls made for the distribution of organs. WhatsApp groups are made that help in the allocation of organs and help to see the progress too.

Challenge to appease people who overreact due to their limited awareness about organ donation and transplantation

Complaints pour in, and it becomes challenging for NOTTO officials to calm people who overreact owing to their limited awareness about organ donation and transplantation.

"There was a 3-month-old baby whose parents were medical professionals inclined to donate organs in Nagpur. The parents felt convinced that their child's brain is not functioning and was brain dead. The family of doctors wanted to retrieve his organs, which could not happen due to the non-availability of a recipient. While trying to locate recipients of the baby organs, the baby crashed. It took two days and a night to find recipients of organs. The family could not reconcile with the situation and complain to Prime Minister’s Office regarding the carelessness of the authority for causing a delay which ended in complete death of the baby".

Challenge to address the issue of aggressive relatives compounded by their limited awareness

There is a myth percolating among the public that organs can be donated after death when the heart has stopped beating.

"There was a call from Meerut. There is no transplant hospital in Meerut. The call was from a relative who wanted to donate his relative's organs who probably was on a ventilator. He wanted to donate organs there only. He called me several times. He threatened me that I would lose my job if I do not help him in donating his relative's organs in that hospital only. He threatened with following narratives: I will terminate

you from service, get you transferred. ***Mai Yahee Par Organs Donate Karwaoonga"*** *(*Meaning I will get organs donated here only*).*

A 92-year-old person had died, and the family wanted to donate his organs. We told organs of such an older person are not retrieved. His narrative was," You don't want to do work that is why you are saying so". "Who am I? You will come to know tomorrow. I will change the rule. You don't know me. Wait and watch".

Lack of awareness among medical professionals about organ donation from BSD donors

There is an immense lack of awareness among medical professionals about organ transplantation from BSD donors, as was depicted by several medical practitioners in various hospitals.

"In one case, a doctor from a Govt. hospital called and told me that they have a family that wants to donate all organs of their dead donor. His words were," please send organ retrieval team to retrieve kidneys, heart etc.". On enquiring further, he said that the patient is in the mortuary. Then I had to explain the difference between tissues and organs, brain death and cardiac death".

"There was a phone call from a private hospital from an intensivist who wanted us to send teams for organ retrieval. On enquiring further, a senior intensivist told that death had taken place. On enquiring further to know whether it is brain death. He said, yes, both brain death and cardiac death has taken place".

Challenges to address the issues of imported organ retrieval teams in retrieval hospitals

"Several phone calls are received on small issues from transplant retrieval teams. These teams expect a lot of cooperation from retrieval hospitals in terms of supply of material, human resources and infrastructure required for retrieval of organs. NOTTO is intimated even for a scalpel if not provided by the hospital. These hospitals expect interventions of NOTTO for rectifying small issues and problems".

Status of Organ and Tissue Donor Registry

Organ and Tissue Donor Registry is a web-based registry. It registers the choices of its countrymen regarding their will to donate organs or tissue or both after their death/ brain death. NOTTO has registered 155243 people as on 7.10.2018 in this electronic registry. NOTTO also issues organ donor cards to people who have either pledged to donate organs or tissues or both.

The efforts of various networks and people have also been consolidated by registering their registered donors with this national web register. The efforts are on to increase the number of such donors.

Status of Organ Transplant Registry

The NOTTO Transplant Registry is a web-based registry. Its purpose is to collect transplant-related data from all transplant centres from time to time. The Registry would help in understanding short-and long-term outcomes in the field of transplants. It is unfortunate that up to 26.10.2017, there were 267 heart recipients, 995 liver, 3859 recipients and 58 lung recipients only waiting for a transplant (as per a key official). Data depicts the reluctance of hospitals to share relevant data.

Status of Donor Follow-Up Registry

Living kidney and liver donation by “near relatives” and “other than near relatives” requires donor follow up register to understand long term health outcomes of such donations. As on date, the donor follow-up registry is not yet formed at NOTTO.

Summary: - This Chapter reveals the role of National Organ and Tissue Transplant Organization (NOTTO) in context of Transplantation of Human Organs Act (THOA), 1994, and National Organ Transplant Program (NOTP), 2009. It was envisioned that NOTTO would develop various procedural and personnel guidelines for organ donation and transplantation with the help of its technical expert advisory groups; initiate liaising activities with transplant centres all over the country; identify centres for conducting training and establish a 24-hour helpline as part of IEC as and when NOTTO becomes fully functional.

In the absence of expertise in the field, NOTTO had the dual responsibility of leading and learning as media supported this cause vehemently. It was to set up a website for making linkages with transplant hospitals all over the country and establishing various online registries. NOTTO chose to make its presence felt by organizing conferences, workshops, training and public engagements. In the beginning, NOTTO had to focus on registration of all organ transplant hospitals, and later it went for sharing of organs of BSD donors. NOTTO's emergence threatened long-established hospital brands – private and autonomous alike. They felt NOTTO would impinge on their autonomy and independence. NOTTO found that there are 301 hospitals (approximately) dealing in organs donation and transplantation. Out of this only 199 hospitals across 16 States and 4 UTs were registered with NOTTO on 16.9.2017. Of these, 159 (97.54%) were dealing with kidney transplants, 62 (38.03%) in liver transplants and 34 (20.85%) in heart transplants.

Forty hospitals registered In Delhi and the National Capital Region (NCR) with 28 in Delhi and 12 in NCR. Of these, 34 (85%) are in the private sector, 4 in Government and 2 are autonomous hospitals.

NOTTO faced a considerable challenge resulting from underreporting of data by transplant hospitals. Only 85 organs were shared through NOTTO, of which 69 were utilized, and rest remained unutilized in 2016. Next year, 80 organs were shared (up to 26th November). In a nutshell, NOTTO coordinated sharing of 164 organs of BSD donors. The NOTTO followed a system of rotational allocation of organs that faced with many challenges.

From the data, it can be concluded that the Southern States were least cooperative with NOTTO in registering and sharing data. Telangana had not furnished any data to NOTTO. Likewise, the gap from Andhra Pradesh was 96.16% gap, Karnataka 79.41%, Tamil Nadu 74.19% and Kerala 38.46%. The scene is reverse when it comes to the Northern States (till 6.9.2017). Also, the southern States had a higher number of hospitals registered with their respective organ sharing networks in comparison to the northern States.

CHAPTER 5

The Historical Genesis of Organ Transplant Coordinators (OTCs) in India and Their Perspectives Towards Organ Donation and Transplantation

This Chapter gives an overview of the historical genesis of Organ Transplant Coordinators (OTCs) in India and reveals perspectives of a few selected OTCs towards organ donation and transplantation from BSD donors. The first part of this Chapter gives an overview of OTCs in India in the context of Transplantation of Human Organs Amended Rules 2008 and Transplantation of Human Organs and Tissues Act (THOT Act 2011). It also reveals various milestones in Training OTCs in India before the establishment of the National Organ and Tissue Transplant Organization (NOTTO) and after it came into existence. The second part of the Chapter gives us an understanding of nuances, intricacies and issues associated with organ donation from Brain Stem Dead (BSD) donors through an in-depth case report of a BSD donor as revealed by an OTC Ms. N. The third part reveals the perspectives of Organ Transplant Coordinators based on a questionnaire administered to 20 OTCs. Besides, in-depth interviews, telephonic clarification on specific issues, informal and formal discussions with OTCs on several occasions as described in the "Methodology Chapter" form part and parcel of this section of the Chapter.

An Overview of The Historical Genesis of OTCs in India

Appointment of OTCs is one of the significant factors that has made an enormous dent in deceased organ donation programme in many countries like Spain and Croatia (Matesanz and Miranda, 2002; Živčić-Ćosić S et al. 2013). In India, the nomination of Organ Transplant Coordinator was made mandatory for the initial registration or re-registration of all organ transplant hospitals for the first time in 2008. An amendment in the GSR NO. 51(E) of THOA Rules 1995 (THOA Rules, 1995) was made vide GSR 571(E) in 2008 (THO Amended Rules 2008). Through this amendment, it was mandatory for any transplant hospital to nominate one Organ

Transplant Coordinator for initial registration or renewal of registration through "Appropriate Authority".

It was probably done to ease the process of organ donation from BSD donors. On one side, some professionals believe that BSD patients are completely dead individuals, while others don't think so. As a result of this professional conflict, the professionals don't feel at ease for asking people to donate organs of their BSD relatives. This dilemma has led to restructuring and retraining a new band of professionals among medical and nursing professionals usually, entrusted with the responsibility of motivating people to donate organs. These OTCs are also supposed to identify BSD donors in ICUs for facilitating declaration of Brain Stem Deaths. They drive families to donate organs, take care of donor families during organ retrievals and assist in organ donation and transplantation processes. They are called Organ Transplant Coordinators (OTC) or Organ Procurements Coordinators (OPC) in USA (UNOS, 2011). The legislative system of almost all countries has made it mandatory to recruit OTCs in all hospitals involved in organ retrieval and transplant surgeries. In the UK, they have separate DTC (Donor Transplant Coordinators) and TC (Transplant Coordinators). Also, there is EOS (Electronic Organ Sharing) in place which makes organ sharing a straightforward process (NHSBT, 2011).

Indian Scenario in Relation to The Training of Organ Transplant Coordinators

India has eye donation counsellors (tissue donation) in place as a part of National Blindness Control Programme initiated in 1976. These counsellors are supposed to ask people to donate eyes after complete death and are not required to counsel families to donate organs after BSD declaration. Their focus of counselling has neither been on body donation nor organ donation but exclusively on eye donation. There was no formal training given to professionals after THOA -1994 to become Organ Transplant Coordinators till 2009. The first Organ Transplant Coordinators programme started in 2009; the same year incidentally the National Organ Transplant Programme was also launched in the country (Dar and Kumar, 2015).

It is not the Govt. but Multi Organ Harvesting Aid Network (MOHAN) Foundation, that owes credit to initiating training of OTCs from 2009 in India. Mohan Foundation has its base in Chennai where most of the transplant surgeries take place. MOHAN Foundation received funds for OTC training programmes from the “Sir Ratan Tata Trust and Navajbai Ratan Tata Trust”, Mumbai since 2009. It was revealed to the researcher by a key person associated with this Foundation. The Trust keeps track of activities MOHAN Foundation does in the context of training of Organ Transplant Coordinators in the country through an audit after one and a half years. The Foundation sends reports to the Trust after every three months. They gave funds to MOHAN Foundation for three years initially, and after three years they reduced the funds and want this Foundation to be self-sustainable.

The first "Transplant Coordinators Training Programme" conducted in 2009 by MOHAN Foundation was of one-month duration. The OTC trainees were from NGOs, Government and corporate health sectors. They were trained in all aspects of counselling BSD donor families. They were made aware of the importance of working within narrow time frames for a timely transplant of various organs. Besides this, they were made to learn how to establish linkages with multiple transplant hospitals, the police (in Medico-Legal Cases) and the forensic department for timely transplant and handing over the body to BSD donor families.

As per the training reports (MOHAN Foundation Annual Reports), all other OTC training programmes except in Chennai were of one-week duration. In Chennai, OTC training programmes were of one-month duration. In Delhi, Armed Forces Organ Retrieval and Transplant Authority (AORTA) conducted the first transplant coordinators course in 2012. National Organ Transplant Programme (NOTP) officials also participated as faculty members as reported by a key person in DGHS. The NOTTO after its establishment in 2014 under the aegis of NOTP pitched in during 2015 and conducted the first training programme on OTCs in collaboration with MOHAN Foundation.

In 2016 the second course was conducted at NOTTO along with MOHAN Foundation. Some of the participants were those who had already been trained by this foundation earlier. NOTTO does not charge any fee for these training programmes.

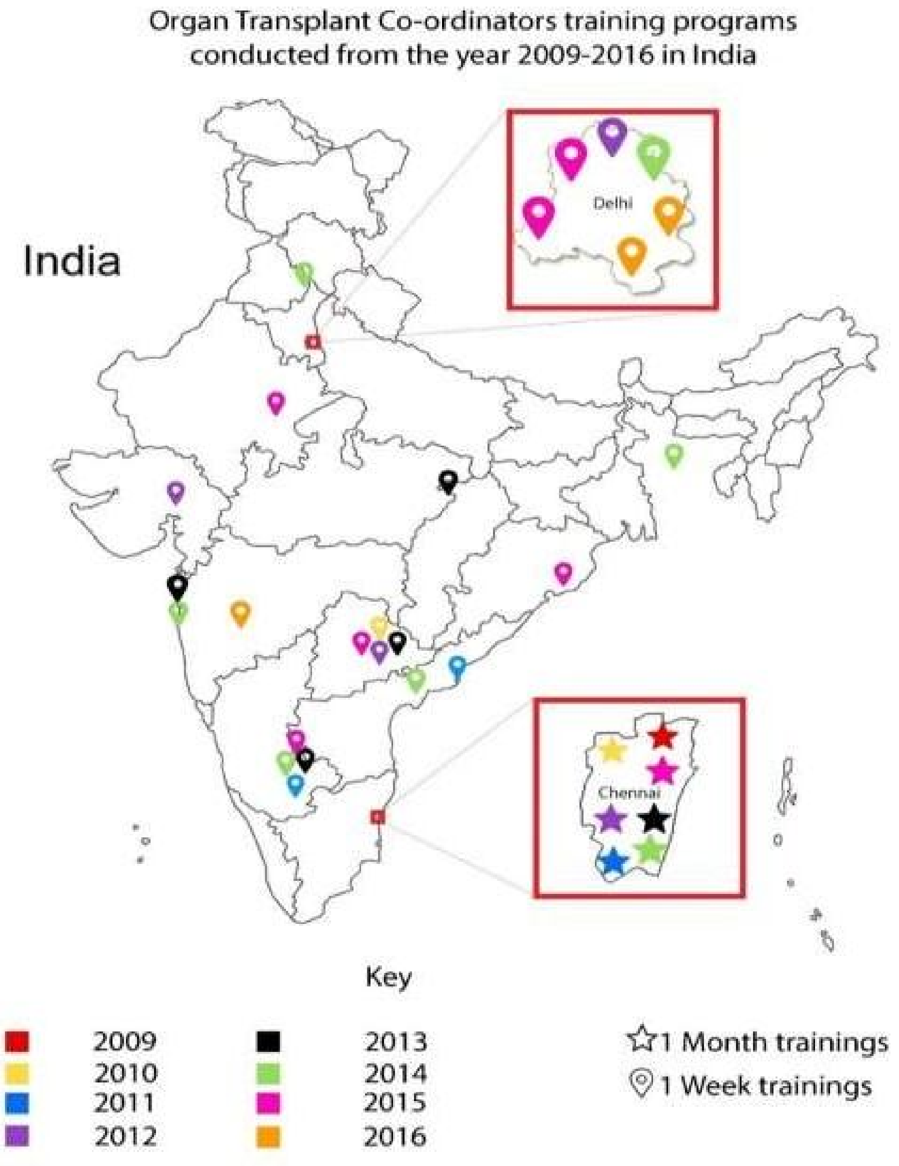


Figure 5.1 Duration wise and year wise Organ Transplant Coordinators Training Programmes conducted in India from 2009-2016

Figure 5.1 reveals that most of the Organ Transplant Coordinators training programmes were conducted in Chennai, followed by Delhi &NCR as per the annual reports of MOHAN Foundation and researcher's observations. Besides, all training programmes were of one-month duration in Chennai in comparison to the rest of the country where they were of one-week duration.

Mohan Foundation had trained more than 1100 OTCs. The training programmes were for one week, one month, three months and one-year duration. The trainees usually are from various fields like medicine, nursing and social sciences. The intermix of such groups is an added advantage as there are ample chances of cross-learning. But now it has been restricted to one week and one-month programmes only as long programmes were not feasible.

MOHAN Foundation had developed an e-learning programme of one-year duration for OTCs too to be started by Indira Gandhi National Open University (IGNOU) that failed to materialize. Since they have invested heavily on its preparation and development of modules, they are contemplating to conduct this course through a different mode. It is because IGNOU suspended Community College scheme in 2012 after initiating the same in 2009.

As per the records available with NOTTO, there are 301 designated transplant centres/ hospitals in different States in the country (Isalkar, 2017). All these transplant centres should have at least one Organ Transplants Coordinator in place.

MOHAN Foundation has established its office in Gurgaon too. MOHAN Foundation and FORTIS hospital Gurugram conduced first training programme under the aegis of NOTTO in 2016. There has been a mutual association between NOTTO, FORTIS and MOHAN Foundation. After two OTCs training programmes at NOTTO, third was held in April 2016 at FORTIS along with MOHAN Foundation for which trainees had to pay, but NOTTO issued certificates.

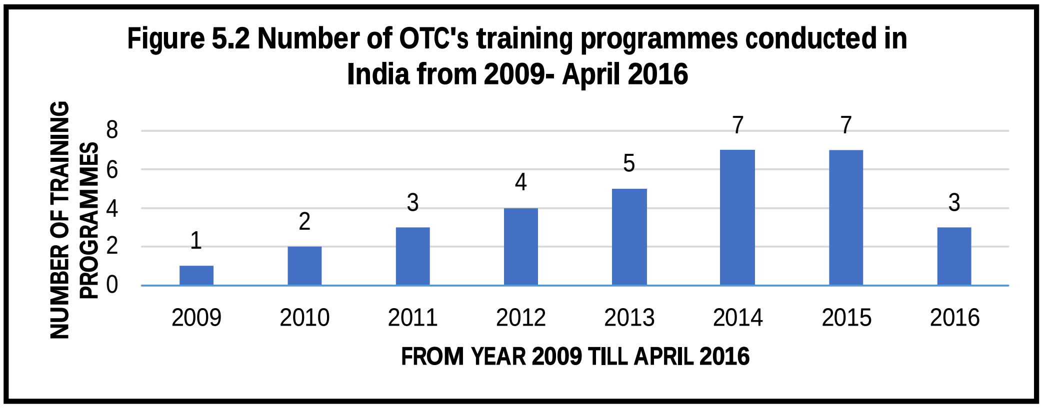


Figure 5.2 Number of OTC's training programmes conducted in India from 2009- April 2016

Source: -Based on data shared by MOHAN Foundation and NOTTO.

Figure 5.2 reveals an increasing number of OTC training programs from 2009 onwards in the country.

One of the key employees of MOHAN Foundation interviewed by the researcher, who is also associated with NOTTO for training Organ Transplant Coordinators has conceptualized OTC training programme in India. She is a core team member of the transplant coordinators training programme conducted by MOHAN Foundation alone or in collaborations with other organizations including NOTTO.

Anticipated Qualities of a Transplant Coordinator

As per one of the trainers in the OTC training programme Ms.M, an OTC is required to have some traits to be a good OTC. An OTC should be honest and sincere with effective communication skills, should be knowledgeable about medical and legal aspects of organ, tissue and body donation. An OTC is also required to be brave, resilient, passionate and committed to the cause of organ donation. These skills shall help her convince people to donate organs.

The job of OTC starts with counselling the grieving family, although the intention behind this post is to motivate families to donate organs of their Brain Stem Dead relative for transplantation. In the Indian context, introducing the grieving family to designated Organ Transplant Coordinator in a hospital is not that acceptable as the word speaks about the intention.

Types of Transplant Coordinators in India

From the interviews held with many OTCs and key professionals, Transplant coordinators are of various types in India. Their roles and responsibilities also vary in India, depending on the kind of job assigned to them. The two main types of OTCs are: -

- Internal transplant coordinators
- External transplant coordinators

Internal Transplant Coordinators: -

These transplant coordinators are recruited by the organ transplant hospitals or organ /tissue retrieval hospitals to counsel dead donor/ BSD donor families for tissue /organ donation. It is mandatory to have Organ Transplant Coordinators in all organ retrieval and transplant hospitals as per THOA-2011. These internal OTCs can again be classified into various types as follows depending on the kind of jobs assigned to them: -

Organ-specific transplant coordinators: -

Some of the hospitals have organ-specific transplant coordinators depending on the load and transplant activities of a transplant Centre. They are liver transplant coordinators, kidney transplant coordinators and heart transplant coordinators. One of the NOTTO registered private hospital in Delhi that performed heart, kidney and liver transplants had all three organ-specific transplant coordinators. These transplant coordinators are supposed to facilitate the psychosocial, nutritional, radiological, and medical evaluation of recipients as well as living donors. The transplant surgeries are costly surgeries and involve substantial post-transplant costs as well. The OTCs ensure that families understand the financial implications of such operations and post-transplant investments as well. They prepare families in advance for meeting the cost of such surgeries. The transplant coordinators are also responsible for making the donor recipients cases for evaluation by "Authorization Committees "or "Competent Authority". They present the arguments to the "Authorization Committees" or "Competent Authority" for getting consent for transplantation. They are supposed to counsel the donor and recipient pairs in case of living swap transplant as is possible for liver and kidney transplants in India.

Tissue-specific coordinators-

Tissues can be retrieved from any dead body, and there is no need for Brain Stem Death declaration. Tissues, unlike organs, can be extracted at home also. However, tissue retrieval too requires the consent of the relatives. Different tissue retrieval teams do tissue retrievals. These tissues need transportation to the tissue banks also. In tissue banks, the tissues are processed as per the tissue-specific protocols and stored. Once processed, some tissues can be stored for five years in defined conditions and distributed as per the need and guidelines to transplant centers. Eye donation coordinators, Skin donation coordinators, Heart valve donation and Bone donation coordinators could be a few examples of tissue donation coordinators in India. The Tissue Donor Coordinators motivate families to donate tissues, coordinate with retrieval teams, retrieve tissues, pack various tissues and transport tissues to tissue banks.

Living organ donation and transplant coordinators: -

These transplant coordinators are responsible for all living organ donation and transplantation processes of donors and recipients like kidney and liver transplants. Their services focus on file preparation, donor evaluation, recipient evaluation, donor file maintenance, recipient file maintenance, approval by “Competent Authorities” or “Authorization Committee”, donor cum recipient preparation for surgery and keeping records etc.

Living cum deceased organ donation and transplant coordinators

These coordinators perform the work of living as well as Brain Stem Dead donation and transplantation**.**

Organ and Tissue Donation cum Retrieval Coordinator (OTDRC)

These coordinators are supposed to coordinate both living as well as Brain Stem Dead donation and transplantation**.** They are also supposed to coordinate both Organ and Tissue donation cum retrievals.

Tissue Bank Coordinators – The tissue bank coordinators are an important category of coordinators who could be managing the tissue banks in the country at ROTTO, SOTTO and NOTTO. Receiving tissues from Organ and Tissue Donation cum Retrieval Coordinators (OTDRC), processing tissues as per specific protocol, labelling tissues, liaising with laboratories for evaluation of tissues, discarding infected tissues, keeping record of discarded tissues, maintaining uninterrupted desired temperatures of tissues and distributing tissues and keeping records updated are the job responsibility of tissue bank coordinators. Coordinating with tissue retrieval teams is one of the focus areas of Tissue Bank Coordinators (NOTP Cell,2015).

External Organ Transplant Coordinators–

These transplant coordinators are not from the same hospital but are working with organ sharing networks of States or in other hospitals or in NGOs. The transplant coordinators of the same hospital are sometimes viewed as part of the hospital by the potential donor family who feels them interested in making money only for the hospital. In such cases, external OTCs are requested for counselling the grieving families in the hospital to make BSD donation possible.

Under NOTP, it is envisaged to engage various categories of staff for coordination of work at National, Regional and State Level for organ and tissue donation and transplantation. The salaries shall be paid by NOTP as depicted in the Table below:

Table 5.1 National, Regional, State and Institutional Level OTCs as envisaged under NOTP with designations and pay structures

Organization	Designation	Number	Salary in rupees
NOTTO (National Level)	Consultant Cum Sr. Transplant Coordinator	1	60000
ROTTO (Regional Level)	Jr. Transplant Coordinator	2	20000
SOTTO (State Level)	Jr. Transplant Coordinator	2	20000
Retrieval Hospital and Trauma Centers	Organ and Tissue Donation cum Retrieval Coordinator (OTDRC)	1	20000
Each of the 75 Govt. Medical Colleges and Tertiary Care Hospitals	Organ and Tissue Donation cum Retrieval Coordinator (OTDRC)	2	20000

Table 5.1 reveals the variation in designations and pay structure at various levels ranging from Rs. 60000 to 20000/-at National, Regional, State and institutional levels. (Source: NOTP Cell, 2015)

Case Report Revealing Issues and Challenges of Donation of Organs from a BSD Donor as Narrated by An OTC in an In-Depth, Extensive Interview

This part of the Chapter is a BSD donor case report based on a detailed, comprehensive discussion of Dr. N, an Organ Transplant Coordinator (OTC). Dr. N was working in one of the NOTTO registered private kidney transplant hospitals in Delhi. This case study highlights the nuances of organ donation and transplantation from a Brain Stem Dead donor. It gives us an understanding of the various steps of organ donation from a Brain Stem Dead donor and their transplantation in patients at various hospitals of Delhi. The processes involved in such donation and transplantation are full of roller coaster rides. Such processes consume a lot of time, emotions, money, material and human resources as depicted in this case study.

"In a cold winter day, a boy of 17 years age was not wearing a helmet when he met an accident at a particular place in one of the States of India. As reported by the family stringent laws for wearing a helmet by bikers are not followed in that place. The boy had a collision with another bike. He was hospitalized in an unconscious state in a local hospital in his place of residence. But he could not show any improvement in his condition for three consecutive days. His parents were advised to take him to Delhi for treatment. They did as was suggested to them and brought him to a private hospital in Delhi in the hospital ambulance. The hospital happened to be a transplant hospital doing kidney transplants only.

On reaching the hospital, he was admitted in ICU and put on a ventilator. The patient was in a coma and was not showing any improvement even after three days of ICU treatment.

The preliminary tests done on the patient revealed that the boy had lost consciousness forever. In this condition, he could continue to be on a ventilator without any hope for his recovery. The same was communicated to his family by his treating doctors. The cost of ICU treatment per day comes to Rupees 35000 -40000/- usually in this hospital.

The boy had no chance of improvement and was probably brain dead. The family was informed about this situation, and it was a tough time for the family to cope up with the same. As we are aware, a person adopts various coping mechanisms at the time of grief, and the immediate reaction of this family was denial. They denied that the child had no hope of recovery. They portrayed their anguish towards the staff and quarrelled with them insisting on stopping treatment then and there. They decided to take the patient to some other hospital. It was difficult for them to believe that their son could never regain consciousness. Their son was on the *ventilator breathing, had a pulse and other signs of life. How could he be as good as a dead person? The family was inconsolable with the immense emotional turmoil that was portrayed in the form of anguish, hope for life and fear of death as well.*

Meanwhile, the father of the child was visited by a friend from the United Kingdom who knew about organ donation from Brain Stem Dead donors. He had given them a hope of keeping their child alive via organ donation. Also, one of their relatives who visited them happened to be a policeman, knew about the green corridor, organ donation and transplantation. He too supported the cause of organ donation.

While these things were going, I was called to counsel the family. On seeing the family, I felt scared and apprehensive of their reaction. I preferred to call a male nurse to accompany me so that he could protect me in case relatives maltreat me. What if they abuse, kick, slap or misbehave with me were some of the threats perceived by me? The Intensive Care Unit of this hospital had a family counselling room which was used to give a comfortable position to family members. The family members were taken to a counselling room and motivated for the donation of organs. The room had photographs of a few previous BSD donors. The walls of the room were decorated with newspaper cuttings depicted generous acts of families who had preferred to donate organs of their Brain Stem Dead relatives. The aura of this room, the time gap of almost 24 hours and relative's explanations had helped them in accepting that their child had no hope of recovery. All these things together paved the way to organ donation by this family. The explanations by relatives had helped them in coping with the loss, and they preferred to keep him alive by donating his organs. They, however, put an obligation on me to ensure that none of the organs retrieved from the body gets wasted. The moment family verbally consented to donate organs, the billing for further medical interventions was stopped. The family was informed about the time-consuming procedure of "Apnoea Test" and the legal formalities required by such an act. The prerequisite for "Apnoea Test" was negative as sodium levels of the blood were high. Sodium levels had to be brought down to normal before proceeding for "Apnoea Test". The first "Apnoea

Test" was performed only after their verbal readiness. Two doctors did the procedure, and four doctors signed the documents as is required by law. The family was informed about the delay who by now had settled and did not mind waiting. The family signed Form 8, the consent form of THOT Rules -2014 after first "Apnoea Test". Donor maintenance team/ anaesthetic team had taken over the patient.

We all talk about maintaining a donor, but we never talk about how important it is to keep a family comfortable throughout this event. They must wait, they are keen to get back the body, and their relatives are waiting for the dead body. They have tears, they have grief, and they have lost a dear member of the family. They are finding solace in knowing their dear one's death can give happiness to a few unknown people who had a will to live further. How long will it take, madam, was repeatedly asked. It was essential to provide all the comforts to the family as they kept waiting. Luckily, there were some unoccupied suites in this hospital, and we shifted the family there, offered tea, lunch, dinner water and other utilities. Guard, kitchen ward boy and dietician from the kitchen too provided help.

It was also the time to take permission from the forensic department regarding organ retrieval. They did not know the protocol. They were informed about the whole procedure, and they offered their cooperation wholeheartedly. The permission was granted by the forensic department of a nearby Government hospital via an email.

It is must to take permission from the police for Medico-Legal Cases. The police station of the native State where the accident had happened was supposed to grant the permission to retrieve organs. Delhi police and also the native State police were informed. Police did not know about this form of death, but they helped. Police officers of his native State were requested to come for giving written permission for organ retrieval. One policeman from that police station came to Delhi at 5.30 am after boarding the bus at midnight from that State. He volunteered to reach on his own to give consent although the hospital offered a van to pick him up from the bus

stand. On his arrival, he provided legal consent for donation of organs after enquiring from doctors and relatives.
Meanwhile, pre-anaesthetic check-up was carried out as muscle relaxants during organ retrievals are given to patients to relax muscles; otherwise, the recovery of organs becomes difficult.

As this hospital had only kidney transplantation facilities, the two kidneys were transplanted in this hospital only. The liver and heart transplant facilities were not in this hospital; hence, two hospitals were informed about the availability of a liver and a heart after the first diagnosis only. Other hospitals had to call recipients and prepare them for transplantation of organs. Besides, they had to send a liver retrieval and a heart retrieval team to retrieve organs in this hospital. Before proceeding for organ transplantation, medical check-ups of the recipient are carried out. Among many recipients called for an organ transplant, the best-matched recipient receives an organ for transplantation. Recipients were informed about the availability of organs only after ensuring the family is willing to donate. They too are required to shift to the hospital before retrieval of organs. Such patients also require psychological, physical, medical and financial preparation before actual transplantation of organs. Two recipients for each organ having the same blood group as that of BSD donor were informed, and the best-matched recipient received the kidney for transplantation.

The blood sample was transported to the transplant hospitals to get T&B Lymphocyte cross match done with that of the recipient. The blood sample was sent via metro rail to heart hospital as it was peak hour, and the metro was the rapid mode of travel. Patient workup was done to oversee the process and prepare the patients for transplantation.

After a gap of 6 hours, the second diagnosis procedure of Brain Stem Death was carried out. All below mentioned teams had to coordinate their activities to ensure safe retrieval of healthy organs.

- *Donor maintenance team*
- *Organ retrieval teams*
    - *Internal kidney retrieval and transplant teams*
    - *The external liver retrieval team*
    - *The external heart retrieval team*
- *Tissue Retrieval Teams for the eyes from AIIMS*

Before the donor shifted to operation theatre relatives were told to have a last look at the donor. They offered "Ganga Jal" (holy water from river Ganga) to the donor. In the operation theatre, the doctors belonging to different transplant teams retrieved organs one by one. The heart transplant team removed the heart first, packed the heart in the custodial fluid. The liver transplant team extracted next, and, in the end, the kidney transplant team retrieved kidneys. Tissue retrieval team retrieved corneas. The custodial solution keeps the organs safe. Custodial fluid for one deceased donor amounts to fifty thousand rupees.

Two green corridors were created to transport two organs to these hospitals. So many people in the police were there to make it a success. The timing of transportation must be very accurate, and accuracy is what concerns traffic police. Ambulances with organ transplant teams transported organs. Two ambulances for each organ (one from the organ retrieval hospital and another from the organ transplant hospital) were there to carry an organ. One police gypsy in front and one behind the second ambulance with each organ. Four police gypsies and four ambulances were there to facilitate the transportation of two organs to two different hospitals. In a nutshell, eight vehicles transported two organs. While retrieving organs one cyst was found in the liver, and it was required to rule out malignancy.

Services of pathologist were invited, who revealed that the cyst was non-malignant.

- *The liver was then transported to a Government run hospital and transplanted to a 50-year male.*
- *Heart went to 50 years female in a private hospital*
- *Cornea went to AIIMS.*

- *A 22-year-old male and a 37-year-old female in the same hospital received one kidney each for transplant.*

The general surgeon did the dressing as retrieval teams are more interested in quick transplantation of the organs. Before the donor came out of Operation Theatre, it was made sure that there is no oozing or blood stain on the body. Approximately a 5-inch surgical dressing was done skilfully from sternum till pelvic region. The doctor covered the wound with adhesive Dynaplast tape. After ensuring proper cleanliness of the donor, the body was shifted back to ICU bed and body was packed for the mortuary. The donor was taken to OT at 7.30 pm on 6th February 2016 and brought back to ICU at 1.30am on 7th February 2016(Dates changed by the researcher). He was packed in clean sheets and sent for post mortem. Death summary/patient discharge summary was kept ready. The body was handed over to police in the presence of relatives. Letter of request for post mortem along with a certificate about retrieved organs was sent to the forensic department of nearby Govt. hospital, which is a usual practice in our hospital.

Meanwhile, relatives were briefed about the progress of retrieval frequently. It took about 22 hours from their verbal consent to final handing over the body to them for post mortem. The hospital vehicle that carried the body to the mortuary for post mortem also took the body to his home State along with relatives.

*The whole process requires lot of Documentation work. It required Form 8 of THOT Rules-2014**,** Form 10 of THOT Rules-2014**,** Request letter to police for permission to retrieve organs for Medico-Legal Cases (MLC) **,** Request letter to forensic team for permission to retrieve organs(name of organs and tissues)**,** Permission letter from police for retrieval of organs and tissues **,** Permission letter from forensic department for recovery of organs and tissues**,** Request letter for post mortem along with history of organs retrieved and their condition, Post mortem summary**,** OT summary sheets, Pre-Anesthetic Checkup (PAC) ,documents and organ Receiving letters from organ recipient hospitals for legal safety of the hospital.*

When relatives reached home, it was an entirely different story. They faced the brunt of society who charged them of having sold the organs of their child. Incidentally, it was a time when the father of the child was fighting elections for the post of Sarpanch in the village. The opponents started blaming him for selling organs of his son. It created an opportunity for the opponents to defame the father and the family.

*The tension involved in the whole event was unbearable for the family. They not only had lost their young male child but had to face the wrath of their society. They decided to inform our hospital authorities about their ordeal in the village. On knowing this, we thought of appreciating their decision of donating organs by felicitating them in public in their village. Before doing that, I felt a need to know the cultural practices of this family. We decided that a team of three health professionals from the hospital will pay a visit to the village and felicitate the family. We were requested on the telephone that we should not only think of felicitating his parents. But elders like the grandmother and aunt of the child too should be felicitated. It was because they were elder to the parents of the child. As per their village traditions elders are to be respected first in that community. On reaching there, the mourning places of two genders were different in this part of the village. Males and females were seated in separate rooms. The male doctor spoke to males, and the female doctor spoke to females. We spoke about brain death and the generous acts of family. The visiting team said that the family saved the lives of so many people through organ donation but did not get a single penny themselves. We had gone there with shawls and felicitating all the adults of the family with shawls and praises. We handed over a certificate of commendation too to the family. It gave us a platform not only to say thanks but to propagate organ donation from Brain Stem Dead donors as well. The grandmother said****, "Hum to Sirf Khal Hee Wapas Laye- Sab Kuch Zarrioratmand Logo Ko Diya"*** (Meaning we gave everything to the needy people, got back the skin only).

The case report, as mentioned above, reiterates the importance of wearing helmets before riding scooters and motorbike to prevent head injuries and loss of life. The case study brings into focus the importance of allowing a time gap for relatives before they accept brain death. It also reveals the importance of donation friendly Counseling room. Counselling room should have the photographs of donor families, photos of donors, donor felicitations etc. Such arrangement eases the process of convincing the BSD donor family. It also reveals the long waiting hours needed for donor family after deciding to donate organs. It also focuses on the moral obligation of the hospital to take care of the family by providing a family-friendly atmosphere till the time they get back the body. Keeping family well informed with great honesty till they leave the hospital builds trust and creates a supportive environment as depicted in this case report. Ensuring written consent before retrieval of organs is a must for preventing legal implications for OTC. Police play a key role in organ donation and transplantation and don't mind going the extra mile to save lives. Giving due recognition to the police is important in organ donation. For transplant recipients, we need to make them aware that it is not always the number in waiting list register that makes an organ available for transplantation. The organ must be best matched with the recipient body as well, to prevent rejection of that organ in the body. More than one recipient with same blood group comes from home for one organ transplant, but the organ is transplanted for the best-matched recipient only. Information to police and forensic teams is crucial in Medico-Legal Cases before the retrieval of organs. For MLCs, it is must to take permission from both the police and forensic experts. Briefing and continuous maintaining of the family are very crucial to sustain the approval and cooperation of the family. The job of organ donation is not over once the donor family leaves the hospital. Social ostracism after the donation of organs is an issue faced by donor families. Social recognition is essential for social acceptance, as well. There is an urgent need to tell people that there is no monitory benefit given to the family through IEC messages. Creating awareness on various aspects of organ donation is important as people who are aware can promote the donation of organs directly or indirectly. It is immaterial whether they have pledged to donate organs or not as depicted in this case study where well-informed relatives paved the way for organ donation. It was a great opportunity for this transplant coordinator, who said, *“you cannot believe I did not pass urine for 24 hours while coordinating this case. I could not realize that I had not taken food for 36 hours. I got engrossed with this event and forgot myself as a human being. I am a meticulous follower of religious activities. I always lit "Diya" in my home, but I didn't do so this time for 36 hours while coordinating the whole process of organ donation and transplantation. But I have no regrets for my failure to lit "Diya" this time. I was instrumental in giving lights to many people who were desperately waiting for organ transplantation. For me, it was an opportunity to give lives and lights to so many people. It was an opportunity to spread awareness, to reciprocate to the donor family, to forget myself and forget my own biological needs for 36 hours. I want to get many more opportunities in future too. I was in euphoria for about a week".*

Regarding post donation felicitation at home, it was essential to help them in winning back the lost respect in society. Post donation, similar stories were shared by many OTCs. They reported having visited the donor families along with hospital teams, especially on 4th and 13th-day mourning ceremonies of donor's death. On these occasions, they gave certificates to family, garlanded the photograph of the donor and gave Mementos to family in the presence of friends and relatives there. By doing so, they busted the myth of their relatives and acquaintances who believed that the donor family had sold the organs.

Perspectives of Organ Transplant Coordinators (OTCs)

The part of the Chapter deals with the perspectives of OTCs and reveals the findings of a questionnaire administered to 20 OTCs. These findings are presented in three sections. The first part deals with socio-demographic information about 20 OTCs. The second part reveals their perspectives towards the donation and third part reveals their knowledge, experiences, practices and opinions on organ donation and transplantation. Tables and Figures present the quantitative data of the study. The qualitative data, the narratives of OTCs during informal and formal discussions on various occasions, telephonic clarification with them on certain issues and in-depth interviews held with selective OTCs have also been amalgamated with the data presented in the various Figures and Tables.

Socio-demographic information about Organ Transplant Coordinators who were administered the questionnaire

Figure 5.3 Socio-demographic information about Organ Transplant Coordinators (N=20)

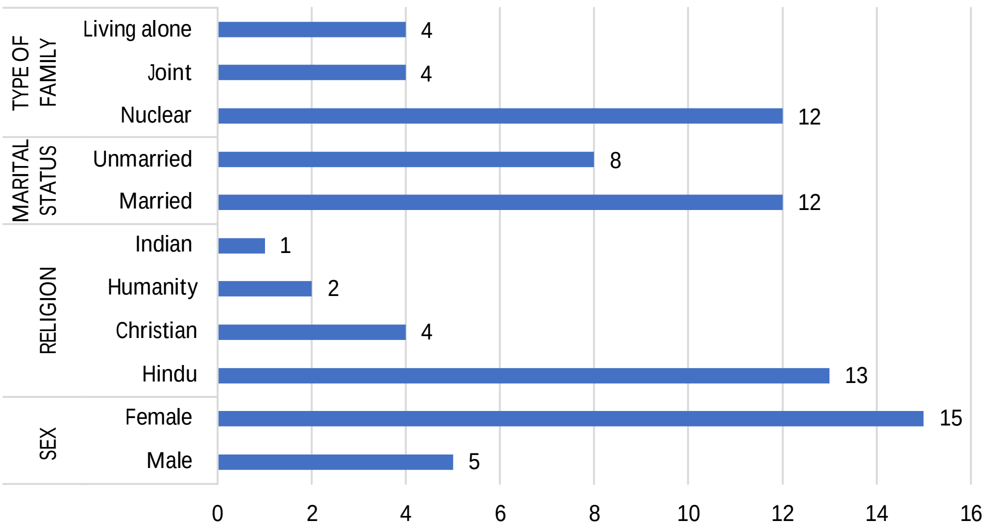


Figure 5.3 reveals that majority of Organ Transplant Coordinators, i.e., 15 were females, and 13 were Hindus. Interestingly two people choose humanity as their religion and one felt being Indian is his religion. Majority of OTCs, i.e., 12 were married in comparison to 8 unmarried. Majority of OTCs, i.e., 12 were living in nuclear families, and four (4) were living alone.

Figure 5.4 Organ Transplant Coordinators' family income per month in rupees (N=20)

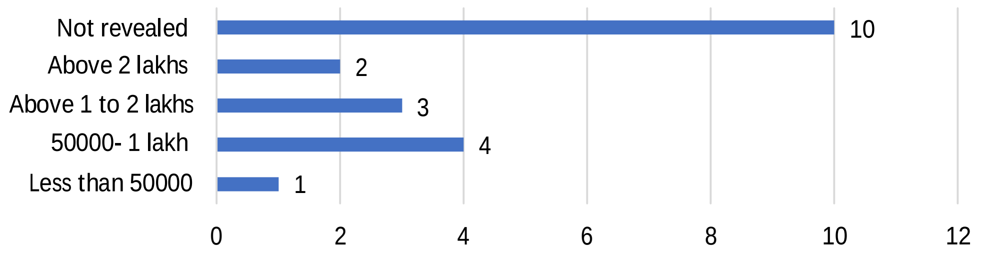


Figure 5.4 reveals that the majority of respondents, i.e., 10, refused to tell their family income. As per the statement of a few OTCs, their parents do not divulge their income to children. Only 4 OTCs revealed their family income between Rs. 50000-1 lakh per month.

Figure 5.5 Personal income of Organ Transplant Coordinators' per month (N=20)

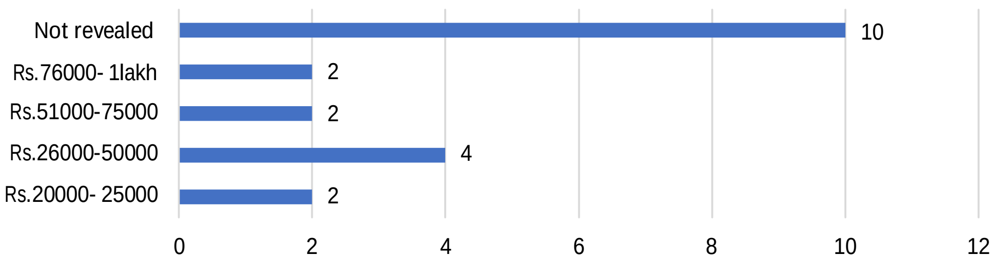


Figure 5.5 reveals the majority, i.e.,10 OTCs refused to reveal their income. Only 4 announced their income between 26000- 50000 rupees. The varying personal income is because of their different work assignments, work environments and designations in various health facilities.

Figure 5.6 Professional qualification of Organ Transplant Coordinators (N=20)

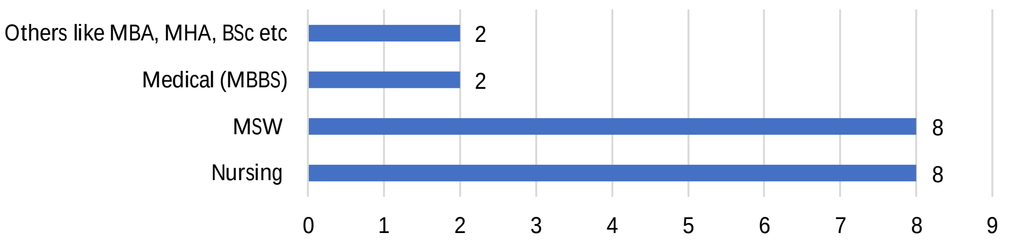


Figure 5.6 reveals that majority of OTCs, i.e., eight (8) had done nursing (BSc and GNM) and an equal number were qualified as Medical Social Workers.

Figure 5.7 Main designations of Organ Transplant Coordinators in hospitals (N=20)

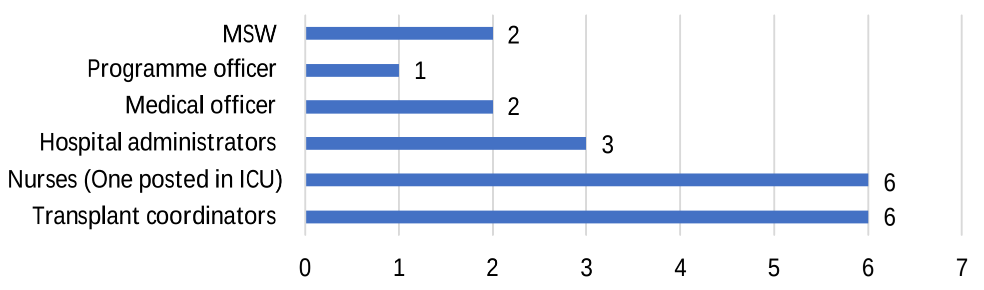


Figure 5.7 reveals that only 6 OTCs were working as Organ Transplant Coordinators primarily. Rest all other professionals were working in the hospital on other posts and were assigned the additional work of Organ Transplant Coordinators, like 6 nominated OTCs were nurses mainly, and 3 OTCs were hospital administrators.

Figure 5.8 Total work experience of Organ Transplant Coordinators (N=20)

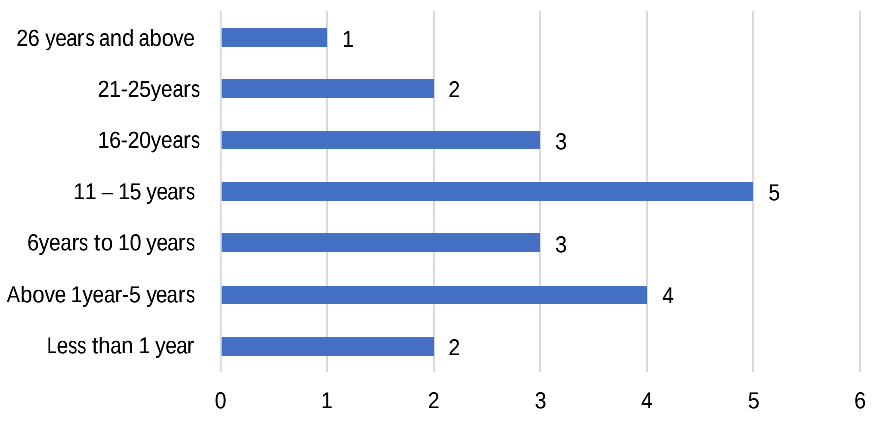


Figure 5.8 reveals the majority, i.e., 5 OTCs had 11-15 years of work experience. With relation to experience, this group of OTCs was a heterogeneous group with their expertise ranging from less than one year to above 26 years.

Figure 5.9 Experience of working as Organ Transplant Coordinators (N=20)

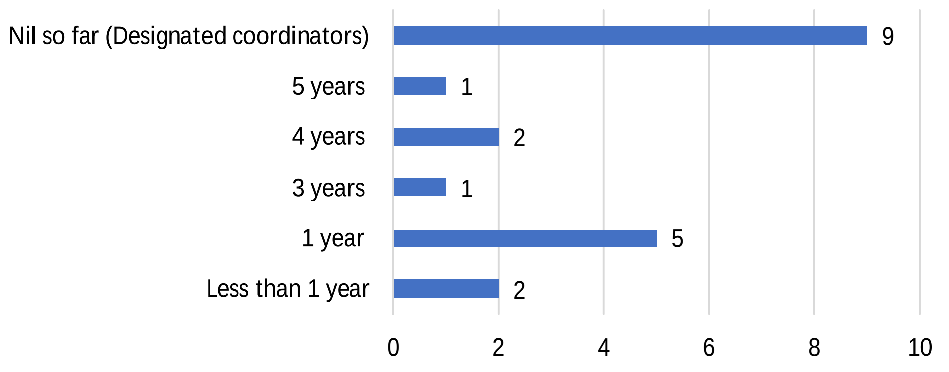


Figure 5.9 reveals that majority of designated OTCs, i.e., 9 had no work experience as Organ Transplant Coordinators. Also, none of the designated OTCs had more than five years of work experience as an Organ Transplant Coordinator. Only 5 OTCs had one-year experience as Organ Transplant Coordinators.

Whether Organ Donation Card Holder or Not?

Only 6 OTCs were Organ Donor Card holders. And a total of 10 members in only three (3) families of these OTCs were Organ Donor Card holders, i.e., three (3) members each in two families and four (4) members in one family.

Assigned Areas of Organ Donation and Transplantation in Hospital

The study revealed that 10 OTCs were primarily assigned the job of living organ donation and transplantation. Among them, two transplant coordinators had experience of swap transplants as well. Rest 10 OTCs were assigned the task of counselling the Brain-Dead Donor families along with overall coordination of such cases. Besides, conducting awareness programmes, providing social support to the family, handling end of life care, medical and legal consent for a kidney transplant, data entry, maintenance of data for proper legal safety were some of the responsibilities assigned to many transplant coordinators.

Perspectives of Organ Transplant Coordinators Towards the Donation

This part reveals the perspectives of OTCs towards the donation.

Significant Donation Made by OTCs

Figure 5.10 Significant donations made by OTCs during their lives (N=20)

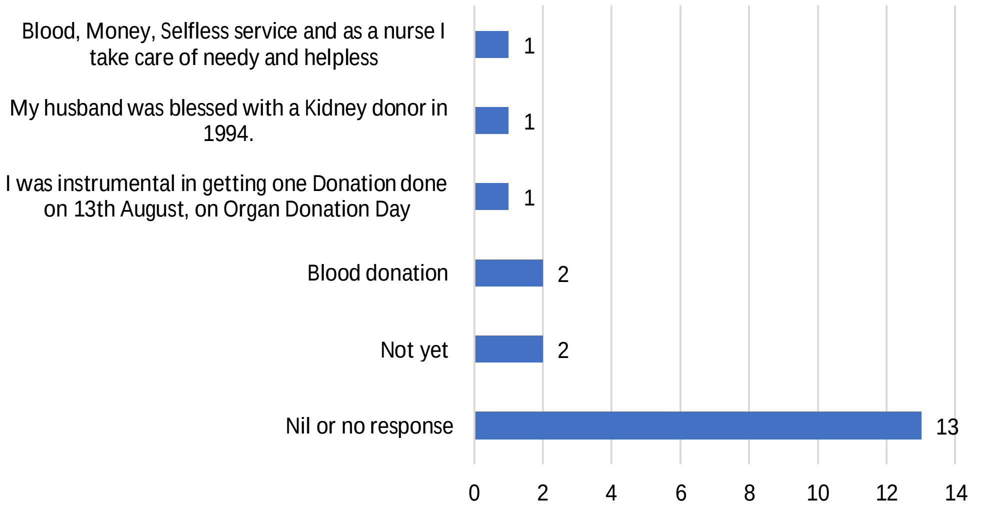


Figure 5.10 reveals that majority of OTC that is 13 did not report any significant donation, one OTC felt that her significant donation was organ donation and she had made it possible by being instrumental in getting organs of a Brain Stem Dead donor donated on Organ Donation Day, i.e., 13th August. Two respondents felt that their significant donation was blood donation. One OTC felt her contribution did not make any significance as she received a kidney from a BSD donor for her husband way back in 1994.

It is important to note that Organ donation day is observed by "Times of India" in partnership with Kokilaben Dhirubhai Ambani Hospital, Mumbai every year on 13th August. But NOTTO observes this day in November every year usually. The former was well known day among OTCs than the one observed by Govt. of India. Interestingly even the National Health Portal (NHP) displays 13th August as Indian Organ Donation Day.

History of Blood Donation by OTCs

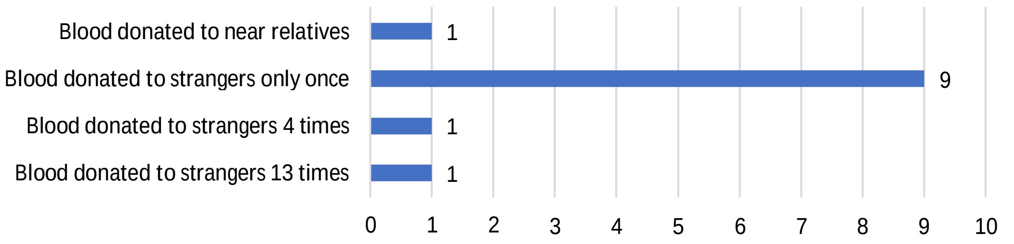


Figure 5.11 Blood donation history of OTCs to family members and others (N=20)

Figure 5.11 reveals the majority, i.e., 9 OTCs had donated blood to strangers at least once, and only one OTC had donated blood to near relatives. In addition to it, one OTC had given blood 13 times to 13 strangers as reported by her from the age of 18 years. She had a rare blood group "A Negative" and volunteered to be a generous blood donor whenever required by strangers. Incidentally, for her, the significant donation was the donation of organs, made possible by her from a Brain Stem Dead donor. Another OTC had donated blood four times to strangers.

The data reveals that some of the OTCs were generous blood donors and did not mind donating blood to strangers who were not their family members. We don't care if a person is generous blood donor as many times as possible, but selfless acts of people concerning organ donation are always suspected. Altruistic organ donation is not allowed in India barring a few States and in most of the cases donation of organs within relatives are perceived with high suspicion as was observed by the researcher during the study period while interacting with people and professionals.

Expressed Willingness of OTCs to Donation of Organs for Family Members

Figure 5.12 Willingness of OTCs to donate an organ (kidney or liver) during life to their own family member if required (N=20)

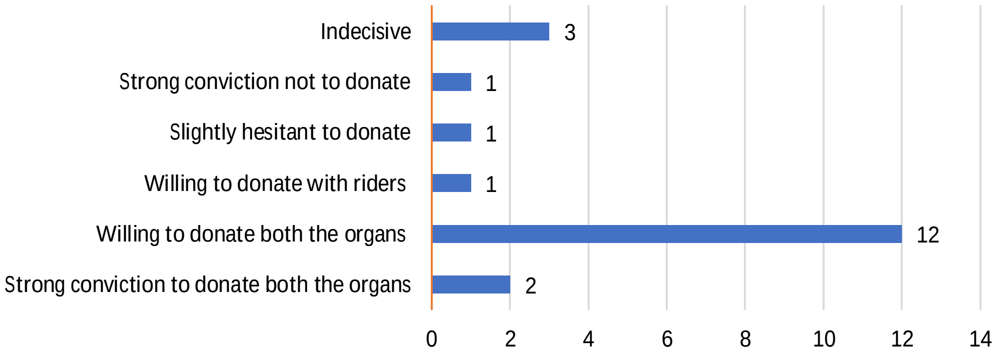


Figure 5.12 reveals the majority, i.e., 12 OTCs exhibited a willingness to donate both organs like kidney and liver to family members. Also, 2 OTCs depicted a firm conviction to donate both organs. They said, yes definitely, I am a universal donor (referring to the blood group O), and I can give an organ to any person in my family and the like. One OTC was willing to donate with a rider. She was ready to donate a part of the liver only as it regenerates. Three (3) OTCs chose to give no comments, One OTC was little hesitant by saying yes, I can, I may do so. Only one OTC said 'No' to organ donation for family members.

The data reveals the commitment of most OTCs towards family members about the donation of organs. The data also reveals the comfort level of one of the OTCs with liver donation only and not for kidney donation.

Expressed Willingness of OTCs to the Donation of Organs for Others Outside the Family

Figure 5.13 Willingness of OTCs to donate an organ (kidney or liver) during life to someone outside family out of affection without anticipating anything in return(N=20)

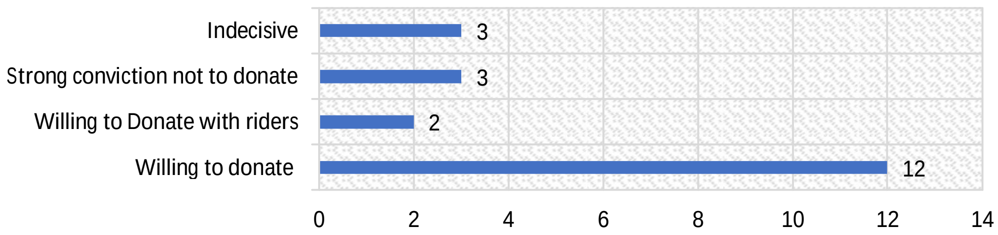


Figure 5.13 reveals that 12 OTCs exhibited a willingness to donate both organs (kidney or liver) during life to someone outside family out of affection without anticipating anything in return. About three categorically said 'No' to such donation, which was not the case with the donation of organs to near relatives. Also, 3 OTCs were indecisive. Two OTCs were willing to donate with riders, while one was willing to give a kidney another was willing to donate a part of the liver only.

The data reveals the commitment of most OTCs towards 'other than their family members' about the donation of organs. The data also shows selective preferences of OTC to the kidney or liver donation. While one OTC was comfortable with the liver donation as the liver can regenerate the other OTC was satisfied with kidney donation as there are two kidneys. Perspective varies from person to person. These findings question the suspicion involved in living organ donations in most of the cases by the authorities while evaluating living donor and recipient pairs.

Expressed Wish of OTCs for Getting BSD Donor Organs for Family Members

Figure 5.14 God forbid, would you like to get an organ for your family member from a BSD donor in case the need arises? (N=20)

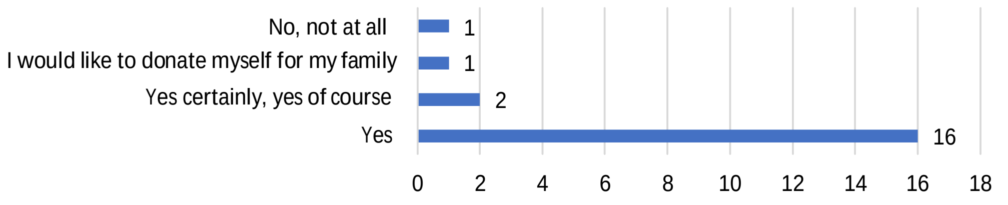


Figure 5.14 reveals majority, i.e., 16 OTCs preferred to get organs from BSD donors for their family members in case the need arises, two (2) OTCs strongly favoured such donation; one (1) OTC expressed desire to donate her own organ instead, and only one said ‘No’ to BSD donation for a family member.

The data reveals BSD donation as the most acceptable form of organ donation for transplantation amidst debates and dilemmas with such donation.

OTCs Belief in Living Organ Donation by Family Members

Figure 5.15 Who in your family will be ready to give an organ to you like kidney or a part of liver if needed ? (N=20)

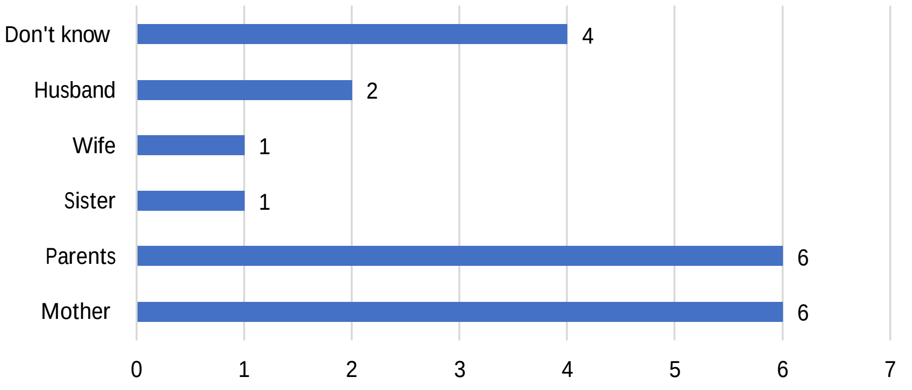


Figure 5.15 reveals female gender-specific expectations for organ donation by most OTCs. Out of 20 OTCs, 6 OTCs believed that it was their mother only who would donate an organ. The reasons revealed were: She gave me birth, and she must save me. Also, she must keep her child alive and she is the only person who can provide

an organ unconditionally etc. Their mixed responses varied from expectation to ownership of female organs, especially mothers' organs. Gender neutral answers were given by six (6) respondents only. Only two (2) respondents revealed male gender-specific (male spouses) responses. And four (4) OTCs were indecisive as to who could provide them with an organ.

The data reveals the expectation of OTCs for living organ donation rested on female mostly. The narratives also show a thin line between expectation on mothers' organs and a feeling of ownership on mothers' organs. Incidentally, one of the OTCs would never miss a chance to focus on gender issues ingrained with living organ donation to the researcher. Strangely, she also had filled the form giving the choices for mother and sister only that could be living organ donor for her. She had unintentionally left her brother and father as a choice for living organ donors. On being asked the next day, about these choices, she had no explanation to it and felt strange herself.

OTCs Liking for Getting an Organ from BSD Donor

Figure 5.16 God forbid, would you like to get an organ for yourself from a BSD donor in case you need one during your life? (N=20)

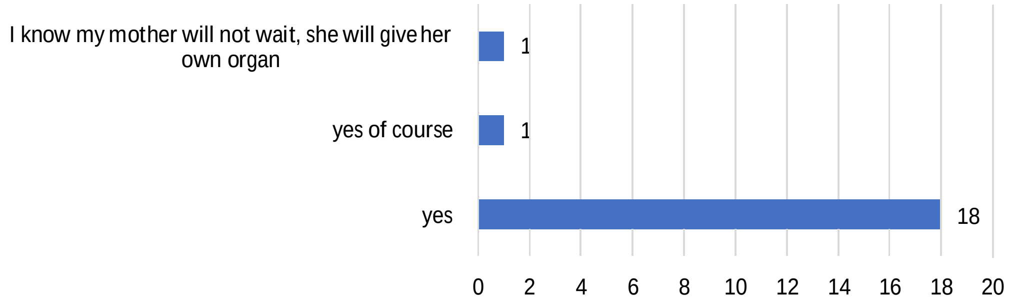


Figure 5.16 reveals the majority, i.e., 18 OTCs felt that they would like to get an organ from BSD donor in case the need arises. One OTC told that his mother would not wait for a BSD donor and will donate herself.

The majority preferred to get an organ from BSD donor in case the need arises. The narratives of Mr. B, *"My mother will not wait for a BSD donor, she will donate her* *organ"* speaks of great trust a male child has on his mother. The researcher would like to bring in focus the other such story also. A male person Mr. Bx asked a question in a mass awareness program of which researcher and OTCs were also a part. The question asked was, *"if my mother dies, can her kidney be transplanted to my sister, who is born with a single kidney only?"* The question here is why did that male think of mother to help his sister at death. Any other person could die in the family. Naming mother only shows the perception of people towards mother. A mother is not only considered the first preference during life but at death, also for the donation of organs.

OTCs First Preference for Organ Donation for Self If Required

Figure 5.17 God forbid, in case you need either a kidney or liver for yourself whom would you prefer first for donation of an organ? (N=20)

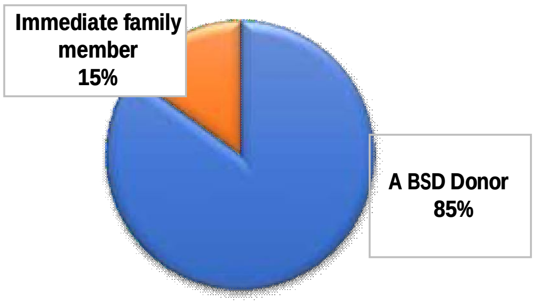


Figure 5.17 reveals majority 85% (17) preferred to get an organ from BSD donor and only 15% (3) preferred to get the same from their immediate family members.

Knowledge, Experiences, Practices and Opinions of OTCs

This part of the Chapter reveals the understanding of OTCs about Brain Stem Death, practices followed at their workplace concerning Brain Stem Dead donation and their opinions on a few related issues.

Understanding of OTCs about BSD

Figure 5.18 OTC s understanding about Brain Stem Death (N=20)

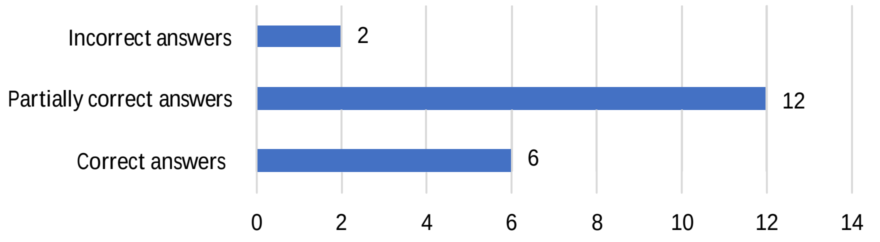


Figure 5.18 reveals the majority, i.e., 12 OTCs had a partial understanding regarding BSD. They gave partially correct answers. Only 6 OTCs gave correct answers to questions showing their adequate knowledge of BSD. The OTCs who gave correct answers knew that a BSD donor has a loss of reflexes, permanent loss of consciousness, permanent loss of the capacity to breathe and is on a ventilator. Regarding 12 OTCs who gave partially correct answers did not mention cessation of respiratory function and the support of ventilator to a BSD donor. Incorrect responses were given by 2 OTCs who indicated that a BSD donor has a loss of reflexes only.

Knowledge of OTCs About Tests That Are Done in Case of BSD Declaration

Figure 5.19 Knowledge of OTCs regarding tests done for declaration of BSD in India (N=20)

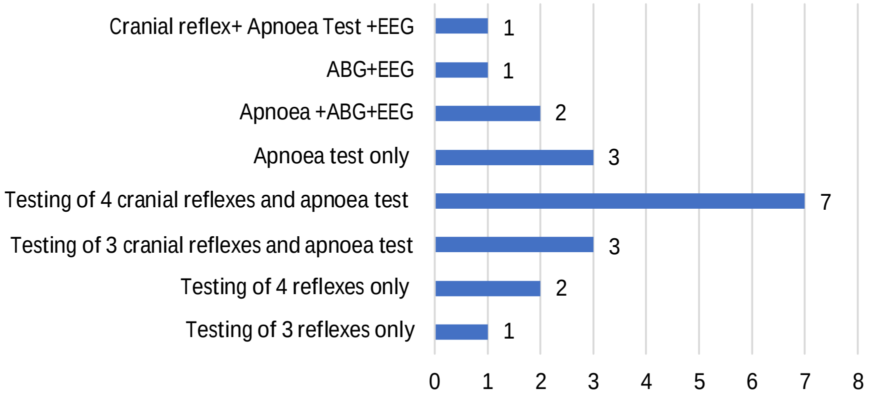


Figure 5.19 reveals the majority, i.e., seven (7) Organ Transplant coordinators could list all the four tests done before the “Apnoea Test”. It was surprising to see four

transplant coordinators informing about the use of EEG also. In fact, EEG is not done in India.

The researcher, while attending two training programmes for OTCs at NOTTO had for the first time, heard about the actual processes of “Apnoea Test “done for BSD declaration in India. It was a straightforward way of doing the “Apnoea Test”, by removing the patient from the ventilator for 3 minutes only, when brain death as a form of death evolved in 1968. But the way it was done now revealed unimaginable modifications as communicated by two different trainers in two OTC training programmes attended by the researcher. The test involves removing the patient from the life support of ventilator for 8-10 minutes and 10-12 minutes in two different training programmes while doing the “Apnoea Test”. These findings reveal a change in protocol over time and a lack of a Standard Operative Protocol for declaration of BSD in India.

Also, EEG is a vital aspect of the declaration of brain death and is not required in India for declaration of BSD. The data shows limited knowledge of OTCs about BSD donation.

Knowledge of OTCs About Different Criteria of BSD Diagnosis

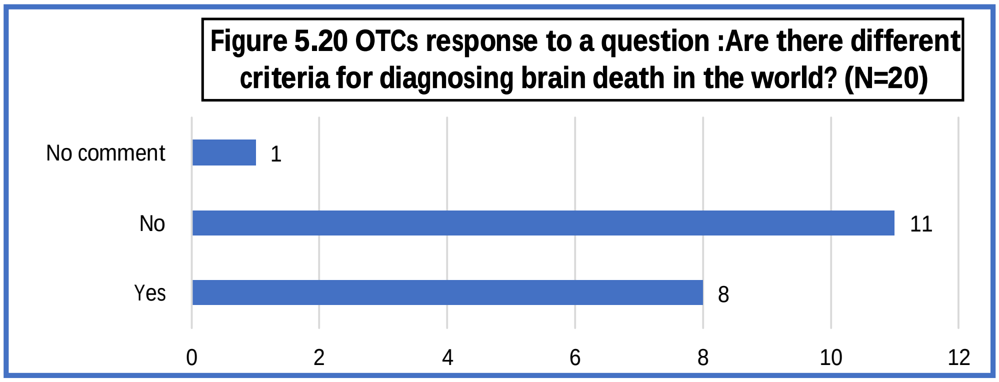


Figure 5.20 OTCs response to a question :Are there different criteria for diagnosing brain death in the world? (N=20)

Figure 5.20 reveals the majority i.e., 11 OTCs, did not know that there are different criteria for diagnosing brain death in the world. Out of 8 OTCs who said “yes” to different criteria for diagnosing of brain death in the world gave their opinion as well. The view of one transplant coordinators was that the tests done to diagnose brain death should be same everywhere and two OTCs wrote that EEG should also be done in India also.

Experience of OTCs About Counselling Donor Families

Table 5.2 Number of families counselled by OTCs and the number of families that refused organ donation (N=20)

Number of OTCs	No of families counselled for organ donation by OTCs	No of families who refused to donate organs
14	Nil	NA
1	1	1
1	3	3
1	12	9 refused, one crashed and two donated
1	25	16
1	42	30
1	50	40
Conversion rate *24.81%		

Table 5.2 reveals the majority, i.e., 14 OTCs had no experience of counselling families for organ donation. There was one coordinator who had counselled 50 families out of which 30 had refused to donate. The refusal rates were more for all transplant coordinators who had experience of counselling families, revealing lower acceptance of BSD among people. The average conversion rate was 24.81%, which is too less.

There is a vast gap between the number of families counselled and the number of families who eventually consented to donate organs of their BSD donors. All OTCs were working in various Government and private hospitals of Delhi only. A conversion rate of mere 24.81 per cent speaks of the low level of acceptance among people in northern India. Interestingly the OTCs had not much information about those cases whose families had communicated their refusal for the donation of organs. What happened to those cases was none of their concerns.

Experience of OTCs About Identifying BSD Donors in ICUs.

Figure 5.21 Number of OTCs visiting hospital ICUs for identifying BSD donors (N=20)

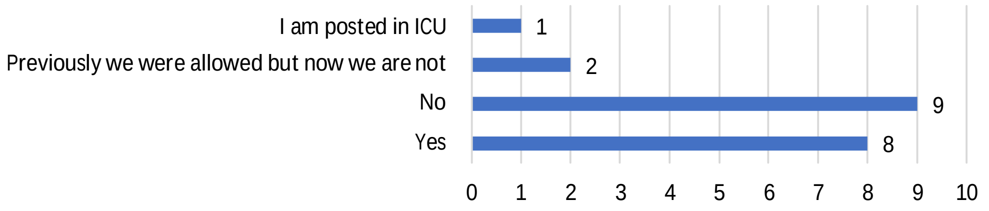


Figure 5.21 reveals majority, i.e., 9 OTCs were not paying a visit to the Intensive Care Units (ICUs) to identify BSD donors and only 8 OTCs were doing so. Also, 2 OTCs were stopped by neurosurgeons for visiting ICU for identifying BSD donors.

OTCs Ms. Klb said, *"I see the reflexes of patients in ICU and motivate nursing staff for getting the brain death declaration done. One of the neurosurgeons feels that it de-motivates the staff in ICU, who rather than focusing on saving lives shift loyalties towards Brain Stem Death declaration. I was scolded by this doctor many times. The moment he sees me, he says,* ***"Yam Raj Aa Gaya"*** *(Meaning God of death has come). I have stopped paying a visit to neuro ICU now".*

One senior most officer in DGHS, MOHFW working with NOTP, Dr.Ak also revealed this conflict of interest while relating one incident to the researcher. "I feel awful with a neurosurgeon. Dr. B of a very reputed hospital said in the presence of so many people that he is not aware of BSD, and he has no idea of this kind of death. How to declare such deaths is also not known to him. He said that this death has no other purpose except to increase organ donation. He told so many things that he should not have told at least in the presence of so many people".

There is a conflict of interest in some cases, as neurosurgeons want to prolong the life of the person in their care, no matter whether they have a chance of recovery or not. The transplant surgeons also want the same for their patients, but they need organs for transplantation from patients who usually are under the care of neurosurgeons. There is a conflict of loyalties. The OTC coordinating between the two gets sandwiched in the fight to either continue treatment or declare death. Neurosurgeons want to continue treatment for patients under their care, and on the other hand, transplant surgeons or recruiters expect OTCs to get organs for transplantation. It is ultimately OTC who faces the brunt of such unavoidable conflicts.

In Spain it is the timely identification of brain-dead donors by their OTCs, that is responsible for increased organ donation rates there (Dar, 2016). But it cannot be denied that organ donation from brain dead donors involves shifting of loyalties not accepted by most of the professionals in India. There is projection and counter projection coping mechanisms involved in these acts as narrated and witnessed by the researcher on many occasions (Dar, 2016).

Practices of Taking Consent from BSD Donor Families Before Performing Tests for Diagnosing BSD

Figure 5.22 Is consent from relatives taken to do "Apnoea Test" for declaration of BSD? (N=20)

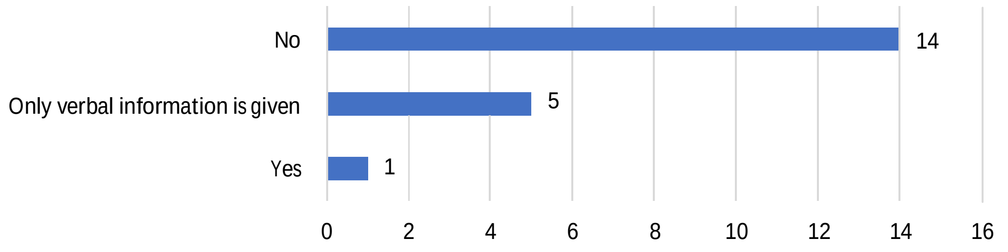


Figure 5.22 reveals the majority, i.e., 14 OTCs communicated that Consent from relatives for declaration of Brain Stem Death is not taken. Also, 5 OTCs told that relatives are verbally informed. Only one OTC reported that Consent is taken from the family before doing the “Apnoea Test”. They further added that relatives are told that some tests will be done to understand the condition of the patient or see the prognosis. The real purpose of this test is to declare the patient BSD, but that is not informed.

Ms. G, an OTC, said, "I feel disgusted with the system. There were problems in getting BSD certification done, and a lot of time was lost involving all four team *members. The wife stood for this great cause, consented to donate organs and did not succumb to pressures of her family. The family wanted to take the body home at the earliest. Every moment lost means deterioration of the quality of organs. We cannot wait. Let there be a white code for this event. There are different emergency codes in hospitals like blue, red, yellow, pink etc. Let there be some colour code for the diagnosis of BSD also in the hospital".*

Not taking consent from families for doing the "Apnoea Test" is also unethical. This test is not done to improve the prognosis of the patient but to declare a person brain dead. Relatives have every right to know the procedure done on their patient and the purpose of the same. Giving wrong information or divulging half-truths, that is in not going to help the patient is a most unethical practice followed in hospitals. It shows medical hegemony ingrained in the processes of organ donation from BSD donors.

The narratives of OTC reveal the problems faced by BSD declaration teams. BSD declaration involves four team members, one of whom is the Head of the hospital. At two consecutive occasions in a bustling Government hospital at times, it becomes painful and leads to frustration and inconveniences among professionals and relatives too who give consent to donate organs. The suggestion to use a white code for such death declarations needs to be debated and considered as a policy level decision.

Opinion of OTCs About Taking Consent from Donor Families Prior to Performing Tests for Diagnosing BSD

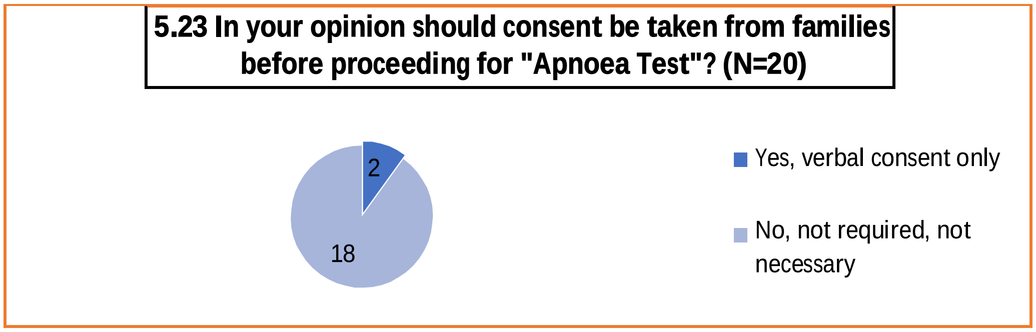

5.23 In your opinion should consent be taken from families before proceeding for "Apnoea Test"? (N=20)

Figure 5.23 reveals the majority, i.e.,18 OTCs were of the opinion that consent should not be taken from the relatives before proceeding for “Apnoea Test”.

The majority of OTCs, i.e., 18, did not approve of taking consent from relatives for doing the “Apnoea Test” as they don't want the family to interfere with such decisions. OTCs want more organ donors and seeking permission from relatives might bleak their chances of getting more BSD donors for organ donation and their job may be at stake.

Practices in Relation to Family Involvement During “Apnoea Test”

Figure 5.24 Is "Apnoea Test"done in presence of relatives? (N=20)

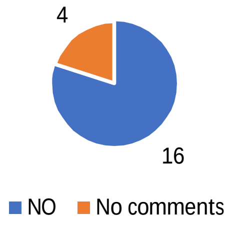


Figure 5.24 reveals majority, i.e., 16 OTCs, had no comment to offer regarding the presence of relatives during the “Apnoea Test” and 4 OTCs reported that relatives are not involved.

Opinion of OTCs About the Involvement of Donor Families During “Apnoea Test”

Figure 5.25 In your opinion should "Apnoea Test" be done in presence of relatives of the BSD donor? (N=20)

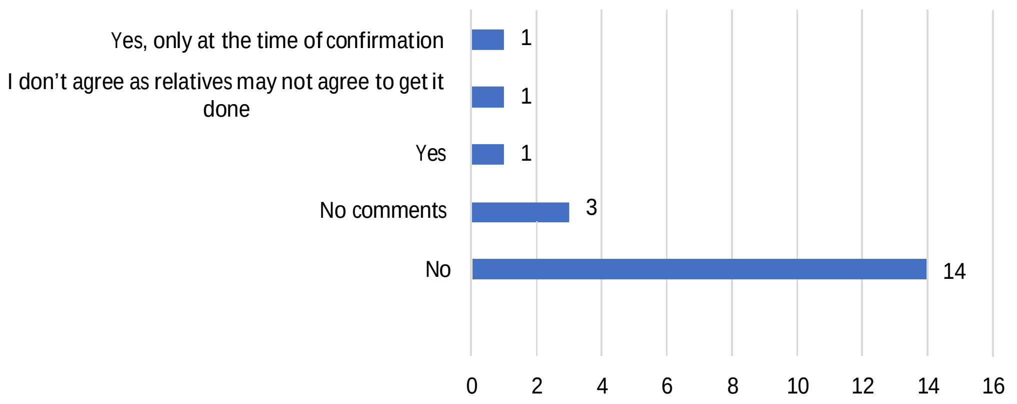


Figure 5.25 reveals the majority, i.e., 14 OTCs were of the opinion that the "Apnoea Test" should not be done in the presence of relatives.

As per Mr. Kn, *"In this State, the bad news is spreading on deceased organ donation. People are complaining that premature brain death certification is happening in private hospitals. So, doctors are hesitant to verify brain death now. There is an RTI in this State and NOTTO has become the party to this RTI. People blame the State for making the premature declaration of brain deaths. People are asking for mandatory EEG and video recording of the procedure".*

Non-involvement of relatives during the "Apnoea Test" can allow Medical practitioners pronouncing death (BSD) for organ donation without much interference. Involving relatives is not required as per laws. For living donor-recipient pairs, there are a lot of checks to prevent financial transactions, and the donor-recipient interviews are video recorded. But such financial gains from BSD donors in Private hospitals have been overlooked so far. There is no video recording of the event and EEG is not done. India follows the BSD criteria, and this test is not required. The commercial gains of private hospitals cannot be overlooked and need some remedial measures to prevent people from falling prey to such commercial intention of private hospitals

Experiences of Movements Made by BSD Donors and Reactions of the Donor Families

Out of 6 well-experienced OTCs, 4 OTCs found some movements of the body after the first diagnosis of Brain Stem Death. These four OTCs reported movements of toes and fingers, slight drawing of an arm, small breathing movements of a brain-dead person. According to one OTC, in one case, they did not proceed with the "Apnoea Test" seeing spontaneous breathing moments that meant the brain stem had not died. The four coordinators, however, added that all those body movements were the result of spinal reflexes or ventilator.

Three coordinators reported body movements of Brain Stem Dead donors in the presence of relatives too that made things worse for them. Body movements of their patients shocked a few relatives, and a few relatives got angry with OTCs. A few felt confused regarding life and death.

Three OTCs said that they convinced relatives by telling them that it was because of spinal reflexes and ventilator. Only one coordinator reported that in one case, the family donated organs after she convinced them, while the other two said that families never went ahead for organ donation, and straightaway refused to do so.

All signs of life are present when BSD is declared. Respiration, heartbeat, movements that are the common signs of life are usually present in a BSD donor. The issue of BSD declaration with all intact vital signs and few body movements is debatable and questions death and life. The common man, including professionals, has every right to be perplexed with this form of death.

OTCs Opinion About Whether It Is A Tough Decision for Families

A total of 14 coordinators reported that it is a tough decision for families to donate organs, while six (6) chose to remain silent.

Mr.Kn reported, "I was told to motivate a family to donate organs. It was a young male 24 years old, who had a subarachnoid haemorrhage. He was unconscious and on the ventilator. I went to the mother and told her about the brain death of her son. With great persuasion, she agreed for donation. However, she expressed her desire to see the patient in ICU. When I took her to see her son in ICU, the sister was introducing some medicine through Ryle's tube. Brain dead patients are given such medications routinely. The mother felt her son is alive getting medicines. She created great commotion in the hospital, raised her voice to the peak and shouted at me like hell. She felt some organ trade racket is going on in the hospital. I felt embarrassed. I can never forget my odd situation in this case".

A transplant coordinator, while counselling a family to donate organs of their brain stem donor, spoke to the family for long hours. She had long discussion and deliberations throughout the night. Ms. M narrated her story, *"The family was a very well educated. The person who was Brain Dead had pledged to donate his body. They spoke to so many people, including his married daughter who lived in the US. She was an organ donor herself. The family did not budge even after long hours of my counselling. They were reluctant to donate anything".*

As per Mr.K, "Usually people don't accept this death".

The narratives point to sufferings and frustrations of OTCs when they are not able to motivate families. It is a tough decision for a family to donate organs of a heart beating person. For a mother whose son is given the medicine through Ryle's tube, how can she be convinced that her son is dead? The ethical issue points to selective information provided to relatives to get consent for retrieving organs of BSD donors. The narratives of Ms M. reveal frustration and limited knowledge. She blames the family who did not donate organs. Laws and procedures of India and the USA are different. The USA follows a very stringent criterion of brain death while India follows Brain Stem Death criteria only. Organ donation, tissue donation and body donations are different as per laws that govern this country. If a person had pledged to donate body, does not mean he had promised to donate organs. In India, organs are donated for transplantation into people needing organs after Brain Stem Death. It is essential to mention that when a person is declared Brain Stem Dead, his organs are functioning, and his heart is beating. The same does not hold in the case of tissue donation (eye donation) or body donation. Gift of the body is made after complete death when the heart has stopped beating forever. After the whole-body dies, organs are not transplantable. The body is donated for scientific and educational purposes and is of great use to anatomical departments of medical colleges and not to transplant surgeons. The transplant coordinator could not cope with her failure to motivate the family to donate organs after whole night deliberations with the family. Instead of understanding the nuances of such a decision, she tried to cope with frustrations by blaming the family.

OTCs Experiences with Donor Families When Convincing Became Difficult

Six OTCs had come across such a situation when they failed to convince families that their patient is dead. Explanation by ICU doctors also could not help in convincing the families was reported by 2 OTCs. One OTC said that families wait for some magic to happen. One OTC reported that they are not convinced about the death of their relative when they find their patient breathing with a beating heart. One OTC reported that they do not understand the concept of brain death. Another OTC said that she came across so many cases whose families did not believe the patient is dead.

Ms. F, who was from a private hospital narrated, *"In one case a poor person was requested to donate organs of his Brain Stem Dead son in ICU. The poor man neither had money to continue treatment nor had the will to donate organs of his brain-dead donor. He did not consent to donate organs. Instead, he chose to leave the situation. Later he did not respond to any phone calls from the hospital as if the situation to decide did not exist".*

The thought of near and dear one dying is not without pain to the relatives. Several people deny accepting Brain Stem Death as death. They face an odd situation in the case of BSD. Within a short period, they have to consent for organ donation or continue treatment. Both these options are painstaking for the family. They are caught in a conflicting situation and trapped into organ donation. The third option to discontinue life support without donating organs that could serve the purpose of a poor person is missing from such acts. A family is supposed to either donate organs or continue futile money consuming treatment for the patient. The ethical dilemma here is, if a family decides to donate organs, professionals will declare the patient BSD. And if they refuse to do so, then the donor is a living person only, and the family is bound to pay through the nose. The plea given is that there are no laws that say to discontinue life support. It again proves medical hegemony under the shade of legal bindings.

Pressure Felt by OTCs to Motivate Relatives to Donate Organs

Figure 5.26 Have you ever felt pressure to motivate relatives for organ donation of a Brain Stem Dead person? (N=6)

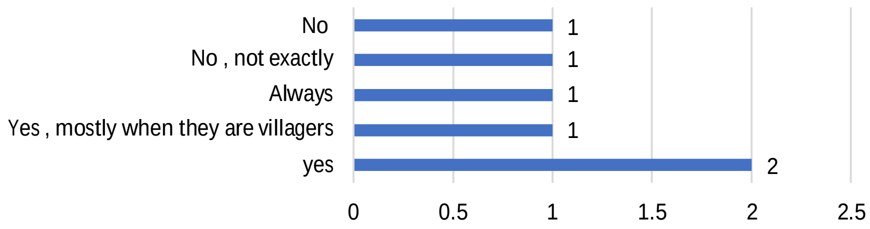


Figure 5.26 reveals that the majority of experienced OTCs, i.e.,5 out of 6 did accept some pressures put on them to motivate relatives to donate organs. One transplant coordinator felt she was always pressurized to motivate villagers whom they felt would succumb to pressure for the donation of organs.

An OTC from an organ sharing network once rang the researcher from other State, only to vent out her feelings. She said that she has seen it is usually the poor people who are pressurized for donating organs of BSD donors in comparison to suited-booted people in the hospital.

It is incredibly unethical to exert pressure on OTCs to approach people, especially villagers for organ donation.

Questions Asked by Family Members When Requested for Organ Donation

Regarding questions asked by family members at the time of the decision-making process, the transplant coordinators experienced a variety of questions asked by the relatives when approached for donation. These questions depicted various BSD donor concerns like Ethical Concerns, Knowledge Concerns, Consensus Concerns, Religious concerns, Financial Concerns, Intrafamily donation concerns, Time Concerns, Recipient Concerns, Beauty concerns of Donor Body, Concern for Future of the Donor and Documentation Concerns.

The relatives had pleaded OTCs not to disfigure the body and not to sell the retrieved organs. While some relatives would ask questions with sole intentions to weigh the financial gains to the hospital, others felt suspicious of the intentions of these hospitals also. The questions asked by families as narrated by OTCs have been classified into various categories as follows:

Ethical Concerns: **-**Will you use organs ethically? Give organs to the right people. Do you know that person who is getting organs? What would you do with these organs? How can you say he is dead? He is breathing. How dare you ask me for organ donation?

Knowledge Concerns: - What is brain death? Why cannot our patient come out of this situation? Are you God?

Consensus Concerns: -Reaching consensus within the family takes a lot of time to decide in favour of donation. The stories communicated by OTCs also point to, the presence of several relatives when a person is in ICU that influence decision making processes of the family. The stories also reveal how private hospitals go the extra mile to retrieve organs. Males force their decisions on vulnerable females and suppressed them too.

As per Ms Jb, *"Some relatives of the BSD donor say, let his mother come, let maternal uncle come, let paternal uncle come etc. In most cases, eventually, no one comes forward and decides to donate. All the family members are usually not willing".*

As per Mr. C, *“Presence of too many relatives and discussion on death and donation among several relatives usually terminates into lack of consensus with varied opinions”.*

As per Ms. M, *"In one case an Indian family was ready to donate organs of their Brain Stem Dead relative. They were told to call his wife for signatures for getting her consent. They informed me that she could not come as females are not supposed to decide. They further added that once males have decided to donate, she cannot refuse to sign. They decided to get her signature at home saying that she will sign anything and everything we give her to sign. Aghast with such narratives, we did not proceed with the case seeing the aggressive and oppressive atmosphere of male members".*

As per Mr. Ai, *"In one case the brother of the BSD donor was willing to donate organs. On being informed that his wife's consent is a must for donation, he got offended. He said who is she to sign? She will never dare to refuse for signing when we decide it.* ***"Mai Fatwa Jarree Karwoonga. Who Kaun Hotee Hai Manna Karney Ke Liyey".*** *(Meaning I will get Fatwa issued to her if she refuses to do so).*

The stories also point to private hospitals going the extra mile to retrieve organs.
As per Dr. Ak, *"In one case the hospital authorities were willing to pay the airfare of wife from Bihar and back to Bihar in an accidental case for getting her permission to donate organs of BSD donor".*

Religious Concerns

The OTCs also communicated the religious sentiments of people and felt disgusted with such religious views of relatives too.

As per Ms. M, "I was told by one family that they will give their consent to organ donation only if organs go to same religion recipients".

As per Ms. Ao, "I felt greatly disappointed when a donor family asked me whether the organs of their BSD kin would find Brahman recipients only. Since we are Brahmans, we want assurance they said. I wanted to ask them whether they thought of the person's caste who admitted her to the hospital? Also, what about *the caste of treating physicians, nurses or housekeeping personnel and the mortuary in charge? It is ridiculous".*

Financial Concerns:

The financial concerns put relatives in a dilemma whether to continue costly treatment or to avoid it by consenting to donate organs. They also ask questions like, have we to pay for all the activity that shall be done to retrieve organs? What is the cost of these transplant surgeries? Will you waive off the ICU bill if we consent to donate?

