PERCEPTION AND AWARENESS TOWARDS ORGAN DONATION AND TRANSPLANTATION AND POLICY SUGGESTIONS: A STUDY OF HARYANA STATE

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DECLARATION

I, hereby declared that the presented work in the thesis entitled "Perception and Awareness towards Organ Donation and Transplantation and Policy Suggestions: A Study of Haryana State"in fulfilment of degree of Doctor of Philosophy (Ph.D.) is outcome of research work carried out by me under the supervision of Dr. Pooja Kansra, Professor, Mittal School of Business of Lovely Professional University, Punjab.

In keeping with general practice of reporting scientific observations, due acknowledgements have been made whenever work described here has been based on findings of other investigator.

This work has not been submitted in part or full to any other University or Institute for the award of any degree.

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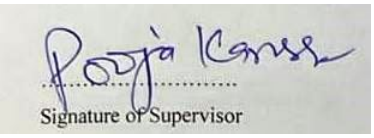
CERTIFICATE

This is to certify that the work reported in the Ph. D. thesis entitled "Perception and Awareness towards Organ Donation and Transplantation and Policy Suggestions: A Study of Haryana State" submitted in fulfillment of the requirement for the award of degree of Doctor of Philosophy (Ph.D.) in the Management, is a research work carried out by Dr. Shyamli Varshney (Registration No.- 41800687), is Bonafide record of his/her original work carried out under my supervision and that no part of thesis has been submitted for any other degree, diploma or equivalent course.



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ABSTRACT

The world is becoming increasingly technologically advanced, leading to notable improvements in healthcare in the country. The life expectancy has increased significantly, aided by innovations such as new treatments and vaccines etc. However, these advancements have also contributed to faster-paced, more stressful lives, which have been linked to a rise in chronic diseases like hypertension, diabetes, coronary heart disease, and liver disorders. In severe cases, some chronic illnesses progress to organ failure, affecting the kidneys, liver, or heart. Despite these challenges, individuals and healthcare systems continue to seek solutions. The organ transplantation has emerged as a viable treatment option, with procedures now commonly performed for the heart, liver, and kidneys. The organ transplant and retrieval activities in India are centrally regulated by the National Organ & Tissue Transplant Organization (NOTTO), supported by regional and state transplant authorities (ROTTO and SOTTO). While, many states have been slow to adopt the THOA Amendment Act 2011, Haryana has implemented the act and established a SOTTO unit. Despite these efforts, the state lags significantly in organ donation and transplant activities compared to other states. Haryana has 14 transplant centres, 11 of which are private and primarily perform kidney transplants.

Whereas, hospitals under SOTTO Haryana conduct only kidney transplants, with the number of procedures remaining low rising from 28 in 2019 to just 94 in 2023. The deceased organ transplant is yet to be performed in SOTTO Haryana hospitals, although two facilities act as stand-alone retrieval centres for organs from brain-dead donors. The present study has analysed the organ donation and transplantation in Haryana, focusing on awareness, perceptions, and stakeholder concerns to identify pressing implementation challenges. The study has been conducted in five representative clusters in Haryana—Panchkula, Gurugram, Yamunanagar, Faridabad, and Mewat. However, data has also collected from all 14 transplant hospitals, SOTTO office in Rohtak, and the DGHS office in Panchkula. The study is both on structured questionnaire and interviews with stakeholders for the collection of data.

The findings revealed that none of the surveyed families, urban or rural, had registered for the organ donation in Haryana. Whereas, it was found that 60 percent of the respondents were aware of the fact that organs could be donated and transplanted but most were undecided or unwilling to donate. A video-assisted teaching (VAT)

session among 300 respondents has shown that improved awareness and attitudes toward organ donation. The analysis of the pre-test and post-test comparisons have clearly shown that a notable improvement in knowledge and attitudes and thus it clearly directs the need for targeted awareness campaigns to change the attitudes. The perceptions of organ donation highlighted that respondent believed that organ donation conflicted with religious teachings and traditions, leading to hesitancy. The concerns over ethical and transparent practices were also prominent and it was particularly regarding the fears of black-market organ sales. These findings underscore the need for culturally sensitive and transparent educational campaigns especially involving religious and community leaders from the societies to bridge gaps in understanding Sand acceptance towards organ donation and transplant. The demand for organ transplants in Haryana is rising day by day and with kidneys being the most demanded followed by liver, heart, lungs, and intestines. However, Haryana meets only 5 percent of demand and primarily through living donors related to the recipients. Whereas, cadaver donations established just 1 percent of fatal accidental deaths. In order to reduce the gap between the demand and supply it is required to increase public awareness and simplify legal procedures to increase transplant and donation.

It has been observed that most of the transplants were conducted in private hospitals, with some patients relying on Ayushman Bharat empanelled healthcare facilities. While, transplantation greatly improved patients' quality of life but cost of transplant is very high as most of them were relying heavily on the borrowed funds for treatment and post-transplant care. The stakeholders unanimously advocated for a well-funded, sustained IEC campaign to make organ donation a cultural norm. The suggestions included involving celebrities, family counselling sessions in ICUs, and providing clear information on the donation process. However, stakeholders expressed mixed views on transitioning from an 'opt-in' to a 'soft opt-out' system for organ donation. While, government and hospital administrators supported the move, others raised concerns about potential misunderstandings and implications. Haryana's organ donation and transplantation system requires targeted interventions to improve awareness, address cultural and legal barriers, and streamline procedures to meet the growing demand effectively.

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(Dr. Shyamli Varshney)

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AA	-	Appropriate Authority
AC	-	Authorization Committee
ANOVA	-	Analysis of Variance
ICU	-	Intensive Care Unit
IEC	-	Information, Education & Communication
GODT	-	Global Observatory on Donation and Transplant
MOHAN	-	Multi Organ Harvest Aid Network
MoHFW	-	Ministry of Health & Family Welfare
NOTP	-	National Organ Transplant Program
NOTTO	-	National Organ & Tissue Transplant Organization
NHP	-	National Health Policy
NHPS	-	National Health Protection Scheme
NHM	-	National Health Mission
ROTTO	-	Regional Organ & Tissue Transplant Organization
SOTTO	-	State Organ & Tissue Transplant Organization
SPSS	-	Statistical Package for the Social Sciences
THOA	-	Transplantation of Human Organ Act
THOTA	-	Transplantation of Human Organ& Tissue Act
UNOS	-	United Network for Organ Sharing
WHO	-	World Health Organization
UHC	-	Universal Health Coverage

CHAPTER I
INTRODUCTION

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1.1 Organ Donation and Transplantation

The world is becoming more technologically advanced. Even in medicine, new technological methods are used for either diagnostic purposes or for treating purposes (Thimbleby, 2022). People are becoming aware of different diseases and their treatments (Drexler, 2020). Life expectancy rate has also gone up by five years due to new modalities and vaccines (Rughini et al., 2022). On the other hand, these advances have resulted in faster and more stressful lives. (Epelet al., 2018). The number of chronic diseases has increased significantly such as hypertension, diabetes, coronary heart disease, liver disease, etc. (Jamisonet al., 2006). Some chronic diseases lead to organ failure such as renal failure, liver failure, and cardiac failure. (Xanthopoulos et al.,2018). Despite the fact that problems exist, people strive to overcome them or solve them. The replacing non-functioning organs with transplants is one of the treatment options available (Cascalho and Platt, 2006). Hearts, livers and kidneys are currently being transplanted. Diseased people have a good chance of surviving this treatment, but for the availability of organs which is possible only if people donate their organs (Grinyo, 2013).