As per Ms. N, "We start with an appositive note telling them it is a great opportunity to give organs as the person on a ventilator has no chance to recover. We start asking them for the donation of eyes and see their reactions. If we find a positive reaction, we proceed further and ask for organs. We usually waive of their fee for the day when brain death is declared. We give them enough time to think".

As per Ms. M, "There was a case of BSD donor whose family wanted to donate organs only after their hospital bill is waived off. The hospital where the patient was admitted was a non-retrieval hospital. Hence, the patient was shifted to a retrieval hospital. After a lot of inter and intra-hospital deliberations, the bill of 2 lakh was waived off, and the donor shifted to another hospital".

As per Ms. J, "They feel that by donating organs of family members, the medical bills shall be waived off. The ICU bills are too much ranging from 10 lacks to 50 lacks. They want the hospitals to waive off the full fee in case they decide to donate organs. The moment family consents to donate organs verbally the billing stops usually".

Intra-Family Donation Concerns

As reported by OTCs, sometimes the families also put precondition before deciding to donate organs.

As per Ms. Md, *"in one BSD donor case, the family wanted to donate one kidney to their relative who was waiting for a kidney transplant. They put a condition that one of the retrieved kidneys will go to their relative. The hospital authorities accepted the condition, but the donor's kidney did not match with the relative. The family considering this as God's wish, did not question further and allowed us to proceed with the donation of two kidneys, heart, liver and two corneas".*

Two transplant coordinators also reported that on one occasion, relative wanted organs to be allocated to their own relatives who were suffering from CKD.

Time Concerns:

As reported by most of the OTCs, it usually takes 24 hours from Brain Stem Death confirmation to give the body back to the family after retrieval of organs. Retrieval of organs involves multiple teams of various organ retrieval and transplant hospitals. When shall we get back the body? How long will they live after this transplant? These are the questions that are asked by most of the family members.

As per Ms. Mabs, *" During my first successful donor family motivational case, I was unaware myself about the time-consuming procedure of organ donation. The time taken to retrieve organs was very long. Convincing family to wait for long hours about which I had not given them prior information was really giving me high blood pressure and uncontrolled palpitations. They were feeling awful for this".*

Recipient Concerns:

Most of the OTCs faced the following questions: - Who will be the recipients? What is the cost of these transplant surgeries? Can we meet the recipients in future?

As per Ms. Z, *"A donor family wanted assurance that none of the organs retrieved is wastes and all the organs transplanted go to needy persons only".*

Beauty Concerns of Donor Body:

Most of the OTCs faced several questions that relate to the beauty of the body after the retrieval of organs. How will the body look like after so many organs are retrieved? Shall the body be disfigured?

Concern for The Future of The Donor:

The donor also has a future after leaving this world and that is what concerns donor families the most. The families feel that the donor is going to be born again. The questions usually asked are, What, if he does not get these organs in next birth? When will the soul leave, the heart is still beating?

As per Ms. S, *"People assume that the person has a life after death and shall have to consume food in another world after death. If some of his organs are removed for transplantation how he will assimilate the food, there?"*

As per Ms. M,*"A medical doctor asked about the soul of her mother. She enquired, when did the soul leave my mother's body? My mother's heart is still beating".*

As per Mr.D , *"Daughter-in-law after consenting to donate organs of a brain-dead husband was questioned by lamenting and crying mother in law asking her, "What had she done? What about Moksha of her child? (MOKSHA is a Hindi word depicting human belief that the soul leaves the body at death and unites with God) Will my child get moksha? Daughter in law regretted her decision and communicated the same to me on the telephone".*

As per Ms. R, *"A family refused to donate heart of their brain-dead donor thinking that if they donate the heart, the soul will not unite with God".*

Documentation Concerns:

The procedure for retrieval of organs is very cumbersome as was reported by many OTCs. The relatives, at times, feel disgusted with elaborate procedures and a lot of documentation work when they are in grief and have decided to donate organs. They get disillusioned with very intricate documentation work.

As per Ms. F, "People usually ask why they are made to do so much of documentation work for a good cause like donation of organs."

Many concerns are depicted by donor families when confronted with the request for organ donation by OTCs. It is essential to develop a booklet for donor families that could address some of the issues by ethically answering their queries. It shall be worthwhile if some of the concerns are addressed by taking policy level decisions. There is a dire need to allow the donation of one organ to a family member of a BSD donor who may need a transplant. The burden of documentation could be reduced so that the donor family are not put in trouble when they are grieving. Financial aspects also need to be relooked for poor patients, especially. The hospitals follow different policies, very few hospitals waive the previous bills, but most of the hospitals don't do so. However, financial investments of any kind from family after giving consent to donate organs is stopped at once by many hospitals that should be made mandatory for all hospitals.

Procedure Followed for Requesting Donor Families to Donate Organs of BSD Donor

Figure 5.27 Procedure of requesting relatives for organ donation from a BSD donor (N=20) (Multiple Choice)

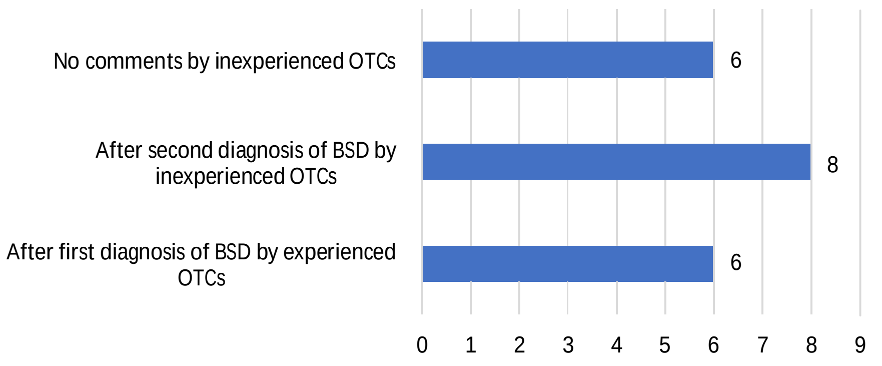


Figure 5.27 reveals that according to the majority of inexperienced Organ Transplant Coordinators, i.e., 8(40%), the request to donate organs is made after the second

diagnosis only. However, it was surprising to find that all six (6) experienced OTCs revealed that the demand for organ donation is placed after the first diagnosis of BSD.

As per Mr. Kn, *"Mandatory diagnosis of BSD has a history in this part of the country. In one case before the “Apnoea Test”, I was told by doctors to counsel a family after they found loss of reflexes in the patient. I counselled the family and they accepted to donate organs. But before proceeding for* “Apnoea Test”*, doctors found the patient had hypothermia. Hypothermia is a contraindicated for the* “Apnoea Test”. *The BSD was not declared. The family on knowing this gave me right and left. It is for this reason that it has been made mandatory to declare brain deaths here in this State".*

Procedure Followed For 2nd Diagnosis OF BSD

Figure 5.28 If relatives refuse to donate organs after first diagnosis of BSD, is second diagnosis done on the patient? (N=20)

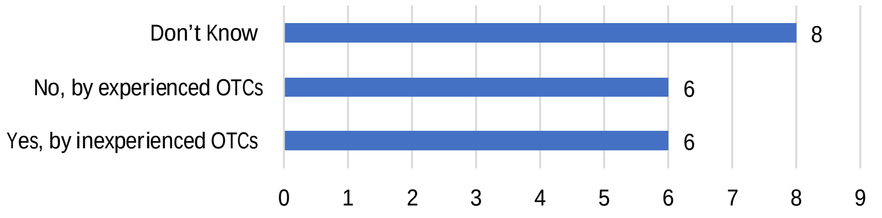


Figure 5.28 reveals that according to 6 experienced OTCs, the second diagnosis of BSD is not done in case the family refuses to donate organs. The other 6 OTCs who had no experience believed that second diagnosis is also done. The second diagnosis confirms death and not the first diagnosis. The majority, i.e., 8 OTCs, did not know the nuances of this diagnosis.

A few transplant coordinators brought several issues into focus with such diagnosis through narratives as follows: -

As per Mr. K, *"The major problem faced by us is if a family does not give consent for organ donation. In such cases, the second “Apnoea Test” that becomes the time of* *death is not done. It should be done, and artificial support should be withdrawn. It will help the family to avoid prolonged grieving and financial loss. It will also improve the utilization of vital infrastructure like artificial ventilation. What is your view, madam?"*

As per Ms. M, "*The second confirmatory test is not done in such cases as the law is not clear. We cannot stop ventilatory support".*

As per Mr. Fb, *"Ideally all four doctors should be present, but it is not always possible. When asked should the whole procedure be video recorded, he said, no, it shall again act as a barrier in diagnosing these deaths".*

The researcher asked this question informally to a few OTCs, and most of them said that the second diagnosis is not done if the family refuses to donate organs after the first diagnosis. In addition to it, two OTCs revealed that family is counselled even before the first diagnosis of brain death. If a family refuses to donate organs, even the first brain death diagnosis is not done, and the patient continues breathing through a ventilator. The ethical issue relates to medical hegemony in pronouncing deaths and raises doubts about this BSD definition of death. Are laws misleading the doctors, or is it doctors who are misleading relatives by misinterpreting laws for financial gains? The case studies also point to the problems faced by professionals in diagnosing this death. Such declaration needs the cooperation and presence of 4 medical practitioners twice with a minimum gap of 6 hours. The team comprises of head of the institution also in busy hospitals that becomes difficult at times. The presence of 4 doctors to prevent human error in diagnosing such deaths is side-lined by professionals. However, they ensure getting signatures of all the four professionals for BSD declaration to avoid legal problems.

OTCs Having Come Across Situations When Relatives Did Not Want to Donate Organs and Wanted the Body Back

Figure 5.29 Have you ever come across a situation when relatives did not want to donate and wanted you to hand over the body to them? (N=20)

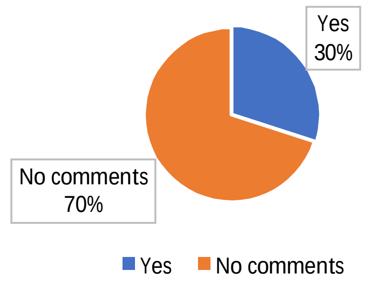


Figure 5.29reveals that 30% (6) OTCs (experienced OTCs only) affirmed that they had come across a situation when relatives did not want to donate and wanted them to hand over the body. Out of these six (6) experienced OTCs, three OTCs further added that this happened many times, very often and always.

Ways of Dealing with Situations When Families Wanted the Body Back to Them Without Donating Organs

Figure 5.30 Ways of dealing with situations when relatives did not want to donate organs of BSD donor and wanted the body back (N=6)(Multiple Response)

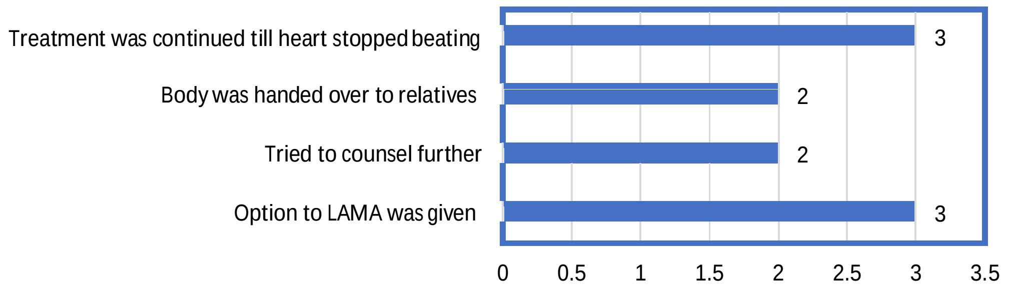


Figure 5.30 reveals that 6 OTCs (experienced OTCs only) dealt with the situations in different ways. Three OTCs said the option to go for LAMA was suggested. Two OTCs said the treatment was continued; two said that they continued counselling for long and 3 OTCs said the treatment continued till heart stopped beating.

As per Ms. Mgh, “The relatives are told to get the patient to another hospital in ventilator fitted ambulance or take LAMA (Left Against Medical Advice)”.

As per Ms. F, "The patient is shifted on Ambu Bag and escorted by ward boy till he is out of the hospital premises and we do not know what happens later".

As per Mr.K, “The patient on the ventilator after the first diagnosis is entitled to all the death care. It is called death care and not life care".

During one transplant coordinators training program at NOTTO attended by the researcher, one of the external transplant coordinators who had experienced several such incidents asked a question to the faculty from AORTA. She asked him what should be done in such cases where the family is not willing to donate organs and want to take back the patient? He answered that the family should be trained to use an Ambu Bag, and the patient should be sent home along with Ambu Bag.

There are a lot of confusions with this form of death. A person who is diagnosed brain dead should be removed from the ventilator to avoid adding cost to futile treatment. It can be done with prior information to the family. The purpose of Brain Death was to remove the patient from the ventilator and not for organ donation. But in the current scenario, the real goal is to retrieve organs and not to remove him from the ventilator. Further, a person is either dead or living, but words like death care or life care depend on the decision of relatives. LAMA (Left Against Medical Advice) does not come under death care. LAMA is advised for patients, not for dead bodies. But with this debatable definition of death having the sole purpose of organ donation, there are enormous ethical concerns to be redressed.

Experiences with The Matching of Blood Group and Crossmatch

Regarding experiences in matching blood group and doing crossmatch, hospitals call a few recipients from home with the same blood group as that of the BSD donor. The blood sample of BSD donor is crossmatched, through some laboratory tests with all these recipients. Only the best-matched recipient is allocated the organ to prevent rejection of the organ. Six experienced OTCs reported that two to five hospital registered patients waiting for a transplant are called for transplantation to avoid the wastage of organ. The number of patients called for operations varies as per the policy of transplant hospitals. In case the organ is allocated to another hospital, a blood sample is sent to that hospital in advance for crossmatching.

Opinion of OTCs About Who Should Be the Recipients of Donor Organs

Figure 5.31 Opinion about who should be the recipients of BSD donor organs (N=20) (Multiple Choice)

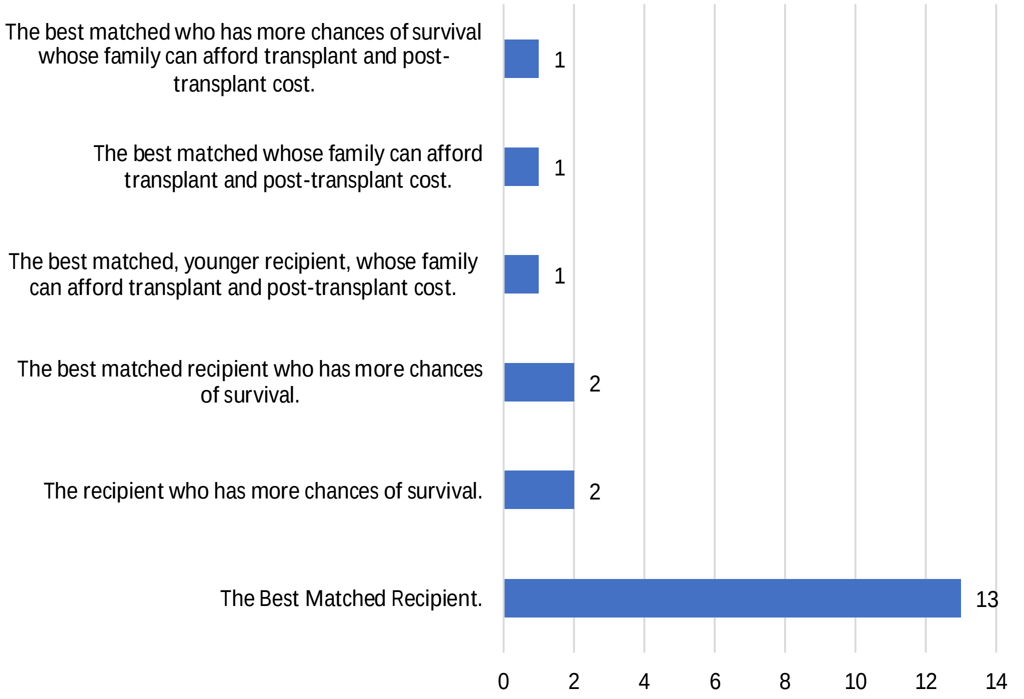


Figure 5.31 reveals that according to the majority, i.e., 13 OTCs, the best-matched recipient should be the recipients of the organs. It depicts a belief in the law of natural justice by most OTCs.

Experiences of OTCs About BSD Donor Families Wish to Know the Recipients

There were only three transplant coordinators who had come across situations when donor families wanted to know the recipients. There were no comments from the rest of the coordinators.

Regarding revealing information about recipients to the BSD donor family, three Organ Transplant Coordinators explained that they give selective information to the donor families. While one transplant coordinator told that donor families are informed only about the age, sex and place of residence of the recipients, the other reported that they handover a "Thank you letter" from the recipient family without name and address of the recipient. And the third coordinator said they provide information about the age of the recipients and the name of the organ recipient hospital only.

Recipients wish to know donor families

Figure 5.32 Reasons of the recipients to know the BSD donor families (N=6) (Multiple response)

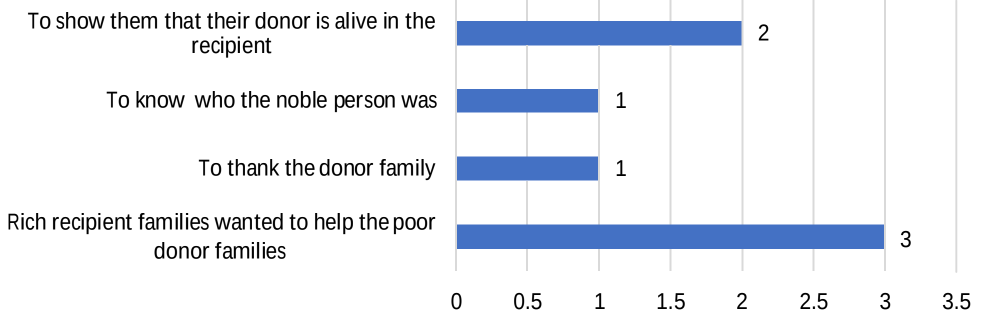


Figure 5.32 reveals that only six experienced coordinators had experienced such requests of recipient families with various reasons. The reasons for such wishes varied, like 3 OTCs revealed that the rich recipients wanted to provide help to the poor donor families. One OTC revealed that the recipient wanted to say thanks to the donor family. One OTC told that the recipient had the curiosity to know who the noble person was.

Out of two OTCs who reported that the recipient wanted to inform the family that their family member (BSD donor) is still alive in him, one OTC herself wished to show to the children that their mother is still alive. It was because her husband had got a kidney of a female BSD donor. Her husband too wanted to see the family even after ten years of a BSD donor kidney transplant.

The data reveals that recipients want to reciprocate to donor families by helping the donor families financially. There is no harm if recipients are told to donate for poor people through some Govt. approved system. Many donor families are devastated due to the death of the person whose organs give lives to unknown people. Participants discussed the same in details during the second Conclave organized by ORGAN India along with NOTTO. The participating NGOs revealed that there is an urgent need to provide help to BSD donor families through CSR funds, NGOs and Governments. Such willing recipients who desire to reciprocate to donor families can also contribute to this fund for donor families as is urgently required for low-income families.

Opinion About Revealing Donor-Recipient Identities

Figure 5.33 Opinion about revealing donor recipient identity for increasing donation rates (N=20)

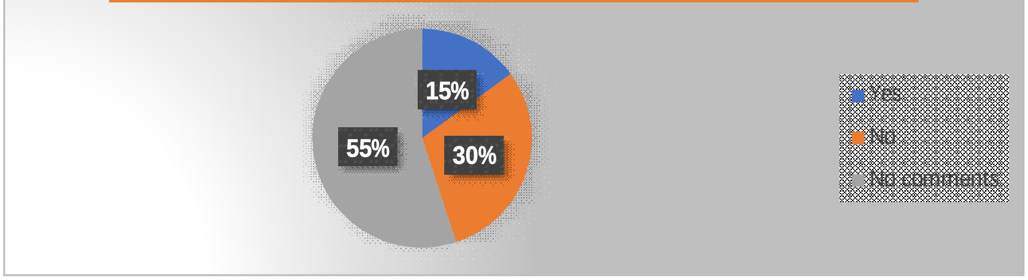


Figure 5.33 reveals majority, i.e., 55 % (11) OTCs had no comments to offer for revealing donor recipient identities and 30 % (6) OTCs were against such revelation. Only 15 % (3) OTCs thought of revealing donor-recipient identities.

Some of these OTCs who were against such revelations believed that there could be negative repercussions of such disclosure in the long run while others who believed in revealing donor recipient identities felt that it will help the relatives to know that their dead donor is living even after death.

Experiences of OTCs With Reasons of Refusal by Donor Families to Donate Organs of Potential BSD Donors

Figure 5.34 Reasons of refusal by families to donate organs of potential BSD donors as per the experiences of OTCs (N=20) (Multiple Response)

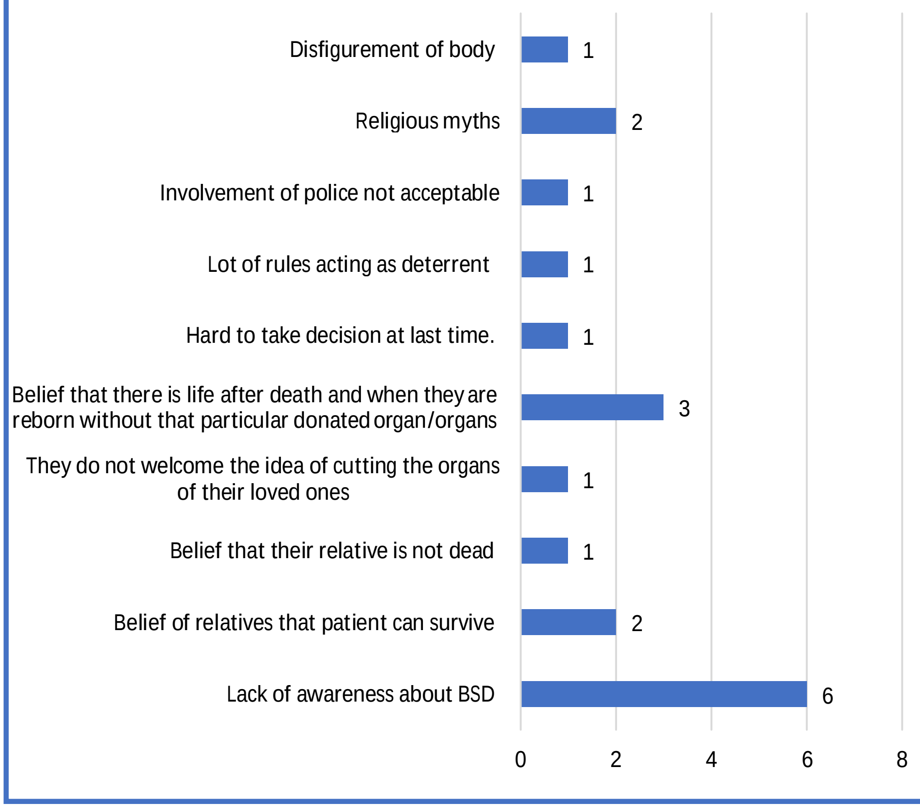


Figure 5.34 reveals that according to the majority, i.e., 6 OTCs lack of awareness was the primary cause of refusal, 3 OTCs told that families believed that there is life after death and the person will be born without the donated organs, and 2 OTCs revealed that the religious myths among donor families were responsible for refusal for organ donation.

Reasons of Acceptance by Families to Donate Organs of Potential BSD Donors as per the Experiences of OTCs

Figure 5.35 Reasons of acceptance for donation of organs as per the experiences of OTCs (N=20) (Multiple Response)

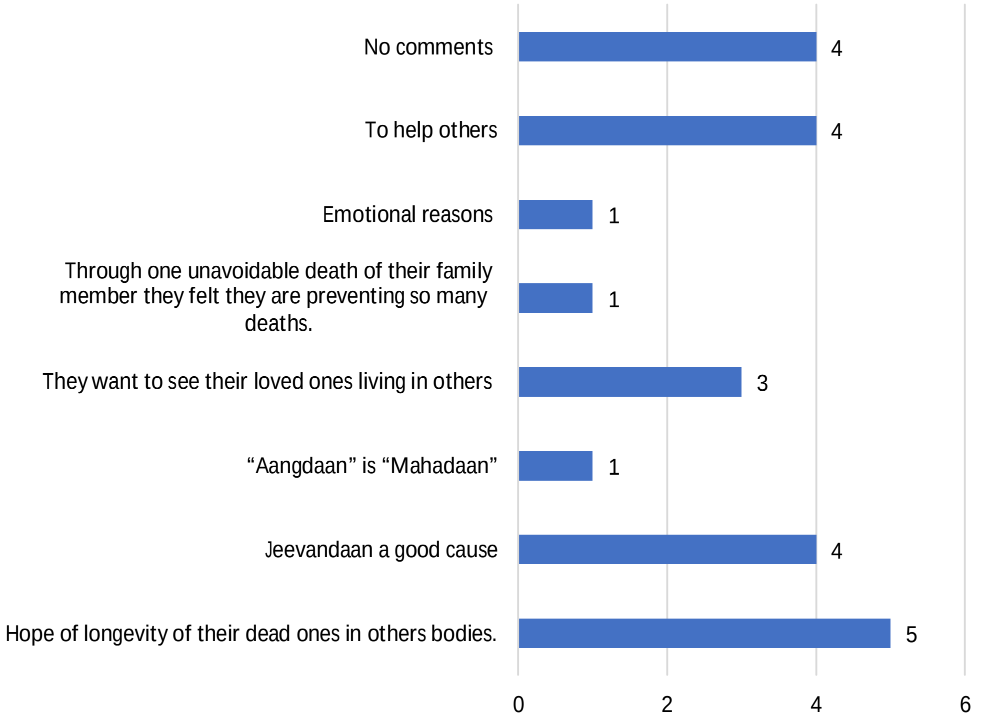


Figure 5.35 reveals that according to the majority, i.e., 5 OTCs, the BSD donation was accepted because of the hope of longevity of their BSD donor in other bodies. Also **"Jeevandaan is the good cause"** (Meaning donating lives is the best donation) was the reason given by 4 OTCs.

As per Ms. M, *“A mother was asked by her relatives as to why she donated her son's organs? She replied that she saw several helpless families desperate to save their near and dear ones in the hospital. She too was helpless and wished someone could help her. It was not possible as her son was brain dead and had no chance to recover. Empathizing with others, she decided to donate the organs of her son. She felt she should do something for others through this selfless act of organ donation.She was sure that her son would not survive for long. She did not want her son to die; she wanted him to live in others”.*

Issues Faced with Police in MLC

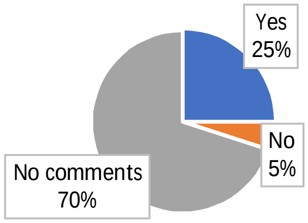


Figure 5.36 Issues faced with police on Medico Legal Cases (N=20)

Figure 5.36 reveals that the majority, i.e.,70% (14) OTCs had no comments to offer. Only 25% (5) OTCs had faced issues with police. Most of the OTCs said that even police are not well informed about this form of death and donation. Understanding the concept of BSD is difficult for them. Narratives of OTCs reveal the challenges faced in BSD donation while taking permission from the police.

As per Ms. Mb, *"Organ donation from Medico-Legal Cases requires consent for retrieval of organs from two police stations. One police station is where the accident occurred, and another is where the retrieval of organs takes place. It sometimes leads to a lot of painful efforts by the transplant coordinators. In one case, I had to make almost 1000 calls to make the retrieval possible".*

As per Ms. R, *''The family waited for 15 hours to get rid of the processes involved in it. I felt frustrated for pleasing, pleading, requesting and begging the authorities to make the donation possible. I felt annoyed and exhausted with the system".*

Meeting Problems with Forensic Experts on Post Mortem

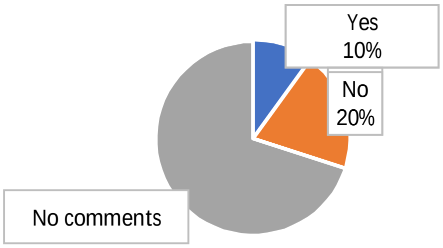


Figure 5.37 Meeting problems with forensic experts on post mortem (N=20)

Figure 5.37 reveals that only 10% (2) OTCs had met some problems with forensic experts, and 20% (4) had not faced any problem. The challenges faced were due to the lack of knowledge about the legal procedures required for BSD donations among forensic experts.

Opinion About the Inclusion of Incentives for Donor Families

OTCs were asked to give their opinion about the inclusion of incentives for donor families for increasing acceptance of organ donation from Brain Stem Dead donor's. The majority, i.e., 8 OTCs did not favour giving incentives, out of which 2 OTCs added that focus on awareness is important than incentives to the donor families. And 7 OTCs were indecisive. Only 5 OTCs gave their opinion in favour of incentives to donor families like 3 OTCs supported social recognition, 2 OTCs recommended medical insurance to the next of kind, 3 OTCs wished that Government should support the education of children and 3 OTCs endorsed Government reward to donor families.

Mr. G narrated, *"I am very much in favour of poor donor families; I had motivated a woman to donate her husband's organs. She was a needy woman. I could not do anything for them. There should be some organization that should take care of these aspects of donor families like education of children, the job of a person within the family etc. Aren't we giving petrol pumps to widows of army personnel? Why can't we think of such things for these motivated people? I am in favour of incentives to donor families. Why not? It should be 110%. I feel we have cheated on her by taking away her husband's organs and leaving her to her fate".*

Experience of OTCs Regarding Wastage of Organs

Out of 6 experienced transplant coordinators, three transplant coordinators had come across situations when organs retrieved got wasted because of the unavailability of the recipients. Their expressed feeling terrible and angry with such wastage of organs.

The reasons for such wastage were many like non-availability of recipients or finding a malignant nodule in the liver by organ retrieval team. Two coordinators said that non-availability of recipients happened once only, but one transplant coordinator said it happened three times.

According to one OTC, this situation could be avoided by calling many recipients for one organ transplant. According to two OTCs, the situation can be avoided by making a list of transplant recipients of nearby hospitals and maintaining it regularly. Keeping in touch with other organization was reported by one coordinator. One coordinator said that data entry at the National level by NOTTO should tackle the situation and prevent wastage of precious organs.

One of the crucial functions of NOTTO is to prevent wastage of organs. NOTTO Is trying its level best to avoid the wastage of organs by persuading transplant hospitals to share data with it. It requires the cooperation of all transplant hospitals to make recipient data available to NOTTO.

Understanding About the Difference in Opt-In and Presumed Consent

Figure 5.38 Understanding of OTCs about the difference between opt-in and presumed consent (N=20)

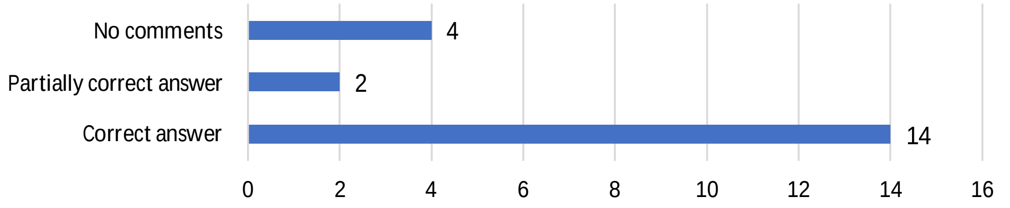


Figure 5.38 reveals the majority, i.e., 14 OTCs had a correct understanding of the difference in opt-in and presumed consent system of organ donation.

Opinion About the Opt-In System of Organ Donation

Figure 5.39 Opinion about current legal options like Opt in System (N=20) (Multiple Response)

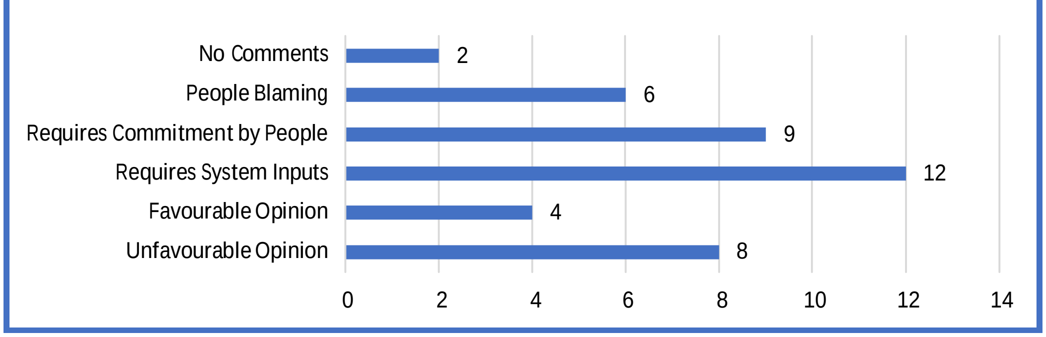


Figure 5.39 reveals the majority, i.e., 12 OTCs were of the opinion that opt-in option requires systemic inputs like creating a lot of awareness among people besides strengthening the system. Nine (9) OTCs revealed that this option requires a commitment by people. Eight (8) OTCs did not favour this option because they felt this option is not very productive, and it is tough to motivate people through this option. In addition to it, 6 OTCs blamed people for not opting to donate themselves.

Opinion About Presumed Consent System of Organ Donation

Figure 5.40 Opinion about use of presumed consent system in India (N=20)

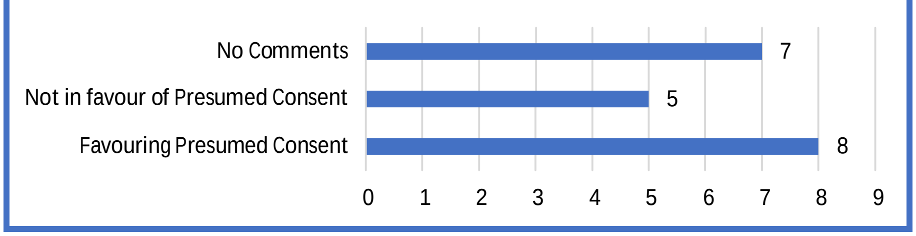


Figure 5.40 reveals the majority, i.e., 8 OTCs were in favour of presumed consent and gave reasons also in support of their statement telling that such a move shall revolutionize the transplantation area, it could increase the rate of organ donation, and it should be there as there are more Road Traffic Accidents in India. The 5 OTCs who did not favour presumed consent revealed that presumed consent is not safe, it may worsen things for people, the family may be caught unawares and trapped into the donation, all families will not understand it, and not all families will come to know about this option.

Opinion About the Misuse of The Presumed Consent System of Organ Donation

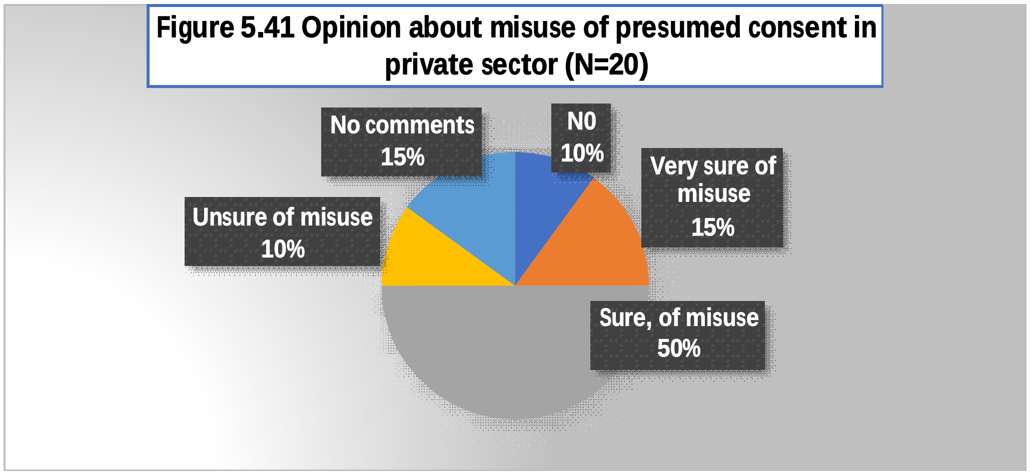


Figure 5.41 Opinion about misuse of presumed consent in private sector (N=20)

Figure 5.41 reveals that while the majority, i.e., 50 % (10) OTCs felt sure, an additional 15% (3) OTCs were very confident of misuse of presumed consent in the private sector.

As per Mr. Kn, *"I am not in support of presumed consent. Professionals may misuse it for economic benefits only. Here in this part of the country, there is one hospital that does Heart, Liver, Kidney, Lungs, Pancreas, Cornea, Small Intestine and transplant of Hands also. In one BSD donor case, it shares only one kidney with other hospitals and all other organs are transplanted in this hospital only. It may be making a business of about two crores for all these transplants from one BSD donor only. I am very sure of its misuse in this country".*

Opinion About Giving Equal Chance to Indians And Foreigners for Organ Allocation

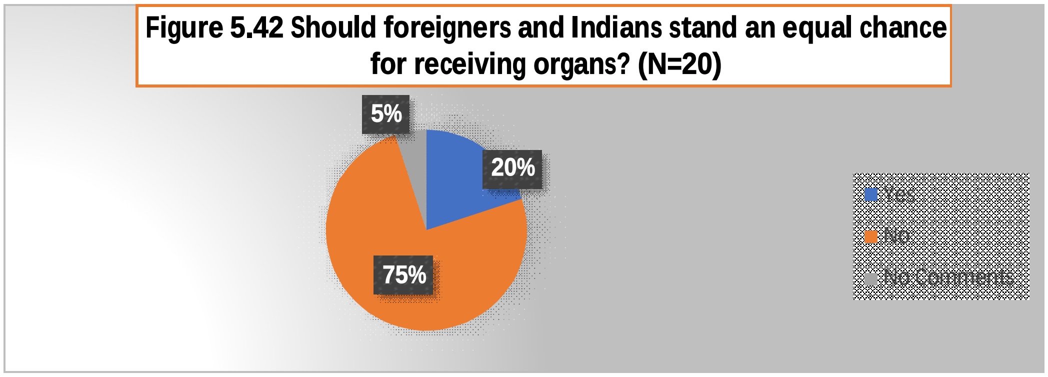


Figure 5.42 Should foreigners and Indians stand an equal chance for receiving organs? (N=20)

Figure 5.42 reveals the majority, i.e., 75% (15) OTCs were against giving equal chances to foreigners in organ allocation as that of Indians. NOTTO strictly follows the same in the distribution of organs.

Suggestions of OTCs About the Ways to Increase Organ Donation

Figure 5.43 Suggestions of OTCs about how to increase organ donation from BSD Donors in India(N=20) (Multiple Response)

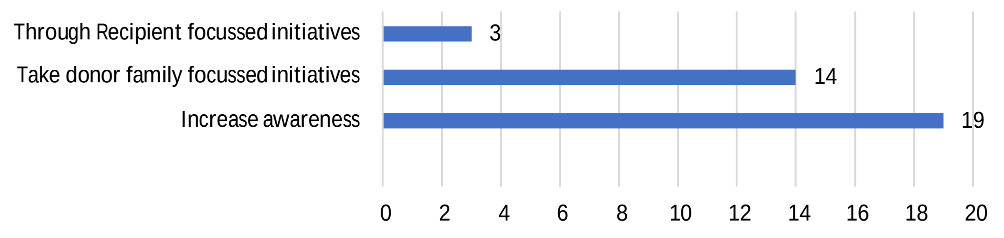


Figure 5.43 reveals the majority, i.e., 19 OTCs suggested that we should increase awareness about organ donation from Brain Dead Donors through awareness programmes. They suggested conducting mass awareness campaigns in schools, colleges and villages. Messages of organ donation can reach people through street plays, slogans, posters, use of brochures, advertisement in newspapers, TV and Radio. They also suggested adding this topic in the course curriculum of school children, involving relatives of donor families for creating awareness among the public. A few of them felt that there is a need to create awareness among ICU Doctors. They felt ICU doctors are not promoting organ donation and have restricted their entry in ICU's.

Also, 14 OTCs expressed that we can increase organ donation from Brain Dead Donors by taking donor family focussed initiatives. Like right counselling at the right time, reducing delay caused by the whole process, making a documentary on donor families, giving Importance to the loved ones who have donated organs, rewarding donor families and giving social recognition to donor families.

And 3 OTCs expressed that we can increase organ donation from Brain Dead Donors by taking recipient centric initiatives. These were like shifting to presumed consent, appointing counsellors in all ICU, especially for counselling family of Brain-Dead Donors and making BSD certification mandatory.

Need for Further Training and The Suggested Areas of Training for OTCs

Figure 5.44 Need for further training perceived by OTCs (N=20) (Multiple Response)

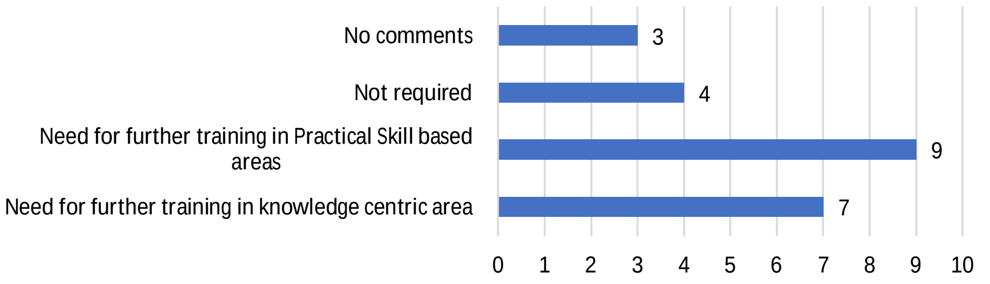


Figure 5.44 reveals the majority, i.e., 16 OTCs felt five days training programme for OTCs inadequate and felt a need to get training in different areas.

There were two areas where transplant coordinators wanted to get training. Their responses fall into two areas, i.e., knowledge-centric areas and skill-centric areas. Skill centric areas: transplant coordinators wanted further training in Counselling skills 20%, motivating skills 5%, convincing skills 5%, in all practical work 5%, handling of bodies in accordance with the religion of people 5%, packaging and labelling of Organs after retrieval till transplant by 5% of OTCs.

Knowledge centric areas: transplant coordinators wanted more knowledge about Laws and Act as revealed by 15%OTCs, about various forms as revealed by 10% OTCs and documentation as revealed by 10%OTCs.

Summary: This Chapter reveals the Historical Genesis of Organ Transplant Coordinators (OTCs) in India and the perspectives of a few selected OTCs towards the donation of organs from BSD donors. Training of OTCs was started by MOHAN Foundation, an NGO, in India in 2009 with funds from Sir Ratan Tata Trust and Navajbai Ratan Tata Trust. NOTTO pitched in during 2015 and conducted the first training program on OTCs in collaboration with MOHAN Foundation. It continued training programs in partnership with various organizations. The transplant coordinators are given different roles and responsibilities in a donor-transplant situation.

The role of OTCs starts with motivating a family to donate organs of their BSD donor. However, her responsibility does not always end until the family leaves the hospital. It extends to home visits for the purpose to help them to save them from social ostracism that can happen because often unaffected people lack knowledge and understanding. Therefore, the process of organ donation and transplantation is full of challenges as depicted in the in-depth case study reported by Dr. N.

The background information of 20 OTCs who were administered questionnaire revealed that majority -15- were females, 8 were from nursing (BSc and GNM) background, and an equal number were qualified as Medical Social Workers. Only 6 OTCs were organ donor card holders.

Perspectives of these OTCs towards donation varied. Majority – 11 - had donated blood to others, and only one had given blood to a family member. Similarly, there was no difference regarding their willingness to donate organs for family members or to others as the majority 12 OTCs were willing to do the same for both. Majority – 18 - liked to get organs from BSD donors for family members and 19 for themselves. The expectation of OTCs for living organ donation for themselves rested on female members of their family. A few displayed ownerships on the organs of their mothers' in case they would need an organ in the future.

The significant findings of the study revealed the knowledge deficit of OTCs about BSD donation. The researcher also came to know about variations in diagnostic procedures. The conversion rate of mere 24.81% speaks of a low level of acceptance among people in northern India as all 20 OTCs were working in various Government and private hospitals of Delhi only. In some cases, the conflict of interest between neurosurgeons and OTCs regarding BSD declaration also came to the fore.

The majority -14- OTCs revealed that consent from relatives for doing "Apnoea Test" is not taken. Interestingly, 18 OTCs believed that such consent should not be taken and 14 thought that the “Apnoea Test” should not be done in the presence of relatives.

Four OTCs reported the movements of toes and fingers, slight drawing of an arm, slight breathing movements of a BSD person. Also, 14 coordinators reported that organ donation is a very tough decision for families. It was revealed that several people deny accepting Brain Stem Death as complete death.

When OTCs approached family members for organ donation, they would ask questions that pertained to ethics, knowledge, consensus issue, religious issues, finances, intrafamily donation, time requirements, recipients of donor organs, the beauty of the donor body, future of the donor and documentation requirements.

As per the experienced transplant coordinators - 6 (30%) - the request to donate organs is made after the first diagnosis only. In addition to it, two OTCs revealed that family is counselled before the first diagnosis of brain death. If they are not willing to donate organs, even the first brain death diagnosis is not done, and the patient is continued on the ventilator. A family is such cases is supposed to either donate organs or continue futile expensive and often unaffordable, treatment for the patient. If a family decides to donate, professionals will declare the patient BSD. And in case, they refuse to donate organs, the patient is a living person, and the family has to pay through its nose. The plea given is that there are no laws on discontinuing life support. It reveals medical hegemony under the garb of legal bindings.

The case studies also point to the problems faced by professionals in diagnosing BSD. It can be done only in the presence of 4 medical practitioners, including the head of the institution, twice. The presence of 4 doctors to prevent human error in diagnosing such deaths is often ignored by professionals who manage signatures of all.

All 6 (30%) experienced OTCs affirmed that they had come across situations when relatives did not want to donate and wanted to take away the body. Three OTCs said that in such cases the option to LAMA was given; two OTCs said the treatment was continued; the other two said that they continued counselling and 3 OTCs revealed that treatment was continued till heart stopped beating.

For matching blood groups and cross match, two to five recipients are called from home for one organ, and the organ is transplanted into the best-matched recipient. In case the organ is transplanted in other hospitals, a blood sample of the donor is sent in advance for cross-matching with the recipients.

According to the opinion of 13 OTCs, the best-matched recipient should be given the organ revealing a belief in the law of natural justice by the majority of OTCs.

Only 15 % of OTCs were of the opinion of revealing donor-recipient identities. Three had come across situations when recipient families wanted to know the donor families with an aim to help them financially.

The majority of OTCs – 6 - revealed a lack of awareness, three showed a belief that there is life after death and the person would be born without the organs, and two revealed that the religious myths were responsible for not donating organs.

The reasons for acceptance of organ donation by BSD donor families were the hope of longevity of their dead donor as reported by 5 OTCs and good cause as revealed by 4 OTCs.

Of the interviewed OTCs, 25% faced issues with police for MLC, and 10% faced some problems with forensic experts.

Regarding their opinion about the inclusion of incentives for donor families that could increase acceptance of organ donation from BSD donors, 5 OTCs spoke in favour and said it would be a social recognition as well.

Out of 6 experienced transplant coordinators, three had come across situations when organs retrieved were wasted as the recipient could not be found.

The majority - 14 - OTCs had an adequate understanding of the difference in opt-in and presumed consent. Regarding their opinion about the current legal opt-in option, 12 OTCs said that this option required systemic inputs like creating awareness and strengthening the system. Majority - 8 - were in favour of presumed consent. They said such a move should revolutionize the transplantation domain; it could increase the rate of organ donation. They felt it should be in place as India registers a high number of Road Traffic Accidents. Five OTCs who did not favour presumed consent revealed that this option was not safe; it may worsen things for people, the family may be caught unawares or may be trapped into donation as there was a lack of understanding about this option. Interestingly, irrespective of their positive opinion, 65 % coordinators felt it would be surely misused in the private sector.

Of these, 75% were against giving equal chances to foreigners in organ allocation. On suggestions for increasing organ donation rates in India, 19 said a higher awareness about organ donation from BSDs not only among the public but also ICU Doctors would help. Fourteen suggested taking donor family focussed initiatives like right counselling at the right time, eliminating fear about disfigurement, reducing delay caused by the whole process, making a documentary on donor families, giving Importance to the BSD donor, rewarding and giving social recognition to donor families. Of these, 3 suggested recipient-centric initiatives like shifting to presumed consent, appointing counsellors in all ICU for talking to the family of BSD and making BSD certification mandatory.

The OTCs did not have enough knowledge regarding the cost of various transplant surgeries and immune suppressants; it was not imparted to them during the training.

On the adequacy of training, the majority – 16 - OTCs felt five days training was insufficient and felt the need to make the process skill-centric and knowledge-based, for such a challenging job. The OTCs adopted several coping mechanisms in dealing with BSD donors (Dar, 2016).

CHAPTER 6

Perspectives of Brain Stem Dead (BSD)Donor Families

This Chapter reveals the perspectives of Brain Stem Dead donor families interviewed by the researcher. The first part of this Chapter presents the socio-demographic information about 14 Brain Stem Dead (BSD) donors. The second part deals with pre-donation perspectives of donor families. It reveals their reasons for donating organs and understanding of Brain Stem Death (BSD). It depicts infrastructural issues in BSD donation, precondition posed for organ donation, social influences and impediments on their decision-making processes and the role played by organ sharing networks in donation as well as transplantation of organs. The third part gives an account of post-donation perspectives of donor families. It reveals the time-consuming processes of organ retrievals and passionate feeling about heart donation. It also focuses on infrastructural constraints in organ transplantation and deliberate attempts of male members to get away with last rituals for donor body and unpleasant experiences post-donation. Salvage of donor families by social media from social ostracism, the need of donor families to know the recipients, emergence of new social relationships between donor families and recipients are well explained. It reveals how donor families boast about making records through the donation of organs, got social recognition through multiple felicitations and had a few expectations after organ donation. It reveals how donor families promote the cause of organ donation but nurture some myths about organ donation, as well.

Socio-Demographic Information About BSD Donors

The interviews with 14 respondents who were immediate family members of the BSD donors helped in knowing the socio-demographic information about their BSD donors.

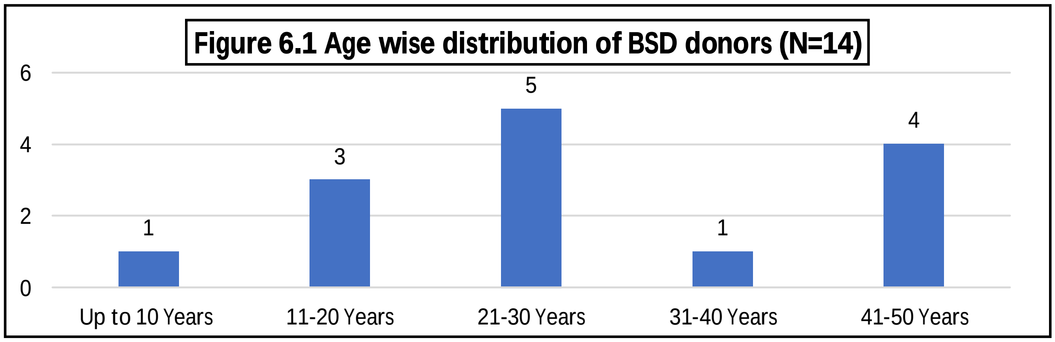


Figure 6.1 Age wise distribution of BSD donors (N=14)

Figure 6.1 reveals that majority, i.e., 5 BSD donors were in the age group of 21-30. There was only one donor below ten years and none above 50 years of age.

Table 6.1 Socio-demographic information about Brain Stem Dead donors (N=14)

SEX	
Male	6 (43%)
Female	8(57%)
RELIGION	
Hindu	11(79%)
Christian	3(21%)
OCCUPATION	
Students	4(29%)
MBBS student	1(7%)
Differently Abled Student	1(7%)
Housewives	2(14%)
Maid	1(7%)
PVT. Courier Service	1(7%)
Navy (Sub Lt.)	1(7%)
Civil Engineer	1(7%)
MARITAL STATUS	
Married	5(36%)
Divorcee	1(7%)
Unmarried	8(57%)

Table 6.1 reveals that majority, i.e., 8 were females. The majority, i.e., 11, were Hindus. The majority, i.e., 6 were students (that included one MBBS student and one differently abled student as well) and majority, i.e., 8 were unmarried.

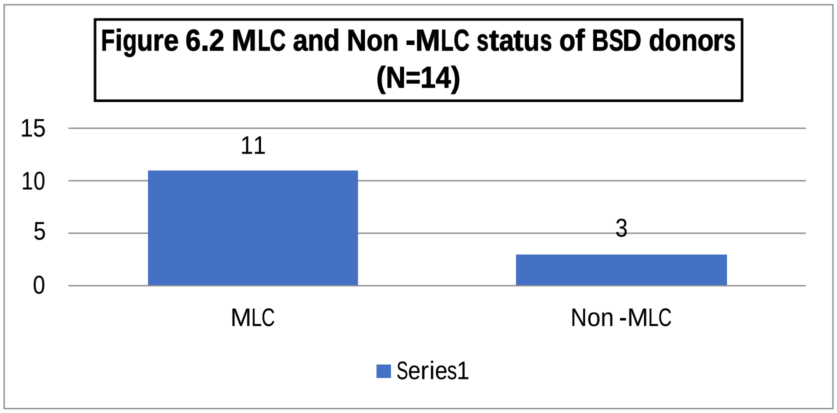


Figure 6.2 MLC and Non -MLC status of BSD donors (N=14)

Figure 6.2 reveals that majority, i.e., 11 were Medico-Legal Cases (MLC)

Medico-Legal Cases (MLC) require permission from police and forensic experts before donation of organs. Most of the relatives among MLC donors complained of a lengthy procedure of such formalities but did not report any hassles for getting permission from police and forensic experts.

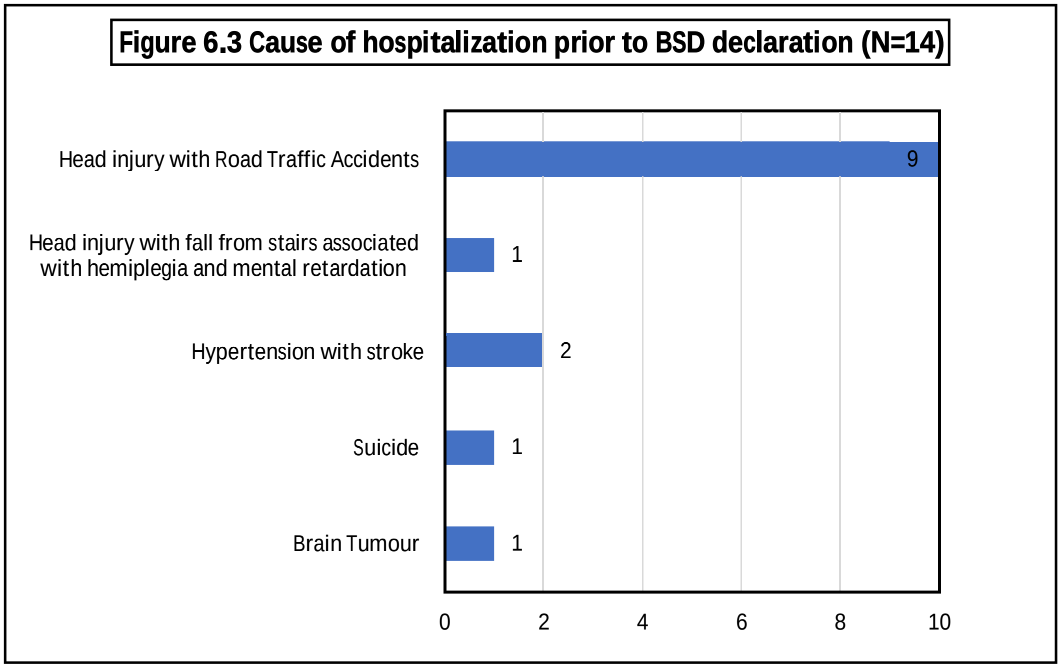


Figure 6.3 Cause of hospitalization prior to BSD declaration (N=14)

Figure 6.3 reveals that 9 BSD donors had met with Road Traffic Accidents. The in-depth interviews revealed that in five such cases, the head injury was avoidable if BSD donors had used a helmet. There was one donor who had brain tumour before the donation of organs, but that was not harmful to the recipient.

Table 6.2 State-wise number of BSD donor families interviewed and their contribution towards organ and tissues donation through BSD donors (N=14)

State /UTs of Donor Family	No of families	Total organs and tissues donated					
		Kidneys	Liver	Heart	Corneas	Skin	Arms
Kerala	2	4	2	1	2		
Bombay, Maharashtra	2	4	2	2	2		
Puducherry	1	2	0	0	2		2
Chandigarh	1	2	0	0	2		
Indore, MP	4	8	4	4	8	4	
Haryana	1	2	0	1	2		
Rajasthan	1	2	1	1	0		
Telangana	1	2	1	1	0		
Tamil Nadu	1	2	1	1	2		
Total	**14**	**28**	**11**	**11**	**20**	**4**	**2**

Table 6.2 reveals that BSD donor families interviewed were from various States and UT's. These BSD donor families had contributed 28 kidneys, 11 livers, 11 hearts, 28 corneas and 2 hands through their BSD donors. Besides, four donors had contributed skin in Indore. Also, the two arms were donated by a female donor in Puducherry Govt. Hospital and were transplanted to an adolescent girl who had lost her limbs to an accident.

The above figures and facts reveal that most of the BSD donors had accidental head injuries. In many cases, such head injuries could be avoidable if donors had used a helmet, a simple gadget to avoid loss of life and sufferings of the families. The data also reveals the availability of skin bank in Indore that paved the way for retrieval and storage of skin as well. Doctors in Government hospital transplanted two hands of one BSD donor to a female recipient in Puducherry. The interviews also revealed time-consuming elaborate procedures in Medico-Legal Cases. Such cases required permission from police and forensic experts before donation of organs.

Pre-Donation Perspectives of BSD Donor Families

Several issues with Brain Stem Dead donation were revealed by donor families that are explained in Figures and narratives as recorded during interviews.

Reasons for the Donation of Organs

BSD donor families narrated various reasons to donate organs of their BSD donor.

Figure 6.4 Main reason for donating BSD donor organs

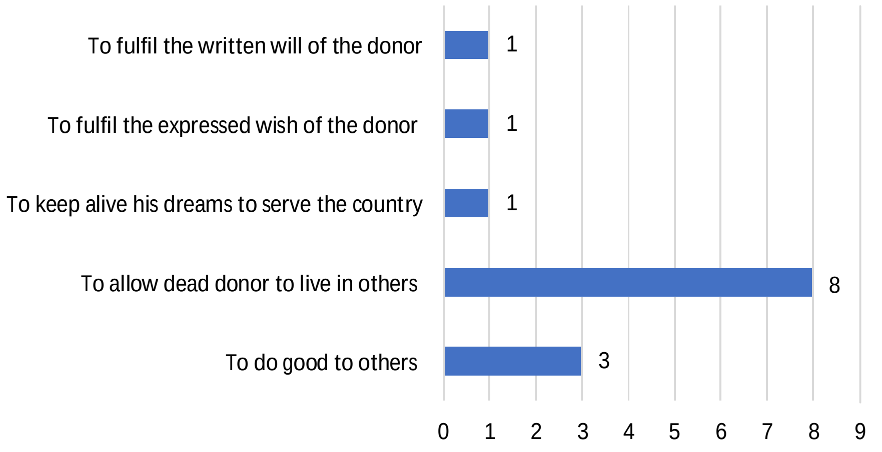


Figure 6.4 reveals that majority of donor families, i.e., 8 wanted their donor to live in others, 3 donor families wanted to do good to others. Besides, one donor family each wished to fulfil the expressed wish, honour the written will and keep alive the dreams of their donor to serve the country.

The narratives are described below: -

They Did Not Want Their Child to Die but Wanted Him/ Her to Live in Others. - Majority of donor families did not want their donor to die but wanted their donor to continue living in others.

Mr M narrated, *"Let her not die but live in others. Instead of wasting her organs in the fire, I preferred to give life to others."*

Mr K narrated, *"For my satisfaction, she has split into five. She will continue to live as long as her five recipients are alive. She will die only when the last of her recipient is dead. Till that time, she is alive".*

Mr. I narrated, ***"Kahhee To Jeevit Rahega Mera Betta. Usko Jeevit Rehney Do, Uskey Organs Donate Karo*** *(Meaning let my child live in other, donate his organs) --- were the words of my mother when we told her about our brother's condition. We informed her that he would stop breathing within a short period if removed from ventilator".*

Mr U narrated, *"My son was a very diligent child. He got an MBBS seat. We feel we kept alive his urge to study when we came to know that his heart was transplanted in a PhD scholar. This way, we feel he is continuing to study even after his death".*

Mrs D narrated, *"We don't think she is dead. We have not put a garland on her photograph. She is still living".*

Wanted to Do Good to Others: -The three donor families felt that they are doing well to others by donating organs and tissues.

Mr H narrated, ***"Humari Bachchi To Nahee Rahee, Par Kissi Ki Jaan Bach Jaye To Achcha Hai"*** *(Meaning we have lost our daughter, but it will be good if someone is saved). We will see her in recipients who get her organs. We also pray for their speedy recovery after organ transplant".*

Ms A narrated on the telephone, *"We belong to the Jain community and believe in the donation. Incidentally, it was my mother's birthday. They guided us that we have an option to donate organs of our brother as he was brain dead. Every year my mother had been donating various items like food, clothing etc. on her birthday. She felt God had wished her to donate life through her son's organs. She felt she is going to do good to others. But she never wanted to see the processes that are followed for retrieval of organs and requested that she be taken home to mourn her son's death".*

Wanted to Fulfil the Will of The Donor: -There was only one donor who had pledged to donate organs during life. And her family members felt that they were bound to fulfil her will to bestow life.

Ms B narrated, *"My sister was the first organ donor who had pledged to donate her organs. She was a great person who would help everyone wherever a need would arise. She was a voluntary blood donor. She was a self – motivated volunteer for arranging blood donation camps and health awareness camps in one of the very reputed hospitals in Chandigarh".*

Wanted to Fulfil the Expressed Wish of The Donor - There was one donor who had expressed a desire to donate organs to his `family members verbally.

Ms F said, *"Our family members were a great supporter of organ donation. There was an awareness programme in my medical college where we understood about organ donation from brain dead donors. I talked about this topic to my family members and asked about the will of each person. We all had supported the cause of organ donation. We hardly knew that in a brief period, we would be placed in a situation to decide about the donation of our brain-dead father. All of us agreed to donate organ of my papa as he had verbally consented to donate organs".*

Wanted to Keep Alive His Dreams to Serve the Country: - One family wanted their son to serve the country even after his death as reported by his father.

Mr C said, *"We wanted him to serve the nation even when he is no more. We ensured that his organs get allocated to people in defence services. My son would always tell his mother that he will bring fame to the family and will do something great for the country. He was a navy officer. We were devastated after knowing about his death. But we chose to keep him alive in various bodies".*

The narratives of family members portray the good intentions behind the donation of organs and reveal the adoption of healthy coping mechanisms by family members at the time of loss. Families tried to rationalize their loss by giving life to others. The donor families revealed that they wanted their donors to continue living in others and performing roles in this universe from where they had left. Like, for a student donor, the father was pleased he is continuing his studies in a PhD scholar. Similarly, for a navy officer's father, it was a great solace knowing that his son would continue to serve the nation through the donation of an organ to a defence officer. The data reveal that only one donor among 14 donors had pledged to donate organs, and it was the wish of the families that helped in the donation of organs. The researcher has seen the tireless efforts made by NOTTO to motivate people to fill Form 7 of THOT Rules 2014 for pledging to donate organs. She feels that such tireless efforts are not going to be that fruitful as family still can supersede the wish of the donor. Families can decide to donate in the absence of such will of the donor. It happened in 13 cases in the study.

The narratives also focus on the importance given to birthday and practice of donation on birthdays by a respondent who chose to bestow lives to others by donating organs of her brain-dead son. The researcher would bring to focus her observation that two donors belonged to the Jain community. The researcher would also like to reveal one of her essential observations. All professionals and people in our country say brain death rather than Brain Stem Death. There is a procedural difference between these two forms of death. India uses Brain Stem Death criteria for organ donation and not Brain Death criteria but the majority use Brain Death for Brain Stem Death. It was with great persuasion that NOTTO officials started using Brain Stem Death instead of Brain Death in official communications. Use of BSD was requested by the researcher to avoid legal hassles in future.

Understanding About Brain Stem Death/Brain Death

Some of the donor families had heard of brain death before donation of organs whereas a few had not heard of it earlier. It was interesting to find that all the donor families had the same understanding of brain death. For them, their BSD donor had a dead brain, but his organs were alive and functioning. They also believed that doctors could transplant the organs of their BSD donor in needy patients. None of the donor families interviewed was coerced to donate organs.

Mr C said, *"He was on the ventilator, and there was no hope of his recovery. He was dying, his body was warm, the heart was beating, but he was not conscious. I did not want him to die but live, and that was possible only by donation of his organs as made clear by the doctor. We waited long to help him come back but could not".*

Mrs U narrated, *"Doctors convinced us that he would cease to breathe if removed from the ventilator. He was breathing because he was on a ventilator; otherwise, he was dead".*

The donor families from States like Chennai and Kerala were well informed about brain death before donation of organs.

Mr K from Kerala said, *"I wanted to donate my daughter's organs after doctors informed that there was no hope of her recovery. I was given an option by doctors to continue her life on the ventilator for a few days more. But I chose to keep her alive for long by donating her organs. Instead of keeping her alive for a few days with few borrowed breaths, I preferred to keep her alive by donating organs".*

For all the donor families, brain death meant the death of the brain only and not of organs as revealed by their narratives. Also, the families felt convinced that the death of their family member was prolonged only because of the ventilator. Also, there was no possibility of recovery or coming back to life. Family members in southern States were well informed because a lot of media campaigns are going on there. These campaigns shape the opinion of people there as reported by one of the donor families.

Infrastructural Issues in Organ Donation from BSD Donors

Figure 6.5 Brain Stem Death declaration and certification issues faced by donor families (N=14)

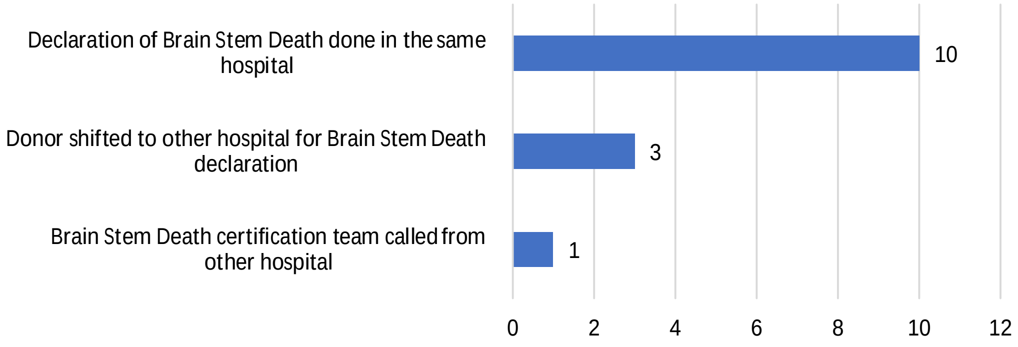


Figure 6.5 reveals that out of 14 BSD donors, three donors had to be shifted to other hospitals for declaration of Brain Stem Death. And for one donor, a BSD certification team of other hospital was called for such certification. However, in all these cases, the families were self-motivated. They believed that their relatives were in an irreversible coma.

Mr J said, *"My daughter had met a severe accident and had a severe head injury. The private hospital was charging money unnecessarily. We paid three lakhs for five days, but there was no improvement. I knew there was no hope of recovery. I contacted an NGO for the donation of organs and brought them to this private hospital. The authorities in the hospital did not want their interference. We shifted her to another hospital where she was declared brain dead. The organs were later retrieved and transplanted".*

Organ donation is not that simple. Neither all hospitals nor all doctors can declare Brain Stem Deaths as is given an impression through Information Education and Communication (IEC)campaigns of which researcher had been a part on many occasions. A team of four designated doctors in organ transplant hospitals usually have the legal authority to declare such deaths. All hospitals do not have the BSD certification committees. Three donor families shifted their patients to other hospitals where Brain Stem Death certification committees were available. And organ retrieval could be made possible there in those hospitals. In one case, the BSD certification committee of other hospital was made to come to the hospital where the patient was hooked to a ventilator to declare such death. The narratives also focus on the issue of the exuberant cost incurred by family members in private hospital amounting to 3 lakhs for five days when there was no hope for life.

Preconditions Set by Donor Families Before Donation of Organs

Most of the families did not put any precondition for the donation of organs. However, there was a donor family whose donor was a defence personal. In this case, the family wanted their son's organs to be given to defence personnel only. They felt it would allow him to serve in defence ministry even after death; a wish their deceased son had cherished throughout his short life. In another case, the precondition put by the family was that the recipients of his organ should not be charged anything for his organs.

Mr C said, *"To fulfil the wish of my family, naval officials contacted the members of National Organ & Tissue Transplant Organization (NOTTO). NOTTO initiated efforts to transfer organs to the army cantonment hospital in Delhi. Unfortunately, things could not work due to technical difficulties. NOTTOs hard work helped eventually. One kidney of my son was transported via a special Indian Air Force (IAF) plane and transplanted in a defence personal at Air Force Command hospital in Bengaluru".*

Mr S said, *"I donated my son's organs requesting them that they will not charge anything from the recipients of his organs. I am not sure whether they did it or not".*

A few BSD donor families put certain preconditions before giving consent for organ donation that revealed patriotism and pro recipient feelings.

Social Influences and Impediments on Decision-Making Processes

As reported by donor families, the decision to donate organs of BSD donors was not an easy task. Disagreements within family members influenced decisions; the final decision rested with male members predominantly and State-specific organ sharing network facilitated decisions.

Decision to Donate Organs of BSD Donor Rested with Male Members Mostly

Male members in most of the cases decided to donate organs. Mother usually did not want organs to be retrieved from her child and took a long time to accept BSD. Mothers had to be persuaded by spouses to allow organ donation. Male spouses usually imposed their decision on female partners for the organ donation.

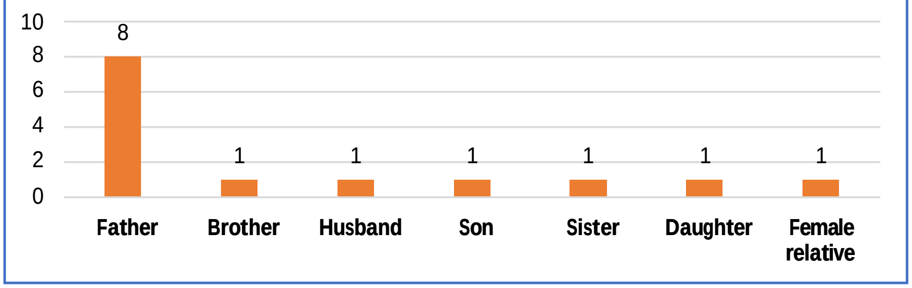


Figure 6.6 Relatives who played major role for giving consent for organ donation(N=14)

Figure 6.6 reveals that in the majority, i.e., eight (8) BSD donor cases, father played an important role in giving consent. The Figure also shows that only three female members (one sister, one daughter and a female relative) in the family played an important role in comparison to 11 male members for permitting organ donation.

Mr K said, *"None of the family members was involved. It was my own decision which was not approved by family members, but I was adamant".*

Mrs T said, *"My husband decided to donate her organs on his own. He did not bother to take consent from me. He first said she is dead, but later he said she is in operation theatre. I felt some surgical treatment for her recovery is going on in the operation theatre. I hardly knew that shifting to operation theatre was done to recover her organs and was never meant for her recovery".*

Mr M narrated, *"I was not sure of the reaction of her family members for donation of my wife's organs. I called her brother before communication of my consent to hospital authorities. When he too agreed then only I decided to donate her organs".*

The narratives and facts reveal the patriarchal values ingrained in the decision-making processes of organ donation. Male members are the decision makers primarily who take females for granted and force their decisions on them in some cases. The narratives also reveal engagement of safeguards by male members in case of spousal donation. The male spouse ensured the consent of his wife's brother before permitting the donation of organs. The narratives reveal the unconditional love of mothers towards her child at death as well. The stories also reveal confusions between surgical interventions for life and death in operation theatres.

Decision to Donate Was Influenced by Disagreements Within Family Members and Reaching Consensus Took Time Within the Family

In most of the cases, the family members could not come to consensus immediately. Reaching agreement took a long time as some members did not support organ donation. The maximum time to reach a consensus within family members reported was 48 hours.

Mr K narrated, *"My father and mother readily agreed, but there were issues with my wife. She accepted with great difficulty. She took one day to decide in favour of donation. I kept pleading her the whole day to allow organ donation of our daughter". (The researcher felt that decision to donate was forced on her by her husband. She started crying while the husband was narrating this story during the interview. She later admitted that she was not willing to donate her 'daughter's organs)".*

Mrs U recounted, *"My husband did not want to donate his organs, but my daughters wanted to keep their brother alive. Daughters persuaded father to donate his organs. The sisters had an innate desire to keep their brother alive even after death. It was difficult for us to take the decision, but with no hope of recovery, we agreed almost after 24 hours".*

Mr J narrated, *"My grandfather was against such donation, but doctor counselled him for hours together, and in the end, he consented to donate. It took us two days to convince him before we communicated our decision to donate organs".*

The narratives and facts reveal that reaching consensus takes time within family members. The descriptions also show that declaration of death can be prolonged for long hours and even days till the time there is consensus within family members. In other words, the BSD declaration is not in the hands of God but the hands of a team of legally designated doctors.

Decision to Donate Was Facilitated by State Specific Organ Sharing Network

The interviews held with respondents revealed that NGOs and State level organ sharing networks helped in motivating people to donate organs of their Brain Stem Dead relatives. These State-level networks have Organ Transplant Coordinators who were made to motivate the potential donor's family for the donation of organs and tissues from their BSD donors.

Figure 6.7 NGOs and Organ Sharing Networks that motivated BSD donor families (N=14)

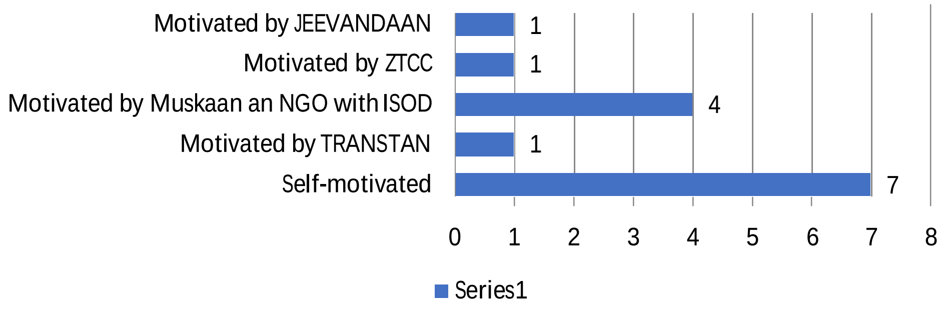


Figure 6.7 reveals that most cases, i.e., 7 were self-motivated but Muskaan Group, an NGO associated with Indore Society of Organ Donation (ISOD) was instrumental in getting four donor families motivated in MP. Three other State-level organ sharing networks like TRANSTAN, Jeevandaan and Zonal Transplant Coordination Committee (ZTCC) were instrumental in driving donor families for donating organs of BSD donors in their respective States, i.e., Tamil Nadu, Telangana and Maharashtra, respectively.

Impediment to Donation

In one case, the donor family was misguided that they could sell one kidney and get money.

Mrs D. narrated, *"I was told by people that why you donated all organs to this hospital without getting a penny from them, and you are struggling for getting the pennies waived off. They informed me that kidney costs 3.5 lack rupees".*

The data reveals the motivation level of people across the States. Majority of families were self-motivated, showing a high awareness and motivation level of people overall, especially in those States where organ donation activities were taking place regularly. The data also focuses on the importance of NGOs and organ sharing networks in organ donation. One of the donor families was told that they could sell the organs. The researcher did not understand the same as such things are not possible in BSD donation. Probably it is a myth percolating among the people.

Various Organ Sharing Network Facilitated the Sharing of Organs

Sharing, transportation and transplantation of BSD donor organs were facilitated by various organ sharing networks existing in respective States and UT's.

Figure 6.8 Organ Sharing Networks that facilitated transplantation of BSD donor organs (N=14)

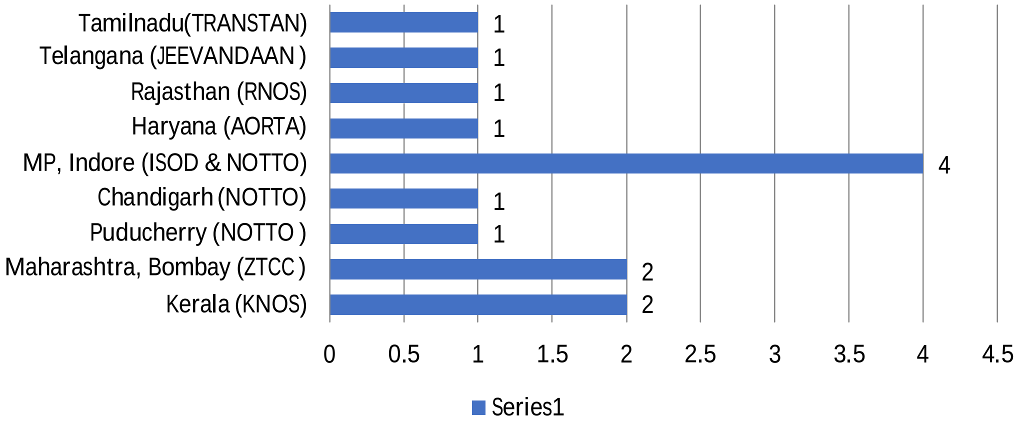


Figure 6.8 reveals that in most cases, i.e., 4 in Madya Pradesh alone, NOTTO along with ISOD played a vital role in the transportation and transplantation of BSD donor

organs. In addition to it, NOTTO facilitated transplantation of BSD donor organs for one case each in Chandigarh and Puducherry.

One BSD donor from Haryana was shifted to AORTA at Delhi for organ retrieval as the hospital in Haryana was a non-organ retrieval hospital. The donor moved from Haryana in army hospital ambulance on the ventilator as the family was self-motivated in favour of donation of organs.

The organ sharing networks are essential as they facilitate sharing of organs between various hospitals for transplantation as per the waiting list and help in preventing wastage of organs. Data also reveals that southern States managed organ sharing and transplantation of these BSD donor organs on their own. A few States like MP, Chandigarh and Puducherry took help of NOTTO.

Post Donation Perspectives of BSD Donor Families

This part of the Chapter discusses post donation experiences and perspectives of donor families**.**

It Took Long Hours to Retrieve Organs and Handover the Body

Most of the donor families expressed they spent long hours in hospital after consenting to donate organs. A few donor families communicated delays in post-mortems also.

Mr K said, *" I shifted my child to another hospital for organ donation. The hospital provided a room to stay during an elaborate procedure. My family members, especially my mother in law, refused to stay in the room until the retrieval was over. So, I took my family back home and came back the next morning to take the body".*

Mr T said*, "I was informed about the lengthy procedure of organ retrieval. My wife felt happy when I told her that our daughter was shifted to the operation theatre. She was interpreting as if she is in an operation theatre for treatment. I knew her confusion* *over death and life. For her operation theatre meant some therapy for my daughter. She did not realize that operation theatre was not for her treatment but retrieval of her organs. I did not try to alleviate her confusion and made sure her confusion prevailed till the next day. I kept my family in dark till the morning. By this time all organs were retrieved, and the body was handed over to me".*

Mr M said, "It was a long procedure for retrieval of organs. After retrieval of organs, we received poor treatment for getting post mortem done. If a donor family meets such treatment, I would suggest people should not donate organs. I was badly treated by the doctors in a Govt. hospital who were to perform the post mortem of my donor wife. I cursed myself for why I donated her organs when I had to get humiliated by a doctor. I cried after the doctor abused me. Post mortem was not done in organ retrieval hospital, but the body was shifted to another hospital for post mortem. Post mortem papers were handed over in duplicate that was not accepted as the post mortem doctors wanted original papers. Anyway, we got it from the retrieval hospital that made me go from pillar to post several times. The legal demands, of course, were also much of a problem but the un-courteous behaviour was a serious problem I would never want to recollect. I had to move tirelessly to get the body back for last rites".

The narratives of donor families highlight the long hours of retrieval process involved in organ donation and transplantation that was not told them in advance in many cases. There is an urgent need to address this issue by giving correct information to donor families. The donation, death and post-death rituals are to be managed and pre-planned by donor families. Accurate information could help them in planning things accordingly. Lack of post-mortem facilities in organ retrieval hospitals bring in focus the ordeal of people. Families donate organs in one hospital and shift to another hospital for getting post mortem done. The uncourteous attitude of doctors not only hurts them but gives birth to the feeling of guilt. It leaves them disillusioned with such donation that is not going to do good to society in the long run.

Donor Families Were Passionate with The Donation of Heart

The researcher found a tremendous emotional attachment of the donor family with the donor's heart. The emotional attachment was perceived in two cases when the donor's heart was transplanted, and when it was not.

When Donor Heart Could Not Be Transplanted?

Mr K said, *"Doctors did not retrieve her heart as the size of her heart did not suit the child who was to be transplanted her heart. My wife heaved a sigh of relief, saying that my daughter would have never liked to part with her heart as she loved us wholeheartedly. While interviewing, she said with tears rolling her eyes, "We lived in her heart and how could she part with her heart".*

Ms B. narrated, *"I wished her heart was also retrieved and transplanted into some person but could not as there were some medical problems. Only her kidneys were retrieved".*

When Donor's Heart Was Transplanted?

Mr T said, *"At 6.10 am her heart was retrieved and sent to Bombay in a charter plane for transplantation. At 11.00 am on the same day, doctors informed me that her heart has started beating in a 16-year-old Christian girl".* The mother knew the name of the heart recipient. She was sharp to announce "Sweden Dsouza with a lot of contentment" in between my interview with the father.

The heart is not an anatomical organ for donor families but a container of emotions, a large vessel of love and an organ of life. Maternal attachment with the heart of donor child irrespective of whether transplanted or not speaks volumes about motherly love for her child. The heart of her child carries love for her to heaven or gives life to others on earth. In case heart beats in others body means her child is continuing to live in others and is not dead. In case the heart is not transplanted means her child carried her love for her mother to heaven.

Infrastructural Issues: Organs Travel Long Distances

Not all hospitals are equipped to do all kinds of transplant. Kidney transplant hospitals are more in number as compared to other organ transplants in our country. There are fewer chances of kidneys leaving a State and getting transplanted in other State. Liver and heart transplant hospitals are less in number. These two organs cannot survive outside the body for more than 4 hours in case of heart and more than 8 hours for the liver. Sometimes, these organs are required to be airlifted from one State to other to reach the recipients in time involving green corridors and hundreds of human resources in the police.

Mr T, a truck driver said, *"The heart of my daughter covered about 550 kilometres in 2 hours in the morning hours to beat in a 16-year-old girl from Mumbai. My daughter had never left Indore or travelled by air. But after death, she received VVIP treatment when her heart and liver travelled via a green corridor to different parts of the country. Her organs kept country on toes for at least a day. She had never visited Mumbai or Delhi. But after her death, her heart is beating in Mumbai now. And her liver is working in someone's body in Delhi. The recipient of the heart was suffering from a disease called cardio-sympathy (father could not say cardiomyopathy). It gave me immense pleasure to know my daughter's heart gave a new lease of life to a girl".*

Mr. I said, *"We don't have liver and heart transplant hospitals in our area. Two green corridors were created twice at Indore with the help of district administration and traffic police to shift heart and liver to Airport Indore. At Mumbai again one green corridor from airport to the private hospital for heart transport was created and at Delhi airport fourth green corridor was created to shift liver to liver transplant hospital".*

The narratives describe how organs fly and travel from one place to another and reach the recipients in different parts of our country. The descriptions also reveal how a poor man's wish to fly her daughter gets fulfilled through organ transportation after death. Interstate transportation of organs for transplantation is made possible by immense intrastate and interstate cooperation. It involves extensive use of infrastructure, material and workforce resources as well. This kind of regional collaboration strengthens unity and solidarity among States and dilutes the value of State subject at death.

Families Deliberately Bypassed A Few Last Rituals for The Donor Body

The final bath at home, a usual ceremony followed in all religions at death was not done in most of the cases.

Mr T said, "The body was well packed and was not given the last bath at home. I ensured all the arrangements at home. I kept the body at home only for 5 minutes and took her for cremation within five minutes. Since I had decided to donate all her organs and skin as well, I was worried about the reaction of my family. I was thinking of what would happen to stitches on her body if any of the family members unknowingly touches her body while weeping and crying,".

Mr M said, "I kept the body of my wife only for 5-10 minutes. We were getting late for cremation. The body as packed by the hospital was taken to the cremation ground after doing minimum rituals at home, a deliberate attempt on my part".

The narratives depict decision-making ability of male members and highlight the conscious efforts made by them to keep dead body rituals at home to the minimum. Body bath, an intimate last ceremony was not performed deliberately to avoid the unpleasant sight of the body, avoid things getting worse at home and prevent delay for the funeral also.

Unpleasant Experiences of Family Members at Home After the Donation of Organs

Some respondents revealed bitter experiences in family and society after the donation of organs. Several families reported that the idea of organ donation did not go well with their relatives. Relatives felt that they had sold donor organs. The male members reported facing the anger of spouses and families for donating organs that were usually triggered by taunts and heckling of relatives, neighbours and friends.

Mr T said, *"My wife did not talk to me as I had consented to donate organs without consulting her or any other family member.* ***Mai Apne Ghar Mai Hee Paraya Ho Gaya Thaa. Mere Biwi Aur Mere Bacchey Mere Decision Se Narraz They. Unko Log Taney Martey They Ki Humney Apnee Apahij Beti Ke Organs Bechey"*** *(Meaning, I got reduced to an alien in my house. My wife and children were angry with my decision. People taunted and blamed them for selling the organs of our disabled daughter.)*

Mr K said, *"My wife did not talk to me for three months as I had decided to donate organs. She reluctantly had approved to donate her organs on my repeated insistence".*

Mr R narrated, "My parents are angry with me even today for donating my daughter's organs".

Mrs T said, *"We were ill-treated by relatives too who thought that we had sold the organs of our daughter. I would always question him for donating her body parts, what did we get? Some of our relatives taunt us even today".* Mr T also felt that irrespective of doing good to the society, they have become notorious among their community.

Salvage of Donor Families by Social Media from Social Ostracism

Social media rescued some of the donor families from social exclusion.

Mr M said*, "My decision to donate my wife's organs did not go well with my relatives. But the moment I shared my story on Facebook, there were many likes, shares and comments as well. People gave comments that not only brought tears in my eyes but changed the heart of my relatives as well. Social media rescued me from the apathy of my relatives and friends".*

Mr C said, *"My family members at home did not like the idea of donating organs. But my younger son would make them understand through Facebook and Twitter posts to help them change their mind. The comments were many for my son not only on Facebook but on twitter as well. The comments touched the hearts of all who could have raised their eyebrows otherwise".* The comments, as read by the researcher, were many. Father showed these comments on his mobile to the researcher like **"Jeetey Jee Deswasiooon Ki Raksha And Marthey Waqt Kuchko Jevandaan Diya**" (Meaning during life you protected our citizens, and at death, you gave life to many). **"Appney Jeevan Aur Mritu Dono Hee Desh Ko Samarpit Kar Diya"** (Meaning you sacrificed your life both during life and at death.) "Protector in life and protector at death". "Salute for his service and sacrifice". "The true soldier saved the four lives after his death, May God bless his soul." "Great soul is still alive in the heart of four". "Salute to his relatives for a noble cause".

The narratives depict unpleasant experiences of male members at home who had to pay the price for not taking family consent in organ donation and taking decisions on their own. These narratives also focus the silent male sufferers who lived like aliens in their homes post-donation. The stories depict limited knowledge of people playing havoc with the lives of people who do good for society.

Expressed Need of Donor Families to Know the Recipients

Most of the donor families had an urge to know the recipients of BSD donor organs.

Figure 6.9 Felt need of BSD donor families to know the recipients (N=14)

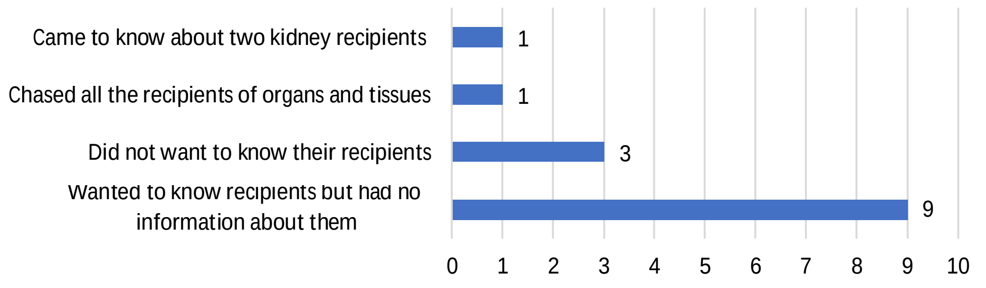


Figure 6.9 reveals that the majority of the families, i.e.,9 wanted to know their

recipients but had no information about them. There were only three (3) families who did not want to know the recipients. One (1) family had chased all the recipients of his daughters' organs and tissues as well, and one (1) family could find two kidney recipients.

The perspectives of these donor families to know the recipients varied as depicted in the narratives below: -

The reasons for knowing the recipients by nine donor families were many. Donor families wanted to see their donor alive in others. They wanted to see what difference their donation has made in the lives of people. Some of them desired to make the recipients participate in their celebrations of social importance.

Ms F said, *"My mother feels like calling all the recipients of my father's organs, especially the one with his transplanted heart on my marriage. It would make her feel the presence of my father by my side when I get married, and blessings of that person on my marriage shall help me too. I want you to help me in finding the recipients".*

Two donor families had found the recipients of their BSD donor organs. One BSD donor family was helped by one NGO to interact with two kidney recipients of their BSD donor in one of the felicitation programmes. The programme was conducted for donors and recipients by that NGO.

Another donor family had chased all the recipients of his BSD donor daughter. This donor family had taken the help of newspaper information and the help of an OTC.

Mr. K said, *"I tried my level best to trace all the recipients of my donor daughter. (shared the photographs of his donor daughter's three recipients with the researcher). There was a 5-year-old recipient who had received two kidneys and one liver of my daughter. Unluckily, my daughter's organs could not help the recipient survive for long. The child died within 45 days after multiple organ transplants. I did not lose* *courage and traced the two recipients of my daughter's corneas(eyes) as well. I was relieved to see my daughter's eyes had given sight to two blind children".*

Three donor families did not want to know the recipients described reasons as well. Their three individual statements were, *"We don't want to disturb the recipients"*; ***"Neki Ker Kuan Mai Daal"*** (Meaning do good and forget); and *"I am concerned about the future of her orphaned sons rather than her recipients. She has given lives to others is a good feeling itself".*

Emergence of The New Social Relationship Between BSD Donor Families and Recipients

The donor families had developed new social relationships with the recipients. The families were sharing a great bond. The recipients made pleasant friendly visits to donor families and vice versa. Not only this, BSD donor's birthday was celebrated with the recipient and recipient's birthday with the donor family. Donor family also empathised with the recipient of organs.

Festivities and Organ Donation

Mr K said, *"This year I celebrated her birthday with two male children who had her corneas. I went with clothes and gave it to them. I had tears in my eyes. Probably I may not revisit them as it always reminds me of my cute angel".* However, next year, the same donor family rang the researcher. He told that one cornea recipient family had invited them to celebrate the birthday of their son with his daughter's gifted eyesight.

Mr. I said, *"She lives with my brother's kidney that has prevented her children from becoming orphans. We called her on his birthday that falls on 10th October. My family members rang her number of times on that day and celebrated his birthday with her. She was made to cut the cake as we could see him in her. His absence was not felt on his birthday because her presence made us feel he is alive. My daughter even calls her* ***"Badey Papa".*** *My mother always rings her as if she is her son. She feels excited about* *her decision and feels proud of him as he could help so many after his death. We met another kidney recipient also, but he lives far off, and only telephonic interactions are possible. He cried while embracing my mother in a felicitation programme after knowing my brother's kidney is residing in him. My mother could not hold her tears, seeing him along with his family. We all cried seeing his two recipients, but it was a moment of pride for all of us to have given life to people in death".*

Mr K said, *"Doctors transplanted two kidneys and one liver of my BSD donor daughter in the child. The child had some problem with the liver that was resulting in stone formation. Stones had damaged both his kidneys. Doctors believed that the recipient should lead a normal life with her liver and two kidneys which did not happen, unfortunately. The child did not survive. I met his father who was charged 25 lack rupees for operation, and the father could not pay three lack rupees at the time of death. The greedy hospital did not give him back the body. The hospital ensured that he writes on stamp paper that he will deposit the money within a few weeks. With great difficulty, the hospital handed over the body. I feel for my friend and curse the greedy people in the hospital where the organs were transplanted".*

Reciprocity by Recipient Families in Facebook Post A Real Reward to The Donor Family

The donor family also felt happy with reciprocity in the virtual world.

Mr. I said, "We feel happy when we see the recipient reciprocating and communicating love and respect for our donor. One of the recipients whom we know now wrote a birthday wish for my dead brother on her Facebook post that reads (shared post by the family)

- □ □ □ □ □ □ □ □. (name changed), आज

मद द न ह . त म ह र य द आ ह .लस ग आजक ल य नह
.हर द द न क ल य .रव

त म ह र क स श य कर .(Meaning Dear Rav, today it is your second birthday in heaven. I am sending you my blessings today from earth. Not only for today but for every day. Dear Rav , I have no words to thank you for giving me a new lease of life.

HAPPY BIRTHDAY DEAR □ □ □ □ □ □ □ □ □ □ □always Loved
□Forever Missed...).

The narratives of the family members depict the strong need of families to know the recipients of donor organs. Most of the donor families did not know the recipients but had an innate desire to see their donor living in others. While one had chased all the recipients another had found two kidney recipients. The knowledge of recipients had given meaning to their good deed of organ donation. The families had developed healthy relationships that were non-existent before donation and transplant. Organ donation and transplantation had united people and given a good feeling to donor families as well as the recipients. Celebration of birthdays united donors and recipients.

Donor Families Had Something to Boast About Making Records Through the Donation of Organs

While interacting with donor families, the researcher felt that most of the donor families had something or the other to boast about the donor, having created new records with the donation of organs. Their narratives were: -

Ms B said, *"My sister has created a record in Chandigarh. She was the first donor who had pledged to donate organs".*

Mr U said, *"My son was the first MBBS student who had donated organs".*

Mr C said, *"My son was the first navy officer who had donated organs".*

Mr T said*, "My daughter made her State proud whose organs were distributed by doctors with other States".*

Mr J said, *"My daughter was a helpful child during life; she made a record of helping others even at death".*

The narratives focus that even at death, people want to create records and history. It also brings in focus the wrong information given to people for the donation of organs. Motivators told the father of the navy officer that his son is the first officer to donate organs. It is unlikely as AORTA has initiated brain death certifications from 2007. There are no records available that can help in identifying whether his son was the first navy officer or not.

Multiple Felicitations Provided Multiple Opportunities to Donor Families

All the BSD donor families were felicitated at least once. There were various levels of donor family felicitations. Local felicitations for donor families were arranged by local organ retrieval/ transplant hospitals. State organ sharing networks usually did State-level felicitation. Organ recipient hospitals of other States did the same at their level for BSD donor families. And Centre felicitations were done at NOTTO level.

Mr T said, "I got certificates from many hospitals and organizations. I was felicitated in Bombay by ''Sonakshi Sinha' and ''Shatrughan 'Sinha' also. I would have never dreamed of meeting such dignitaries had I not donated her organs".

Mr H said, "I feel happy about my decision to donate her organs. It has given me a new identity. I have been invited by JEEVANDAAN several times".

Felicitation had saved many families from a negative impact in the society, providing them with an opportunity to meet Bollywood celebrities and Political dignitaries. In some cases, it had given a new identity also. In many instances, a few mothers could not hold themselves and wept inconsolably on the stage. At times, it was difficult for organizers to help them meet the dignitaries and get felicitated. The event made them revisit their loss. A senior OTC reported that many times, families 'don't accept felicitations as they 'don't want to revisit their loss.

Expectation of Families from Hospitals and Governments Post Donation

Most of the families did not expect anything in return for the gift of BSD donor organs. However, very few families had an immediate expectation and lifelong expectations too for such donations. Some of the expectations revealed by donor families were: -

Waiving Off Hospital Bills Following the Donation of Organs

Mrs D said, *“Hospital did not waive off the bills after we donated all her organs even after repeated requests. They reduced the amount from Rs. 62,500 to 57,500 only after I applied jack from somewhere but did not waive off the whole amount”.*

Status of A Martyr

Mr C said, *"He has given life to four people, but what about his sacrifice. He may be considered a martyr. He was a martyr. But the facilities given to a martyr after death are not given to BSD donors. The Government does not mind giving crores of rupees to beauty pageants, giving petrol pumps to widows but what about my son who gave life to 4 people after death".*

Mr C, the father of the donor in October 2018, rang the researcher and informed that Govt. did not pay any heed to his repeated requests. He had requested to Chief Minister and Prime Minister as well to treat his son a martyr. Unfortunately, his tireless efforts did not yield any fruit.

Monetary Support to Children Who Are Orphaned

Mrs D said, *“We feel good about donation, but what about this family who has given life to many people. They are struggling for basic survival. She left two minor kids behind her who have none to support. Of course, her two children are getting free education, but how can they survive for education without food. Something has to be done; otherwise, it is like giving life to others and dying yourself. These are small kids. They are very hard working. They secure very high marks, but their survival is at stake. I am not their immediate relative. I am one of their acquaintances. With felicitations, none survives".*

Free Treatment in Hospital

Mr R said, "Everyone got something out of this donation. My relative's heart gave life to someone; his liver and kidneys are functioning for many people who needed organs and could not do without them. Everyone benefitted, but what did we get in the end.

We are from a low-income family. The hospital did not even assure us of giving free treatment in future".

The donor families don't get anything in return after the donation of organs. It does not go well with many donor families as described in the narratives. Waiving hospital bills, free treatment in hospital for family members, monetary support to orphaned children and giving the status of a martyr to defence personnel were some of the anticipated expectations of donor families.

Donor Families Promote Organ Donation

Mr T said, "I talk about our experience of organ donation at various events, and I also talk about it to my colleagues".

Mr H said, "I regularly attend all events wherever I am called to promote the cause of organ donation. I was shy of public speaking, but now I am not, I do talk to people on a personal level to further the cause of organ donation. I carry the organ donor card now. I often propagate organ donation. I tell them, we are nuclear families usually. Social norms do not bind us to a great extent. We should choose to register our will to donate organs for giving a direction to the family at the time of death. Technology has revolutionized everything; we should put everything to use even after death".

Donor families are the best persons to promote organ donation from BSD donors. They can relate with people and help them come in terms with the loss.

Myths Persist with Organ Donation and Transplantation Among Donor Families

Two of the relatives also had a belief that organs of post-mortem cases retrieved in all accidental cases are transplanted.

Ms B said, *"Why are people dying because of organ failures? Organs retrieved during post mortem should be used for transplantation extensively".*

Mr U said, *"None of the patients will die if organs of post-mortem cases are transplanted".*

Although having donated organ of BSD donors, the myths prevail even among donor families. It shows a lack of awareness among ordinary people.

Summary: - This Chapter reveals the perspective of BSD donor families. The 14 donor families were from various States and UT's that contributed 28 kidneys, 11 livers, 11 hearts, 28 corneas and two hands for transplantation. Also, four donors also contributed skin in Indore, Madhya Pradesh. The families adopted healthy coping mechanisms at the time of loss of life and rationalized their loss by giving life to others.

Only one donor had pledged to donate organs while in the remaining cases, it happened due to the wish of the families. All donor families were well informed and not coerced. Only in two cases, the families had set precondition.

The families went through disagreements and lengthy discussions before reaching consensus on organ donation. Also, the decision to donate organs rested with male members predominantly. State organ sharing networks also facilitated it. Male members also faced the wrath of the family after donation as some relatives suspected they had sold organs. It even led to their social ostracism. The donor families were kept in the dark about the long duration of the retrieval process. It led to unhappiness and anger with the hospital staff. To make up for the loss of time in organ retrieval and to prevent other relatives from seeing the sewn body of the donor the male members often manipulated the last rituals like skipping bathing of the body etc. before cremation.

Some of the anticipated expectations of the donor families were waiving off hospital bills after the donation of organs. A few wanted free treatment in hospital for family members. One donor family wanted monetary support to children who are orphaned, and another wanted to give the status of a martyr to defence personnel.

Donor families had an innate desire to meet the recipients. They intended to see their donor alive in others. They wanted to know the difference their donation has made in the lives of people. Some of them desired to make the recipients participate in their celebrations of social importance like marriage to bless the daughter.

Felicitation of donor families gave them social recognition and boosted their morale. It also provided an opportunity to organ donation promoting organizations to spread awareness.

CHAPTER 7

Perspectives of Kidney Recipients

The first part of this Chapter reveals the socio-demographic information about kidney recipients. The second part of the Chapter reveals that probable medical causes were not aligning with the perceived cause of the illness influencing treatment-seeking behaviour of the recipients as well. The third part of the Chapter explains dialysis a significant concern of kidney failure patients and what it meant to patients. The experiences of dialysis varied from one person to another with the same or different type of dialysis. It also reveals the physical and financial sufferings of patients with dialysis that were complicated by starving Government infrastructural facilities. The fourth part shows problems faced by recipients due to lack of BSD donors and the negative role played by media. It also reveals that recipients were denied registration for organs from Brain Stem Dead donors if they had near relatives willing to give organ in the family. In a few cases, they were not able to shift in time for BSD donor kidney transplants. The fifth part of the Chapter reveals the infrastructure and human resource concerns of the recipients. It shows cost variations of medical procedures in various health facilities and unwanted experiences of the recipients with the same. It also shows how recipients empathized with staff at SJH, were grateful to them for pro-poor initiatives. In some cases, however, recipients felt suspicious too based on their misunderstanding and misinterpretations of terms. Professionals playing safe was adversely affecting the financial health of the recipients. The sixth part of the Chapter reveals the most significant challenge for the recipients was to lead a productive life.

Socio-Demographic Information About Kidney Recipients

This part of the Chapter reveals the background /socio-demographic information about kidney recipients.

Background Information About 30 Kidney Recipients

Figure 7.1 Distribution of Kidney Recipients as per blood group(N=30)

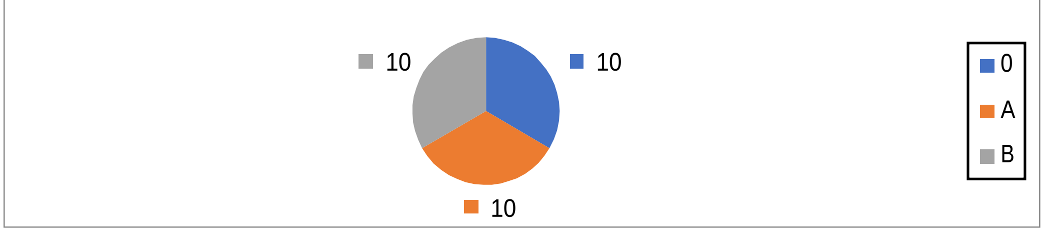


Figure 7.1 reveals that 30 kidney recipients interviewed comprised of 10 recipients each from three blood groups only that is A, B and O. None of the interviewed recipients was having AB blood group.

Figure 7.2 Socio-demographic information of Kidney Recipients (N=30)

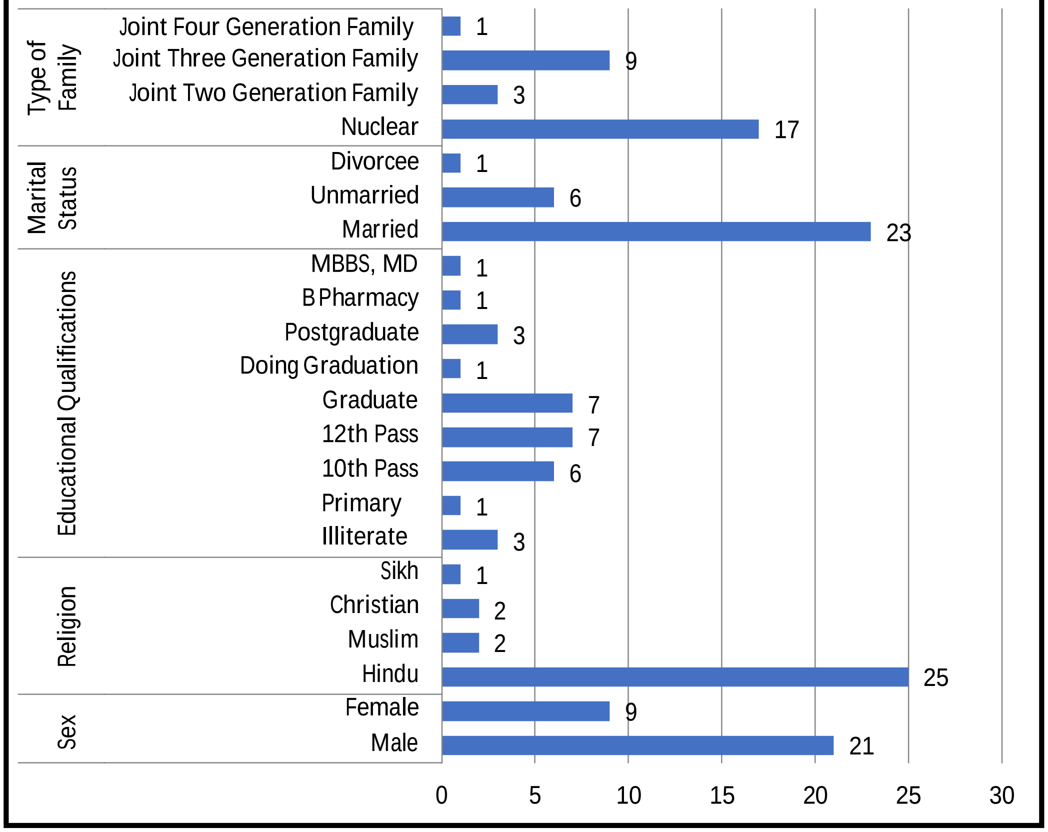


Figure 7.2 reveals that the majority of interviewed Kidney recipients were males, i.e., 21, majority, i.e., 25 were Hindus, majority, i.e., 7 were 12th pass, and an equal

number were graduates, majority, i.e., 23 were married and majority, i.e., 17 were living in nuclear families. One recipient was living in Joint Family with four generations.

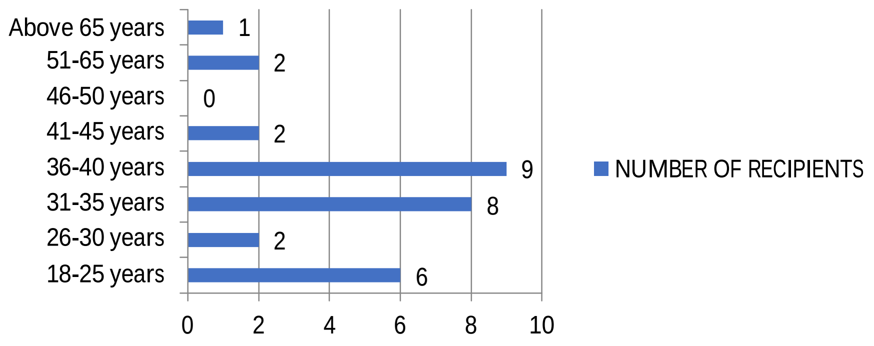


Figure 7.3 Age wise distribution of Kidney Recipients (N=30)

Figure 7.3 reveals that the majority of recipients, i.e., 9, were in the age group of 36-40 years. It also shows that six (6) kidney recipients were in the age group of 18-25 years too.

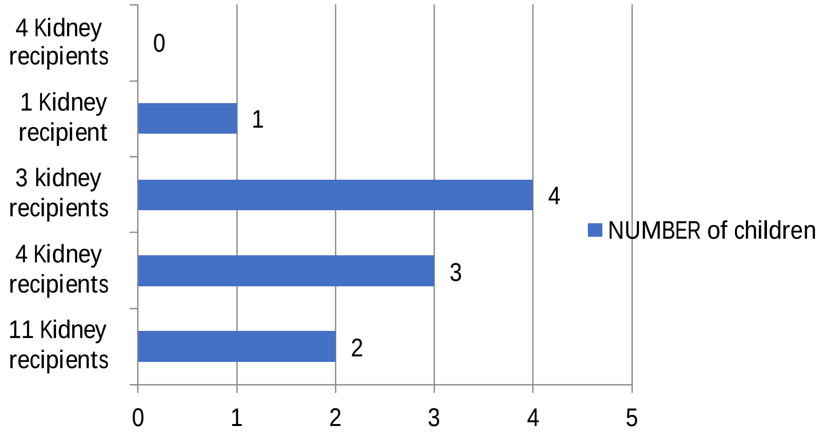


Figure 7.4 Distribution of married Kidney Recipients by number of children (N=23)

Figure 7.4 reveals that the majority of married kidney recipients, i.e., 11 had two children and four (4) kidney recipients had no child.

Table 7.1 Distribution of Kidney Recipients by Living and Brain Stem Dead Donor Kidney Transplantation (N=30)

Type of donors	**Male Recipients**		**Female Recipients**		**Number and Percentage**
	Waiting for transplant	Transplant was done	Waiting for transplant	Transplant was done	
BSD Donors	5	2	**2**	**2**	11(36.67%)
Living Donors	4	10	**2**	**3**	19(63.33%)
Total	9	12	4	5	30(100%)

Table 7.1 reveals that male kidney recipients waiting for kidney transplants were 9 in number in comparison to 4 female kidney recipients. Also, 12 kidney transplants were done for males in contrast, only 5 in females. There was a massive gap between living kidney transplants and kidney transplants from Brain Stem Dead donors. The burden of 19 (63.33 %) kidney donations rested on living kidney donors in comparison to 11(36.67%) on Brain Stem Dead donors. Most kidney recipients, i.e., five (5) males and two (2) females, were waiting for Brain Stem Dead (BSD) donor's kidneys. Only two (2) kidney transplants were done with Brain Stem Dead donor kidneys for males and 2 for females. In comparison, ten (10) living donor kidney transplants for males and only 3 for females were done.

TABLE 7.2 DISTRIBUTION OF KIDNEY RECIPIENTS BY THE YEAR OF TRANSPLANT SURGERIES (N=17)		
YEAR OF KIDNEY TRANSPLANT SURGERY	Number of Recipients	Percentage
1994	1*	6%
2014	1	6%
2015	2	12%
2016	7	41%
2017	6	35%

(*recipient from AIIMS)

Table 7.2 reveals most transplant surgeries happened in 2016 and 2017, that is 41% and 35%, respectively. Only 6% of transplant surgeries occurred in 2014, and 12% in 2015.

Cause of End Stage Renal Disease (ESRD) or Kidney Failure and Treatment Seeking Behaviour

This part of the Chapter reveals the probable medical causes of the disease that were different from the perceived causes of the disease as reported. It also shows how the treatment-seeking behaviour of kidney recipients was affected by the perceived cause of the disease.

Probable Medical Cause of ESRD:

The probable medical causes of the ESRD were high Blood Pressure; Diabetes Mellitus before kidney failure, Congenital, Genetic, etc. But for most cases, the disease came without any prior problems or associated conditions as reported by the recipients. Most of the patients had suddenly found that their kidneys had stopped functioning

High BP - Five patients had suffered from kidney failure following the diagnosis of hypertension. Some were taking anti-hypertensive medicines regularly, but a few consumed medicines irregularly also. The narratives reported by recipients that include their family members too, in some cases, are: -

Mr. A reported, *"I had high Blood Pressure, but I took medicines intermittently. One day I had breathlessness, and doctors found high BP, very high creatinine and urea levels in the blood. Doctors created Neck Line at once and started dialysis. Within a month fistula was prepared".*

Mr. Br (son of the recipient) reported, *"He was suffering from very high BP. He did not take care of himself for 2-3 years. He took medicines off and on and ended in kidney failure".*

Figure 7.5 Probable medical cause of ESRD (kidney failure) (N=30)

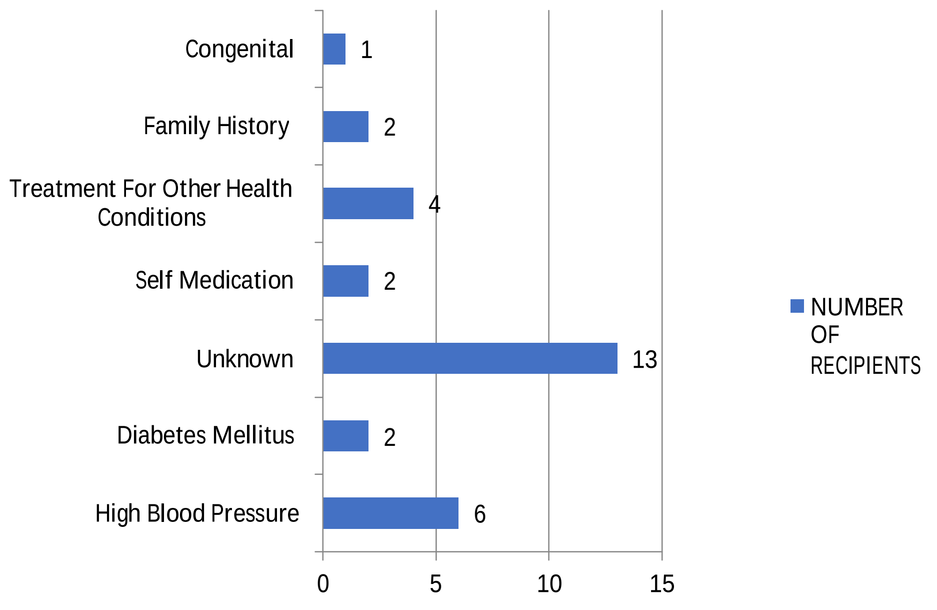


Figure 7.5 reveals various probable medical reasons for kidney failures, but even among medical fraternity in most cases numbering 13, the medical cause was unknown.

Mr. C reported, *"I had high BP from the age of 21years. I avoided medicines".*

Mrs. Dr (mother of the recipient) reported, *"She was operated upon at the age of 21 years for a hearing problem. The operation was okay, she was able to hear, but hypertension started. She would complain of headaches and giddiness, and now she is on dialysis. She used to take antihypertensive drugs regularly".*

Mr. E reported, *"I was okay, but during an annual medical check-up, doctors found me hypertensive at the age of 35 years. My BP was 170/110. They prescribed antihypertensive drugs, but I did not consume them as I did not have any symptoms. Occasionally, I would feel tired and giddy during daily exercises. However, I used to have hot feet all the time".*

Mr. Fr reported (brother of the recipient), *"He was suffering from aplastic anaemia and hypertension. He was taking medicines regularly".*

Chronic Diabetes Mellitus: -Two patients had suffered from kidney failure because of Diabetes Mellitus.

Mr. G reported, "I was a chronic case of Diabetes but was okay a few months back before dialysis. I was taking regular treatment for Diabetes, but a few months back, I developed a fever and had uncontrolled vomiting and was diagnosed with kidney failure".

Mr. H reported, "I was previously suffering from Diabetes Mellitus and was taking medicines regularly. After performing pilgrimage to many religious places for 21 days, while coming back, I suddenly became unconscious and was diagnosed with ESRD".

Sudden Loss of Kidney Functions Detected /Unknown: - Thirteen (13) patients were caught unawares with kidney failures, much to their surprise with very common symptoms.

Mr. Ir (husband of the recipient) reported, *"She was okay but suddenly complained of weakness, loss of weight, face and leg swelling, and it was revealed that her kidneys had failed".*

Mr. Jr (husband of the recipient) reported, *"She was complaining of abdominal pain from October 2015. I had taken her for treatment to many hospitals in Lucknow, PGI* *and AIIMS. She was complaining of weakness as well. After many consultations in hospitals, in Jan 2016, it was declared that both her kidneys had failed ".*

Mrs. Kr (wife of the recipient) reported, *"He was okay one year back. Suddenly he had a headache and came to know of high BP. Within a month he was told that both his kidneys had failed. It was silent BP. His parents were suffering from high BP".*

Mr. Lr reported, *"He was okay three (3) years back. He was a labourer at a construction site but was feeling weakness with oedema in face and ankles. Doctors told that both his kidneys are not functioning".*

Mr. M reported, *"I came to know about high BP in the month of Dec.2013 only. The kidney had already damaged. I was taking Gutkha (chewing tobacco) in abundance as I owned a shop selling Gutkha. RML hospital told me that recovery is not possible".*

Mr. Nr (relative of the recipient) reported, *"He had palpitation and weakness in limbs. A doctor treated him but did not check his BP at that time. He was distributing his marriage cards. We thought it could be exertion and went on with marriage preparations. He got married on Nov 2016 and on 8th January 2017 he got a stroke and was taken to hospital. His* serum creatinine *was 3.83 and blood urea 240. Doctors put him on dialysis".*

Mrs. Or (relative of the recipient) reported, *"He was suffering from vomiting, headache from 6-7 months. We were getting his symptoms treated. When symptoms showed no sign of respite, we took him to SJH where doctors diagnosed him with kidney failure".*

Mr. Pr reported (relative of the recipient), *"She was well otherwise, but in May 2016 she had persistent vomiting and diagnosed with both kidney failures".*

Self-Medication / Superstitious Medication: -Two patients were accustomed to taking medicines not prescribed by doctors.
Mrs. Qr reported, *"He was well but was obsessed with taking medicines from the counter without a prescription from the doctor for the headache.* ***Harey Pattey Ke Tablets Humesha Leta Rehta Thaa"*** (Meaning he was taking tablets with green

label). *He consumed too many pills. Whenever he used to get his salary, he would never miss getting the tablets first".* Neither the relative nor the patient was able to name the tablet but knew the green colour wrapping of the pills only.

Mr. Rr reported, *"Ours is a four-generation joint family, influenced by superstitions. She gulped down every herb, every medicine given to her from saints and priests, to give birth to a child".*

Associated Condition and Treatments - Two patients had a history of taking antipsychotic drugs for years. One had a history of taking steroids for long, and one had a history of taking anti-tubercular drugs.

Mrs. Tr reported, *"She was suffering from psychiatric illness and was on antipsychotic drugs from 2008 onwards. She suffered from pneumonia for ten (10) days and later had chikungunya. The disease accompanied by respiratory distress and swelling all over the body, and doctors diagnosed ESRD".*

Mr. Ur reported, *"She was taking medicines for psychiatric illness, and later doctors diagnosed her with kidney failure".*

Mr. Vr reported, *"He was okay but was taking steroids for the skin problem for a long period following which doctors diagnosed him with high BP. He took medicines irregularly".*

Mr. Sr reported, *"She had chickenpox, had treatment for Tuberculosis continued for 5-7 years back. She had arthritis and taking medication for that as well. She was well, but in May 2016, she had persistent vomiting and doctors diagnosed both kidney failure. She is working as a security guard in a company and covered by ESI about which we were unaware. After getting treatment from a private hospital and exhausting resources, she came to know that she can avail ESI health facility free of cost".*

Family History of Kidney Failure: -Two patients had a family history of kidney failure.

Mr. Wr reported, *"He had a brother who died of kidney failure at the age of 15 years. One year back, he had vomiting and fever. Medical investigation revealed increased creatinine and blood urea levels. He, too, was diagnosed with kidney failure".*

Ms. Xr reported, "*Ours is a family with polycystic kidney, running in three generations. Even his sister and her grandchild are suffering from polycystic kidney".*

Congenital: -There was one patient who had a congenital problem with kidney.
Mrs. Yr reported, *"From birth one of his kidneys was small sized, but he had no problem. He would go to the gym and do exercise etc. He suffered from chikungunya recently and later had swelling in feet, vomiting and persistent headache. Doctors diagnosed kidney failure".*

The probable medical causes behind ESRD were many, ranging from hypertension, diabetes, genetic, irrational use of medicines and congenital, etc. Unfortunately, many of the patients were caught unawares and had suddenly found that their kidneys had stopped functioning. ESRD for such recipients was like a bolt from the blue. While some had taken medicines for diabetes and hypertension regularly, there were a few who not done it irregularly. Taking medications daily for diabetes and hypertension did not guarantee ESRD free life for many recipients. Some patients could recollect having complained of headache only which they would control with the use of analgesics without getting their BP checked. A few had histories of taking drugs for years like anti-psychotic, steroids and anti-tubercular drugs. But for most cases, the disease came without any prior problems or associated conditions.

Perceived Cause of ESRD: Abuses and Demonist Activities by Relatives

Irrespective of the medical cause of kidney failures, the respondents had a different understanding of the disease cause. As a result, the treatment-seeking behaviour of some of the respondents also varied.

Ms. Xr reported, *"His mother had polycystic kidney. His sister and her grandchild are also suffering from this disease. I am his daughter; I am also suffering from the polycystic kidney. He believes it a sort of curse on our family. He took treatment from everywhere after being diagnosed with kidney failure. He believed this disease was the result of jadoo tona (sorcery) done on him by his brother's wife. He tried to get rid of it by jadoo tona (sorcery) only. He did believe in everything like ayurvedic treatment, homoeopathic treatment, use of unknown herbs and money-consuming special prayers to fight the disease and reverse its effects. But now he knows, his disease cannot be reversed and is waiting for kidney transplantation".*

Mrs. Yr reported, *"He had no problem. My sister might have done some jadoo tona (sorcery). Otherwise, why did my two sons die in the prime of their youth? And this is the condition of my third son. I am fighting a legal battle with her as there is a property dispute".*

Mrs. Or reported, *"I believe the reason for this disease is the result of some tantric activities by my sister-in-law. She works against us and often goes to tantric (Occultist). She does some paranormal activities there for our devastation only. We are devastated now. I have sold half of my property in the village for one and a half lakh rupees, and I am penniless now".*

Mr. Ur reported, *"Sometime back my mother might have abused her saying* ***"Bhagwaan Tumhey Uss Jagah Le Jayee Jahan Tumhey Panni Bee Nassb Na Ho"*** *(Meaning May God take you to a place where you are unable to quench your thirst). It is verbal abuse that is usually hurled by people in a fit of anger. She feels my* *mother's wish has come true and blames my mother. My mother is the one who is more perturbed because of her illness".*

Incidentally, irrespective of the medical cause of the disease the perceived cause of ESRD by many patients and relatives were altogether different ranging from hurling of abuses to performance of some planned demonist activities like jadoo tona (sorcery) and tantric (occultist) activities. One of the patients after being diagnosed with End Stage Kidney Failure believed that the abuses hurled on her by mother in law was the cause of her disease and, in many cases, the patients thought that some intangible demonist activities carried by relatives were the cause behind their illness. Not only this, they also believed in the reversing the disease by shifting to other forms of treatment.

Treatment Seeking Behaviour Outside Allopathic Medicine

Some of the interviewed patients had taken treatment outside allopathic medicine. They did so mainly to reverse the damage of their kidneys as advised by family and friends.

Figure 7.6 Other treatment availed by kidney recipients (N=13) (Multiple Answers)

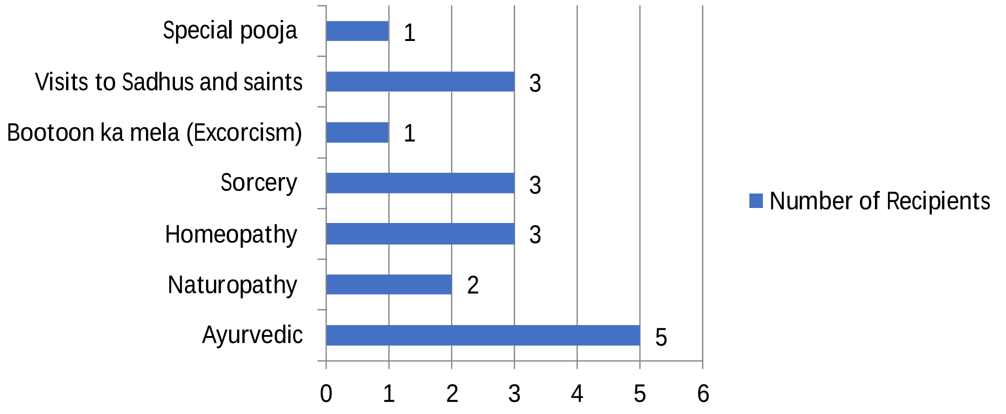


Table 7.6 reveals that many patients had availed other treatments also. Five (5) recipients availed Ayurvedic medicine. Three (3) recipients took homoeopathy treatment. Three (3) resorted to treatment by sorcery and the same number paid visits to sadhus and saints.

They all wanted to have control over failed kidneys, but eventually, all of them resorted to dialysis treatment only. Some were transplanted a kidney, and a few others were waiting to get a kidney transplant done.

Mr. Rr reported, *"She was okay. She has a sister elder to her, and she has two kids. She loves them a lot but wants to have her children too. She was not able to conceive for a long time after marriage. Our family is a 4-generation joint family influenced by superstitions. She was told to go to various places so that she gives birth to a child. She was told to take a variety of medicines,* ***jadibuti*** *(herbs),* ***basam*** *(ashes), etc. None of the places was left in India to help her to give birth to a child. Whosoever would tell her to do this; I would immediately rush her to that place and follow the instructions. I have toured the whole country, from Ajmer to Udaipur to Baitul".* As per the recipient Mrs. Rr, *"I was given some instructions to follow. Like, don't touch feet of elders for one year, don't go to the parental house for one year, don't take rice till conception or give up one thing of choice till conception, etc".*

Mr. M reported, *"I had taken Ayurvedic product also in the name of "DE active" (as informed) but it did not affect".*

Mr. Ur reported, *"I took her to Thrissur Naturopathy Centre where they were giving her hot and cold-water therapy. She remained there for 20 days, but when serum creatinine levels increased to a life-threatening level, I brought her back for dialysis".*

Mr. H reported, *"I sought Ayurveda treatment and spent three lakhs also. It did not help for long. Increased blood creatinine levels forced me to return to allopathic medicine".*

Mr. Fr reported, *"He took Ayurveda treatment for one and a half years to control the disease. It cost him 2.5 lakh rupees. Ayurveda assured him of reversing the disease. For some time, he felt he had some effect, but later his creatinine levels increased horribly, and he gave up".*

Mr. Rr reported, *"I had been to Betul situated at about 300 km from Bhopal as per the instructions of great grandmother. A fair for pacifying ghosts is held there annually. It is an annual fair organized every year for exorcising of ghosts.*

Thousands of people from Andhra Pradesh, Madhya Pradesh, Maharashtra, and Rajasthan visit this place for exorcising of ghosts. It is a month-long ***'Bhoot Pret Ka Mela'*** *(meaning fair of ghosts) that is held in a temple on the first day of* **"Paush Poornima”** (one of significant day for Hindus that falls on the 'Purnima' i.e., full moon day) *and continues till "Basant Panchami". As per the priests, exorcism there is a centuries-old practice. People who are under the influence of ghosts and evil spirits are treated there during this month. I also went there with her to help her produce a child, but all in vain. She instead lost both her kidneys".*

Patients and relatives initially coped with the medical diagnosis by denying the seriousness of the disease and attempted to reverse the same by resorting to different modes of treatment. They used unknown special herbs and resorted to Ayurveda, Homeopathy, Naturopathy treatment, etc. They did so as was suggested by relatives and acquaintances to reverse the disease that was not assured by allopathic medical practitioners who diagnosed them with ESRD. All such attempts to find solutions through alternative medicines ended in vain and these recipients returned to allopathic treatment with complete submission. Religious remedial measures like performing special prayers and visit saints were also done to get rid of the disease. But all such attempts proved futile draining their pockets only. All these recipients were made to invest in such alternative treatment heavily; in some cases, the treatment cost came to lakhs of rupees. An adage is iron cuts iron, sorcery eliminates sorcery could be a new adage for a few such recipients. Believing sorcery, the cause of disease, some of these recipients tried to eradicate the ill effects of the same through return sorcery and resorting to sorcery performances. The ghosts, in many cases, are thought to be spelling evil and causing disease.

Interestingly, the same ghosts were also believed to be treating disease as well in a "fair of ghosts" called "Bhootpret ka Mela" (meaning fair of zombies). One recipient had, in fact, developed kidney failure as a result of seeking all other available treatment for bearing a child. Unfortunately, all such treatment ended in the collapse of both her kidneys without helping her to carry a child.

Dialysis A Major Concern of Kidney Failure Patients and Families

This part of the Chapter gives a brief introduction to various types of dialysis, meaning of dialysis to recipient's, experiences with different kinds of dialysis, physical sufferings, financial sufferings and sufferings associated with lack of adequate infrastructure and human resources in dialysis units.

A Brief Introduction to Types of Dialysis

Dialysis is most often the first stage of treatment recommended for patients with end stage kidney failure. It is a lengthy procedure that cleans the blood of waste products and removes extra water from the body through a process of filtration, which otherwise is done by healthy kidneys. Two forms of dialysis can eliminate wastes from patients with kidney failure, but unfortunately, there are a lot of sufferings associated with both. There are two types of dialysis like Peritoneal Dialysis (PD)[1] and Haemodialysis[2].Peritoneal Dialysis is again of two types

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[1] **Peritoneal Dialysis (PD)** is a procedure of removing extra water and waste products of the body in patients with kidney failure. The whole process of removal of water and wastes takes place within the abdominal cavity of the body. However, it requires a surgical procedure of 15-30 minutes duration to stitch a small, soft plastic tube into the abdomen. The tube remains there for repeating this procedure and is closed with a sterile pad after every process. The dialyzing fluid is entered into the abdominal cavity and is made to stay there for some time. The blood capillaries of the abdomen allow water and waste products of the body circulating in the blood to pass into the dialysis fluid. The dialyzing fluid with the body impurities is then drained out of the body again through the inserted tube. This procedure of dialysis can be done at home after training the patient and the family members to do so. This method is reasonably mild and an effective method of dialysis. The catheter remains in place until the patient shifts to haemodialysis (Bloembergen et al. 1995).

[2] **Haemodialysis (HD)** is a process of eliminating waste products of the body using a filter outside the body. A few ounces of blood are made to flow uninterruptedly and pass through the filter. The filter filters the impurities and sends back the blood to the body. Since fistula takes time for preparation as well as maturation, most of the patients start on haemodialysis via a catheter introduced into neck, legs or arms. The catheter remains there until the fistula is created and matures. Each haemodialysis session consumes 3-4 hours every time. The procedure is repeated after 2-3 days. During each session, the blood gets filtered several times. It is an

Continuous Ambulatory Peritoneal Dialysis (CAPD): this can be done manually four times a day.

Automated Peritoneal Dialysis (APD). It is done by a machine overnight at home. The patient can perform everyday routines and get attached to this automated machine at night.

Creating Fistula, a necessity for haemodialysis: - It is crucial to create Fistula as it allows a smooth flow of blood to and from the body, which is not possible otherwise. Fistula is created through a minor surgical procedure. An artery is joined with an adjacent vein under the skin; the high pressure of the artery gradually expands the size of the vein. After a few weeks/months, it grows enough to become an ideal place to insert the needles. It is rare for people to receive a transplant before they go for dialysis.

Meaning of Dialysis to Recipients

For some patients, dialysis day was a much-awaited productive day that brought them back to their lives while for a few others, it was a day of problems.

Mr. H reported, *"I am retired now and well-adjusted with this dialysis routine. I have been on haemodialysis for three years now. I am perfectly okay with this. I follow a strict diet schedule taking Dalia in the morning and evening, two cups of tea and a half litre of water only. I do not take fruit, take less sugar and less salt. I am waiting for Cadaver Donor".*

Mr. C reported, *"It is a nightmare. I don't want this day to come. The day starts with an unpleasant feeling of the outcome of dialysis.".*

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effective method in comparison to Peritoneal Dialysis and most people adjust with it within few weeks. For long-term patients, it is advantageous as it offers a longer survival rate (Bloembergen et al. 1995).

Mr. Jr reported, *"She gets some problem or the other during dialysis. After dialysis, she gets restless for the whole night, but the next morning, she becomes okay".*

Mrs. Rr reported, "*I used to have weakness, chills, fever, backache, palpitations and feet pain whenever I was getting dialysis done. It was a nightmare to get dialysis done. I am happy now after the transplant. I said goodbye to dialysis".*

Many had counted the number of dialyzes done via the catheter and via fistula also:-

Mr. Rr reported, "She had got a total 85 long and problematic dialysis sessions, 72 via a catheter and remaining via fistula, but now we are relieved of her sufferings after transplant".

The researcher found a varied perspective of recipients regarding dialysis. For some well-adjusted patients, dialysis was a lifesaving procedure that restored them their lives, that helped them get back to life routines, refreshing or rejuvenating. Some patients were on dialysis for a very long period of about three years but well-adjusted with the same. But for others, it was a journey to hell, a procedure that gives goose bumps, the gateway of suffering, etc. as the patient suffered from one problem or the other during the process. Many patients encountered many difficulties during dialysis like breathlessness, palpitations, anxiety, loss of consciousness, etc. A few patients who were getting haemodialysis complained of insomnia and restlessness the whole night following dialysis.

Experiences with Different Types of Dialysis Varied from Person to Person

Only two recipients among the study sample had experienced Continuous Ambulatory Peritoneal Dialysis (CAPD). While one had good experiences with peritoneal dialysis for a long duration of one year, another had an awful experience with the same. However, both later shifted to haemodialysis. But haemodialysis was problematic for one recipient and smooth sailing for the other. The latter recipient, however, faced the problem with fistula that failed in the first attempt and the patient was on haemodialysis via the neckline.

Mr. Nr reported, *"He was put on peritoneal dialysis for 36-48 hours on 14th Jan 2017. Later he was put on haemodialysis. Peritoneal dialysis was problematic for him, whereas haemodialysis is not. He suffered from palpitations and restlessness during the peritoneal dialysis".*

Mr.Zl, the father of multiple organ recipient said, *"He was put on peritoneal dialysis for a year and then he was put on haemodialysis one month before surgery. He was okay with peritoneal dialysis but not with haemodialysis. My wife got training to do peritoneal dialysis every day for 24 hours. From 10 pm in the night till 8.00 am and again connecting the tube for dialysis from 2 pm to 8 pm".*

Almost all the patients and relatives were disgusted with unavoidable long hours of the procedure. And some complained of pain at times at the site of dialysis too. However, experiences varied from person to person.

There were both good and bad experiences of the same procedure with different patients concerning the development of fistulas, haemodialysis, peritoneal dialysis, adjustments to diet and water, etc. Experiences varied from person to person. But almost all the patients and relatives were disgusted with unavoidable long hours of the procedure. The requirement to shift near the dialysis facility was further complicating their problems.

Physical Sufferings Associated with Dialysis

Dialysis as such was not an easy procedure. It was associated with several sufferings as narrated by patients and their relatives. Most of the patients revealed painful experiences while shifting the site of the catheter for haemodialysis and creation of a fistula.

Dialysis patients need to have vascular access for uninterrupted blood flow for dialysis by introducing catheter in the body. The shifting of catheter site becomes a necessity if there is clot formation in the catheter, infection or reduced blood flow.

For most of the patients, the dialysis started by inserting a catheter mostly in the neck. But some patients' first dialysis line started in chest, arm or legs as well. Most patients faced problems whenever the site of the catheter was shifted by doctors as required by their conditions. All such patients had bruises at many places on the body. The complications associated with the site of catheter varied from person to person.

The experiences related to catheter varied: -

Mrs. Or reported, *"He has been getting one problem or the other with dialysis. Dialysis site shifted from one leg to another and from one arm to another arm".*

Mr. Wr reported, *"His dialysis started with neckline and remained restricted to it only till transplant".*

Mr. Nr reported, *"He has been on dialysis treatment via neckline for one month. His fistula in the arm was created, and now after two months of fistula operation, they say the fistula has not matured".*

For some, creating fistula was a problem, and for others, it was a straightforward procedure. In two cases, fistula preparation failed in the first attempt. While in one case fistula was possible the second time, but in another case, the fistula was a failure in the first attempt at the time of interview.

Mr. E reported, *"Usually patients go for fistula dialysis after one month of fistula creation. Fortunately, in my case, it started within 18 days as fistula had matured within a brief time".*

As reported by a doctor Dr. Hrml, *"The vascular access becomes difficult in some cases. A woman was about to die when her husband came forward to donate his kidney. Her fistula did not work for more than 14 days".* The doctor showed the same female recipient to the researcher. Her body was full of pinprick scars showing the unlimited number of attempts made on her body for creating access for haemodialysis'. As per doctor Dr.Hrml, *"Her kidney transplant was done in an emergency as vascular access to her body had become impossible".*

Dialysis was a significant concern for kidney failure patients and their families. Dialysis, although a treatment option in place of a kidney transplant, poses a lot of problems not only for the waiting recipients but their families as well. Physical sufferings start with the insertion of a catheter, repeated shifting of the site of the catheter as and when required, the creation of fistula that matures in some cases and does not in a few others. Besides, repeated visits to dialysis centres after every 2-3 days without any gap add to the sufferings of patients and relatives. However, these sufferings varied from person to person, for some, creating fistula was a problem, and for some, it was a simple procedure. There was a case whose vascular access had become unmanageable and needed a kidney transplant in an emergency.

Financial Sufferings Associated with Dialysis

Mr H reported*, "I am on dialysis, and monthly cost comes to 30000 as I pay 2200 rupees and change filter every time to avoid infection. I get it done three times a week".*

A mother requested for admitting the patient to the hospital permanently as she could not afford his dialysis outside. According to her, his friends had donated money for his dialysis sessions.

An NGO named SAPNA was helping patients suffering from kidney failure and knew about varying cost of the dialysis. They had provided help to one of the interviewed recipients and had supported him for dialysis for three years from 2013. On talking to Mr. M of the NGO, it was revealed that they had a good understanding with one of the hospitals in Janakpuri. They get dialysis of their patients for 1300-1400 rupees only there. They would prefer Yusuf Sarai for its proximity of Dharamshala, the stay house for the BPL patients near SJH. But for the exuberant cost of dialysis amounting to 2200-2400 rupees at Yusuf Sarai, they avail dialysis services at Janakpuri.

From the narratives of all the recipients, the cost of one session of dialysis varied from 1100 to 3200 rupees outside in private facilities. The poverty-ridden sick patients were finding great difficulties in manage finances for dialysis sessions. One NGO named SAPNA was helping BPL patients in getting free dialysis. The address of one more organization giving free dialysis was shared with patients who could not afford dialysis cost. But even that place was overburdened as reported. Not all benefitted with these organizations.

Sufferings Associated with Inadequate Infrastructure and Human Resources in Dialysis Units

Mrs. Yr reported, *"I want my son to be admitted here till kidney transplant. Why do they discharge him? Hospital discharge him, he gets sick, and again admits him. I cannot afford his dialysis outside. I have borrowed enough money for his dialysis sessions".*

Two patients who were on dialysis felt their associated health problems a blessing in disguise for getting admitted to the hospital.

Mr. M reported, *"I was admitted in the hospital for one year as I was suffering from low platelet count too. That was a blessing in disguise for me. It is because my dialysis was done in this hospital only that could have cost me a lot outside. I had 102 dialysis sessions before transplant surgery. Total of 100 dialyzes done free of cost in this hospital, and only two were done outside with 2400 rupees per dialysis".*

Sufferings of poor patients resulting from lack of adequate infrastructure and workforce in dialysis units in Government hospital makes their condition miserable and pathetic at times. The interviews and observations of the researcher revealed that the dialysis department in the hospital is understaffed. Also, the dialysis unit is not functioning round the clock because of the shortage of staff and infrastructure. There are only ten dialysis machines for both indoor and outdoor patients, that work from 10.00 am to 4.00 pm every day, excluding holidays. Hospital prioritizes indoor patients. The out-patients on the waiting list for dialysis in this hospital get their turn for dialysis usually after 15 days. Till that time, they are required to make their own arrangements outside the hospital. Every patient requires dialysis twice or thrice weekly. In a few cases, relatives wait for the patient to become seriously ill as Government hospital admits such patients on priority. In this way, they get free dialysis, which is not the case when they are discharged from the hospital. Lack of infrastructure and human resources forces them to avail private health care that drains them financially. Under such circumstances, an additional medical problem for a few long-term Government hospitalized patients was considered a blessing in disguise. It was because they were provided with free dialysis as inpatients not possible otherwise.

Problems with Availability and Accessibility of BSD Donors

This part of the Chapter reveals some problems with BSD donor kidneys. There is less availability of organs from BSD donors that is due to negative influence by media. It also shows that recipients with living kidney donors don't get registered for cadaver donors and recipients are unable to shift in time for BSD donor kidney transplants.

Less Availability of BSD Donors

The BSD declaration of potential donors is not a very common feature and are sparingly done in hospitals. There is a huge demand for BSD donor organs in comparison to their availability. As per two transplant coordinators posted in SJH through NOTTO, they had experienced reluctance of professionals posted in ICU for declaration of Brain Stem Deaths.

As per the transplant coordinator Ms. Votc, who was making files of the patients, *"The doctors are not interested in declaring BSD as they achieve nothing by doing so. The media also gives social recognition to transplant surgeons only. It is not taken well by those who make such things happen. The nephrologists also feel alienated in* *such endeavours. In one case, I could feel the hands of the doctor trembling while declaring such death".*

Media Playing A Negative Role

As per the transplant coordinator Mr. Motc, who was making files of the patients, *"There was a brain death certification done in March in this hospital. Media played a very negative role by saying that the person was not dead, and the organs were retrieved".*

Recipients with Living Kidney Donors Not Registered for Cadaver Donors

Recipients are denied organs from Brain Stem Dead donors if they have near relatives willing to give organ in the family. The ethical issue here is why professionals should refuse such registration?

Recipients Not Able to Shift in Time for BSD Donor Kidney Transplant

For families waiting for a BSD kidney organ, long distances and moving within a short duration is a problem for many. It was difficult for recipients within the neighbouring States to come for a BSD donor kidney transplant.

As reported by Organ Transplant Coordinator Mr. Motc of the hospital, *"Some recipients could not reach within a short time for Brain Stem Dead donor kidney transplant. They continue to suffer in their place as happened with three such recipients who failed to reach the hospital in time. As a result, a young girl registered for cadaver kidney transplantation jumped the waiting list and received a kidney transplant. The girl was getting treatment in this hospital. People do register for cadaver donors but reaching in time is not possible for every registered case".*

The narratives of registered waiting recipients reveal their plight of sufferings.

Mr. GGR reported, *"We are supposed to report to the hospital within one hour of information. I was called for a cadaver kidney transplant on 24.1.2017 but was out of the station. I will never get a kidney staying away from Delhi although I registered for cadaver transplant".*

Mr. Jr reported, *" I was not a suitable donor for my wife. I registered her in Delhi hospital for a cadaver donor. I was told to reach within one hour for a cadaver kidney. Travelling from Bihar to Delhi takes a long time. How could I reach there within one hour? My wife is suffering. I am paying through my nose for her dialysis. Could you please tell me when they will call me again? When will the kidneys come?"* This man was asking about the availability of a BSD donor kidney.

Recipient-specific concerns regarding kidney transplant emanate from the restricted intake of water (one litre only) and salt. After a successful transplant, these restrictions ease. After a kidney transplant, a person can take 4 litres of water and adequate salt. But when he is on dialysis only one litre of water with salt restriction is to be strictly followed. The time consuming, painful, inaccessible and unaffordable long duration of dialysis procedure in dialysis health facility drains recipients and their families in all possible ways. The researcher found several problems with the availability and accessibility of BSD donor kidneys. The professionals' reluctance to declare BSD and negative role of media serve a barrier to organ availability. The recipients having living kidney donors not registered for a cadaver donor kidney and their inability to shift in time for BSD donor kidney transplant hinder accessibility for recipients. Recipients registered for cadaver donors were unable to reach in time for BSD donor kidney transplants in most of the cases.

Infrastructure and Human Resource Concerns from The Perspective of Recipients

This part of the Chapter reveals some infrastructure and human resources concerns raised by recipients and coordinating coordinators. It shows the cost variation and unwanted experiences of recipients. Patients felt SJH is a boon to poor people and empathize with hospital staff. Pro-poor initiatives by hospital staff was a boon to patients coming from far-flung areas. However, the hearsay allegations by recipients were far from the truth. And misinterpretation of terms and treatment among recipients raises suspicion on hospital staff. Professionals playing safe were adversely affecting the financial health of the recipients

Cost Variations and Unwanted Experiences

The research revealed specific issues regarding cost variations and affordability of treatment. There was ample variation in costs for transplant surgeries, surgical procedures, dialysis and various tests in the market as per the analysis of data done by the researcher.

The cost of fistula that is an operation done to create a vascular supply of blood for long term dialysis ranged from Rs. 5200 to 15000 as per the information shared by recipients. Hence most of the people preferred to get the fistula made in Government hospital where it costs nothing.

The cost of one dialysis session ranged from Rs.1100 to 3200 in different health facilities as per the statements of relatives and patients. In one case, it was Rs.4000/-.

PRA is a test called Panel Reactive Antibodies. There have been instances when patients getting the tests done outside had to pay Rs.21000 -25000/- and the same test costs Rs. 6000 in AIIMS.

The patients had been to different parts of the country before their complete submission to SJH, where they were told to arrange Rs. 20000/- only for the surgery, especially for specific medical tests that are done outside the hospital. The cost of kidney transplant surgery ranged from Rs. 4 to 16 lakhs in various other private health facilities.

The costs of various medical procedures, tests and even dialysis varied from one health facility to another. Most of the patients had been to private health facilities where prices were much higher for dialysis. But with time and interaction with fellow patients, they resorted to those health facilities where costs were less. Many recipients revealed extreme cost variations, unaffordable treatment and unwanted experiences in private health facilities.

In nutshell, the recipients had been to different parts of the country before their complete submission to SJH. The cost of fistula ranged from Rs. 5200 to Rs 15000, the cost of one dialysis session ranged from Rs. 1100 to Rs. 3200/-, cost of PRA test ranged from Rs 6000 to Rs.21000 -25000/-, the cost of kidney transplant surgery ranged from Rs. 4 lakhs to Rs. 16 lakhs in various private health facilities. In SJH, fortunately, the price of a kidney transplant was Rs. 20,000/- only and all such recipients were told in advance to arrange Rs. 20000/- only.

Patients Feel SJH is a Boon to Poor People and Empathize with Hospital Staff

Many patients felt that this hospital is a blessing for the poor and believed that they would have died if this hospital (SJH)was not there. They also thought that the hospital is overburdened and understaffed that results in staff negligence at times. Some relatives had suffered due to the negligence of staff in the hospital. But instead of blaming them, they attributed this negligence to the understaffed and overburdened health facility.

Mrs. Qr reported, *"This hospital is overburdened but blessings for poor people like me. I have been here attending my husband for one year. I have seen several deaths too.* ***"Yahan Kutey Biliyoon Kee Tarah Log Mar Jatey Hai"*** *(Meaning people die here like dogs and cats). The admissions made in this hospital Wards are much more than the capacity. Several needy patients are made to lie on floors. The hospital staff members are overburdened".*

Mrs. Ur reported, *"My daughter had swelling in feet. The conversation of professionals in the Ward hinted at some negligence on the part of a sister. My daughter was probably given a double dose of a costly injection inadvertently. I* *don't blame them. There are a lot of patients in the Ward beyond capacity. Attending to all patients and remembering every patient is a problem for the staff.* ***"Iss Hospital Mai Humesha Mela Laga Hota Hai****"(Meaning the patients throng the hospital like a fair in the Ward). I could afford my daughter's kidney transplant because of this hospital only ".*

Mr. Nr reported, *"We were treating him in one of the reputed private hospitals of Jaipur. Transplant cost was 4, 20,000 rupees there. But two of my friends said not to get his kidney transplant done there and suggested Safdarjung Hospital (SJH) instead, for its well-experienced doctors".*

Pro-Poor Initiatives by Hospital Staff A Boon to Patients Coming from Far-Flung Areas

Facilitating stay in Dharamshala for relatives, helping poor patients in getting low-income certificates prepared in the absence of BPL cards, filling formats and preparing documents for recipients to avoid mistakes by notary personnel were some of the initiatives taken by this hospital that were entirely pro-poor initiatives.

Distribution of costly immune suppressant drugs was one of the significant pro-poor initiatives taken by the hospital that was appreciated by every recipient. Two important costly medicines called immunosuppressant were given free of cost in the hospital Ward itself. It was done to avoid inconvenience to the recipients who otherwise had to stand in long queues in the pharmacy counter.

Mr. M reported, *"We are happy that we get costly medicines in the Ward itself. We are supposed to get the rest of the medicines in the pharmacy counter. We prefer to purchase those medicines from outside to avoid long queues. The amount for medicines that are purchased outside comes to 1000-2000 rupees per month only. We don't mind that. You see the big lines in the OPD medicine counter. We may not get the medicines today even if we wait till evening. At times this has happened. The next day we again come to get medicines".*

Hearsay Allegation by Recipients Far from The Truth

The people often allege Govt. hospitals for malpractices which are not often true. One of the hearsay allegations by a recipient was "*I heard fistula prepared in this hospital doesn't work".*

In some cases, unfortunately, the compromised vascular system of people makes them unable to have a fistula. Not all cases are the same. In some cases when it is felt that the vascular system is greatly compromised, a fistula is not even attempted. Some of the drawbacks of fistula are that it takes several months to mature and sometimes it never matures at all. In fact, the researcher had met several patients whose fistula was prepared in SJH without any cost. They had not faced any problem.

Misinterpretation of Terms and Treatment Raises Suspicion on Hospital Staff

There was a great problem pertaining to the understanding of brain death, cadaver donor and organ retrieval from accidental cases. Organ retrieval from accidental cases was viewed differently from brain death resulting in a false interpretation of facts and allegation on the hospital for selling organs of post mortem accidental cases. The same is discussed in details in the fourth part of Chapter 10 that deals with issues common to kidney, liver and heart recipients.

Besides, the patients are desperate to get transplant done and go back to home, but medically both the donor and recipient should be in good health before transplant operation is done. Any deviation from health either of the donor or the recipient is a medical requirement for postponing transplant, which is not understood by relatives and patients.

Mrs. Jr reported, ***"Agar Aapko Ek Cheenk Be Aayegey Yeah Log Operation Postpone Kartey Hai" (***Meaning, even if you sneeze once only, the operation is postponed here in this hospital).

Professionals Play Safe That Adversely Affects the Financial Health of The Patients

A few instances were seen when it was felt that professionals were playing safe as they did not want to be trapped in legal and bureaucratic hurdles that ensured their safety but jeopardizes with the financial health of the patients.

As per transplant coordinators Ms. Votc, *"If we tell people to get PRA done from path laboratory, they feel we get a commission. But the PRA done by path lab or AIIMS Lab is the one that suites our population and is required by doctors in this hospital. There have been instances when patients getting the tests done outside had to pay as much as Rs. 21000 -25000. The path lab tests cost little less than what it costs them in AIIMS. We restrain ourselves from guiding them lest we may be suspected of getting a commission".*

As per transplant coordinators Mr. Motc, *"Professionals always try to play safe. They are not bothered about the socio-economic condition of the patients. See this patient. Small mistakes in the papers are not accepted. Medical papers are made and remade that take time, efforts and increase sufferings of patients and relatives".*

As per one of the transplant coordinators Ms. Votc, *"The hospital system is obsessed with the completion of legal formalities. They want to play safe only to safeguard their fame and reputation. The media makes hue and cry of small incidents in Govt. Hospitals that drives them to play safe".*

Recipients felt SJH overburdened and understaffed but a boon and blessing for poor. They empathized with the hospital staff also. Empathy and understanding were found to be more with long term patients who had experienced the workload of the understaffed hospital and even forgave the inadvertent mistakes done on their own patients.

Pro-poor initiatives by hospital staff for people coming from far-flung areas like facilitating stay in Dharamshala for relatives, helping poor patients in getting low-income certificates prepared, helping poor people in getting notary affidavit for free of cost treatment in the absence of BPL cards, filling formats and preparing documents for recipients so that they could get the same made by the court without any mistakes were some of the initiatives taken by this hospital that were entirely pro-poor initiatives. Distribution of costly immunosuppressant's in Ward itself to prevent patients from standing in the queue at medicine counters was one of the significant pro-poor initiatives taken by the hospital and was appreciated by every recipient.

The researcher also found some patients and relatives believe in hearsay allegations that allege Govt. hospitals for malpractices which are not often true.

Also, in certain cases, the recipients felt suspicious of hospital staff as a result of their misunderstandings and misinterpretation of terms and treatment.

Challenge to Lead A Productive Life: A Predominant Issue Post- Transplant

Emotional health, follow-up care, maintenance of clean environment at home and providing only fresh foods to the recipients were some challenges faced by the recipient families. The post-transplant issues like a challenge to lead productive life was a significant worrisome concern for many recipients. A person always wants to lead a productive life and contribute to the family income. Pre-transplant and post-transplant life were problematic for those who were looking for a suitable job or had no job security. Most of the recipients faced occupational problems after kidney disease or a kidney transplant.

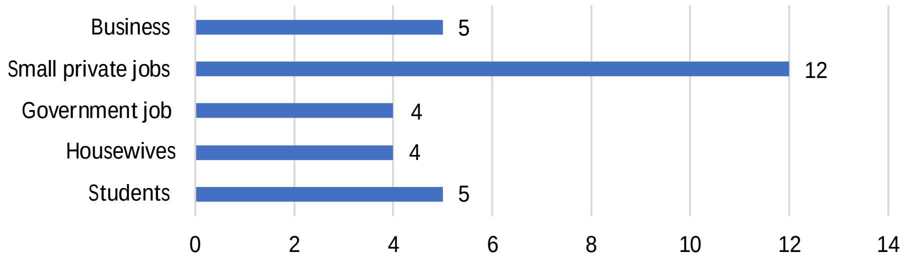

Figure 7.7 Distribution of kidney recipients by occupation (N=30)

Figure 7.1 reveals that most of the recipients, i.e., 12, were in small private jobs. They were performing small tasks like the job of labourer, driver, making bags, carpenter, airport trolley mover, small shop owners, off and on occupation, bakery supervisor, beautician, a rickshaw puller, etc. There were five students and four housewives only. Only four recipients were in Government jobs, and five were having their own business.

Talking to the recipients who had either got kidney transplant done or were waiting for a transplant, four categories of recipients could be identified.

Recipients Not Earning

The nine recipients like students and housewives were not contributing to the family income. Hence, they had no employment problems. However, the two young people had stopped education in between after getting diagnosed with both kidney failures.

Recipients with Job / Financial Security

There were only five people only who had no occupational problems. They had a job or financial security that was a boon to these recipients. One was a retired Govt. employee and three were serving in Government. One person had secured himself by getting rent from rental property and had an agency as well. He had made himself secure financially, even when he was not active as there was a regular source of income through rentals and other sources.

Mr. E reported, *"I am working in CRPF. I am in a secure job, and my work will be adjusted and substituted with a less demanding job. I will get a suitable posting now, like posting in the canteen or gas agency".*

Recipients Unable to Enter into A Suitable Job

A person feels himself in dual misery when he struggles for life and a proper career simultaneously.

Mrs. Mitta reported, *"His medical condition had unfortunately rendered him medically unfit for getting a Government job which haunted him. He had to be happy with a private job only".*

Recipients Lacking Job Security

Most of these recipients had problems with taking up occupation after disease and transplant that was an excruciating struggle for them. The recipients who could not continue being productive were either having a private job or self –employed without any job security. Long hours of dialysis harmed their occupation. As recipients are advised not to lift weight after operation, this causes technical concerns with recipients whose jobs require lifting of weight like laborer, driver or shopkeeper.

Mr. Br reported, *"He was managing a bakery shop which was owned by someone, but he got devastated with the disease. He had 30 -35 laborer under him. Now he is without any occupation".*

Mrs. Qr reported, *"My husband got a new life, but there is neither work nor money. He has lost his job, cannot lift weights which, as a driver, he is required to do for his employer. I have taken a loan of Rs. 40000 which I am to return. We spent that amount for treatment at a private hospital, and now I feel like strangulating myself".*

Mr. M reported, *"I have rented a part my small house in Delhi. I am not earning, and I am hardly able to manage life with meagre resources and feel like committing suicide. I am on psychiatric drugs. I have two children, 13 and 11-year-old. How will I continue my life?"*

As reported by Mr. C, *"I am a Driver covered under ESI. I am constantly trying to keep my bosses happy, but I feel tired in between dialysis sessions. I hope to get a kidney from a dead donor. At many instances, I plead with the authority not to remove me from the job. I am earning about 15000 rupees per month. I want to make my wife self-reliant, who has been trained to stitch clothes; if she too earns it will be an extra source of income much needed".*

Recipients are also required to wear masks as they are on immunosuppressant drugs. They have a constant threat to infections. To prevent infections, they are required to wear masks which are also considered a deterrent to the occupation.

Mr. M reported, *"I don't work in a shop now. How can I? I must put a mask for prevention of infection. People will not visit my shop thinking that I have Tuberculosis (TB). It is an embarrassment".*

Almost all the recipients faced post-transplant challenges like regular follow up care, taking immunosuppressant medicines, strict maintenance of the clean environment, and consuming fresh foods only. But the major problem was leading a productive life. A person always wants to lead a productive life and contribute to family income and take care of his self. The morbid condition before transplant and post-transplant life was problematic, especially with those recipients who either were looking for a suitable job or had no job security. The researcher could categorize these recipients into four categories. The first category was of non-earning recipients; the second category was of job secured /financially secured recipients. The third category was declared medically unfit and unable to enter a suitable job. For the fourth, the job had no security, and for them, it was a very painful struggle to continue with their lives. For the third and fourth category of recipients, it was dual misery to struggle for survival on the one hand and strive for a suitable job on the other side. Some of them were in a depression and felt like committing suicide, and some were putting extra efforts to keep their employers happy to continue in the job. Post-transplant medical restrictions like wearing a mask or not lifting weights were reasons for loss of employment by some of these recipients.

Summary: - The findings reveal that the probable medical cause behind End Stage Renal Disease (ESRD) for 30 recipients were hypertension, diabetes, genetic, irrational use of medicines and congenital, etc. but the perceived causes were altogether different in some cases. These ranged from hurling of abuses to belief about the curse due to occult forces invoked against the person (*jadoo tona* etc) by jealous relatives. Some recipients attempted to reverse the disease by resorting to reverse sorcery, use of mysterious herbs, Ayurveda, Homeopathy, Naturopathy or exorcising evil spirits by visiting certain shrines and some mystic saints. This not only took a heavy toll of their emotions, but it also drained their pockets.

Poor patients found it difficult to arrange finances for dialysis sessions in private hospitals, a situation created by a lack of infrastructure and manpower in Government hospitals. As a result, long term hospitalization for an associated medical condition and waiting for a patient to become serious came as a blessing in disguise for the poverty-ridden people. Such medical condition guaranteed them easy admission for availing free dialysis in Government hospital.

The perspective of recipients regarding dialysis varied. For some well-adjusted patients, dialysis was a lifesaving procedure, refreshing and rejuvenating while for others it was a journey to hell, a gateway of suffering etc. There were mixed experiences for the same procedure with different patients. The time consuming, the inaccessible, unaffordable and prolonged procedure of dialysis in health facilities was draining recipients and their families in all possible ways.

Several problems were reported with the availability and accessibility of BSD donor kidneys. These were: the reluctance of professionals to declare BSD in ICU, negative role played by media by blaming doctors for premature declaration of brain deaths, recipients having living kidney donors not registered for a cadaver donor kidney and recipients not able to shift in time for BSD donor kidney transplant.

There was an enormous cost variation in treatment and procedures related to kidney disease. In SJH, fortunately, the cost of a kidney transplant was Rs. 20,000/- only and all such recipients were told in advance to arrange the same. Recipients realized that despite SJH being overburdened and understaffed, it was a boon and blessing for the poor. They empathized with the hospital staff also. Initiatives like distribution of costly immune suppressant drugs inside the Ward as against the normal practice of long queued medicine counters, helped people, especially those from far-flung areas. However, in some cases, the recipients were suspicious of hospital staff, mainly because of misunderstanding and misinterpretation of terms and treatment. Fear of legal cases, media, and police for lapses made, professionals play safe even though it adversely affected the patients' financial condition and caused them agony.

The post-transplant issues like regular follow up care, taking immunosuppressant medicines, strict maintenance of the clean environment and consuming only fresh foods were some of the challenges faced by almost all the recipients. But the major challenge was their inability to lead a productive life.

CHAPTER 8

Intra and Interfamily Influences of Kidney Transplantation

This Chapter elaborates on intra and interfamily influences of kidney transplantation and reveals sufferings, support, compulsions, conflicts, apprehensions and anticipations of family members. The first part of this Chapter explains the intra and interfamily influences of End-Stage Renal (Kidney) Disease (ESRD) in context of family support and sufferings; unavoidable compulsions of recipient family members and family suffering associated with delays in kidney transplants. The second part of this Chapter reveals domestic compulsions, conflicts, apprehensions and anticipations concerning living kidney donation for transplantation. The third part is an in-depth case study of Ms. Pitta that shows continuous sufferings of a Chronic Kidney Disease patient and her family. She lived on dialysis for six years. Eventually, her life changed for better once she got one kidney of a Brain Stem Dead donor. Post-transplant, her commitment to trace her Brain Stem Dead donor family emerges into an extremely satiating social relationship between the donor and recipient families.

Intra and Interfamily Influences of End Stage Kidney Disease, Kidney Donation and Transplantation

This study explored several intra and interfamily impacts of End Stage Kidney Disease, kidney donation and transplantation. The support and sufferings impacted the financial, social, physical and biological health of the family members in different ways. However, the main aim for them was to prolong the life of the ailing member.

Family Support and Suffering

Interviewing recipients and attendants, morbidity and pain of one person led to the suffering of many others and even the small kids were not spared. The sufferings were of various kinds within families.

Mr. G reported, *"I am away from home living in a rented house with my daughter and son. I want to go back, but because of dialysis I cannot do that".*

Mr. L reported, *"I am living with a village brother. He does not want to keep us, but I have no alternative. I feel humiliated at times, but I tolerate".*

Mr. Nr reported, *"I come from Rewari. I brought my brother -in -law for treatment. I often take short leaves from office".*

The study revealed that not only family but colleagues too, were supporting and suffering. Also, association with the religious groups was helpful for some recipients.

Mr. E reported, *"Working in CRPF is an advantage for me. One CRPF colleague is always attached to me to accompany me for each dialysis session in hospital".*

Mrs. Fr reported, *"I am associated with a Church and acquaintances there have been very helpful financially and emotionally too".*

The expectation of care was not only limited to the sick person but for his dependent family members, his living donor family and their dependent children as well. In most of the cases, 6-10 families got affected by one person's sickness.

Mrs. Kr reported, *"We live at my sister's house in Delhi. My brother in law called him from home, and we are staying with this relative for seven months getting treatment in hospital. Back home, my two children are also separated, one is living with a maternal uncle, and another is living with a paternal uncle. His brother is going to donate a kidney now. His family has to be looked after as well".*

Mrs. Dr reported, *"She is my daughter. She lives with her uncle and aunt here in Delhi. Her husband is not having a regular income but gets employed for some time* *only and then a period of non-employment ensues. He is living with his sister here in Delhi. Our family is an agricultural family. My husband looks after agricultural land in the village, and his brother does a job here and is staying with his family here in rented accommodation. He bears the cost of her treatment usually, and we all stay with them. Their landlord troubles seeing so many relatives".*

Mrs. Or reported, *"Our whole house disintegrated. I am living with him in nearby Dharamshala (Meaning an inn). My daughter, who has some heart problem, is also attending to the patient. Because of one person's sickness, we feel as if all family members are sick".*

The narratives of caretakers and the observation by the researcher revealed the harsh effects of short shifts of persons from their place of residence to the area of treatment, especially within close-knit joint families. Temporary disintegrations of families were also a part of such morbidity. The children of not only the morbid person only but also the attendants were relocated to other relative's families and left at the mercy of others. They unknowingly had extended other families compromising even with their education. Some attendants had lost jobs and some had got postings near to the place of treatment. Some relative attendants had taken leaves from their offices, and some had taken favors from bosses for short leaves to accompany patients for dialysis sessions and investigations.

Caring involved the suffering of attendants too who accompanied the patients. Many attendants could not stop their tears rolling down their cheeks while relating their pains associated with taking care of the patient and their own families. The attendants, along with patient required shifting near to dialysis institution or transplant center in many cases.

Since most of the patients were outsiders, some had taken rented accommodation while others had burdened migrated relatives and village acquaintances in Delhi. These Delhi migrated village acquaintances were made to give shelter to many recipients of their native villages along with their family members. Some recipient families even stayed against the wish of host acquaintances. With no better alternative in hand, they faced embarrassments. At times, they had to compromise with their dignity also.

Attendants compromised with their own lives and responsibilities. They accompanied the recipients for dialysis, got their routine tests before dialysis, stayed with them during four long hours of dialysis and managed any untoward incident then and there.

Unavoidable Compulsions of Family Members of The Recipients

The family members faced certain compulsions as a result of kidney disease and treatment for its recipient. The poor families were compelled to stay away from home on roads, corridors of hospitals and under bridges. A few faced the arduous task of managing two surgeries in one day simultaneously. The inability to celebrate festivals and social gatherings was very common suffering reported by many attendants. Most of the families faced harsh economic sufferings, a few had to tolerate cheating and forgery by host families and a few had to go through the repercussions of living in the nuclear family.

Stay Away from Home on Roads, Corridors of Hospitals and Under Bridges

The 28 patients at SJH had come from different parts of the country along with their relatives as shown below:

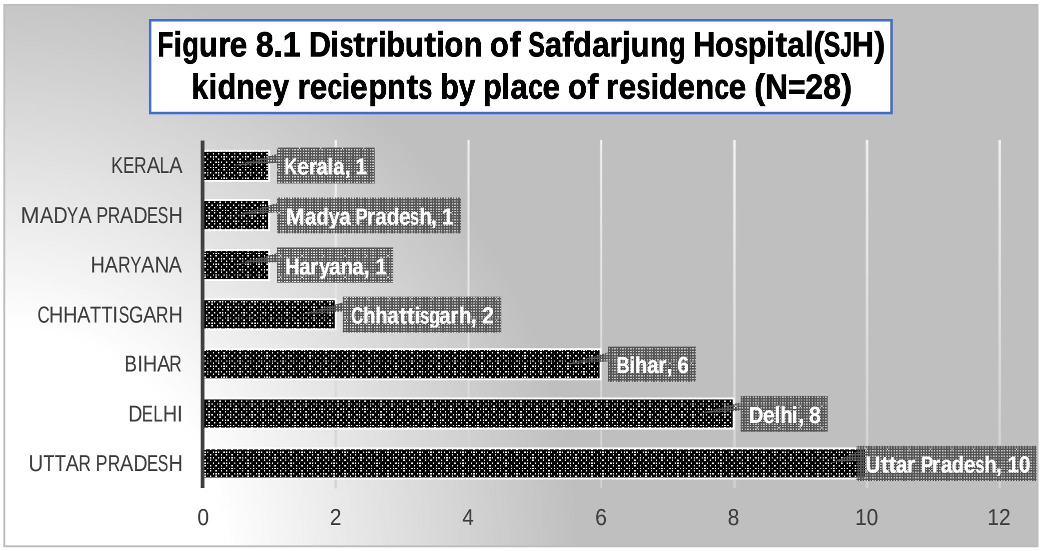

Figure 8.1 Distribution of Safdarjung Hospital(SJH) kidney reciepnts by place of residence (N=28)

Figure 8.1 reveals that most of the recipients numbering ten (10) were from Uttar Pradesh and six (6) from Bihar.

Most of them were either having Below Poverty Line (BPL) cards or had submitted low-income certificates to the hospital authorities.

During my interview, one kidney donor's father Mr. Lr came to me; he had developed post kidney donation-related complications. He had swelling near the operation site and was not able to sit. He and his recipient son depicted their story of coming from a far-off State for check-ups.

Mr. Lr reported, *"We were staying overnight in the corridors of hospital after coming from other State. I don't have any place to live and did not get any place in "Dharamshala". Money is a significant constraint for us. I know, it is not suitable for the health of my son and is anti-therapeutic to my recipient son. But there was no other alternative."*

Another relative narrated his saga of sufferings: -

Mr. ORR reported, "*I want to get a transplant of my son done as soon as possible. I have been living on roads, sometimes under bridges while coming for his check-ups. I am a rickshaw puller. I am living away from home, spending borrowed money, and I* *have only one son. I want to keep him alive. SAPNA NGO is helping me, in dialysis of my son. They arrange one dialysis, free of cost for my son alternately and expect me to spend my money for the next dialysis session. I cannot afford to spend money. I have already borrowed one lakh from different relatives and friends. SAPNA NGO has also helped me in getting fistula prepared at a much lesser cost in one of the hospitals".*

Staying away from home on roads, corridors of hospitals and under bridges to be near to dialysis centre or transplant hospital was an unavoidable compulsion for many waiting recipients and their families. It was because they did not have such facilities at their place of residence or even if available was out of reach for them. Dialysis facilities and transplant centres are not everywhere. And patients waiting for a BSD donor kidney transplant continued to suffer. These recipients were finding it difficult to stay near to a transplant hospital.

Simultaneous Management of Two Surgeries

Operation day involving living donor kidney transplant involves two surgeries simultaneously. The management of two surgeries in one day within a single family was a hectic task for other family members in most of the cases.

Mrs. Qr reported, *"The day of surgery was a day I never want to think about. Two surgeries were simultaneously going on. Moving from one operation theatre to another to look after mother-in-law and my husband simultaneously drained me physically and financially. It involved continuous struggle. I was on toes taking care of one thing or the other".*

Managing two surgeries of two family members in one day was a hectic task for all recipient families who had to go for living kidney donation and transplant from near relatives.

Inability to Celebrate Festivals and Family Events

The inability to celebrate festivals and social gatherings was very common suffering reported by many attendants.

Mrs. Qr reported*, "I spent all my festivals Diwali, Rakhee, Holi, Navmi, Navratri, with my husband in the hospital. On those special occasions, I would always cry".*

Mr. G reported, *"While everyone was celebrating New Year Eve, I was in the hospital for dialysis".*

Mr. Pr reported, *"I could not participate in the marriage of my nephew. I was in the hospital taking care of her. This disease is a curse for all kinds of family gatherings".*

Mr. Rr reported, "We had to manage two surgeries and marriage of our sister also on the same day. It was pathetic".

Most of the attendants and family members were perturbed and expressed a feeling of sadness for their inability to celebrate festivals and attend family gatherings. Although the researcher never asked this question, yet most of the attendants and patients narrated their failures to celebrate festivals and social gatherings on their own with tears rolling down their eyes.

Face Economic Sufferings

I sold my land; I sold one part of my house; I have taken a loan from friends and acquaintances were conventional narratives of most of the families.

Mrs. Qr reported, *"I was a fool. I came to this Government hospital only after exhausting my saved money, taking loans from friends and relatives. I am under debt now. I have to repay a loan of 40,000 rupees".*

Mr. M reported, *"I too was a fool. I spent 2.5 lakhs for his treatment outside in a private hospital, and now I am penniless. But this hospital is like heaven to me".*

Mrs. Yr reported, *"I have a dispute over property with my sister. We don't have our own house. I have wasted money in court cases; I don't have money to get his dialysis done frequently. His friends donate money for his dialysis. I do not have money to continue his dialysis".*

Mr. Sr reported, *"All our savings have been exhausted by private hospitals. When we had money, we took treatment from a private hospital. The private hospital was charging hefty money for tests. Also, the seriousness of his condition was kept hidden. We came to this hospital only after we were rendered penniless by the private hospital".*

Mr. Wr reported, *"It takes me 700 rupees for every follow-up trip from UP every month and investigation takes another 300 rupees. It is difficult for me with very meagre resources, but I get medicines free of cost. I would have not survived if this hospital was not there".*

Selling land, a part of the house, taking a loan before coming to SJH were the conventional narratives of many recipient families. Some of the recipient families had been to private hospitals before coming to SJH. Knowing the exorbitant costs of transplant surgeries varying from one hospital to another, some relatives chose this hospital eventually. Most of them had come to this hospital after exhausting their resources in private hospitals for which they were feeling horrible and blaming themselves. They wished they could have come to this hospital before exhausting their resources.

Tolerate Cheating and Forgery by Relatives

In one case the transplant recipient Mr.NNN was weeping inconsolably for getting cheated by relatives with whom he had decided to stay. He said, *"I had brought money (one lakh rupees) for treatment from home that was handed over to my relative on my visit to this place, thinking that he could keep it safe in his home. Today when I asked him for money, I am told that someone stole it".*

Mr. Br reported, *"The cost of blood unit was 2800 in some hospital, but I was charged 3800 for the same by the relative with whom I was living with the patient. I came to know about this later".*

In most cases, people had wholeheartedly helped their relatives in need of the hour. But some had cheated the poor people as well.

Face the Repercussions of Nuclear Family

Mrs. Mitta reported, "Being in the nuclear family, I had to suffer alone along with my daughters. I was troubled in office for taking leave every month as procuring life-sustaining medicines for my husband was a three-day affair every month. Getting reimbursements was a harrowing experience".

Managing the ill health of the recipients was a problem for people living in nuclear families.

Family Sufferings Associated with Delays in Transplants

There were some avoidable and unavoidable causes behind delays in kidney transplants that could be avoided in many cases. Some delays happened due to unavoidable medical evaluation and associated medical problems. Some delays were however avoidable like the delays caused by bureaucratic hurdles, errors in names, date of birth, etc, casual attitude of people in making legal documents, limited understanding of relatives and swap transplant not happening.

Table 8.1 Distribution of kidney recipients as per the time gap between their first dialysis and kidney transplant (N=17)

The time period between the first dialysis and kidney transplant	Number of Kidney transplant done with living donor	Number of Kidney transplant done with BSD donor kidney
Less than a month (AIIMS)		**1**
1-3 months in SJH		**1**
4-6 months in SJH	**3**	
7-9 months in SJH	**4**	
10-12 months in SJH	**5**	
13 -15 months in SJH		
18- 24 months in SJH		
25 -30 months in SJH	**1**	
31- 36 months in SJH		**1**
6 Years (Indore Hospital Recipient)		**1**
Total	**13**	**4**

Table 8.1 reveals that most of the kidney transplant surgeries, i.e., 13 were done with living kidney donors and four (4) with BSD donor kidneys. Such transplants had not taken much time in SJH. Kidney transplants were performed within 4-6 months, 7-9 months and 10-12 months for three (3), four (4) and five (5) recipients, respectively. In SJH one recipient had got kidneys from BSD donor within a gap of 1-3 months, and another had got after 31-36 months. Indore Hospital recipient had got a kidney transplant after six years from a BSD donor. There was only one recipient who got a kidney from a BSD donor in AIIMS in less than a month after dialysis.

The delays in kidney transplants for waiting recipients, who had living kidney donors were caused by various reasons as follows: -

Donor-Recipient Evaluation: Time Consuming

A donor, as well as the recipient, goes through a battery of tests that takes time. The interviews revealed that it usually takes two months for both the donor and recipient evaluation as it is not only the tests and investigation but the donation and transplant clearance from various overburdened departments for the donor and recipient pairs. The assessment is done in multiple phases, as mentioned below: -

Phase – I: - The first phase begins with blood investigations that reveal the functioning of organs within the body. The investigations are mainly biochemical routine blood investigations like:

- Complete blood count, Hb, TLC, DLC, Platelet, PSA (M>45 yrs.), PT- Test, PTTK – Test, Glucose – F/PP, HbA1c, Urea, Serum Creatinine, Serum uric acid, Sodium level, Potassium level, Serum Cholesterol, Serum Bilirubin, Serum Protein, Albumin, Globulin, SGOT (AST), SGPT (ALT)etc.

- Urine routine microscopic test is also done along with urine culture and sensitivity. 24 Hrs Urine (Volume, creatinine, and protein).

- The thyroid function is also evaluated by getting T3/T4/TSH tests done.

To rule out the possibility of viral infections

HIV test is done for detecting AIDS virus; HBs Ag for detecting Hepatitis B infection, Anti HCV for detecting Hepatitis C virus and CMV (IgM and IgG) for detecting Cytomegalovirus. These tests are important for these infections can lead to organ failures.

Radiological Examination: ECG is done for detecting heart abnormalities, X-ray chest PA view for diagnosing any pulmonary disease, USG abdomen and pelvis (post void residues in case of male>45 years) for detecting abdominal or pelvic diseases and 2D Echo is also done.

During this phase, the Departmental Clearance is also required, and the person is supposed to go to cardiology, Gynaecology, Psychiatric, Pulmonary Medicine and Ophthalmology for Cardiac Clearance, Gynaecological Exam (if female), Psychiatric Evaluation, Respiratory Clearance and Fundus Examination, respectively.

DTPA Renogram is also done to find the Glomerular Filtration Rate (GFR ml/min) of right and left kidney and their functioning in percentage.

Phase- II: -CT Renal Angiography

Phase – III: Human Leukocyte Antigen **(**HLA) Test and Donor specific Complement Dependent Cytotoxic (CDC) crossmatch is done. This phase tells about whether the donor's kidney is best suited to the recipient or not. If this phase is okay, then only does the donor move to the next phase.

Phase – IV: -With the reports of all these tests Urology Review is done and the acceptance for transplant is sought. Once this is done the PAC, a Pre-Anaesthetic Check-up is done, and clearance is sought. The donor-recipient case is forwarded to the Clearance of Competent Authority of the hospital (with date).

During my visits to the hospital a few living donors were rejected, the reasons were:

a) Low Glomerular Filtration Rate (GFR) of both the kidneys of the father who wanted to donate a kidney to the daughter of 26 years.

b) Mismatch with the recipient

c) Some donors were first given treatment for a diagnosed ailment like correcting their thyroid problem and were reconsidered for donation later.

However as reported by recipients, it was troublesome for the intended donor to go through a battery of tests up to Phase- II that was consuming a lot of time, efforts and involved staying away from home only to find that they are a mismatch in the end. The same could be avoided by doing the HLA Test and Donor specific CDC cross Match of Phase – III first followed by the remaining tests of Phase 1 and Phase- II.

Delays Due to Medical Problems

The living donor and the recipient must be free of other medical problems before surgeries. It takes time to get donor-recipient clearance for surgery from various departments.

Mrs. Kr reported, *"His platelets are going down and fluctuating for the last 4 months hence surgery is postponed".*

Ms. Xr reported, *"Donor blood group was B positive and the recipient is B negative. In the beginning, we felt she is not the best match, but doctors said there is no problem with Rh incompatibility. ".*

Mr. Wr reported*, "Thyroid was to be brought to normal for donor mother before surgery".*

Mr. E reported, *"My father wanted to donate but his GFR was low, and doctors refused his kidney donation".*

Delays Due to Bureaucratic Hurdles

Bureaucratic hurdles in the recruitment of contractual Organ Transplant Coordinators lead to delays in transplants. These contractual employees make the files of donor-recipient pairs, and their absence delays the process.

Delays Due to Errors in Names, Date of Birth, etc.

Some delays happened on account of different names that get written during paperwork in hospitals. The officials who make hospital documents do not verify with precision. They write what they comprehend from the spoken words of the relatives, for example, writing Anjni for Anjali. In some cases when such spelling mismatches come to the notice of doctors, they refuse to recommend the file to the competent authority for approval of kidney transplant. Instead, they suggest remaking all the documents with the correct spelling to play safe and avoid legal hassles in the future. Not only this, the researcher's observations revealed people have a very casual way of making documents during life. Different records of the same patient bear the name with various spellings and at times have a different date of birth in different cards like Aadhar card has a date of birth different from the Electoral card, etc. All such intentional or unintentional errors lead to confusion, suspicion, and delay in transplants.

Delays Due to The Casual Attitude of People in Making Legal Documents

In some cases, some documents are made in the court to certify relationships. Unfortunately, the people while making legal documents of the patients are very casual in their attitude. They commit mistakes several times either in names or in relations, etc. All this not only causes delay but the financial loss to such patients. The legal document preparation of a single page costs 150 rupees. Many such documents are required while making the medical file of donor-recipient pairs for transplants. A simple mistake in the name only means much more to patients in the form of time investments, extended stay on roads, delays in transplantation and additional financial investments.

Delays Due to Limited Understanding of Relatives

Some delays happened on account of poor understanding of relatives. They approach a department with different or irrelevant papers which turn them down, saying that they have nothing to do with the documents shown to them. The treating professionals tell the relatives something that they understand at that spur of time but forget later.

In one case, the relative of a recipient waited from 5.30 am to 11.30 am on Wednesday to get the endocrinology clearance from the department for the donor who happened to be his wife. When his turn came, he handed over different papers to the department among many medical documents in his bag. He was not attended for this and sent back. When he came back to the department, his mistake exposed. Being a rickshaw puller and having come from Bihar, he started crying saying where will he stay for one more week. It is essential to mention that the endocrinology OPD opens on Wednesdays only. On enquiring, he said he stays under bridges, in hospital corridors, on roads and takes care of his ailing son with borrowed money. He had borrowed 1.5 lakh from relatives and acquaintances.

Delays Due to Swap Transplant Not Happening

Many recipients waiting for kidney transplant had mismatched willing donors. Swapping donors could eliminate their problems that do not happen due to a scarcity of workforce and infrastructure.

Mrs. Qr reported, *"I wanted to give my kidney, but it did not match. I am B positive, but my husband is A positive. I also opted for swap transplant, but they say it takes time".*

The interviews revealed that it usually takes two months for donor and recipient evaluation as it is not only the tests and investigation done for them. But such donation and transplantation require clearance from various departments that are already overburdened. It was troublesome for the living donor to go through a time-consuming battery of tests up to Phase- III. In case they were found a mismatch in the end in Phase – III thorough HLA Test and Donor specific CDC crossmatch, the transplant would not happen. The same could be avoided by doing Phase – III tests first followed by the remaining tests of Phase 1 and Phase- II. The kidney transplant recipients with living donors had not taken much time in SJH. Medical problems, bureaucratic hurdles in the recruitment of contractual Organ Transplant Coordinators, errors in medical paperwork, date of birth, documentation, casual attitude of notary people in making legal documents, problems with comprehension levels of relatives and swap transplant not happening lead to delays in a few cases. Many recipients waiting for kidney transplant had mismatched willing donors.

Swapping donors could solve their problem, but that does not happen due to the scarcity of human resources and infrastructure.

Family Compulsions, Conflicts, Apprehensions and Anticipation with Living Kidney Donation

The study revealed family compulsions of living kidney donation by ‘near relatives’ and compulsions to purchase the same. Besides, it revealed domestic conflicts with living kidney donation and high cost of treatment. It also revealed apprehensions and concerns of ‘near relatives’ as kidney donors and anticipated emotions from recipients after the donation of a kidney.

Compulsions of Living Kidney Donation By ‘Near Relative’

Living kidney donation by the near relatives was found the best option to rescue family members from sufferings, shifting, borrowing and selling family assets. Kidney transplantation is not a cure. But most of the patients and their relatives don't want to comprehend that because it is their necessity. There is a risk that kidney disease may return after transplant. There is a health risk to the living kidney donor, and there is no guarantee that the recipient will not reject the donor's kidney. All this is very well explained to the living donors and their recipients as well.