India has a very high waiting list for organ donation (Asia, 2024). More than 100,000 people are waiting for kidney donation and around 50,000 people are waiting for heart and liver donation (Nayak and Nayak, 2023). However, many of these people die too soon because they don't receive an organ in time (Miller and Currie, 2019). Organ shortage is a major issue not only in India, but across the globe (Beyar,2011). Cadaver donation is also beneficial in cases where live organ donation is not possible (Dalal, 2015). The road traffic accidents claim the lives of three Indians every minute, which shows that the number of young people lost is particularly high (Gopalakrishnan, 2012). Therefore, government and citizens must make more concerted efforts for the promotion and acceptance of organ donation (Sun, 2014). Teachers, religious leaders,

and politicians should also be included in this task along with health team members (Cotrauet al., 2019).

Organ donation is a noble cause (Panwar et al., 2016). It is inevitable that people born into this world will one day die (Breitbart,2017). The truth is people are hesitant to organ donation even ignoring the fact how the organs of a deceased person can be used for others (Mohan Foundation,2013).Even individuals belonging to the health care team who are to bear the responsibility of promotion of organ donation, also exhibit this type of behaviour (Dalal,2015). Due to busy schedules or disregard for social or charitable causes, people forget to bid the best possible farewell to a deceased person by donating their organs to most needy (Siminoffet al., 2013). Doing so, their closed eyes can once again see this world, their heartless bodies can once again beat, even though they are no longer with us (Miller et al., 2018).

1.2 Legal Binding for Organ Donation and Transplantation in India

Transplantation of human organs for restorative purposes is authorized under the Transplantation of Human Organs Act (THOA), 1994. A countermeasure was taken to control the sale of human organs. Except for the state of Andhra Pradesh and the state of J&K, all states have adopted THOA, which is comparable to their laws. Under THOA, source of the organ might be (a) a close relative(mother, father, son, daughter, brother , sister, spouse); (b) non-relative donors: based on attachment or affection with the permission of the governing board; (c) after an individual's brain stem dies, it is often possible to restore his or her organs through aid of ventilation and life support, for example, when a victim of a street car crash has died without his brain stem; (d) another kind of deceased donor are the ones who die of cardiovascular disease (Yadla,2021).

THOA defines brain death in India as a form of legal death, which has revolutionized the concept of organ donation after death (Starret al.,2024). When hearts stop functioning (cardiovascular death), only a few organs and tissues can be donated (like corneas, bones, and skin), but when brain stems stop working (brain death), donor is able to donate a wide variety of organs, including kidneys, liver, and lungs (Sade, 2011). Notably, National Organ and Tissue Transplant Organization (NOTTO), the

apex national network division, coordinates the procurement and distribution of organs and tissues throughout India.

It has the database on organ and tissue donation and transplantation and it creates and publishes a national registry to facilitate organ transplantation in the most secure way possible in the shortest amount of time. The organizational branches of NOTTO are located at the regional-level (ROTTO - Regional Organ and Tissue Transplant Organization) and the state level (SOTTO - State Organ and Tissue Transplant Organization). At the first term which is of the State, SOTTO will oversee organ donation and transplantation. The organ is then offered to ROTTO, that is, to be utilized in any of the regions, following which it is offered to NOTTO if it is not utilized for reasons of no demand or no suitable recipient available (Vasanthi, 2020).

In Haryana, SOTTO is being set up at Post Graduate Institute of Medical Sciences Rohtak to encourage organ donation in the state. In addition to Haryana, Punjab, Himachal Pradesh & Union Territories of Chandigarh, Jammu, Kashmir & Ladakh, fall under the northern ROTTO, a regional organization headquartered at the PGI Chandigarh. As a part of the public awareness campaign, SOTTO is spreading information about the importance of organ donation and removing misinformation among locals. In addition, it is motivating family members to donate organs after their loved one's death. This is expected to impact the demand supply gap and the program's success.

It is estimated that there are 14 multispecialty hospitals, under SOTTO Haryana that are accredited for organ transplantation. The two government-owned, are only the retrieval centres, while remaining transplant centres are operated by private operators and mainly perform kidney transplants. As there are only 2 government centres in the state (Panchkula and Rohtak) at present, emphasis is more on deceased organ donation as organs like the heart, cornea and liver can only be taken from brain dead donors.

According to THOA and the Government of India's gazette, the following provisions must be followed for organ transplant -

Table 1.1: Provisions to be Followed for Organ Transplant

Case	Legal Provisions
For living donation	No legal formalities are needed to donate. In addition to mothers, fathers, brothers, sisters, children, and spouses, relatives can also donate organ/tissue (kidney, blood, marrow). Recent changes to the gazette make grandparents eligible to be listed as first relatives. A genetic test and/or a legal document are required to prove the relationship of the first relatives. There is a requirement that the recipient and donor, in the case of no first relatives, apply for authorization from the government appointed authorization committee and appear for an interview with committee to establish altruistic motives or affection for the recipient as the reason for such donations.
Brain-death and its declaration	Two certifications must be provided before a brain death can be declared: one from the appropriate government authority and the other from a leading neurology expert. Transplant activities will be regulated on a state or federal territory-by-state basis by forming authorization committees (AC) and appropriate authorities (AA).
Authorization Committee (AC)	Responsible for regulating the authorization process for transplants between recipients and non-family donors. It will ensure that no monetary considerations are placed on the donation of their organ. It will monitor that the AC is satisfied with the motivation behind the donation and that the donor understands the potential risks of surgery, a personal interview with the recipient and the donor is crucial. Hospitals are notified by mail regarding the approval or rejection of the donation. Under sub clause (3), clause 9 of chapter II of the Transplantation Health Organization Act, a decision to accept or reject a donor is governed.
Appropriate Authority (AA)	Authority to inspect and register hospitals for transplant surgery, to enforce hospital requirements, to conduct inspections of hospitals for the purposes of examining the quality of transplantation and follow-up medical care of donors and recipients, to suspend or cancel registrations for erring hospitals, and to investigate into complaints of any breach of the Act. It issues license to hospitals for period up to 5 years. License can be renewed after it expires. A license is required for each organ. An eye retrieval can be performed at donor's home.

Source: THOA,2014

The authorization committee and registered medical practitioners have interpreted the THOA incorrectly to a large extent. The current gazette attempts to

correct this a great deal. Before the state governments make it mandatory for hospitals to follow the ruling, this gazette must be adopted by the state governments.

Table 1.2 Interpretation of THOA, 2014

Provisions under THO Act	Interpretations
The Transplant Clinicians	When there is no suitable match for the recipient or no family member willing to donate, why should they refuse an arrangement between the donor and recipient if the law itself provides a clause in order to help? They view the recipient's plight as more important than any objections they may have. Further, they are of the opinion that they do not understand so-called true affection. Those who hold this belief believe the executive branch is responsible for finding love and relationships.
Misuse by the Paid Donor	This clause can be used by a patient who has failed his/her kidneys in order to find an instant emotional attachment to a stranger is willing to donate his/her organ for money, except that AC is never informed of this. After being duped into donating an organ, same donor claims to the police or the media that they weren't paid for the organ. In these cases, it does not matter if they were affectionate or not towards the recipient. Without knowing that the donation for money is illegal, the police go to the middleman, doctor, or hospital immediately. In certain instances, authorization committee tightens its regulations after a media expose and stops even clearing genuine cases.
	In light of the laws, AC concludes that recipients and donors should not object to gestures of affection when they are presented with them. This is unless there is a complaint or a serious mistake. Also, they believe that since the doctor addressed the committee directly with such an allegation, they ought to verify it. AC

Provisions under THO Act	Interpretations
Authorization Committee	applications are usually approved in the vast majority of cases. Unrelated donations are most likely to occur when a donor expresses their true affection for an AC. Approximately 5,000 cases in Haryana were reviewed by the AC between 1995 and 2002. An additional memo by the Haryana Department of Health noted that out of 1,868 applications received between January 2000 and May 2002, 1,559 unrelated transplants were approved. Transplants are done in other state in the country that have similar situations to Haryana. "The act does not prohibit a person who is not a close relative by definition, from donating a kidney if the close relative is not regarded by the family as a potential donor for a kidney transplant. By refusing to grant permission to the petitioners, the committee misdirected itself in this regard." “The committee would ascertain from the second petitioner whether she would be donating the kidney out of ‘affection and attachment’. The donor’s relationship with the recipient, period of acquaintance and the degree of association, reciprocity of feelings, gratitude and other human bonds are perhaps some of the factors which would sustain ‘affection and attachment’ between two individuals. The committee has to ensure that the human organ does not become an article of commerce. The main thrust of the act is against commercial dealings.” “The stalwarts of the unrelated live donor program continue to do as many transplants as they did before the legislative assembly of Haryana adopted the Act. What is more, they do them with the seal of approval from the authorization committee and are therefore a very satisfied lot. The law, which was meant to

Provisions under THO Act	Interpretations
Authorization Committee	prohibit commercial dealings in human organs, now provides protection for those very commercial dealings.” Haryana's department of health notified the state about an AC kidney racket, via a 'Government Order'. They were then released from providing evidence of AC's involvement. In the document, it explicitly states that the doctor signing the questionnaire must prove the relationship to the patient. In this act, the authorization committee plays a key role that is prohibited by the THOA act itself. After the legality of the order was questioned, it was withdrawn. It is now mandatory for the Gazette to videotape the entire interview. There are also guidelines provided to the AC, which state clearly that touts or middlemen are not to be allowed. It is also important that the donor provide a specific explanation for his gift, alongside documents of his living together (such as old photographs) and specifics about his profession, such as financial statements from the previous three years. By removing ambiguity of affection a lot can be done to prevent kidney sales by giving it the seriousness it deserves.

Source: THOA,2014

1.3 Lack of Awareness Regarding Organ Donation and Transplantation

One of the major problems in India is the lack of awareness about organ donation and transplantation not only among the general population, but also among those in health care. However, different healthcare workers work both in urban and rural areas for the health of the people (Nayak, 2023). There are doctors, physicians, pharmacists, and nurses, and in addition there are people who specialize in Ayurveda, Unani and Homeopathy who are also involved with the health care of the people. Medical faculty and nursing faculty in the colleges for future doctors and nurses are also included in these hospitals. As a matter of fact, the syllabus for them varies according to the current issues and the advances in the field and their curriculums are

also revised often. Nevertheless, studies have revealed that a large portion of these students, whether medical or nursing, have inadequate knowledge, awareness, and attitudes toward organ donation. According to a study conducted to determine the knowledge and attitudes, there is limited coursework that puts sufficient weight on this topic. This also implies that nurses and physicians who are part of the health care team do not take this matter seriously (Shrivastav, 2024). In part, this lack of importance to organ donation is due to the limited number of hospitals carrying out transplantation, most of which are located in large cities. Moreover, very few hospitals have the capability to procure and harvest organs. Heart and liver transplants are not common in most hospitals, but kidney transplantation is the most common. There are very few doctors involved in this field and the procedures are also few in number (Shroff S., 2009).

The success rate is low if calculated in terms of its percentage. One of the reason for the above situation can be that the procedure of organ transplantation is done on a trial-and-error basis, and people's notion on organ transplant turns down to be a treatment on trial and error. Transplantation entails getting an organ donor whose organ matches perfectly with the recipient. This matching by the healthcare team poses a risk which also creates a negative impact on society questioning the reliability of the treatment and hesitancy towards organ donation (Vanholder et al., 2021). When the recipient is from an affluent family, they start looking for an organ in the market. In developing countries like India where poverty, illiteracy and corruption are at high level there are high chances of frauds by the organ peddlers who connects the receivers who are in dire need and the sellers who are desperate for money (Panwar et al., 2016). Though organ donation and transplantation are governed by strict laws, often times this is violated and the legal actions taken afterward against the hospitals and medical community have again created a negative impact on organ donation and transplants (Shah and Shah, 2018; Milaap, 2024). Whereas, due to strict guidelines the doctors do not consider organ donation for transplants if the recipient is not related to the donor. Often, medical fraternity, especially those in charge of managing people at different levels of authority, authorities granting permissions, doctors and hospitals performing the procedure, take advantage of the situation to fulfil their need for easy money. Due

to this a lot of people think that transplantation and donation procedures are always in doubt. As the families of the deceased are urged to donate organs, they are always concerned about the destiny of the organs retrieved from their loved ones that whether it will be donated to the needy or sold (Yousefi, 2014). Families of brain-dead patients who are encouraged to donate organs have the misconception that their loved one will not be taken care of properly and willingness to participate (Optn, 2015).

1.4 Perception of Organ Donation and Transplantation in Rural and Urban Areas

The rural and urban areas have wide differences in the medical services availability and also in the social and economic conditions. The urban population tends to have a higher level of education than rural populations, but it is no less susceptible to the myths about organ donation and transplantation. Many urban people have myths about receiving organs from different families and post-death rituals indicating their negative attitude towards organ donation mainly due to lack of awareness (Chen et al., 2018).

The rural areas are in a worse condition than urban areas. Although India is a country with a large rural population, all the advanced facilities are located in urban areas. The rural population are ignorant and illiterate and health care workers and the doctors who work in the rural areas are considered to be indigenous or to be from ayurveda or homeopathy (Barik and Thorat, 2015).There is no access to super specialists in rural areas. The rural areas have government-run programs for non-communicable diseases such as diabetes and hypertension. Organ failure due to these health conditions is becoming more common in rural areas, while there are no existing facilities. Due to the fact that rural people are illiterate, lack awareness and medical facilities, they are in a dire situation (Greiner and Knebel,2019).

1.5 Challenges in Execution of Organ Donation and Transplantation

The other problem related to health care is that the health care members working in this area are not highly educated and there are no in-service educational opportunities or training sessions for them to improve their current knowledge and hence, problem

solving is not possible. Furthermore, they are unable to spend time on newer things because of the burden of other work.

Cities are the destinations for campaigns and propaganda on organ donation and transplantation (Babiker et al., 2014), but the healthcare team members as well as the general population in the rural areas, are not being informed about organ donation. The rural people still have a lot of myths about death and changing their attitudes towards organ donation is very difficult (Greiner and Knebel, 2019).

However, even educated people are unaware of the importance of organ donation and their awareness and attitudes towards it are not directly influenced by education. Whereas, a very little effort is being made to change the attitude or to bring change for the better. Many studies identified that hospital workers, nurses, and medical students have inadequate knowledge and therefore are unable to encourage patients' relatives for organ donation (Mithra et al., 2013; Abbasi et al., 2018; Acharya et al. 2019, Ahlawat et al., 2013; Akbulut et al. 2020 Alghamdi et al., 2023).In many ICUs (Intensive Care Unit), nurses fail to inform their respective coordinators and doctors, as well as patients' family members, regarding potential donors because they do not understand the importance of organ donation (Groot et al., 2014). Some believe in myths and some of them witness fraudulent organ donation. These lead to poor attitudes towards organ donation. (Hoseini et al., 2015). The lack of adequate organ retrieval and follow-up care is another reason for organ shortages (Saidi and Hejazii,2014). Lack of tertiary care hospitals in the area having this facility and the dominance of private hospitals providing this service at very high prices makes it unaffordable to the general public (Abouna,2008).