The complications of the transplant surgery include bleeding, infection, and failure of the donor's kidney in the recipient body, rejection of the donated kidney, death, heart attack and stroke. After a kidney transplant, the patients are required to take medications called immunosuppressants throughout their lives to help their body from rejecting the donor's kidney. These medications, unfortunately, can cause a variety of side effects, including excessive hair growth, thinning of bones, diabetes, weight gain, high blood pressure, cancers, high cholesterol, etc. All this is explained very well to the families and documented too.

Deciding whether to go for a kidney transplant is a family decision that deserves careful thought and consideration. Not all dialysis sessions can be carried out in

Govt. hospital as dialyzing machines and human resources are scarce. The relatives are required to cough out money for dialysis which in most cases is unaffordable. The families face a dilemma. They either must spend borrowed money, sell assets or donate a kidney. To get rid of problems associated with living away from home and spending money on dialysis, the near relatives feel it best to donate a kidney to their ailing relative. For them donating one kidney means saving money, saving assets, reducing borrowing and returning to their place of residence. Besides, it rescues them from living away from home at the mercy of others.

Compulsion of Purchasing A Kidney

It is often quoted that family purchases a kidney from outside. The families often do so in the absence of a family donor compatible with the recipient. Donor non-availability leads to a lot of frustration within family members. Mismatched family donors, lack of facilities for swap transplants, lack of family support and disintegration of the joint family system results in trading in of organs. Families in such cases are left with no option except to seek paid donors outside the family.

As reported by a family member Ms. AZZ in an awareness program, *"We wanted to purchase a kidney for my father-in-law a few years back. We had paid three lakhs to the male donor. But he fled with money and did not donate a kidney".*

As per Mr. Jr, "I am determined to save my wife. My kidney is not the best match for her. Mine is a nuclear family. My friend's wife wants to give a kidney. But she is not related to us. Her husband is working as a guard in my office. She is willing to donate, but how can I prove that she is related to us. The castes are different. The places of permanent residences are different. I can get forged certificates made, but I want the truth to prevail. Nowadays, the truth is not trusted. Documents are more trusted than individuals. Life is not important, but documents are important. I have written to Prime Minister also. I will fight till death. I have lost my job taking care of my wife, taking her to a painful dialysis session, but I can't see her dying. My children are so small, they need her, and I need her for my children. But I doubt whether my *friend's wife will continue to be interested in donating kidney till the time I succeed in getting permission for this unrelated donor".*

The narratives speak how people manage to purchase kidneys. The stories also reveal high anxiety and desperation of a spouse when his kidney does not match with the recipient wife. Absence of swap transplant facilities, a viable option for mismatched donor-recipient pair leads to frustrations and heightens the fear of losing mother for his children as reported by Mr. Jr. The person lost his job but is determined to save his wife, reveals the sufferings of people. He wants to purchase a kidney for his wife but knows he cannot. Writing to Prime Minister about his plight shows the tremendous need for working towards swap transplants that are not happening much in our country.

Domestic Conflicts with Living Kidney Donation and High Cost of Treatment

Kidney donation and transplantation has given rise to conflicts within many families resulting from recipient expectations from its family members.

Conflicts Within Kidney Donation By 'Near Relatives'

Kidney donation and transplantation has given rise to new hopes from people when it comes to need for love towards the recipient. A woman is expected to prove her love towards the recipient through donation of an internal organ. Some people don't mind donating organs but some shy away from doing so in many cases. There have been instances when kidney donors withdrew their intention to donate as a result of perceived threats or as a result of other family members coming in between such acts. In a few cases, kidney donation by family members gives rise to family conflicts. This, in turn, affects family ties either temporarily orpermanently.

Table 8.2 Reasons for withdrawing the decision to donate kidney by willing living donors (N=9)

S.No	Relationship of the living willing donors with the recipients.	Number of willing donors	Total number of willing donors	Reasons for not donating
1.	Husband	2	5	Mismatch with donor
	Wife	2		
	Mother	1		
2.	Father	2	3	Family members intervened against the donation of a kidney.
	Mother	1		
3.	Father	1	1	Change of heart at the eleventh hour.

Table 8.2 reveals that in five (5) cases, the donation of organs could not proceed as a result of mismatch with the recipient. In three (3) cases, family members intervened to prevent a kidney donation by a 'near relative' and in one case father changed his heart to donate a kidney.

Five willing donors were found mismatch with the recipient. In two such cases, however, donor wives who were found mismatch with the recipients, mothers of these two recipients had donated a kidney. In other words, female mismatched spouse donors were replaced by matched living mother donors only.

But on the other hand, the two husbands who were found mismatch for wives had no donor in sight. One was struggling to trade in a donor, wrote to Prime Minister, and another was seeking option for swap transplant. In the case of 3 willing kidney donors in three families, other family members had intervened and prevented living donors from donating a kidney. Also, in one case father changed his heart to donate a kidney to the son at the eleventh hour after found the best match for his son.

The narratives of the recipient reveal the emerging conflicts within families.

Mr. G reported, *“My wife wanted to donate a kidney to me. She was evaluated and was a perfect match. My son came in between and pressurized mother not to donate. I feel bad on account of this, and I have developed a strained relationship with my son and family”.* However, on talking to his son on telephone, the researcher came to know that his son was unaware of brain death. He felt professionals retrieve kidneys for transplantation after post-mortem of accidental cases. He, however, was not willing to let his mother donate a kidney. He could not imagine himself without his mother and was afraid of life consequences for her. He never wanted himself to be orphaned. He said it is my mother who takes care of the family in the absence of the father. The recipient Mr. G had compromised with the situation later when researcher met him the third time. The waiting recipient said, *“How long can I be angry with my son now? I cannot survive without his support”.*

Ms. Xr reported, *“My grandmother wanted to give kidney but was found to be suffering from some ailment. She is medically unfit to donate her kidney. My grandfather wanted to be the donor for my father. But he is supposed to come from the village for medical evaluation. We insist him to come here, but he is not coming for his evaluation/tests in the hospital saying who will take care of agricultural land. He is dissuaded by my grandmother too, as she is concerned about his life and agricultural land. For a fortnight now, our grandfather does not pick up the phone even, and our grandmother scolded us when we persuaded her to send grandfather. She says, who will take care of us here if he donates a kidney? She has changed completely”.*

The living kidney donation and transplantation has created new domestic battlefields perceived by the researcher. Kidney donation and transplantation have widened the gaps within family members as a result of expectations for kidney donation by family members. Children prevented the willing mother from donating a kidney to their father. A willing mother found mismatch with donor son did not allow her husband to donate a kidney for the same son. These stories speak of love on one side and the obligations of changing social milieu on the other side. The family anticipations for kidney donation and perceived threats make the situation tough for both the donor and recipient who feel it difficult to come in terms with each other.

Children in nuclear families in cities expect parents of their breadwinner father to come from the village and rescue the family by donating a kidney. And feel cheated if his parents refuse their father a kidney. Relations get strained as a result of expectation for a kidney donation.

Conflicts with High Costs of Treatment for Kidney Failure

The researcher also witnessed domestic conflicts associated with high costs of treatment for kidney failure that needs high investments for regular dialysis, medicines, and diagnostic procedures.

With tears in his eyes and a choking voice, Mr. O said, *"I had worked for my family when I was a child. I started earning when I was only 15 years old only. I took care of my two younger brothers, like my children. Ours is a joint family and now my two brothers are pressurizing to get separated. They feel that my disease needs a lot of investments, and they don't want to invest in me now. Their wives want to get separated. I am devastated financially, physically, psychologically and socially as well, at this young age of 38 years".*

The high cost of treatment for kidney failure for regular dialysis, medicines, and diagnostic procedures tears a joint family apart, the patient Mr.O feels cheated by his own joint family for whom he started working from childhood.

Apprehensions and Concerns of ‘Near Relatives’ as Kidney Donors

The living donors in all cases are counselled before kidney donation. Psychiatric evaluation is done before kidney donation. Some of the living near related kidney donors had several apprehensions regarding kidney donation. These concerned their self, fate of donor–kidney in the recipient body and concern for the progeny of the recipient.

Concern for Self

Will I be okay after the donation of a kidney? It was a question usually asked by female near related kidney donors. In many cases, such willing female donors interacted with other female donors who had already donated kidneys to understand how they are functioning after the kidney donation. Dealing with societal pressures also were making female donors apprehensive**.**

Donor –Kidney Concern in The Recipient Body

Several patients whose kidneys had stopped functioning were not given any medical reason for failure of their kidneys. The cause of kidney failure was unknown to many. The donors in such cases had apprehensions regarding the fate of donor kidney in recipients.

Mr. Ur reported, *"I am told to donate a kidney but what is the guarantee that my kidney will not meet the same fate in her body when the reason behind her own kidney failure is unknown. I am not only dissuaded by my own family members but by her family members also for giving a kidney to my wife. I want to give one kidney to her as I love my children and they cannot survive without her".*

Concern for The Progeny of The Recipient and Continuity of Recipient Lineage

Most of the donors were willing to donate for the continuance of lineage mainly. Their apprehensions were revolving around the perpetuation of family.

Mrs. Dr reported, *"I will donate my kidney as I am her mother. Only a mother can donate a kidney. I feel I must help her. But will she deliver kids after my kidney is transplanted?"*

Mrs. Yrr reported, *"I have only one nephew now. My only brother lost two sons earlier. I want to donate a kidney to my nephew as I want my brother's house should always remain open to my children and me. His mother is not a compatible match for him. Even my husband wants me to donate a kidney to my nephew. He is very sensible and expects me to prevent my brother's lineage from coming to an end. He expects me to do my duty and donate a kidney.* Interestingly *Mrs. Yrr* was told that living kidney donation from 'other than near relatives' is not allowed there as there is no "Authorization Committee" in hospital. However, this case could be referred to the "State Authorization Committee**"** for approval as per law.

Mr. Rrs reported, *"I have given my kidney to my sister, who is married to my brother in law. Our in-laws and her husband expected her to deliver a child. She could not do so even after undergoing all the treatments available within this country. I wish she delivers a child after transplant surgery".*

During interviews, the willing living kidney donors revealed several apprehensions and concerns. These concerns surrounded their bodies, their functional abilities post-transplant and the fears with the fate of donated kidney in the recipient body. The significant concern regarding the recipient was apprehension with the continuance of lineage by the recipient. The researcher had written an article on "Semblances of Aanagdan (organ donation) with Kanyadaan (marriage of a daughter) under Hindu Marriage"[3]. When a daughter gets married, a family is

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[3] The article (Dar, 2017) attempts to compare daughter's marriage in Hindu religion with organ donation and transplantation. The author makes a comparison between the two by relating the importance of love in both cases. She compares matchmaking of a bride with the matching of the donor organ with the recipient. She compares the engagement ceremony of the bride with the approval by the "Authorization Committees" in organ donation and transplantation. She concludes her article saying that maintaining a harmonious relationship in both the cases is full of adjustment problems eased by gifts cum dowry post marriage and use of different types and doses of immunosuppressants in organ transplantation. The

concerned about itself, wish daughter to be safe in a new milieu and at the same time desire her to produce children. The same holds for kidney donation as well. The three significant concerns revealed by living kidney donors were the concern for self, for the donated kidney in the recipient's body and the progeny of the recipient and continuity of recipient lineage.

Anticipated Emotions After Living Donation

Post-transplant, while some recipients expressed their gratitude towards living kidney donor, a few were indifferent too. The emotions varied from case to case.

Mr. M reported*, "My wife donated a kidney. There are no words to express my gratitude for her. I am not earning yet. It is an embarrassment when your wife continues with her job even after the donation of one kidney and husband survives on her earning".*

Mrs. Fr reported, *"I donated my kidney, and I am thankful to God as my husband's anger has reduced after kidney transplant. He treats me well and does not get angry on trivial matters as he did earlier".*

As per Ms. Xr, the daughter of one of the kidney recipients said, ***"Dekh Lena Unkee Yeah Kidney Bee Ek Saal Se Zyada Nahee Chalegee"*** *(Meaning I am sure his transplanted kidney will not continue to work for more than a year). He is full of anger and abuses everyone, including my mother, who has donated one kidney to him. His attitude to life has not changed even after his miseries".*

The researcher found varied emotional experiences of the 'near relatives' after the kidney donation. Some families felt the anger of the recipient had reduced after kidney donation, while a few others did not feel so. In a few such cases, family members expected the recipient to be thankful to the family members after kidney donation but feel disillusioned after doing so. The recipient must maintain a calm

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post-event management in both cases requires a lot of investments and adjustments.

environment at home without hurling abuses and expressing anger is the minimum expectation of family members. Family members perceive recipient violence as a threat to the survival of the donated kidney and anticipate the rejection of the organ in the immediate future.

The Story of Ms. Pitta

It is an in-depth case study revealing the suffering of kidney failure patient and emergence of the biosocial relationship between a BSD donor family and kidney recipient after transplant. Mrs. Pitta, a 36-year-old lady resident of MP, revealed her suffering during her 6-year ordeal with haemodialysis and life-changing experiences post BSD donor kidney transplant. She related her story right from the day she got married as marriage had changed her life.

"As a straightforward girl, I was married in 2001 to my love, Mr Ashok (name changed). In October 2002, I delivered a lovely baby girl. Our family was happy, and we were contented with our lives and living happily. One day I developed a high fever, and I went to a doctor, but it did not help. High fever was not coming down irrespective of treatment by the doctor. The doctor prescribed some tests and came to know that both my kidneys had failed, and dialysis was the only treatment. I got admitted to a nearby hospital. Neither was I told of my disease, nor did I have an understanding of this disease. There was no improvement in my health; instead, my health was deteriorating. I was repeatedly asking my husband when we are going back home. My daughter was only seven years old, and my son was three years old. I was taken to the operation theatre for the creation of a fistula. Unaware of the severity of my disease, I did not understand as to what had happened. The doctor said there is an infection and fistula cannot be created. My husband was very disturbed, I could see turmoil in his eyes, but why he was scared was beyond my comprehension. I could not understand why a person should be afraid of fever that is so common? I was trying to find the cause of his worry but did not understand anything. I knew my husband was a strong person, and there could be something that worried him. I shifted to another hospital called "Yabmob Hospital" (name

changed) in an ambulance as there was no improvement in this hospital. In other hospital, doctors told me that a needle would be introduced in the neck and blood will be purified and then within one or two days, I will be discharged from the hospital. Doctors' words relieved me, and my husband also would encourage me not to panic. He would say you are a brave woman, and very soon, we will go back home. My mother had come to my home, and my children were being taken care of by her. Then I was taken to the dialysis room. This experience was horrible. Some patients seemed in pain, and some were in grief. Many patients were lying on beds. Experiences of that day give me goose bumps even today. Presence of my husband there was a great consolation to me. I knew my husband from childhood; childhood love had bloomed into a beautiful relationship, an intense and strong relationship that I can feel even today. While these thoughts were going in my mind, the doctor came and told my husband to leave the dialysis unit. I was scared and started crying, telling him to be there only. I started crying like a child, holding his hands and saying no, I will not allow you to leave me. You will stay here only. Then the doctor explained to me that a small needle would be introduced into the neck, and my husband may feel that pain and may not like that. You, too, will not like to see that pain in his eyes. Thinking that it is going to be my first and last treatment before I go back home, I allowed my husband to leave. My neck was ready for dialysis. This procedure was of 4 hours duration. But my first dialysis was a nightmare for me. My health condition deteriorated. I felt as if I would die at that moment only. I felt death is standing right in front of me. I felt as if death is running after me, and I am fighting with death and pushing it back continuously. The presence of my husband and his continuous support was giving me the energy to push back my death. At 11.30 pm, the four-hour dialysis procedure was over, and I shifted in the room. Ashok Ji was with me and was talking to me normally, and I was regaining my courage. I was not feeling the pain with his presence, continuous support, and encouragement. But I would ask him why I should get through so many tedious procedures, why so in simple fever. I had never gone through such procedures in fever before, why so now? Everything was beyond my comprehension. After one day, I was again prepared for dialysis. Dialysis was done twice, and I was discharged from the hospital within a *week. I felt good leaving the hospital, thinking the tough time is over. I thought I would go back home and lead a normal life without this procedure of dialysis. What is this; I was advised to live without water, salt and food. How is it possible? Then I was told that due to hypertension, both my kidneys have failed, and the only treatment is dialysis or a kidney transplant. My transplant was not possible as none in my family had a blood group that matched my blood group. I felt devastated. My weight was 65-70 Kgs, which went down to 27-28 Kgs within a short duration of time. My complexion had turned black that used to be fair. My hair had left my skull. I started hating myself. I had turned ugly. I had become dependent on every task. My whole family was disturbed. Every day seemed the last day of my life and every breath my last breath. The threat of dialysis continued with my deteriorating health condition. Everyone suggested me to go to some other place for a change so that I feel better. Out of desperation, we did what we felt would help us. I went to "Nadiyalin Gujarat". Dialysis was done every day. My health, instead of improving deteriorated further. My condition became serious that I can't express in words. My brother, my husband and my son were there with me who would leave no stone unturned to save me and keep me alive. My neck, my both hands, my both feet were used for doing dialysis procedure. The pressure was applied with bricks on my feet to prevent leaking of blood from my feet. My whole bed would soak in blood at times. I would reciprocate to every conversation with tears in my eyes; words were not coming out of the mouth. I was like a living zombie, I remember that moment when I was in ICU, my husband was crying and yelling at me as if ordering me .... you have to live, you can't leave us, live for me please, please live for my children, you have to accompany me back to our home. I will not go back without you. With these words, I prayed to God for giving me that much courage so that we reach back to home. Doctors also told us that only dialysis could keep me alive.*

Now I was not able to stand on my own feet. My husband was carrying me in his lap from one place to another. We reached back to our home and thanked God. On 7th June 2010, my first dialysis was done, and that was the most painful incident of my life. That kind of suffering was continuing and not coming to an end. After one *month, I reached home, my husband carrying me in his lap. I don't have words to express my feelings at that time when he was moving me inside the house in his lap; I cried a lot looking at the condition of my home. The state of my home was horrible as it had remained closed for one month. But home is home. I can't tell you how much relief it was to me after I reached my home. We don't get that relief anywhere. The next morning, I went to the hospital and remained in ICU for many days. I felt I am approaching death. I was not afraid of my death but was worried as to what will happen to my two kids and my husband. I had no hope for my survival for long. I was only 27-28-year-old. My son was in nursery and my daughter in 4th standard. My husband would get up at 4 am and prepare food for everyone. My children would go to school. My son, even at this age, had become responsible and would take care of me, feed me and try to keep me happy. In the evening, my husband would come and take me to hospital for dialysis but leaving my three-year-old son at home was exceedingly painful. We both would hide tears from each other and move towards the hospital. But dialysis was necessary for one- or two-day's survival. My elder daughter would go to school at 11.30 am and come back at 5.30 pm. She would become a mother to her younger brother for 5-6 hours in the evening in my absence; I don't know how she acquired this intelligence. We would come back from the hospital at midnight. Both my kids would sleep, sometimes without food also. Sometimes their father would wake them up at midnight to offer food. Sometimes they would get up and sometimes they would not. My husband was the worst sufferer; on one side, he was taking care of me who had no hope of survival, on the other hand, he had two innocent kids who were suffering like hell. Life had given us so much pain that we never thought. When you are sick, in the beginning, a crowd of your relatives and friends gather around you, and then one after another they start moving out, the group begins thinning and a time comes when every person vanishes from the scene. A saga of disappointment sets in without any support from others except your family members. We lost everything during this disease. Home, money, this disease consumed everything. We were in great turmoil. My husband was in service, and we were getting some help. One month's dialysis cost us Rs. 35000/- excluding medicines and ICU treatment. We had forgotten the excitement of social* *gatherings and festivals. Even on Diwali, we were not lighting a single lamp (Diya). Every festival emerged with sadness and despair for my family. On every festival, my husband and I would be in the hospital because we would be begging for a two days life and my children would be at home. Now I had reconciled with the situation and knew that this is going to continue. I knew my weakness inside but would always put a brave face in the presence of my children.*

During dialysis sessions, I had become friendly with patients and staff, and it had become a new family now. We all felt connected. I have seen the deaths of many patients during dialysis, and while going for dialysis, I would not be sure whether I will come back and see my children again. But still, I would go to get a new short lease of life for two days.

We had sold our house and had shifted to rented accommodation. Our children had become older now, and there was no cessation of our sufferings. The problem was there, but time was passing and draining our resources and energies. For a few days, I would feel like I am recovering, but within a few days, I would be in ICU. We were tired of moving here and there and had decided that we will not run away from MP. When an organ stops functioning in your body then only, we realize it's worth otherwise we take everything for granted. I too started understanding the worth of my kidneys only when both stopped working.

With time, struggles with my life continued, and it had become a way of my life, but sufferings also teach you a lot. We may or may not learn, depends on us. I was not living for myself but my kids and husband. Only these three people had served me; my husband had stood like a rock for me. He had supported me wholeheartedly, encouraged me at every step. I felt him like an obstacle standing day and night between me and my death. My husband would keep fast on ***"Karva Chauth",*** *do special prayers and keep many other fasts too for my longevity. I was put on a ventilator twice, but death was defeated.*

The sufferings of this kind continued, and this kind of six years life was worse than death. These six years of experience of dialysis were full of fear of death. I knew that death follows me and could swallow me anytime. But suddenly we felt a ray of hope. We would see the newspaper daily, one day we came across a news item in 2015 for the first time about organ donation and transplantation from a brain-dead person. A brain-dead person had given life to so many people. But this was not easy. My heart became the house of many questions. Could this also happen to me? Can I get back my life? Will God take mercy on me? Can I live again? Can I fly in the sky again? Everything was going on in my mind. Everybody was telling me that I will get a kidney soon. But I would say to them that I am not that lucky that I get back to life. I would think that in case I get a new lease of life; I will do some good work and giving life will be my main aim. But all this was a wish far from the truth. The truth was that
(Meaning our
death is already decided by
God)

In 2015 at 9 pm in the night my health started deteriorating. I immediately rushed to the hospital. My blood pressure was very low; I was feeling breathless. New Year 2016 had started in ICU for my husband and me. My children were at home. In between doctor said that my body has deteriorated, we wouldn't know anything now how long dialysis will help her. Now probably hope had started fading, but there was still a little hope left. Within 8-10 days, I was discharged. I would fight with God in the heart of hearts and request him for life, beg for life. I had no other hope now. Somehow two months passed. On 9th March, on the day of my dialysis, I was called by a doctor who enquired whether I am willing for a kidney transplant. Without giving it a thought, I said yes, I am coming, sir. I felt so happy, I had become mad with happiness, and words were not coming out of my mouth because of tremendous joy experience. I immediately rang my husband, and he was surprised. He immediately left for the hospital. I took my 9-year-old son along with me to the hospital as his sister was in school. Everybody was happy there and waiting for my arrival. They all wished me to be alright. My husband had reached the hospital. When my husband is around me, my strength multiplies one thousand times. My *dialysis started and continued for 5-6 hours on the day of the transplant. I was not at all afraid as the struggle with life and death for 6-7 years had made me strong. And I knew I am getting a new life now. I was happy now. I felt God had listened to my conversations with him that I used to have all these years. I was thanking God from the core of my heart.*

While I was on dialysis, my husband was trying to pool the resources and arranging fees deposition for operation because we were left with nothing. We were already under debt because of this disease. But this was the biggest test, and we had to succeed. Only my husband was with me at that time. I was not afraid but happy to be in Operation Theatre, don't know when I was made unconscious. At 6.45am, a green corridor to this hospital within MP was created, and one kidney transported. Within a short duration, new life had made its entry in my body. My new birth date is 10th March 2016. It is a miracle, a blessing from God and my husband's hard work. The operation was over, but probably my condition was not good. The health was deteriorating. I was put on a ventilator. On 13th March I heard some noise around me. Doctors and staff were around me; I opened my eyes slowly and smiled a little. I held the hand of a doctor and asked him, is my operation over? Has a kidney been transplanted?

Everyone started laughing. The doctor asked whether I am having pain, I said no, moving my head only. They informed me about my kidney transplant. The day of my transplant was World Kidney Day also. Sweets were distributed. Everyone was happy. After one week, the doctor came to me and told me that I should thank the person who donated his kidney. I knew what that person meant to me. I started taking a lot of water, taking enough food, my weight started increasing. After 15 days, I was discharged from the hospital. At home, my small children were waiting for me. It was a feeling as if a mother is coming to her house with a new born, a new life and that new life was my donor's kidney. Indeed, an unknown donor's kidney had given me a new lease of life.

We were living in a rented room that was very small; now we took one more house on rent as proper disinfection had to be maintained to prevent infection. My children had to appear in exams. We were facing many challenges, but my husband took care of each and everything. He would take care of all small and big things, like my medicines, food, bath, follow -up etc. My husband brought me back to life.

Then one day I asked my husband whose kidney it was. He had gathered all the information about the donor, showed me all the newspapers of 10th date that spoke of Saurav and his brain death, green corridor, etc. His family had consented to donate his organs for unknown, unrelated people. And their decision had saved many lives, including mine. A person who had no relation with me, I don't know which duty had bound him to bring me out of death, prevent my children from becoming orphan and which association he had served. He saved my family from breakdown. Saurav, my kidney donor, not only filled my life with colour but helped me in getting rid of a life where I was dying by inches. He restored long lost happiness in my life, in my family life.

But sometimes I feel sad. I think someone whose house went into darkness preferred to light my home first. I ask God what this is, for someone there is light, and for others, there is darkness. On the day of my rebirth, the last rites were performed for the same person who saved my life.

After the transplant, we become extraordinary persons. We must take special care of ourselves. We are supposed to handle our new life with utmost care. The prolonged sufferings and pain had vanished. I was afraid to see my face in the mirror; I had become ugly (bayanak in Hindi used by the recipient) during dialysis.

But this was also the truth that someone death gave me life. I don't understand the two words now "life and death". Is it Saurav who got a new life or is it me who got a new life? Today my life starts with prayers for Saurav. All my prayers are Saurav's prayers. With the improvement in my health, I wished to see his family. My husband *had the phone number of Saurav's brother Lalit. I messaged him from WhatsApp. Within a few hours, I got a phone call from him after 22-25 minutes, and he talked as if he had seen me for years.*

Then one-day Indore Society of Organ Donation (ISOD) organized a function, and we both attended the gathering. When I met Saurav's mother, I touched her feet, and we both wept inconsolably. It was a very different kind of emotion. We sat together, had lunch together. She brought me home and took me to Saurav's room. She talked to me about him. She immediately said that my face resembles her son Saurav's face. Even the MUSKAAN team felt as if Saurav and I were brother and sister. They had seen Saurav in Operation Theatre. I felt good to know that. Maybe we were related in our previous birth. From that day onwards, we are regular visitors to his house. On his birthday everyone in his family called me and wished a happy birthday to me. His mother, brother, sister in law bless me as if they are blessing Saurav. They feel happy when I talk to them. They say that I have kept their Saurav alive. Life lives even after death. Thank you, dear Saurav.

Not everyone gets this chance at death, and I want to live each second of this new life. I know I got a life after death. I owe this life to Saurav, my husband, and my kids. My kids lost their childhood, and my husband worked 24 hours for me. We were on the verge of collapse, but Saurav saved us.

After the transplant, I became healthy within a few months only. I am back to my original health and started living again. Zombie is back to life. I have counselled many people now. I help them in getting rid of fears. I had not only died physically but psychologically, too, but I never wanted to die. I wanted to live and do something useful. And maybe because of this good intention only, God helped me. I am thankful to all those people who have prayed to God for me. I don't have words to thank everyone.

I know that it is not only the disease sufferer who suffers but family members too suffer. The family gets devastated and getting rid of such sufferings becomes impossible. Had Saurav not given his life to me, I would have died long back. Every donation is easy, but organ donation can be done only by the 'Messiah of God' and not an ordinary person".

The in-depth case study divulges the suffering of kidney failure patient and emergence of the biosocial relationship between a BSD donor family and kidney recipient after transplant. The story shows how this disease is devastating for a family more so when the family is caught unaware of both kidney failures. Pitta's story also reveals how a minor daughter assumes maturity in adverse family conditions. She takes care of her brother by trying to act as a substitute to mother, showering him all the possible love and care. The story speaks about the intense struggles and suffering of the husband to keep his wife alive. The story also reveals the emotional outbursts of the couple at times. On many occasions, the couple is seen hiding pain and mental turmoil from each other to boost each other's morale much required during hours of crisis. Pitta wanted her husband, to be on her side during any medical procedure. It speaks of the trust Pitta had on her husband. Pitta develops a poor body image during illness. Her narratives speak of beauty an essential concern of the morbid person. One session of dialysis was guaranteeing a life of two days only. Pitta perceives dialysis depressing. The story reveals a woman's obsession with the cleanliness of her house. Pitta got upset with the condition of her house even when she had come out of death like situation. She was brought back home by her husband in his lap after being away for one month on treatment.

Pitta also understands the plight of her husband, who suffered silently. The financial implication of costly treatment of Rs. 35000/- per month on dialysis alone drained family financially who sold their house like many other transplant recipients in this study. A significant concern in this story also was the inability to celebrate festivals and social gatherings. During struggles, a person becomes part of different groups as was the case with Pitta also who became a member of the dialysis group in the hospital.

Pitta remained on dialysis for six years, and her husband wholeheartedly supported her. She faced many episodes of death like situation but felt her husband stood like a rock between her death and life. The story also points to the belief of persons in keeping fast and prolonging the life of the spouse. The role reversal of the husband to keep "Karwa Chauth" fast speaks of his true love to keep his wife alive, but this story reveals male sufferings at the helm of affairs. Males suffer in silence and are also supposed to be strong and supportive in all situations. Pitta went to the hospital when a BSD donor kidney became available without giving a second thought as to how finances will be managed, and the husband manages everything. It speaks of the capability of a male in managing crisis and funds as well.

Pitta feels terrible for her donor family who lit her life before going into darkness themselves. Pitta traces her donor family through social media and feels awesome meeting her BSD donor's mother. They both hug and cry. This feeling gives a lot of consolation to the mother, who felt her son alive in Pitta. Pitta celebrates her donor's birthday at his home, and the mother of the donor feels her son has celebrated his birthday after death as well. The mother feels Pitta has kept her son alive. With a new kidney, Pitta feels her beauty has restored and says Zombie is back to life. According to Pitta she would have died long back, had a mother refused to donate her BSD son's organs. Pitta feels organ donation can be done only by the 'Messiah of God' and not an ordinary person.

The researcher would like to add that Pitta's husband kept fast on "Karwa Chauth" in 2018 and clicked beautiful pictures with his wife and shared with the researcher. Also, in 2018 on "Bhaiya Dooj" a festival of brother and sister, the donor family members visited Mrs. Pitta at her home, celebrated the festival with her and clicked pictures together as they feel their BSD donor brother alive in her. The photos were shared with the researcher also.

Summary: -This Chapter reveals that to avail treatment for the patients at far off places, the families had to disintegrate, and it also impacted the education of children. These families had to depend on relatives and friends for accommodation in big cities. They, in turn, would face trouble from landlords for having guests for a prolonged period. In the absence of a dignified alternative, poor recipients had to live with indignity and insults. Some attendants (males usually) had lost jobs, some had got posted to nearby places, and some were taking leaves from work and favours from bosses. Some poor recipients and their family members had no option but to stay on roads, corridors of hospitals and under bridges. Simultaneous management of two surgeries of living kidney donor and recipient in one day was an arduous task for the most.

Kidney donation by 'near relatives' was a cost-effective option, but it also created domestic battlefields. Some 'near relatives' who donated kidney were concerned for their own health. They wondered if the donated organ would work and had apprehensions about the recipient's reproductive capacity after transplantation.

Purchasing kidney or finding living donors outside the family was sometimes a compulsion due to the incompatible family donor, lack of possibility of swap or domino transplant and family circumstances. The high cost of treatment for kidney failure was also seen as a factor tearing joint families apart. The living kidney donors expected improved behaviour from the recipients after the transplantation. In most cases, they felt disappointed.

The unknown families, in some cases, had looked beyond their sufferings and rescued such patients by donating BSD donor organs of their relatives. The six-year ordeal of Ms. Pitta hooked to dialysis ended with the transplantation of one kidney of a BSD donor as is revealed in the in-depth case study. Pitta traces her donor family, meets them, and makes them feel that she has kept their donor alive. These interactions emerge into an extremely satiating social relationship between the donor and kidney recipient families.

CHAPTER 9

Perspectives of Liver and Heart Recipients

The first part of this Chapter reveals the socio-demographic information of liver recipients and their perspectives to liver disease and liver transplants. It reveals medical and perceived cause of the liver disease, treatment-seeking behaviour of liver recipients, problems faced by them with the availability of BSD donor liver, measures taken by them to ease the financial burden, family support and sufferings, financial investments of liver transplant surgeries, care post-transplant, post-transplant problems and hospital episodes. The second part of this Chapter divulges the socio-demographic information of heart recipients and reveals their perspectives by illustrating their medical condition before transplant, financial investments on heart transplants, contravention of geographical boundaries in such transplants, post-transplant problems and recipients' feelings post-transplant.

Socio-Demographic Information and Perspectives of Liver Recipients: -

This part of the Chapter reveals socio-demographic information about seven liver recipients and explores the perspectives of these recipients and their families.

Socio-Demographic Information About Liver Recipients

The research reveals the information about seven (7) liver transplant recipients. Some were alive at the time of study and a few were dead also.

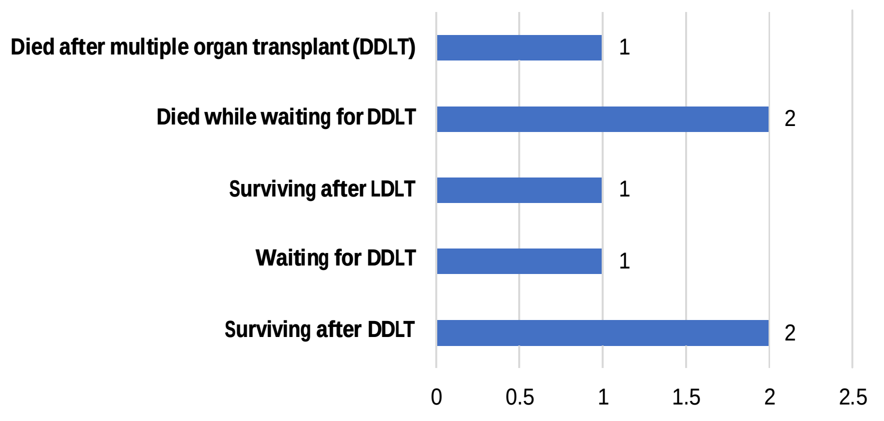

Figure 9.1 Status of liver transplant recipients(N=7)

Figure 9.1 reveals that two (2) recipients were surviving after DDLT (Deceased Donor Liver Transplant), one (1) recipient was waiting for DDLT and one (1) had LDLT (Living Donor Liver Transplant). There were total four surviving recipients among seven recipients that formed a part of this study. Among the remaining recipients, two (2) had died waiting for DDLT and one (1) was dead after multiple organ transplants (Deceased Donor liver and two kidney transplants).

Table 9.1 Socio-demographic information about liver recipients (N=7)

BIO DATA	NUMBER
AGE	
Minor	1(14%)
Major	6(86%)
SEX	
Male	5 (71%)
Female	2(29%)
RELIGION	
Hindu	4(57%)
Christian	1(14%)
Sikh	2(29%)
OCCUPATION	
Student	1(14%)
Housewives	2(29%)
Lab technician on contractual basis	1(14%)
Policeman	1(14%)
Retired employee in Pvt. Company	1(14%)
Agricultural land	1(14%)
MARITAL STATUS	
Married	6(86%)
Unmarried	1(14%)
TYPE OF FAMILY	
Joint	2(29%)
Nuclear	5 (71%)
PLACE OF RESIDENCE	
Uttar Pradesh	2(29%)
Delhi	2(29%)
Punjab	1(14%)
Kerala	1(14%)
Jammu	1(14%)

Table 9.1 reveals most liver recipients 6(86%) were major, majority 5(71%) were males, the majority were Hindus 4(57%), the majority 2(29%) were housewives, and the majority 6(86%) were married. The majority of the recipients 5 (71%) were living in nuclear families and the majority of recipients that is 2 (29%) were from Delhi, and 2 (29%) were from Uttar Pradesh.

Medical Causes of Liver Disease

The causes of the disease were different for different recipients.

As reported by Mr.XI, *"I have been a Liver Cirrhosis patient for over 34 years because of Hepatitis C infection. Doctors believed that I acquired it through a blood transfusion following my road accident at Delhi in 1979. During all these years, I managed the disease primarily through medication, strict dietary control, regular monitoring and exercise under the supervision of specialist doctors and with the support of my wife & later my children. Just five days before my wedding in 1979, I met a road accident. I suffered from Left femur bone fracture, police shifted me to a Government Hospital and a major surgery was done, with five units of blood transfusion".*

As reported by Mr.ZI, *"The boy presented the disease with some abdominal pain. He was okay till the age of 4 years, but after four years he suffered from one ailment or the other. He had an episode of multiple problems like blood vomiting, weakness, leg pain, bad breath, etc. We went to Kerala, his Blood Urea was found to be 350, and Serum Creatinine was very high. But he was walking, singing and smiling too. The child had some problems with the liver that was resulting in stone formation. Stones had damaged both his kidneys. The medical tests revealed that the child was suffering from PH 1[4]. He was admitted in liver transplant hospital in Kerala on 30 7. 2015 for transplant and died on 16.9.2015. He was on Ambulatory Peritoneal Dialysis for one year".*

As reported by Mrs.YI, *"I got jaundice very frequently after marriage from 2006. And it was on 23rdFebruary that I got admitted in hospital and on 10thMarch 2015 I got liver transplanted".*

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[4] PH1 (Primary hyperoxaluria type 1) is a disease that is caused by a deficiency of the liver peroxisomal enzyme called Alanine Glyoxylate-amino Transferase (AGT). This enzyme is important for the conversion of glyoxylate to soluble glycine. When Alanine Glyoxylate-amino Transferase (AGT) activity is absent, the glyoxylate instead of getting converted into glycine is converted into oxalates. These oxalate forms insoluble calcium salts that amass in the kidney and other organs resulting in kidney failure (Marion B et al. 2014).

As reported by Mr.Sul, *"His disease started showing signs from 2013. He had a loss of appetite, vomiting, and fever with increased Bilirubin levels. He was diagnosed with Cirrhosis of the Liver but was given the medical treatment only. His medicines were costly, not less than Rs.13000/- per month but could go up to Rs.30000/- per month also. In 2015 CT scan and MRI revealed nodules in his liver, and he is suffering more now. His Bilirubin levels remain high, and he has fluid retention in the body. His blood group and MELD[5] score had been done in the hospitals before registration for cadaver transplant".*

As reported by Mr.Sil, *"Her Bilirubin levels were high, and she had water retention in the belly (ascites)".*

As reported by Mr.Dl, "*I was suffering from Cirrhosis of the Liver with Hepatitis C".*

The researcher found a different understanding of the patient with the diagnosis of liver failure. While some respondents could name the disease, some knew the symptoms only. Most patients had Cirrhosis of the Liver. One paediatric recipient was suffering from Primary Hyperoxaluria type 1 (PH1) disease. The inability of his liver to function normally had resulted in damage of two kidneys as well. One recipient had spent 34 years with Hepatitis C acquired through blood transfusion before he was transplanted liver.

Similarly, occasional jaundice for approximately seven years before marriage followed by repeated jaundice for nine years lead to the cirrhosis of liver and need for a liver transplant. However, with liver recipients, the liver failure was not sudden as reported in most of the kidney failure recipients. But the liver patients continued costly medicines for a few years to a few decades before their liver reached a stage when the liver transplant was required.

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[5] MELD stands for Model of End Stage Liver disease. It is a number value indicating the severity of the liver disease in a patient. MELD score ranges from 6 to 40. The closer the score to 40, the greater the need for a liver transplant (Moraes,Oliveira and Fonseca-Neto, 2017).

Perceived Cause of The Disease

Irrespective of the medical cause believed to be behind liver failures, the respondents had a different understanding of the cause of diseases, and as a result of this, the treatment-seeking behaviour of respondents also varied.

As reported by Mrs.YI, *"I got jaundice in Delhi immediately after marriage once I came to this place. Probably Delhi did not suit me. My father never wanted to send me back after the "pagphera ceremony" (Meaning a post-marriage Hindu ceremony when a female goes to her paternal house for the first time after marriage). My husband sometimes tells me maybe I was suffering from this disease beforehand when I was unmarried. But how can he say that I have four sisters and one brother and none in my family suffered from jaundice? Had it been there, my family members would have got this disease. My daughters also do not have this disease".*

Irrespective of the medical cause well mentioned in some case files, the aetiology of disease as perceived by one of the female recipients was her marriage that required shifting to Delhi. In this case, there were allegations and counter allegations within the male and female spouse regarding the cause of disease, a coping mechanism of projection and counter projection adopted by people in crises.

Seeking Treatment Outside Allopathic Medicine to Arrest the Disease

Two liver transplant recipients reported using alternative treatment as narrated by them.

As per Mrs.YI, "I have been to "Jadfook Wale Baba" (exorcist) to get rid of this disease that has unique skills of dusting off the disease with a special broom. The procedure varies in Delhi and UP. In UP, at my parental house, these Ojjhas also called Jadfook Wale Baba are well versed in comparison to Delhi Ojjhas where I got married. Early in the morning, I was supposed to go to Ojjhas (exorcist) with a few special prayer items. The items used by these people in these two places vary. In a "Brass Plate (Petal Ki Thali)" they put lime (choona) in UP and would tell me to put my hands in it, after chanting prayers in their own language doing other rituals too *and……….within minutes it becomes yellow in colour. But in Delhi, these Ojjhas use bitter oil (kadwaa tel) instead of lime. It does not change colour. The procedure seems ineffective here in Delhi. However, the flowers, dhoop (incense), incense sticks (aggarbatti) are a part of the ceremony in both the places".*

As per Mr. XI, "In 2005 CT scan started showing Liver de-generation (Cirrhosis). Oedema in ankles started with increased constipation, sometimes blood in the stool. Allopathic doctors started saying - At some stage, Liver Transplant would be required. I could never reconcile to this suggestion. I felt that I would face destiny rather than a liver transplant. Hence, I started with alternative treatments like Ayurvedic and Homeopathic, consulted even Baba Ram Dev at Patanjali Yogpeeth. I had learned about Dr.Jammi an Ayurvedic Consultant in Chennai–for Liver Diseases. My cousin had benefitted with his treatment. But at the same time, I kept visiting Chennai for allopathic consultation and treatment from Abu Dhabi almost every three months. Liver function parameters showed improvement. I was on stringent diet restrictions, Low or no salt, no oil/no ghee, no fried items and no food that was hard to digest. I was doing regular Lab Tests, Ultrasound Scans & MRI to monitor Liver Parameters/liver condition. But on 15th March 2012, I got up in the morning with very low energy. There wasn't BP meter at Home, checked Blood Sugar (since Glucometer was available). Blood Sugar was very low, 37only. Immediately I took honey, lime and recovered. On 17th March 2012 similar low energy condition repeated. I consulted the family doctor who is an Internal Medicine Specialist in Abu Dhabi. Since he was aware of my case history; he suspected something abnormal with my Liver as I was not diabetic and referred me to Chennai".

Two liver transplant recipients, who eventually got liver of the BSD donors transplanted, reported of seeking alternative treatment also in addition to allopathic treatment prior to liver transplant surgeries. The alternative treatments were Ayurvedic consultations, Homeopathic consultation, consultation of Baba Ram Dev at Patanjali Yogpeeth and exorcists as well. The use of alternative treatment could be attributed to denial, a coping mechanism usually adopted by the recipients to believe that the disease can be eliminated not assured in allopathic medicine. In one case, the female recipient had resentment with the procedure of dusting off the disease by exorcist ("jadfook wale baba") at Delhi near to her in-law's house. On the other hand, the exorcists at her paternal home in UP were well versed with the same procedure revealing an ethnocentric feeling of the recipient. One of the case studies also points to the changing perspectives of the recipient. Mr. XI could not think of a transplant in the initial stage when told he would require a liver transplant in future. He believed he would never go for the liver transplant but accept fate in future. However, the same recipient later waited and prayed for the availability of the Brain Stem Dead donor for a liver transplant.

Problems with Availability and Accessibility Related to Deceased Donor Liver Transplant (DDLT)

Problems were encountered by recipients with availability and accessibility related to the Deceased Donor Liver Transplant (DDLT). People called for Deceased Donor Liver Transplants are not always lucky to get the organ transplanted.

Call for Deceased Donor Liver Transplant (DDLT) Does Not Always Result in Liver Transplant

The waiting recipients registered with hospitals for Deceased Donor Liver Transplant (DDLT), usually called cadaver donors, wait and pray for getting liver. They are called several times, and in many cases, they go back without any transplant.

As per Mr. XI, *"I received five calls from the hospital for a transplant, went to the hospital, completed formalities and even got admitted, but every time returned without surgery. Once, my family members flew to Chennai from Delhi. Another time, (we - the family of five) flew to Apollos Hyderabad (name changed) on receiving a Donor Call but in vain – the donor family withdrew their consent. Meanwhile, my Albumin level became low, and Albumin transfusion was done. Doctors told that Albumin transfusion could be fatal, but I had no other alternative. Gradually started feeling lethargic and sleepy almost the entire day. Tumours grew almost to 3 cm size in my liver. They could come out of the Liver mass, and these cancer cells would mix with blood leading to surgery of no use. On 13th July 2013, resorted to TACE (Trans Arterial Chemo Embolizing) procedure for killing Tumours,* *and the procedure was partially successful. I became anxious when the doctor told me that I had only a week or two weeks before I would become "Unfit" for transplant. There was no donor in sight. While recovering from the partially successful TACE procedure, the Coordinator informed me that a 19-year-old boy was admitted in the hospital after a severe accident, and it could be your donor. I kept waiting for the whole day on 13th July 2015 with no confirmation. I was made to fast since morning and prepared for operation. I was also put on the intravenous fluids. Hospital asked me whether I would like to go for Surgery as Dr. K (reputed surgeon) was away in the US. Earlier, we had insisted that Dr. K should only perform the surgery. But now, we could not afford to miss the chance, so we agreed for surgery by any of the Surgeons".*

As per Mrs.YI, *"I was called only once, and other patents who too were waiting for transplant felt jealous of me when they found me the best-matched recipient. They suspected of some foul play by the hospital".*

Living Donor Liver Transplant (LDLT) Replaced by Deceased Donor Liver Transplant (DDLT)

Deceased Donor Liver Transplant (DDLT) was performed in place of Living Donor Liver Transplant (LDLT) in two cases. Two living liver donors were prepared for liver donation but were rescued by Deceased Donor livers at the nick of time. In one case, the living liver donor was the father of the child, and in the second case, it was the husband.

As per Mr. ZI, *"My wife was not a match with this boy. She wanted to donate. I too wanted to donate. My son was worked for sequential liver-kidney transplantation with me as a donor, and they started his haemodialysis before planned Living Donor Liver Transplant (LDLT). However, with the availability of a 3-year female cadaver donor, he was taken for a combined composite Liver kidney transplant on 2.8. 2015. He got three organs transplanted from a single donor that is Liver and two kidneys".*

As per Mrs.YI, *"They had finished with the tests for me and had to start tests for my husband. My husband wanted to donate his Liver, but we were apprehensive too,* *what if something goes wrong with my husband? Who will take care of my small children? I was hospitalized on 23rd February 2015 and operated on 10th March 2015. It was a male child of some family living in Lucknow whose organs were donated by his family".*

Patient Needed A Liver Transplant but Died Without Any Transplant

As per Mr. Brl, *"My brother died before liver transplant. He was an ESI beneficiary, but ESI officials were demanding a bribe to help him in getting transplant surgery done. They were only finding faults with paperwork several times. They were asking for bribe".*

As per Mr.Sil, *"My mother in law died waiting for a transplant. We were not given proper information by the medical doctors in a private hospital. They would only ask for payments and give no information about the condition of patient".*

Waiting for Deceased Donor Liver Transplant (DDLT) But Rescued by Living Donor Liver Transplant (LDLT)

As per Mr.Dl, *"I registered for Deceased Donor Liver Transplant (DDLT). But my daughter of 22 years donated liver to save me as we could not wait long as per the instructions of treating doctors and my daughter volunteered to donate her liver".*

Waiting for Deceased Donor Liver Transplant (DDLT): Registered with Various Hospitals

As per Mr. Su, *"He has registered at three different places. One at 'Jeevandaan', with 3000 registration fees and in another hospital at Bangalore with registration fees of Rs. 2000. He registered himself in Delhi also with one of the NOTTO registered transplant hospitals. In one hospital, his waiting number in the list is 4, and his turn for a transplant there is expected within three months. The hospital will apprise him shortly about the availability of cadaver donor liver".*

Recipients keep praying for getting a deceased donor call from hospitals. Some are lucky to get a liver transplant done within the first call, and some get calls many times. While one recipient got a liver transplant within the first call for DDLT, the second recipient shifted five times to the hospital before getting a suitable BSD donor liver. The case studies reveal how Living Donor Liver Transplant (LDLT) was replaced by Deceased Donor Liver Transplants (DDLT) in the nick of time for two recipients. Similarly, a male recipient who was waiting for a DDLT was rescued by LDLT at the nick of time. His medical condition did not allow him to continue his wait for DDLT. In this case, his 22-year young daughter rescued him by donating 65% of her liver, revealing gender issues ingrained with such donation in Chapter 10. There was one recipient who had cleverly registered at three different places. It could not be possible if the organ transplant registry at NOTTO were functional. Two recipients died waiting for a liver transplant, and the relatives of both these recipients had some complaints with the authorities. One had a complaint with the private hospital where his mother in law was under treatment. He alleged that the hospital did not divulge the truth about her condition resulting in the death of the recipient. In the second case, the brother of the recipient was annoyed with ESI authorities who did not believe the seriousness of his brother's disease. Hence, they were not giving consent for liver transplant and were asking for a bribe also. The inability of the recipient to pay the bribe, the ESI officials were finding faults with his medical paperwork and were not giving their consent for liver transplantation. In this case, the relative is determined to fight his brother's case through the legal channel. The story points out the moral degradation of people who try to cash on the opportunities even when it concerns human life.

Coping with The Financial Burden of Disease by Rationing Medicines

The relatives apprised the researcher about ways and means adopted by the recipients to cope with the financial burden of disease.

As per Mr. Ylh, *"We had to purchase medicines from the market which cost us Rs. 1500 per day before liver transplant. Not able to meet the exuberant costs of the medicines I would give only the morning dose and skip the evening dose. Post-transplant, the family, was happy as they did not have to purchase medicines from the market".*

As per Mrs. Ylh, *"I am delighted as we do not have to purchase medicines from the market. All the medicines are given free as a result of a new initiative by AAP Government in Delhi".*

Researchers family visit found the family could not purchase a water purifier. The recipient was advised to get purified water only. Hence safe water was obtained from the market for the recipient only, and the rest of the family was using tap water. They wanted someone to help them to donate a water purifier**.**

The family coped with financial aspects of liver disease by rationing of medicines, skipped one dose of medicine every day to deal with finances before transplant. Incidentally, the researcher interviewed the liver recipient and her husband Mr. Ylh also. He was a roadside hawker about whom our Prime Minister had talked in his "Mann ki Baat" in 2015. Mrs. Ylh had a lot of appreciation for AAP Government. She was not skipping any dose of medicine Post-transplant. All costly medicines were given free of cost that was not the case with previous Government. But his struggles to keep the recipient free from infections had not decreased. he was not able to purchase a water purifier much required for the recipient and wanted someone's help in this regard.

Family Support and Sufferings

Support of family is vital for the recipients before, during and after transplant.

As per Mr. Zl, *"My wife got training to do peritoneal dialysis every day round the clock although the main problem was with his liver. I don't know how he faced his sufferings. We thought he would recover as he was attended by well-known doctors, one from liver speciality and another from nephrology. His abdomen was kept open after multiple organ transplant. He was on the ventilator for three days, developed Hepatic artery thrombosis. He had spikes of fever post-transplant and repeated diarrhoea. He had several drugs that were changed repeatedly. We suffered a lot as we were devastated with his suffering at a very young age".* The reports of his case file revealed that he had developed fulminating liver failure with CMV (Cytomegalovirus) hepatitis post combined kidney-liver transplant.

As per Mrs. Yl, *"I have a very supportive family. My husband is like God to me. My daughter has become very responsible for my disease. She takes care of many things, she even injects insulin to me, and doctors have taught her to do so. I sometimes get low sugar sometimes high. I have got diabetes now".*

During home visits to the family of Mrs. Yl, the researcher found her husband was doing the household chores. Her eldest daughter was also very supportive. Her husband was very co-operative with his wife, and he always wanted to see his wife happy. He would often ring the researcher to talk to his wife at times whenever she used to feel low.

As per Mr. Xl, *"We were soon joined by our two daughters in Chennai during our stay there, waiting for a deceased donor. My whole family was with me waiting, hoping, wishing, inquiring and praying. With time at my hands running out within a couple of months, any transplant happening at the hospital made us think - When would I get a call for the same? - Why was I not shortlisted for this surgery? - Where am I in the waiting list? - What are the tumours' sizes? - How close am I to my last day? Of course, every day, something or the other was happening. We were in contact with the doctors, Hospital staff and others (even temple priests) to get the donor as soon as possible. Only I and my family can count those moments, hours, days, weeks and recall how they passed by. The process (pre and post) liver transplant is excruciating, stressful, agonizing, and of course, very expensive".*

As per Mr. Brl, *"I supported my brother, and I am taking care of his two kids and wife after his death. I will fight the case in court. Justice was not done to his life by ESI".*

The pre and post liver transplant period was harrowing, stressful, disturbing and of course, very expensive as per the narratives of the recipients. Family members provided the financial, emotional, psychological and physical support. The descriptions of the family reveal how Individual health suffering becomes the suffering of the whole family. For timely availability of BSD donor liver, the entire family keeps waiting, hoping, wishing, inquiring and praying for their loved ones. The family members keep waiting for BSD donation as they feel time running out within a couple of months. The cooperation of family members and concern for the ailing person's happiness shows the importance of a family for such recipients.

Financial Investments of Liver Transplant Surgeries

Out of 4 liver transplant recipients who were transplanted liver, only three recipients were surviving at the time of interview while the fourth had died after multiple organ transplants (one liver and two kidneys together).

As per Mr.K, *"The Government gave me 17 lakhs, and they accepted the hospital bill of 15.5 lakhs only. I arranged the rest of the money. I took a loan from private parties. I don't know when will I finish my loan, but I am sure I can pay back. It needs some years. Now, also I am proud of my boy (He sent several photos of his dead son receiving prizes for his paintings in school). I only feel bad for my boy who suffered like hell after transplant and died before reaching his 6th birthday; he went through a lot of pain".*

As per Ms.DlDa, *"My papa (Mr.Dl), is a CGHS beneficiary. They paid him 13 to 14 lakhs only. The remaining amount was taken as a loan from friends and relatives as the matter was urgent. My papa later sold his plot of land and paid the loan to his friends and relatives later".*

As per Mr.Yl, "The surgery was done free of cost. I had to incur Rs. 50000/- that too on certain tests that had to be done outside the Government hospital".

As per Mr.Xl, *"Deposited advance for surgery (Rs. 20 Lacs) on 28th March 2012 and arranged 35-40 units of blood (at least 50% of my blood type) through volunteers. Arranging blood was tough, but with God's grace, it got managed. The pre-evaluation cost was Rs. 1,91,500/-and Post evaluation cost was Rs. 57, 627/-.Liver Transplant cost was Rs. 23,40, 189/-.Post-Liver Transplant was Rs. 1,76,278/-.* You may safely add another 20-25% towards the essentials relating to transplant/treatment etc. (*of course, excluding our stay at Chennai, travel by family and various other expenses, etc. My daughter decided to buy a second hand Santro Car for local movement in the city, primarily to avoid infection"*.

Table 9.2 Age-wise, disease-wise, year of transplant, type of hospital, type of liver transplant, financial cover and investment incurred for transplant surgeries (N=4)

Age in years / sex	Disease	Year of operation	Type of hospital	Type of transplant	Financial Cover	Expenses in rupees
Mrs.Yl,36 Year	Cirrhosis of liver	2015	Govt.	DDLT	Nil	50,000
Mr. Xl,62 Year	HCV Cirrhosis	2012	Private	DDLT	Pvt. insurance	25 Lakhs
Mr.Dl, 45 Year	Liver Cancer	2016	Private	LDLT	Govt. insurance	40 Lakhs
Master Klk, 5 Years	PH type1	2015	Private	DDLT	Govt. insurance	40 Lakhs

Table 9.2 reveals that out of four liver recipients who were transplanted liver, the lone female 36-year-old recipient Mrs. Yl who had DDLT spent minimum that is 50 thousand only in Government Hospital. The cost in private hospitals ranged from 25-40 lakh rupees.

Liver transplant surgeries are very costly surgeries and complicated too. The expenditure on liver transplant surgery was only 50 thousand in Govt. hospital and extremely high in private hospital ranging from 25 to 40 lakhs. Out of two respondents who spoke of investing 40 lakhs each for a liver transplant, both had Govt. insurance, but that could not meet the transplant expenses fully. Both had to cough out extra money to meet the transplant expenses. One was in debt even after two years of transplant surgery, and another had sold a piece of ancestral land to pay off the loan taken from friends and relatives. In the former case, the recipient died within 45 days, leaving his father in debt and agony. The narrative of Mr.K, *"My son, suffered hell after transplant till death"* speaks of volumes of pain and sufferings of patients and relatives. These surgeries need investment for shifting, living in rented accommodation and taking the second-hand car to be near to the transplant hospital. It speaks of huge investments required for such surgeries that are not within reach of ordinary uninsured people.

Care After Liver Transplant Including Adjustments with Drugs

The care of transplant recipients is very demanding and requires the cooperation of family members. The adjustments with drugs are very challenging not only for recipients but medical professionals as well.

Medicines and Immunosuppressant- A Tough Adjustment

The recipients narrated difficulty in adjusting with medicines.

As per Mr.X, *"I landed in the Cardiac Care Unit (CCU) for the next 12 days after transplant. Doctors from different specialities were visiting every hour or so. There used to be long discussions amongst Doctors and Nurses with my reports outside the CCU. Now and then, a blood sample was taken, X-ray, Heart monitoring and very often, some special tests performed. One or two sisters were always in attendance. On the 2nd day in CCU, they started Immunosuppressant Tacrolimus – first dose 5 ml – it did not go well – abnormal feelings. The second dose increased to 10 ml – experienced virtual collapse. Doctors/sisters were running in and out, and there was a sort of chaos. Virtually I had been to the door from where no one ever returns. After two days of the most difficult and stressful time, the Doctors could control the situation. Post Liver transplant the new immunosuppressant – Cyclosporine and Myfortic was advised in varying doses along with other medicines. Initially, about 30 Tabs /Capsules/medicine through intravenous route were given, and 4 - 6 doctors of different specialities were attending me. After 5 - 6-days post-surgery, doctors made me walk, 4 staff supported me, I felt like as if I was a skeleton with no control on my movements. Intensive physiotherapy 3-4 times initiated, to ensure lung health".*

As per Mr.X, *"I had extreme sweating while in sleep after one month of the transplant. Major checks over one month were done to rule out any heart problem. Tingling sensation all over the body continued with great discomfort, primarily due to immunosuppressant. Fortunately, the body settled now. Right thigh area had acute pain, some Neurological problem was there, now under control with medicines. Lying flat was difficult and could lie reclined only".*

As per Mrs.YI, *"Previously I had to take 20-22 tablets/medicines a day immediately after discharge from hospital. But now, after two years of transplant, I take 10-12 tablets a day. I had to develop a friendship with this person (liver) who is with me now. Doctors used to say he is my new friend who has to be taken care of well".*

The liver transplant recipients face adjustment problems with the new organ and the immune suppressants. The medical condition of the recipient and expertise of medical professionals decided dose and type of immune suppressants from time to time. The recipients take time to get adjusted with different doses and different combinations of medicines. A settlement with drugs sometimes takes a long time as was reported by these recipients. The recipients narrated death-like experiences with the treatment in the earlier period, which eventually faded with changes and adjustments with the medicines. Initial problems were many with the medication. The number of drugs is very high at the beginning ranging from 22-30 per day, which reduces later with time.

Care at Home After Transplant

As per Mr.XI, *"When I was discharged from the hospital after transplant surgery, I was given a lot of medical advices including diet and cleanliness. House was converted to a mini CCU to avoid any infection. Till one month after surgery: Morning blood sample, daily dressing of stitches was done. The hospital visit was required after every 2-3 days for review and later for stitch removal. Weight chart, BP chart and Sugar chart were monitored at home. Frequent changes in medicine were done based on Lab reports. The body movements were painful and difficult* *initially. I was not able to turn side as I had no energy, and I had no or little sleep. I had total hair loss and weight loss. I stayed in Chennai for 2½ months for a complete recovery for consultation with Doctors / Physiotherapist".*

As per Mrs. YI, "Before discharge from the Govt. hospital, a team of doctors visited my house to see how I could be taken care of at home. Doctors gave a lot of advice to my family members regarding how I had to be taken care of at home".

The patients are required to be taken care of well after transplant. Post-Operative care is critical that emphasis on overall cleanliness to prevent the spread of infection. Environmental hygiene, food hygiene, personal hygiene and intake of safe water determine the fate of transplanted organ and the recipient. This aspect becomes vital as a patient on immunosuppressant medicines is vulnerable to infections. Before discharge from the Govt. hospital, a team of doctors visited the house of the patient to ascertain that the recipient is taken care at home. It reveals the commitment of doctors to ensure the safety of the transplanted organ. The recipient told the researcher that she was called on her second transplant anniversary in hospital and doctors celebrated her anniversary there. The liver transplant surgeries are complicated surgeries and seeing patients alive after transplant surgery is an achievement for doctors as well. The male recipient had lost hair, but it never raised any beauty concern for him as was found among female recipients.

Post-Transplant Problems

A liver transplant does not guarantee a life without illness but adds to several other problems as reported by the liver recipients. The other body organs and systems face many transplantation-related issues. The narratives of recipients depict the type of problems faced by recipients.

Diabetes and Thyroid Problems

Two recipients after transplant reported of developing diabetes and thyroid problem. People with diabetes are prone to infections and immunosuppressants add to the problems. Immunosuppressants suppress the immune system of a patient and make him more vulnerable to infections.

As per Mrs.Yl, "I am okay, but I have developed a problem of thyroid and diabetes too. I usually take 18-24 units of insulin for diabetes only. I have now some problems with feet too; there is some infection in my feet".

Irregular Periods/Cessation of Menstrual Bleeding for 3-4 Months

The other systems of the body are also affected due to hormonal imbalances caused by changed body environment after liver transplant.

As per Mrs.Yl, "My menstrual periods got very irregular. After transplant operation, I did not get periods for three months. Doctors were apprehensive of my pregnancy. They were concerned. Now I have regular periods".

Loss of Hair

After two years of transplant, Mrs Yl complained of having lost her hair due to some skin infection while the researcher contacted her on the phone. She said, *"I look ugly now. There are patches of baldness on my skull. People have started taunting my baldness and call me ganjee (bald woman) although they do it lovingly, it hurts me internally. I had such symptoms twice earlier also but with medicines; it would be okay. Unfortunately, medicines don't affect these patches now".*

After some time, she rang me and told me that she has lost all her hair, including eyebrows and eyelashes and feels depressed for the loss of her beauty. She said, *"My nephew is getting married. How will I attend marriage without a single hair on my head, eyebrows or eyelashes? I look ugly".*

Irritability

Irritability was also a matter of concern for the recipients.

As per Mrs.Yl, "I have become very irritable after the operation. My behaviour has changed, and I have lost tolerance now. Very trifle affairs disturb me and bring tears in my eyes. I am unable to control my tears".

As per Mr. Xl., "This disease has made me irritable I feel more so after transplant".

Reduced Lung and Kidney Functions

Immunosuppressants adversely affect other organs, and it had done so with the recipients as depicted by narratives.

As per Mr.Xl, *"Lungs capacity has reduced a lot. Immunosuppressants have affected both my kidneys adversely. My kidney functions have reduced to less than 30%".*

Transplant surgery and post-transplant recovery and adjustment with the new organ are a continuous struggle between life and death. The recipients face many problems after liver transplantation. These recipients faced both physical and psychological issues. Irritability and a tendency to cry for small affairs were found to be problematic for the caretakers. At times recipient felt low. The researcher boosted the morale of depressed recipients by talking to them on many occasions as requested by the caretakers. Recipients faced problems related to endocrinal functions like thyroid problem, diabetes and cessation of menstruation in the female recipient. Problems were associated with the functioning of organs like there were reduced lung capacity and reduced function of kidneys.

"How will I attend marriage without a single hair on my head, eyebrows or eyelashes? I look ugly" as narrated by one female recipient speaks of serious beauty concern of the recipient due to the side effect of immunosuppressants. Self-resentment with the changing beauty with complete hair loss not only of the skull but of eyebrows and eyelashes too had led to low body image and was detrimental to the social health of the recipient. The researcher felt the beauty concern less in the male recipient in comparison to female recipients in the event of loss of hair.

Post-Transplant Hospital Episodes

Two patients reported post-transplant hospital episodes as well.

As per Mrs. YI, *"In between, I had profuse vaginal bleeding. I was hospitalized for ten days and was given a blood transfusion. A lady doctor gave me medicines, but I recovered fully".*

As per Mr.XI, *"After six months of liver transplant one day I felt I was unable to eat, speak, drink, move or walk. I had severe and painful ulcers in the mouth. Local treatment outside India was ineffective. I was rushed to a Pvt Hospital in Chennai from Abu Dhabi, practically on a wheelchair. I remained in and out of the hospital for three weeks. Doctors reverted to Cyclosporine with Myfortic was added. Now the immunosuppressant dose has got set, and there are no issues".*

As per Mr.XI, *"I developed hernia after one year. Hospitalized for five days and operation was done for Hernia repair. Mesh in three areas - Mesh hurts even today".*

Two recipients who reported of hospital episodes, both the recipients were admitted twice in the hospital. One recipient was admitted for the menstrual problem at one time for ten days and was even transfused blood. When the researcher contacted the same recipient after two years and four months post-transplant, she was hospitalized and had complained of nausea vomiting and weakness. She had developed jaundice once again, as reported by her husband. The other recipient was hospitalized twice. Once six months post-transplant, he was in and out of the hospital for three weeks, and his condition became normal with immunosuppressants adjustments. Another time he was hospitalized for five days, one-year post-transplant as he had developed a hernia, a post-operative complication. All these episodes in the lives of liver transplant recipients reveal that these patients are alive, but sufferings are on.

Socio-Demographic Information and Perspectives of Heart Recipients

Heart Transplant surgery replaces the diseased heart of the person with a healthy heart from a brain-dead donor. A heart transplant is the only treatment for people who have end-stage heart failure, and all other available treatment is not effective.

A heart was transplanted in two recipients in 2017 and for one recipient in 2013 only.

Table 9.3 Socio-demographic information of heart transplant recipients (N=3)

Socio-Demographic Information		Number
AGE	**Minor**	1(33%)
	Major	2(67 %)
SEX	**Male**	2 (67%)
	Female	1(33%)
RELIGION	**Hindu**	2(67%)
	Christian	1(33%)
OCCUPATION	**Student**	1(33.33%)
	Housewives	1(33.33%)
	Govt. Job	1(33.34%)
MARITAL STATUS	**Married**	2(67%)
	Unmarried	1(33 %)

Table 9.3 reveals that 2 (67%) recipients were major in comparison to 1 (33%) minor, 2(67%) were males, 2(67%) were Hindus, only one recipient was working and had a Government job and 2(67%) were married.

Out of the three heart recipients who had got heart transplant done, there was direct interaction with only two recipients. The researcher visited one of the recipients in her home after taking an appointment with her. She was 65 years old and had got a heart transplant done three and a half years back in Chennai with the heart of a male BSD donor and had forgotten about heart transplant. She was feeling very nice. The researcher found her getting a truck offloaded that was full of flower pots, etc. The researcher was astonished to see her moving here and there at ease without any problem at all. She even had a cup of coffee with the researcher while interacting with her at her home.

Table 9.4 Age and sex of heart transplant recipients in relation to their BSD donors (N=3)

S. No	Heart Recipients		BSD Donor	
	Sex	**Age in years**	**Sex**	**Age in years**
1.	Male	13	Female	32
2.	Male	46	Male	38
3.	Female	62	Male	20

Table 9.4 reveals that 13-year male was transplanted the heart of a 32-year female BSD donor and a 62-year-old female was transplanted the heart of a 20-year male donor.

The youngest of three transplant recipients were a male 13-year-old child who had received the heart of a 32 years old female BSD donor. It had been a bit difficult for surgeons to do this surgery as reported by the father of the child. Similarly, a female recipient of 62-year-old received the heart of a 20-year-old male BSD donor, and she was 65-year-old at the time of interview. Only one male adult of 46 years old had been transplanted heart of a 38-year-old male only.

The findings reveal that gender and age is no bar to heart transplantation.

Condition of Patients Before Heart Transplant

The condition of the three recipients before the heart transplant was terrible.

Mr. AHr said, *"Master RH had a loss of appetite, and he was not able to walk. He would get exhausted after walking a few steps only at the young age of 13 only. He was on treatment in the hospital and got registered for cadaver. He had a paralytic attack on the right side on 2nd December 2016. On 29th March 2017, he was admitted in the hospital, and on 9th April 2017 he got heart transplanted".*

Mr. BH said, *“I was suffering from genetic cardiomyopathy from 2011 onwards and was on treatment. I had three heart attacks but survived. I was on pacemaker before transplant surgery”.*

Mrs. CH said, "We were four sisters who had a family history of cardiomyopathy. It is a hereditary disease that was detected the first time in my elder sister in 1998. She had her first heart transplant in America in 2001. But within a year her heart was rejected by the body. She later had a second heart and two lung transplants simultaneously in America. That, too, was rejected by her body. She died immediately after a second heart transplant. All four sisters kept a constant vigil over their bodies going for regular check-ups, and I got a heart transplant done in Chennai after developing cardiomyopathy. Once detected with cardiomyopathy in 2011, I was advised to adopt a healthy lifestyle like doing yoga, doing mild exercises, taking less salt and fats. Blood thinners were also given to keep a check on my health. In 2012 Dec, I got a mild heart attack on my birthday while we were out on a family picnic”.

The condition of patients was not good as per the narratives of recipients. The youngest of three recipients who was only 13 years old had a loss of appetite and was not able to walk or talk. He would get exhausted after walking a few steps only, had a paralytic attack as well. The two other adult recipients were suffering from the same disease cardiomyopathy and had heart attacks before going for a heart transplant.

Financial Investments on The Heart Transplant

The heart transplant costs are beyond the reach of many patients. All these transplant surgeries took place in three different private hospitals in India.

Table 9.5 Expenditure of heart transplant surgeries with the place, year/ time of transplant (N=3)					
S.No	**Age and sex**	**Place of transplant**	**Date/year of transplant**	**The time gap between surgery and date of interview**	**Expenses on surgery**
1.	13 year Male	Delhi Private Hospital	9th April 2017	6 months	22.5 Lakhs but paid only 15 lakhs
2.	46 year Male	Karnataka Private Hospital	9th March 2017	7 months	13-14 Lakhs
3.	62-year Female	Chennai Private Hospital	14th Dec.2013	3 years 10 months	35 Lakhs

Table 9.5 reveals the varied costs of heart transplant surgeries.

The costs of heart transplant surgery varied in different places as per the statement of the respondents. The maximum money incurred on transplant surgery was 35 Lakhs by Mrs. CH and minimum was 13-14 Lakhs as per Mr. BH. The cost in case of interstate retrieval and transplant came to 22.5 lakhs for Master RH.

The transplant surgery of Master RH had a catastrophic effect on the financial and emotional health of the retired Subedar father Mr. AHr. Master RH is the only child in the family, and two of his siblings had died within a few days after their birth. The exorbitant cost of this surgery included hiring a charter plane also was not within reach of the father. Furthermore, none took father's prior consent for engaging a charter plane. The hospital withheld his bills because of non-payment of the whole amount.

Table 9.6 Place of transplant, place of heart retrieval and mode of transport used for transportation of heart (N=3)				
Place of transplant	**Place of heart retrieval**	**Number of green corridors created**	**Charter plane hired**	**Distance covered**
Delhi	Chandigarh	Two	Yes	18 Kms in 18 minutes from Airport to hospital.
Karnataka	Karnataka	one	Not required	25 km in 19 minutes between two hospitals
Chennai	Chennai	One	Not required	NA

Table 9.6 shows that Place of transplant, place of heart retrieval and mode of transport used for transplantation of heart in three cases of heart transplants. It also reveals the hiring of a charter plane for interstate heart transplantation.

It is a must for the heart to be transplanted within 4 -8 hours after retrieval. Hence it needs the establishment of a green corridor for quick transportation of heart from the heart retrieval to transplant hospital. In one case, the heart transplantation involved interstate movement and creation of two green passages, one in the retrieval State and another in the transplant State. It put a burden not only on police, transplant team but on the financial health of the recipient family as well. The family had to bear the cost of transportation of heart in addition to the transplant surgery, not informed earlier. The heart required a charter plane for transportation from Chandigarh to Delhi. Transplant team of transplant hospital flew from Delhi to Chandigarh and brought the heart in a charter plane.

However, the ethical issue with these surgeries is the cost factor. Families receive incomplete and selective information regarding the cost of heart transportation. Families should not be trapped. They should be informed before hospitals engage in organ transportation of any organ from other States. Also, such transplant surgeries need to be done only after getting consent from the recipient family. Withholding bills and putting recipient families in trouble is not at all ethical and speaks of the unethical trap laid by a private hospital. Varying costs of heart transplants should be a matter of concern for NOTP.

Boundaries Don’t Matter in Heart Donation and Transplant

Boundaries do not matter when it comes to Heart donation and its transplant.

Mr. BH from the northeast moved two months in advance to his maternal uncle's residence at Karnataka as none of the hospitals in Mizoram was equipped to do heart transplants. His uncle registered him in one of the heart transplant hospitals there. Interestingly he was registered with NOTTO also through one of the hospitals in Delhi and NCR. He shifted to Bangalore in Jan 2017 and got a heart transplant done on 9th March 2017. There were two separate dates of registration of the same patient on and 8th and 17th Feb. 2017 in the same NOTTO registered hospital at Delhi. It was an error detected by the researcher during the study. The same was brought into the notice of NOTTO too with a request to be cautious in future.

The female heart recipient, Mrs. CH, who was 62 years at the time of heart transplant surgery, never wanted to go to America. Her sister had gone to America twice for a heart transplant. But she chose Chennai to get her heart transplant done. She had to take a rented accommodation in Chennai for six months in advance. During this period, she was called thrice for heart availability. Once the donor family did not proceed with the donation of their relative's organs and the second time, the retrieved heart did not match her body. Incidentally, she was suffering from a hereditary disease.

In the third case for Master RH, an Uttar Pradesh based recipient, the heart was flown from Chandigarh to Delhi in 2017 and transplanted in a private hospital authorized to do a heart transplant.

Table 9.7 Donor-recipient residences, place of donation, place of transplantation and involvement of transportation of heart (N=3)

S.No	Residence of recipient	Residence of donor	Place of donation	Place of transplant	Heart transported or not
1.	Agra (UP)	Faridabad	Chandigarh	Delhi	Yes
2.	North East	Rajasthan	Karnataka (in heart retrieval hospital)	Karnataka in heart transplant hospital	Yes
3.	Delhi	Chennai	Chennai (in heart retrieval hospital)	Chennai (in heart transplant hospital)	Yes

Table 9.7 reveals that all three recipients had to shift from their place of residence to a place near to heart transplant hospital. A female recipient from Delhi shifted to Chennai; male recipient from Northeast moved to Karnataka, and a male child shifted from UP to Delhi. In this way, Delhi recipient got the heart of a Chennai resident in Chennai. A resident of Northeast received the heart of a Rajasthan resident in a Karnataka hospital. Faridabad donor's heart was flown from Chandigarh to Delhi for transplantation in a child who was a resident of UP himself. All these transplants were retrieved in three different retrieval hospitals and transplanted in three other transplant hospitals. Two hearts had to travel small distance within the heart retrieval State while the third heart had to cover a long distance via a charter plane.

Transportation of all these three hearts involved the creation of a green corridor for timely transport and transplantation.

Heart transplants transgress not only State boundaries but social boundaries as well. Media creates hype whenever a heart is transported from one State to another. The researcher had come across the issue of the charter plane several times that cost not less than ten lakhs. Regarding heart transplants, the top officials at NOTP revealed that hearts are given to foreigners in Tamil Nadu and not to Indians. There could be a possibility of such transplant operations. The heart needs transplantation within a time interval of 4 -8 hours maximum but earlier, the better. Working within narrow time frames could be the possibility of such hearts going to foreigners who come for heart transplants in Tamil Nadu. The transportation of heart from one State to another is an extremely costly affair as reported by many officials at NOTP.DGHS was once requested by a private hospital to ask Army Head Quarters for Pawan Hans services for airlifting a heart from Chandigarh to other State. DGHS put a request to army headquarter without understanding the cost involvement of the services. Army Head Quarters informed that they understand the amount of 10 lakhs for each sortie shall be borne by DGHS. The DGHS quickly withdrew its request.

As per the opinion of the researcher, it is better the heart goes to a foreigner rather than getting wasted. During 2016 and 2017 a total of 14 hearts made available to NOTTO for sharing but could not find a recipient as per the mandated rules of NOTTO. Also, there was a news item circulating in WhatsApp groups that nine hearts die in 10 days at during August 19-28, 2018 in a top organ lab amid a shortage of donors referring to NOTTO. And that was due to logistics reasons and non-availability of appropriate blood groups in various institutions that were offered hearts by NOTTO as reported by Director NOTTO. As per THOT Rules 2014, all organs are allocated based on Hospital-based list first, then to the State waiting list, then to Regional waiting list, then to National waiting list at NOTTO. At NOTTO also, the organ is considered for a person of Indian origin and if none is available then only it may go to a foreigner in the hospital. Following this procedure is too difficult, time-consuming and cumbersome for an organ like a heart. This way, the heart may not find a recipient within a small-time frame and may be wasted without getting transplanted as has happened during 2016 and 2017. Patriotism for sharing of organs like heart may end in wastage of the same and none of the donor families would like a heart to get wasted. The heart needs to be transplanted within a State no matter it may go to a foreigner and following the Rule as mentioned above, may only result in wastage of organs.

Hospital Episodes Post-Transplant

Out of three patients, only one recipient had a single post-operative hospitalization episode after transplant surgery.

Mrs. CH said, *"I got hospitalized in one of the private hospitals in Delhi only once for three weeks post-transplant in 2014. I had become unconscious after having some stomach infection. I go for follow-ups to private Heart Institution in Delhi as per my Chennai doctor's advice. The two doctors are in close association with each other. The doctor who performed the surgery on me is very cordial. The teams of doctors here keep sharing information with the heart surgeon at Chennai. I get a biopsy of the heart done, and has been done thrice by this time, and everything is okay. Blood tests and echocardiogram is also okay as on date".*

Heart transplant teaches us many things that bind human beings together, teaches lessons of love for humanity and patriotism. Heart transplant recipients are given a new lease of life full of vigour and vitality by BSD donors. One of the heart transplant recipients had only one post-transplant hospital episode. She was transplanted heart three years back and was on continuous follow-up. But other two recipients were transplanted heart recently**.**

How Do the Recipients Feel Now?

All three recipients were feeling good after the transplant. The eldest recipient was found energetic even at the age of 65, carrying the heart of a young male recipient.

Mr. BH said, *"I was not able to breathe, and now I am back to normal. I feel I am living now. I was dying by inches at the beginning of this year. I know it was a 38-year-old*

Lalit Kumar whose heart I am carrying. I was not allowed to meet the donor family. I am feeling perfect now. I was hardly breathing before heart transplant".

Mr. AHr said, *"Master RH is much better now. Overall his condition is okay. He is walking and talking now".*

Mrs. CH said, *"I am well-adjusted with life and very active, too at the age of 65. I hardly remember I have a heart of 20-year-old boy beating in my chest. My other health parameters are okay. Now, I am perfectly well".* The researcher also observed that she looked much younger than her age and was very energetic.

As per the interviews conducted with three heart recipients, all of them were doing well in comparison to their pre-transplant state of life at the time of the interview. However, in two cases time gap was too small between the time of heart transplant and the time of interview.

Summary: -This Chapter reveals that a few surviving liver transplant recipients used an alternative treatment like Ayurveda, eating medicine from "Patanjali" stores and visiting exorcists ("jadfook wale baba)." The pre and post liver transplant period was painful and stressful; it also was a drain on the pockets. The liver transplant surgeries cost in private hospitals ranges from 25 to 40 lakhs while it costs Rs. 50000/- in Govt. hospitals. Two of them had taken a loan and sold the property. In one case, a family had to face the unprecedented tragic situation when the recipient died soon after transplantation. In addition to it, the hospital refused to give the body till full payment for the futile treatment not paid. In this sense, individual suffering due to ill-health became the suffering of his family. Financial implications of the family or caregivers involved shifting near to the transplant hospital, sometimes to other States also. Such shifts required taking rented accommodation, purchasing a second-hand car for easy mobility making such surgeries unaffordable for ordinary and uninsured people.

The liver transplant recipients faced adjustment problems with the new organ and the immune suppressants. The dose and type of immune suppressants were adjusted almost daily post-transplant. The recipients narrated death-like experience during the treatment in earlier stages. It gradually changed with medication. Post-Operative care is critical to keep high standards of hygiene to prevent infection. Environmental sanitation, food hygiene, personal hygiene and intake of safe water determine the fate of transplanted organ and the recipient. Out of three dead recipients, two families had grievances against the private hospitals. One had a complaint against ESI authorities for delaying paperwork and asking for a bribe.

All three persons who had been transplanted heart reported that the cost of this surgery varied in different places and ranged from 13-35 Lakhs. In one case, the heart involved interstate transportation needing creation of two green corridors and police involvement and resulting in increased cost of treatment. Unable to pay the full amount, the hospital refused to hand over the bills of transplant surgery for insurance purposes. However, all of them were doing well in comparison to their pre-transplant state of life.

CHAPTER 10

Gender Inequalities in Organ Donation and Transplantation

This Chapter explores the gender issues associated with kidney & liver donation and transplantation. The first part of this Chapter reveals quantitative and qualitative data about 30 kidney recipients skewed towards female kidney donation. It explains the pressures, prejudices and dynamics of gender in kidney donation and transplantation. The second part is an in-depth case study of a caretaker wife Ms. Mitta. Her husband got one kidney of a Brain Stem Dead donor way back in 1994 and survived for eighteen and a half years after kidney transplantation. This case study reveals gender issues and gender suppression ingrained within various stages of life from the childhood of a female caregiver. She knowingly married a patient with Chronic Kidney Disease after going through a lot of troubles and turbulence in life. The third part of this Chapter explores gender and liver recipients. The fourth part reveals common issues with kidney, liver and heart transplants.

Gender Issues: - Analysis of data revealed several problems not only with female kidney transplant recipients but with female living kidney donors as well.

Quantitative Kidney Transplantation Data and Gender

Out of a total of 30 kidney recipients in this study, 28 recipients were selected randomly in Safdarjung Hospital (SJH). Among them, there were 20 male kidney recipients and only eight (8) female recipients. The remaining two kidney recipients were from other hospitals; one was from an autonomous hospital in Delhi and another from Indore.

Figure 10.1 Status of kidney transplant recipients (N=30)

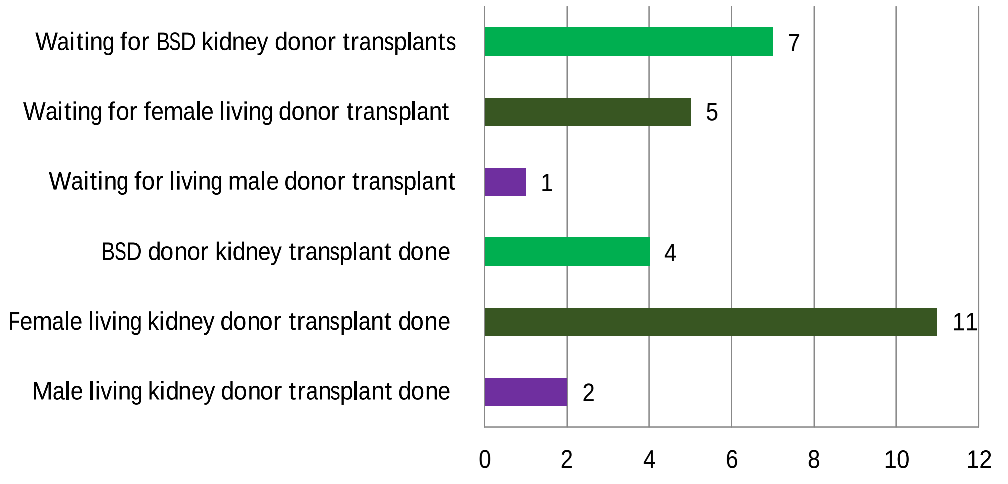

Figure 10.1 reveals gender bias in kidney donation not only among the patients who had been transplanted kidney but also among the waiting recipients. Majority of females, i.e., 11 had donated a kidney for transplantation, and five recipients were waiting for kidney transplants from female donors. In comparison, only two male living donors had donated a kidney, and only one recipient was waiting for a kidney transplant with a living male donor. The figure also shows that recipients waiting for BSD donors were 7 in number, and only four kidney transplants were done with BSD donor kidneys.

Figure 10.2 Transplant status of female kidney recipients (N=9)

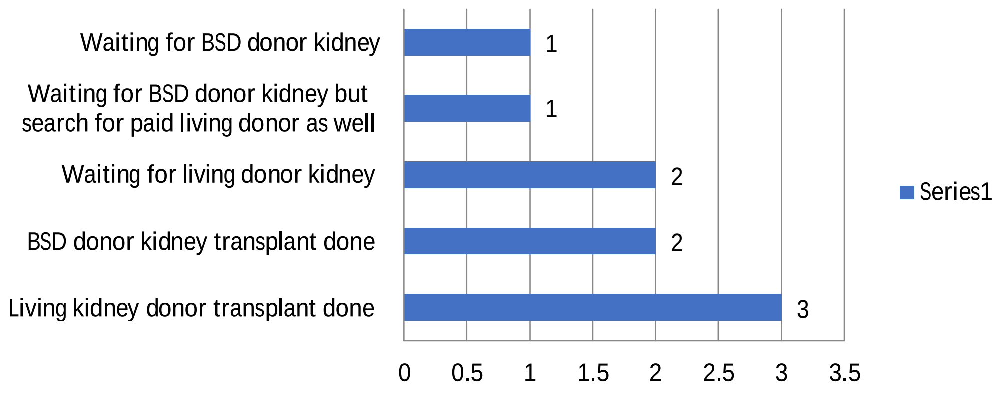

Figure 10.2 reveals that among nine female recipients, three female recipients were transplanted living donor kidneys, and two were transplanted BSD donor kidneys. Two female recipients were waiting for a living and one for BSD donor kidney

transplant. For a female recipient who had no matched living kidney donor at home, her husband was trying his level best to find a paid donor whom he could pay as reported to the researcher.

Table 10.1 Gender Wise Relationship of Living Kidney Donors with The Recipients (Who Had Donated or Were Waiting to Donate A Kidney) (N=19)

MALE LIVING DONORS		FEMALE LIVING DONORS	
Relationship with recipient	**Number**	**Relationship with recipient**	**Number**
Father to son	1	Mother	8
Husband	1	Wife	5
Brother to brother	1	Sister to brother	1
		Sister & sister in law	1
		Aunt	1
Total	**3**		**16**

Table 10.1 reveals that the burden of living kidney donation rested on female living donors only. Majority of living donors were females, i.e., 16 in comparison to three (3) males. Majority of female donors were mothers, i.e., eight (8) followed by five (5) wives. Out of three (3) male living donors, the recipient in two (2) cases were males only.

Regarding gender issues, Dr. Sa said, *"There is nothing to be surprised when we see female living kidney donors more in comparison to male counterparts. We should not blame anybody. We often blame society. Say, who loves a person more than mother and wife. In life, these are the two persons on whom one can have faith, and there is no surprise that they come forward to donate for their loved one first. More males than females are suffering from hypertension and diabetes too. But females having less road mobility are less prone to be a potential source of deceased donation in comparison to* *males. So, everything justifies on a scientific basis and reasoning. While females donate during life, males donate more after death, and the number of organs donated by males is more in almost all countries. In 2700 living kidney transplants in my hospital, I have found all types of relations coming forward intermittently, but most of them are mothers and wives".*

A living kidney transplant coordinator Ms Fotc while taking a session on living organ donation in a training programme at NOTTO said, ***"Aurat Hamesha Hee Balli Ka Bakra Bantee Hai"*** (Meaning a woman always becomes a sacrificial goat).

Figure 10.3 Age wise distribution of living kidney donors (N=19)

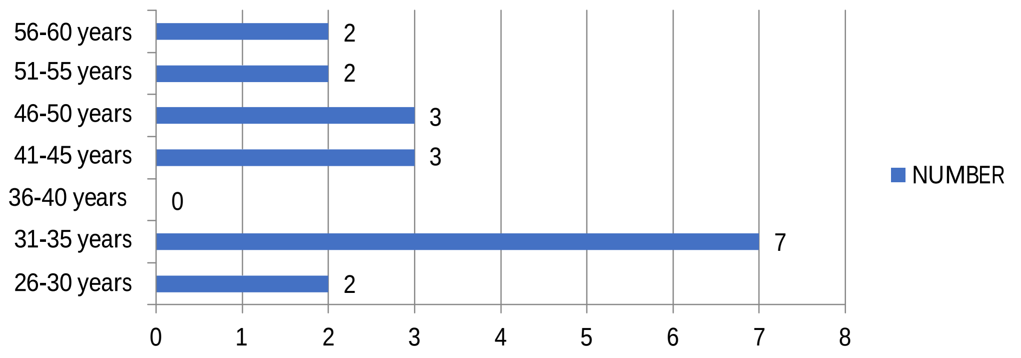

Figure 10.3 reveals that majority of Living kidney donors, i.e., 7 were in the age group of 31-35 years. Also, two Living kidney donors were in the age group of 26-30 years.

The quantitative data reveals gender issues ingrained with kidney donation and transplantation. Among 19 living kidney donors, the majority, i.e., 16 were females only, comprising of eight (8) mothers, five (5) wives and three (3) sisters. The remaining three male living kidney donors who donated a kidney, the recipient in two cases were males only. Dr. Sa justified gender issues having an experience of about 2700 kidney transplants. However, the female kidney transplant coordinator, Ms.Fotc, did not believe the same. The kidney donors, in most cases, i.e., seven (7) were in the age group of 31-35 years.

Gender Issues in Kidney Donation and Transplantation Based on Qualitative Data

Several issues were identified based on qualitative data interferences.

Apprehensions Related to Reproduction Associated with Kidney Disease, Kidney Donation and Transplantation

Apprehension with reproductive functions was one of the central concerns seen in kidney failure, kidney donation and transplantation as well. Some stories pointed to infertility and associated superstitions ending in kidney failure. Kidney donation by female living donors took place once their reproductive functions were over. The anxiety for reproduction by females did not vanish even after their kidney transplantation by childless married women.