1.6 Scope of Deceased Donation Program (DDP)

The number of kidney transplants in India is between 3,500 - 4,000 each year. Approximately 120 transplant centres offer this service. There are approximately 150-200 liver transplants performed annually at four of these transplant centres and some of these centres do occasional heart transplants as well (Shroff, 2016). The majority of liver transplants are performed on living donors, with approximately 50 transplants

done on deceased donors. There have also been 100 heart transplantations so far. However, there would not be any need for a living person to donate an organ if even 5 percent to 10 percent of all deceased patients became organ donors (Dalal, 2019). There is a need to promote deceased donation program in order for organ transplants of all kinds in the country to thrive, including kidneys, livers, hearts, pancreases and lungs (Brown, 2008).

However, various hospitals have been successful in sharing organs between themselves and with deceased donors. An organ sharing network built by a non-governmental organization (NGO) called MOHAN (Multi Organ Harvesting Aid Network) foundation has successfully shared over 450 organs in Tamil Nadu (280) and Hyderabad (170) since 2000 (MOHAN Foundation,2013). Since the Jain community is very large in Gujarat, eye donation program has had considerable success in the past. In this community, eye donation is considered a form of charity that transcends all others, consistent with the community's belief that 'daan' (charity) and 'moksha' (salvation) are intimately linked (Gupta et al., 2009; Acharya et al., 2019). Nowadays, an increase in the number of deceased solid organ donations in the state suggesting that a deceased donation might be an alternative to living transplantation (Shroff, 2009; Gupta et al., 2022). Organ donation programs for deceased individuals have the potential to absorb the majority of the state's demand for liver, kidney, and heart transplants if properly organized (Delmonico, 2011).

With cutting edge regenerative medicine, such as stem cell transplants, cloning, and tissue re-engineering, it is necessary to become knowledgeable about the ethics of organ donation (Walton et al., 2023). Many future ethical issues can be addressed and resolved by applying the ethical principles of organ donation (Abbasi et al.,2018).

1.7 Organ Donation and Transplantation in India

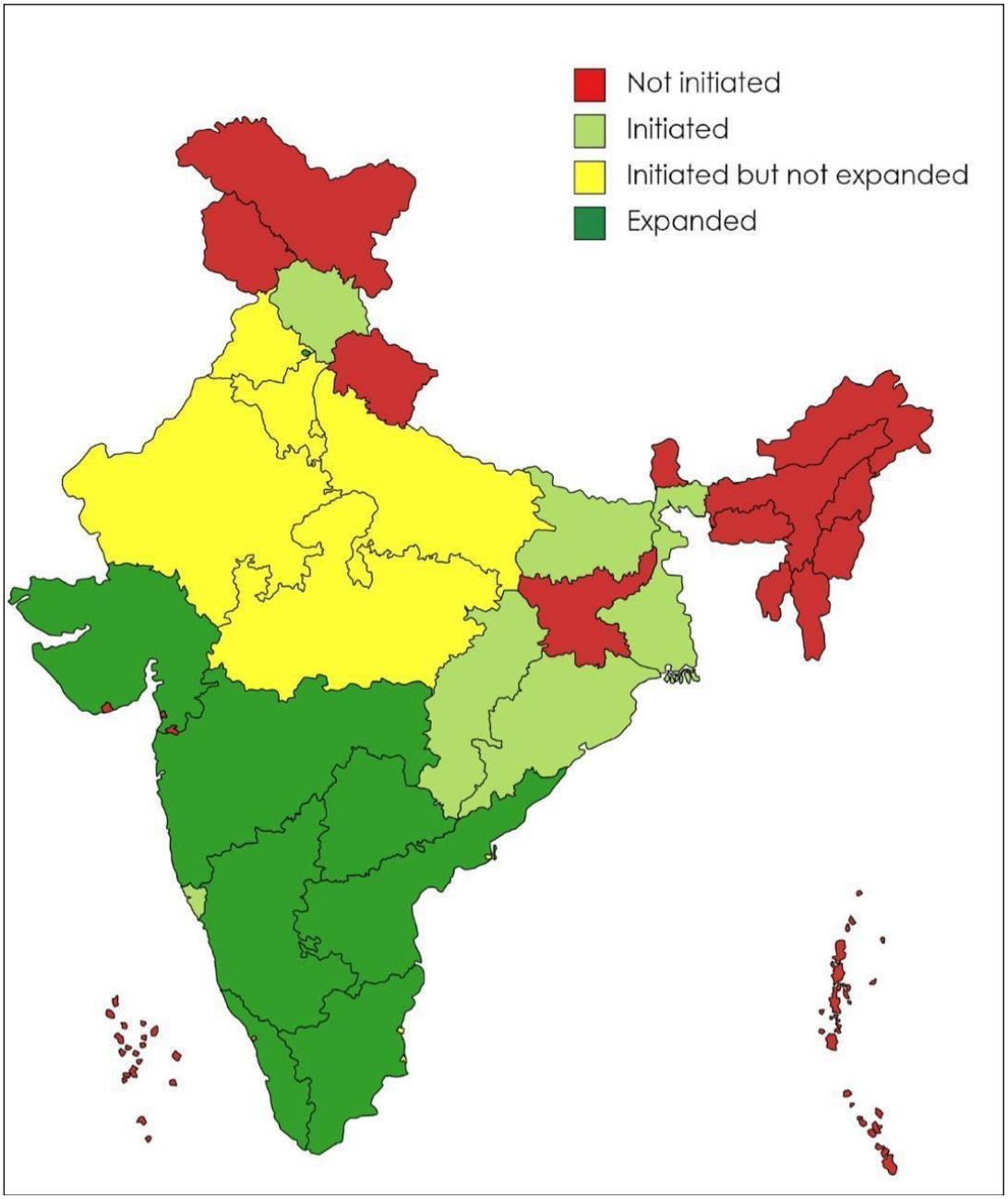
The living and deceased donors can donate kidneys, livers, and other organs, but only deceased donors can donate heart and cornea. In India, a national deceased donation rate of 1 donation per million Indians is unfortunate given the country's 1.3

billion population (Sarveswaran et al., 2018). The number of live donor transplants undertaken in India is second only to the United States, but the country doesn't rank anywhere in the list of deceased donor transplants (Asia,2024). Although corneal donation and transplant programs are quite developed in India, it is relatively rare to find donors after death (Wykrota et al., 2022). Haryana and Punjab are among the states in the northern part of India with the lowest rate of organ donation (Vincent et al., 2022). The differences in such donations after death may be due to misinformed perceptions or insufficient awareness (Carola et al., 2023).

1.8 Organ Donation and Transplantation in Haryana

Organ transplant and retrieval activities in India are controlled centrally by NOTTO, who in turn are supported by regional and state transplant authorities (ROTTO & SOTTO respectively). There is reluctance of many states to adopt THOA amendment Act 2011, however, Haryana has adopted this act as well as established SOTTO unit but the organ donation status is dismal as compared to the various states of the country as shown in figure1.These are the national figures, where Haryana falls behind miserably as far the number and activity of transplants is considered. It has a total of 14 transplant centers out of which 11 are private and majorly doing kidney transplants only. Till date, hospitals under SOTTO Haryana are doing kidney transplants only. In spite of, laborious efforts by the State Government the yearly figures of transplants done are dismal as compared to the demand. Over the last 5 years the number of kidney transplants done have barely crossed the triple digit figure. From 28 kidney transplants done in 2019, progressively this figure has reached to 94 in 2023 (NOTTO, 2024). However, till date, none of the hospitals under SOTTO Haryana is doing deceased organ transplants. These figures are also due to the fact that, Faridabad and Gurugram which falls in NCR region, are not covered administratively by SOTTO Haryana but because of their proximity to the national capital, these have best medical setups for organ transplant.