Mr Rr reported, *"She was okay when she got married. She was directed to go to various places by elders in the family so that she could reproduce a child. Or else they would feel bad and hold her responsible for not listening to their experiences. As a result, she had been to saints, sages, priests, temples who would give her all kinds of treatment. She, unfortunately, did not bear a child but suffered from kidney failure, which was without any clear warnings. I felt responsible for her condition and wanted to donate my kidney to her. But all the elders sat together and concluded that her sister, who is my brother's wife as well would donate as she already had two children. Sister also volunteered to donate a kidney to her.* (After successful transplant Mrs.Rr again wanted to have a child and was asking the researcher, "*Can I bear a child now"?)*

A 48-year-old mother of a 26-year-old daughter was the only willing donor in the family but a very apprehensive donor too. This daughter of hers was married but had no issue. Her daughter had a bad obstetric history having given birth to one stillbirth and whose other child had died within two days after delivery. Mother's apprehensions came to fore when she asked the researcher, *"Will she deliver a child if I donate my kidney for transplantation"?* As such donation and transplants are given approvals by "Competent Authority" in case of near relatives. And the same applied to this donor-recipient pair also. Probably because of her apprehensions, she was not approved to donate a kidney but recommended for psychiatric evaluation second time when the researcher met her next. Well, on meeting her next, her apprehensions came to the fore. She said, *"My daughter is sick and married, and if she does not deliver a child, why will her husband keep her. How will she continue her sick life?"*

Mr. A reported, *"My sister, who is 26 years, willingly gave me a kidney. She needs not to worry. She has already produced two male children. Her husband was also willing and never opposed her decision".*

Mrs. Or reported, *"My son is very young, and both his kidneys are damaged. I wish he had developed this disease late. God could have postponed this disease by a few years at least until he was married and produced children may be by 26-27 years. At least the lineage could continue. He is the only son in my family. I have three daughters".*

In one case, the paternal aunt who happened to be the sister of the recipient's father, wanted to donate to his only nephew. When asked by the researcher, whether her husband consented to her decision to donate a kidney to her nephew. She was happy to announce that her husband too wanted her to donate a kidney to her nephew. Her husband had said, ***"Tunney Mujey Waris Diyye Hai, Tu Bateejey Ko Baccha, Apney Bai Ka Khandaan Ko Nasht Honey Se Bacchae"***(Meaning you have given me sons to continue my lineage, now you help your brother to keep his dynasty by donating a kidney to his son).

Not only this wherever ladies had produced children husband wanted to give a kidney to his wife for the love of his children.

Mr Pr reported, *"I want to donate a kidney to my wife for my children as I feel my children are more attached to mother. They need her; that is why I am donating. I cannot see them without their mother. "**Woh Sara Din Mummy Mummy Bulatey Rehtey Hai"** (Meaning they keep calling her the whole day).*

Apprehension with reproduction was one of the essential concerns seen in kidney failure, kidney donation and transplantation as well. Not only this, wherever women had produced children, husbands wanted to give a kidney to their wives. It was not for love for wife but for love of their children whom they could not think of without their mother.

Societal Pressures on Females for The Donation of a Kidney

The research revealed subtle societal pressures on a few females for the donation of organs. These pressures could be the result of patriarchy and female suppression inherent with patriarchy. A few such interactions through narratives are:

Mrs TRR reported*, "I am not willing to donate, but they brought me here to donate a kidney to my husband. I could not tell them that I will not donate when I was home. If I had revealed my intentions for not donating a kidney, they would have beaten me and abused me too. I know their attitude towards me will not change even if I donate my kidney. They don't treat me well but anticipate me to donate a kidney".*

Mrs Dr reported, *"Is it possible to take my kidney and keep it in the bank till all the formalities are over for transplantation? I am teased and taunted by people in the village. I make repeated visits from village to hospital without retrieval of my kidney for transplantation into my sick daughter. It makes them think of my dubious intentions to donate a kidney to my daughter. They feel I am not willing to donate my kidney to my daughter and taunt me for that. They tell others in my presence **"Yeah Denna Hee Nahee Chahtee Hogee....Isseliye Kabi Aatee Hai Kabi Jatti Hai"** (*Meaning she does not want to donate a kidney, that is why she goes for donating a kidney and comes back without doing so*).*

Mr RRR narrated *"Why shouldn't my wife donate for me? After all, she will feel secure only if I am alive; she is a homemaker, and I have given her security. Aren't people giving blood to strangers and what is the harm if the spouse who usually is not a breadwinner donates an organ for her partner? A woman giving an organ is not a big deal in society".*

Mrs TTT, *"I am a widow, stay in my in-law's house. In case I do not donate a kidney to my brother-in-law, I may have to face the consequence. I have two children and where will I go?".*

Mrs YYY, *"A female donor who had donated her kidney to her husband, was counselling a mother who had apprehensions with the donation. Her narratives were "**Kaise maa hai**?" (What kind of mother are you?) Look at me, I have donated a kidney to my husband and told doctors to take my second kidney as well if required. I am not at all afraid. **"Tumhara To Apna Khoon Hai Phir Bee Dene Se Katratee Ho?**" (Meaning it is your blood relation and still, you are hesitant to donate).*

The researcher observed subtle societal pressures on female donors not only in narratives but also during interviews with a few female donors. Patriarchy and female suppression associated with it could be the reason behind such societal pressures.

Female Sufferings as Kidney Recipients

The condition of recipients if they are females was not very comforting. The issue of patriarchy prevails not only in kidney donation but in transplantation as well.

As per Mr MMM working in an NGO who was helping these recipients, *"There was a woman who was on dialysis for two years. Her husband abandoned her after taking care of her for two years. He sold all his land in Bihar, for her treatment in Delhi. He later managed to get four lakhs for her treatment from Prime Minister's Fund also. But unfortunately, she was found to be suffering from hepatitis just before admission for transplant surgery. Her surgery was postponed for six months. Her husband, out of extreme frustration expected her to come home and accept her fate, beat her up when she refused, abandoned her near the hospital. She was helped with dialysis* *thrice a week by the NGO. NGO SAPNA helped her by spending Rs.36000/- per month on her dialysis ".*

Mr Jr reported, *"She gets haemodialysis done at her mother's place. I do not allow her to be here. It is not possible for her to stay here in her in-law's house because of expectations from a daughter in law. Her parents are at Gorakhpur, and the cost of treatment on dialysis comes to Rs. 20000 per month that is Rs. 2000 per sitting".*

Females in need of kidney transplant were taken care of, but at the same time in a few cases, they were either left with their parents, divorced or abandoned too.

Females Sufferings as Attendants to Male Kidney Recipients

The females were also found tolerating the unabated frustrations of the morbid status of the recipients not only during dialysis but after transplant as well. The beatings, abuses and displacement of anger by males on females did not vanish even in their morbid state. A person on dialysis is advised to take one litre of water only as his kidneys are not able to excrete extra water. Restriction of water, unquenched thirst and belligerence, especially in hot summer cause problems. Further, the absence of cooling facilities for poverty-ridden people cause problems for the attendants who supervise these patients and see to it that they keep water intake to the minimum.

Mrs Qr reported*, "Staying in the hospital for over a year had made him extremely irritable. He would get irritated with me without any provocation. He would curse me, abuse me and tell me that all his sufferings are because of me. He would often request me to leave him. It was tough to manage him. I could neither leave him nor be with him. He would often beat me for creating restrictions on salt intake and water intake as well during dialysis period. It was the sister in Ward who would rescue me during his beating sprees".*

Mrs M reported, *"I had been staying in the hospital for three months with my husband. He was on dialysis and had been advised to restrict the intake of water and salt. It had made him extremely irritable. He would tell me all his sufferings are* *because of me and my parents. He would not spare my brothers and sisters as well and would abuse everyone for his sufferings. How could he say that when I was doing so much for him and was even ready to give my kidney*, *which eventually did not match".*

As reported by Ms Xr, "In a fit of rage to avoid the restriction on water intake, he went near the tap which is not even drinkable and had enough of water. When confronted not to do so, he slapped my mother many times".

The female attendants were also found tolerating the unabated frustrations of the morbid status of the recipients. The beatings, abuses and displacement of anger by the male recipients on females did not vanish even in their unhealthy state.

Divided Gender Roles in Families in Managing ESRD Patients

There were clear cut gender divided tasks. While females were donating organs male contribution to the welfare of recipients cannot be undermined as depicted in the narratives.

Mr Vr reported, *"While his sister gave him a kidney, brother supported him financially. His brother supports him. He has four kids, and the youngest is only eight years. Two are male, and two are female. He is not working for the last three years. His brother was not willing to donate but is supporting his family financially".*

Mr A reported, "*My brother supports my family. He brings me every time to this place one day before follow-up. We stay at his brother- in- law's home, and he takes me back after dialysis. My brother spends on the education of my children as well".*

Ms Xr reported, *"I have a boyfriend that helps me in taking care of my father. He only arranged six units of blood for my father's operation, that was not possible for us. We are three sisters and don't have any male member in the family except our sick father. My parents would have killed me under normal circumstances knowing about my inter-caste love affair, but they know their condition and ignore our relationship".*

Mr Wr reported, *"When will she lift heavy weights, two months have passed after retrieval of one of her kidneys for her son. I am made to do her job for two months. I am picking up buckets of water and do certain household chores. How long will this continue?"*

While female members were mostly donating organs and taking care of people at home, male members were found to be supporting dependent members of the recipients. Males only stayed in the hospital with the recipient, moved from one department to another for getting both the donor and recipient evaluated and arranged blood. Males had shifted near to dialysis facility or transplant facility from the place of residence, spent on the education of dependent children and took care of them at home. Females do not usually perform some roles. The narratives of a daughter *Ms Xr* divulge how family members accepted her inter-caste boyfriend in a crisis. She admits that she would have been killed for the same affair, otherwise. Boyfriend was acting as a substitute for a son who was arranging blood and other things for the recipient. All these things were not possible by three daughters, revealing gender-specific roles in kidney donation and transplantation as well.

The Story of Ms. Mitta: -

It is an in-depth case study of a female caretaker of a kidney recipient revealing gender issues ingrained with various stages of her life.

"My husband lived for eighteen and a half years after a kidney transplant. I married him when I knew that he was suffering from Chronic Kidney Disease (CKD) and will need a kidney transplant in future. There is a big story which I would like to tell you so that you understand my plight thoroughly as a woman. I was born in a family where females were subjugated and threatened for their survival. My father would often beat my mother mercilessly for no fault of hers. At times even when her children were at fault, the father would displace his anger on my mother. My mother

had accepted this as her fate and probably had no regrets. When I would object to such mishandlings, I was made to keep quiet even by my mother.

My father was a teacher and taught high values to children. Once I was told to call my father from school as some unexpected distinguished guest had arrived at home. His school was at a stone's throw from our house. When I reached school, I saw him teaching students about "union is strength". He was explaining it so well as if he believed it in his own life. All his teaching and preaching in the classroom were contrary to what he did at home. I felt my father had a dual personality, one for education at school and another for his own family. One day I confronted my father for the same asking how he could teach something to students, which he never believed himself. A girl was not supposed to question her father. And my attitude of confrontation was not liked by anyone in my family, including my mother. I was never considered a good girl.

I had three brothers and two sisters. My elder sister and I shared a strong bond while the second sister had been a real reporter to my father. She would try to be in the good books of her father by divulging our secrets whenever she accidentally came across. My elder sister and I were not on good terms with her. My eldest brother was taken care of very well and became a doctor. My eldest sister joined General Nursing & Midwifery (GNM) course after 10th Standard as she wanted to earn as soon as possible and never wanted to be a burden on parents. Job security was the most important things at that time for her as she tried to be self-reliant and self-dependent that was possible through this course.

After my 12th, I joined B.Sc. Nursing from a very reputed institution. My father had brought various proforma for specific courses. He instructed me to apply for B.Sc. Ophthalmology or B.Sc. course only. He also warned me never to opt for B.Sc. Nursing. I was a rebel and did the opposite of what my father wanted. I opted for B.Sc. Nursing and got the seat as well. In the heart of hearts, I feel I too wanted to be independent and self-reliant at the earliest like my elder sister. I also knew that I had *better job prospects after pursuing a B.Sc. Nursing course than the other two. Opting for this course, further deteriorated my relationship with my father. He said that the reason for his aversion for B.Sc. Nursing was that nurses don't get better marriage partners.*

To this, I told my father that I would never object even once. I assured him that I would get married to any boy he selects for me and will never ask anything about the boy. I promised that I should abide by my promise no matter what comes. I did B.Sc. Nursing, and immediately after passing my fourth year, my father selected a match for me and without trying to see who the boy was, I got married. It was a hush-hush marriage; a marriage solemnized within two weeks. The boy was living in the USA, and my family would often boast of it. After five to six months, I joined my husband in the USA. While preparing visa, I came to know that the boy is almost 14 years elder to me. It infuriated me, and I told father why he married me to a boy who is so 14 years more aged to me. Father said to me that I should be thankful for getting a match in the USA. I went to the USA to join my husband. I thought of doing a job there after passing TOFEL. When I talked about my occupation to my husband, he got furious. He said that he had married me for his brother's children who needed a caretaker at home. He was very much against my job and was probably indebted to his family members. His brother was an ophthalmologist, but his wife was an obstetrician. My husband was assisting my brother in law in his clinic as an ophthalmologic assistant. Probably they needed a nanny for their children and found me the most suitable person.

After a few months, I realized that I am wasting time, and the role of a nanny was not acceptable to me. I pressurized my husband to shift to rented accommodation, and we did. I never expected that the eldest child of his brother would be sent along with me so that he could be in my safe hands. The boy would stay with us for the whole week and go back on weekends.

I was not going on well with my husband as he was curtailing my aspiration and was a full supporter of his brother's family only. Once, in a fit of anger, I was locked by my husband in the rented apartment for two days. He left this rented apartment in a fit of rage and did not come back for two days. I did not know how to get rid of this situation. At that time the mobile phone was not there. There was no food at home. It came to me several times that I shall commit suicide. I wanted to jump out of the window, but I could not. I was alone and did not know how to act. Unluckily by this time, I had become pregnant too. There was none whom I could contact. I was in a land of foreigners, insecure and unsafe. The two days of mental turmoil had helped me in deciding the future course of action. I decided that I will not stay with this man and leave this place forever.

After two days, my husband came back without any regrets, and by now, I had gained courage and wanted to move out of this marriage and go back to India. I took some money and rang my mother from a public booth. My mother listened very carefully but, in the end, said, "see we have married you and now it is your fate". Don't come back. Don't complicate the lives of your siblings. Remain there only and accept your fate. ***"Tere Doli Ghar Se Gayee Hai Tere Arthi Wahee Se Jaanee Chahiye".*** *(Meaning you are married to a person till your death). I felt ditched; I felt alone, how could my mother disown me like this. But the instinct of survival kept me alive. Next day I rang my friend who was married to a doctor in a reputed hospital. I told her about my mother's conversation too. I told her everything in brief and persuaded her to help me. I had no money to come back to India. My friend consoled me and told me to ring her again. Her consoling words gave me a ray of hope. Next time when I rang her, she gave me the address of one of her friend's associate, whom she thought could help me in this crisis hour. She proved of great help. I was instructed to act wisely and be cautious too. My passport; documents certificates were in my custody, and I ensured that these documents remain with me only.*

The second thing that came to my mind was to get the foetus aborted. Luckily my sister-in-law helped me in that. I told her that since our relations were not getting on *well and two of us needed to concentrate on marriage first. She being a gynaecologist helped me in getting the foetus aborted.*

Now it was time to act wise, find avenues and cash to get back to India. I went to my friend's acquaintance riding a couple of buses. The man was a genuine person and gave me a blank cheque in the name of a travel agent whom I could provide the bank cheque for the ticket. I was instructed to tell the agent that my mother is very sick and nothing else. It was required to avoid the legal hassle of getting the ticket. He also gave me 200 dollars for a safe journey. I purchased a ticket, luckily my passport; documents certificates were in my custody. My gold was with my sister in law, and I did not know how to get that back. I did not want anyone to feel suspicious of my intentions. I packed my belongings and did not give the slightest hint of my plans either to my husband or in-laws.

My flight was in the afternoon, but I left earlier to avoid getting caught. I kept hiding my belongings from the landlady too and heaved a sigh of relief when I reached the airport. As I was hiding, I saw an acquaintance of my brother in law there. I did not allow him to see me. I remained in one corner of the airport lobby lest someone sees me. The flight was via Singapore. I decided to save money as much as possible and decided not to rent a room in Singapore during my waiting hours. I had very little money, and at the same time, I was bleeding profusely. My clothes soaked in blood. My condition did not permit me to stay outside for long. I took a hotel room in Singapore at a very cheap rate, checked out before scheduled time for the next flight.

When I reached India, I saw my friend along with her husband, waiting for me. I hugged her and cried inconsolably. She took me to her hostel and later to the hospital. In the hospital, doctors informed us that I had an incomplete abortion. I got treated for incomplete abortion there. My friend sheltered me and took care of me for a few days. After recovery, I wanted to do a job and got the post of sister in charge in one private hospital. My brother met me once in that hospital but refused to talk and ignored me deliberately. Later, he might have informed the family. I was *in good books with the Deputy Nursing Superintendent. One day as I was in the room of Deputy Nursing Superintendent, my mother came and told me that my brother is getting married. She said it is better I do not come for marriage as she felt I had brought a bad name to the family. She shouted and said that it was better not to have me as a daughter. She defamed me, screaming to the peak of her voice, telling everyone about my past. By this time, I had not revealed to the staff that I was married. It was unbearable for me to continue with this job with so much negativity spread by my mother. I thought of resigning from this job.*

Meanwhile, I had got a job in one more hospital and one international organization as well. I preferred the international organization. In this international organization, I was supposed to scrutinize the letters except for the confidential ones. I came to know about the womanizing behaviour of a Doctor in this international organization. One day, I was approached by the same doctor who kept his hand on my shoulder and said that in case I want to go to Geneva, sleep with me for one night. I felt the blood leaving my body; I did not respond. It surprised me; I was taken aback and felt pathetic. I was not safe anywhere.

I went to my friend and talked to her about this episode. I was prepared to slap him on the face and get rid of tension. I was guided by a lawyer friend to complain about the doctor at the police station. I did the same. I was also given a teddy to practice slapping so that I do the same with the doctor the next day. I did the same throughout the night but, in the morning, said that I could not do it. They warned that in case I don't do so, these friends will not support me.

I could not afford to lose my friends. I prepared a resignation letter. I kept waiting for the doctor to come to the office. I took the second half day leave and sat in the corridor and waited for the doctor to arrive. The receptionist asked me repeatedly as to why I was not leaving the office to which I replied that I was waiting for a friend to come. At 2.30 pm the doctor arrived and without looking at anything he moved *towards stairs. I called him from behind as if I had an important thing to talk. He walked down a few steps.*

Meanwhile, I had prepared myself, and I slapped him once on his cheek so hard that stunned everyone. While hitting, I said this is the answer to your yesterday's request. I hit the doctor near the lawn of the international organization. There was a great commotion, and people rebuked me for doing so. Without waiting a minute, I handed over a letter of resignation to the receptionist. Police had also come, but they were not supposed to go inside the premises of the international organization. To my surprise, my friend, along with the lawyer, had come and known the happenings inside. They enquired as to why I did not slap him several times. I don't know why I could not do so. They, however, felt happy to make me bold. The next day, I Joined a private hospital and my ward in charge was holding the newspaper. In this paper, there was a news item about nursing personnel who slapped a doctor. She had high praise for the person in the nursing profession who had guts to hit the wrong man. It was only after a few days that I divulged the facts to which she felt happy.

During my tenure, I came across one patient who was suffering from the early stages of renal failure. He was in the hospital and was unconscious with no one to take care. I saw his family coming, and to my surprise, his parents left him without any attendant. I probably empathized with him and could see the other side of the parents too even with this doctor. I don't know how I felt his story the same as that of mine. One day I called him for having tea with me after he got discharged from the hospital. He accepted to come. I told him that I want to marry him and told him about my previous history of marriage. I did not hide anything from him. He did not say anything but said that he would talk to his family of 6-7 siblings. A few days later, his sister came and spoke to me. She tried to dissuade me from this marriage giving his medical history. He was suffering from high blood pressure before being diagnosed as a case of Chronic Renal Failure (CRF). He was apparently in good health before the diagnosis of Chronic Renal Failure at the age of 28 years only.

I told my mother in law that this condition could arise even when I would have married a normal healthy being. I remembered one of my friends had come to know about the deteriorating health of the kidney only after marriage. Anyway, I got married, and only my friends and his family members were a party to it. My mother in law took the lead to marry me. We got married in the early nineties. He remained on conservative treatment for four years before getting a transplant done in the year when Indian Organ Transplant Act was enacted. A female brain-dead donor's organs were donated. The doctor told him to have a child at the earliest. Within 11 months of my marriage, I delivered a female child. I have one pre-transplant daughter and another post-transplant daughter. Both are doing well.

A time came when my husband required a kidney. My father in law consented to donate but refused later. He categorically told that he would not part with his organ as he was afraid to do so. It was a great shock to me, but I had to accept the fact.

I had to purchase a kidney for my husband, and the estimated cost was 3.5 lakhs. His family members not only refused to donate a kidney but did not feel like parting with their money as well to purchase an organ for him. I had no option except to get money to buy a kidney. I went to Saudi Arabia much to the reluctance of my husband. My mother in law did not believe me. She knew I could not leave my daughter. My daughter was 11 months old, and I was a doting mother. I could not think of keeping my daughter under the care of anyone else. I did not believe anyone when it came to the custody of my daughter until this time. In fact, not trusting anyone I had given her the first baby bath myself in the hospital. It was traumatic, yet I had to save my husband. My husband did not want me to go and said that he might die before I come back. Anyway, I was determined to move. I handed over my daughter to my husband and said that your mother would take care of the child when I am not around.

Within two months I got a fax that my husband is serious. I rushed home, but he was not serious. He was probably apprehensive and felt that I might not return. But my immediate arrival gave him strength, and before one month was over, I rushed back to Saudi Arabia. I would save maximum money and send the same to my husband. I avoided going for shopping to save maximum. I took night duty and would prefer sleeping the whole day to prevent a desire to go out. I desired to save maximum money. I completed one year and went back on vacations.

Within a few months, a call from hospital came about the availability of a BSD donor kidney. I rushed him to the hospital and admitted him in the night. Before transplant surgery, the first dialysis was done on him to flush out the wastes from his body. He got operated on 30. 8.1995 (Date changed). The day happened to be his actual birthday too. Getting a donor kidney on birthday seemed a good omen also as I felt God had gifted him a new lease of life on his birthday. He got a kidney from a brain-dead female donor who had Sub Arachnoid Haemorrhage.

After a few days post-transplant, the surgical stitches of his transplant site opened, and a massive amount of pus oozed out from the operation site. It was a horrifying sight and a pathetic thing that had happened to my husband. Immediately the attending doctor came out and after a while told me that the new kidney might be removed. I could not believe; how could this happen. I felt shattered. I never wanted God to do this to me. The wound was kept open to allow drainage, but with proper medical management at hospital, he came out of the hospital after 58 days with a third kidney. Since it was a Government hospital, his cost of treatment was not more than 20000 rupees.

His medical condition had unfortunately rendered him medically unfit for getting a Government job which haunted him. He got the post of assistant professor twice after transplant surgery but was declared medically unfit. He survived for 18 years, but to his great disappointment, he did not get a Government job for medical reasons. He had cleared civil services exams too, got a job in railways but was *deprived of the same because he was living with a transplanted kidney. He used to feel very bad for not getting a good job. He got an appointment in Mediclaim and earned a reasonably good amount through that job, but he was not satisfied with the situation.*

It was after 18 years the rejection of this kidney had set in. The doctors seeing his serum creatinine levels increasing divulged that probably he had to go for another transplant. Now, who could give a kidney? One of his brothers came forward to give his kidney. He was self-motivated. But my mother in law and his wife did not approve of this. One day my mother in law rang my husband and told him how shameful on his part to take one kidney from his brother who had small kids and is just 38 years old. What if something happens to him, who will take care of his wife and little daughter? After hearing this husband felt very bad. His mother's words had pinched him a lot, and after that, he never recovered. His condition deteriorated. I talked to the doctor and said, let me part with my kidney to save my husband's life. But before that could take place, my husband took leave from this world. As a result of the transplant, he developed diabetes. In the end, he had multiple infections one after the other, multi-organ failure and then death".

The story of Mitta reveals gender suppression in an Indian family experienced by a female child right from early childhood and repercussions of the same on the psyche of the child in later years of life. Mitta's story is full of struggles right from her childhood and full of fights to evade gender suppression. The male child looked after well in comparison to female children, female left on her own after marriage in adverse conditions in a foreign land. Female suppression not only in in-laws but in the parental house also is highlighted in this story. A friend in need is a friend indeed is very well experienced by Ms Mitta. Her paternal family denied any support from India and advised her to accept fate there in a foreign land.

On the contrary, her friend in India ensured her evacuation from a foreign country. Her friend gave her a new lease of life by facilitating her removal from a foreign land, and her mother denied any support. Friend's support continued with the struggles of Mitta. Her friend supported her through thick and thin. She motivated her to be bold, fight the system and stood supportive in her tribulations. Male psyche asking for sexual favours in exchange for progress in the career ladder and the difficulties encountered in teaching lesson to an influential person exposes the system. Mitta faced challenges of the aggressive social environment of which her mother formed an important part. Mitta intentionally married a man with CKD, knowing he will require a kidney transplant in future. Story of Mitta reveals the struggles of a woman to leave her small child to keep her husband alive and an accepted norm to purchase kidney way back before 1995. This story reveals that a friend proved better than the family.

Gender and Liver Recipients

The researcher, having interviewed seven liver recipients, found gender issues playing a significant role in a few such cases as well.

Need for A Liver Transplant for A Female Recipient Doubted by Family Members

As per Mr Sil, *"We were not sure whether she required a liver transplant or not. Probably doctors want to make money by advising liver transplant surgery. The whole thing is commercialized now. She was in ICU for 40 days, and we had to pay ten lack of rupees on her treatment alone".*

The interactions with the relatives revealed that none of her family members was willing to donate liver to her. Also, they felt it was not required and were doubting the need for a transplant.

Gender Suppression and Living Liver Donation

The telephonic conversations by the researcher on many occasions with a female living liver donor Ms. DlDa from 27.10.2017 onwards revealed many aspects of the living female liver donation from her perspectives.

As per Ms. DIDa, "*We did not know that there is no problem with the positive-negative mismatch in liver transplant. My blood group is 'O negative' and my papa was 'O positive'. For a long, I knew that I could not donate liver to my papa. My joy knew no bounds when I came to know that I can do so. It is possible for me to give liver as Rh incompatibility does not matter in organ transplant".*

On being asked whether she was discrimination as a girl child, she said, *"yes, as a female child, I was discriminated. My brother went to a better school than me, but it hardly matters. I could feel that my grandmother was discriminating me as a female child. I was not given equal opportunities as that of my brother".*

The donor daughter sent the researcher a clipping of another donor daughter whom media had glamorized after she had donated liver to her father. Ms. DIDa had written to the researcher that parents never realize the importance of girls.

On being asked why others in the family did not donate, she said, *"My mother was willing to donate, but I was worried if something happens to her, too, we will be left orphan. The doctors told me to go through some videos of liver operation, told me to get mentally prepared to donate liver and weigh pros and cons before deciding. It took about ten days to get all the tests done before I was declared fit for donation. The cost for my tests came to about 1.5 lakh rupees. They also told that in young people, liver regeneration is a bit easier in comparison to older people, so I felt I should donate. I went through the literature but not through videos as I was scared to see those videos".*

They removed 65% of my liver along with gall bladder. I have developed some gas problem after the operation, but I have no regrets. My mother says it usually happens after the surgery. When I think today as to what made me donate my liver, I feel it is because I am very emotional. I never wanted anyone else to give liver and take that special place in my papa's life. My second thought was how I could leave my family in that situation. How could I ask someone else to do the favours for my *father? Also "**Koi Aur Deta To Mujhe Achha Nahee Lagta**"(Meaning I would have regretted my whole life for not doing good work). Some people dissuaded me from donating my liver because they felt that I am not yet married **"Aur Usme Dikkat Aayegi. Aur Mai Saree Nahee Pahen Paoongi".** (Meaning I will get some obstacles in getting married and I won't be able to wear saree throughout my life because of ugly operation scar). But at that time, nothing could dissuade me from doing so, and I never listened to such advice. I internally wanted to donate my liver. At that time, I felt my papa would be all right if I give my liver to him. That really was the proudest moment for me at that time but having done so, I still fail to see that satisfaction in my father's eyes. I was in ICU for 7- 10 days after liver retrieval. I was feeling good at hearing that my father was doing well with my donated liver. Only once during my ICU days did I feel pity for my condition, but I could not leave my family in trouble. Now, after entering into an institution for further studies, my friends in hostel give me a feeling as if I am inferior to them. They keep on asking me "**Kya Tune Papa Ko Liver Diya Hai?". "Kya Tumharey Papa Ne Tumse Liver Liya Hai?"** (Meaning have you given liver to your father? Has your papa taken your liver?) I do not like these words. It pinches me. The tone of their verbal conversations makes me restless. I have stopped talking to them".*

The story of Ms. DIDa reveals gender bias in rearing a girl in the family. Girl child wanted to prove to her family that she also is essential and donated 65% of the liver. The liver donation was an opportunity to prove her worth in the family and get an acceptable status in the family that she was not enjoying previously. Rh incompatibility does not affect organ donation and transplantation. Usually, people are not aware of this aspect of organ donation, and transplantation and the same was the case with donor daughter. She was mentally prepared by doctors very well in advance. When a person decides to do something, nothing dissuades a person from doing so, sometimes denial a coping mechanism is adopted by the person as was done by the donor daughter. She did not go through the videos as she never wanted to see something that could have dissuaded her from donating liver to her father. Her joy knew no bounds having known that she could give her liver even when there is Rh incompatibility between the donor and recipient. The pre-transplant evaluation of the donor is a costly affair too and, in this case, it was 1.5 lakhs. She was dissuaded by relatives not to donate liver as that could bleak her chances to get married. With beauty concern in mind, the relatives also attempted to help her reconsider her decision to donate a part of the liver. They even warned her that the surgery could culminate in an ugly abdominal scar, result in loss of her beauty and prevent her from wearing saree throughout her life. But nothing dissuaded her as she was determined to prove her worth to her family. It was her proudest moment when she donated her liver to her father. Having given liver, her friends leave no opportunity to make her feel low. Her friends taunt her, look down upon her asking her "how come her father took away her liver". She gets hurt but does not regret her decision. However, the most significant remorse for her is her father's dissatisfaction. She does not find that satisfaction in her father's eyes as she anticipated after donating a substantial portion of her liver. Her narratives and paper clippings that she shares with the researcher now and then, express her feelings that girls not treated well in society. These clippings show her inner urge to prove to the world that daughters are also important and please reconsider your opinion about daughters.

Issues Common to Kidney, Liver and Heart Recipients

The researcher found a few issues common to kidney, liver and heart transplants. People understood the cadaver donor differently, who interestingly happens to be a BSD donor only. Recipients craved to meet Brain Stem Dead donor family. The unethical practices of private hospitals, bureaucratic obstacles and poor- rich divide were rampant. However, the new lease of life was an inspiration for the recipients towards the social cause.

Varied Understanding About Cadaver Donor

There was different understanding about cadaver donor as reported by recipients of kidney liver and heart transplants.

For many recipients, it was an organ which comes from outside the hospital. The understanding could be attributed to their experiences as depicted by OTCs in the following narratives:

As per Ms Votc, *"There were five occasions when a kidney was transported from Chandigarh to this hospital through NOTTO within a short period. The recipients who failed to reach for transplant on those occasions would now enquire telephonically asking us, when will the kidney come?"*

For some recipients, it was an accidentally dead person having healthy organs whose organs were donated by family members during post mortem.

In one case a recipient Mr Fr on being asked what is meant by the cadaver, he said, *"A cadaver is an accidental death case. An accidental dead person has all healthy organs as he dies accidentally and is not sick. Doctors use retrieved organs from such cases during post-mortem for transplant".*

The understanding of brain death and accidental cases was viewed by many as two different happenings.

Mr Vr once asked the researcher, "***Brain Dead Cases Nahee Miltey Hai Par Accidental Cases To Hotey Hai, Tab Bee Organ Kaha Jatey Hai Patta Hee Nahee Chalta Hai" (***Meaning so what, if brain dead cases are not there but what about accidental cases? There are many accidental deaths. We don't know where those organs go?)

For some, it was a person who was on a ventilator in the hospital.

For one transplant recipient, Mrs Yl, who was lucky to get a liver transplant done with a liver of a BSD donor, all patients who were on ventilators were brain dead. She would accuse the people of not donating organs. She said, ***"Kitna Log Ventilator Par Hota Hai Per Organ Nahee Deta Hai"*** (Meaning there are so many patients on ventilators in the hospital, but they do not donate organs).

For Mr Ur reported, *"Brain dead persons are completely dead persons. After death, when the heart stops beating, a person remains alive for some time as the brain takes time to die. And when a person's brain also dies, that is brain death".*

For some, it was a person whose relatives could give advertisement in the newspaper regarding the availability of organ from a brain-dead donor.

In one case a recipient Mr E reported, "*During dialysis treatment only, I came to know of donor availability from a brain-dead donor on newspaper. Someone had written to contact him for a donor who is brain dead and family is willing to donate organs".*

It could be the modus operandi of some organ trade racket. Mr.E was not aware of brain death, but he came to know about it through the newspaper.

For some, it was a donor who was half-dead and half-alive.

One recipient who was luckily transplanted one kidney of a 17-year-old male Brain Stem Dead donor about a year back had a different understanding. He said in Hindi--- ***"Hum To Suney Hai Accident Wala Case Thaw, Aada Zinda Ka Case Thaa: Mara Hua Ka Nahee, Marra Hua Ka Kidney Kam Nahee Karegaa Naa".*** (Meaning I heard it was a kidney of a half-dead person and not a completely dead person. He further said that the completely dead person's kidney could not function).

It was interesting to note that none of the three heart recipients who had got beating heart transplanted understood Brain Death. For them, the heart was retrieved by the doctors after it stopped beating in the patient. For one heart recipient, brain death is different from accidental death.

As per Mrs. CH, "The heart was retrieved from a patient who had died after an accident. Brain death and accidental death are different. In my case, it was an accidental case not a brain-dead case".

As per Mr.BH, "Organs are retrieved after post-mortem, and if a heart retrieved during post-mortem is healthy, doctors transplant it in patients who need a heart transplant. But family consent is important during post mortem. All families may not like to get their relative's Heart transplanted because of some religious issues".

Almost all the recipients misunderstood Cadaver donor. While cadaver donor meant Brain Stem Dead donor only, recipients misunderstood the same. The word cadaver donor used for BSD donor was responsible for many confusions, suspicions and apprehensions within recipients. Cadaver donor is a dead donor, and only eyes are usually retrieved from a cadaver donor. People could not perceive the difference between tissue (eye donation) and organ (kidney, liver or heart) donation. While the former, i.e., eye donation is possible after complete death, but for the latter, BSD declaration and acceptance of this new definition of death by relatives is a must. Most of the people believed that an accidental death could help them in getting organs. These misinformed recipients would ring the transplant coordinators repeatedly and inquire when will they get kidneys. They think that such accidents happen regularly, and post-mortems are compulsory. Most of the patients did not know about BSD donation because they had registered for a cadaver donor, a term usually used for this form of death. And most of the recipients were very optimistic about kidney transplant after getting registered for a cadaver donor. Some long waiting recipients suspected kidney trading by the hospital. At times the waiting recipients believed the hospital sells those post mortem organs to elite patients. They would blame the hospital while they kept waiting for organ availability call and did not receive the same for long. The reasons for this optimism ending in suspicion could be associated with their understanding of this form of death as revealed by their narratives. For most of the recipients and their relatives, a cadaver was an accidental death case only with no other information and accidental death cases were in abundance for them. They could not explain further as they had never tried to understand it. It is interesting to reveal that NOTTO prepared a video spot of 30 seconds duration. However, it did not get the concurrence of DGHS for explaining Brain Stem Death for some time. He believed that people don't need to be told about the intricacies of organ donation since the researcher also was a part of one such meeting. Also, our Prime Minister Mr Narendra Modi twice talked of the importance of organ donation in his radio address to the nation in his "Mann Ki Baat" program in October and November 2015. However, he also mentioned that in case of death in Road Traffic Accidents, organs of a body can be donated. NOTTO officials briefed our PM before the talk as was revealed to the researcher. NOTTO chose to give selective information to our PM also. However, it was not a deliberate attempt on their part, but they aimed to make the messages simpler to public. Intending to increase the organ donation rate in the country by using confusing and ambiguous terms, has not provided a flip to BSD donation but has led to misunderstanding and accusation by the patients on the hospital.

A Craving of Recipients to Meet BSD Donor Families

Most of the recipients who had received the organ from BSD donors wanted to meet the donor family, but most of them also knew that they could not do so.

As per Ms Mitta, *"He was always thankful for his second lease of life. He wanted to meet the donor family but was not allowed to do so. He wanted to thank them and tell them that their mother is still alive".*

As reported by Mrs Tr, "*I want to meet the donor family. The cadaver donor was a young boy of 20 years whose family donated his kidney, which matched with my daughter, who is 25 years old. She is not married. I want to meet this family in Chandigarh and see if they have a son who can marry my daughter. In this way* ***"Ghar Kee Cheez Ghar Mai Hee Rahegee" (****Meaning in this way the kidney donated by them will be back to their home).*

As reported by Mrs.Yl, *"I have celebrated the 2nd birthday (referring to the transplant anniversary) with the hospital authorities on 10th March 2017. It was a male child of some family living in Lucknow whose organs were donated. Madam, I touch my liver site on my body and feel as if I am touching my son who gave me his organ. Yes, he was my beta (son) only. Earlier I felt that God had not given me a son, but now I don't feel so. My son is there with me all the time. My son, who shared his life with me (referring to her liver). I am thankful to this son. My son probably would not have given me his organ. I am thankful to this son. My sister –in- law knows that family. She has been able to trace the family. I will visit them to thank them for giving me a second lease of life*". She spoke to the researcher for one hour without any pause.

As reported by Mr.Zl, *"I met the donor family, and I feel bad for them also. The father of a 3-year-old female child whose three organs were transplanted in my son,* *wanted to see his daughter living in my son. He had come with great hope of meeting my son to see his daughter alive in my son. He felt terrible for my recipient son who had received two kidneys, and a liver of his dead daughter. My son died within 45 days after transplant. Both families were devastated. He has become my friend now and feels bad for me as I am under debt now".*

As reported by Mrs.YI, "*People say the soul is immortal. I too feel so. I would tell you there was a cat that would come to me in my parental house when I visited them after one-and-a-half-month post-transplant. The male cat would see me as if it was the donor who had donated his liver. He would sit with me, even sleep next to me. It needed to be loved and caressed, and I would always do so. My parents did not like that, but I don't know how it got a great affinity for me. Madam, it was my son who was sitting with me, and my son wanted to see how I was doing with his organ. Maybe I was wrong. But it gave me a lot of solaces caressing that soul. After I left that place, it ceased to visit them".*

Most of the recipients who had received the kidney from cadaver donors wanted to meet the donor family but knew that they could not. However, all of them were thankful to the donor families who had donated the organs of their near relatives. There are three categories of such recipients who had a yearning to meet the donor family.

The first category of recipients waited for an opportunity to meet the donor family. This category of recipients wanted to thank them, tell them that their donor is still alive and to find an alliance for marriage in the donor family for the recipient daughter.

The second category of the recipient was those recipients who had met the donor family. While one recipient Ms Pitta had traced her donor family through social media, both donor and recipient families have become relatives forever. Another recipient was located by the donor family itself as reported by Mr ZI. In this case, both the donor and recipient family felt devastated as multiple donor organs (two kidneys and one liver transplants) could not keep alive the recipient. Interestingly, in the latter case also both the donor and recipient families have become friends now.

In the third category, the recipient knew the donor family but reported of meeting them later as the place was far off. She had a strong urge to meet the donor family, had traced her donor family but had not reached them yet. Meanwhile, she had substituted a male new-born cat to repay the good deeds believing that the donor soul is reborn in a cat. The strong urge to have a son could also be satisfied through the act of donation and transplant. One of the recipients who had produced two daughters only, felt God had given her a son who donated his liver to her.

Unethical Practices of Private Hospitals

The recipients revealed several unethical practices adopted by doctors in private hospitals.

Mr XI reported that he paid an amount of 20 lakh rupees in advance for transplant surgery in March 2012 without a BSD donor in sight. It raises suspicion and speaks of pressures on the declaration of Brain Stem Deaths in hospital. The transplant surgery took place in July 2012 only. Meanwhile, the patient was called five times for BSD donor liver.

As per Mr.ZI, *"I was convinced by doctors that my son would recover 100 per cent after surgery. The two well-known doctors of a reputed hospital had assured me that he would be all right after surgery, which did not happen. My son was transplanted two kidneys and liver from a cadaver donor who was a 3-year-old girl. It was a multi-organ transplant, and a very major surgery conducted from 6.30 am to 11.30 pm. It was very prolonged surgery. They told that it would take time for the child to regain consciousness, but within 12 hours, he was asking for water in ICU. He was desperate to get water which doctors refused to give. His abdomen was kept open; his body was not stitched to allow dilatation of abdominal organs. He had to be operated twice even after this major surgery. Within three days he was again operated to remove some blockage and then again after three days they felt some blockage which needed surgical intervention. I only feel bad for my boy who suffered like hell in the hospital. How we all lived during that one year, I don't want to tell. We all were badly sufferings. He accepted the organs very well but developed a fever.*

His reason for fever remained undiagnosed. I think there was some negligence on the part of doctors who could not ensure he survives after surgery".

As per Mr Dl, *"Doctors told me that the cost of the surgery might be 25 lakhs only. But the actual price came to 35-40 lakhs as I developed some complications and my 22-year-old daughter who donated a part of her liver was in ICU for ten days. I remained in the hospital for 40 days after transplant surgery. I am a Govt. employee. Govt. paid me 13-14 lakhs only. My friends and well-wishers loaned me the rest of the transplant cost".*

As reported by Mrs. Qr*, "At one time there were four gazetted holidays. Dialysis was not possible here in this hospital as dialysis unit remains closed on gazetted holidays. My husband became unconscious and severe as he required dialysis badly. Well-wishers guided us to move him to a private hospital. We did as was suggested. They told us to deposit 80000 rupees before getting the patient admitted, but we could not do so as we did not have the money. Not only this, they further told us to keep three lakhs ready for further treatment. We kept roaming from one hospital to another till 9.00 pm and eventually came back to this hospital only and got him admitted again".*

As reported by Mr AHr, "The cost of heart transplant surgery for my son was estimated to be around 15 lakh rupees. But the heart was retrieved in one State and transportation via airways into another State. The surgery cost came to 22.5 lakhs. I was not informed about transportation cost beforehand and could not arrange the whole amount. Having no other alternative in hand, they waved off the remaining amount but did not give me the bills. The bills were essential for me as I have to claim this amount from the authorities as a CGHS beneficiary. I am desperate to get this amount as a CGHS beneficiary. I was astonished and shocked to know about the huge cost of this surgery".

The procedure of advance payment for a cadaver donor liver as reported by Mr Xl raises suspicion about the processes followed in the hospital. It builds a concern about the pressures exerted on the declaration of Brain Stem Deaths in hospitals.

Narratives of Mr ZI reveal how relatives are trapped to get complicated surgeries done by giving false assurances that is most unethical. A small child transplanted three organs in a single go with false assurances to parents; guarantee of 100 per cent speaks of degrading ethical commitments of medical professionals. It is probably done to sensationalize the organ donation and transplantation business. Multi-organ transplants gain media attention and bring a hospital in great limelight as could be seen by the researcher in several online sensational media coverages of these events, including this case.

The narratives of Mr. DI also reveal a trap of different kind laid by doctors. Doctors gave underestimates of transplant surgery that almost doubled the estimated cost when the actual transplant happened. It left him with no choice except to borrow money and sell assets. The unforeseen complications of the donor and recipient surgeries are not explained in advance so that recipients come prepared for transplant surgeries.

The plight of Mrs Qr, to save her husband by trying to get his dialysis done in a private hospital was a situation created by starving Government hospitals. Lack of adequate dialysis workforce to run the dialysis centre in the event of continuous holidays forced her to leave the Govt. hospital and run to private hospitals. The private hospitals required her to deposit an advance. In one hospital an advance payment of Rs. 80000 just for admission and arrangement of an extra amount of 3 lakh for treatment forced Mrs Qr to roam from one hospital to another till 9.00 pm. She came back in the evening to the same Government hospital and got him readmitted ".

Narratives of Mr AHr, reveals the unethical diplomacy of private hospitals to airlift heart, invest lakhs of rupees in doing so without taking prior concurrence of relatives. Relatives are later supposed to pay for the expenses for airlifting the organ. It is one of the most unethical practices of private hospitals. Withholding bills of patients, after relatives exhaust all their resources towards payments is not at all justifiable. And is the most unethical practice of private hospitals.

Bureaucratic Obstacles Met by Recipients and Their Families

The stories of recipients pointed to bureaucratic hurdles like harassment for the exuberant monthly cost of immunosuppressant's, delays of continuation of recruitment of temporary contractual employees and getting permission for a liver transplant.

As reported by Ms Mitta, *"I faced many problems because of immunosuppressant and medicines required for his treatment post-transplant. My office people did not believe that my husband required 25 - 30 medicines a day postoperatively. The cost of medicines per month was more than the pay given to me at that time in Govt. hospital. They were reluctant to reimburse an amount of Rs. 6000 in 1995 per month (year changed). They referred my case to the vigilance department. I was harassed by the administrative people a lot for proving that my husband required 25-30 types of medicines per day. Once I was told to keep all the wrappers of his medicines for a month. The purpose was to let the vigilance committee find the truth after seeing the wrappers. The cost of medicines came to Rs 22000/- at the time when he took leave from this world after 18 years".*

As reported by Mrs.Dr, *"I have been coming every week for last one month to get the file for transplant surgery made by Ms.Votc. She is not coming (not knowing that her tenure after one year of completion of contractual employment is over). How long will I stay in other's house? I can see the unease in their family, as three members of our family are staying with them. Back home, my family is suffering in Bihar".*

As reported by Mr.Brl, *"I was made to run from pillar to post to get it written whether my brother requires a liver transplant or not. The two well-known doctors of Govt. hospitals had advised for his liver transplant. But the authority did not believe the papers. They felt that it is not required as he was ambulatory and was walking. How could he be sick? He is walking, was a question asked by many. They did not believe it. They harassed us. His wife was willing to donate her liver, but the documentation requirements created havoc in his life.* ***"Wohh Kagzoo Mai Kamiya Nikaltey Rehtey They Aur Humara Time Barbad Kartey Theey"(****Meaning they were* *finding faults with documents and wasting our time). They wanted bribe from us, some 4-5 lakhs. I have made a complaint with the authorities now.* ***Court Case Kiya Hai"*** *(Meaning the case is pending in court).*

The story of Ms Mitta points to exuberant costs of the immunosuppressant's amounting to Rs. 22000/- way back in 2012. The narratives also lead to the unbelievable number of medicines that are required by a transplant recipient post-transplant ranging from 25-30 types of medication per day. It was unbelievable for the officials too who had to reimburse the bills to the medical claimant. The cost of the drugs was more than the pay of the employee who was claiming the medical bill reimbursement of her dependent husband. The authorities stooped to low by telling the female employee to keep all wrappers of the medicine for one month and present the same to the committee to verify the truth.

The plight of Mrs. Dr is the result of bureaucratic delays of continuation of recruitment of contractual employees. The bureaucratic hurdle in the extension of recruitment of contractual employees causes delays to the movement of medical files of sick patients. It, in turn, causes immense sufferings and financial loss to patients and relatives. Contractual employees are hired for one year only, and before their employability is over, they are not given extension again. The file moment to continue their tenure depends on whims and fancies of permanent administrative staff. In such delays not only, the organization fails, but it creates a lot of problems for the people who wait for their medical file movements and suffer.

The transplant recipients who need a liver transplant are ambulatory patients, but their life may be short if they are not transplanted liver in time. But people don't understand that. They think a patient needing a liver transplant could be a very sick person and not an ambulatory person. As reported by Mr Brl, ***"Woh Kagzoo Mai Kamiya Nikaltey Rehtey They Aur Humara Time Barbad Kartey They".*** Finding faults in documents submitted to the authorities is one of the ways to harass people and put them to agony. The flaws in medical reports are repeatedly exposed to dissuade people and hints towards payment of a bribe. Asking for a bribe of lakhs of rupees to allow the patient to go for a transplant is most unethical. It also speaks of the moral degradation of people, even for those who are dying.

Poor- Rich Divide Was Highly Visible in Organ Donation and Transplant

The researcher found a gap in the sufferings of the rich and poor. The rich suffered but with comfort and dignity. On the other hand, the poor suffered from a lot of discomfort and indignity.

BPL families of other States were denied free treatment on the pretext that their BPL cards do not belong to this part of the country.

It is a compulsion for many poor people like Mrs Dr, Mr Lr or Mr QRR to donate a kidney to relatives. It helps them to save money, reduce sufferings and minimize borrowing.

Poor people are not able to avail the deceased donor kidneys like Mr.GGR and Mr Jr in case they are from neighbouring States. They cannot afford to fly to the transplant centre when called. On the other hand, rich people like Mr. Xl fly from other country at the nick of time.

The poor- rich divide was highly visible in organ donation and transplant. Poor people are not able to avail the deceased donor organs. Poor person's organs can fly from one part of the country to another in charter planes. But a poor person cannot come to the transplant hospital in time because of the scarcity of resources. A poor person cannot afford to move to a place near a transplant centre. Whenever he does, he will burden the acquaintances who have come out of the village to earn a little and save money. He is also compelled by his meagre resources to spend nights in hospital corridors, under bridges or on roads. A rich person on the other can afford to live in rented accommodation, purchase a second-hand car and fly back to his residence with a transplanted organ.

New Lease of Life of Transplant Recipients an Inspiration for The Social Cause

The donor organ had given a new lease of life to many recipients. It had inspired them to contribute to the social cause in some cases. They were motivated to give back to society, and NGOs utilized their services for promoting the cause of organ donation and transplantation.

As reported by Mr.XI, *"Always thankful to GOD, and to the donor family for giving me a 2nd life ... Three Years after transplant, I feel happy and satisfied. I am alive – could do my professional job for over 2½ years after Liver Transplant and could see myself retiring as a normal person. Returned from Abu Dhabi to India and was able to settle in Delhi. Whatever I have got, it is best for me. I accepted the way it is (no complaints) and learned to make the best use of my 2nd life. I have been able to manage my schedule of medicines (missing doses @ Zero), Lab Tests, diet, routine activities, and rest as required. I am maintaining a schedule of exercises and Yoga with my new life. It motivated me to do something new, and I wish to do something for the social cause and enjoy the retired life to the fullest. My wife and I have undergone structured training with MOHAN Foundation, Gurgaon (MOHAN - Multi Organ Harvesting Aid Network). We are certified trained Volunteers for Organ Donation campaigns. We are now working for the mission: "To make it possible that every Indian who is suffering from end-stage-organ failure be provided with the 'Gift of Life' through a life-saving Organ". We feel privileged to be committed to this noble social cause of Organ Donation through our time, effort, energy and fundraising. I always look forward to talk about this social need for organ donation among family, friends, colleagues and social circles.*

As reported by Mrs.YI, *"Madam, I want to donate every part of my body after I die. Let others use my body parts. Let it give life to people who cannot do without them. My life has changed. I too want to give back to society. Madam, I will tell the doctor also about my wish. My daughter too wants to donate her organs as she has felt the importance of donation".*

As reported by Mrs CH, *"I am happy to have started working in the field of body and organ donation. I am the chairperson of 'Parashar Foundation' that was started by my late husband long back. The Foundation was granted registration u/s 12A and initial exemption certificate u/s 80G on August 24, 2005. The Foundation was formed to improve the fate of the poor and underprivileged in general. Providing education and healthcare to the needy, but now we are working on organ donation as well".*

Organ transplant was the commencement of a new life or a second lease of life, and most recipients felt like giving back to society and making use of their potential. In many cases, they committed themselves to promote the cause of organ donation and transplantation. The researcher observed the critical role played by many such recipients in creating awareness on organ donation and transplantation. The new lease of life had become a socially productive life for many such recipients. Most of the recipients were committed to spreading awareness in their respective State organ sharing networks and organization that had helped them in getting the transplant done. Similarly, since 2013 after getting heart transplant done the chairperson of Parashar Foundation founded in 2005 felt the importance of organ donation for end-stage organ failure patients and plunged into the area of organ donation by creating awareness on Organ Donation under the ORGAN (Organ Receiving & Giving Awareness Network India) after 2015.

ORGAN India employees revealed that it is working hard to execute an organ donation and transplant system, including body donation. They were educating the public about organ donation and introducing them to the idea of Brain Stem Death using various mediums and platforms. It has established itself in the area of organ donation and is involved in many programmes conducted by NOTTO. NOTTO and DGHS officials are usual invitees to many events organized by this Foundation. Among many other initiatives, they compiled a Body Donation Directory launched by the Honourable Union Minister of Health & Family Welfare, Shri J.P. Nadda on May

12, 2017. However, the heart recipient died on November 3, 2018, as communicated to the researcher by the employees.

Summary: - This Chapter on gender inequalities in organ donation and transplantation reveals the burden of living organ donation rested on females predominantly. This trend was seen both in kidney and liver donation. Out of 19 living kidney donors, 16 were females. Out of three male living kidney donors, two had given the organ to males only. The issues that emerged from the donor-recipient equation linked to fertility. Also, in one case study, the woman's kidneys had failed because of the overdose of medicines taken for infertility. The in-depth case study of Ms Mitta and Ms DlDa reveal gender suppression from early childhood and repercussions of the same on the psyche of the females in later years of life. Weakened by the aggressive social environment, including her mother, Mitta intentionally married a man with CKD knowing he will require a kidney transplant in future.

Similarly, the story of Ms DlDa, reveals that donating 65% of liver was an opportunity for her to prove her worth to the family. And get an honourable status like that of her brother. It was missing in her life. Ironically, she did not find love and respect from her father, even after the donation.

In a few cases, females in need of kidney transplant were dumped with their parents, divorced or abandoned. The females often faced abuse and violence at the hands of husbands during dialysis and afterwards. Researcher witnessed gender divided roles in the study. Female members mostly donated organs and took care of people at home. Male members supported dependent members of the recipients, stayed in the hospital with them and moved from one department to another for getting both the donor and recipient evaluated. Males only arranged blood, shifting near to dialysis facility or transplant facility from the place of residence, spent on the education of dependent children and took care of them as well at home.

This Chapter also reveals some issues common to all transplants, i.e., kidney, liver and heart transplants. The word cadaver donor used for BSD donor was responsible for many confusions, suspicions and apprehensions for recipients. Most of the recipients who had received the organ from BSD donors wanted to meet the donor family. Taking full advance payment for a transplant surgery with cadaver donor reveals unethical practices of private hospitals. It also raises suspicion concerning the pressures exerted on the declaration of Brain Stem Deaths in hospitals. Relatives were also trapped by giving underestimates and giving false assurance of 100% recovery for multiple organ transplant surgeries. It revealed bureaucratic hurdles met by recipients and their families, poor-rich divide and a new lease of life of transplant recipients an inspiration for the social cause.

CHAPTER 11

Perspectives of Organ Donor Card Holders Who Had Pledged to Donate Organs

This Chapter reveals the perspectives of people who had pledged to donate organs. The first part reveals socio-demographic information of the respondents and the choices they made for organ and tissue donation in the Form 7 of THOT Rules 2014.The second part reveals their knowledge regarding Brain Stem Death and classifies these organ donor card holders into four categories like genuine, fake, less aware and unaware innocent organ donors based on the knowledge scores on BSD donation and narratives revealed to the researcher. The second part also reveals their knowledge scores regarding organ donation and transplantation in general. Third part reveals general perspectives of respondents towards donation and fourth part elicits their opinions about various aspects of organ donation and transplantation under study. The fourth part also reveals the findings of FGDs on two issues, i.e., presumed consent and revealing recipient identity in the context of Brain Stem Death. The results of FGDs on these two issues are incorporated with the opinions of 30 organ donor card holders on similar subjects.

Socio-Demographic Information of Organ Donor Card Holders and Their Organ Donation Choices: -

This part reveals socio-demographic information of organ donor card holders and organ and tissue donation choices made in Form 7 of THOT Rules.

Table 11.1 Socio-demographic status of organ donor card holders (N=30)		**Number / Percentage**
AGE	18-25 years	15(50%)
	26-35 years	11(36.66%)
	36-45 years	2(6.67%)
	46-55 years	2(6.67%)
SEX	Male	13(43.33%)
	Female	17 (56.67%)
RELIGION	Hindu	24(80 %)
	Christian	2(6.67%)
	Muslim	2(6.67%)
	Indian	2(6.66%)
MARITAL STATUS	Unmarried	27(90 %)
	Married	3(10%)
QUALIFICATION	Undergraduates	13(43.33%)
	Graduates	11(36.67%)
	Postgraduates	6(20%)
OCCUPATION	Student	13 (43.33%)
	Employed	17(56.67%)
TYPE OF FAMILY	Nuclear	22(73.33%)
	joint	8(26.67%)

Table 11.1reveals that majority 15(50%) were in the age group of 18-25 years; majority 17 (56.67%) were females, majority 24(80 %) were Hindus, majority 27(90 %) were unmarried, majority 13(43.33%) were undergraduates, majority 17(56.67%) were employed and the majority 22(73.33%) were living in nuclear families.

Regarding the status of organ donor card holders based on the choices made by them in form 7 of THOT Rules 2014 (Pledge Form) in well-organized awareness programmes conducted by NOTTO, it may be important to reveal that the pledge form had various options, and respondents had to give their preferences for each organ and tissues individually, that they wished to donate after BSD/death (Annexure3.5). It was interesting to see the variation in their choices about each organ and tissue pledges with reasons too.

Figure 11.1 Organs and tissues pledged by organ donor card holders (N=30)

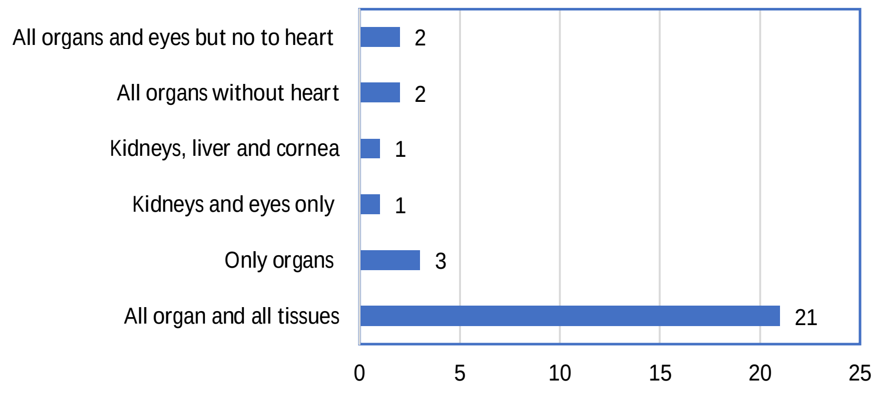

Figure 11.1 reveals that majority of respondents 21 had pledged to donate all organs and all tissues.

The respondents who had pledged to donate only organs, i.e., 3 did so to remain intact from outside and remain beautiful after death in their final journey as narrated by them.

Mr. P1 narrated, *"I don't want to look ugly when I am dead. My relatives should not feel bad to see my ugly body without skin and gouged eyes after death. The retrieval of heart, kidneys do not alter beauty from outside That is why I have pledged to donate only organs and not tissues".*

As shown in the Figure 11.1 above, many respondents did not wish to donate their heart. Their perceptions related to such choices, as depicted in their narratives below: -

Mr. P2 narrated, *"I don't want to donate heart as I don't want to wander as a ghost after my death. What about my last journey when I am supposed to unite with God through my soul? I am not dead when my heart beats in someone else's body; the concept of donating heart does not go well with me. Heartbeat means life and soul intact, and when the heartbeat stops, that means death has happened, and the soul has united with God".*

Mr. P3 narrated, *"I don't want to donate heart as I want to remain loyal to my wife after death. I have given my heart only to her during life, and I don't want to give to someone else at death".*

Mr. P4, who had chosen to remain unmarried, said, ***"Jeetey Jee Dil Kisse Ko Bee Nahee Diya Ab Marney Ke Baad Kyon Doon"*** **(**Meaning I have not given my heart to anyone during life and there is no purpose to do so after death).

The respondents had different choices for donating organ and tissues based on their thinking. The beauty of body post-death and perception of soul uniting with God were two significant concerns of organ donor respondents. Heart donation was not accepted by many as heart and soul was considered blended. Fear to become a ghost after death through the gift of heart had prevented a few from pledging to donate the same. The heart was also considered a container of love and trust for the life partner as well.

Knowledge of Organ Donor Card Holders on BSD and Organ Donation & Transplantation.

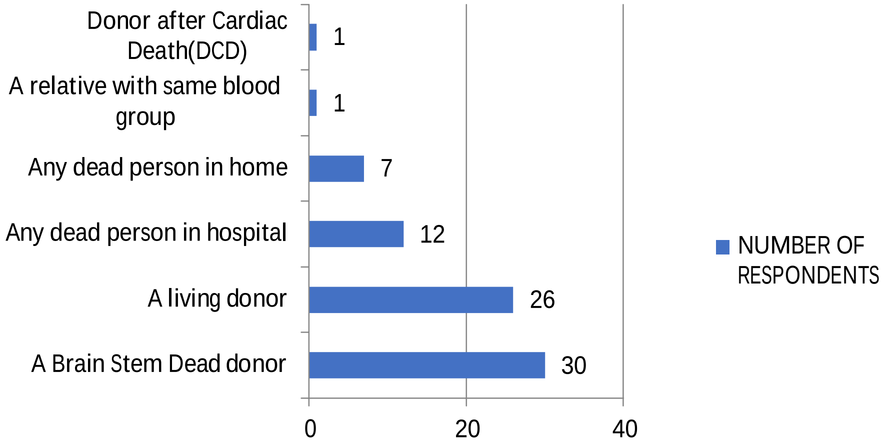

Figure 11.2 Knowlegde of organ donor card holders regarding who can donate organs like kidney/liver in India (Multiple Choice) (N=30)

Figure11.2 reveals that 12 organ donor card holders knew that any dead person could donate organs in the hospital and seven (7) respondents knew that organs could be given by any deceased person in the home as well, that is not true.

The ethical issue here is, can we assume that all the respondents who have pledged to donate organs are willing to do so when most of them think that it is a completely dead donor who can donate organs.

Figure 11.3 Knowledge of organ donor card holders based on number of correct answers to statements on BSD donation(N=30)

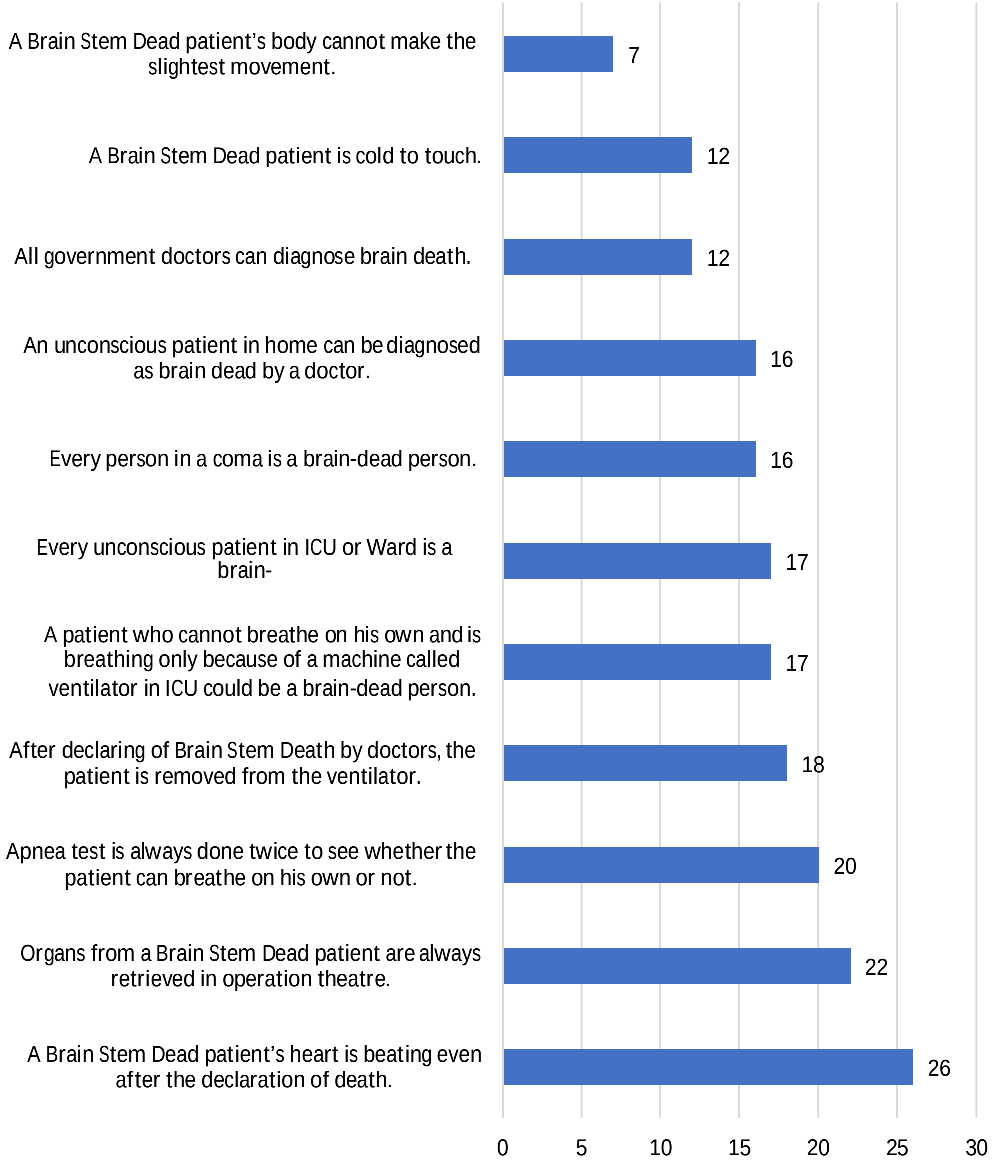

Figure 11.3 reveals knowledge deficits among organ donor card holders in all the 11 critical areas. Only seven (7) knew that the donor body could make some movements after the declaration of death in some cases. Only 12 respondents knew that the donor body is not cold to touch. Not all knew that heart of a BSD donor keeps beating even after the confirmation of death. Only 18 respondents reported that the patient is not removed from the ventilator after the declaration of death.

Knowledge gaps in almost all the areas depict lack of requisite knowledge among most of the organ donor respondents. Again, this raises an ethical concern with their minimal understanding of organ donation from BSD donors. How can we assume that all the respondents who had pledged to donate organs are willing to donate organs?

Based on the marks scored by individual organ donor card holders in the area of BSD after having pledged to donate organs and telephonic interviews with them, four categories of donors identified are **Genuine, Fake, Less Aware and Innocent Unaware** organ donors as shown in the Table 11.2 followed by a description in details below: -

Table 11.2 Classification of organ donor card holders based on their scores obtained in understanding Brain Stem Death (Max Scores=11) (N=30)

THEY HAD PLEDGED TO DONATE ORGANS	**THEY KNOW**		**THEY DON'T KNOW**	
	SCORED 9-11 MARKS		**SCORED 5-8 MARKS**	**SCORED 0-4 MARKS**
Classification of organ donor respondents	Very well-aware **"GENUINE/ TRUE,"** Organ Donors	Very well-aware but **"FAKE"** organ donors	**"LESS AWARE"** Organ Donors	**"UNAWARE INNOCENT"** Organ Donors
Number /percentage of respondents	**7**	**2**	**13**	**8**

Table 11.2 reveals that majority of 13 organ donor card holders were "Less Aware" and 8 were "Unaware Innocent" organ donors. Only seven (7) organ donor card holders were "Genuine /True" organ donors, and interestingly two (2) respondents were "Fake" organ donors as well.

1. **“Genuine/ True”, Well Aware Organ Donors**- They had scored 9-11 marks out of maximum 11 marks. They were very well-aware organ donors. They aimed to help people suffering from organ failures.

Ms. P6 narrated, *“I want to help the society by donating organs if I am declared brain dead”.*

Ms. P7 narrated, *“Donation of organs will get translated into virtues as organs will alleviate sufferings of human beings”.*

Ms. P8 narrated, “*Take every part of my body and let it not get waste if I am declared brain dead. I believe in helping people during life, and I don’t want to change my attitude at death”.*

Ms. P9 narrated, *“What else can doctors do if they come to know that patient has no chance of recovery. Let them declare brain death. At least donation of organs will provide a chance for others to live”.*

2. **Well-Aware “Fake” Organ Donors:** They also had scored 9-11 marks out of maximum 11 marks, were very well-aware but fake organ donors.

Mr. P10 narrated, *"I don't mind pledging the organs as it does not have any legal standing. I have decided to communicate my unwillingness to donate organs to my family. I know that my family still can say no to organ donation".*

Mr. P11 narrated, *"I have pledged to donate organs. I don't want to do so. I know that it would never be a possibility to donate organs as I live in a far-off village where facilities of organ donation are missing".*

3. **“Less Aware” Organ Donors:** Their awareness about organ donation was less and had scored 5-8 marks out of maximum 11 marks.

4. **“Innocent Unaware” Organ Donors:** They had scored 0-4 marks out of maximum 11 marks and were unaware organ donors and did not have enough knowledge regarding organ donation from BSD donors.

NOTTO officials, on many occasions, revealed that many respondents fill the form 7 as they are required to do so in mass awareness programs. Ms. Asaid narrated, *"The organ donor had written on the back page of Form 7 that he did not want to donate any organ after death. But he filled it casually and unintentionally to show his solidarity with others".*

Figure 11.4 Number of correct answers to statements on organ donation and transplantation revealing knowledge of organ donor card holders (N=30)

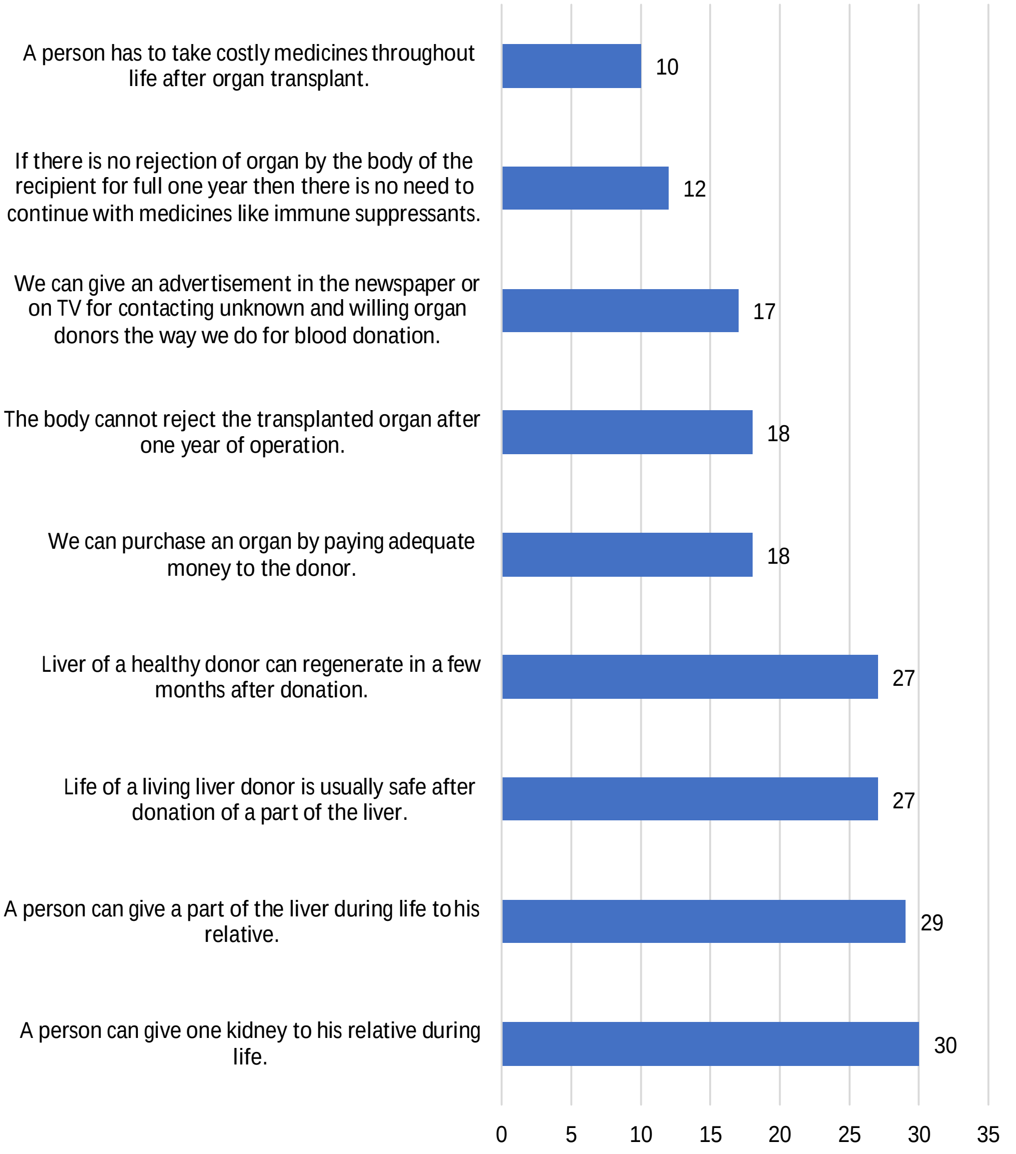

Figure 11.4 depicts knowledge deficits in significant areas. Only ten (10) respondents knew that recipients of the transplant have to take costly medicines throughout life.

Only 12 respondents knew that there is a need to continue with medicines like immune suppressants even if there is no rejection of the organ for complete one year. Only 17 knew that they could not give an advertisement in the newspaper or on TV for paid donors and 18 respondents knew that they could not purchase an organ.

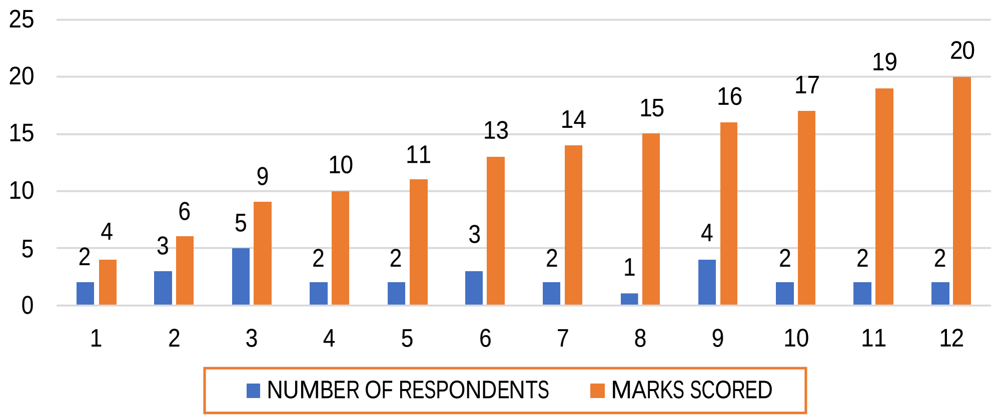

Figure 11.5 Distribution of organ donor card holders with their aggregate scores on BSD , organ donation and transplantation (Max. Marks =20) N=30

Figure 11.5 reveals two (2) respondents scored a minimum score of 4 and two (2) respondents a maximum score of 20. The majority, i.e., five (5) respondents scored nine (9) marks in aggregate. These knowledge scores revealed their understanding of organ donation from Brain Stem Dead donors (Max.Marks-9) and organ transplantation in general (Max.Marks-11).

The data reveals that most of the organ donor card holders who had pledged to donate organs had limited knowledge in most of the areas.

Organ Donor Card Holders' Perspectives Towards Donation

This part reveals the perspectives of organ donor card holders towards donation.

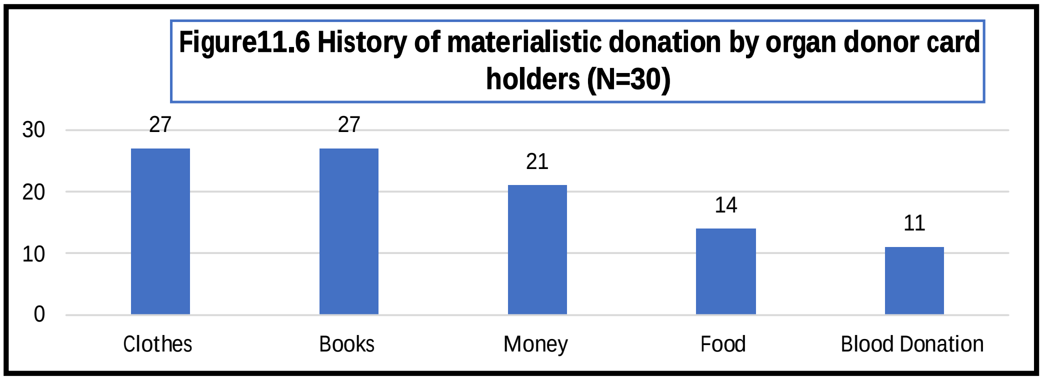
Figure11.6 History of materialistic donation by organ donor card holders (N=30)

Figure 11.6 reveals that 27 respondents had donated clothes to respondents, and an equal number had donated books also. Only 21 respondents gave money also and 11 respondents donated blood.

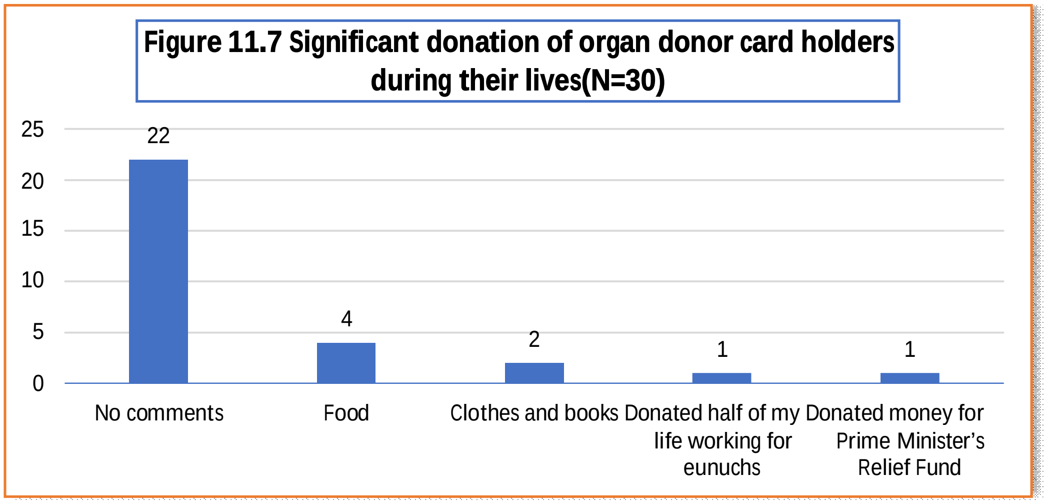
Figure 11.7 Significant donation of organ donor card holders during their lives(N=30)

Figure 11.7 reveals that majority of organ donor respondents, i.e., 22, did not report any significant donation. Four (4) organ donor card holders believed that food they donated was the most significant donation. Interestingly, for one (1) respondent, working for eunuchs for 20 years was like giving half-life and a substantial contribution too. For one (1) respondent giving money for Prime Minister's relief fund was the significant donation.

Figure 11.8 History of blood donation to family members by organ donor card holders (N=30)

Figure 11.8 reveals that majority of organ donor card holders 26 had not donated blood to their family members, and only four (4) had donated blood to their family members.

Figure 11.9 History of blood donation to other than close relatives by organ donor card holders (N=30)

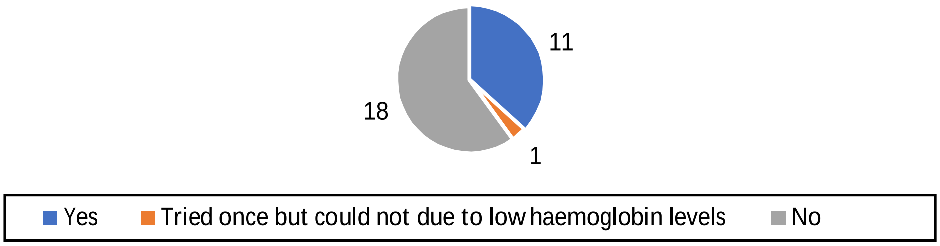

Figure 11.9 reveals that the majority, i.e., 18 respondents had not donated blood to others who were not their close relatives, and only 11 had donated blood to others than their close relatives. There was one donor who expressed that she had once tried to give blood to the stranger but could not do so as her haemoglobin levels were low.

Comparing the data in Figure 11.8 and Figure 11.9, it is interesting to see that only four (4) respondents had donated blood to close relatives in comparison to 11 who had given blood to others.

Figure 11.10 Willingness of organ donor card holders to donate kidney or liver during life to their own family member if needed (N=30)

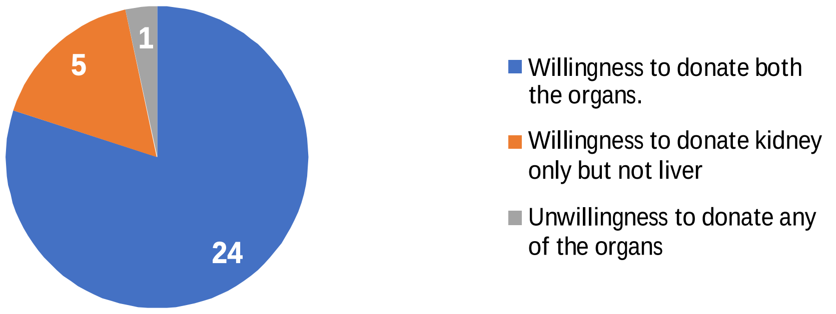

Figure 11.10 reveals that the majority, i.e., 24 organ donor card holders exhibited a willingness to donate both organs like kidney and liver to family members. However, five (5) respondents were willing to give the kidney only as they felt they had two kidneys and can live with one. Donating half organ that is liver was not acceptable to them. Only one (1) respondent expressed his unwillingness to donate organs to family members.

Figure 11.11 Willingness of organ donor card holders to donate kidney or liver during life to someone outside family out of affection without anticipating anything in return (N=30)

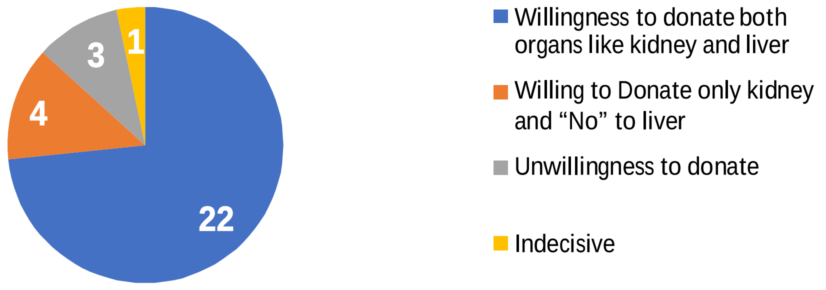

Figure 11.11 reveals that majority 22 exhibited a willingness to donate both organs like Kidney and liver to someone outside the family out of affection without anticipating anything in return. Only four (4) expressed willingness to donate Kidney only and an unwillingness to liver donation, to someone outside the family. A tiny

proportion of 3 expressed reluctance to donate organs and only one (1) was indecisive.

It is interesting to note that there was not much difference among respondents regarding their willingness to donate organs during life to their own family members or outsiders, an area which is always the cause of commercial suspicion among “Authorization Committees” who are very strict in approving such transplants.

Figure11.12 Willingness of organ donor card holders for getting an organ for family member from a Brain Stem Dead donor (N=30)

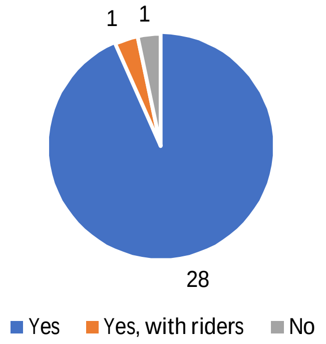

Figure 11.12 reveals that majority, i.e., 28 respondents preferred to get organs for their family members needing organ transplant from Brain Stem Dead donors. However, one (1) respondent said "yes" with riders saying that he will never ask the brain-dead donor relatives to donate organs for his relatives. Only one (1) said "No" to such donation.

Figure 11.13 First preference of organ donor card holders for donation of an organ for close relative in need of a transplant (N=30)

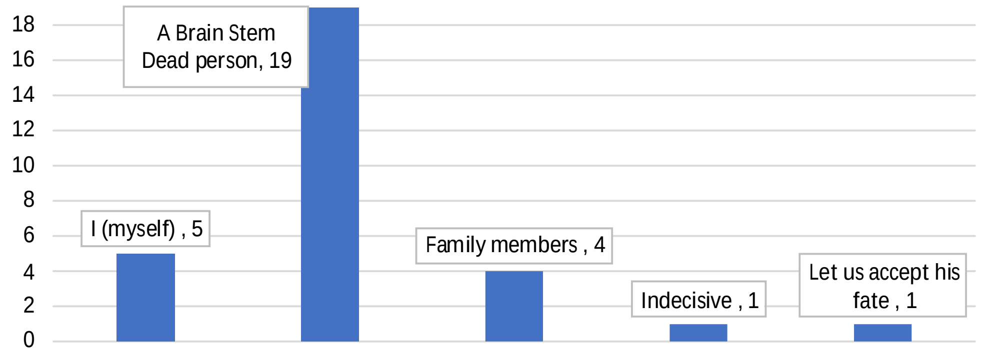

Figure 11.13 reveals that the majority, i.e., 19 organ donor card holdrs would prefer a

brain-dead donor organ for their relatives first. Also, 5 respondents preferred themselves, four (4) respondents preferred other family members and only one respondent preferred to accept the fate of relative. Only one (1) respondent was indecisive.

Figure 11.14 In case the need arises, who in your family will be the first to come forward to give you an organ like kidney or a part of liver? (N=30)

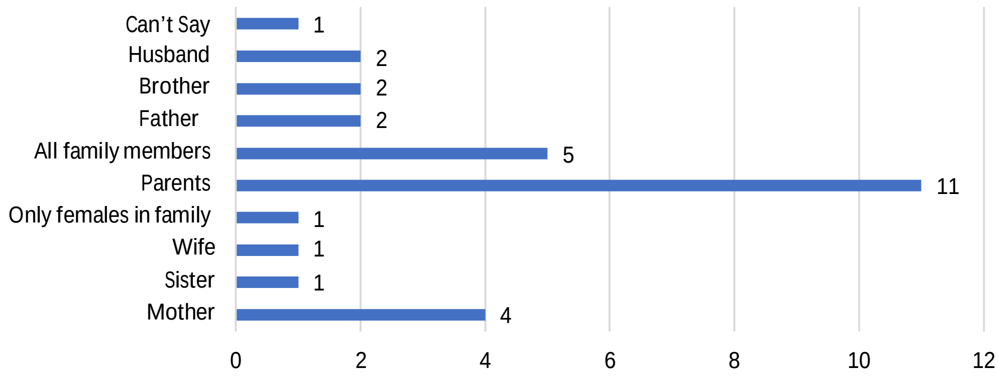

Figure 11.14 reveals that majority of respondents 11 believed that their parents would be the ones who would donate an organ for them, but most of these respondents named mother first among parents, and four (4) respondents thought that their mother would donate organs to them if required.

Figure 11.15 God forbid, in case you come across a situation when you need either a kidney or liver transplant yourself who could be your first preference?(N=30)

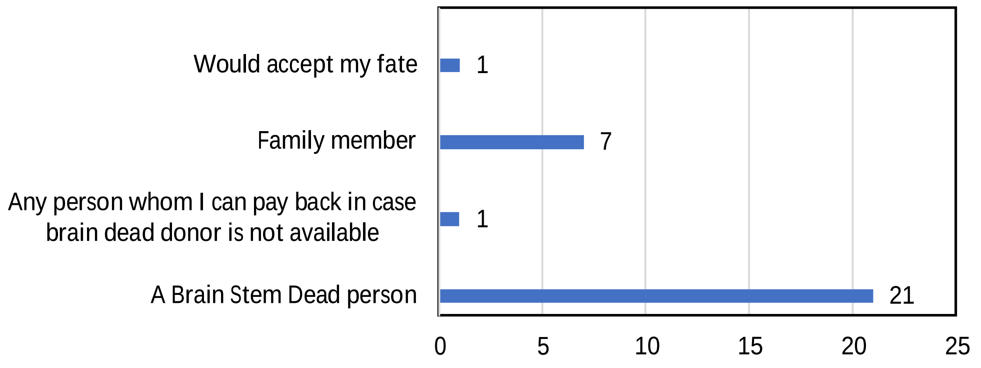

Figure 11.15 reveals that majority 21 preferred brain-dead donors for getting an organ for self, out of 7 who preferred family members first, mother was the first

preference given by three (3) respondents. Only one (1) respondent preferred to accept fate without any transplant, and one (1) respondent preferred to purchase an organ in case a brain-dead donor is not available.

Opinions of Organ Donor Card Holders Regarding Various Aspects of Organ Donation

This part elicits opinions about numerous aspects of organ donation from the perspectives of organ donor respondents.

Figure 11.16 Opinion of organ donor card holders about respecting the organ donation will of the potential donor (N=30)

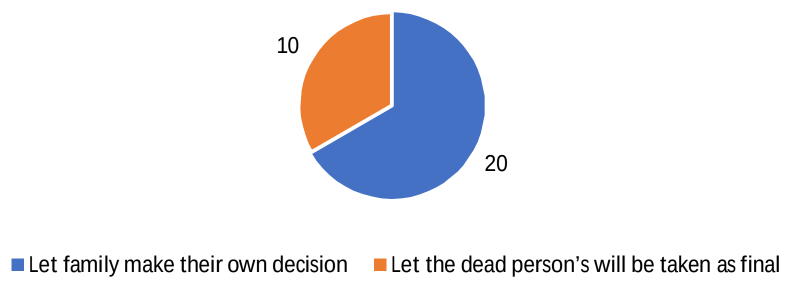

Figure 11.16 reveals that majority, i.e., 20 respondents were of the opinion that family should make their own decision at the time of death, and only ten (10) wished the will of the donor be respected

It is interesting to note that will of the family was of paramount importance to most donors irrespective of the fact they had volunteered to pledge donation of organs. In other words, the majority don't mind if family members override the wish of organ donor respondents.

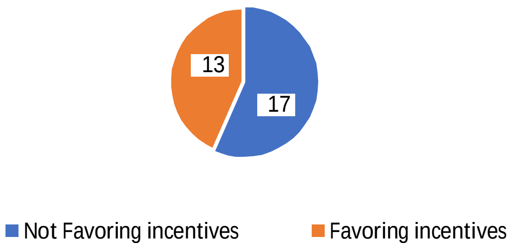

Figure 11.17 Opinion of organ donor card holders about inclusion of incentives for those people who pledge to donate organs (N=30)

Figure 11.17 reveals that majority, i.e.,17 respondents did not favour the inclusion of incentives for those respondents who pledge to donate organs. The remaining13 were in favour of including incentives.

Most respondents who supported incentives revealed their choices as well, e.g., free medical check-up, free health insurance, free treatment, and giving a certificate of appreciation. Only one respondent believed in providing monitory benefits.