Figure 1.1: State-wise Distribution of Deceased Organ Donation Activity



Source: NOTTO (2022)

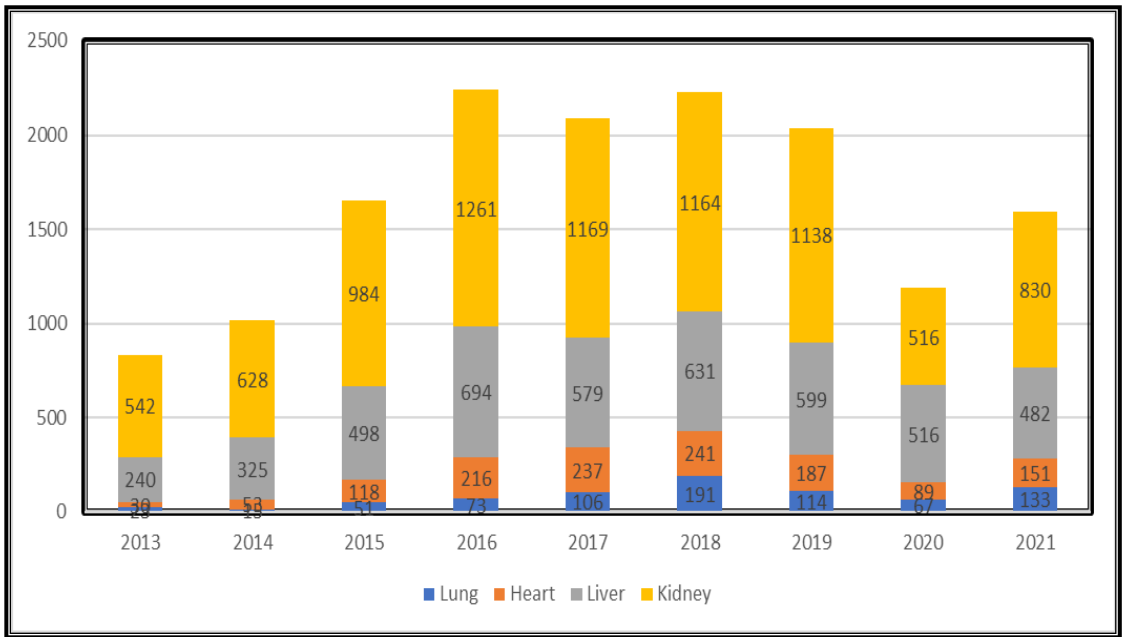
1.9 Steps to Promote Organ Donation and Transplantation

The only way to reduce the demand supply gap of organs for transplantation is to encourage deceased organ donation (Saidi and Hejazii,2014; Lewis et al.,2021; Saxena et al.,2023). Though there has been a marginal increase in deceased organ donations, a lot further has to be done as shown in figure 1.2. We are living in a time when young people are highly influenced and aware about the current issues. As a result, it is good to make them more aware of the importance of organ donation because in the future they will be able to affect change in the attitudes of people around them as they can influence their family. The students in high school and college should also learn about organ donation in the curriculum (Selvanathan et al., 2021), not only medical and nursing students. The schools and colleges should organize campaigns to raise awareness (Nurafizah, 2015; Ganesh et al., 2018).

Currently, organ donation is promoted by government but there are some positive moves being made by health teams and NGOs. Numerous programs were held on world organ donation day to spread awareness about organ donation (Tamuli et al, 2019). These rallies took place throughout the country. Politicians and celebrities joined in on the registration drive. Different groups of youth worked together to make it a success. Nevertheless, there is still a lot of work to be done because people often participate in different programs or campaigns without registering themselves.

Organ failure is no longer a problem confined only to urban areas, but is a problem that is prevalent in rural areas as well (Chen et al., 2019). Making people aware will help to resolve or reduce the severity of the problem and also reduce the frauds in organ donation and transplantation (Caulfield et al., 2016). The political leaders need to be sensitized on organ donation and transplantation and current changes must also be enforced regularly through seminars, workshops, rallies, and campaigns (Subitha et al., 2016). In order to improve the attitude of the people in the country there is a need for coordination between countries and states in urban and rural areas. The social leaders and religious leaders can help to change myths about organ donation . The changing people's attitudes about organ donation might also result in positive changes in their thinking (Somaili et al., 2022).

Figure 1.2: Year-wise Deceased Organ Donation Status (2013-21)



Source: NOTTO (2022)

1.10 Rationale of the Study

The present study involves analysis of the real data on the organ donation and transplantation program in Haryana. The study would analyse the awareness, perception and the stakeholders concern with regard to the scheme in the state and therefore could throw light on the real pressing issues in scheme implementation which could have relevance to similar green-field states like that of Haryana. This would augment the literature with evidences on the organ donation. This study will improve an understanding about the reasons for low organ donation rates and develop remedial strategies in order to enable wider acceptability of organ donation by the society. Understanding the demand supply analysis for different organs would lead to effective streamlining of the scheme such that it satisfies the interests of various stakeholders and sketches the path to achievement of the national commitments of universal health coverage (UHC) and provision of organs for the needy. The study can be of relevance to the various stakeholders as it supports various stakeholders in varying dimensions of scheme implementation. It can be used to improve policy to create awareness amongst the local population in an effective manner understanding their regional and religious customs and beliefs. This can further help to identify and breaking barrier of

misinformation. It can help the administrators in effective implementation of program by plugging the operational gaps.

1.11 Objectives of the Study

The present study intended to provide insights into organ donation and transplantation in the state of Haryana and has following specific objectives:

1) To identify the awareness level of organ donation and transplantation among the people of Haryana.
2) To understand the perception about organ donation and transplantation among the people of Haryana.
3) To analyze the demand supply gap of various organs for transplantation in the state of Haryana.
4) To study the economic aspect of organ donation and transplantation in Haryana by analyzing the cost benefit ratio.
5) To understand the stakeholders concern regarding the organ donation and transplantation scheme in the state.

1.12 Chapter Scheme of the Study

The objectives of the study have been presented in various parts of the study and are detailed out into nine chapters. The introduction of organ donation and transplantation has been given in Chapter I. Chapter II presents a comprehensive structure of review of literature and its present status in Haryana and its various dimensions like awareness, perception, demand supply gap, cost benefit analysis and stakeholders concerns. Chapter III highlights the detailed research methodology applied for analysing the findings, Chapter IV, discusses awareness about organ donation and transplantation in Haryana. Chapter V assesses the level of perception about organ donation and transplantation. Chapter VI examines the factors that affected the demand supply gap of organs for transplantation. Chapter VII evaluated the cost benefit analysis of organ transplantation. The concerns of the various stakeholders like the Govt. officials, hospital administrators, transplant surgeons, transplant recipient patients, have been highlighted in Chapter VIII. Summary, conclusion and policy implications are conversed in Chapter IX.

CHAPTER II
REVIEW OF LITERATURE

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REVIEW OF LITERATURE

An extensive review of the existing literature was conducted, focusing on various aspects of organ donation. The existing literature was conducted in the different focus areas of organ donation by reviewing research studies conducted at national and international level. Reviewing different literature relating to the area of study is one of the crucial steps in any research study as it helps to understand the magnitude of the problem under study and formulate the research problem for the main study objective. It helps devise the research plan including the different methodology and tools that can be used for research, the typical difficulties that the researcher may face during the study and the summary of work already done on the same topic and therefore, avoid duplication. The literature review was sectioned into the following sub-headings:

1) Studies related to legal and ethical issues of organ donation
2) Studies related to people's knowledge, attitude and perceptions about organ donation.
3) Studies related to demand-supply mismatch and shortage of organs across globe.
4) Studies related to costs of organ transplant.

2.1 Legal and Ethical Issues in Organ Donation

The organ donation refers to the process of removing tissue from one person's body with the purpose of transplanting it into another person's body (Muco et al.,2023). Organ donation embraces the concept of the "gift of life" which encompasses voluntary blood or organ donation (UNOS, 2020). In this selfless act, an individual donates blood or one or more organs to an anonymous recipient without expecting any financial or other rewards in return (Shaw and Webb, 2014). These acts of altruism, such as blood or organ donation, transcend formal contracts and legal obligations (Dopelt et al.,2022). These selfless acts are devoid of power dynamics, coercion, guilt, or financial expectations. Instead, they emerge from the realm of free will, conscious choice, and a sense of moral duty unburdened by shame or the need for reciprocity (Carola et al.,2023). Globally, there are various legal and ethical issues related to organ donation

activities. The rules and ethics of different countries may be different as per the prevailing law and culture.

2.1.1 Legal Considerations in Organ Donation at the Global Level

The organ transplantation faces ethical and legal challenges worldwide due to the persistent shortage of organs. In this context, professionals grapple with issues related to both deceased and living organ donation and transplantation (Ambagtsheer et al., 2024). The countries worldwide strive to eradicate unacceptable practices related to organ transplantation while promoting self-sufficiency in meeting transplant needs (Haberal et al., 2019). Legal and ethical frameworks are developed to encourage responsible practices and improve organ donation rates globally (Oxford University Press, 2024)

The ’gift of life’ doctrine has been contended by many countries due to the shortage of organs they face and the malpractices that arise in the process of organ donation (Fahrenwald et al., 2010). A study by Thomas and Klapdor (2008), argued that the ‘gift of life’ doctrine is to be viewed as flawed on various grounds and suggests viewing the act of donation as that of a rational, autonomous decision-maker. According to Durur and Akbulut (2017) and Akbulut et al. (2020) organ transplantation policy in Turkey specified that Turkey also faces difficulties in providing the organ necessary for organ donation and transplantation because of various legal, religious, educational, administrative and psychological problems due to organ procurement. In addition, quality of life, life expectancy and treatment costs of the patients all these reveals that there is necessity of policy development and implementation and in organ transplantation and donation.

In many countries, like Oman and Hong Kong, there exists a critical shortage of solid organ donors, exacerbated by a growing number of potential recipients (Buckley, 2020). While limited local data indicate public support for organ donation, several challenges persist (Nasar et al., 2023). The common reason for objection to organ donation is the uncertainty about the deceased’s wishes (Rodrigue et al., 2008). Without clear information, families hesitate to consent (Pan et al., 2021). Despite the absence of specific legislation, medical community in Hong Kong has embraced the expressed consent model. This approach emphasized obtaining explicit consent from potential donors or their families (Simin-off et al., 2013). The utilization of non–heart-

beating donors, the practice of elective ventilation in futile cases, and the consideration of financial incentives all present significant ethical and legal challenges (Escudero et al., 2017). Implementing effective organ donation programs requires substantial resources, particularly within intensive care units (ICUs) (Buckley, 2000). The persisting global organ shortage, in combination with fast-moving medical, technological, geopolitical and socio-economic changes, has given rise to an array of legal challenges for professionals working in the field of organ transplantation (Abouna, 2008; Weimer et al.,2014; Shah and Shah, 2018; Martin et al.,2020; Shroff and Gill, 2021). The various legal challenges in deceased organ donation (Lewis &Gardiner, 2023) and transplantation, range from survey studies on opt-in -and opt-out systems (Mihály et al.,2023) and radiological screening methods (Chotkan et al., 2023), to difficulties in comparing deceased organ donation rates, even between countries that have similar cultures and organ donation systems (Milross etal.,2022).

Many countries have changed their laws from an opt-in to a presumed consent system, among which the United Kingdom and Netherlands (Jansen et al.,2022) reflect on the experiences in these countries during these major changes, thereby offering valuable knowledge and guidance for professionals and policymakers who are considering changing national organ procurement laws. To address these challenges, World Health Organization (WHO) has taken efforts to establish a legal binding for organ donation at the global level (World Health Organization, 2009). These principles aim to promote ethical and transparent practices, prevent commercialization and ensure equitable access to transplantation services (Sheime et al., 2017). More recently, WHO has launched the Global Observatory on Donation and Transplantation (GODT), a platform that provides data, resources, and guidance to support countries in strengthening their organ donation systems. The GODT promotes ethical practices, transparency, and international cooperation. (Matesanz et al., 2009; Transplant-Observatory, 2021)

Another significant development is the council of Europe's Convention on Human Rights and Biomedicine, also known as the Oviedo Convention (Andorno, 2005). It was signed in 1997, this treaty sets out a framework for organ donation and transplantation, emphasizing informed consent, privacy, and non-discrimination (Council of Europe, 2014). While progress has been made towards establishing a legal

binding for organ donation at the global level, continued efforts are necessary to ensure a unified and ethical approach to this lifesaving practice.

2.1.2 Legal Binding for Organ Donation at Global Level

Given the differences in the contexts and issues in the different countries the legal provisions adopted by the countries for organ donation is also different. Overall, amended versions of 'Opt-In" and 'Opt-out" systems are being adopted by countries (Pérez et al., 2022). In an opt-in system, individuals must actively sign up or register to become organ donors after their death. This system ensures explicit consent that only those who willingly choose to donate their organs are included in the donor registry. It respects individual autonomy as it provides the individuals with the control over their decision to participate. However, opt-in approach lacks awareness or proactive steps to resulting in lower organ donation registration rates (Etheredge, 2021). India and United States of America, operates primarily on an opt-in system where individuals voluntarily register as donors.

On the contrary, in an 'opt-out system', organ donation is presumed unless a specific request is made before death for organs not to be taken. Since everyone under opt-out system is automatically considered a potential donor, participation rates tend to be higher which can help bridge the gap between organ demand and supply (Donor Alliance, 2020). England adopted an opt-out system (deemed consent) since 2015, where everyone is considered a potential donor unless they explicitly opt out. Nonetheless, the opt-out system has drawn criticism across the globe on the contexts of presumed consent infringing on individual autonomy. This is more so in case of a 'hard opt-out' system where the individual is presumed to have consented for organ donation and the donor's wish takes precedence over family objections (Iacobucci, 2020). Austria and Singapore follow a hard opt-out system. In 'soft opt-out' system as in England and Spain, family consultation remains crucial for decision-making on organ donation which questions the success rates of increased organ donation (McIntosh, 2014; Conversation, 2023).

At present Spain is one of the leading countries in world with an opt-out system for organ donation and has an exceptionally high organ donation rate. The first reason for this high organ donation rate is that Spain follows presumed consent means if person is not showed disagreement for organ donation it will be consider as agreement.

Secondly, each hospital having an intensive care specialist should have transplant coordinators compulsorily, and they should have undergone special training and are often on duty in rotation to prevent psychological burnout. Thirdly, training and education of almost sixteen thousand health workers so that medicals and nurses will be in position teach at grass route levels by following right protocols to protect organs (Matesanz et al., 2017).

2.1.3 Ethical Aspects of Organ Donation at Global Level

In the current generation, there is an increasing emphasis on ethical considerations in the field of organ donation and transplantation (Ambagtsheer et al., 2024).Ethical issues in Nigeria were discussed by Ajayi et al. (2016) where different aspects like need of incentives for donor, trafficking as well as trading of organ, different criminal activities carried out during transplantation and the more important is economics of eliminating the waiting list were discussed. They also specified that there is need to have extensive efforts to monitor transplant activities especially in those developing countries where there is high rate of corruption and poverty leading to organ trade and trafficking.