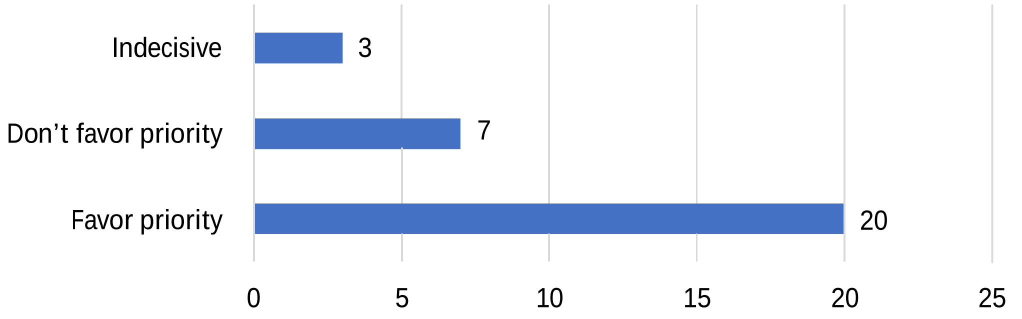

Figure 11.18 Organ donor card holders'opinion towards giving priority to people who pledge to donate organs, in waiting list register if they require an organ transplant themselves (N=30)

Figure 11.18 reveals that majority, i.e., 20 respondents favored priority and seven (7) did not support such priority for people who pledge to donate organs, in waiting list register if they require an organ transplant themselves. According to one such respondent, doing so will be discriminatory as people are not well informed, and professionals may persuade wealthy and affluent to pledge organs.

Figure 11.19 Organ donor card holders'opinion about involvement of families in diagnostic tests of Brain Stem Death (N=30)

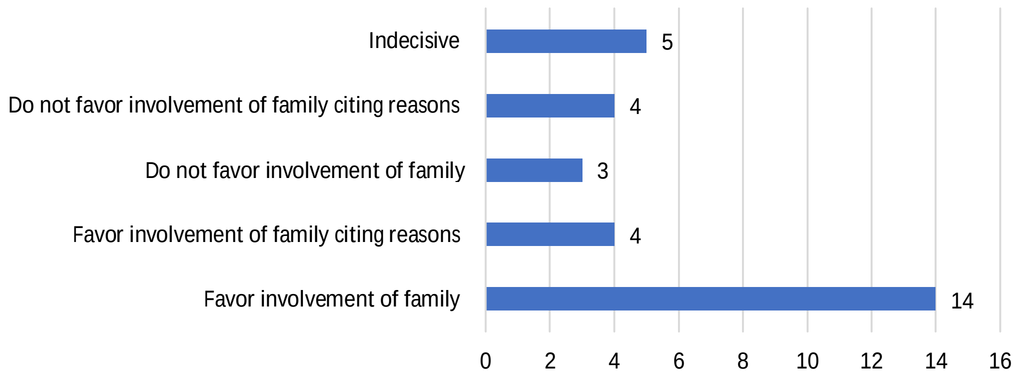

Figure 11.19 reveals that majority, i.e., 14 respondents were in favour of involving families in diagnostic tests for declaration of brain death. Four respondents who supported the involvement of families cited reasons as well. Three respondents cited it is their right and one (1) respondent cited it is essential for the satisfaction of family. Only four (4) respondents did not favour family involvement citing the reason too. Three (3) such respondents believed that medical persons know better than the family. One (1) respondent said that family involvement would increase family stress.

Figure 11.20 Opinion of organ donor card holders regarding taking prior consent from family members for doing "Apnoea Test" that is done for the diagnosis of Brain Stem Death (N=30)

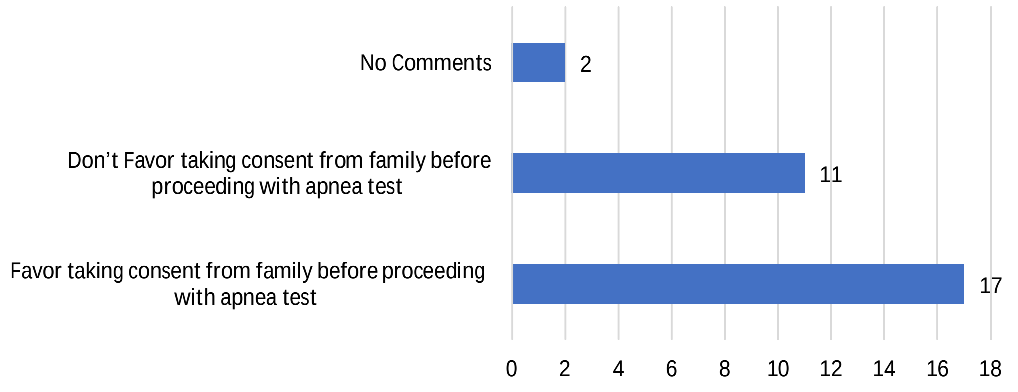

Figure 11.20 reveals that majority of the respondents, i.e., 17 favoured taking consent from family before proceeding with "Apnoea Test" done for the declaration of brain

death only. Only 11 respondents did not advocate taking permission from the family before proceeding with “Apnoea Test”, and two were indecisive.

Figure 11.21 Opinion of organ donor card holders about revealing identity of organ recipients to donor families (N=30)

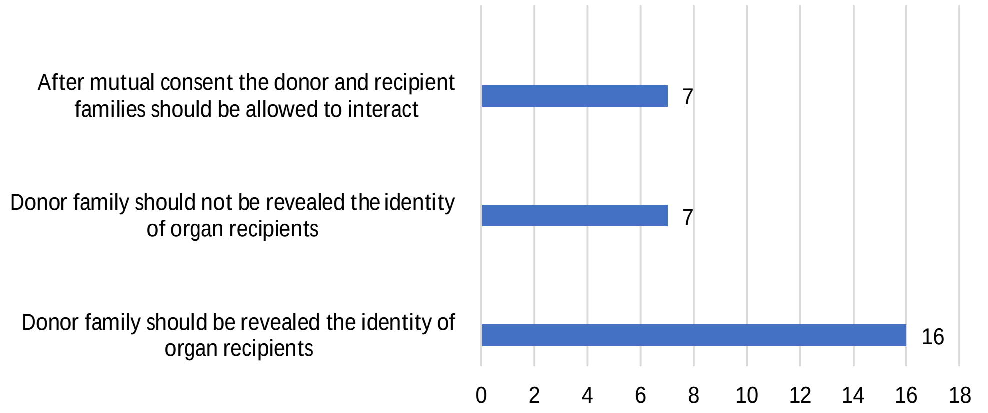

Figure 11.21 reveals that majority, i.e.,16 respondents believed the donor family should be allowed to see the recipients, seven (7) were of the opinion that after mutual consent, the families should be allowed to interact. Only seven (7) were of the view that families should not be allowed to see the recipients.

FGD with a group of 30 respondents, asking their stance on revealing organ recipient identities to donor families and vice versa, majority, i.e., 22 were in support of the same. Only eight (8) did not support revealing donor-recipient identities. The reasons were many for both who either supported and opposed such revelations.

Non-supporters narrated many reasons as described below: -

As per Ms. Drio1, *"To my understanding, what is important is to donate organs to those who need them. Who are the recipients of such organs is a secondary issue? Even so, I well understand those donor families want to know the recipients of organs of their relatives".*

As per Ms. Drio2, *“It could be a mismatch with the food habits of the donor like donor may be vegetarian and recipient nonvegetarian".*

As per Ms. Drio3, *“There may be conflicts if the donor was a nonvegetarian and recipient vegetarian and vice versa. The different eating habit of donor and recipient might lead to regret and guilt either in the donor family or in recipient family".*

As per Ms. Drio4, *“It should not be revealed as the donor may be of a criminal background and vice versa that could hurt the sentiments of the respondents”.*

As per Ms. Drio5, *“An upper-caste donor family may feel bad if the kidney of their donor goes to lower caste recipient for flushing waste products in his body”.*

As per Ms. Drio6, *“As India has a diverse population, it may create resentment and unhappiness among donor as well as recipient families due to the difference in caste, religion. Hence, confidentiality must be maintained”.*

As per Ms. Drio7, *“It should not be revealed as it may not go well with inter-religion organ transplants both with donor and transplant family”.*

As per Ms. Drio8, *“If the recipient is involved in criminal activity or may also be of different religion, this may hurt the donor family, and they may regret their decision”.*

As per Ms. Drio1*, “If the donated organ did not do well in the recipient, the donation purpose may be undermined, it will negatively impact the rate of donation".*

As per Ms. Drio2, *“In case of death of recipient or recipients, the donor family may grieve again and again. It may multiply the grief of a donor family".*

As per Ms. Drio5, *“Donor family may get unnecessarily involved in recipient’s life”.*

The opponents of revealing donor-recipient identities believed that donation is more important than revealing identity. Some of the opponents of revealing recipient identity to donor were opposed to this revelation because of the possibility of mismatch of food habits or social orientation that could unnecessarily invite regret and guilt. The fate of donor organ post-transplant if not useful in recipient body may multiply grief of donor family was also the reason quoted by opponents of this revelation. Also, it may invite guilt *if* the recipient is involved in criminal activities. Some of them even believed that such a disclosure might invite unnecessary interference in recipients' lives by the donor family.

Supporters of such revelation narrated many reasons

As per Ms. DriP1, *"With mutual consent, the identities can be revealed so that the two families share sorrows and happiness. A successful transplant can encourage other members to pledge. It will increase the meaning of oneness. It is not only a procedure, but it involves emotions as well".*

As per Ms. DriP2, *"The recipient's identity should be revealed as most of the donor families agree to donate the organs to see the loved one living in another".*

As per Ms. DriP3, *"This may also encourage the donors to get them registered so that their families could see them serving human beings even after their death".*

As per Ms. DriP4, *"This will also prevent the chances of organ trafficking and change the view of donors regarding organ trafficking or commercial activities in organ donation".*

As per Ms. DriP5, *"It shall help in social integration and lead to extended families. It is good in case donor and recipient belong to different religions, and they will feel positive about unity among different religions".*

As per Ms. DriP1*, "Organs eventually will unite the religions. As it will help people to understand that our religion may be different, but our organs speak the same language of humanity and unite us all".*

Proponents favouring revealing donor-recipient identities believed that families could encourage and motivate others to donate organs. Also, such revelations would help the donor family to see their loved one living in others. It could prevent organ trafficking, might unite religions and lead to social integration. Supporters of such revelation narrated many reasons.

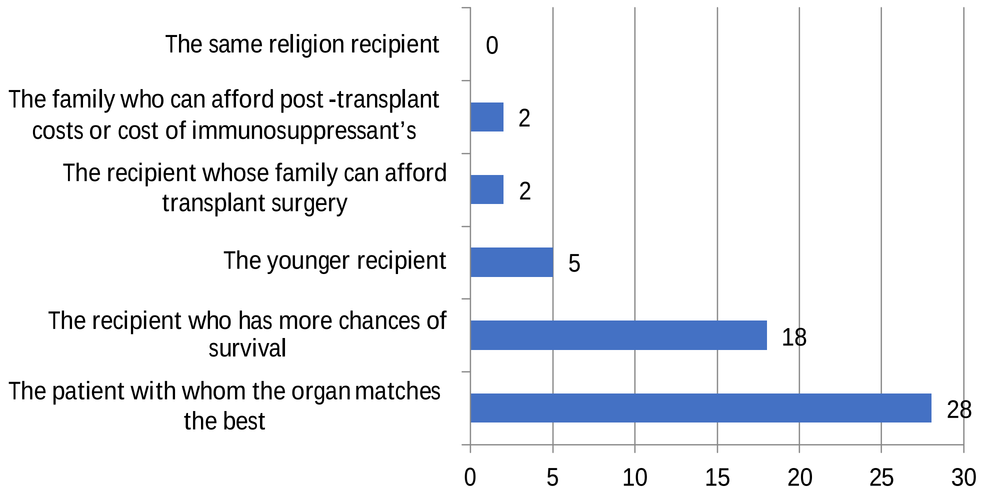
Figure 11.22 If given a choice to decide , who should be the recipients of BSD donor organs according to your opinion?(Multiple Choice) (N=30)

Figure 11.22 reveals that majority, i.e., 28 respondents favoured organ allocation to those recipients with whom the donor organ matches the best, depicting natural justice is accepted by the majority. Also, 18 respondents supported recipients who have more chances of survival, and only five (5) respondents favoured younger recipients.

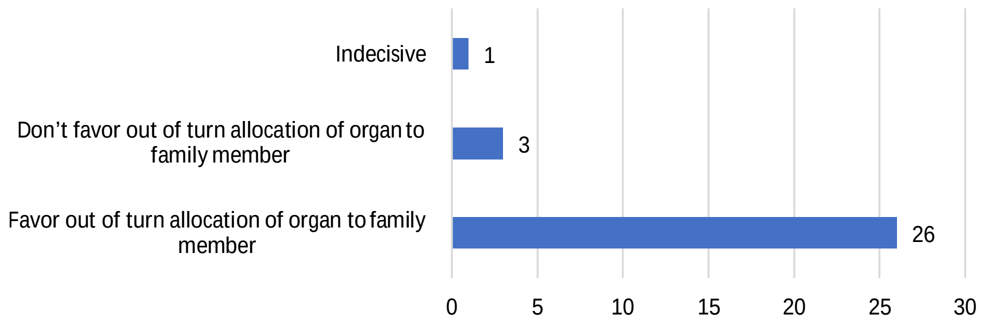
Figure 11.23 In case the family of a BSD donor has a relative waiting for an organ transplant, should one organ be allocated to him/her in case family insists to do so?(N=30)

Figure11.23 reveals that majority of respondents 26 were in favour of allocating organ to a family member out of turn. Only three (3) did not favour out of turn allocation of an organ to a family member.

Figure 11.24 Should India go for an opt-out system like Spain wherein everyone is an organ donor except the one who has communicated his unwillingness to donate organs in legal document?(N=30)

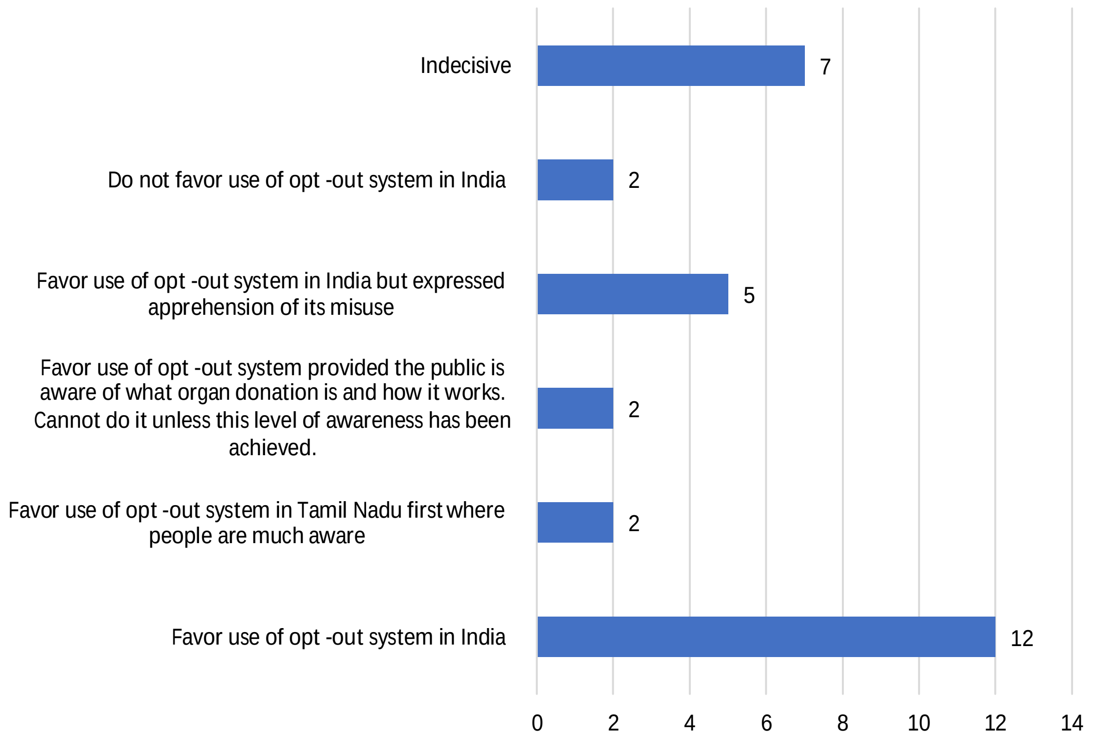

Figure 11.24 reveals the majority, i.e., 12 respondents were in favour of using the opt-out system of organ donation while only two (2) were not in favour of using this option. Some respondents favoured this option with riders.

FGD on presumed content done by the researcher with a group of 20 respondents, only five (5) respondents supported presumed consent option while majority 15 respondents were against this option.

As per Ms. PcO 1, *"It is not at all ethical. With this option, we are impinging upon the emotional, spiritual and cultural believes of dead person's family members. So, it is not OK as it will harm the spiritual believes of the patient as well as family".*

As per Ms. PcO 2, *"The private sector can make money out of this option. Maybe the person is not exactly brain dead, and with this option, in place, they could take organs from a living person. The organs should never be retrieved without the consent of the family".*

As per Ms. PcO 3, *“Private doctors can misuse organs to earn money”.*

As per Ms. PcO 4, *“Health professional can also diagnose live persons as dead for profit”.*

As per Ms. PcO 5, *“Corruption in Private Hospitals is going on at an unabated pace. It can be misused is the private sector for money".*

As per Ms. Pc0 6, *“If misused by the private sector, feelings of even the ethically willing persons could be hurt. This option demeans cultural and spiritual values”.*

As per Ms. PcO 7, *"Presumed consent will give birth to new social issues. People will take time to accept brain death as death, and at this point, they may not accept brain death as death. It could lead to mistrust".*

As per Ms. PcO 8, *"Family must be involved in the decision to prevent professionals from inviting any blame from relatives. We can try to motivate people but cannot force them to donate organs through this option. For the wilful donation of organs, focus on education of the masses about it first. It is a moral obligation to educate patient's family first because it involves sentiments of the donor family ".*

As per Ms. PcO 9, *“Because of lack of information among people about brain death, the mediators can take advantage of the situation. This option shall provide an opportunity for professionals who will win out of this situation like transplant coordinators and doctors”.*

As per Ms. PcO 10,*"There could be frauds in diagnosis and in transplantation too. This option will result in the purposive killing of persons in India. This option could lead to a lucrative money-making business rather than life-saving business".*

As per Ms. PcO 10, *“There will be an increase in the number of crimes & criminals in the country”.*

Opponents of presumed consent expressed their concern with this option. They believed that this option would impinge on the belief system of donor families; may hurt the sentiments of even the willing persons and feared an increase in mistrust on the medical system. The opponents of this option also warned of inviting unnecessary blame on professionals through this option. The negative repercussions envisaged by opponents were that there are chances of its misuse for financial gains. The mediators could become the opportunists for economic benefits. It could result in lucrative money-making business rather than life-saving business, could lead to purposive killing. It could produce more criminals and crimes will increase with this option.

As per Ms. PcP 1, *“Organs after death are no use to our body and will be brunt or buried in any case. By this protocol, we can save lots of life at a time. But this it is justifiable only if it is not misused but as we all know that it is nearly impossible in India”.*

As per Ms. PcP 2, *“Presumed consent can improve the quality of life for many people through organ transplants ".*

As per Ms. PcP 3, *“This option can increase the life span of many recipients”.*

As per Ms. PcP 4, *“It could reduce the economic burden of recipients who are struggling on dialysis. It would help many recipients who are not financially strong to arrange organs”.*

As per Ms. PcP 5, *"I wish this option is there, but prevention of its misuse in all possible ways needs assurance first".*

As per Ms. PcP 2, *"There should be law within this system that could keep an eye on all the brain-dead donors, and also on the ways and processes of organ retrievals”.*

The proponents of presumed consent believed that this option could save more lives and can improve quality of life, increase life span and may reduce the economic burden of people. However, a few of them had apprehensions too about its misuse, and a few supported this option with riders suggesting the use of this option only after ensuring prevention of its abuse.

Figure 11.25 Opinion of organ donor card holders about giving equal opportunities to foreigners and indians for allocation of organs of a BSD donor (N=30)

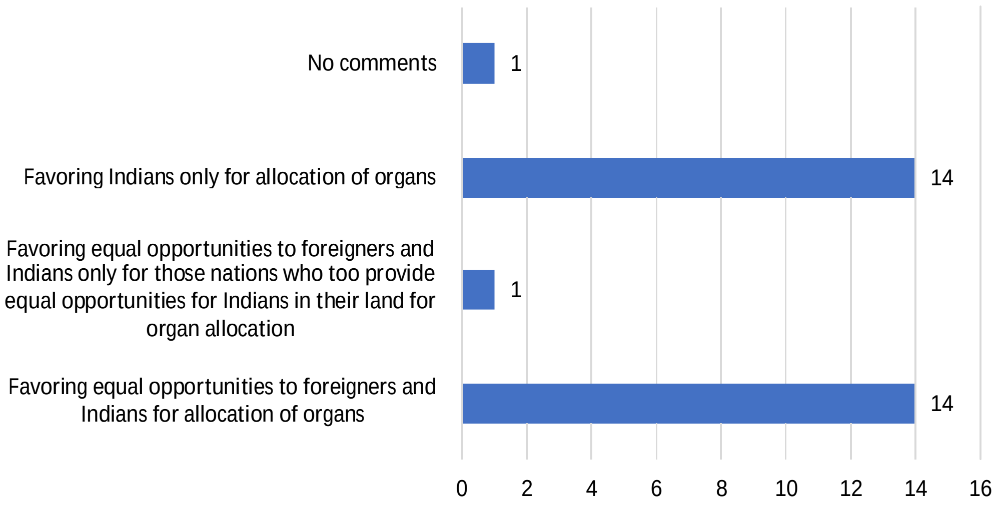

Figure 11.25 reveals the majority, i.e.,14 respondents were in favour of giving equal opportunities to foreigners and Indians for the allocation of organs. A similar number of 14 respondents favoured Indians over foreigners for distribution of organs, one (1) favoured equal opportunity to foreigners and Indians only for those nations who provide equal opportunities for Indians in their own land for organ allocation.

Figure 11.26 Opinion of organ donor card holders about giving priority to females in the waiting list for BSD donor organs (N=30)

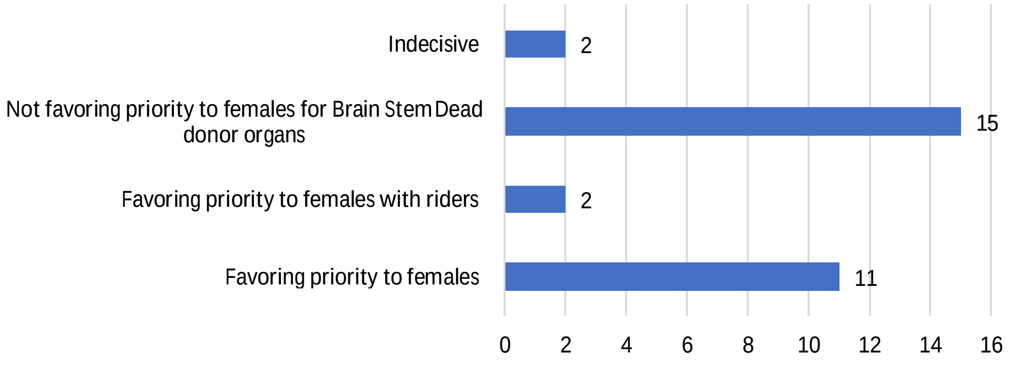

Figure11.26 reveals that majority, i.e., 15 respondents did not favour giving priority to females for Brain Stem Dead donor organs. Only 11 supported giving priority to

females, and two (2) respondents preferred giving priority to the female recipient only in case she had donated an organ during life.

Figure 11.27 Opinion of organ donor card holders regarding incentives that could be provided to BSD donor families (Multiple Choice)(N=30)

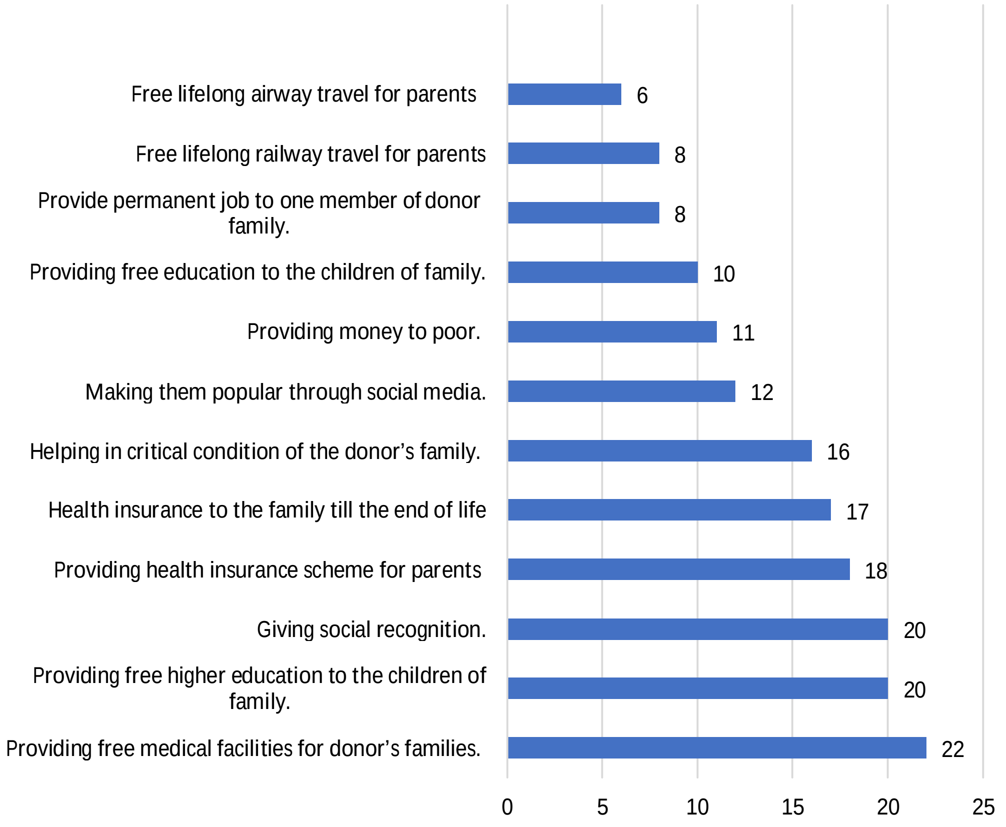

Figure11.27 reveals that majority, i.e.,22 respondents were of the opinion of providing free medical facilities for donor's families, 20 respondents favoured providing free higher education to the children of the family and 20 were in favour of giving social recognition.

Table11.28 Reasons of pledging to donate organs in awareness programs conducted by NOTTO (N=30)(Multiple Response)

Figure 11.28 reveals that majority, i.e.,12 respondents had pledged to donate organs for helping others, and 10 respondents considered it as a true virtue. There were varied reasons of these respondents as depicted in above table.

Narratives of a few such organ donor card holders were: -

Mr S said, *"I want to donate my body for transplantation. I do not mind if my skeleton is standing upright in any medical college after I am no more. Let doctors learn from my bones. God gave me everything in life, I want to do some good deed after my death".*

Ms G said, *"I want to donate each and every part of my body. Let people benefit from my body parts. Let nothing get perished in fire after I am no more".*

People had pledged to donate organs to do good to the society. They did so with an intention to help others, repay for sins, give life to others and prevent wastage of organs. They also felt it a virtue to donate life to others.

Summary: - This Chapter reveals a lack of adequate understanding of BSD donation. The knowledge scores of 30 organ donor card holders showed that only 9 (30%) were well-aware donors, out of which only 7 (78%) were genuine and rest 2 (22%) were fake. In other words, pledging to donate organs with only 30 % having adequate knowledge does not give an accurate picture of societal intentions regarding organ donation.

Regarding the perspective of organ donors towards donation in general, 27 respondents had donated clothes to people. An equal number of 27 had donated books, 21 had donated money, 14 had donated food, and 11 had donated blood. There were four (4) organ donor card holders who believed that the food they gave was the most significant donation. For one respondent, donating money for Prime Minister's relief fund was a significant donation. Interestingly working for eunuchs was a considerable donation for one respondent. While 11 respondents had donated blood to others, only four respondents had donated blood to near relatives. Also, 24 respondents were ready to donate organs during life to family members and 22 who were willing to do the same for others outside the family.

BSD donation invites a lot of global debates and dilemmas. But such global controversies do not affect the respondents as 28 were willing to get BSD donor organs for their family members. Besides, 21 respondents preferred BSD donor organs for self if the need arises.

Regarding expectations from family members for living organ donation, 11 respondents believed that their parents would be the ones who would donate an organ for them. But most of these respondents named mother first among parents, and four thought that their mother would donate organs to them if required.

Regarding "organ donation will" of the person at the time of death majority, 20 respondents thought that family should make their own decision at the time of BSD declaration. Interestingly, the majority don't mind if family members override the wish of organ donor card holders again showing less importance given to their own expressed will. Seventeen respondents did not favour the inclusion of incentives for those people who pledge to donate organs. Giving priority to people in waiting list register who pledge to donate organs was supported by 20 respondents.

The majority, i.e., 18 respondents were in favour of involving families in diagnostic tests for declaration of brain death. Seventeen respondents favoured taking consent from a family before performing the “Apnoea Test”, and 16 thought that donor family should be allowed to see the recipients. Interestingly FGD with a group of 30 respondents asking their stance on revealing donor-recipient identities showed a mixed response.

Regarding opinion on the allocation of organs, the majority, i.e., 28 respondents' favoured best-matched recipients, thus favouring natural justice. Twenty-six were in favour of allocating one BSD donor organ to a family member out of turn, and the majority 12 respondents were in favour of using an opt-out system of organ donation. Interestingly, FGD on presumed consent system done by the researcher with a group of 20 respondents, only 5 supported presumed consent option while the majority 15 respondents were against this option. Opponents of presumed consent expressed their concern with this option believing that it would impinge on the belief system of donor families. They felt it would hurt the sentiments of even the willing persons, may invite unnecessary blame on professionals and increase mistrust of the medical system. The negative repercussions envisaged by opponents were that there are chances of its misuse for financial gains. They believed that mediators could become the opportunists for economic benefits, and the life-saving business could become a lucrative money-making business. Also, with this option in place purposive killing, criminals and crimes will increase. The proponents, on the other hand, believed that this option could save more lives, can improve quality of life, increase life span and may reduce the economic burden of recipients. However, a few of the proponents favoured this option with riders. They supported this option only after ensuring the prevention of its misuse in the private sector.

Majority 14 respondents were in favour of giving equal opportunities to foreigners and Indians for the allocation of organs and 15 did not favour giving priority to females for BSD donor organs. Regarding providing incentives to donor families' majority, 22 respondents believed in providing health-related incentives to family. However, 20 were in favour of giving social recognition, and an equal number favoured providing free higher education to the children of the family.

The organ donor card holders expressed various reasons for pledging to donate organs for the benefit of society.

CHAPTER 12

Perspectives of Non -Organ Donor Card Holders Who Had Not Pledged to Donate Organs

This Chapter reveals the perspectives of people who had not pledged to donate organs in well organised awareness programs conducted by NOTTO. The first part of this Chapter reveals their socio-demographic information and their choices made in Form 7 of THOT Rules 2014. The second part shows their knowledge regarding Brain Stem Death and classifies respondents into four categories like well-aware “Genuine”, well-aware “Indecisive”, “Less Aware” and “Unaware” non-organ donor respondents based on their scores obtained in this area and narratives revealed to the researcher. The second part also shows knowledge scores about organ donation and transplantation in general. Third part reveals general perspectives of respondents towards donation and fourth part elicits the opinion of the respondents to various aspects of organ donation and transplantation under study. The fourth part also reveals the findings of FGDs done by the researcher on three issues, i.e., trust on medical fraternity, the inclusion of incentives for organ donors and acceptance of brain death as a form of death. The findings of FGDs on these three issues are amalgamating with the opinions of 30 organ donor respondents on the similar subject.

Socio-Demographic Information of Non-Organ Donor Respondents Who Had Not Pledged to Donate Organs: -

This part reveals socio-demographic information of non-organ donor respondents and their status of donation based on the choices they had made in Form 7 of THOT Rules.

Table 12.1 Socio-demographic information (N=30)		**Number/Percentage**
AGE	Minor	Nil
	Major	30
SEX	Male	7(23.33%)
	Female	23(76.67%)
RELIGION	Hindu	27(90 %)
	Christian	1(3.33%)
	Muslim	2(6.67%)
MARITAL STATUS	Unmarried	26(86.67%)
	Married	4(13.33%)
QUALIFICATION	Undergraduates	22(73.33%)
	Graduates	5(16.67%)
	Postgraduates	3(10%)
OCCUPATION	Student	22(73.33%)
	Govt. employed	8(26.67%)
TYPE OF FAMILY	Nuclear	25(83.33%)
	joint	5(16.67%)

Table 12.1 reveals that all the respondents 30(100%) who had not pledged to donate organs were major, majority that is 23(76.67%) were females, the majority were Hindus 27(90 %), majority 26(86.67%) were unmarried and majority 22(73.33%) were undergraduates. Majority of respondents 22(73.33%) were students' and majority 25(83.33%) were living in nuclear families.

Figure 12.1 Status of non-organ donor respondents in relation to their choices made in Form 7 of THOT Rules-2014(N=30)

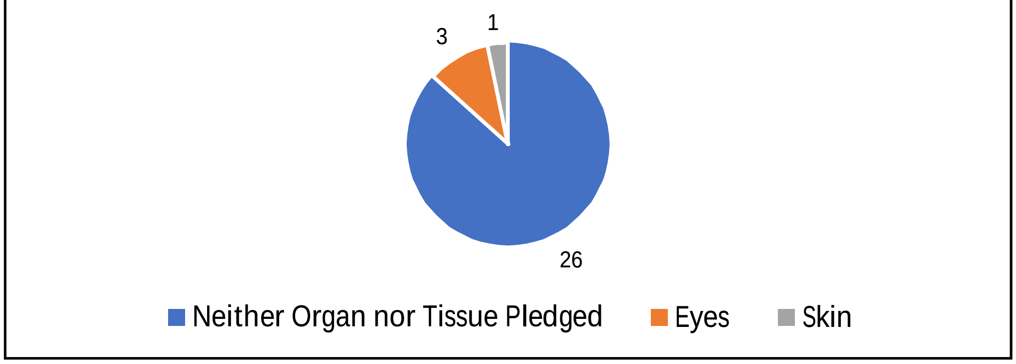

Figure 12.1 reveals the majority, i.e.,26 non-organ donor respondents had neither pledged to donate organs nor the tissues. Only three non-organ donor respondents had promised to give eyes. Also, one (1) respondent had opted for skin donation. Incidentally, all these tissue donors said that they were organ donors as they had got organ donor cards with them.

Knowledge of Non-Organ Donor Respondents on BSD and Organ Donation & Transplantation.

Figure 12.2 Knowledge of non-organ donor respondents regarding who can donate organs like kidney / liver in india (N=30) (Multiple Choice)

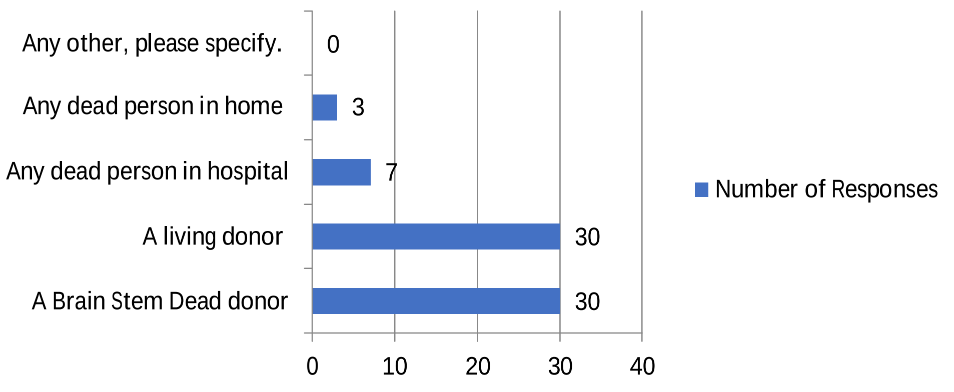

Figure12.2 reveals that seven (7) respondents knew that any dead person could donate organs in the hospital and three respondents knew that organs could be given by any deceased person in the home as well, that is not true.

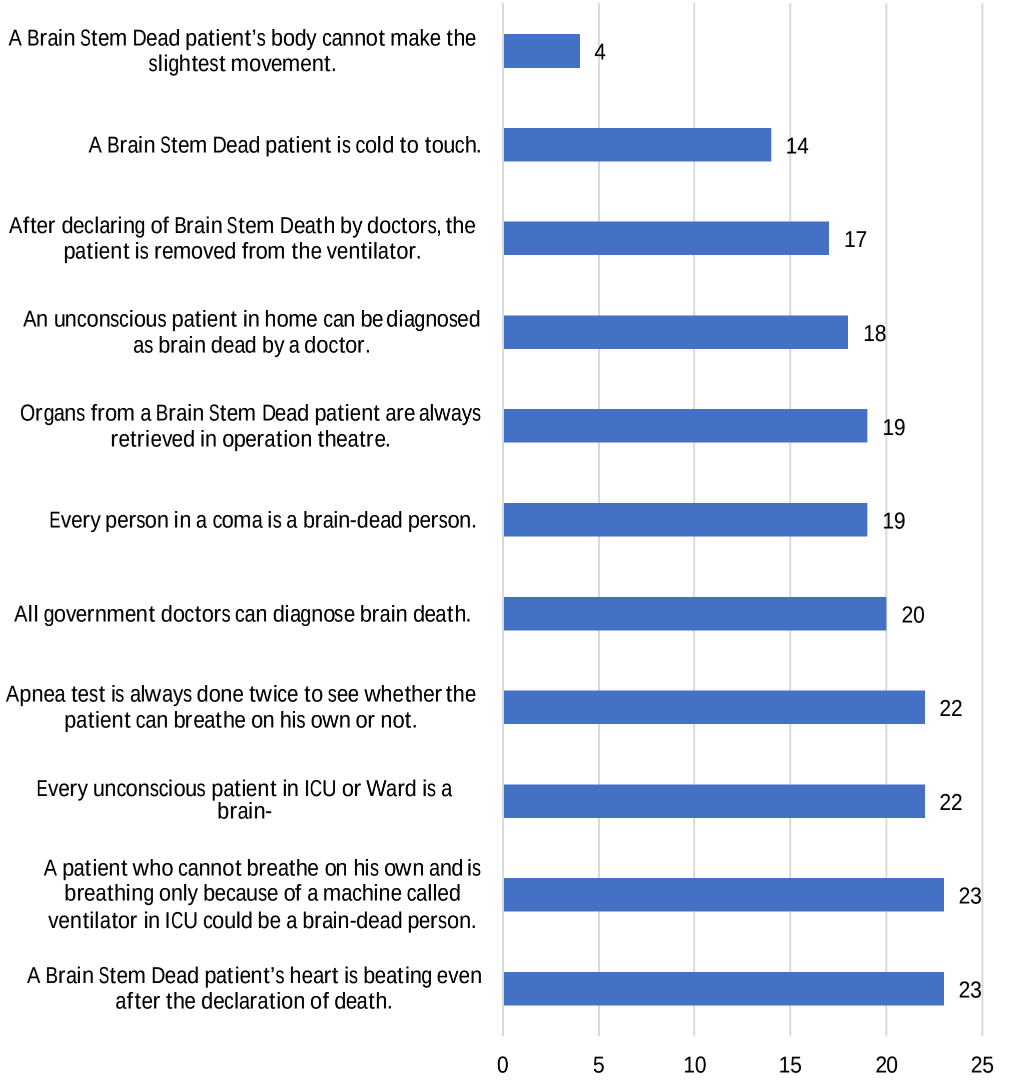

Figure 12.3 Knowledge of non-organ donor respondents based on correct answers to statements on BSD donation(N=30)

Figure 12.3 reveals knowledge deficits among non-organ donor respondents in all the areas regarding their understanding of brain death. Only four (4) respondents knew that the donor body could make slight movements after brain death declaration and only 14 respondents knew that the donor body is not cold to touch.

Based on the marks scored by individual non-organ donor respondents in the area of BSD and telephonic interviews with them, four categories of non-organ donors identified are '**Genuine', 'Indecisive', 'Less Aware' and 'Unaware' non-organ donors** as shown in Table 12.2, followed by a description in details below: -

Table 12.2 Classification of non-organ donor respondents based on their scores obtained in the understanding of Brain Stem Death (Max Scores=11) (N=30)

<table>
<tr><td rowspan="2">THEY HAD NOT PLEDGED TO DONATE ORGANS</td><td colspan="2">THEY KNOW</td><td colspan="2">THEY DON'T KNOW</td></tr>
<tr><td colspan="2">SCORED 9-11 MARKS</td><td>SCORED 5-8 MARKS</td><td>SCORED 0-4 MARKS</td></tr>
<tr><td>Classification non-organ donor respondents</td><td>Very well-aware 'Genuine' non-organ donor respondents</td><td>Very well aware 'Indecisive' non-organ donor respondents</td><td>'Less Aware' non-organ donor respondents</td><td>'Unaware' non-organ donor respondents</td></tr>
<tr><td>Number of respondents</td><td>5</td><td>4</td><td>15</td><td>6</td></tr>
</table>

Table 12.2 reveals that majority 15 respondents were 'Less aware' and 6 were 'Unaware' non-organ donor respondents. Only 5 were 'Genuine' and 4 were 'Indecisive" non-organ donor respondents.

A) **Very well-aware Genuine non-organ donor respondents -** They had scored 9-11 marks out of maximum 11 marks, were very well informed and only 5 in number. These people had not pledged to donate organs because of the following reasons as communicated to the researcher.

As reported by Ms. Node1, *"Unethical commercial practices are going on in private hospitals and organ transplantation may not be an exception to it".*

Ms. Node2 narrated, *"How to answer God in another world after death, who takes stock of all our sins and virtues and wants us to return to heaven with the intact body".*

Mr. NodB3 narrated, *"The recipients may indulge in criminal activities, and I don't want that to happen with my donated organ".*

Mr. NodN4 narrated, *"Being a vegetarian myself I don't want the recipient to take non-vegetarian food, and none can guarantee that".*

B) **Very well-aware "Indecisive" non-organ donor respondents -** They had scored 9-11 marks out of maximum 11 marks, were well informed and only 4 in number. These non-donor respondents wanted some time before they decide. They did not pledge to donate organs but may do so in future.

As reported by Ms Nodk and Ms Nodl, *"I have decided to donate on my birthday".*

Ms. Nodm narrated, *"Not filling the form 7 does not mean that I am against organ donation. I may do so in future. Give me some time".*

C) **Less aware non-organ donor respondents -**They had scored 5-8 marks out of maximum 11 marks, were 15 in number and less aware non-organ donor respondents. These respondents had not pledged to donate organs and had also less awareness about organ donation from Brain Stem Dead donors. Some of them knew that all patients on a ventilator are brain dead.

As reported by Ms Nodp, *"A person can come back to life even if he is on a ventilator".*

D) **Unaware non-organ donor respondents-** They did not have enough knowledge about BSD organ donation. They had scored 0-4 marks out of maximum 11 marks and were only 6 in number.

As reported by Ms Neeta, *"My family will not like me to donate organs."*

As reported by Ms Meeta,*"My parents will feel bad if my organs are retrieved at the time of death".*

These non-organ donors were not aware that Form 7 has no legal standing, and the wish of their families has the last say in organ donation. They can say no to donation even if the donor has pledged to donate organs.

In a Focus Group Discussion (FGD) done on 11 respondents, nine (9) respondents expressed a lack of trust in the medical fraternity, while only two respondents expressed faith in them. They presented several case studies based on their individual experiences that depicted their lack of trust.

As per Ms. Tvm 1, *"My son at the age of 13 years suffered from pain abdomen, and the doctor diagnosed Renal colic. Then we went to one of the prestigious corporate hospitals and had an ultrasound done. The doctor told that surgery was compulsory and needed immediately. Then I prayed to God and went to Osmania Hospital (name changed). In this hospital doctor told me that there was no need for surgery; only medicines will help him. He prescribed medicines and sent us home. Next day I took my son to the hospital and had an ultrasound done. The result revealed no stones present. The doctor told to continue the medicines for one more week and give him plenty of fluids and restrict tomatoes. Now he is doing well. If I would have followed the first corporate hospital doctor's instructions, my son may have undergone unnecessary surgery. By God's grace, my son escaped the un-required surgery. So, I believe that the prescription of a Government hospital doctor is always right".*

As per Ms. Tvm 2, *"One of my uncles got bitten by a snake when he was doing work in a field, and he ignored it. After one day, he got a burning sensation all over the body. We took him to a private hospital. They told us he is okay, and they never allowed us to see him for two days. After two days they told us he had a heart attack and died. They charged 80 thousand for treatment and 4000 for bed charges".*

As per Ms. Tvm 3, *"When I was eight years old, my brother got burnt, and my parents took him to a private hospital. They ignored the case, and they charged for bed without treatment for 30 minutes only, and they told my parents to take the* *case out of the hospital as there was no hope and they told us that he might die within hours. Finally, we went to a Government hospital, and they told us that they would try, and after six months he was okay".*

As per Ms. Tvm 4, *"My aunt was admitted to hospital because of body pains and fever. She got treated within one week and came back home. Then suddenly she got a severe headache and was again admitted in the hospital. Doctors checked her, told there is no problem, and pain will subside within hours, but she died within 5 hours. Doctors could not identify the exact cause of the disease and told that she died of sudden brain death".*

As per Ms. Tvm 5, *"My mother complained of chest pain for a few days. We took her to a hospital, got certain investigations including angiogram done for her. They diagnosed that her heart had 65 % heart block, and she will not survive for more than a few months. It was perturbing, and we took her to another hospital. She underwent the entire tests again, and the doctor said that she does not have any heart block. She is all right, and because of stress and tension, she had chest pain. The doctor showed me the video of the angiogram. There was no heart block. However, it does not mean that all doctors are wrong, but we cannot trust every doctor who does brain death diagnosis".*

As per Ms. Tvm *6, "I had Rh incompatibility at birth and had severe jaundice and underwent a whole blood transfusion. A very efficient physician treated me in a medical college in Kerala. My bilirubin levels were very high, and health was too bad. The doctor informed my parents that I had only a 50 % chance of survival, and even if I survive, I may be mentally retarded. It did not happen as on date. I am a very bright student, I have secured 90 % in 10th class and 88 % in 12th standard. I am pursuing post-graduation having secured 1st division throughout".*

As per Ms. Tvm 7, *"I worked as a staff nurse in the post-operative Ward. One patient was admitted in our Ward after open cholecystectomy and had a colostomy. The patient was okay as per doctors' observation and shifted him to the Ward. Within half an hour after shifting the patient to the Ward, he had internal bleeding and died within half an hour".*

As per Ms. Tvm 8, *"One patient underwent coronary angioplasty and stayed in ICU for two days. On the third day, the doctor said the patient is good and shifted him to the Ward. Within an hour at 5.20 pm we got a call that patient is serious at 5.40 pm we received the patient back and intubated him. Within minutes he was declared dead".*

As per Ms. Tvm 9, *"Everything is in the hands of Almighty. Humans may not be right every time. There were many situations when health personnel went wrong in their diagnosis because of unreliable tests. It was an event that took place in one of the biggest hospitals in Hyderabad. The patient was admitted for heart problem. All investigations before surgery revealed coronary artery block. But during operation, when the patient was on the operation table, it was found out that he had triple vessel disease and the condition went wrong".*

The remaining two respondents who trusted medical fraternity also narrated the experiences that had built their trust in them.

As per Ms. Tvms 1, *"I have seen doctors working for the welfare of patients all the time, and I know a doctor is a human being and may commit mistakes. But I believe that people who pledge to donate organs should have all information regarding the process involved in organ donation".*

As per Ms. *Tvms 2, "I always trust doctors who are committed to the welfare of patients. They are a great support to people. I am willing to donate my whole body for transplantation because I believe that saving lives is 1000 times better. I want to extend the lives of many people through organ donations by some more days than avoiding or disagreeing to donate. There may be one to two % who could misuse the law, but we can't keep ourselves away from good deeds".*

The narratives of respondents in FGD depict lack of trust based on personal experiences. The experiences revealed the predominant financial interests of private hospitals, causing inconveniences to people. It also exposed the unreliability of certain tests that impact the efficiency of the diagnostic skills of doctors. The observatory and prognosis skills of medical professionals were also found to be deficient by a few respondents. However, in a few cases, respondents also believed in good deeds done by the doctors.

Figure 12.4 Number of correct answers to statements on organ donation and transplantation revealing knowledge of non -organ donor respondents (N=30)

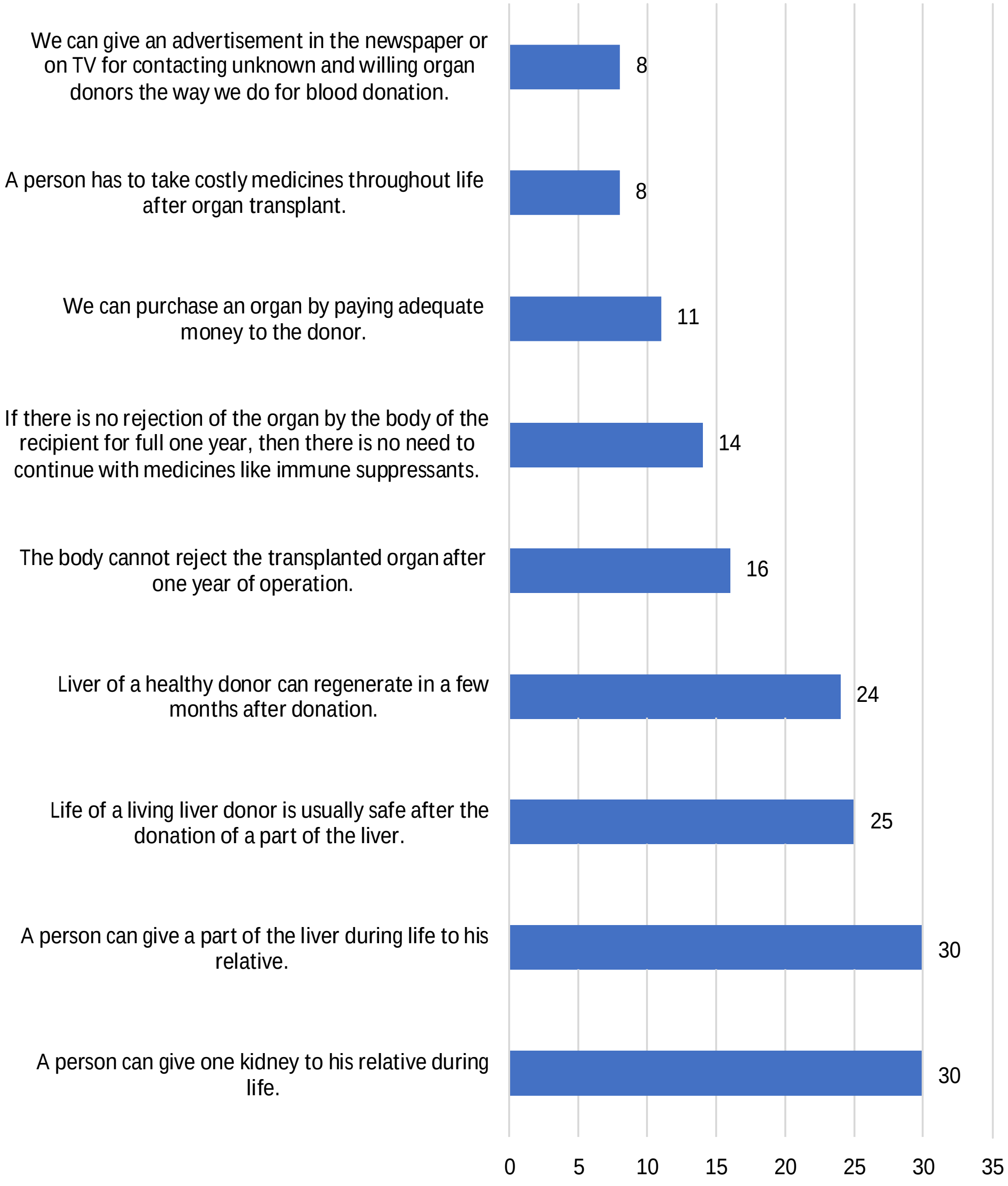

Figure12.4 depicts knowledge deficits in significant areas. Only 8 respondents knew that they could not give advertisement in the newspaper or on TV for contacting unknown and willing organ donors and only 8 persons knew that recipients of the

transplant take costly medicines throughout life. Only 11 non-organ donor respondents knew that they could not purchase an organ by paying adequate money to the donor.

Figure 12.5 Distribution of non-donor respondents with their aggregate scores on BSD, organ donation and transplantation (Max.Scores=20) (N=30)

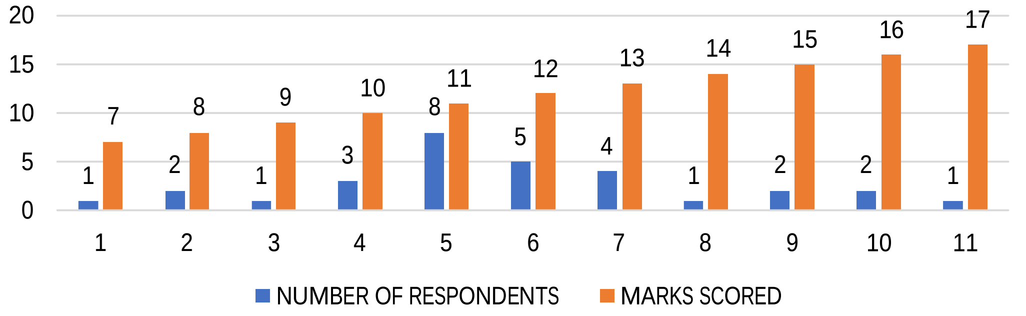

Figure12.5 reveals majority, i.e., eight (8) respondents had scored 11 marks out of maximum 20 allotted marks in aggregate that included their knowledge scores regarding organ donation from Brain Stem Dead donors (Max.Marks-9) and organ donation in general (Max.Marks-11). The minimum score obtained by one respondent was seven (7) marks only, and the only one (1) respondent scored a maximum score of 17.

Non-Organ Donor Respondents' Perspectives Towards Donation

This part reveals the perspectives of non-organ donor respondents towards donations.

Figure 12.6 History of materialistic donation by non -organ donor respondents (N=30)

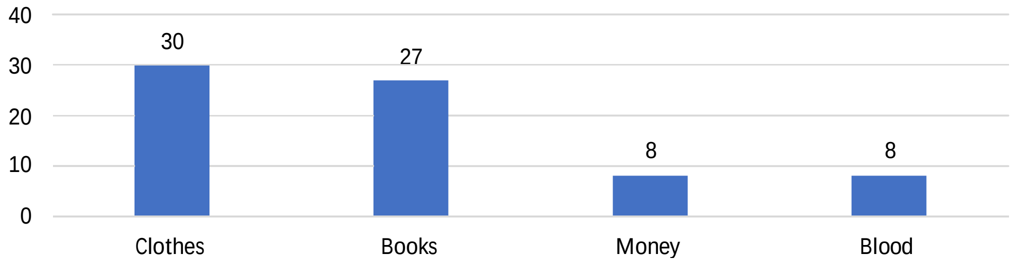

Figure12.6 reveals that all 30 non-organ donor respondents had donated clothes to people, 27 had donated books, eight (8) had donated money, and eight (8) respondents had donated blood.

Figure 12.7 Significant donation of non-organ donor respondents during life (N=30)

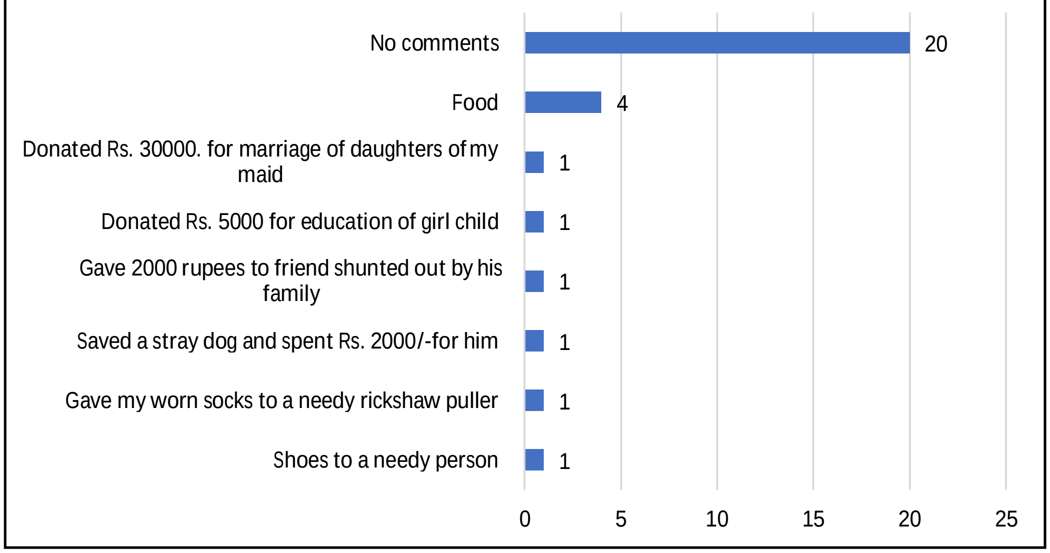

Figure12.7 reveals the majority, i.e., 20 non-organ donor respondents did not report any significant donation; four (4) non-organ donors believed that food they donated was the most significant donation. There were others for whom donating socks to a needy, taking care of a street dog, giving money for education and marriage of daughter were the significant donation.

Figure 12.8 History of blood donation to family members by non organ donor respondents (N=30)

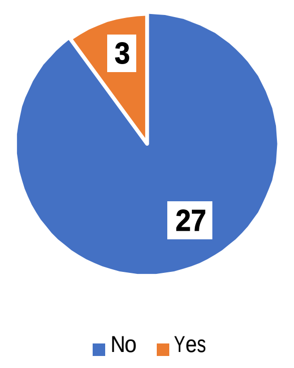

Figure 12.8 reveals the majority, i.e.,27 non-organ donor respondents had not donated blood to their family members, and only three (3) had donated blood to their family member.

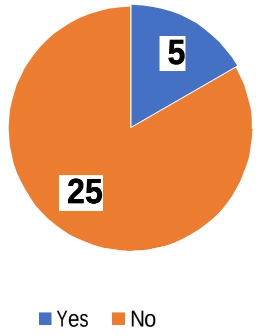

Figure 12.9 History of blood donated to other than close relatives by non-organ donor respondents (N=30)

Figure 12.9 reveals the majority, i.e.,25 non-organ donor respondents had not donated blood to other than their close relatives, and only five had given blood to others who were not their close relatives. Out of these five donors, one donor stated that she had donated blood to army personnel, and this act of hers gave her immense pleasure as she could save the saviour of her country.

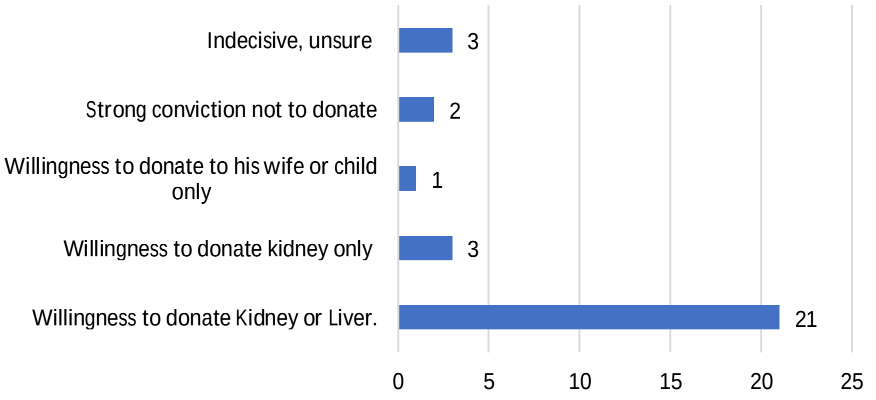

Figure 12.10 Willingness of non-organ donor respondents to donate kidney or liver during life to their own family member if needed (N=30)

Figure12.10 reveals the majority, i.e., 21 non-organ donor respondents expressed willingness to donate both organs like kidney/ liver to family members. However, three (3) respondents were willing to donate a kidney only as they felt they had two (2) kidneys and can live with one. Only one (1) respondent expressed his willingness to donate only to his wife or child and no one else in the family. Only two (2) respondents depicted unwillingness to organ donation for family members, and three were unsure.

Figure 12.11 Willingness of non-organ donor respondents to donate kidney or liver during life to someone outside family out of affection without anticipating anything in return(N=30)

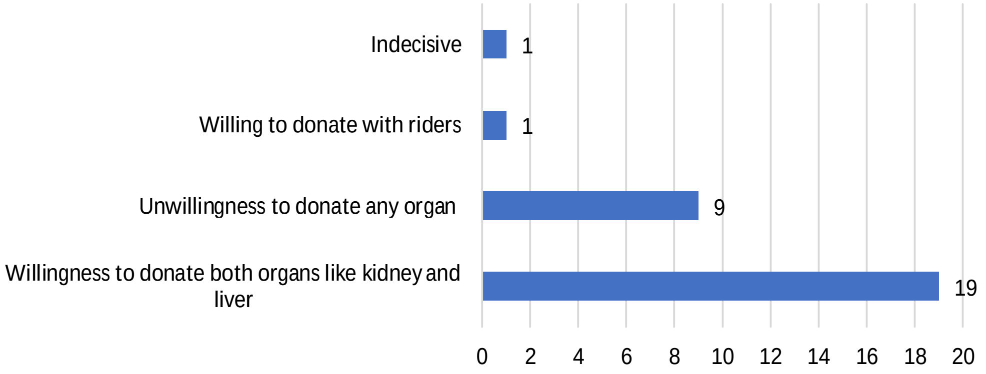

Figure12.11 reveals the majority, i.e.,19 non-organ donor respondents expressed willingness to donate both organs like kidney and liver to others outside the family. However, nine (9) respondents expressed unwillingness to give an organ to others outside the family. Only one (1) respondent was willing to donate with riders. He said, *"I will donate to others also if I am convinced that it is safe to do so, and I will not require the same organ in future. Otherwise, it is going to be a business for doctors. They will earn first from others, then from me and so forth".* Only one (1) respondent was indecisive.

Figure 12.12 Willingness of non-organ donor respondents for getting an organ for a family member from a Brain Stem Dead donor (N=30)

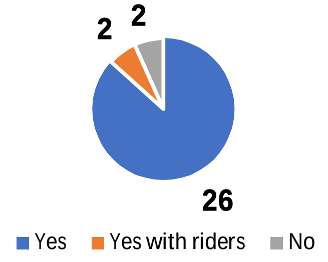

Figure 12.12 reveals the majority, i.e.,26 respondents wished to get organs for their family members from Brain Stem Dead donors if the need arises. However, there were two (2) respondents who said yes with riders. Mr. Anod said, *"I do not mind getting an organ from a brain-dead donor provided the donor had made a will and knew everything about brain death donation".* On asking to elaborate during a telephonic interview, he said, *"If a donor organ is transplanted without the will of a person, the ghost of that donor will haunt my relative. And donor organ might not do well if transplanted without a decree of the person".* Ms. Bnod narrated, *"I would like to get such organ for my family member provided the donor family is well informed and takes a voluntary decision".* Only two (2) respondents said "No" to such donation.

Figure 12.13 First preference of non-organ donor respondents for donation of an organ for close relative in need of transplant (N=30)

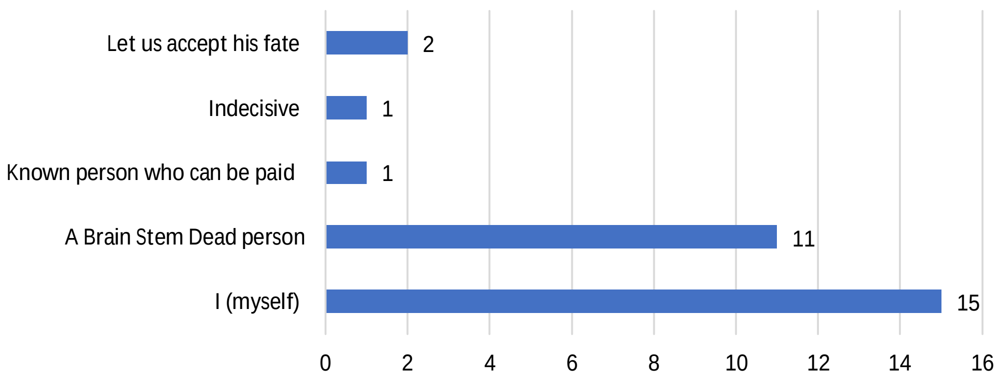

Figure 12.13 reveals the majority, i.e.,15 non-organ donor respondents preferred themselves to donate organs for their relatives, and only 11 preferred a Brain Stem Dead donor. Only two (2) preferred to accept the fate of their relative.

Figure 12.14 In case the need arises, who in your family will first to come forward to give you an organ like kidney or a part of liver? (N=30)

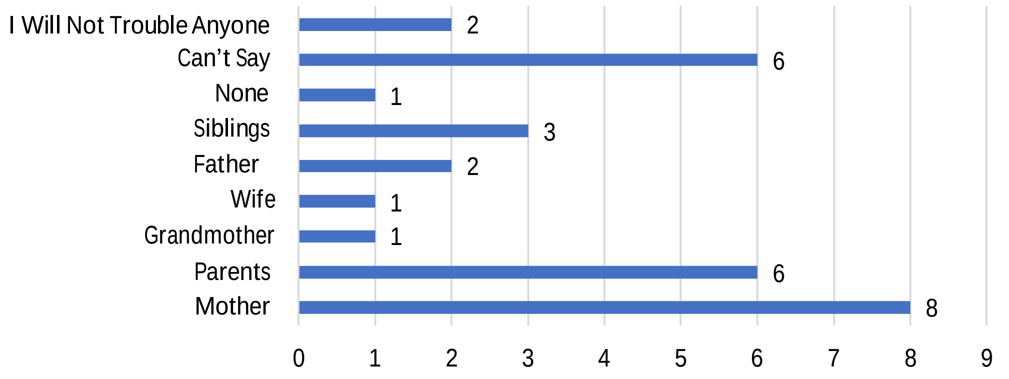

Figure12.14 reveals the majority, i.e., eight (8) non-organ donor respondents believed that their mother would be the one who would donate an organ for them.

Figure 12.15 God forbid, in case you come across a situation when you need either a kidney or liver for yourself who could be your first preference?(N=30)

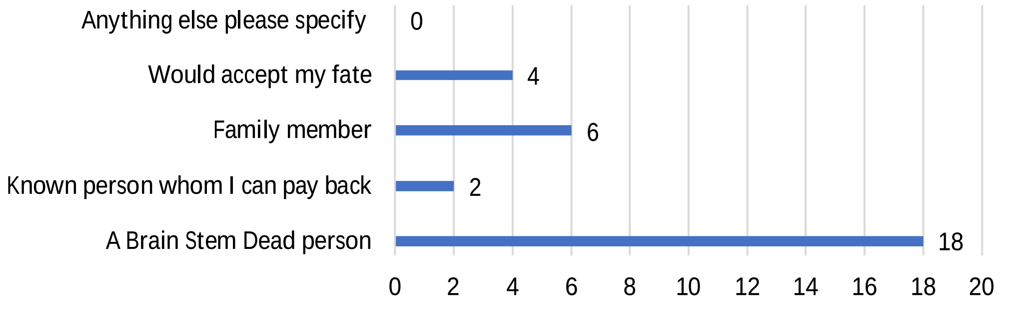

Figure 12.15 reveals the majority, i.e.,18 non-organ donor respondents preferred Brain Stem Dead donor for getting an organ for self. Also, out of 6 respondents who preferred family members, mother was the first preference given by three (3)

respondents, parents by two (2) respondents and sister by one (1) respondent. Only four (4) preferred to accept their fate without any transplant.

Opinion of Non-Organ Donor Respondents' Regarding Various Aspects of Organ Donation

This part elicits opinions about different issues of organ donation from the perspectives of non-organ donor respondents.

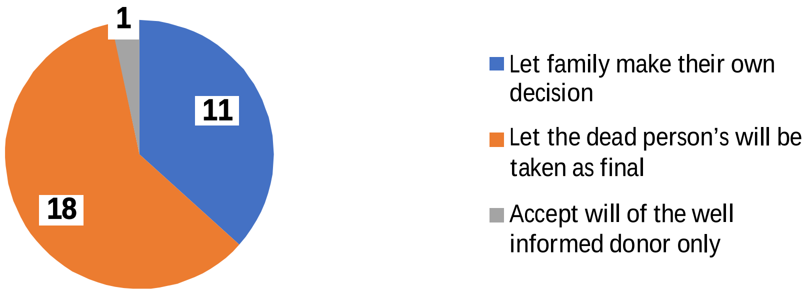

Figure 12.16 Opinion of non-organ donor respondents about respecting the organ donation will of potential donors (N=30)

Figure 12.16 reveals majority, i.e.,18 non-organ donor respondents were of the opinion that organ donation will of the person be accepted and 11 respondents thought that families should make their own decision at the time of death. According to one (1) respondent, the will of the donor should be respected only in those cases if the donor knew everything about brain death donation at the time of pledging.

Figure 12.17 Opinion of non-organ donor respondent about inclusion of incentives for those who pledge to donate organs (N=30)

Figure 12.17 reveals the majority, i.e.,23 non-organ donor respondents did not favour the inclusion of incentives for those people who pledge to donate organs. The remaining seven (7) who were in favour of including incentives, two respondents thought of giving monitory benefits, two (2) thought of providing a certificate of appreciation, two (2) supported free medical check-up, and one (1) recommended free health insurance.

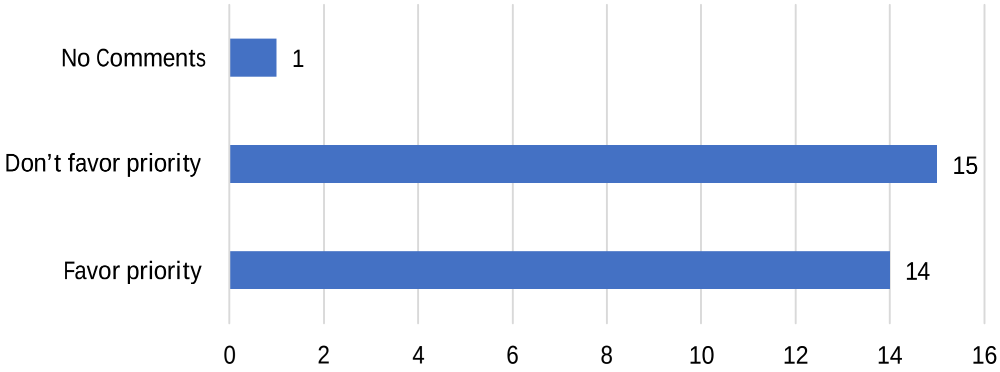

Figure 12.18 Opinion of non -organ donor respondents towards giving priority to people who pledge to donate organs, in waiting list register if they require an organ transplant themselves (N=30)

Figure 12.18 reveals that majority, i.e.,15 non-organ donor respondents did not favor priority to people who pledge to donate organs in waiting list register if they require an organ transplant themselves.

Figure 12 .19 Opinion of non-organ donor respondents' about involvement of families in diagnostic tests of Brain Stem Death (N=30)

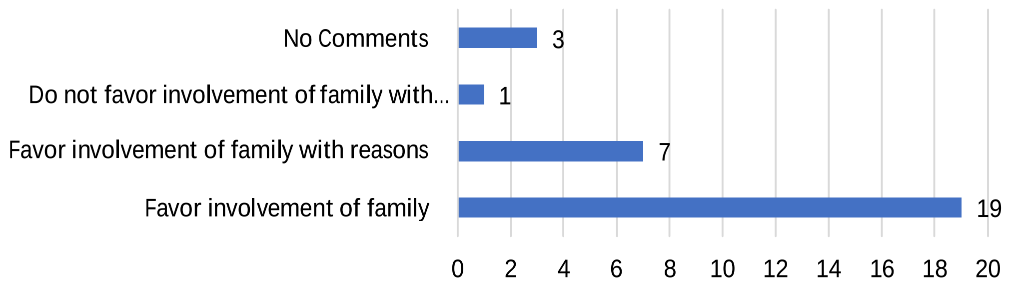

Figure 12.19 reveals the majority, i.e.,19 non-organ donor respondents were in favour of involving families in diagnostic tests for declaration of brain death, seven (7) respondents supported the involvement of families giving reasons too.

The reasons given by two(2) respondents was that it is their right, they should have liberty to consult doctors from outside hospital also was reported by two(2)respondents, for emotional and last ritual purposes was reported by one(1)respondent, they should be part of the entire process to gain trust was reported by one(1)respondent and for 1 respondent it should be compulsory to involve family. Only one (1) respondent who did not favour family involvement; the reason stated was that non- participation is required to avoid the psychological stress of family members and that medical person knows better.

A Focus Group Discussion done by the researcher with 15 respondents on organ donation and acceptance of BSD revealed a positive attitude of all these respondents to organ donation. But most of the respondents believed that they would only donate if they are completely dead or alive. Brain death was not at all considered death by this group of students. It was surprising to know that all 15 students were in favour of live donation and said that they would donate in case their family needs organs. Besides, three (3) respondents said that they would like to do so for their friends also and two (2) respondents did not mind providing such organs to poor people too. It was surprising to know that none of the 15 students in this group accepted Brain Death, a form of death. The reasons were many.

As par Ms Nabd 1, *“A person is dead only when his heart stops functioning. A person with a beating heart is not dead”.*

As par Ms Nabd 2, *“How come doctor says a person is dead when his heart is pumping blood. This amounts to Euthanasia”.*

As par Ms Nabd 3, *"This kind of death is equivalent to legalized murder. The doctors pronouncing death are legal murderers".*

As par Ms Nabd 4, *"This death may be declared for monetary gains of the hospital and may not have a good effect on the recipient".*

All the students in the group said that they would never donate their relative's organs if they are declared brain dead.

Ms. Nabd 4, said that he doesn't accept this form of death for anyone. Ms. Nabd 6 and Ms. Nabd 7 said that they would wait for the miracle to happen for their relatives". They further said that they might consider the donation of their brain-dead relative's organs, only if the relative had wished so.

Figure 12.20 Opinion of non- organ donor respondents about taking prior consent from families for doing “Apnoea Test” that is done for the diagnosis of Brain Stem Death (N=30)

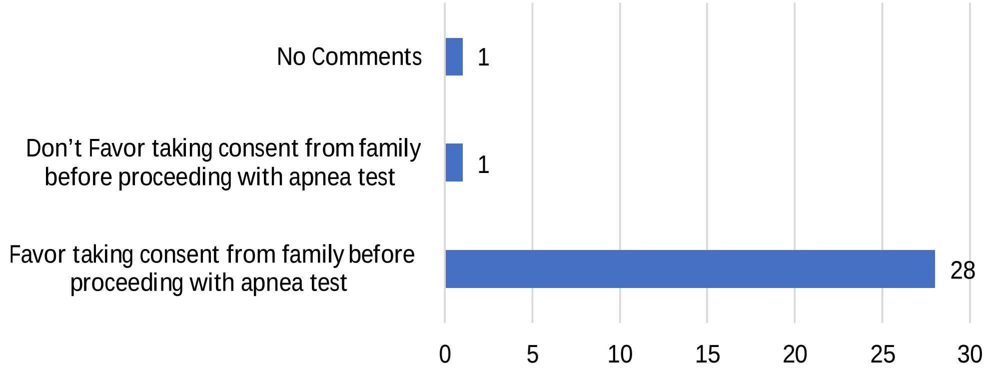

Figure12.20 reveals the majority, i.e., 28 non-organ donor respondents favoured taking consent from family before proceeding with the “Apnoea Test” done for declaration of brain death only. Only one respondent did not Favour taking

permission from the family before proceeding with “Apnoea Test”. The reason stated was that that medical person knows better.

Figure 12.21Opinion of non-organ donor respondents about revealing identity of organ recipients to donor families(N=30)

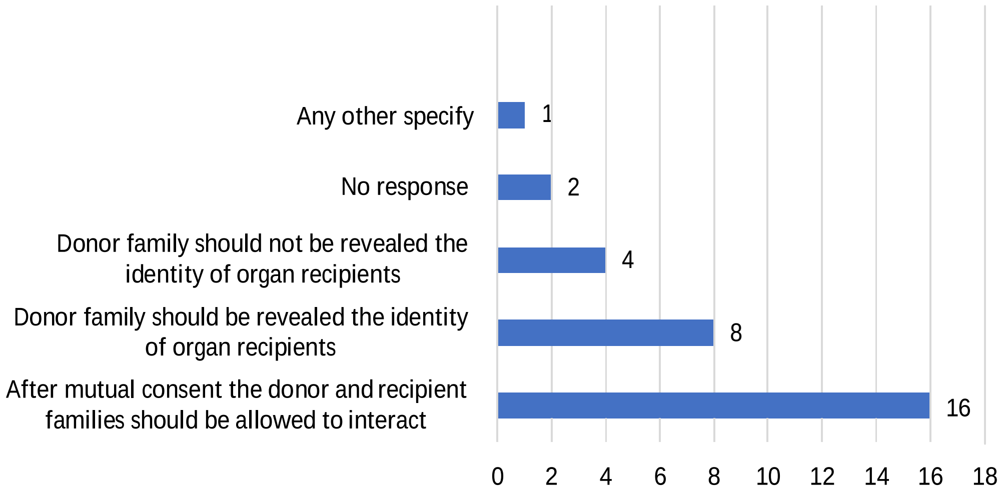

Figure12.21 reveals that majority, i.e.,16 non-organ donor respondents were of the opinion that after mutual consent the families should be allowed to interact, eight (8) respondents were of the opinion that the donor family should be allowed to know the recipients of their donor organs, four (4) respondents suggested that donor family should not be informed about the identity of recipients.

Only one (1) respondent was of the different opinion and stated that families should not be allowed to see the recipients as he believed in **“Neki Ker Darya Mai Daal”** (Meaning do good and forget about it).

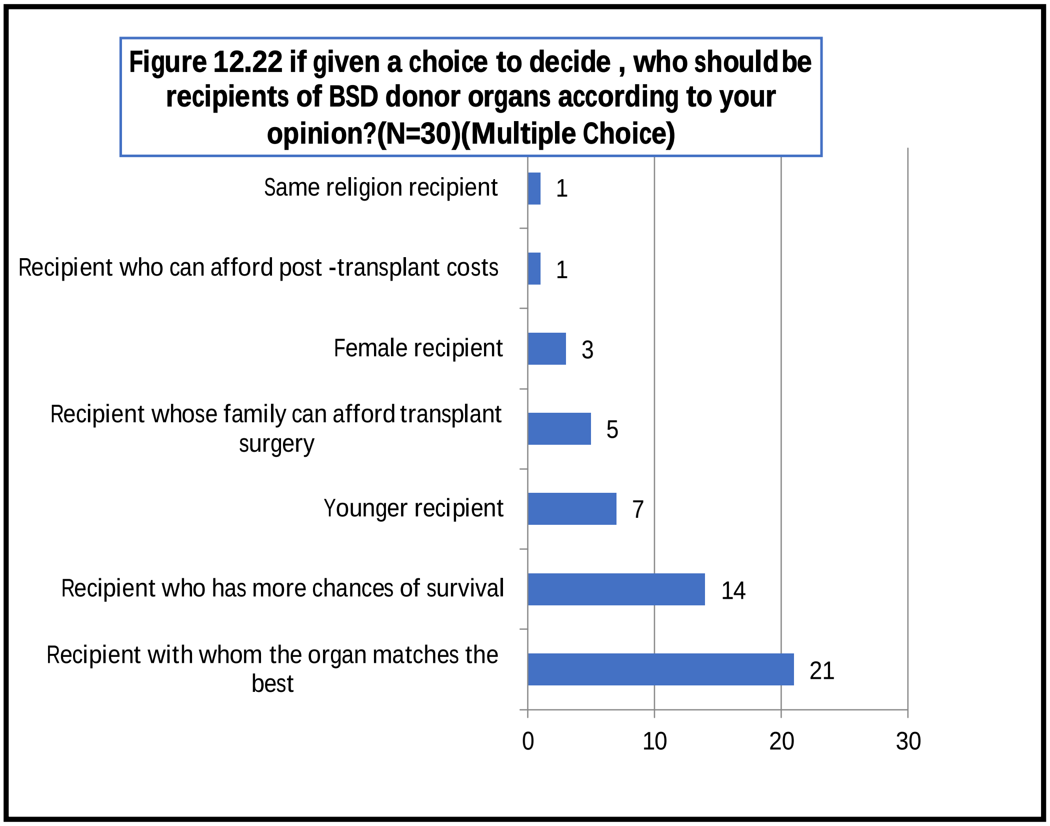

Figure 12.22 if given a choice to decide , who should be recipients of BSD donor organs according to your opinion?(N=30)(Multiple Choice)

Figure12.22 reveals majority, i.e.,21 non-organ donor respondents favoured recipients with whom the organ matches the best, 14 respondents favoured recipients who have more chances of survival and 7favoured younger recipients.

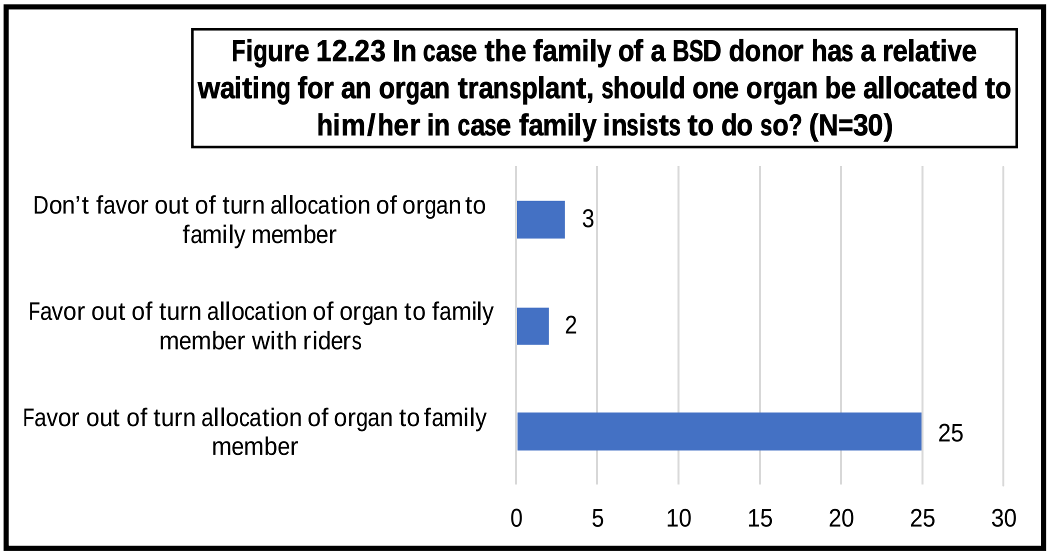

Figure 12.23 In case the family of a BSD donor has a relative waiting for an organ transplant, should one organ be allocated to him/her in case family insists to do so? (N=30)

Figure 12.23 reveals the majority, i.e., 25 non-organ donor respondents were in favour of allocating one BSD donor organ to a family member out of turn. In addition to it, two (2) favoured allocating one BSD donor organ to a family member out of turn with riders. One (1) respondent wished to assign to the relative only in case he had pledged to donate his organs. And another respondent advocated out of turn allocation to near relatives only like a brother, sister, parents, wife and children.

Figure 12.24 Should India go for an opt-out system like Spain; wherein everyone is an organ donor except the one who has not communicated his unwillingness to donate organs in a legal document?(N=30)

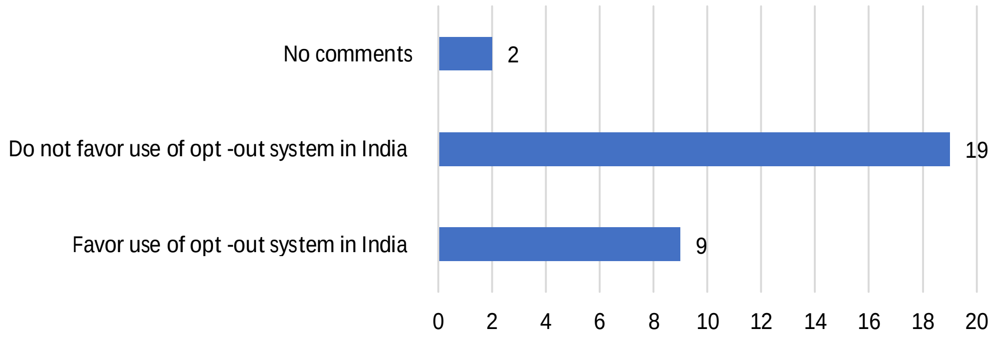

Figure12.24 reveals the majority, i.e.,19 non-organ donor respondents were not in favour of using the opt-out system of organ donation, while only nine (9) respondents were in favour of using this option.

Figure 12.25 Opinion of non -organ donor respondents' about giving equal opportunities to foreigners and indians for allocation of organs of a BSD donor (N=30)

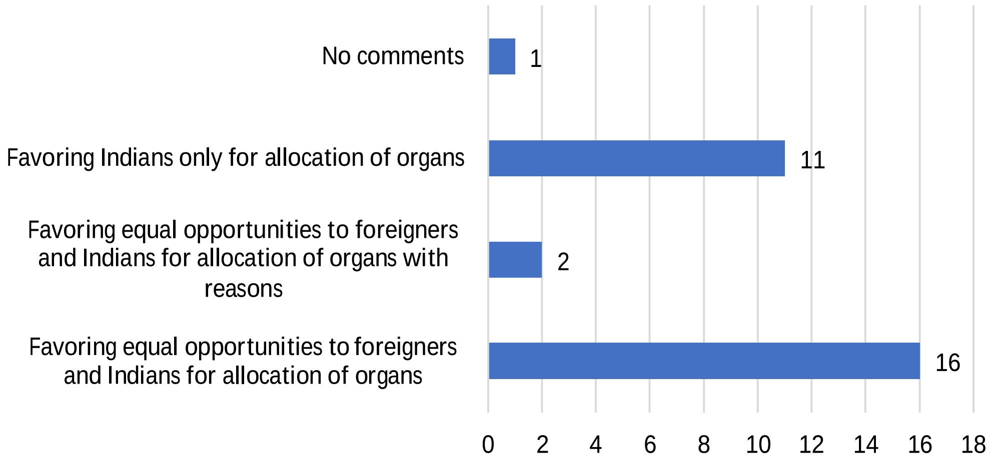

Figure 12.25 reveals the majority, i.e.,16 respondents were in favour of giving equal opportunities to foreigners and Indians for the allocation of organs. Additional two respondents also supported equal opportunities giving reasons as well. One (1) such respondent said, *"Life is precious for everyone; boundaries in organ donation in a globalized world are unaccepted".* And according to One (1) more respondent, *"India is a sovereign country and recognized for secularism, and in this global world no discrimination is acceptable".* Only 11 favoured Indians over foreigners for allocation of organs.

Figure 12.26 Opinion of non-organ donor respondents for giving priority to females in the waiting list for BSD donor organs N=30)

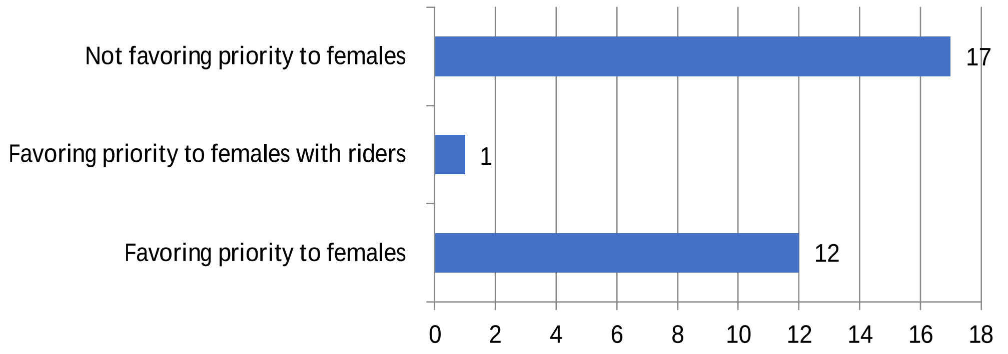

Figure 12.26 reveals the majority, i.e.,17 respondents did not favour giving priority to females for Brain Stem Dead donor organs. Only 12 respondents were in favour of giving priority to females for allocation of organs of a Brain Stem Dead donor. Besides, one (1) respondent was in favour of giving priority to the female recipients with riders saying females should be given priority in allocation only in case she had donated an organ during life.

Figure 12.27 Opinion of non-organ donor respondents about incentives that could be provided to BSD donor families.
(N=30) (Multiple Choice)

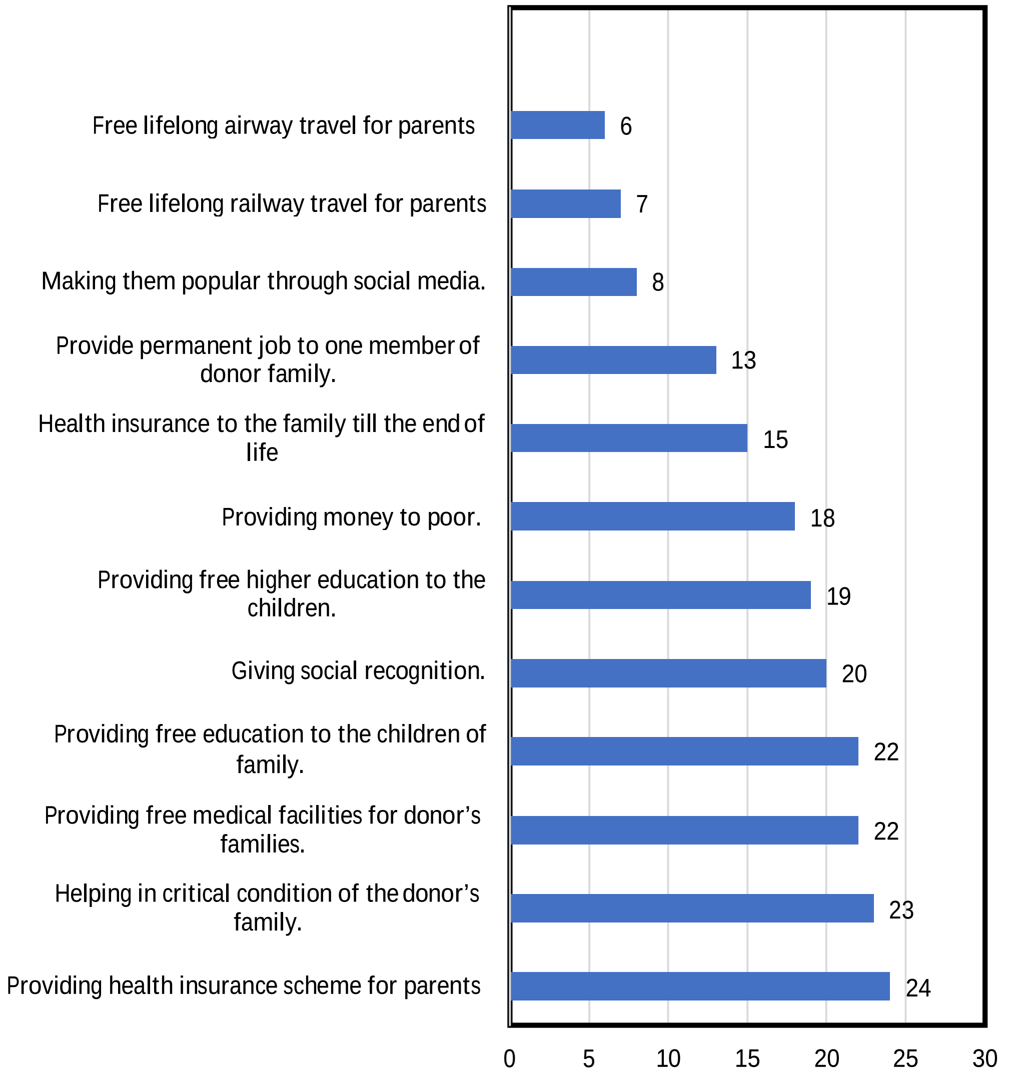

Figure 12.27 reveals that majority of respondents thought of providing health-related incentives to the family, like providing health insurance scheme for parents was voted by 24 respondents, helping in critical condition of the donor's family by 23 respondents and providing free medical facilities for donor families by 22 respondents.