According to Pasha and Albar (2006) there is wide gap in demand and supply resulting in very long waiting time and increasing deaths. It is also creating certain social, moral and ethical issues such as exploitation of the poor for the allocation of organs and using live donor for the benefit of wealthy. However, Atreya et al. (2023) highlighted cultural and religious considerations, in organ procurement systems. The success of program depends upon economic situation, religious approval, public views, medical expertise and existing legislation. Increasing the awareness amongst the religious leaders is vital to remove the social taboos and improve the public attitude towards this noble cause.

In order to cope up with the demand supply gap in organ donation and transplantation, options of deceased donation after euthanasia under ethical considerations had been raised by Dijk et al. (2023).There are ethical considerations in living organ donation and transplantation too, Choi et al.(2023) evaluated the knowledge of and attitudes toward liver and kidney transplantation from minor donors in South Korea. They further assessed if receiving structured information on the outcomes of living organ transplantations and donations may change attitudes towards

liver and kidney transplantation from minors (Ashwin et al., 2024). However, Marcus et al. (2023) in their research studied various reasons for and against anonymity in kidney paired donation. A study by Ambagtsheer et al. (2024) found that public opinion in Europe supports removing financial disincentives and introducing incentives for both deceased and living organ donation. The study suggested that societal backing for incentivizing organ donation basically depends on the specific characteristics and institutional design of the proposed incentive scheme.

During the literature research, it looked into a cutting-edge topic in organ transplantation, namely the development of bio-artificial organs (Wang,2018). To address the lack of ethical guidance for the safe and responsible design and conduct of early-phase clinical trials of bio-artificial organs. Jongh et al.(2022) conducted a systematic review to examine the literature on early-phase clinical trials in these adjacent fields. The study presented a thematic analysis of relevant ethical points to consider for early-phase clinical trials of transplantable bio-artificial organs.

2.1.4 Religious and Social Taboos

It was observed that certain communities and religion have various taboos associated with organ donation (Exley et al., 1996; Bhengu and Uys, 2004; Davis and Randhawa, 2004) like as in Jewish law, if there is procurement of organ from living donor it should only for saving someone's life provided that the donation will not affect the health of the donor then only it is permitted and encouraged and if the organs are procured from dead persons, it will only be allowed if it is used for saving someone's life. The living donor will not donate his or her organ if there is risk of his life or possibilities of death though purpose is to save some one's life (Feld et al., 1998).

According to Bilgel et al. (1991); Hai et al.(1999); Bilgel et al. (2004);AlKhawari et al., (2005); Ashraf et al.(2005); Alvaroet al. (2008) attitude of conservative Muslim communities towards organ donation and concluded that a few Islamic nations like Turkieye are liberal about organ donation. Even, in Abu Dhabi, both the deceased as well as living person can donate organs. The rule out there specifies that any human organ or any part of body organs of human will not be sold for the purpose of transplantation. The law also bans all the unlicensed advertisement working for human organs transplantation. Strict laws have been enforced to provide a safeguard against fraud which may take place during transplantation, which may vary

from life imprisonment to heavy monetary fine or blacklisting of such medical practitioners or hospital (Government of UAE, 2024).

There has always been a debate worldwide that the prosecuted prisoners given death penalty should be made to donate their organs. Lin et al. (2012) in their study concluded that not much benefit may actually be realized by this enforcement. There may be a greater number of donors than the actual executions in the same period (DeRoos et al., 2019). However, by conventional criteria such as age, medical conditions, and communicable disease, many of these prisoners did not fit into the criteria of being eligible donors. Increasing public awareness of organ donation (Timar et al., 2021) and creating donor registries are less controversial methods to increase the number of donor organs. Evans (2007) in his study specified that the dead people who are declared dead unequivocally are not suitable for organ transplantation. In cases of inevitable death, there is a need to redefine death and willingness for organ donation is taken before the actual death. The certification of propounding death is done in little earlier stage in dying process. The concept of deceased cardiac death (DCD) will help in availability of organ without much of legal issues (Gupta et al., 2022).

2.2 Legal Aspects for Organ Donation in India

The ways in which governments can support the ethical development of organ donation and transplantation programmes is by ensuring that appropriate legislation, regulation and oversight are in place, and monitor donation and transplantation activities, practices and outcomes(White et al., 2014). According to WHO hospitals and institutions should follow highly qualitative and safe and effective procedures for both the donor as well as recipients. All the procedures such as procurement of organ and then organizing same for transplantation and the outcomes of the procedure should be very transparent and open to scrutiny. It is also important to maintain the anonymity and privacy of both recipient and donor (Petrini et al., 2020).

Organ transplantation in India falls under the Ministry of Health and Family Welfare (MOHFW). The Transplantation of Human Organs Act (THOA) was passed by government in 1994. It highlights the procedures and regulations to be followed for organ donation and transplantation. However, to make the process simpler and encourage organ donation the THOA was amended in 2014. The recent amendments include provision of enrolment and renewal of retrieval and transplant centres and

simplification in the brain death certification, wherein now onwards the brain death certification can be awarded in the presence of surgeon/physician and an anaesthetist intensivist, if neurosurgeon/neurologist is not available (Srivastava et al., 2018), authorization advisory group should be hospital based if number of transplants undertaken is twenty-five or more in a year at the individual transplantation, and if the number are <25 in a year, at that point the state or region level approval committee would allow approval(s); medical expert associated with transplantation group won't be an member of approval panel.

It has now become obligatory on intensive care unit/treating medical staff to request relatives of brain-dead patients for organ donation and the definition of term "close to family members" has now been amended to include grandparents and grandkids in addition to parents, children, brother, sister, and spouse. A major step taken by government to increase the organ donation is to permit the swap donations of organs between close to family members. Procedures for foreign national's notification, if they happen to be donor or recipient and methods advised in detail to prevent business activities and abuse of minors. However, to maintain transparency an organ retrieval regulatory body-national organ retrieval, banking, and transplantation network has been established which maintains registry of donors and recipients waiting for organ transplants. It has been made mandatory to fill up position of a "Transplant Coordinator" in all hospitals registered for Organ Donation and Transplantation (ODT) (Johnston-Webber et al., 2023); every approved transplantation centre should have its own website. The identity of the people in the database shall not be in public domain; the approval board is required to take a final decision within 24 hours of holding the meeting for grant of permission or rejection for transplant (Yadla, 2019). The website of transplantation will be connected to state/regional/national networks through the online framework for organ procurement, sharing, and transplantation.

According to Kries (2005), amendments were carried in the THOA, regarding the cost for maintenance of the cadaver (brain-stem dead declared person), retrieval of organs or tissues, their transportation and preservation. According to the amendments, now on the cost will not be borne by the donor family and might be borne by the recipient or institution or government or nongovernment association or society as chosen by the respective state government or union territory administration (Govil et

al., 2017). A detailed methodology with respect to quality affirmation, donor screening, capability and experience of specialist/transplant organizer, research centre examinations, laboratory investigations, equipment, documentation, and other requirements have also been notified (Henry,2005).

2.2.1 Brain Death Declaration/Certification

If planning procurement of organ from the person who is suspected to have brain stem death the procurement or removing of organ should not be carried out unless the death is not certified by medical board of experts. A doctor (registered medical practitioner) is authorized to remove an organ from a brain-dead patient only if the, patient is certified as brain dead and his family had consented for the organ donation. It is the job and responsibility of the transplant coordinator he/she should work along with the doctor to counsel families of patients in ICU and of brain-dead patients about organ donation (Gracious and Jose, 2020).