FGD conducted by the researcher with a group of 25 respondents asking their suggestions on incentives for BSD organ donor families in case India introduces such incentives, there were various suggestions given by the respondents.

As par four respondents, *“Publishing donor names, their family names on magazines, journals, national papers, making them famous through social media and using them for creating awareness on organ donation”.*

As par three respondents, “*Provide permanent job to one member, to next of kin; a job with excellent earnings to donor’s wife or husband”.*

Three respondents suggested incentives like, “Providing free education, free higher education to children, sponsoring free formal education to the children of donors till they earn, helping donor’s children in education by giving a written assurance on bond paper and creating Donor Children Scholarships”.

As per three respondents, *“Provide them insurance schemes, health insurance to the family till the end of life, and free medical facilities for donor’s families”.*

As par two respondents, *“Provide free medical services to the family members, and giving priority in the allocation of an organ for transplant if required in future”.*

As par two respondents, “*Provide money and provide a one-time fixed deposit to donor family”.*

Most of the respondents in this FGD suggested giving recognition to donor and donor families. Almost all group members supported this option. Social security like employing the family members, free education, creation of donor scholarships for donor children, health insurance and free medical services were other incentives suggested by group members. Only two respondents indicated financial incentives that were disapproved by almost all other group members.

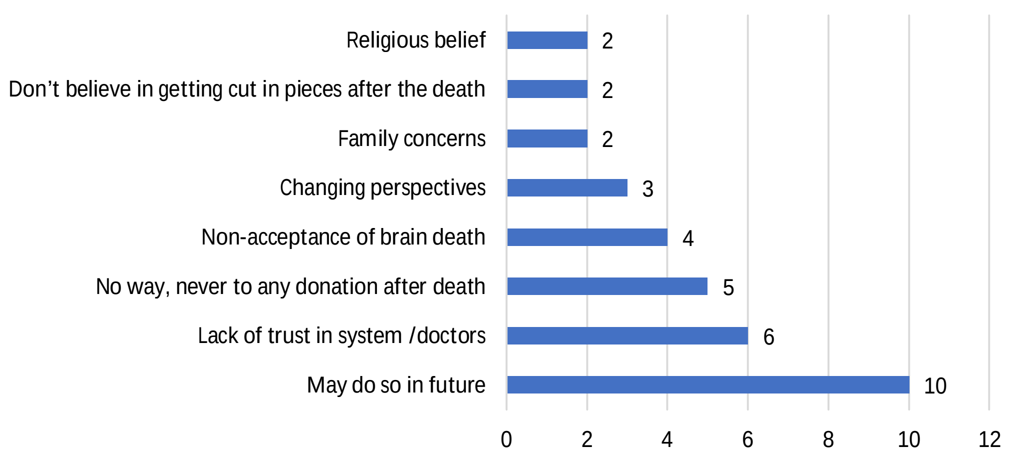
Figure 12.28 Reasons for not pledging to donate organs in awareness program conducted by NOTTO(N=30)

Figure12.28 reveals that majority of respondents, i.e.,10 were not averse to organ donation and wanted some time to decide. Similarly, 6 respondents revealed lack of trust in the system or doctors.

Their narratives are depicted as follows: -

May Do So in Future: - Ten (10) respondents wanted some time to decide to fill form 7 of THOT Rules. They said, *“I have not pledged as I have not still made up my mind to do so”. “There is no specific reason, but I do not want to decide right now”. “I did not avail the opportunity, but many opportunities will come to do so”. “I have not decided yet. Want to take my own time”. “I want to be the part of this after some time not now, maybe in later years of my life”. “I am a student, and I need more time to go through this and prepare myself mentally and psychologically”.*

Lack of Trust: - The narratives of respondents who expressed a lack of trust were, *“I have not pledged because of lack of trust”. “Organ donation activities could be discriminatory and commercially exploited if I pledge to donate organs”. “I don’t trust the system. My pledge could be misused”. “There is a possibility of intentional accidents with such pledges”. “My pledge could be used for commercial gains”. “I do not believe in doctors”.*

Changing Perspectives: The narratives of respondents who expressed their reservation with such decision said, *"I don't know what will be my decision in future. It may change even when I pledge to donate organs. So, I do not want to make any false promise". "I am not sure of my future wish regarding organ donation, and I don't want to commit any wrong promise".*

Non-Acceptance of Brain Death: - The narratives of respondents who expressed their reservation with BSD said, "I don't believe in Brain Stem Death". "What kind of death it is? It is unbelievable. It is legalized murder". "It is euthanasia for organ donation".

Religious Belief: -The narratives of respondents who expressed their reservation quoting religious belief said, *"This body is debt on our soul. I must die with it without donating any part of my body. I believe this debt is higher than any other thing". "**Chitragupta Ko Kya Muh Dikhayengey*** (Meaning how will I face Chitragupta in other world who would enquire from me about my organs). *He is the Comptroller and Auditor General (CAG) in another world. He is the one who keeps all records of sins and virtues. How will I answer him when he would ask me about my organs with which God sent me to earth"?*

Family Concerns: - The narratives of respondents who expressed their reservation quoting family concerns were, *"My family would not like the donation of my body parts after death". "I don't know how my family will take my will. They may feel offended".*

Don't Want Body Getting Cut in Pieces: - The narratives of respondents who expressed their reservation with body getting cut into pieces said, *"It is butchery, I don't want my body to get cut into pieces after death". "The thought of a knife terrifies me and visualizing my body getting cut in pieces is unimaginable".*

No Way, No to Any Donation After Death: - There were 5 respondents who said no to organ or tissue donation. They were opposed to any kind of donation after death or BSD.

Summary: - This Chapter reveals perspectives of non-organ donor respondents. The knowledge scores of 30 non-organ donor respondents showed that only 9 (30%) were well- aware non-organ donors out of which only 5 (55%) were genuine and rest 4 (45%) were indecisive donors. In other words, not filling Form 7 of THOT Rules 2014, does not give an accurate picture of societal intentions regarding organ donation. Lack of trust in medical fraternity and non- acceptance of BSD as complete death were two significant concerns for not pledging to donate organs by many non-organ donor respondents. The same was corroborated by FGD findings with 11 respondents as well, wherein nine (9) respondents depicted a lack of trust in medical fraternity based on their personal experiences. They had experiences of different nature like surgery advised was not required, private hospitals indulged in commercialization and levied irrational costs. A few faced inaccuracies in diagnosis and prognosis as well. Others found inefficient observatory skills of medical practitioners and unreliable medical tests.

Similarly, in another Focus Group Discussion on acceptance of BSD for organ donation, all 15 respondents had a very positive attitude towards organ donation. But most of the respondents believed they would only donate if they are completely dead or alive. Brain death was not at all considered as death by this group of students.

Regarding perspective towards donation, all respondents had donated clothes to people, 23 had donated books, eight (8) money and blood. Only four (4) respondents believed that the food they gave was the most significant donation. There were others for whom donating socks to a needy, taking care of a street dog, donating money for education and marriage of daughter were significant donations.

While five (5) respondents had donated blood to others, only three (3) respondents had donated blood to near relatives, a condition seen among organ donor respondents as well.

Also, there was not much difference between 21 &19 respondents who would not mind donating organs to family members and others outside the family, respectively.

Irrespective of all the debates and dilemmas surrounding BSD, majority 26 preferred BSD donor organs for family members but only 18 preferred such organs for self if required in future. The same situation was revealed in Chapter 11 among organ donor respondents as well.

Majority 8 non-organ donors believed that their mother would be the one who would donate an organ for them.

Regarding “organ donation will “of the person at the time of death, 18 respondents wished such will, be taken as final at the time of BSD declaration. Also, 23 respondents did not favour the inclusion of incentives for those people who pledge to donate organs. And 15 respondents did not endorse priority to people in waiting list register who swear to donate organs.

The majority, i.e.,19 non-organ donor respondents favoured involving families in diagnostic tests for BSD declaration, and 28, supported taking consent from family before proceeding with the “Apnoea Test”. And the majority, i.e., 16 respondents felt that after mutual consent, the donor and recipient families should be allowed to interact.

The majority, i.e., 21 respondents favoured allocation of organs to best-matched recipients, thus advocating natural justice. Also, 25 respondents preferred allocating one BSD donor organ to a family member out of turn.

The majority, i.e.,19 respondents advocated using the opt-out system of organ donation. Sixteen favoured giving equal opportunities to foreigners and Indians in organ allocation, and 17 did not support priority to females for BSD donor organs. Majority of the respondents suggested providing health-related incentives to the family. For example, 24 voted for health insurance schemes for parents, 23 suggested help in critical condition of the donor's family and 22 favoured free medical facilities for BSD donor families.

FGD conducted with a group of 25 respondents asking their suggestions on incentives for BSD organ donor families in case India introduces such incentives. And various ideas were put forth. Most of the respondents suggested giving recognition to donor and donor families. Social security like employing the family members, free education, and creation of donor scholarships for donor children, health insurance and free medical services were other incentives suggested by group members. Only two respondents indicated financial incentives that were disapproved by almost all other group members.

A few categorically stated they would never give any part of the body after death. There were other concerns of these respondents revealing a lack of trust in system /doctors and non-acceptance of brain death. While some believed it is legalized murder others said it is euthanasia for organ donation. A few were averse to organ donation and did not want abuse of their organs in transplant recipients in case recipients indulge in criminal activities or have different food orientation not aligning with the donor. A few believed that perspectives keep changing, and any false promise at present is not ethical. Others revealed family concerns and aversion to an idea of bodies getting cut in pieces after the death. A few also revealed a religious belief that they have to report to "Chitragupta" in another world after death with all body parts intact. However, a majority of non-organ donor respondents had not said no to organ donation as is given the picture of such non-organ donors globally. There were many reasons revealed by non-organ donors for not pledging to donate organs. A majority said that they might do so in future and not now. They wanted time to decide. A few of such respondents wanted to pledge organs on birthdays or later in life.

In other words, pledging or not pledging to donate organs does not give an accurate picture of societal intentions. It shall be better if we stop blaming people for not pledging to donate organs. Many of them have not said no to organ donation, if they have not pledged to donate organs. Some of them may do so in future or may not. Let their families decide at the time of BSD declaration.

CHAPTER 13

Summary and Conclusion

This Chapter summarizes the major findings of the study and gives policy recommendations. It is organized into four sections. The first section provides background information about the study. The second section summarizes and discusses the significant findings based on the major outcomes of nine Chapters from Chapter 4 to Chapter 12. The third section gives the study implications. The fourth section deals with the conclusion and recommendations.

Background

The study tried to explore the medical, social, ethical and legal issues related to organ donation and transplantation from Brain Stem Dead (BSD)donors through a case study of National Organ and Tissue Transplant Organization (NOTTO). Brain death is a new definition of death and is only 50-years old. It got introduced into the medical system in 1968. On the one hand, it was introduced to avoid continuing life support to patients hooked to ventilators, who had no hope for life. And on the other hand, it was added to retrieve viable organs for transplantation into patients who needed organs to continue life probably. The study tried to analyse the issues at micro, meso and macro levels. It attempted to find interrelation of findings at each level to gain insights for the National Organ Transplant Programme (NOTP) and National Organ and Tissue Transplant Organization (NOTTO). At the micro-level, the researcher studied the BSD donor family perspectives (who had donated organs of their Brain Stem Dead relatives). It explored the perspectives of recipients and their relatives also. These recipients were either waiting for kidney, liver or heart transplantation or were transplanted such organs. It attempted to study the perspective of people who had pledged to donate organs and who had not done so in well-organized awareness programs conducted by NOTTO. At the meso level, the researcher tried to explore issues from the viewpoint of organ transplant coordinators, NGOs, Organ sharing networks of India, NOTTO and NOTP officials. At the macro level, the researcher attempted to analyse the study findings in the context of Act & Rules on organ donation and transplantation of India and policies of NOTP and NOTTO.

The study was undertaken to understand why donation from Brain Stem Dead donors had not picked up after India enacted the Transplantation of Human Organs Act in 1994. No such research study was conducted in India. National Organ Transplant Programme had started in 2009; NOTTO had established itself in 2014 and was trying to amalgamate data from hospitals all over the country. A few State-based organ sharing networks had taken up BSD organ sharing and allocation activities in their respective States. However, the researcher did not come across any study in India that could have looked at the broader aspects of organ donation and transplantation from Brain Stem Dead donors.

Limited literature was available on Brain Stem Death, organ donation and transplantation in India. But the literature review from other countries revealed a lack of knowledge, lack of acceptance of brain death not only among people but professionals as well(Dar and Adhish, 2014).The literature revealed different conversion rates of Brain Deaths globally with Spain, the best country globally(Shroff, 2010)and Tamil Nadu the best State in India(Abraham et al.2016)The literature revealed varied medical, social, ethical and legal aspects of organ donation from BSD donors(Dosemeci et al. 2004; Paul 2001; Spittler et al. 2000; Saposnik, 2009).

To achieve the primary objective of the study, data was collected from people and professionals by employing qualitative and quantitative research design using various tools. Both quantitative and qualitative research methods were used to elicit information from the respondents and get in-depth insights into various issues of organ donation and transplantation, mainly in the context of BSD. The study consists of six sub-studies. First is the study of NOTTO and other organizations. Second is the study of Organ Transplant Coordinators. The third is the study of BSD donor families who had consented to donate organs of their BSD relatives. Fourth is the study of recipients and their family members. The fifth is the study of people who had pledged to donate organs during well-organized awareness programmes conducted by NOTTO. And sixth is the study of people who had not pledged to donate organs during well-organized awareness programmes undertaken by NOTTO. The observational methods, case-study method and survey methods were used to collect data. A total of 56 respondents in the study were administered interview guides, 80 respondents were administered questionnaires, and unstructured interviews were conducted with eight (8) respondents. Also, five FGDs were done with Organ Donor Card Holders and Non-Organ Donor Card Holders, the number of respondents varied in each FGD, as discussed in Chapter 11 and Chapter12.

Findings

The findings of the study are presented in nine Chapters (Chapter four to Chapter twelve) that are organized under specific themes addressing the main objective and research questions of the study. This section of the Chapter discusses the major findings of these nine Chapters as follows: -

NOTTO and Its Challenges

As per THO amendment Act 2011, it was recommended to establish National Human Organs and Tissues Removal and Storage Network along with National Registry for Transplantation of organs. In response to the recommendations, the National Organ and Tissue Transplant Organization (NOTTO) established in 2014 as an apex level organization in India. It is supposed to build a well-established network for procurement, allocation and distribution of organs and tissues for transplantation in the country. It established within the vision of NOTP (National Organ Transplant Programme) in India. It occupies 4th and 5th floor of pathology department of ICMR building in the campus of SJH at New Delhi.

When NOTTO took over, there was no central waiting list registry for organ transplant patients. Instead, all hospitals had their hospital-based list of patients waiting for organ transplants. These hospitals shared BSD donor organs within their network of hospitals resulting in loss of precious organs many times.

NOTTO had to take a leadership role in the country when some States had moved ahead and were performing very well in BSD organ donation programme. Some States, on the other hand, were much behind, and some States had not started organ transplantation services. It had a significant challenge to learn and lead simultaneously.

Development of the NOTTO website was done under National Informatics Centre that faced a lot of teething problems as NOTP is a unique program. The problems were compounded by lack of baseline data, lack of vision and understanding, a missing model of website, lack of vision to address language issues, predominant clinical demands, non-cooperation of hospitals in sharing data and lack of expertise.

NOTTO chose to make its presence felt by organizing conferences, workshop and training programs. The launch of National Organ & Tissue Transplant Registry and observance of Indian Organ Donation Day every year with high political involvement brought NOTTO into the limelight. Besides, it conducted health awareness programs and participated wholeheartedly in awareness programs when invited as guest faculty.

NOTTOs initial focus was on registration of all organ transplant hospitals with NOTTO and later for organ sharing. State hospitals perceived it as a threat and were reluctant to register and share data with it. They felt it was going to impinge on their autonomy enjoyed by groups of hospitals for long.

NOTTO faced a challenge of underreporting of data by registered hospitals. Data shared by transplant hospitals from 2014 till 26.10.2017 revealed that only 267 heart transplant recipients, 995 liver transplant recipients, 3859 kidneys transplant recipients and 58 lung transplant recipients were waiting for a transplant as per a Key official at NOTTO. The data was much less than revealed by DGHS during the year 2011 informing that about 1,80,000 kidneys; 50000 hearts and 30000 livers were needed for patients, but only 6000 kidneys, 15 hearts and 1200 livers had been transplanted (DGHS; NOTP 2011) (Dar and Kumar, 2015).

BSD donor organs were getting wasted in the absence of a common waiting list register and a centralized coordinating organization. NOTTO adopted the rotational system of organ allocation to minimize wastage and bring in transparency. But this system faced many challenges in the beginning. To maintain communication with various hospitals for timely transportation and transplantation was one of the most significant challenges for NOTTO. To maintain a BSD donor during the organ retrieval process, meet financial requirements for retrieval and storage of organs and get viable organs after putting a lot of efforts were challenging for organ retrieval and transplant hospitals. It was a challenge for organ recipients to reach transplant hospital in time for organ transplantation. On one side, NOTTO faced a challenge to calm aggressive people who overreacted due to their limited awareness. On the other hand, it faced another challenge to orient unaware medical professionals to a new definition of death & organ donation. Besides, it was required to address the small issues of imported organ retrieval teams in retrieval hospitals while coordinating BSD organ donation and allocation activities.

Transplant hospitals from the Southern States were reluctant to share data with NOTTO in comparison to the northern part of India. Some NGOs had taken the lead in organ donation and transplantation endeavours before the existence of NOTTO. They had established their roots in southern India and were spreading their tentacles in northern India as well. ‘TRANSTAN’ in Tamil Nadu has Tamil Nadu Network of Organ Sharing (TNOS). Rajasthan has Rajasthan Network of Organ Sharing (RNOS), and Kerala has Kerala Network of Organ Sharing (KNOS). All these organ sharing networks are using the software of one famous NGO, which is 20 years old software. It is not possible for that software to be compatible with NOTTO software as there have been more significant changes in the field of organ donation and transplantation. Instead of making NOTTO website compatible with these networks, there is a need to have their software compatible with NOTTO software as reported by concerned officials of NOTTO.

Although AIIMS like institutions were proposed as State Organ and Tissue Transplant Organizations (SOTTOs), these institutions are still in the process of getting established in some States. Setting SOTTOs is a dream that may not come true very early.

NOTTO had to face the outsiders who had a stronghold on this issue. It had to fight the systemic challenges itself as a dependent organization on NOTP with multiple owners like SJH, ICMR and DGHS. At the same time, it had to deal with its significant dependence on contractual employees who could not be retained in many cases due to bureaucratic problems.

Brain Stem Death, Organ Donation and Societal Confusions

Although willing to increase organ donation rates, NOTTO was not aware of many things in the context of BSD donation. The researcher would bring to focus her observation that all professionals and people in our country say brain death rather than Brain Stem Death. There is a procedural difference between these two forms of death. India uses Brain Stem Death criteria of organ donation and not brain dead. But the majority use the term brain death for Brain Stem Death officially as well as unofficially. After researcher’s persuasion, NOTTO officials started using Brain Stem Death instead of brain death in official communications with an aim to avoid legal hassles in future. Having a close look at the draft Pledge Form 5 and modified pledge form 7 of THOT Rules 2014 (Annexure 3.3 & 3.5), it can be found that even the officials at NOTP were not adequately informed about BSD organ donation. Before doing the actual study, the researcher sought official permission and pretested Pledge Form 5 (Annexure 3.2) with about 200 medical and nursing students of various Delhi colleges. She submitted a report of the same to NOTP following which amendments were made by NOTP. That later became Form 7 of THOT Rules (Annexure 3.4), and BSD was added in the pledge form for the first time.

Looking at the study findings, brain death in the context of organ donation had a different meaning to organ donor families, recipients, people and professionals based on their understanding, exposure and experiences as shown in Figure 13.1 below. It could be attributed to the use of different terminologies in awareness programmes, intentional and unintentional use of ambiguous terms to lure people into organ donation. The varied perspectives had unknowingly led to false - optimism, confusions, suspicions and apprehensions among recipients. People, in turn, were posing a different kind of problems for BSD donor families, professionals, NOTTO and even PMs Office was not spared.

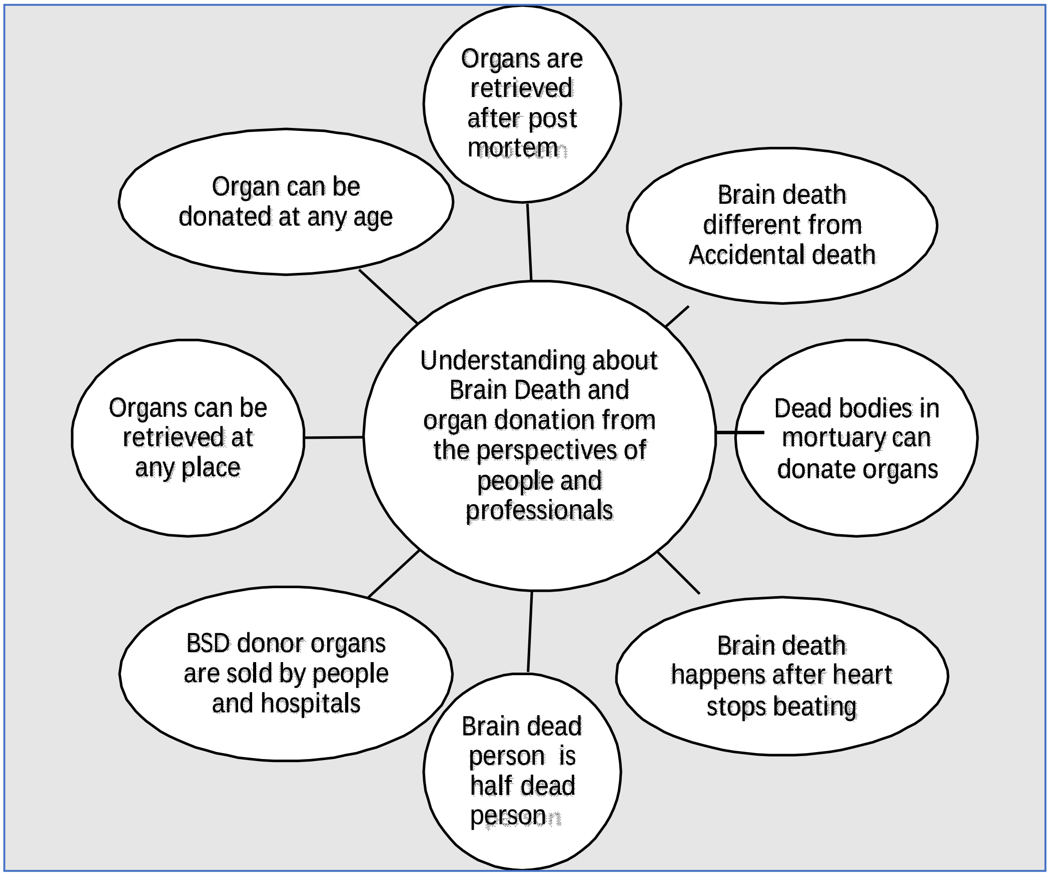

Figure 13.1 Understanding about BSD from perspectives of people and professionals

Very few donor families had heard of brain death before donation of organs of their relatives. However, for all the donor families, brain death meant the death of the brain only and not of organs. The families were convinced that the death of their family member was prolonged only because of the ventilator, and there is no possibility of recovery or coming back to life.

The narratives depict limited knowledge of people playing havoc with the lives of donor family's post-donation. Back home, male members faced the wrath of family members and were reduced to aliens in their own homes. It was triggered by taunts and heckling of relatives, neighbours as well as friends, who blamed them for selling organs. In one case, the father of the donor was fighting elections for the post of Sarpanch in the village. His opponents found it an opportune moment to help him lose the election. They blamed him for selling organs of his son and made attempts to ostracise him socially. It was unbearable for the family who not only had lost their young male child but had to face the wrath of their own society. They had to be rescued by hospital authorities for evading the wrath of the community as reported by Dr.N in Chapter 5.

The recipients had registered for cadaver donor an ambiguous term used for a dead person and BSD donor as well. While cadaver donor meant Brain Stem Dead donor only for registered recipients, the same was not explained well to the recipients. It had led to false-optimism, confusions, suspicions and apprehensions within recipients. People would often think; the way eyes are gifted after death; similarly, organs are also gifted after death. For most of the recipients and their relatives, a cadaver was an accidental death case only with no other information and such accidental death cases were in abundance for them. These misinformed recipients would ring the transplant coordinators repeatedly and inquire when will they get kidneys. They thought that such accidents happen regularly, and post-mortems cannot be escaped. Some long waiting recipients suspected the hospital sells post mortem kidneys to elite patients. However, according to one recipient's understanding of brain death who luckily received kidney of a 17-year-old male BSD donor about a year back had different knowledge of Brain Stem Death. He said in Hindi--- ***"Hum To Sunney Hai Accident Wala Case Thaw, Aada Zinda Ka Case Thaa: Mara Hua Ka Nahee, Marra Hua Ka Kidney Kam Nahee Karegaa Naa."(***Meaning I heard it was a kidney of a half-dead person and not a completely dead person. The completely dead person's kidney cannot function.)

It was interesting to note that none of the three heart recipients who had got heart transplanted, understood Brain Death. For them, the retrieval of the heart took place after it stopped beating in the patients. Lack of awareness about the concept of brain death has been reported in many studies (Seth et al. 2009; Moraes and Braga, 2009).

As a result of this, NOTTO faced a lot of challenges. It had to calm people who overreacted due to misinterpretation of terms used in organ donation and transplantation. It faced aggression of relatives and had to convince medical professionals that organ donation is impossible once the heart stops beating.

There is a lack of awareness about the meaning of organ donation and transplantation from BSD donors not only among the public but among the professionals as well in India (Dar and Adhish, 2014). It is interesting to reveal that for some time, a video spot of 30 seconds duration prepared by NOTTO did not get the concurrence of DGHS for explaining Brain Stem Death. DGHS felt that people don't need to be told about the intricacies of organ donation since the researcher also was a part of one such meeting. Mr Narendra Modi, our Prime Minister reiterated the importance of this topic in his **"Mann Ki Baat"** program in 2015(Dar,2016). However, he also mentioned that in case of death in Road Traffic Accidents, organs of a body can be donated. The reason could be attributed to selective information given to our PM also by NOTTO officials who were required to brief our PM before the talk as was revealed to the researcher. It, however, was not a deliberate attempt on their part but their main aim was to make the message simpler to public.

Intending to increase the organ donation rate in the country, using confusing, ambiguous terms, giving selective information to the public has not provided a flip to

BSD donation. Instead, it has led to misunderstanding and accusation by the patients on the hospitals.

The medical definition of BSD with beating heart is too confusing to be understood at ease and causes a lot of turbulence between the patient's family and the caring physician (Al- Hashim and Al-Busaidi, 2015)

Legal, Medical, Social and Ethical Issues Regarding Declaration of Brainstem Death and Organ Donation

The traditional definition of death in India, as in many other countries, is an irreversible cessation of heartbeats and respiration. On the other hand, Brain death, a new neurological definition of death is the 50-year-old new definition of death that has been legalized in India through THOA in 1994. Brain death is, however, riddled with ethical debates all over the globe. It is because, after the declaration of brain death, the heart keeps beating and respiration is going on, and the patient is on the ventilator. This new definition of death moves us away from the traditional definition of death to the neurological explanation of death. Unfortunately, Brain Stem Death usually called brain death in India is linked to organ donation and transplantation only. This kind of death is not confirmed if relatives refuse to donate organs. The study findings reveal a few ethical concerns that need to be redressed at the earliest as depicted below: -

The researcher observed a variation in diagnostic procedures. The “Apnoea Test” (AT) is one of the essential tests for BSD diagnosis. The “Harvard criteria” developed long back in 1968 define apnoea as a lack of breathing movements for 3 minutes after removing the patient from the ventilator. The researcher found variation in diagnostic procedures for doing the “Apnoea Test” while attending two training programmes for OTCs at NOTTO. The test involves removing the patient from the life support of ventilator for 8-10 minutes or 10 -12 minutes while doing the “Apnoea Test” as revealed by two different experts in two separate training programmes.

Interestingly, globally, there is no uniform criterion for doing the “Apnoea Test”. The standard of diagnosis has evolved over some time with newer definitions and newer ways of diagnostic procedures. For example, Minnesota criteria highlighted the importance of irreversible loss of brain-stem function in brain death in 1971. Similarly, the Conference of Medical Royal Colleges established a code for the determination of brain-stem death in the UK in 1976 (Dhanwate AD, 2014). With time, the American Presidential Commission criteria, American Neurology Academy standards and the modified Canadian criterion for Brain Death diagnosis established in 1981, 1995 and 2006, respectively (Joanna et al. 2015).

Also, while pronouncing BSD, there is a conflict of interest in some cases. Neurosurgeons want to prolong the life of the patients under their care, no matter whether they have a chance of recovery or not. The transplant surgeons also want the same for their patients. But the latter need organs for transplantation from patients under the care of neurosurgeons. The OTC who is to coordinate between the two gets sandwiched in this fight. Neurosurgeons believe in continuing treatment of a Brain Stem Dead person, but transplant surgeons or recruiters want the patient to declared Brain Stem Dead for organ retrievals. It is ultimately OTC who faces the brunt of such unavoidable conflicts and in one case was named as **“God of death”** also.

There are universal debates and dilemmas in organ donation from BSD donors. It involves shifting of devotions from the patient on the ventilator to several patients needing organ transplantation (Dar and Adhish, 2014).

Consent from families for doing “Apnoea Test” is neither required nor taken as reported by OTCs. It is an unethical practice as this test is not done to improve the prognosis of the patient but to declare a person brain dead. It shows medical hegemony ingrained in the processes of organ donation from BSD donors. Interestingly, majority 18(90%) OTCs did not believe in taking consent from relatives for doing “Apnoea Test” as they don’t want the family to interfere with such decisions. OTCs want more organ donors. Seeking permission from relatives might bleak their chances of getting more BSD donors for organ donation, and their job may be at stake.

All signs of life are present when BSD is declared. This issue of BSD declaration with all intact vital signs and sometimes with body movements also is debatable and questions death and life. The narratives in Chapter 5 point to sufferings and frustrations of OTCs when they are not able to motivate families. It is a tough decision for families to donate organs of the heart beating persons having other signs of life as well.

The donor families are given selective information regarding continuation of medical interventions even after the declaration of death. The OTCs provide inadequate information to donor families to lure them into organ donation. An OTC, Mr Kn reported that once he had convinced a mother to give consent for donation of organs of her son. The mother later saw her son being given medicines through Ryle's tube after she consented to donate. She felt cheated and expresses her wrath against Mr Kn. This episode itself speaks of selective information given to the public to lure them into organ donation that is most unethical.

OTCs are pressurized to put pressure on villagers and poor people to donate organs. Ms Fwho revealed a case of a low-income family, who chose to escape from the scene once approached for organ donation. The thought of near and dear one dying is not without pain to the relatives. Several people deny accepting Brain Stem Death. They are often put in an adverse situation when they are required to decide within a short period either in favour of organ donation or to continue treatment. Both these options are painstaking for the family. They are caught in a conflicting situation and trapped into the donation of organs. The third option to discontinue life support that could serve the purpose for a poor person is missing from such acts. A family is supposed to either donate organs or continue futile money consuming treatment for the patient.

The ethical dilemma here is, if a family decides to donate, professionals will declare the patient BSD. If they refuse to do so, then the donor is a living person only, and the family is bound to pay through the nose. The plea given is that there are no laws that say to discontinue life support. It again proves medical hegemony under the shade of legal bindings. Mr Kn, a transplant coordinator of a southern State, revealed that people are blaming private hospitals for premature brain death certification. Under such conditions, organ donation from BSD donors is an immoral trap for poor people and villagers.

Death is not confirmed with a second diagnostic procedure if relatives refuse organ donation. It is an unethical intentional trap to force people into the donation of organs. All 6 (30%) experienced OTCs in the study revealed that the second diagnostic procedure is not done in case the family refuses to donate organs. In addition to it, two OTCs revealed that family is counselled even before the first diagnosis of Brain Stem Death. And in case they are not willing to donate organs, even the first diagnosis is avoided. The ethical issue relates to medical hegemony in pronouncing deaths and raises doubts about this BSD definition of death. Are laws misleading the doctors, or is it that doctors are misleading the people? The ambiguity of legislation reported by Mr K and Mr M prevents doctors from withdrawing support that raises legal concerns. Brain death in 1968 was not framed to retrieve organs but to remove the patient from ventilator primarily. But with time, people have forgotten the original purpose of Brain death declaration and focus on commercial use of such definition only.

The presence of 4 doctors to declare BSD is mandatory, probably to prevent human error in diagnosing such deaths but this legal binding is side-lined by professionals who get signatures of all the four professionals whether they may or may not be present at the time of making BSD diagnosis as required by law.

There is a vast gap between the number of families counselled and the number of families who eventually consented to donate organs. Table 5.2 in Chapter 5, shows the conversion rate of 24.8 per cent only. It speaks of a low level of acceptance among people in northern India as all OTCs were working in various Government and private hospitals of Delhi. Many a times relatives want to discontinue treatment but are not allowed. The option given in such cases is to get LAMA (Left Against Medical Advice). It is not at all ethical.

As per Ms F, *"The patient is shifted from the hospital with an Ambu bag and accompanied by ward boy till he is out of the hospital premises. We do not know what happens later".*

As per Mr.K, *"The patient on the ventilator after the first diagnosis is supposed to get all the death care and not life care".*

During one transplant coordinators training program at NOTTO attended by the researcher, one of the external transplant coordinators who had experienced several such incidents asked a question to the faculty from AORTA. She asked him as to what should they do in such cases where the family is not willing to donate organs and want to take back the patient? He answered that the family should be trained to use an Ambu bag, and the patient should be sent home along with the Ambu bag.

There are a lot of confusions with this form of death. A person is either dead or living, but words like death care or life care depend on the decision of relatives. LAMA does not come under death care. LAMA is advised for patients, not for dead bodies. But with this debatable definition of death having the sole purpose of organ donation, there are enormous ethical concerns that need to be redressed.

There is no follow up of refusal cases. Interestingly OTCs had no information about those cases whose families had communicated their refusal for the donation of organs. What happened to those cases was none of their concern.

The narratives of donor families in many cases highlight the long hours of retrieval process not revealed to them in advance. There is an urgent need to address this issue by giving accurate information to donor families as the donation, death and post-death rituals are to be managed and pre-planned by donor families. Accurate information could help them in planning things accordingly.

As per the findings of this research, Brain Stem Death is linked to organ donation and transplantation only. In other words, it is death declared for retrieval of organs and not for removing the patient from the ventilator and performing last rites. Pioneers in organ transplantation have raised the same concern. According to them, professionals play safe and do not declare such death if a family refuses to donate organs of a brain-dead donor after the first diagnosis. In such cases, the second diagnosis is not made, and the patient is hooked to ventilator until his heart stops beating, and respiration stops (Shroff and Navin, 2018). The legal guidelines for withdrawing or withholding life support are not clear but ambiguous (Balakrishnan and Mani, 2005). It necessitates the development of National uniform guidelines for clarifying such ambiguities (Bardale, 2010).

Lack of Public Infrastructure Taking A Toll on Dialysis, Organ Donation and Transplantation

Out of 40 hospitals in Delhi and NCR registered with NOTTO,34(85%) are private hospitals. Sufferings of poor patients are related to lack of adequate infrastructure and human resources in dialysis units in Government hospital. Such inadequacy makes their condition miserable and pathetic at times. The dialysis department in the Govt. hospital (SJH) is understaffed, and the dialysis unit is not functioning round the clock as a result of the shortage of staff and infrastructure. There are only ten dialysis machines on which only indoor patients are put on dialysis from 10.00 am to 4.00 pm every day, excluding holidays. The out-patients are on the waiting list for dialysis in this hospital. The out-patients usually get their turn after 15 days in this hospital. Till that time, they are required to make their own arrangements outside the hospital as dialysis is required either twice or thrice weekly. In a few cases, relatives wait for the patients to become serious so that patients are admitted in Government hospital (usually done if a person is severe) and given free dialysis. Lack of infrastructure and workforce forces them to avail private health care that drains them financially. For patients who had some associated medical condition that required hospitalization, the associated medical condition had proved a blessing in disguise. It is because the hospital provided dialysis facilities as inpatients only. Like, Mr. M, who reported, *"I was admitted in the hospital for one year as I was suffering from low platelet count too. It was a blessing in disguise for me since my dialysis was done in the hospital only. Otherwise, it would have cost me a lot outside''.*

Organ donation from BSD donors is not that simple. Neither all hospitals nor all doctors can declare Brain Stem Deaths. The same is not communicated through organ donation awareness campaigns of which the researcher had been a part on many occasions. A team of four designated doctors in organ transplant hospitals usually have the legal authority to declare such deaths. Chapter 6 reveals that out of 14 BSD donors, three donors were shifted to other hospitals. And in one case, Brain Stem Death Certification Committee of another hospital was requested to come to the hospital where the patient was hooked to a ventilator to declare such death. The narratives of Mr T and Mr I, in the same Chapter, describe how organs fly and travel from one place to another and reach the recipients in different parts of our country. It also reveals how a poor man's wish to fly his daughter gets fulfilled through organ transportation after BSD declaration followed by organ donation. Transportation and transplantation are made possible by immense intrastate and interstate cooperation, use of the material and workforce resources for sharing of biological assets crossing State boundaries. It also gives an impression of unity and solidarity among States and dilutes the value of State subject at death and questions non-cooperation in hospitals in sharing data.

Besides this, the lack of post-mortem facilities in organ retrieval hospitals brings focus on the ordeal of people. They donate organs in one hospital and are required to move to another hospital for getting post mortem done as reported by Mr M.

Several patients felt that SJH overburdened and understaffed but blessings for poor people. Some relatives who suffered due to the negligence of staff in the hospital blamed understaffed and overburdened health facility. These narratives like, ***"Yahan Kutey Biliyoon Kee Tarah Log Mar Jatey Hai"*** (Meaning people are dying here like dogs and cats) and ***"Iss Hospital Mai Humesha Mela Laga Hota Hai"*** (Meaning the patients get admitted as if there is a fair in the Ward) reveal the plight of infrastructure inadequacy and compulsions of professionals and poor patients in Govt. hospital. The initiatives by hospital staff for poor people coming from far-flung areas like facilitating stay in Dharamshala for relatives, helping them in getting low-income certificates prepared, helping in getting notary affidavit for free of cost treatment in the absence of BPL cards, filling formats and preparing documents for recipients so that they could get the same made by the court without any mistakes were highly appreciated pro-poor initiatives. Besides the costly immunosuppressants were distributed in the Ward itself. It was done to prevent patients from standing in the queue at medicine counters and was one of the significant pro-poor initiatives taken by the hospital and appreciated by every recipient.

Many recipients waiting for kidney transplant had mismatched willing donor as reported. Swapping living donors could solve their problems that do not happen due to the scarcity of workforce and infrastructure. Poor sick kidney patients were not able to reach in time from neighbouring states or districts to SJH. But wealthy liver recipients afforded to shift several times from foreign land to a private hospital in Chennai and got BSD donor organ transplanted.

Government health infrastructure is starving and in shambles. It needs extensive improvements to deal with emerging problems and challenges. India's public health expenditure on health is not rising at pace with its rapidly increasing population, which grow by 26 million each year (Sharma, 2017).

Two-Way, Unethical Traps of Private Hospitals with Donor Families on One Side and Recipients on The Other

The study reveals unethical trap of private hospitals in various forms, as explained in Chapters 5, 7 & 9. They trap poor people and villagers for BSD donation and pressurize OTCs for motivating BSD donor families, as revealed in Chapter 5. These hospitals ask for full advance payment for liver transplant surgery with no BSD donor in sight. False assurance of 100 per cent recovery for multiple organ transplants, the result being the death of the recipient within 45 days reveals unethical trap laid by a private hospital. It is probably done to sensationalize the organ donation and transplantation business as multi-organ transplant gains media attention. It brings hospital in great limelight as could be seen by the researcher in several online sensational media coverages of these events, including this case. The other varieties of the trap like giving underestimates of transplant surgeries before transplant that doubled, asking for an advance of Rs. 80000 just for admission and arrangement of an amount 3 lakh for treatment (for a patient who needed dialysis only). Private hospitals airlift heart and invest lakhs of rupees with no prior permission from relatives to do so. They give incomplete information and later withhold “Bills” and “Bodies” for the inability of the recipients to pay the exuberant cost of transportation &/or transplants. It reveals unethical commercial concerns of hospitals primarily in this organ donation and transplant business.

Private health care infrastructure rules the nation; their primary intention revolves around commercialization. The role of the private sector in the health care system is continuously increasing; getting costly and becoming inaccessible for the common man at large. Besides, the social-welfare aim has lost its essence. The Government hospitals, on the other hand, are facing hardships day in and day out, due to lack of resources and infrastructure (Narain, 2016).

Cost Variations and Economic Sufferings of Recipients

There was an enormous cost variation of medical procedures, tests and dialysis from one health facility to another. Most of the patients had landed first in private health facilities where costs were much higher for dialysis. However, with time and interaction with fellow patients, they resorted to those health facilities where costs were less. Many recipients revealed extreme cost variations, unaffordability of treatment and unwanted experiences. The findings of research in Chapter 7 and Chapter 9 are compiled in Table 13.1 below to show the cost variation.

Table 13.1 Showing cost variation of procedures and organ transplants in public and private health facilities

Type of procedure	**Range of cost in private health facility**	**Cost in Government health facility**
Cost of fistula preparation	Rs. 5200/- to Rs 15000/-	Nil
Cost of one dialysis session	Rs. 1100/- to Rs. 3200/-	Nil
Cost of PRA test	Rs. 5200/- to Rs 15000/-	Not done in SJH
Cost of kidney transplant	Rs. 4 lakhs to Rs. 16 lakhs	Rs.20000/- in SJH
Cost of heart transplant	Rs. 13 lakhs to Rs. 35 lakhs	NA
cost of liver transplant	Rs. 25 lakhs to Rs. 40 lakhs	Rs 50000/-in GB Pant

Table 13.1 reveals the cost variation of procedures as reported by recipients. In Govt. health facilities, fortunately, the financial implication for a kidney transplant was Rs. 20,000/- only and liver transplant was Rs. 50000 only (for tests mostly done outside).

The poor patients were finding great difficulties in managing finances for dialysis sessions. Selling land, a part of the house, taking the loan for treatment were the conventional narratives of many recipient families as revealed in Chapter 8. The story of Pitta in the same Chapter, *"We lost everything during this disease. Home, money this disease consumed everything. We were in great turmoil. My husband was in service, and we were getting some help. One month's dialysis cost us Rs. 35000/- excluding medicines and ICU treatment"* reveal the financial implication of the disease. Some of the recipient families had been to private hospitals before coming to SJH. Three recipients reported that they went to this Govt. hospital only after exhausting their resources in private hospitals. They were feeling terrible and blaming themselves for not coming to this hospital before exhausting their resources.

Similarly, in Chapter 9, the narratives reveal the high cost of liver and heart transplant had drained families financially. One was in debt even after two years of multiple organ transplant surgery. And another had sold a piece of ancestral land to pay off the loan taken from friends and relatives. Although insured, both the recipients had to cough out extra money to meet the transplant expenses.

One liver and one heart transplant recipient revealed that they had to invest heavily in shifting and taking rented accommodation to be near to the transplant hospital. One even bought a second-hand car to be near to transplant centre. These investments are not within reach of ordinary uninsured and poor people.

The casual attitude of people in making legal documents to certify relationships etc. add to the financial and physical sufferings of sick patients. A simple mistake in name costs much more to recipients in the form of time investments, delays in transplant, stay on roads and additional financial investments.

The family coped with financial aspects of liver disease by rationing of medicines, skipped one dose of medicine every day to deal with finances before transplant.

India's public health spending on health is not increasing at pace with its speedily growing population. It is disheartening to see the starving Government hospitals facing ample problems with inadequate resources and infrastructure **(Narain ,2016).** It forces people to abandon jobs, sell land, property and other assets to pay health care costs in private health facilities **(Sharma, 2017).**

Gender Issues, Organ Donation and Transplantation

The data reveals gender issues entrenched not only in organ donation but transplantation as well. Amalgamating the data presented in Chapters 5, 11 and 12, the expectation of organ donation on female members is almost double the male members within the families.

Table 13.2 Expectation of respondents for organ donation from family members (N=80)

Expectation of organ donation from family members	Number	Percentage
Parents	31	39
Mother	18	23
Other female members like wife, sister etc.	7	8
Expectation from male members only	10	12
Can’t say + Will not ask + none	11+2+1	18

Table 13.2 reveals that the majority39% expected parents (mother and father), 23% expected their mother only and 8 % expected other female members to donate organs for them in case the need arises.

The narratives in these Chapters reveal expectation for living organ donation within families rested on females; however, mother formed a significant part. It also demarcated a thin line between expecting the mother to donate organs and exercising rights and ownership on the mother’s organs. A mother was considered as the first preference for organ donation at ease during life and at death also.

The quantitative data in Chapter 10 reveals that 16(85%) of living kidney donors were females. The researcher observed subtle societal pressures on female donors not only in narratives but also during interviews with a few female donors.

Living organ donation has burdened female donors worldwide. The aggregate data of USA (UNOS, 2010) and the United Kingdom (NHSBT, 2010) reveal that female living donor outstripped male living donors every year. Female living organ donors comprise of 80% and 95% in India and Pakistan, respectively (Shakeel, 2009). It highlights patriarchy and female suppression in organ donation as well (Dar, 2015).

Concern for reproduction was one of the essential concerns seen in kidney failure, kidney donation and transplantation as well, as reported in Chapter 10. Not only this, wherever ladies had produced children, husbands wanted to give a kidney to their wives. It was not for love towards wife but for their children whom they could not think of without their mother.

The story of Mitta reveals gender suppression from early childhood and repercussions of the same on the psyche of the child in later years of life. Mitta's story is full of struggles right from her childhood and full of fights to evade gender suppression. The male child looked after well in comparison to female children, female left on her own, after marriage in adverse conditions in a foreign land. Weakened by the aggressive social environment, including her mother, Mitta intentionally marries a man with CKD knowing he will require a kidney transplant in future. Story of Mitta reveals the struggles of a woman to leave her small child to keep her husband alive.

Similarly, the story of Ms.DlDa reveals gender bias in rearing a girl in the family. Girl child wanted to prove to her family that she also is important and donated 65% of the liver. The liver donation was an opportunity to prove her worth to her family and get a good status like her brother not enjoyed by her previously. Her joy knew no bounds on knowing that she can donate her liver even when there is Rh incompatibility between the donor and recipient. She was dissuaded by relatives not to give liver as that could bleak her chances to get married. The relatives also tried to help her reconsider her decision to donate a part of the liver. With beauty concern in mind, they warned that the operation could culminate in an ugly abdominal scar. It could result in loss of her beauty and prevent her from wearing saree throughout her life. But nothing dissuaded her as she was determined to prove her worth to her family. However, the most significant remorse for her is her father's dissatisfaction. She does not find that satisfaction in her father's eyes as she anticipated after donating a substantial portion of her liver. Her narratives point at her remorse that girls are not given that status in society. Also, now and then, she shares paper clippings with the researcher. These clippings also show her inner urge to prove to the world that daughters are also important and please reconsider your opinion about them.

The gender discrimination has its roots in the family itself and not in the society that creates a significant barrier in the development of community and nation (Shastri, 2014). Women usually donate to take care of families and are even coerced to donate kidneys (Carney, 2011).

Females in need of kidney transplant were taken care of well. But in a few cases were either left with their parents, divorced or abandoned also. It was interesting to find that the opinions of the majority of organ donor card holders 15(50%) and 17(56%) non-organ donor card holders did not support organ allocation priority to female recipients. The same is depicted in Figure 11. 26 and Figure 12. 26, respectively.

The females were also found tolerating the unabated frustrations of the morbid status of the recipients not only during dialysis but after transplant as well in the form of violence. The beatings, abuses and displacement of anger by males on females did not vanish even in their morbid state. Restriction of water, unquenched thirst, especially in hot summer and absence of cooling facilities for poverty-ridden people cause problems. The female attendants who restrict these patients to keep their water intake to the minimum face violence.

It can't be denied that violence on women has been there in our culture and has affected women in all aspects of life (Sinha et al. 2017) and organ donation and transplantation is no exception to it.

In the case of BSD donor families, the study revealed that male members were the decision-makers primarily. Males had taken their spouses for granted. Some had forced their decisions on females, and a few had threatened to get them fatwas issued, in case they refuse to donate organs of their relatives.

The patriarchal society structure is responsible for marginalizing women in all spheres that include decision-making process. Gender differences suppress women in decision making on various issues. It happens in their daily activities (Bano, 2014) and organ donation from BSD donors is no exception to it.

The study revealed gender divided roles. Female members were mostly donating organs and taking care of people at home. Male members were found to be supporting dependent members of the recipients and staying in the hospital with the recipient. Males only moved from one department to another for getting both the donor and recipient evaluated. They arranged blood, shifted near to dialysis facility or transplant facility from the place of residence, spent on the education of dependent children and took care of them at home. Females were not found to be performing some roles. The narratives of a daughter Ms Xr divulged how her family members accepted her inter-caste boyfriend in a crisis. She admits that she would have been killed otherwise for the same love affair. Her boyfriend was acting as a substitute for son and was arranging blood and other things that were not possible by three daughters as revealed by her.

Major household decisions are male prerogative and women have low decision-making power within the family. Women are supposed to be submissive and supportive in decisions made by males (Brody et al. 2008). Some societies formally lower the status of women and make them feel inferior through dependency. It increases their vulnerability through disempowerment (Wiest et al. 1994).

India has failed miserably to give job opportunities to its women that impede with their survival, growth and independence (Nagarajan, 2013). The Female Labour Force Participation Rate (FLFPR) is only 33% (Das et al. 2015) as per Census 2011. India is also a country with gross gender inequalities that have percolated in organ donation too.

BSD Donor Family Perspectives and Issues Identified

The study revealed time-consuming elaborate procedures in Medico-Legal Cases requiring permission from police and forensic experts before donation of organs that was unacceptable to most of the families as revealed in Chapter 6. Only one donor had pledged to donate organs, and family respected her wish. The good intentions behind the donation of organs reveal the adoption of healthy coping mechanisms by family members. They tried to rationalize their loss by giving life to others, help recipients and keep their donor alive. Mr U, the father of an MBBS student donor was pleased that his son is continuing his studies in a PhD scholar through heart transplantation. Similarly, for Mr C, it was a great solace knowing that his navy officer son would continue to serve the nation. It was made possible through the donation and transplantation of one of his kidneys into a defence officer's body.

A few studies revealed similar findings. In a survey of 49 donor families, the main reasons given for organ donation were many. The deceased wanted to benefit others during life and would have wished to do so at death also was revealed by 45% donor families. Also, 41% respondents believed that it is an optimistic outcome of death. It could improve the quality of recipient lives was told by 40% respondents. The deceased wished to be a donor was expressed by 28%; and19 % of respondents believed that the dead would continue to live after death (Savaria et al. 1990).

The precondition for BSD organ donation in this study was patriotic and pro recipients. In one case, the family wanted that defence personnel's organs to be transplanted to defence personnel only to help donor serve the nation. And in another example, the wish was not to charge recipients anything for transplant surgeries. These intentions speak of high values among these donors in India and not a social divide. In many studies, donor families set a precondition for same religion person or same race person revealing societal divide (Dar and Dar 2014; Moraes and Braga, 2009).

Reaching consensus took time and declaration of BSD was postponed. Death declaration can be delayed for long hours and even days till the time there is consensus within family members. In other words, the BSD declaration is not in the hands of God but the hands of a team of legally designated doctors. The decision to donate was facilitated by State specific organ sharing networks like TRANSTAN, Jeevandaan and ZTCC. Majority of families were self-motivated in southern States only.

The common reasons of refusal to donate organs of potential donors were differences in opinion between family members, fear of criticism by society and failure to understand the concept of Brain Stem-Death (Seth et al. 2009; Moraes and Braga, 2009).

There are certain expectations of donor families from the society that need the focus of policymakers. Some of the anticipated expectations of these donor families ranged from waiving off hospital bills after the donation of organs and free treatment in hospital for family members post-donation. One donor family expected monetary support to children who were orphaned. Also, one donor family wanted the status of a martyr to their defence personnel son.

All the BSD donor families received felicitations at least once before NOTTO did it for them. Felicitation had helped families to evade social exclusion, fulfil self-esteem needs, meet Bollywood celebrities, meet political dignitaries and see new places also. After the donation of organs, these families got invitations for creating awareness among people. Some of them promoted organ donation from BSD donors wholeheartedly. They could relate with people put in similar situations in hospitals. These donor families helped them coming in terms with the loss.

Many people chose to give life to people, and Reg Green was one of them. Reg Green's son created ripples in organ donation globally (Green,1999). Same ripples were created in northern and southern India too. A doctor couple donated their son Hitenderan's organs in the South, and Anmol's father gifted his son's organs in the north in 2008 and 2012, respectively (Dar et al. 2013)

A Craving to Reveal Donor Recipient Identity

Maintaining anonymity between donor family and recipients has been one of the essential concerns in organ donation and transplantation (Gewarges et al. 2015). Worldwide donor- recipient identities are kept confidential and not revealed. Medical professionals and organisations exhibit reluctance to enable interaction between the donor family and recipients. But over time, social media has played a significant role in smoothing communication and removing donor/recipient anonymity barriers. Wherever people have come to know of recipients or donor families, they celebrate rebirths and festivals together. In Transplant Games in the USA, there is open mingling and searching of such donor and recipient families making new kinship relations possible (Dar, 2014).

Majority 9(64%) donor families in this study wanted to know the recipients of donor organs but had no access to it. One donor family (7%) had chased all the recipients of his daughters' organs and tissues as well, and 1(7%) family could find two kidney recipients of their donor. The nine donor families wanted to see the recipients. They reasoned to find their donor alive in recipients and to see the results of organ donation in the lives of organ recipients. One donor family wanted to invite recipients to participate in their celebrations of social importance. As depicted by Ms F, *"My mother feels like calling all the recipients of my father's organs, especially the one with his transplanted heart on my marriage. It would make her feel the presence* *of my father by my side when I get married, and blessings of that person on my marriage shall help me too. I want you to help me in finding the recipients".*

A person accepts death with difficulty and donates organs of a loved one going through intense psychological processes. He relocates attachment and connection to a new person separate from the loved one's body who happens to be the recipient. After accepting brain death of their relative, the family members tend to relocate attachment with organ recipients (Sque et al. 2008).

Mr K, in Chapter 6, tried his level best to trace all the recipients of his donor daughter. (He shared the photographs of three recipients and his BSD donor daughter with the researcher).

Most of the recipients who had received the kidney from cadaver donors wanted to meet the donor family but knew that they could not. However, all of them were thankful to the donor families who had donated the organs of their near relatives. The recipients who had a yearning to meet the donor family were of three categories. The first category of recipients wanted to know them but had not found an opportunity to do so. They wanted to thank them and tell them that their donor is still alive as reported by Ms Mitta and Mrs Yl, respectively. One recipient family wanted to find an alliance for marriage in the donor family for the recipient daughter. The recipient's mother Mrs Tr felt that it would give them a feeling that their BSD donor son is alive in her recipient daughter. The second category of the recipient was those recipients who had an opportunity to meet the donor family. While one recipient Ms Pitta had traced her donor family through social media, another recipient was traced by donor family itself. In the third category, the liver recipient has a strong urge to meet the donor family but had kept her will in abeyance.

Meanwhile, she had substituted a male new-born cat to repay the good deeds believing that the donor soul is reborn in a cat. The strong urge to have a son could also be satisfied through an organ transplant. The same liver recipient who had produced two daughters only felt God had given her a son who donated his liver to her.

Meeting recipients had given meaning to the good deed of BSD donation. The families had developed healthy relationships that were non-existent before donation and transplant, had united people and provided a gratifying feeling to both donor and recipient families. It had resulted in the celebration of festivals together. There were friendly visits made to donor families by recipients and vice versa. Not only this, donor's birthday was celebrated with the recipient and recipient's birthday was celebrated with the donor family. Such interactions were full of reciprocity and empathy. Mr. I. revealed the Facebook post by recipient thanking donor on his birthday was a real reward to them.

Majority of the organ donor card holders and non-organ donor respondents supported revealing recipient identities to donor families depicted in Figure 11.21 and Figure 12.21, respectively. Similarly, FGD conducted by the researcher with a group of 30 respondents asking their stance on revealing organ recipient identities to donor families showed a similar response. Majority of participants were in support of such revelation. The proponents favouring such disclosure believed that it could encourage and motivate others to donate. They also thought that it would offer an opportunity to donor family to see their loved one living in others. Some said that it could prevent organ trafficking besides provide an opportunity for social integration and uniting religions. The opponents of such revelation believed that donation is more important than revealing the identity. They were apprehensive of the possibility of inviting regret and guilt within donor-recipient families as a result of unmatched food habits, cultural and religious orientation. Some opposed this revelation because they felt it might invite unnecessary interference in recipients' lives. Also, the fate of donor organ if not useful in recipient body post-transplant may multiply grief in donor family.

A study done with 106 professionals revealed that 53% agreed that organ recipients and donor families should be allowed to meet, 27% disagreed, and 20% neither agreed nor disagreed (Gewarges et al. 2015). It is essential to mention that no restrictions were imposed in the late 1960s and early 1970s among recipients and donor families to know each other. Revealing donor-recipient identities was considered fruitful, giving a sense of achievement to donor families (Fox and Swazey, 1992). Also, a study explored the relationship between families of deceased organ donors and transplant recipients through a systematic review of the literature and qualitative synthesis. It revealed that majority, i.e., 91 % of donor families wished to know about recipients, and 60 % were interested in meeting them also (Dicks G S et al. 2018). Hence, it shall be worthwhile to allow such interactions between donors and recipients for a healthy society.

Festivities: Hits and Misses in Organ Donation and Transplantation

The narratives of four persons in Chapter 8 reveal that most of the attendants and family members felt perturbed for their inability to celebrate festivals. They missed family gatherings also due to the illness of their near and dear ones. There was a feeling of sadness associated with such impossibilities by most of the relatives and patients. Most of the attendants and patients narrated these undesirable experiences on their own with tears rolling down the eyes. The narratives of Ms Pitta in Chapter 8, *"We had forgotten the excitement of social gatherings and festivals. Even on Diwali, we were not lighting a single Diya. Every festival emerged with sadness and despair for my family. On every festival, my husband and I would be in the hospital for dialysis begging for two days life and my children would be at home".* In Chapter 6, *the* narratives of Ms F, *"My mother feels like calling all the recipients of my father's organs. She would like to call the one with his transplanted heart on my marriage". It speaks of the importance of festivities in the lives of people during life and after death as well.*

The birthday was considered an opportune moment for pledging to donate organs, donating BSD donor organs and a good omen for organ transplant surgery too. The narratives of non-organ donor respondents in Chapter 12 like Ms Nodk and Ms Nodl, *"I have decided to pledge on my birthday"* reveal the importance of birthdays. Similarly, the narratives of Ms. A in Chapter 6, *"God had provided a great opportunity to my mother on her birthday. She donated life through her son's organs and felt she is doing good to others"* reveals the importance of birthday for BSD organ donation. Similarly, for Ms. Mitta, getting a BSD donor kidney on her recipient husband's birthday seemed a good omen. She felt God had gifted him a new lease of life on his birthday.

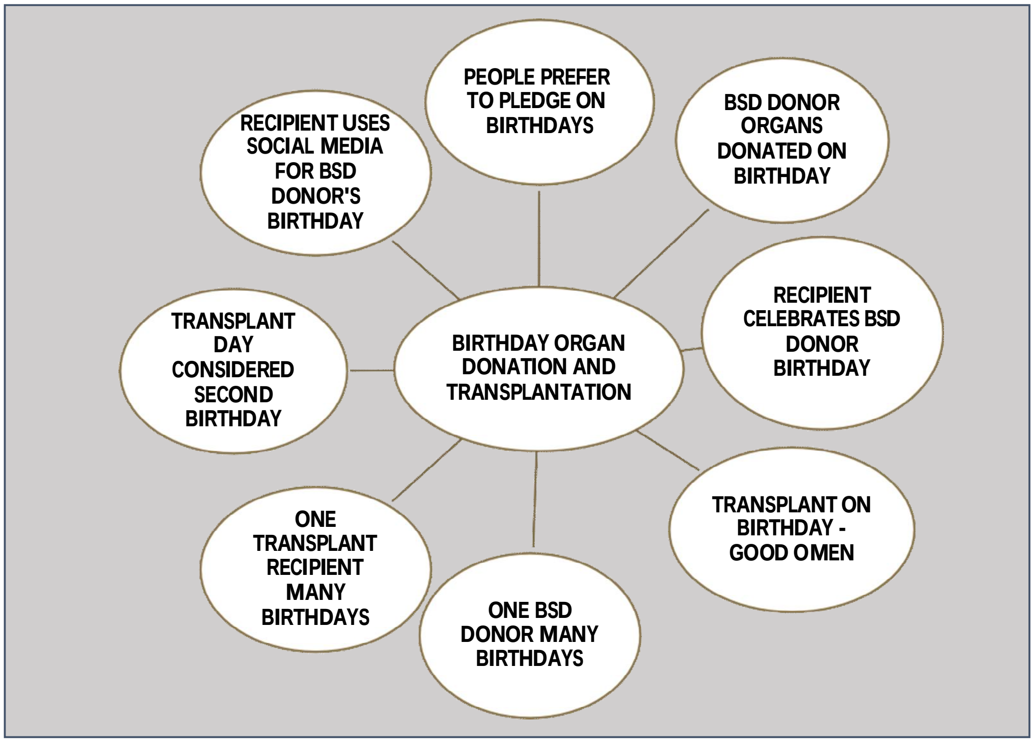

Figure 13.2 Revealing importance of birthdays in organ donation and transplantation

Festivities were also a unique opportunity for the mutual celebration by BSD donor families and recipient families with a fantastic mutually satiating feeling. There were pleasant visits made to donor families by recipients on festivities and vice versa. Donor's birthday was celebrated with the recipient and recipient's birthday with the donor family.

When Pitta celebrated her donor's birthday at his home, the mother of the donor felt her son celebrated his birthday after death as well. The donor family also visit the recipient on other festivities like "Bayya Dooj" and celebrate with her. Celebration and reciprocity by recipient families in the Facebook post was a real reward to the donor family. The donor family felt happy with reciprocity in the virtual world.

As reported by Mrs.Yl in Chapter 9, *"I have celebrated the 2nd birthday (referring to the transplant anniversary) with the hospital authorities on 10th March 2017".* Recently the recipient called the researcher and showed her resentment as the researcher had not wished her happy birthday on her 4th transplant anniversary.

India, is a multi-religious and multi-ethnic society, possesses a diverse, rich cultural heritage and is known as a 'land of festivals'. Its people believe in the celebration of festivals like Ganesh Utsava, Navratri, Diwali, Guru Nanak's birthday, Id and Christmas with gaiety and fanfare. These festivals bring cheer and happiness into a family that strengthens family and community bonds. Festivals also bear an impact on the healthcare system (Yeolekar and Bavdekar, 2007). Since time immemorial human beings have been celebrating their birthdays. It is essential not only to the celebrating person, but also to his or her family, friends, and significant others. The birthday celebration is a possible means of improving public mental health (Rojaka and Lesinskienė, 2018). The happiness and cheer are essential in managing people in any organization and hospitals are not an exception to it. Good governance should encourage the celebration of festivals for promoting efficacy, the bond of friendship, patriotism, national integrity and positive organizational behaviour among professionals and people in hospitals by organizing small events and cultural programme with tea and snacks (Goel, 2009).

Recipient Centric Issues

The patients adopt denial coping mechanism to deal with the disease and want to reverse the same. They are psychologically trapped to seek other modes of treatment to reverse the disease investing vast amounts without any respite. One recipient had, in fact, developed kidney failure as a result of seeking all other available treatment for bearing a child. Unfortunately, all such treatment failed both her kidneys without helping her to carry a child.

Dialysis was a significant concern of kidney failure patients and their families draining them physically and financially. Recipient-specific concerns regarding kidney transplant emanate from the restricted intake of water (one litre only) and salt when he is on dialysis. A person can consume only one litre of water and minimal salt when he is on dialysis. After successful transplant surgery, these restrictions ease. After a kidney transplant, a person can drink four litres of water and adequate salt. The time consuming, painful, inaccessible and unaffordable long duration of dialysis procedure in dialysis health facilities drains recipients and their families in all possible ways.

Recipients registered for cadaver donors were not able to reach in time for kidney transplants in most of the cases. There were many post-transplant issues also. These were regular follow -up, maintenance of the clean environment, taking immunosuppressants and consuming fresh foods only. But the major problem was leading a productive life. A person always wants to lead a productive life and contribute to family income and take care of himself. This area was problematic for waiting recipients and organ transplanted recipients as well. The morbid condition before transplant and post-transplant life was uncertain, especially with those recipients who either were looking for a suitable job or had no job security. Two of the recipients were in a depression and felt like committing suicide, and some were putting extra efforts to keep their employers happy to continue in the job.

The issue here is why the recipients should be denied jobs after transplant surgeries. Is it ethical to save a person and later create situations that make him unproductive? India has many politicians with kidney transplants who are governing the nation at ease and enthusiastically too. Denying jobs is not at all ethical and needs to be reconsidered with empathy.

Donation of Organs By “Other Than Near Relatives”:

Need to Restructure Viewpoint

Blood donation a lifesaving procedure has gained acceptance among the population, whereas altruistic living organ donors are viewed with suspicion mostly. The altruistic organ donation is not allowed in India barring a few States. The gift of organs within extremely willing “other than near relatives” is perceived with high suspicion. It was observed by the researcher during the study period while interacting with people and professionals.

Among 20 Organ Transplant Coordinators in Chapter 5, the majority, i.e., of 11 OTCs had donated blood to strangers. Only one OTC had donated blood to her family member. Further, one OTC had given blood 13 times to 13 strangers as reported by her from the age of 18 years. She had a rare blood group “A Negative” and volunteered to be a generous blood donor whenever required by strangers. Another OTC had donated blood four times to strangers. These altruistic blood donors did not mind giving blood to strangers. Similarly, there was no significant difference regarding their expressed willingness to donate organs for family members or to others as the majority of 12 OTCs were willing to do so for both.

This trend was seen among 30 organ donor card holders also. In Chapter 11, the majority, i.e., 11 had donated blood to others, but only four respondents had donated blood to near relatives. Also, there was not much difference between 24 and22 respondents willing to give organs during life to family members and others outside family out of love without anticipating anything in return, respectively.

Among 30 non-organ donor respondents in Chapter 12, while five had donated blood to others, only three respondents had donated blood to near relatives. Again, there was not much difference between 21 & 19 willing to give organs during life to family and others outside the family, respectively. Hence all “other than near relatives” may not be commercial donors under such circumstances.

We don’t mind if a person is generous blood donor as many times as possible, but selfless acts of people concerning organ donation are always suspected. It is not always that family members are supportive, and all others are not. Even within the family, there are societal pressures exerted on women to donate organs. In Chapter 10, Mitta’s story reveals how her life full of struggles with gender suppression got the support of her friend only. Her parental family denied any help from India and advised her to accept fate in a foreign land. Her friend in India ensured her evacuation from a foreign land. Her friend gave her a new lease of life by facilitating removal from a foreign land while her mother denied any support. Friend’s support continued with the struggles of Mitta. Her friend stood through thick and thin with her. She motivated her to be bold, fight the system and stood supportive in her tribulations. Mitta got weakened by the aggressive social environment of which her mother formed an important part.

With these findings, we need to reconsider our viewpoint for altruistic organ donors as well. During blood donation camps, people voluntarily donate blood for love of humankind. Likewise, living philanthropic organ donors could donate an organ purely out of charitable purposes with no expectation from the recipient. In the UK, one chain of 10 kidney transplants over eight months was made possible with the entry of one single altruistic kidney donor (Rees Michael A et al. 2009). The number of such philanthropic donors is increasing in the UK (NHSBT, 2014).

India has been very careful and has not permitted living altruistic organ donation so far owing to the mounting organ trade rackets disclosed almost every year. The “Authorization Committees” are unusually careful while assessing donor-recipient pairs even in cases of very near relatives. Altruistic organ donation can be allowed in India by ensuring confidentiality of donor and recipient pairs (Dar and Dar, 2014).

Wastage of BSD Donor Organs: Outcome of Adherence to Strict Rules

Heart transplants transgress not only State boundaries but social boundaries as well. Media creates hype when the heart is transported from one State to another, creating many green corridors also. Transportation via airways does not take less than ten lakhs, usually. Regarding heart transplants, the top officials at NOTP revealed that hearts are given to foreigners in Tamil Nadu and not to Indians. There could be a possibility of such transplants. The heart needs to be transplanted within a time interval of 4 -8 hours maximum but earlier, the better. Working within narrow time frames could be the possibility of such hearts going to foreigners who come for heart transplants in Tamil Nadu. The transportation of heart from one State to another is an extremely costly affair as reported by many officials at NOTP.

In one case, one hospital requested DGHS for approaching Army Head Quarters for engaging Pawan Hans services for airlifting a heart from Chandigarh to other State. DGHS, having put a request to army headquarter for the same, was informed at once that they understand, DGHS shall bear the amount of 10 lakhs for each sortie. The DGHS quickly withdrew its request.

It shall be better if a heart goes to a foreigner rather than getting wasted. Figure 4.29 reveals that ten hearts shared with NOTTO by 6 States remained unutilized during 2016. In addition to it, two multiple organs (two lungs and heart together) as explained in Figure 4.30 also could not be shared by NOTTO.

There was a piece of news circulating in various WhatsApp groups that nine hearts die in 10 days during August 19-28, 2018 in a top organ lab amid a shortage of donors. This news was referring NOTTO as organ lab. The wastage was due to logistics reasons and non-availability of appropriate blood groups in various institutions that were offered hearts by NOTTO as reported by Director NOTTO. As per THOT Rules 2014, sec 31(4)(e), all organs are supposed to be allocated based on Hospital-based list first (considering Indian patient only). If a suitable recipient is not there, the heart goes to the State waiting list and then to Regional waiting list, then to National waiting list at NOTTO. At NOTTO the organ will be considered for a person of Indian origin first and if none is available then only it may go to a foreigner in the hospital. Following this procedure is too difficult, time-consuming and cumbersome for an organ like the heart. The heart may not find a recipient within a small-time frame and maybe wasted without getting transplanted as has happened during 2016 and 2017. People show patriotism for the sharing of organs like the heart. However, such patriotic feeling may end in wastage of organs, and none of the donor families would like the heart to get wasted. The hearts need to be transplanted within a State no matter it may go to a foreigner and following the rule as mentioned above, may only result in wastage of organs.

Issues With “National Organ and Tissue Donor Registry”

Organ and Tissue Donor Registry is a web-based registry. It records the choices of its citizens regarding their will to donate organs or tissue or both after their death/ brain death (Dar and Dar, 2014). NOTTO has registered 155243 people as on 7.10.2018 in this electronic registry. It has issued cards to people who have pledged to donate either tissues or organs or both. The efforts of various networks and people have also been consolidated by registering their registered donors with this national web register. The efforts are on to increase the number of such donors.

Lack of trust in medical fraternity and lack of acceptance of BSD as complete death were two significant concerns for not pledging to donate organs by many non-organ donor respondents as revealed in Chapter 12. The same was corroborated by FGD findings with 11 respondents as well, wherein nine (9) respondents depicted a lack of trust in medical fraternity based on their personal experiences. They had experiences of different nature like surgery advised was not required, private hospitals indulged in commercialization and levied irrational costs. A few faced inaccuracies in diagnosis and prognosis as well. Others found inefficient observatory skills of medical practitioners and unreliable medical tests.

Similarly, in another Focus Group Discussion on acceptance of BSD for organ donation, all 15 respondents had a very positive attitude towards organ donation. But most of the respondents believed they would only donate if they are completely dead or alive. Brain death was not at all considered as death by this group of students.

A person, while making a will to donate organs needs to be well-aware. Pledging to donate organs does not guarantee that the person was well-aware of BSD organ donation as can be revealed in Table 13.3 below after amalgamating data of Table and Table 12.2.

Table 13.3 Classification and distribution of organ donor card holders (N=30) and non-organ donor respondents (N=30) based on their scores obtained in understanding Brain Stem Death (Maximum Scores =11)

Form 7 of THOT Rules-2014 filled for organ donation or not	**THEY KNOW**		**THEY DON'T KNOW**	
	Scored 9-11 Marks		**Scored 5-8 Marks**	**Scored 0-4 Marks**
Distribution of 30 organ donor card holders	**"Well Aware Genuine"** Organ Donors **N=7(23%)**	**"Well Aware Fake"** Organ Donors **N=2 (7%)**	**"Less Aware"** Organ Donors **N=13(43%)**	**"Unaware"** Organ Donors **N=8(27%)**
Distribution of 30 non-organ donor respondents	**"Well Aware Genuine"** Non-Organ Donors **N=5(17%)**	**"Well Aware Indecisive"** Non-Organ Donors **N=4(13%)**	**"Less Aware"** Non-Organ Donors **N=15(50%)**	**"Unaware"** Non-Organ Donors **N=6(20%)**

Table 13.3 reveals that majority of organ donor cardholders or non-organ donor respondents who had either pledged to donate organs or had not done so had scored fewer marks.

Among 9(30%) well aware organ donors who had scored 9-11 marks, only 7(23%) were genuine, and 2(7%) were fake organ donors. Two (7%) fake organ donors knew such pledge has no legal standing and were not willing to donate either.

Similarly, among non-organ donor respondents, only 5(17%) were genuine non-organ donors who had scored 9-11 marks with no intention to donate organs. The remaining 4(13 %) were indecisive.

The less aware 13(43%) and unaware 8(27%) organ donor card holders constituted majority 21 (70%) of respondents. Similarly, among non-organ donors, 15(50%) were less aware, and 6(20%) were unaware respondents. They also constituted a majority, 21 (70%) of respondents.

Now thinking that 70% organ donor card holders who were either less aware or unaware are willing to donate organs is a farce. In such cases, shall it be ethical to shape the opinion of their families to donate organs, in case a situation arises?

Similarly, people who had not pledged have not said no to such organ donation as is usually given the impression in research articles. Only a few non-organ donor respondents stated they would never give any part of the body after death. There were other concerns of these respondents revealing a lack of trust in system /doctors and non-acceptance of brain death. While some said BSD is 'legalized murder' others believed it is 'active euthanasia' for organ donation. A few believed that perspectives keep changing, and any false promise at present is not ethical. Others revealed family concerns and aversion to an idea of bodies getting cut in pieces after the death. A few also revealed a religious belief that they have to report to "Chitragupta" in another world after death with all body parts intact. But most of them wanted time to decide. In other words, pledging or not pledging to donate organs does not give an accurate picture of societal intentions. It shall be better if we stop blaming people for not pledging to donate organs.

Fascinatingly, majority 20(67%) of organ donor respondents who had pledged to donate organs didn't mind if family members override their Will as revealed by them in Chapter 11. They thought that family should make their own decision at the time of the BSD declaration.

Also, in Chapter 6, it was the wish of the donor families that mattered in the donation of organs and not the registered will of the donor. Out of 14 BSD donors, only one donor had pledged to donate organs.

Because of the above findings, it is not at all sane to work tirelessly to make people pledge organs and tissues.

Policy Level Implications

There are enumerable medical, ethical and social issues with organ donation from BSD donors. Hence it cannot be accepted wholeheartedly. We cannot abandon it also, as it has helped people all over the globe by alleviating their sufferings and giving them life. It must be made socially and ethically acceptable.

In this study also, the in-depth case studies of Ms Pitta and Ms Mitta reveal how a BSD donor rescued these families in the crisis. Pitta's story is heart-wrenching. Her family struggled to keep her alive with dialysis. While Pitta, along with her husband, would be in the hospital for dialysis sessions in the night, the small children would be at home and go without food for days together. Her treatment drained family financially, physically and emotionally. For them, the BSD donor was a **"Messiah-of-God".** A BSD organ donor prevented Pitta's children from becoming orphan and helped the family to overcome financial crises. His donation helped Pitta to drink plenty of water and take salt as well that was restricted by doctors during six years of her ordeal with dialysis. One organ of a BSD donor could do so many things; we could imagine the impact of other organs and tissues on other persons. Pitta's donor family developed a healthy relationship with her. They feel blessed that Pitta has kept their BSD donor alive, the primary purpose of such donation as revealed in the study. The case study of other liver and heart recipients also acknowledge the importance of BSD donors in their lives. These recipients would have continued to suffer like hell, had BSD donor's organ not been transplanted. We need to make it acceptable to donor families and recipient as well. We must weigh the balance between too. The people involved in such donations and retrievals also face stresses. The processes must be smoothened to make it more acceptable, and NOTTO needs to form clear-cut guidelines for the country to follow.

Seven families were self –motivated and comprised 50% of the study population among BSD donor families. Their main aim was to keep the donor alive by donating his organs in other person's bodies. No one wants a near one to die. In some cases, when a family is given a choice to keep him alive most of them cannot forgo such a viable offer and decide in favour of organ donation. But whether donor families get adequate information about this death and processes of organ donation in Operation Theatres raises ethical questions. Let people make informed decisions. Let us tell them all about the methods of organ donation, including the use of muscle relaxants during organ retrievals. Not everyone will accept to donate organs, but whosoever does, shall do so wholeheartedly without getting a feeling of trapped into the donation. It would prevent professional stresses, as well. Some people don't recognize this form of death; let us not impose our thinking on them. We need to be considerate to them also as they believe in what has been taught to them and learnt by them. BSD is a new form of death not heard and not absorbed by most of the people and professionals. Absorption of this new definition of death shall take time. We are not going to do wonders with organ donation. Not crores of lives will be impacted by coercive measures if adopted in India. Globally less than 1. 5 lakh solid organ transplants are done per annum.

The study reveals the unethical trap of private hospitals that trap BSD donor families as well as recipients. Hence, we cannot say everything is going on well with organ donation from BSD donors. These transplant surgeries are costly surgeries, not within reach of the ordinary person. It is mostly the rich who would benefit through these transplants.

Now, the question is should we accept it, or should we abandon BSD donation. The answer lies in saying that we cannot take it the way it is going on and we cannot leave it also, as it has been helpful. Now the question comes who will decide. Let people decide at the time of BSD declaration only after they are told everything regarding the importance of BSD declaration. Let it be linked with the removal of ventilator support and not with organ donation only. There are many policy level implications for the study, as discussed in this Chapter.

The study reveals that there is an intense need to think beyond organ donation and transplantation when it comes to the population overall. The national focus should be on eliminating poverty, reducing disparities, giving equal status to females, grooming women to be more assertive in life, removing gender bias and gender discrimination in society. Till that time, poor, oppressed or females will be exploited both for living as well as BSD organ donation.

However, in the context of this study on organ donation and transplantation, there is a need to ease the process of organ donation that ensures transparency and eliminates unethical trap. Some of the issues in the context of BSD declaration identified need rectification and a few others need relaxation too. Further, to reduce the sufferings of poor people, there is also a need to relax rigid living organ donation norms for "other than near relatives". We need to resolve issues with several conflicting laws. There is an urgent need to recreate new ways to alleviate sufferings of poor people by increasing Govt. funded dialysis centres; initiating swap and domino transplants and improving infrastructure.

Policy Level Decisions Regarding BSD Donation

A few suggestions in view the medical, legal, ethical and social issues of organ donation from BSD donors are:

Restrictions and Rectifications for BSD Donation

Keeping in view the problems identified in the context of BSD declaration, there is an urgent need to smoothen the process of organ donation. It could be achieved by eliminating ambiguity at various levels, putting certain restrictions and rectifying specific issues as well. There is an urgent need to build consensus at all levels regarding definitions and procedures. Setting a standard operative system of organ donation from BSD donors and keeping checks in BSD donation is essential. Besides making EEG a must and developing robust rules to prevent unethical trap are a few other requirements also. NOTTO has a responsibility to take corrective measures for the following: -

For Organ Sharing Networks All Over the Country

- Building Consensus at all levels calls for having consensus on all the definitions, procedures etc. at all levels. NOTTO should initiate this activity and provide links in its website for its followers only.
- The same should get portrayed in all organ donation and transplantation websites, including NGOs and organ sharing networks of India.
- The "Appropriate authorities" must be taken into confidence for getting this done.

For BSD Donors

There is an urgent need to set a standard process of organ donation from BSD donors.

- Brain Stem Death certification should start with taking written permission with an adequate explanation for doing the first “Apnoea Test” from donor families.
- The purpose of doing the “Apnoea Test” with clear instructions about the second diagnosis also should be mentioned to them. Let family decide either for organ donation or for discontinuing ventilatory support.
- The relatives should not be trapped into a donation and should have the option to stop ventilatory support.
- This procedure if not followed, should be linked with the cancellation of licenses by "Appropriate Authorities".

For Licencing Authorities and NOTTO

- There is a need to keep checks in BSD donation as is done in living donation.

- We need to think of making video recording mandatory for the whole procedure twice, in case of BSD declaration of death.
- Some remedial measures are required to prevent people from falling prey to the commercial intention of private hospitals.
- Make EEG a must for confirmation of such deaths. It could prevent misuse of this definition of death and can give direction to people also who need to give consent for organ donation. A flat EEG has the potential to convince the donor family the way ECG does. India follows BSD criteria, and EEG is not required at present.

For living donor-recipient pairs, there are a lot of checks to prevent financial transactions. The donor-recipient interviews are video recorded also, but such financial gains from BSD donors in private hospitals have been ignored so far. There is no video recording of the process of the BSD declaration. The economic benefits of private hospitals trapping donors and recipients cannot be overlooked as can be viewed in Chapters on donor families, OTCs and recipients.

For Recipients

- Developing robust standards that could prevent trapping of poor people in hospitals. Liaising with appropriate authorities to cancel the registration of hospitals who don’t share data with NOTTO, SOTTO or ROTTO or share misleading data with these networks.
- Data by these networks also need to be entered with the utmost care and after proper verification only.

Relaxation of Certain Norms in BSD Donation

Irrespective of all the debates and dilemmas surrounding BSD donation, such donations were accepted by donor families wholeheartedly. Transplantation of BSD donor organs had given hope to many families besides giving life to so many people. Also, most respondents preferred BSD organ donors in comparison to living organ donors and did not want to accept the consequences of organ failures. Majority

28(93%) organ donor card holders were willing to get BSD donor organs for their family members and 21(70%) for themselves as revealed in Figure 11.12 and Figure 11.15, respectively in case the need arises.

Similarly, majority 26(87%) non-organ donor respondents preferred to get organs for their family members from BSD donors and 18(60%) for themselves if required in future as revealed in Figure 12.12 and Figure 12.15, respectively. It calls for relaxing certain norms as well in organ donation from BSD donors like: -

Allowing donation of one organ to "near relatives "or "other than near relatives" can be done to give meaning to such donation. The same was supported by 26(87%) organ donor card holders and 25 (83%) non-organ donor respondents as revealed in Figure 11.23 and Figure 12.23, respectively.

The burden of documentation can be reduced, so that donor family are not put in trouble when they are grieving as reported by OTCs.

Reducing the burden of financial investments by donor family's needs consideration. Financial aspects also need to be relooked for poor patients, especially. The hospitals follow different policies, as was reported by transplant coordinators in Chapter 5. Very few hospitals waive the previous bills, but most of the hospitals don't do so. However, financial investments of any kind from family after giving consent to donate organs is stopped at once by many hospitals that should be made mandatory for all hospitals.

There is a need for reducing the number of death declaration team to 2-3 doctors for more feasibility. The case studies point to the problems faced by professionals in diagnosing this death as it requires the cooperation and presence of 4 medical practitioners twice at a gap of at least 6 hours. There is a need to reduce the number from 4 doctors to 2-3 doctors to make it a feasible procedure.

Using white code for BSD declaration needs to be debated and considered as a policy level decision. The narratives of OTCs regarding involving four team members, one of whom is the Head of the hospital at two consecutive occasions in a bustling Government hospital at times becomes difficult. It leads to frustration and inconveniences among professionals and relatives too who give consent to donate organs. It could be avoided to using the white code in hospitals, as suggested by one of the key professionals who had encountered such a problem.

Common concerns of donor families should be addressed through print media in ICUs Many fears are depicted by donor families when confronted with the request for organ donation by OTCs. These are about ethics, knowledge, consensus issue, religious issues, finances, intrafamily donation, time requirements, recipients of donor organs, the beauty of the donor body, future of the donor and documentation requirements. It may be essential to develop a booklet and audio-visual material for donor families that could address some of the issues by ethically answering their queries.

Policy Level Decision for People

Policy level decision for common people should focus on creating awareness and setting aside the priority of registering more people in Organ and Tissue Donor Registry. There is an urgent need to evade pressures to introduce Presumed consent system in place of Opt-in system.

There is a widespread lack of knowledge about this form of death as can be revealed in most of the Chapters of the study. Increasing awareness about organ donation from Brain Dead Donors through awareness programmes needs emphasis. These programmes should not only focus on people, but ICU Doctors and professionals also to help them understand this form of death. This form of death needs to be inbuilt in the curriculum at various levels.

Many organ sharing networks give a lot of importance to donor families and recipients as well. It shall be worthwhile to take donor family-focussed initiatives like making a documentary on donor families and giving social recognition to them. The donor families and recipients can be involved in awareness programmes. The public should be made aware that BSD donor families are not paid for organ donation to prevent social ostracism of these families. Fake media messages are in circulation wherein people approach recipients to come for BSD donor organ making them believe that they have a donor in the hospital. People need to understand that the BSD donor family has no authority to call recipients for organ allocation in the hospitals. The organs are transplanted as per the waiting list and not as per the wishes of the donor family. The IEC messages should communicate the same to the public.

Most of the patients fall prey to Ayurveda and other systems of medicine. They do so to reverse the disease as guaranteed to them and narrated by many recipients like Mr Fr, Mr H & many others in Chapter 7 and Mr Xl in Chapter 9. We need to develop IEC messages to prevent them from such trapping and financial loss as well.

NOTTO has started a National Organ and Tissue Donor Register (Dar and Dar, 2014) that registers the will of people to donate organs and tissues. NOTTO is putting a lot of efforts to register more people as per the observation made by the researcher. But keeping in view the Indian scenario at present it shall not be worthwhile to put a lot of efforts to register the will of the people. Such efforts are not going to give fruitful results and have the potential to be misused in private hospitals. In the presence of confusion about this death, the reluctance of hospitals to share data, trap by private hospitals, it shall not be ethical to register the will of people. Besides a lack of understanding about this form of death even after well-organized awareness programs conducted by NOTTO as revealed in Table 13.3 questions the authenticity of “organ donation will” of such misinformed people. Such efforts are not going to give fruitful results and have great potential to be misused in private hospitals.

We need not focus on getting such wills registered. In the absence of such registered will, families still can decide to donate organs as had been done by most BSD donor families 12(86%) in the study as revealed in Figure 6.4 of Chapter 6.

People all over the globe pledge to donate organs /tissues in organ donor registers and India wants to do the same. Millions of people have registered as organ donors in the UK and USA as well (NHSBT, 2014; UNOS, 2011). Getting people registered from the various organization without knowing whether these people had pertinent information regarding this form of donation shall amount to the unethical trap of donor families.

There are soft pressures to initiate the presumed consent system of organ donation in India. Most of the respondents were sure of misuse of presumed consent in the private sector. We need to oppose this option vehemently keeping in view the resistance of transplant hospitals in sharing data with NOTTO, a trap laid by private hospitals, not for organ donor families only but recipients as well. This option is anti-people, anti-poor, unethical and can only encourage money-making business in private hospitals.

Policy Level Decision for Recipients

Policy level decision for transplant recipients requires regularizing market for the cost of treatment. There is a need to eliminate confusing terminology, taking consent of families before interstate organ transportation and focussing on “Organ Transplant Registry.”

The costs of procedures and surgeries in transplant hospitals are unregulated for people all over the country. It needs to be regularized.

People all over the country should be given proper information, and misleading and ambiguous terms need to be avoided. We need to register recipients for BSD donors and eliminate cadaver word as for most of the people cadaver is a dead donor at home or in the mortuary. Most of the professionals also believe the same.

Private hospitals do not give adequate information to the families regarding the exuberant cost involved if the heart is transported from one State to another. Families should not be trapped and should be engaged before hospitals engage in organ transportation of any organ from one State to another. Also, such transplant surgeries need to be done only after getting consent from the recipient family. Withholding bills and putting recipient families in trouble is not at all ethical and speaks of the unethical trap laid by the private hospitals. There is an urgent need to take concurrence of people for interstate transportation of any organ before initiating the process of procurement. Whenever recipients register in private hospitals for cadaver organ, it should be mandatory to ask them whether they shall bear the cost of transportation of organ also.

The NOTTO Transplant Registry is a web-based registry that aims at capturing and integrating all the essential information related to various solid organ transplants. This data concerns kidney transplants, liver transplants, heart transplants etc. from all the registered organ transplant hospitals of the country via SOTTOs and ROTTOs. Transplant Registry involves data maintenance of both living and deceased donor organ transplants.

However, a Key member of a transplant institution can have access to data of its institution and can edit, update and upload the data. The integrated national or regional data can also be viewed, but these individual centres will have no access to data from other institutions. Confidentiality regarding other institutional data is maintained.

NOTTO has already initiated this web-based Registry and hospitals have registered their recipients who are waiting for an organ transplant from BSD donors only. The hospitals do not yet share the living donor transplants on this Registry as per the Key person associated with NOTTO.

The main aim of the National Transplant Registry is to assemble transplant-related data from all registered transplant health facilities in the country. The data shall be gathered from time to time to derive pertinent information. This Registry would help in understanding short-and long-term outcomes in the field of transplants and assist in research as well.

There is a need to eliminate confusion regarding this register also. In addition to NOTTO initiated Transplant Registry, there is one more National Transplant Registry, i.e., Indian Transplant Registry of Indian Society of Organ Transplantation (ISOT) supported by Astellas Pharma India Pvt. A common man may get confused as to which one is authentic and reliable as the mandate of both these two registries is the same.

There is an urgent need to focus on this register rather than on “Organ and Tissue Donor Register” to have access to country-level data. The data entered by transplant hospitals also need to be verified, and data gaps checked and filled with precision. There is also an urgent need to update data regularly.

Policy Level Decisions for Living Donation

Living donors cannot be ignored, and we need to take policy-level decisions for them as well. There is a need to provide insurance cover to all living donors. Dealing with gender issues with the utmost care and relaxing norms for living donation from “other than near relatives” and encouraging altruistic organ donors is the need of the hour. There is a need to focus on maintaining “Donor Follow-up Registry”, also.

It is essential to do health insurance of living donors as many other countries like Israel, and Singapore does. It should be mandatory to do so before the donation of organs even if it involves a near relative.

Gender issues are ingrained in organ donation. Women living donor require extra caution before allowing them to donate organs.

There is a need to reform viewpoint regarding the donation of organs by "other than near relatives". Blood donation a lifesaving procedure has gained acceptance among the population, whereas altruistic living organ donors has not. Generous charitable organ donation mostly raises suspicion from a commercial angle. Philanthropic organ donation is not allowed in India barring a few States. And organ donation by extremely willing "other than near relatives" is perceived with high suspicion. It was observed by the researcher during the study period while interacting with people and professionals.

Living organ donation by “near relatives” and “other than near relatives” requires donor follow up register to understand long term health outcomes of such donations. It can give direction to living donors to donate organs. It is vital for maintaining trust in the system of living organ donation.

At present, the comprehensive data to assess risks by living organ donors before organ donation is unavailable. It makes it impossible for living organ donors to evaluate the risks before making decision for organ donation.

Donor follow-up registry is one of the initiatives to be taken by NOTTO to ensure transparency in establishing long-term health effects of all living donors in the country. Follow- up registry is essential for altruistic living organ donors also to enable them to weigh the pros and cons of such donation before they decide to donate. Altruistic living organ donation is allowed in Kerala. As on date, the donor follow-up registry is yet to be initiated at NOTTO.

Policy Level Decisions for Training of OTCs

The training programme of 5 days duration was not adequate. There is an urgent need to increase the length of training for OTCs for providing skill-based training as reported by them. There is also a need to conduct training programmes for ICU doctors in all hospitals regarding BSD declaration.

Policy Level Decision for BSD Donor Families

For BSD donor families, there is a need to reveal recipient identity, arrange funds for poor and to provide reasonable Incentives for the BSD donor family.

It may be essential to reveal recipient identities. Such a revelation could encourage and motivate others to donate organs. It would offer an opportunity to donor family to see their loved one living in others that could be satiating to both the families. Besides, it shall provide an opportunity for social integration.

Many needy donor families donate organs for the welfare of society. It is needed to arrange funds for low-income families by creating a corpus of funds involving NGOs, CSR funds and organ recipients for providing financial support to family/ spouse/children of donor.

The donor families also need to be offered health-related incentives like health insurance, free treatment in hospitals where donation took place, social recognition etc. Organ donation and transplantation require consolidated efforts of other ministries also. Hence inter-ministerial networking for organ and tissue donation and transplantation was initiated way back in 2016. In this regard, the inter-ministerial committee was constituted to coordinate all activities related to the promotion of organ donation in the country, and the first meeting held on 18.2.2016 as revealed in Chapter 4. Social support, financial support and certain concessions for donor families were recommended. The same has not been followed later and needs to be followed up.

Conclusion and Recommendation

Brain death is a new, neurological definition of death that is only 50 years old definition of death. This new definition of death takes us away from the traditional to the neurological explanation of death. In the former, the heart stops beating, whereas in the latter the heart continues to beat even after death declaration. The latter becomes difficult to accept by people and professionals alike. Unfortunately, Brain Stem Death in India is linked to organ donation and transplantation only and has no other implication. This death is not confirmed, or the second diagnosis denied if relatives refuse to donate organs. In other words, this death is declared for organ donation only and not for cremation purposes.

The professional and people are equally ignorant about this new definition of death. They are under the impression that organs are donated after the heart stops beating as is the case with eye (tissue) donation. The medical and nursing students are not taught this topic in their curriculum. BSD can only be declared in ICUs of registered organ transplant hospitals. However, a few negligible numbers of registered Non-Transplant Organ Harvesting Centres (NTOHC) can also do so in India. This form of death can neither be declared in the home nor in an ordinary hospital. After the BSD declaration, consent from the family is taken, and the donor is shifted to the operation theatre for organ retrieval. Organs are retrieved under the supervision of anaesthetic team like any other surgical procedure done on a living person. All this information is withheld from BSD donor families.

There is no consensus regarding definitions and procedures of organ retrieval from BSD donors either at the international level or at the national level. And in the current scenario, the paramount need is to strengthen NOTTO and give it more autonomy, besides strengthening public infrastructure to alleviate sufferings to poor people.

The media creates hype regarding the excessive number of organs needed for transplantation in India. But that does not get depicted in the data shared by transplant hospitals with NOTTO. Data collected by NOTP, DGHS in 2011 may not be accurate as recipients register themselves in many transplant hospitals for a BSD donor organ. The current study revealed that a single recipient, registers at various hospitals for a BSD donor organ. The same could have led to an exaggeration of data.

Kidneys are much more in demand as compared to other organs, and 97% of organ transplant hospitals are doing kidney transplants. The chances of wastage of livers and hearts, including all other organs, are more as such transplant hospitals, are less in number all over the country and are not evenly distributed. Transportation of such organ in case of interstate transplants needs a lot of human resources and infrastructural inputs. Besides, it makes the costs of such transplant operations exuberant that can only be afforded by highly affluent people. There are a lot of inherent problems and societal confusions in the context of BSD and organ donation, and there is an urgent need to eliminate the same. Some of the issues in the context of BSD declaration identified in the study need rectification while a few others need relaxation too. Problems with conflicting laws need to be resolved as well, as has been discussed in policy-level implications.

Lack of clear-cut legal guidelines for withdrawing or withholding life support needs to be the focus area of NOTTO. It calls for a comprehensive discussion at the national level to address the ethical, legal and medical issues involved therein and arrive at a clear policy. NOTTO needs to focus on building a national consensus on procedures after rectifying specific processes and relaxing others to ease the process of organ donation. It shall ensure transparency, address professional stresses and prevent the trap of donor and recipient families. The legal, medical, social and ethical issues revealed in the study regarding the declaration of BSD and retrieval of organs need to be addressed by NOTTO. The commercial angle of organ donation and transplantation cannot be ignored in present circumstances when we have 85% of private hospitals indulging in such transplants within Delhi and NCR. The same may hold in other States as well.

The study reveals that organ donation from BSD donors is an unethical trap for many people for commercial gains. In fact, at times it is a dual trap, trapping BSD donor families on one side and organ recipients on the other side. BSD donor families are trapped to donate organs or continue futile exuberant treatment. The recipients are fooled to get a liver and heart transplant done. They are given underestimates, false assurances of 100 % recovery and asked for full advance payment for transplant surgeries with a BSD donor organ. The inability of recipients to pay the money as a result of such traps leads to withholding "bodies and bills" causing inconveniences to families. It is recommended to prevent such unethical trap and punish the offenders by cancelling the registration.

People who pledge to donate organs are not adequately aware regarding this definition of death. Hence such pledges cannot be used to convince families into the donation of organs at the time of BSD declaration as has been conceptualized while making rules. The non-donor respondents revealed apprehension with this new definition of death, while some did not trust medical fraternity others did not accept this new definition of death. One respondent even said that BSD declaration amounts to "legalized murder" or a legal murder. As revealed by OTCs, the same apprehensions were revealed by BSD donor families when approached for organ donation. There is a need to increase awareness without focussing on getting their pledges registered. Let families decide at the time of such declarations as was done by most of the BSD donor families in the study. It is essential as the majority of organ donor respondents who had pledged to donate organs wanted their families to have the last say in organ donation. Organ and Tissue Donor Registry is not a priority for NOTTO in the current scenario. Incidentally, NOTTO is primarily focussing on the same at present investing human resources and money.

Presumed consent should not get introduced, and NOTTO should not succumb to such pressures. Instead, there is an urgent need to regularize market for procedures, surgeries and investigations, eliminate confusion by registering recipients for BSD donors, taking prior consent from families for interstate organ transportation with information to NOTTO. NOTTO needs to focus on "Organ Transplant Registry" and "Donor Follow-Up Registry" rather than on "Organ and Tissue Donor Registry" primarily. It is recommended not to succumb to presumed consent instead focus on regularizing cost.

The study revealed that neither all living females are willing organ donors nor all "other than near relatives" are commercial donors. There is a need to restructure such viewpoint to reduce the sufferings of people by relaxing rigid living organ donation norms for "other than near relatives". There is also a dire need to recreate new ways to alleviate sufferings of poor people by increasing Govt. funded dialysis centres, initiating swap and domino transplants and strengthening Govt. infrastructure. It is essential to do health insurance of the living donors before the donation of organs and deal with gender issues with the utmost care.

The relatives are unable to celebrate any festival in hospitals that add to their sufferings. Hospitals could think of ways to involve professionals and people in small festival gatherings in the hospital as well.

There is a need to relook into the rotational system of organ allocation that is too cumbersome to follow. This procedure has led to wastage of organs and shall continue to do so if not rectified. It is recommended to relax rules to prevent wastage of organs.

Hospitals should not trap BSD Donor family into organ donation. They should also provide information regarding families who refuse such donation to NOTTO, ROTTO or SOTTO to do the follow up of such case and bring in transparency. We can think of revealing recipient identities to BSD donor families that could motivate more people into a donation and give meaning to the donor family. The study shows that a lot of donor families are devastated due to the death of the person whose organs gave life. It calls for raising a corpus of funds with CSR funds, NGOs, wealthy recipients and Governments to provide help to donor families in need.

There is a need to prevent OTCs from falling prey to unethical practices of private hospitals. NOTTO, SOTTO and ROTTO have a great responsibility to address their issues by withholding meetings and understanding their perspectives as well. The training programme of 5 days duration was not adequate. It is recommended to increase the length of training for OTCs for providing skill-based training as reported by OTCs.

Many recipients were denied jobs, as revealed in Chapter 7. Ms Mitta's husband felt terrible throughout his life for not getting a suitable job he deserved. How is it ethical to save a person and later create situations that make him unproductive? Denying Government jobs is not at all ethical and needs to be reconsidered with empathy for recipients. It is recommended to give equal job opportunities to recipients.

The study concludes that there are many issues with BSD declaration for organ donation that leads to non-acceptance and refusal of such donation by most people. There is an enormous number of problems deterrent to the donation of organs from BSD donors. But, at the same time, there are a few motivating factors too to donate organs of BSD donors as revealed in the study.

It shall not be immoral to say, "Brain stem Death is too 'Defective to Accept 'and 'Too heart-warming to be Abandoned'.

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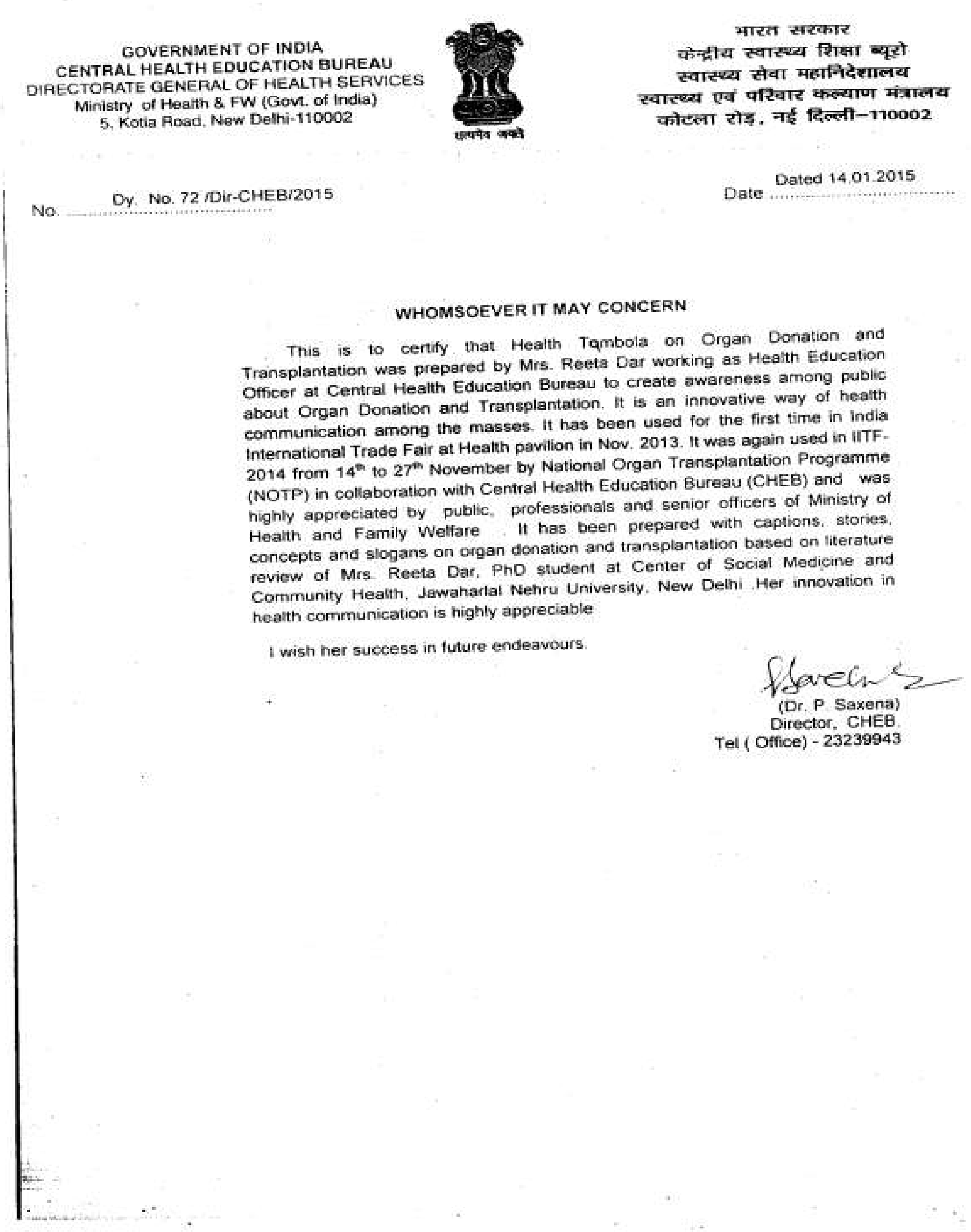
ANNEXURE 3.1

Subject:-Report of Director CHEB on "Tombola on organ donation and transplantation" an innovative way of health communication prepared by the Researcher



GOVERNMENT OF INDIA
CENTRAL HEALTH EDUCATION BUREAU
DIRECTORATE GENERAL OF HEALTH SERVICES
Ministry of Health & FW (Govt. of India)
5, Kotla Road, New Delhi-110002

भारत सरकार
केन्द्रीय स्वास्थ्य शिक्षा ब्यूरो
स्वास्थ्य सेवा महानिदेशालय
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
कोटला रोड, नई दिल्ली–110002

No. Dy. No. 72 /Dir-CHEB/2015

Date Dated 14.01.2015

WHOMSOEVER IT MAY CONCERN

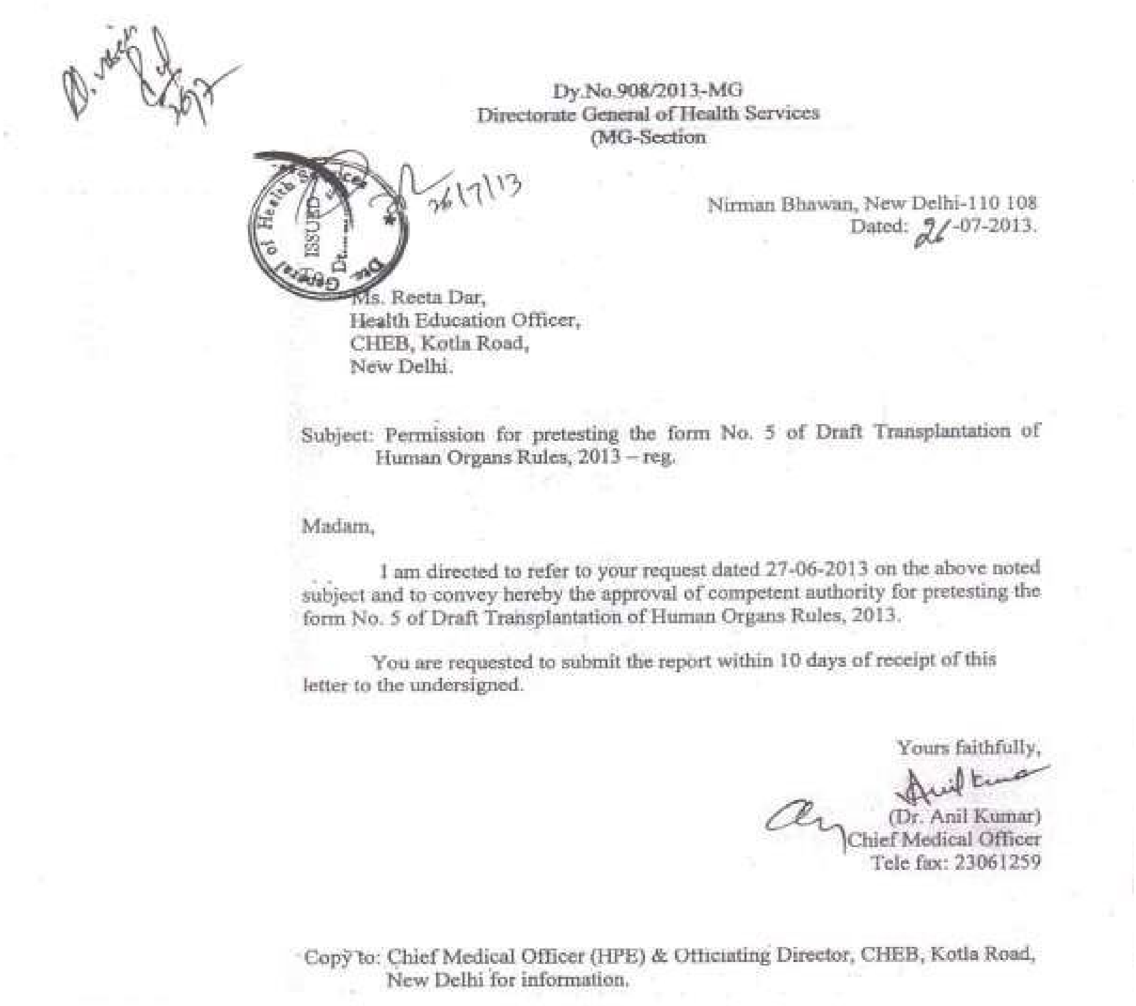
This is to certify that Health Tombola on Organ Donation and Transplantation was prepared by Mrs. Reeta Dar working as Health Education Officer at Central Health Education Bureau to create awareness among public about Organ Donation and Transplantation. It is an innovative way of health communication among the masses. It has been used for the first time in India International Trade Fair at Health pavilion in Nov. 2013. It was again used in IITF-2014 from 14th to 27th November by National Organ Transplantation Programme (NOTP) in collaboration with Central Health Education Bureau (CHEB) and was highly appreciated by public, professionals and senior officers of Ministry of Health and Family Welfare . It has been prepared with captions, stories, concepts and slogans on organ donation and transplantation based on literature review of Mrs. Reeta Dar, PhD student at Center of Social Medicine and Community Health, Jawaharlal Nehru University, New Delhi .Her innovation in health communication is highly appreciable

I wish her success in future endeavours.

(Dr. P. Saxena)
Director, CHEB.
Tel (Office) - 23239943

Annexure 3. 2

Subject: -Official permission sought by researcher for pretesting pledge form of THOT Rules and permission granted by NOTP programme



Dy.No.908/2013-MG
Directorate General of Health Services
(MG-Section

26/7/13

Nirman Bhawan, New Delhi-110 108
Dated: 26-07-2013.

Ms. Reeta Dar,
Health Education Officer,
CHEB, Kotla Road,
New Delhi.

Subject: Permission for pretesting the form No. 5 of Draft Transplantation of Human Organs Rules, 2013 – reg.

Madam,

I am directed to refer to your request dated 27-06-2013 on the above noted subject and to convey hereby the approval of competent authority for pretesting the form No. 5 of Draft Transplantation of Human Organs Rules, 2013.

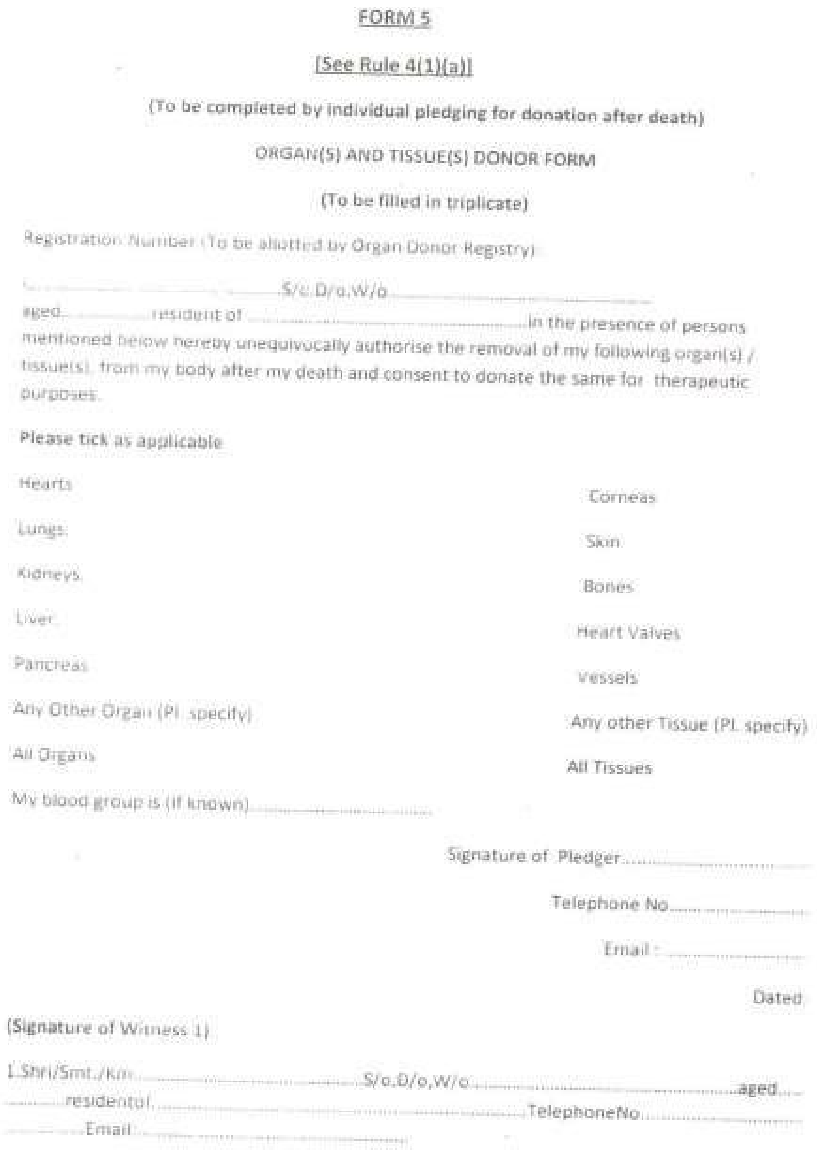
You are requested to submit the report within 10 days of receipt of this letter to the undersigned.

Yours faithfully,
Anil Kumar
(Dr. Anil Kumar)
Chief Medical Officer
Tele fax: 23061259

Copy to: Chief Medical Officer (HPE) & Officiating Director, CHEB, Kotla Road, New Delhi for information.

ANNEXURE 3. 3

Subject: -Pledge form 5 of THOT Rules 2014 before pretesting



FORM 5

[See Rule 4(1)(a)]

(To be completed by individual pledging for donation after death)

ORGAN(S) AND TISSUE(S) DONOR FORM

(To be filled in triplicate)

Registration Number (To be allotted by Organ Donor Registry)

I……………………S/o.D/o.W/o……………………

aged……………resident of……………………in the presence of persons mentioned below hereby unequivocally authorise the removal of my following organ(s) / tissue(s), from my body after my death and consent to donate the same for therapeutic purposes.

Please tick as applicable

Hearts

Lungs

Kidneys

Liver

Pancreas

Any Other Organ (Pl. specify)

All Organs

Corneas

Skin

Bones

Heart Valves

Vessels

Any other Tissue (Pl. specify)

All Tissues

My blood group is (if known)……………………

Signature of Pledger……………………

Telephone No……………………

Email : ……………………

Dated

(Signature of Witness 1)

1.Shri/Smt./Km……………………S/o.D/o,W/o……………………aged……
……residentof……………………TelephoneNo……………………
……Email……………………

Annexure 3. 4

Subject: -Letter of commendation by Addl. DDG, Nodal officer for NOTP Programme

DR. ANIL KUMAR
M.D.
Addl. DDG
Telefax : +91 11 23061329
E-mail : dr.anilkumar@nic.in

सत्यमेव जयते

Directorate General of Health Services
Ministry of Health & Family Welfare
Government of India
Room No. 560, 'A' Wing, Nirman Bhawan,
New Delhi-110 108

Dated 11.04.2018

LETTER OF COMMENDATION IN FAVOUR OF REETA DAR
HEALTH EDUCATION OFFICER

Mrs. **Reeta Dar Health Education Officer working at Central Health Education Bureau (CHEB), Dte.GHS, MoHFW has done commendable work in organ donation.**

She has prepared an innovative game "Tombola on organ donation and Transplantation" a revolutionary way of health communication that was introduced in Health Pavilion in India International Trade Fair (IITF-2013) for the first time. Her innovation in health communication is highly commendable. She also participated in other awareness activities related to organ donation.

She as part of CHEB carried out pretesting of the Form 7 of Draft Transplantation of Human Organs and Tissue Rules (THOT Rules). The findings of her pre-test on 200 professional nursing and medical students of various colleges were submitted to National Organ Transplant Programme (NOTP) Cell in Dte.GHS. Her findings and recommendations were very useful and utilised for finalising Organ Donation Pledge Form (Form 7) in final THOT Rules 2014.

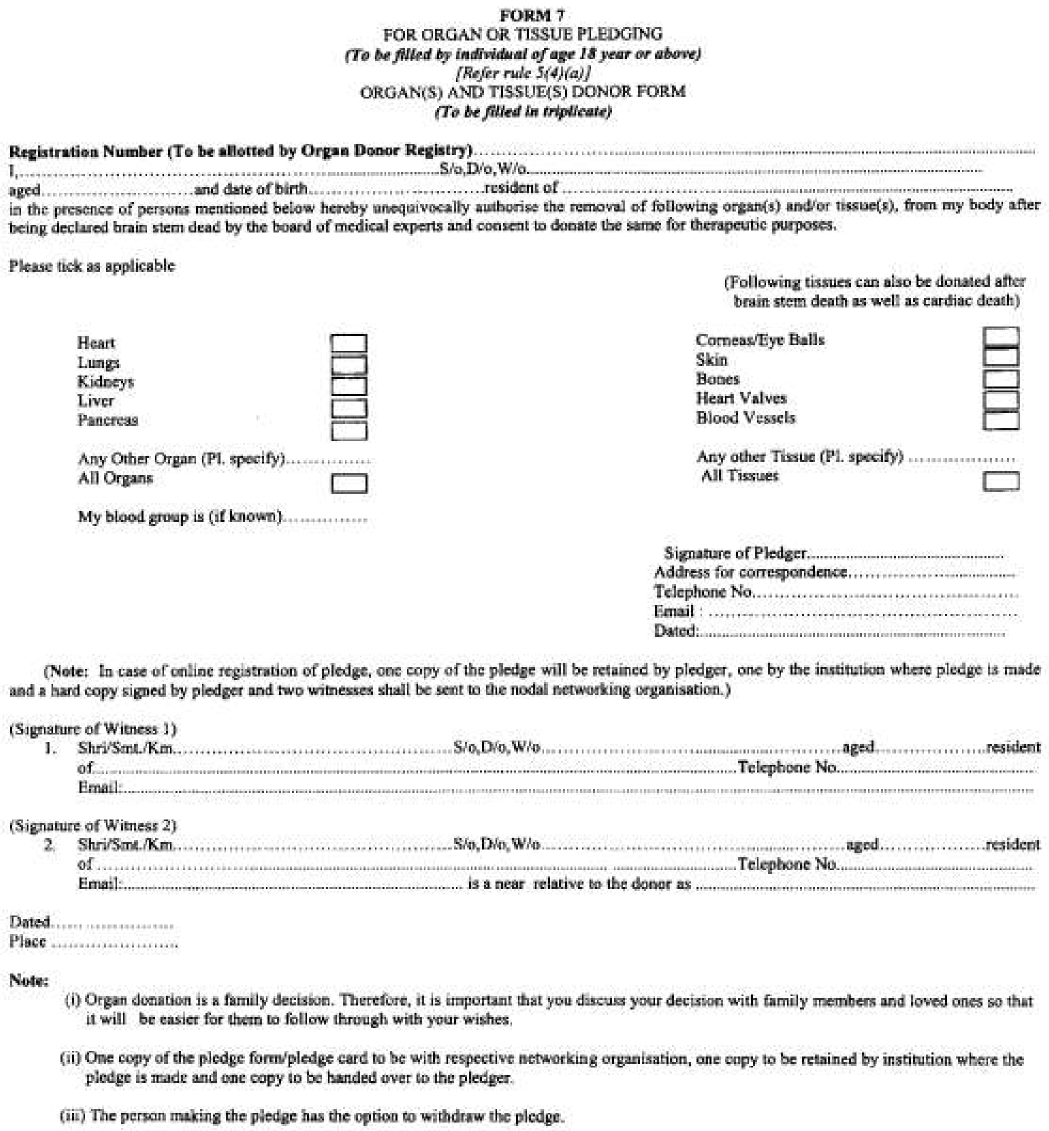
She has contributed immensely towards the cause of organ donation and her contribution is praiseworthy.

I wish her success in all her endeavours.

Anil Kumar
(Dr. Anil Kumar)

ANNEXURE 3.5

Subject: -Form 7 OF THOT Rules after modification post pretesting by the Researcher



FORM 7
FOR ORGAN OR TISSUE PLEDGING
(To be filled by individual of age 18 year or above)
[Refer rule 5(4)(a)]
ORGAN(S) AND TISSUE(S) DONOR FORM
(To be filled in triplicate)

Registration Number (To be allotted by Organ Donor Registry)………………………………
I,…………………………………………S/o,D/o,W/o………………………………………
aged…………………and date of birth…………………resident of ……………………………
in the presence of persons mentioned below hereby unequivocally authorise the removal of following organ(s) and/or tissue(s), from my body after being declared brain stem dead by the board of medical experts and consent to donate the same for therapeutic purposes.

Please tick as applicable

Heart ☐
Lungs ☐
Kidneys ☐
Liver ☐
Pancreas ☐

Any Other Organ (Pl. specify)……………
All Organs ☐

My blood group is (if known)……………

(Following tissues can also be donated after brain stem death as well as cardiac death)

Corneas/Eye Balls ☐
Skin ☐
Bones ☐
Heart Valves ☐
Blood Vessels ☐

Any other Tissue (Pl. specify) ………………
All Tissues ☐

Signature of Pledger………………………………
Address for correspondence………………………
Telephone No.………………………………………
Email : ………………………………………………
Dated:…………………………………………………

(**Note:** In case of online registration of pledge, one copy of the pledge will be retained by pledger, one by the institution where pledge is made and a hard copy signed by pledger and two witnesses shall be sent to the nodal networking organisation.)

(Signature of Witness 1)
1. Shri/Smt./Km.……………………………S/o,D/o,W/o……………………………aged…………………resident
of……………………………………………………Telephone No.…………………………
Email:…………………………………………………………………………………………

(Signature of Witness 2)
2. Shri/Smt./Km.……………………………S/o,D/o,W/o……………………………aged…………………resident
of ……………………………………………………Telephone No.…………………………
Email:……………………………… is a near relative to the donor as ……………………………

Dated…… ……………
Place ……………………

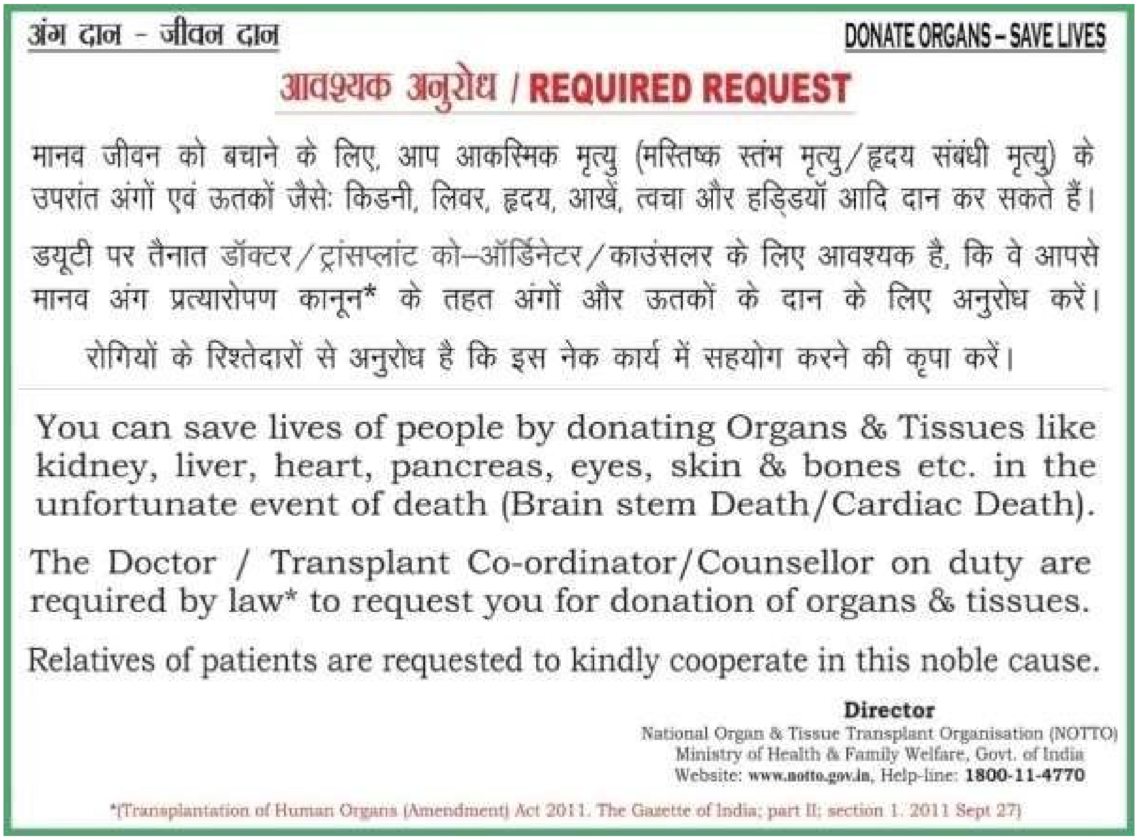
Note:

(i) Organ donation is a family decision. Therefore, it is important that you discuss your decision with family members and loved ones so that it will be easier for them to follow through with your wishes.

(ii) One copy of the pledge form/pledge card to be with respective networking organisation, one copy to be retained by institution where the pledge is made and one copy to be handed over to the pledger.

(iii) The person making the pledge has the option to withdraw the pledge.

ANNEXURE 3.6



अंग दान - जीवन दान

DONATE ORGANS – SAVE LIVES

आवश्यक अनुरोध / REQUIRED REQUEST

मानव जीवन को बचाने के लिए, आप आकस्मिक मृत्यु (मस्तिष्क स्तंभ मृत्यु/हृदय संबंधी मृत्यु) के उपरांत अंगों एवं ऊतकों जैसेः किडनी, लिवर, हृदय, आखें, त्वचा और हड्डियाँ आदि दान कर सकते हैं।

ड्यूटी पर तैनात डॉक्टर/ट्रांसप्लांट को–ऑर्डिनेटर/काउंसलर के लिए आवश्यक है, कि वे आपसे मानव अंग प्रत्यारोपण कानून* के तहत अंगों और ऊतकों के दान के लिए अनुरोध करें।

रोगियों के रिश्तेदारों से अनुरोध है कि इस नेक कार्य में सहयोग करने की कृपा करें।

You can save lives of people by donating Organs & Tissues like kidney, liver, heart, pancreas, eyes, skin & bones etc. in the unfortunate event of death (Brain stem Death/Cardiac Death).

The Doctor / Transplant Co-ordinator/Counsellor on duty are required by law* to request you for donation of organs & tissues.

Relatives of patients are requested to kindly cooperate in this noble cause.

Director
National Organ & Tissue Transplant Organisation (NOTTO)
Ministry of Health & Family Welfare, Govt. of India
Website: **www.notto.gov.in**, Help-line: **1800-11-4770**

*(Transplantation of Human Organs (Amendment) Act 2011. The Gazette of India; part II; section 1. 2011 Sept 27)

ANNEXURE 3.7

INTERVIEW GUIDE FOR DONOR FAMILY (BRAIN STEM DEAD DONOR)

i. BACKGROUND INFORMATION

1. Name of the relative, relationship with the BSD donor, age, occupation etc.
2. Brief description of the donor like Name, Age, Sex, Marital Status, Occupation etc.

ii. INFORMATION REGARDING DONATION OF ORGANS

1. A brief history of hospitalization with dates.
2. A brief history of declaration of Brain Death/Brain Stem Death and organ donation with timings, processes, decisions, counselling etc.
3. Family involvement in the process of donation.
4. Understanding of brain death/brain stem death.
5. Description of Organs donated and transplanted.
6. Main reasons for giving your relative's organs.
7. Any consensus issue within your family?
8. Any problem with getting permission for organ donation from the police?
9. Any problem with getting consent for organ donation from forensic experts etc.
10. Any issue with the hospital?
11. Any problem with getting back dead body after organ donation (timings, body dignity, packing's, etc.).
12. How do you feel now regarding the donation of organs of your relative?
13. The reaction of relatives at home after getting the dead body.
14. Any regrets of the decision of donation.
15. Knowledge about the recipients?
16. Any felicitations received by you from the hospital etc.
17. Your message to the people.

ANNEXURE 3.8

INTERVIEW GUIDE FOR RECIPIENT FAMILY/ RECIPIENT

1. Name of the recipient
2. Brief History of the recipient (age, marital status, Blood group, type of family, occupation, etc.
3. Brief History of the recipient's health.
4. Brief History of the disease.
5. History of dialysis.
6. Problems faced by individual and family during dialysis.
7. Treatment taken for the disease condition.
8. Exploring donors within family.
9. Any attempt to find a living donor outside the family.
10. The date and processes of organ transplantation.
11. Financial implications.
12. Family support and sufferings.
13. Any effect on occupation.
14. Any episode of hospitalization post-transplant.
15. Any incident of organ rejection.
16. Any other disease which erupted after organ transplant.
17. The life of recipient post-transplant.
18. Anything else, please specify.

ANNEXURE 3.9

INTERVIEW GUIDE FOR EMINENT PERSONS IN ORGAN TRANSPLANT COORDINATORS PROGRAMMES

1. The genesis of training transplant coordinators in India.
2. Why, when, how?
3. How many training programmes and the duration of each programme.
4. Their utilization in hospitals.
5. Ethical dilemmas of transplant coordinators.
6. Future scope of transplant coordinators.
7. Problems faced by OTC in India.
8. Any issues with BSD declaration etc.

ANNEXURE 3.10

QUESTIONNAIRE FOR ORGAN TRANSPLANT COORDINATORS

1. SOCIO-DEMOGRAPHIC INFORMATION

Name	
Sex	
Religion	
Marital status	
Type of family	
Mobile number	
Email address	
Family income per month	
Personal income per month	
Professional qualification	
Main designation in hospital	
Total working experience	
Total experience as Organ Transplant Coordinator (OTC)	
Status as to organ donation card holder	
No of family members as Organ Donation Card Holders	
Assigned areas of organ donation and transplantation like Living donation/Swap transplant /Donation from Brain Stem Dead Donors / Counselling/ Any other specify	

2. PERSPECTIVES OF ORGAN TRANSPLANT COORDINATORS TOWARDS THE DONATION

1. Can you list some of your significant donations during your life?
2. Have you ever donated blood for your family member?
3. Have you ever donated blood for other than near relatives?
4. Would you donate an organ during your life to your family member if required? E.g. Kidney/ Liver -
5. Would you donate an organ like (a kidney /a part of the liver) during your lifetime to someone outside family out of affection without anticipating anything in return?
6. God forbid would you like to get an organ for your family member from a Brain Stem Dead donor in case the need arises?
7. Who in your family will be ready to give an organ to you like a kidney or a part of the liver? Please specify the reason?
8. God forbid would you like to get an organ for yourself from a Brain Stem Dead person in case you need one during your life?

9. God forbid, in case you need either a kidney or liver for yourself whom you would prefer first for the donation of an organ?

3 KNOWLEDGE, EXPERIENCES, PRACTICES AND OPINIONS OF OTCS

1. What is your understanding of Brain Stem Death? Who is a Brain-Dead donor?
2. What are the tests done to declare Brain Stem Death in India?
3. Are there different criteria for diagnosing Brain Death in the world?
   - Yes /No
   - What is your opinion about that?
4. How many families of Brain Stem Dead Donors have you counselled till date?
   - How many have refused to donate?
5. Do you make visits to hospital Intensive Care Units (ICUs) for identifying Brain Stem Dead donors?
6. Is consent from relatives taken to do apnoea test for declaration of Brain Stem Death?
7. In your opinion, should consent be asked from relatives before proceeding for apnoea test?
8. Is the apnoea test done in the presence of relatives?
9. In your opinion, should apnoea test be done in the presence of relatives of the donor?
10. Have you ever come across a situation when Brain Stem Dead person's body made some moments?
    - If yes, what all movements were observed by you?
    - How did you take those movements?
11. Have you ever come across a situation when Brain Dead Person's body made some movements in the presence of relatives?
    - If yes, how did they take those movements?
    - Did you require convincing relatives in such cases?
    - How did you convince relatives in such situations?
    - Did the relatives donate organs after finding some of these movements?
    - Do you feel that some of the cases who refused to donate their relative's organs did so because of body movements?
12. Do you feel that it is a tough decision for relatives to donate organs of a Brain Stem Dead person?
13. Have you ever come across a situation when families were not convinced that the patient is dead?
14. Have you ever felt pressure to motivate relatives for organ donation of a Brain Stem Dead person?
15. What questions are asked by the family members when you request them for organ donation?
16. When do you request for organ donation?

- After the first diagnosis of Brain Stem Death by doctors
- After the second diagnosis of Brain Stem Death by doctors
- Any other, please specify

17. If relatives refuse to donate after the first diagnosis; is the second diagnosis done on the patient?
18. Have you ever come across a situation when relatives did not want to donate organs and wanted you to hand over the body to them?
    - If yes, what was done in such cases?
19. What are your experiences in the matching of blood group and HLA of donor with that of recipients?
20. If given a choice to decide, who should be the recipients of brain stem dead donor organs according to your opinion?
    - The patient with whom the organ matches the best
    - The recipient whose family can afford transplant surgery
    - The recipient who has more chances of survival
    - The younger recipient
    - The female recipient
    - The family who can afford post -transplant costs or cost of immunosuppressant's
    - The same religion recipient
    - Any other, please specify
21. Have you ever come across a situation when relatives of the BSD donor wanted to know who the recipients are?
    - Do you reveal some information regarding the recipients to the donor families?
22. Have you ever come across a situation when the recipient wanted to know who the donor was after some months of transplant surgery? If so, what was the reason?
23. What is your opinion about revealing donor-recipient identity? Can this increase acceptance rates?
24. Based on your own experiences, why people refuse to donate their relative's organs in case of Brain Stem Death?
25. What are the reasons for the acceptance of the donation by donor families?
26. Did you face some issues with police on Medico-Legal Cases?
27. Do you meet some problems with forensic experts on post mortem?
28. Could incentives increase the acceptance of organ donation from Brain Stem Dead donors?
    - If yes, what kind of incentives can help in increasing acceptance rates?
29. Have you come across some situation when some organs were retrieved and got wasted?
    - What was your reaction?

  - How many times did this happen, and why?
  - What can be done to prevent such wastage?

30. What is the difference between the opt-in and presumed consent?
    - What is your opinion about current legal options like opt-in system?
    - What is your opinion about the use of presumed consent system in India?
    - In case India goes for a presumed consent system, is there a possibility of its misuse in the private sector?
31. Should foreigners and Indians stand an equal chance for receiving organs in India?
32. What are your suggestions to increase organ donation in India?
33. Are you adequately trained to do the job of the transplant coordinator?
    - Is there a need for further training?

ANNEXURE 3.11

QUESTIONNAIRE FOR ORGAN DONOR CARD HOLDERS

1. BIODATA OF ORGAN DONOR RESPONDENTS

Name	
Age and sex	
Religion	
Marital status	
Qualification	
Occupation	
Type of family	
Mobile number	
Email address	
Please name those organs and tissues that you have pledged to donate after Death/Brain Stem Death?	

2 KNOWLEDGE OF ORGAN DONOR RESPONDENTS ON BSD AND ORGAN DONATION & TRANSPLANTATION.

1. Who can donate organs like kidney or / and a part of liver in India among the following?
    - A Brain Stem Dead donor
    - Any dead person in home
    - Any dead person in hospital
    - A living donor
    - Any other, please specify.

2.Please put a Tick mark for true statements (✓) and a cross mark (X) for wrong statements in context of Brain Stem Death/ Brain Death.

- Every person in a coma is a brain-dead person.
- Every unconscious patient in ICU or Ward is a brain-dead person.
- A patient who cannot breathe on his own and is breathing only because of a machine called ventilator in ICU could be a brain-dead person.
- A Brain Stem Dead patient's heart is beating even after the declaration of death.
- A Brain Stem Dead patient is cold to touch.
- A Brain Stem Dead patient's body cannot make the slightest movement.
- An unconscious patient in the home can be diagnosed as brain dead by a doctor.
- All government doctors can diagnose brain death.
- Apnea test is always done twice to see whether the patient can breathe on his own or not.
- After declaring of Brain Stem Death by doctors the patient is removed from the ventilator.
- Organs from a Brain Stem Dead patient are always retrieved in operation theatre.

3. **Please put a cross mark (X) for wrong statements and a Tick mark (✓) for true statements.**
    - A person can give one kidney to his relative during life.
    - A person can give a part of liver during life to his relative
    - Life of a living liver donor is usually safe after donation of a part of liver.
    - Liver of a healthy donor can regenerate in a few months after donation.
    - We can give an advertisement in newspaper or on TV for contacting unknown and willing organ donors the way we do for blood donation.
    - We can purchase an organ by paying adequate money to the donor
    - A person has to take costly medicines throughout life after transplant
    - The body cannot reject the transplanted organ after one year of operation.
    - If there is no rejection of organ by the body of recipient for whole one year, then there is no need to continue with medicines like immune suppressants.

ORGAN DONOR RESPONDENTS' PERSPECTIVES TOWARDS DONATION

1. Have you ever donated the following in your life till date? **Please put a cross mark (X) for no and a Tick mark (✓) for yes**

Items	
clothes	
books	
Blood donation	
Money	
Any other specify	

2. Can you list some of your significant donation during your life?
3. Have you ever donated blood for your family member?
4. Have you ever donated blood for other than your close relative?
5. Would you give an organ like (a kidney or apart of the liver) during your life to your family member if required?
6. Would you give an organ (kidney or a part of liver) during your lifetime to someone outside your family out of affection without anticipating anything in return?
7. God forbid would you like to get an organ for your family member from a Brain Stem Dead person /Brain Dead person in case the need arises?
8. If a very close relative of yours needs a transplant (a kidney or liver). Whom could you prefer first for donation of an organ out of the following?
    - I (myself)
    - A Brain Stem Dead person
    - A Known person whom you can pay back
    - Immediate Family member, specify
    - Let us accept his fate
    - Anything else, please specify
9. In case the need arises, who will be the first to come forward to give you an organ like a kidney or a part of the liver in your family?

10. God forbid, in case you come across a situation when you need either a kidney or liver transplant yourself who could be your first preference among the following?
    - A Brain Stem Dead person
    - A Known person whom I can pay back
    - Immediate Family member, specify
    - Would accept my fate
    - Anything else, please specify

OPINIONS OF ORGAN DONOR RESPONDENTS' REGARDING VARIOUS ASPECTS OF ORGAN DONATION

1. As per organ transplant laws of India, it is the family who has the final authority to donate organs. The person may have pledged to donate organs, but family can still refuse to donate organs. What is your opinion among the following?
    a. Let family make their own decision?
    b. Let the dead person's will be taken as final?
    c. Anything else please specify
2. Do you think that there is a need to give some incentives to people for pledging to donate organs?
    a. If yes, what kind of incentives should be given to people who pledge to donate organs?
3. In case the person who had pledged to donate organs, requires an organ himself; should he or she be given priority in waiting list for organs in case the need arises?
4. The families are usually not involved in diagnostic tests of Brain Death done on the patients. What is your opinion about that?
5. Should consent from families be taken for doing the apnea test that is done for diagnosis of brain death?
6. Globally, the identity of organ recipients is not given to the donor families. What is your opinion about that?
    a. It is good.
    b. The family should be allowed to see who the recipients are
    c. After mutual consent the families should be allowed to interact
    d. Anything else, please specify

7. If given a choice to decide, who should be the recipients of Brain Stem Dead donor organs according to your opinion?
    a. The patient with whom the organ matches the best
    b. The recipient whose family can afford transplant surgery
    c. The recipient who has more chances of survival
    d. The younger recipient
    e. The female recipient
    f. The family who can afford post -transplant costs or cost of immunosuppressant's
    g. The same religion recipient

    h. Any other please specify

8. In case the family of a Brain Stem Dead donor has a relative waiting for an organ transplant, should one organ be given to him/her in case family insists to do that?
9. Should India go for an opt-out system like Spain; wherein everyone is a donor who has not communicated his unwillingness to donate an organ in a legal document?
10. Should foreigners and Indians stand an equal chance for receiving organs of a Brain Stem Dead donor in India?
11. It is usually females (85-90 %) who donate organs during their lives. Should priority be given to females in the waiting list for Brain Stem Dead donor?
12. There are no incentives given to Brain Stem Dead donor family in India who donate organs of their relative. What is your opinion about the following incentives that could be provided to BSD donor families? Please put **a** cross mark FOR NO (X) or a Tick mark (✓)FOR YES
    a. Providing money to poor.
    b. Provide permanent job to one member of the donor family.
    c. Providing free education to the children of the family.
    d. Providing free higher education to the children.
    e. Giving social recognition.
    f. Making them popular through social media.
    g. Free lifelong railway travel for the parents.
    h. Free lifelong airway travel for the parents.
    i. Providing health insurance scheme for parents
    j. Providing free medical facilities for donor's families.
    k. Helping in critical condition of the donor's family.
    l. Health insurance to the family till the end of life.
    m. Any other please specify

13. What are your reasons for pledging to donate organs? Please explain.

Annexure 3.12

SCORING KEY OF QUESTIONS 2 AND 3 OF TWO QUESTIONNAIRES ONE FOR ORGAN DONOR AND ANOTHER FOR NON-ORGAN DONOR RESPONDENTS

S.No	Question	Correct Answer	Maximum Score
QUESTION NUMBER 2	**(MAXIMUM MARKS =11)**		1
1.	Every person in deep coma is a brain-dead person.	No	1
2.	Every unconscious patient in ICU or Ward is a brain-dead person.	No	1
3.	A patient who cannot breathe on his own and is breathing only because of a machine called ventilator in ICU could be a brain-dead person.	Yes	1
4.	A Brain Stem Dead patient's heart is beating even after declaration of death.	Yes	1
5.	A Brain Stem Dead patient is cold to touch.	No	1
6.	A Brain Stem Dead patient's body cannot make the slightest movement.	No	1
7.	An unconscious patient in home can be diagnosed by a doctor as brain dead.	No	1
8.	All government doctors can diagnose brain death.	No	1
9.	Apnea test is always done twice to see whether the patient can breathe on his own or not.	Yes	1
10.	After declaring of Brain Stem Death by doctors, the patient is removed from the ventilator.	No	1
11.	Organs from a Brain Stem Dead patient are always retrieved in operation theatre.	Yes	1
QUESTION NUMBER 3	**(MAXIMUM MARKS =9)**		
1.	A person can give one kidney to his relative during life.	Yes	1
2.	A person can give a part of liver during life to his relative.	Yes	1
3.	Life of a living liver donor is usually safe after donation of a part of liver.	Yes	1
4.	Liver of a healthy donor can regenerate in few months' time after donation.	Yes	1
5.	We can give advertisement in newspaper or on TV for contacting unknown organ donors the way it is done for blood donation.	No	1
6.	We can purchase an organ by paying adequate money to the donor.	No	1
7.	A person has to take costly medicines throughout life after transplant.	Yes	1
8.	Transplanted organ cannot be rejected by body after one year of transplant.	No	1
9.	If there is no rejection of organ by the body of recipient for complete one year, then there is no need to continue with medicines like immune suppressants.	No	1

ANNEXURE 3.13

QUESTIONNAIRE FOR NON-ORGAN DONOR CARD HOLDERS

BIODATA OF ORGAN DONOR RESPONDENTS

Name	
Age and sex	
Religion	
Marital status	
Qualification	
Occupation	
Type of family	
Mobile number	
Email address	
Please name those organs and tissues that you have pledged to donate after Death/Brain Stem Death?	

KNOWLEDGE OF NON-ORGAN DONOR RESPONDENTS ON BSD AND ORGAN DONATION AND TRANSPLANTATION.

4. Who can donate organs like kidney or / and a part of liver in India among the following?
   - A Brain Stem Dead donor
   - Any dead person in home
   - Any dead person in hospital
   - A living donor
   - Any other, please specify.
5. Please put a Tick mark for true statements (✓) and a cross mark (X) for wrong statements in context of Brain Stem Death/ Brain Death.

- Every person in a coma is a brain-dead person.
- Every unconscious patient in ICU or Ward is a brain-dead person.
- A patient who cannot breathe on his own and is breathing only because of a machine called ventilator in ICU could be a brain-dead person.
- A Brain Stem Dead patient's heart is beating even after the declaration of death.
- A Brain Stem Dead patient is cold to touch.
- A Brain Stem Dead patient's body cannot make the slightest movement.
- An unconscious patient in the home can be diagnosed as brain dead by a doctor.
- All government doctors can diagnose brain death.
- Apnea test is always done twice to see whether the patient can breathe on his own or not.
- After declaring of Brain Stem Death by doctors the patient is removed from the ventilator.
- Organs from a Brain Stem Dead patient are always retrieved in operation theatre.

6. **Please put a cross mark (X) for wrong statements and a Tick mark (✓) for true statements.**
    - A person can give one kidney to his relative during life.
    - A person can give a part of liver during life to his relative
    - Life of a living liver donor is usually safe after donation of a part of liver.
    - Liver of a healthy donor can regenerate in a few months after donation.
    - We can give an advertisement in newspaper or on TV for contacting unknown and willing organ donors the way we do for blood donation.
    - We can purchase an organ by paying adequate money to the donor
    - A person has to take costly medicines throughout life after transplant
    - The body cannot reject the transplanted organ after one year of operation.
    - If there is no rejection of organ by the body of recipient for whole one year, then there is no need to continue with medicines like immune suppressants.

NON- ORGAN DONOR RESPONDENTS' PERSPECTIVES TOWARDS DONATION

1. Have you ever donated the following in your life till date? **Please put a cross mark (X) for no and a Tick mark (✓) for yes**

Items	
clothes	
books	
Blood donation	
Money	
Any other specify	

2. Can you list some of your significant donation during your life?
3. Have you ever donated blood for your family member?
4. Have you ever donated blood for other than your close relative?
5. Would you give an organ like (a kidney or apart of the liver) during your life to your family member if required?
6. Would you give an organ (kidney or a part of liver) during your lifetime to someone outside your family out of affection without anticipating anything in return?
7. God forbid would you like to get an organ for your family member from a Brain Stem Dead person /Brain Dead person in case the need arises?
8. If a very close relative of yours needs a transplant (a kidney or liver). Whom could you prefer first for donation of an organ out of the following?
    - I (myself)
    - A Brain Stem Dead person
    - A Known person whom you can pay back
    - Immediate Family member, specify
    - Let us accept his fate
    - Anything else, please specify

9. In case the need arises, who will be the first to come forward to give you an organ like a kidney or a part of the liver in your family?

10. God forbid, in case you come across a situation when you need either a kidney or liver transplant yourself who could be your first preference among the following?
    - A Brain Stem Dead person
    - A Known person whom I can pay back
    - Immediate Family member, specify
    - Would accept my fate
    - Anything else, please specify

OPINIONS OF NON-ORGAN DONOR RESPONDENTS' TO VARIOUS ASPECTS OF ORGAN DONATION

1. As per organ transplant laws of India, it is the family who has the final authority to donate organs. The person may have pledged to donate organs, but family can still refuse to donate organs. What is your opinion among the following?
    - Let family make their own decision?
    - Let the dead person's will be taken as final?
    - Anything else please specify
2. Do you think that there is a need to give some incentives to people for pledging to donate organs?
    a. If yes, what kind of incentives should be given to people who pledge to donate organs?
3. In case the person who had pledged to donate organs, requires an organ himself; should he or she be given priority in waiting list for organs in case the need arises?
4. The families are usually not involved in diagnostic tests of Brain Death done on the patients. What is your opinion about that?
5. Should consent from families be taken for doing the apnea test that is done for diagnosis of brain death?
6. Globally, the identity of organ recipients is not given to the donor families. What is your opinion about that?
    i. It is good.
    ii. The family should be allowed to see who the recipients are
    iii. After mutual consent the families should be allowed to interact
    iv. Anything else, please specify

7. If given a choice to decide, who should be the recipients of Brain Stem Dead donor organs according to your opinion?
    i. The patient with whom the organ matches the best
    ii. The recipient whose family can afford transplant surgery
    iii. The recipient who has more chances of survival
    iv. The younger recipient
    v. The female recipient
    vi. The family who can afford post -transplant costs or cost of immunosuppressant's

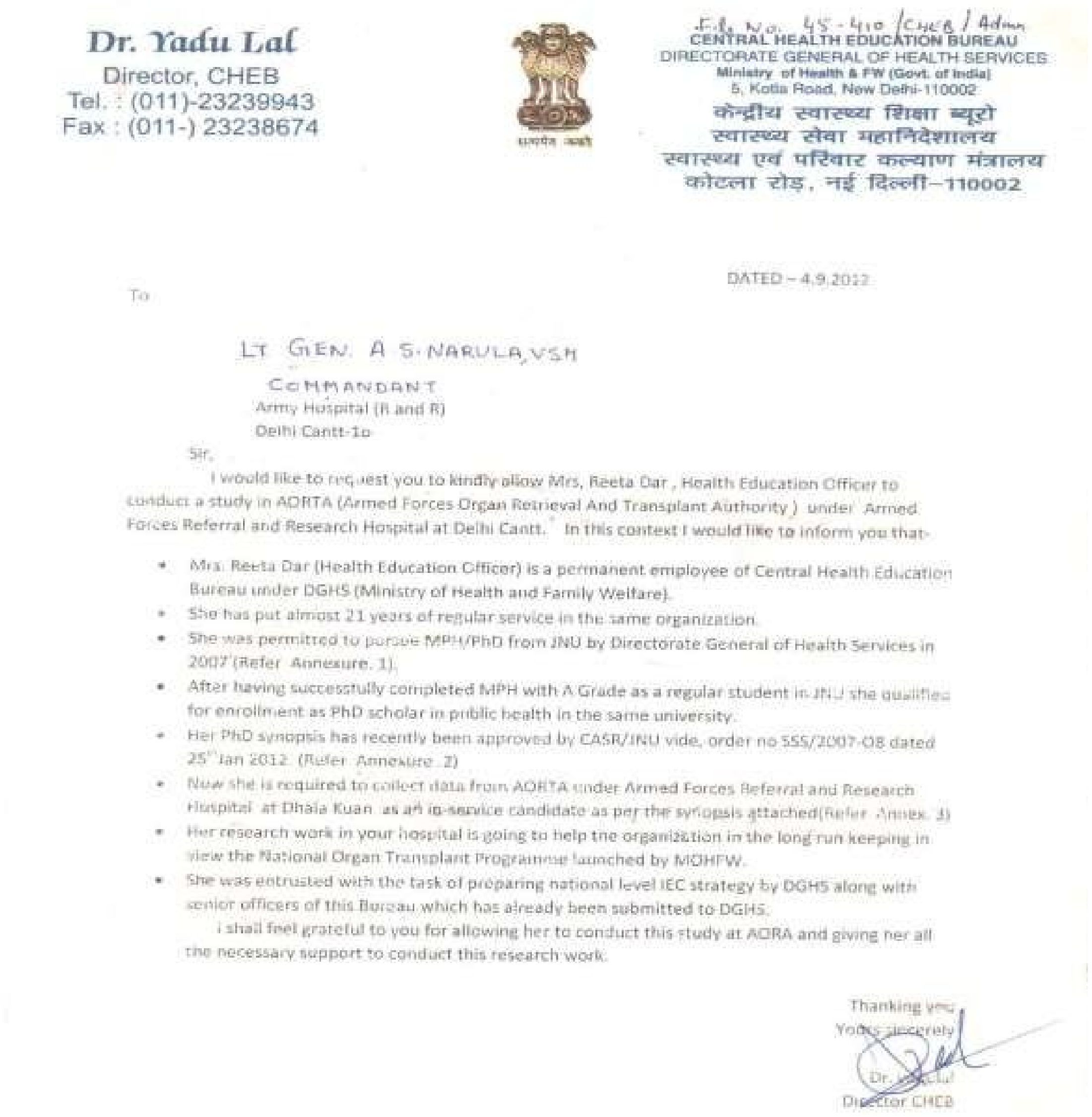
vii. The same religion recipient

viii. Any other please specify

8. In case the family of a Brain Stem Dead donor has a relative waiting for an organ transplant, should one organ be given to him/her in case family insists to do that?
9. Should India go for an opt-out system like Spain; wherein everyone is a donor who has not communicated his unwillingness to donate an organ in a legal document?
10. Should foreigners and Indians stand an equal chance for receiving organs of a Brain Stem Dead donor in India?
11. It is usually females (85-90 %) who donate organs during their lives. Should priority be given to females in the waiting list for Brain Stem Dead donor?
12. There are no incentives given to Brain Stem Dead donor family in India who donate organs of their relative. What is your opinion about the following incentives that could be provided to BSD donor families? Please put **a** cross mark FOR NO (X) or a Tick mark ( )✓FOR YES
    - Providing money to poor.
    - Provide permanent job to one member of the donor family.
    - Providing free education to the children of the family.
    - Providing free higher education to the children.
    - Giving social recognition.
    - Making them popular through social media.
    - Free lifelong railway travel for the parents.
    - Free lifelong airway travel for the parents.
    - Providing health insurance scheme for parents
    - Providing free medical facilities for donor's families.
    - Helping in critical condition of the donor's family.
    - Health insurance to the family till the end of life.
    - Any other please specify
13. What are your reasons for not pledging to donate organs? Please explain.

Annexure 3.14

Subject: official letter to AORTA by CHEB Director



Dr. Yadu Lal
Director, CHEB
Tel. : (011)-23239943
Fax : (011-) 23238674

File No. 45-410/CHEB/Admn
CENTRAL HEALTH EDUCATION BUREAU
DIRECTORATE GENERAL OF HEALTH SERVICES
Ministry of Health & FW (Govt. of India)
5, Kotla Road, New Delhi-110002
केन्द्रीय स्वास्थ्य शिक्षा ब्यूरो
स्वास्थ्य सेवा महानिदेशालय
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
कोटला रोड, नई दिल्ली–110002

DATED – 4.9.2012

To

LT GEN. A S. NARULA, VSM
COMMANDANT
Army Hospital (R and R)
Delhi Cantt-10

Sir,

I would like to request you to kindly allow Mrs, Reeta Dar , Health Education Officer to conduct a study in AORTA (Armed Forces Organ Retrieval And Transplant Authority) under Armed Forces Referral and Research Hospital at Delhi Cantt. In this context I would like to inform you that-

- Mrs. Reeta Dar (Health Education Officer) is a permanent employee of Central Health Education Bureau under DGHS (Ministry of Health and Family Welfare).
- She has put almost 21 years of regular service in the same organization.
- She was permitted to pursue MPH/PhD from JNU by Directorate General of Health Services in 2007 (Refer Annexure. 1).
- After having successfully completed MPH with A Grade as a regular student in JNU she qualified for enrollment as PhD scholar in public health in the same university.
- Her PhD synopsis has recently been approved by CASR/JNU vide, order no SSS/2007-08 dated 25th Jan 2012. (Refer Annexure. 2)
- Now she is required to collect data from AORTA under Armed Forces Referral and Research Hospital at Dhaula Kuan as an in-service candidate as per the synopsis attached(Refer Annex. 3)
- Her research work in your hospital is going to help the organization in the long run keeping in view the National Organ Transplant Programme launched by MOHFW.
- She was entrusted with the task of preparing national level IEC strategy by DGHS along with senior officers of this Bureau which has already been submitted to DGHS.

I shall feel grateful to you for allowing her to conduct this study at AORA and giving her all the necessary support to conduct this research work.

Thanking you
Yours sincerely

Dr. Yadu Lal
Director CHEB

ANNEXURE 3.15

Subject: -Refusal of permission by AORTA without assigning any reason

Tele : 23092562

Ministry of Defence
O/o DGAFMS/DG-1D
'M' Block, New Delhi

8684/SHORT/DGAFMS/DG-1D

31 Dec 2012

Dr. Yadu Lal
Director
Central Health Education Bureau
Directorate General of Health Services
Ministry of Health & FW (Govt. of India)
5, Kotla Road, New Delhi – 110002

STUDY IN ARMED FORCES ORGAN RETRIEVAL AND TRANSPLANT AUTHORITY (AORTA) IN R/O MRS. REETA DAR

1672/CE/ADCHEB.
15.1.13

1. Reference your letter 45-410/CHEB/Admn dated 19 Sep 2012.

2. The application in r/o Ms Reeta Dar, Health Education Officer of CHEB to conduct study in AORTA (Armed Forces Organ Retrieval & Transplant Authority) at AH (R&R), Delhi Cantt has been considered at this Dte Gen and the same has not been agreed to.

3. This is for your info and necessary action please.

(A K Shakya)
Lt Col
Jt Dir AFMS(Trg)
For DGAFMS

Copy to:

Integrated HQ of MoD(Army)
Dte Gen Med Services(Army)/Dir MS(PS) : for info.

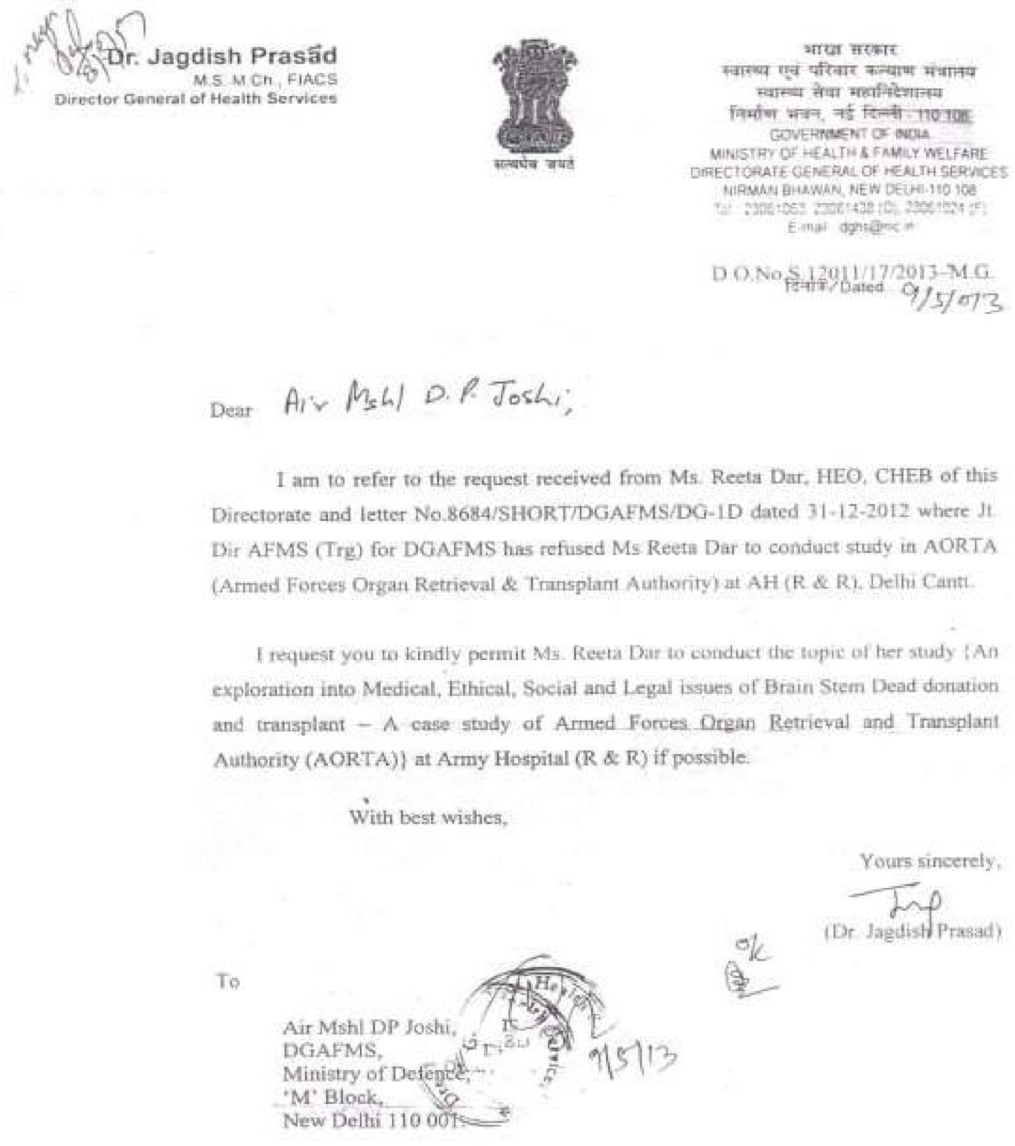
Army Hospital (R&R)
Delhi Cantt : for info.

17/01/13

Ms Dar

ANNEXURE 3.16

Subject: First request letter of DGHS, the chairperson of AORTA to allow researcher to conduct study at AORTA.



Dr. Jagdish Prasad
M.S. M.Ch., FIACS
Director General of Health Services

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
स्वास्थ्य सेवा महानिदेशालय
निर्माण भवन, नई दिल्ली - 110 108
GOVERNMENT OF INDIA
MINISTRY OF HEALTH & FAMILY WELFARE
DIRECTORATE GENERAL OF HEALTH SERVICES
NIRMAN BHAWAN, NEW DELHI-110 108
Tel : 23061063, 23061438 (O), 23061924 (F)
E-mail : dghs@nic.in

D.O.No.S.12011/17/2013-M.G.
दिनांक/Dated 9/5/013

Dear Air Mshl D.P. Joshi,

I am to refer to the request received from Ms. Reeta Dar, HEO, CHEB of this Directorate and letter No.8684/SHORT/DGAFMS/DG-1D dated 31-12-2012 where Jt. Dir AFMS (Trg) for DGAFMS has refused Ms Reeta Dar to conduct study in AORTA (Armed Forces Organ Retrieval & Transplant Authority) at AH (R & R), Delhi Cantt.

I request you to kindly permit Ms. Reeta Dar to conduct the topic of her study {An exploration into Medical, Ethical, Social and Legal issues of Brain Stem Dead donation and transplant – A case study of Armed Forces Organ Retrieval and Transplant Authority (AORTA)} at Army Hospital (R & R) if possible.

With best wishes,

Yours sincerely,

(Dr. Jagdish Prasad)

ok

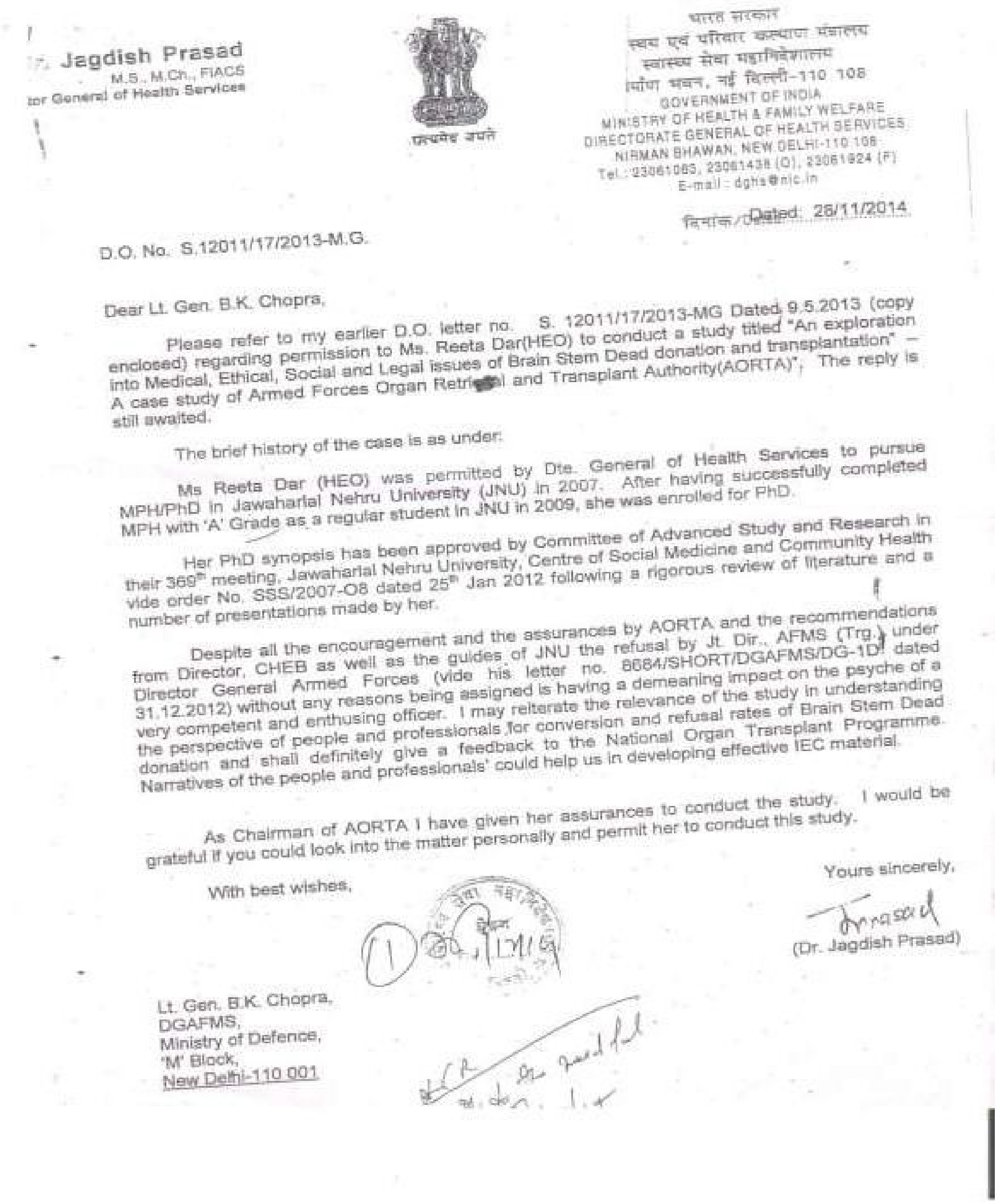
To

Air Mshl DP Joshi,
DGAFMS,
Ministry of Defence,
'M' Block,
New Delhi 110 001

9/5/13

ANNEXURE 3.17

Subject: Second request letter of DGHS to DGAFMS, the chairperson of AORTA to allow researcher to conduct study at AORTA.



r. Jagdish Prasad
M.S., M.Ch., FIACS
tor General of Health Services

सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
स्वास्थ्य सेवा महानिदेशालय
निर्माण भवन, नई दिल्ली-110 108
GOVERNMENT OF INDIA
MINISTRY OF HEALTH & FAMILY WELFARE
DIRECTORATE GENERAL OF HEALTH SERVICES
NIRMAN BHAWAN, NEW DELHI-110 108
Tel.: 23061063, 23061438 (O), 23061924 (F)
E-mail : dghs@nic.in

दिनांक/Dated: 28/11/2014

D.O. No. S.12011/17/2013-M.G.

Dear Lt. Gen. B.K. Chopra,

Please refer to my earlier D.O. letter no. S. 12011/17/2013-MG Dated 9.5.2013 (copy enclosed) regarding permission to Ms. Reeta Dar(HEO) to conduct a study titled "An exploration into Medical, Ethical, Social and Legal issues of Brain Stem Dead donation and transplantation" – A case study of Armed Forces Organ Retri[illegible]l and Transplant Authority(AORTA)". The reply is still awaited.

The brief history of the case is as under:

Ms Reeta Dar (HEO) was permitted by Dte. General of Health Services to pursue MPH/PhD in Jawaharlal Nehru University (JNU) in 2007. After having successfully completed MPH with 'A' Grade as a regular student in JNU in 2009, she was enrolled for PhD.

Her PhD synopsis has been approved by Committee of Advanced Study and Research in their 369th meeting, Jawaharlal Nehru University, Centre of Social Medicine and Community Health vide order No. SSS/2007-O8 dated 25th Jan 2012 following a rigorous review of literature and a number of presentations made by her.

Despite all the encouragement and the assurances by AORTA and the recommendations from Director, CHEB as well as the guides of JNU the refusal by Jt. Dir., AFMS (Trg.) under Director General Armed Forces (vide his letter no. 8684/SHORT/DGAFMS/DG-1D dated 31.12.2012) without any reasons being assigned is having a demeaning impact on the psyche of a very competent and enthusing officer. I may reiterate the relevance of the study in understanding the perspective of people and professionals for conversion and refusal rates of Brain Stem Dead donation and shall definitely give a feedback to the National Organ Transplant Programme. Narratives of the people and professionals' could help us in developing effective IEC material.

As Chairman of AORTA I have given her assurances to conduct the study. I would be grateful if you could look into the matter personally and permit her to conduct this study.

With best wishes,

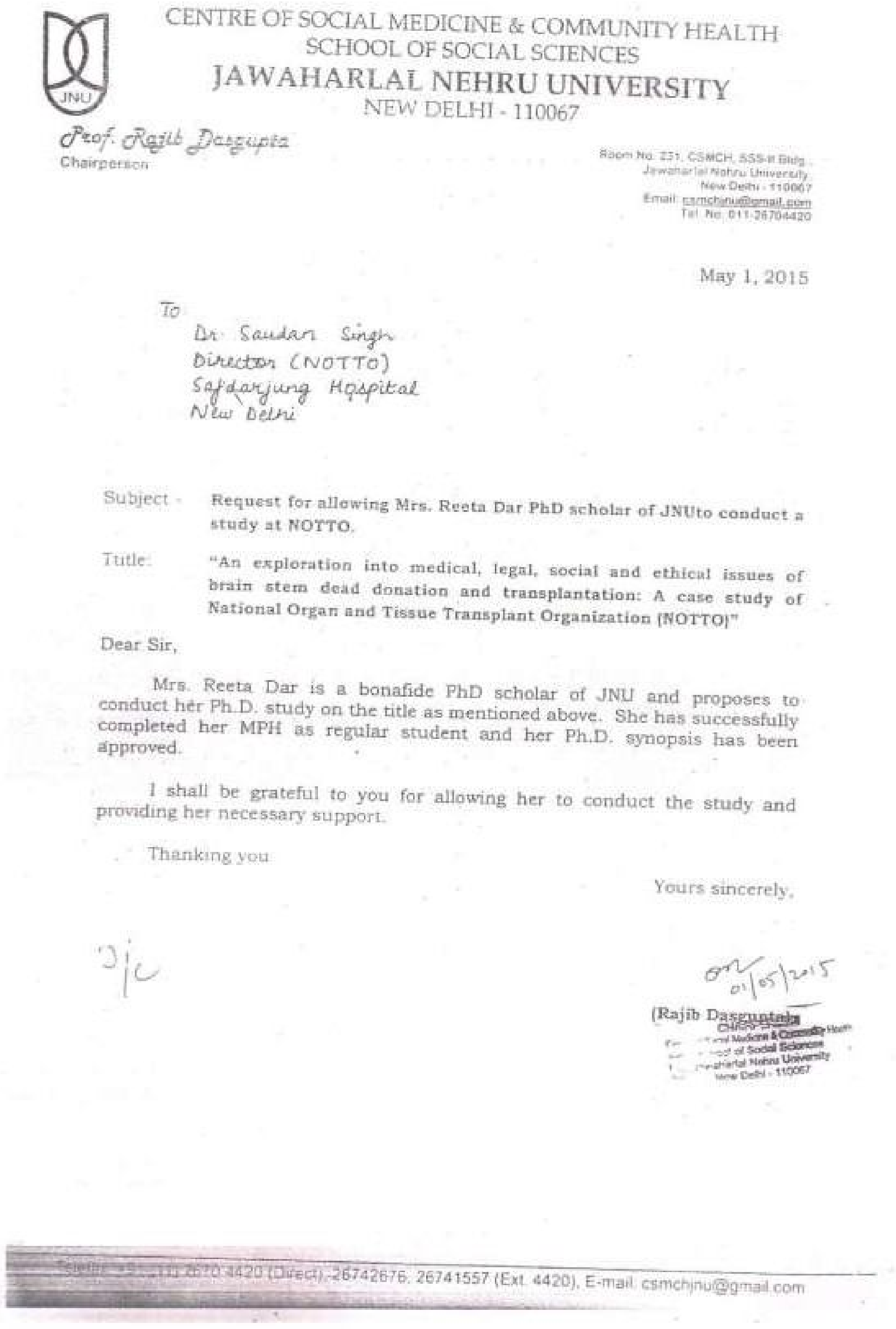
Yours sincerely,
Prasad
(Dr. Jagdish Prasad)

(1)

Lt. Gen. B.K. Chopra,
DGAFMS,
Ministry of Defence,
'M' Block,
New Delhi-110 001

ANNEXURE 3.18

Subject: Request letter of the chairperson CSMCH; SSS; JNU to allow researcher to conduct study at NOTTO



CENTRE OF SOCIAL MEDICINE & COMMUNITY HEALTH
SCHOOL OF SOCIAL SCIENCES
JAWAHARLAL NEHRU UNIVERSITY
NEW DELHI - 110067

Prof. Rajib Dasgupta
Chairperson

Room No. 231, CSMCH, SSS-II Bldg.
Jawaharlal Nehru University
New Delhi - 110067
Email: csmchjnu@gmail.com
Tel. No. 011-26704420

May 1, 2015

To
Dr. Saudan Singh
Director (NOTTO)
Safdarjung Hospital
New Delhi

Subject - **Request for allowing Mrs. Reeta Dar PhD scholar of JNUto conduct a study at NOTTO.**

Title: **"An exploration into medical, legal, social and ethical issues of brain stem dead donation and transplantation: A case study of National Organ and Tissue Transplant Organization (NOTTO)"**

Dear Sir,

Mrs. Reeta Dar is a bonafide PhD scholar of JNU and proposes to conduct her Ph.D. study on the title as mentioned above. She has successfully completed her MPH as regular student and her Ph.D. synopsis has been approved.

I shall be grateful to you for allowing her to conduct the study and providing her necessary support.

Thanking you

Yours sincerely,

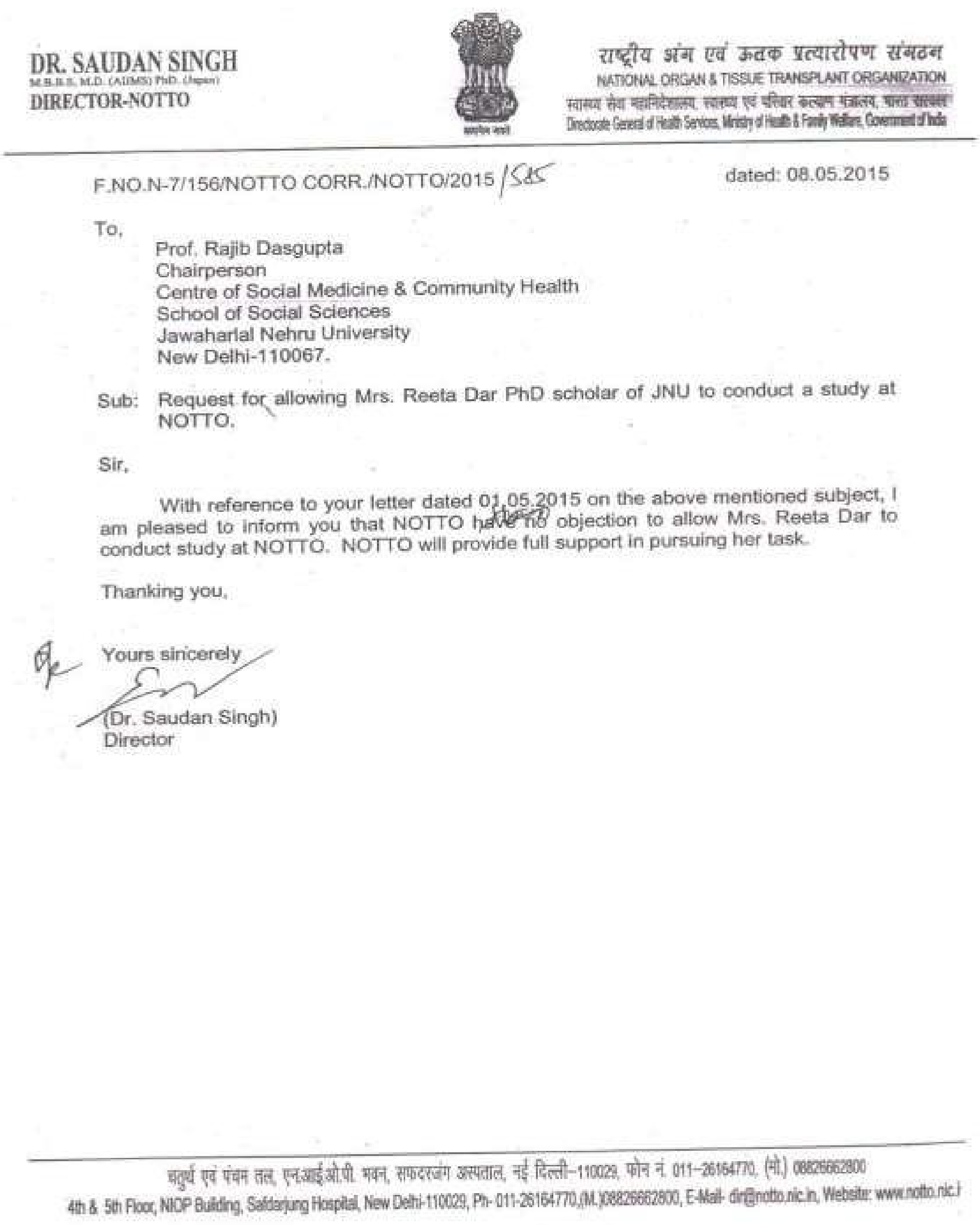
01/05/2015

(Rajib Dasgupta)
Chairperson
Centre of Social Medicine & Community Health
School of Social Sciences
Jawaharlal Nehru University
New Delhi - 110067

[illegible] 2670 4420 (Direct), 26742676, 26741557 (Ext. 4420), E-mail: csmchjnu@gmail.com

ANNEXURE 3.19

Subject: Grant of permission by NOTTO Director



DR. SAUDAN SINGH
M.B.B.S, M.D. (AIIMS) PhD. (Japan)
DIRECTOR-NOTTO

राष्ट्रीय अंग एवं ऊतक प्रत्यारोपण संगठन
NATIONAL ORGAN & TISSUE TRANSPLANT ORGANIZATION
स्वास्थ्य सेवा महानिदेशालय, स्वास्थ्य एवं परिवार कल्याण मंत्रालय, भारत सरकार
Directorate General of Health Services, Ministry of Health & Family Welfare, Government of India

F.NO.N-7/156/NOTTO CORR./NOTTO/2015/585 dated: 08.05.2015

To,
Prof. Rajib Dasgupta
Chairperson
Centre of Social Medicine & Community Health
School of Social Sciences
Jawaharlal Nehru University
New Delhi-110067.

Sub: Request for allowing Mrs. Reeta Dar PhD scholar of JNU to conduct a study at NOTTO.

Sir,

With reference to your letter dated 01.05.2015 on the above mentioned subject, I am pleased to inform you that NOTTO ~~have~~ has no objection to allow Mrs. Reeta Dar to conduct study at NOTTO. NOTTO will provide full support in pursuing her task.

Thanking you,

Yours sincerely

(Dr. Saudan Singh)
Director

चतुर्थ एवं पंचम तल, एन.आई.ओ.पी. भवन, सफदरजंग अस्पताल, नई दिल्ली–110029, फोन नं. 011–26164770, (मो.) 08826662800
4th & 5th Floor, NIOP Building, Safdarjung Hospital, New Delhi-110029, Ph- 011-26164770,(M.)08826662800, E-Mail- dir@notto.nic.in, Website: www.notto.nic.i

ANNEXURE 3.20

Subject: Key Terms and Words Used in the Thesis

- **Organ: -** means internal organs only like kidney, liver, heart, lungs, pancreas and intestines. The organ does not include eye or other tissues.

- **Brain Stem Death:** means the death of brain stem only.

- **Brain Death:** Brain death means the Death of the whole brain. Brain Death is the complete Death of the brain, and the diagnostic procedure requires getting electroencephalogram (EEG) done for the patient to ensure the absence of Brain activity. On the other hand, Brain Stem Death is the Death of the brain stem only and not the complete Death of brain as is the case with brain death. In the former, the patient may have some intact brain activities, and electroencephalogram (EEG) is not done. Brain Death and Brain Stem Death are two different criteria used to declare deaths. India uses Brain Stem Death like the UK, whereas the USA uses brain death criteria (Dar,2014). Interestingly everyone, including professionals, uses the word Brain Death instead of Brain Stem Death in India. People do not understand brain Stem Death. Hence in this study, brain death has been used instead of Brain Stem Death in many places.

- **Cadaver Organ Donation/ Deceased Organ Donation / Brain Stem Dead Donation: -** refers to a donor who is declared Brain Stem Dead/Brain Dead and who's one organ at least is retrieved and transplanted into a recipient.

- **Recipient:** refers to a person who is waiting for an organ transplant or has been transplanted one organ at least.

- **Recipient Case Study: -** refers to the research outcome of an interview conducted with an organ recipient that includes inputs from his/her relatives also in some cases.

- **Organ Transplant Coordinator: -** refers to a person who is designated as an Organ Transplant Coordinator by a hospital with or without any formal training in organ donation and transplant.

- **Donor Family Case Study: -** refers to the research outcome of the interview conducted with family members of a Brain Stem Dead (BSD)donor who had donated organ/ organs of their Brain Stem Dead relative that was/ were transplanted into recipients. Brain Stem Dead (BSD) donors are also called Cadaver Donor or Deceased Donor in this study.

- **Perspectives: -** refers to the way of thinking about something that is influenced by individual belief or experiences. In this study it refers to facts known to the respondents, their thinking, views and practices on the subject as expressed to the researcher.

- **Organ Donor Respondents or Organ Donor Card Holders**: -refers to people who have pledged to donate at least one organ in form 7 of THOT Rules, like kidney, liver, heart, lungs, intestines along with or without tissues like eyes, skin, heart valves etc. It is immaterial whether they have a donor card or not.

- **Non-Organ Donor Respondents: -**refers to people who have not pledged to donate a single organ in form 7 of THOT Rules but may have pledged to donate tissues like eyes, skin, heart valves etc. Even if they hold an organ donor card, such persons are non-organ donor respondents or non-organ donor card holders for this study.

- **Refusal Rate: -** refers to the percentage of Brain Stem Dead donor families who refused to donate organ/organs of their BSD donor once approached by professionals like OTC for organ donation.

- **Conversion Rate: -** refers to the percentage of Brain Stem Dead donors whose organ/ organs were retrieved for transplantation after getting consent from family members.

- **Mass Awareness Campaigns: -**refers to well-organized awareness programmes conducted by NOTTO. These programs are NOTTO initiated, organized and implemented programs that include delivery of one-hour lecture by NOTTO officials on organ donation including BSD donation, question-answer session and distribution of material developed by NOTTO on organ donation and transplantation.