2.2.2 Legal Aspects for Live Donors

In case of organ donation (mostly Kidney) by the donor who is live, The THOA rules that donation by near relatives do not need the approval of authorization committee. But when donation of an organ is done by a person who is not a close in relation with donor then approval from AC is mandatory. If the donor is a spouse, then there should be sufficient evidence to prove that the couple is legally wedded. If the donor is not a near relative then multiple proof are needed to show that the donor and recipient know each other well-to-prove “affection or attachment”.

2.3 Awareness and Perception about Organ Donation

The awareness, attitude and perception of general population towards organ donation in a society, even among the educated, are major hurdles to organ shortage. Whereas, lack of awareness among public and if aware having correct knowledge are quintessential for the success of the organ donation programme in the country. Considering India’s deceased donation rate of 0.08 percent million populations per year. Shroff et al. (2003), opined that organizing a program to create awareness and change people’s perception towards organ donation in India is a logistical challenge. According to them, non-government organization (NGO) called MOHAN (Multi Organ Harvesting Aid Network) played a major role in the early part of the decade in promoting deceased donor organ procurement and distribution. Since 1999, in the

southern states of Tamil Nadu and Andhra Pradesh, this NGO has facilitated the sharing of >400 deceased donor organs which is 33percent of the total deceased transplants done so far in India. The current donation rate is much higher in the four states of Tamil Nadu, Andhra Pradesh, Gujarat and Maharashtra with it being 0.3 per million population (Shroff and Navin, 2003). Another study by Abraham et al. (2012) also highlighted that the MOHAN foundation has majorly helped in deceased donor transplantation, by procuring organs such as the heart, heart valves, lung, liver, kidneys, cornea, and skin through its network. This private-public partnership promoting deceased donor transplantation has effectively eliminated commercialization in transplantation in the state of Tamil Nadu, and become a role model for other Indian states and developing countries.

National Organ and Tissue Transplant Programme (NOTP) in India conducts IEC activities to generate awareness among the masses on organ donation by which the program intends to disprove myths, eliminate obstacles and cooperate with medical professionals and make the gift of life more easily accessible to the needy. However, available literature reveals that even the medical graduates/students or the medical staff do not have complete knowledge about organ donation and even if known there was low willingness to donate organs. Whereas, an interventional study carried out by Sugumar et al. (2017) for medical students found that their knowledge was poor and about 3.93 percent had donor card and 60 percent were willing to donate while 48.63 percent showed distrust against doctors (Sugumar et al., 2017). A study by Adithyan et al. (2017) on knowledge and attitude about organ donation among medical students in Kerala found that the majority of student (88.7percent) had adequate knowledge regarding organ donation but despite this willingness to donate was less (Adithyan et al., 2017).

Whereas, a cross-sectional study carried out on 178 post graduates and 122 interns of medical college in Karnataka showed that the postgraduate students knowing about kidney donation was 99.4 percent, liver donation was 94.9 percent and almost all students aware about corneal donation. The participants who expressed willingness for organ donation was 72.7 percent while only few registered for the same and have donor card (Bathija, 2017). The knowledge and attitude towards organ donation among 100 paramedical workers of SRM general hospital using an attitude scale tool found that

there was inadequate knowledge (Ambiga and Jane, 2016). Another study carried out among interns of a medical college in Telangana found that 79.4percent have adequate knowledge and 77.5 percent were willing for organ donation, while only a 5.6 percent had donor card. It was found that willingness was significantly associated with knowledge and the major fear was misuse of donated organ (Tanna et al., 2023). An assessment of the change in knowledge and attitudes of students of medical education on organ donation and transplantation showed that there was no significant change in knowledge after medical education too (Vinay and Beena, 2016). Even among healthcare staff including doctors and nurses in a public sector tertiary hospital in Chandigarh, only 55 percent agreed for organ donation after death and a 27 percent have not yet decided (Ahlawat, 2013). Another study in 2015 at tertiary care hospital to assess the awareness of nurses showed that 75 percent of them had average knowledge, 22 percent has poor knowledge and only 3.5 percent has good level of knowledge of organ donation (Krishnan et al., 2015; Bharambe et al., 2016).

The above studies highlighted the knowledge and attitudes of budding and experienced healthcare workers on organ donation who were to deal with and propagate the act of organ donation (Tanna et al., 2023). It is observed that there is a lot of resistance from the medical fraternity themselves. Given this context, there also exists quite a lot of research conducted on the knowledge and attitudes of the general public. The precepts from selected studies are summed up below for having an idea about the knowledge and attitudes of the population on organ donation in the country.

It was found that 88 percent were respondents were aware of organ donation in Puducherry and further analysis shows that the younger age group of 18-30 years and the educated (those studied above HSC) were more aware. Their common source for information was media. Whereas, 70 percent were willing to donate their organs and about 57 percent stated family as the cause of refusal (Subitha et al., 2016). A study conducted in Bengaluru highlighted that the percentage of participants who had adequate knowledge about Organ donation were 53 percent and 67 percent had positive attitude for organ donation. While, only 120 of them were willing for organ donation after their death which were significantly associated with demographic variables such as gender, age education and economic status (Poreddi et al., 2016). An observational study by Dasgupta et al. (2014) in West Bengal found that 85 percent samples were

aware of the term organ donation. Only 11.8 percent were ready for donation and also was ready to sign a card for same. About 35.5 percent were willing for donation if required and 40.5 percent said they will ask for money in exchange. A survey conducted by Times of India (2023) revealed that 94 percent of the people are aware of organ donation and 6 percent are not but the sad part is that out of 94 percent of people about 85 percent is not aware of what all organs can be donated and nearby 45 percent are only aware that they can donate organ while living. However, awareness of the legal aspects and mode of registration and procedure for the same were low among the population (Chandrasekaran et al., 2022). In rural settings too, a study on the knowledge towards organ donation in Kerala showed average results with 95 percent having heard about organ donation while only 35 percent had good knowledge and 48 percent had poor attitude towards an organ donation (Nelson et al., 2014).

According to Shah et al. (2015) commerce college students in Ahmadabad found to be aware of organ donation and it was high (88 percent) and about 63 percent of the study sample wanted to become donors. There were about 44 percent of the students that were aware of organ donation in case of brain death. The study suggested that to increase number of donors and awareness amongst people, a multi spectral approach to include electronic and print media, religious leaders, scholars, doctors and teachers to promote awareness of organ donation is required. Annadurai et al. (2013) assessed awareness of organ donation among college students in Chennai, Tamil Nadu. It was found that almost all students were aware about organ donation but were not aware of the legislation and only 2 percent were registered for organ donation.

The awareness of organ donation among 85 patients with chronic kidney disease (CKD) was conducted in a tertiary hospital in Ahmedabad by Balwani et al. (2015). Though all of them at presented a knew about organ donation and transplantation as treatment for most of the vital organ failure, about 47 percent heard about it from the hospital or doctor. However, many were not aware about legislation for same (Balwani et al., 2015). A similar study in a tertiary care centre in Mangalore among 863 outpatients seeking general healthcare found that 59.6 percent willingness for donation those who were willing for donation were higher no of females and people from higher socio-economic condition. Muslim had less willingness compared to Hindu and

Christian, 58 percent said it's an offense to take money, 3.7 percent had organ donation card (Mithra et al., 2013).

A similar situation of the above awareness and willingness levels towards organ donation in the country is experienced in other parts of the globe as well but in different intensities and contexts. A study in Kuwait revealed 68 percent awareness with better knowledge among females and almost everyone wants to donate to their relatives (Bosakhar et al., 2016). According to Janahi et al. (2018); Alghamdi et al(2023) that many respondents in the UAE has correct knowledge about organ donation and transplantation legislations. In Iran, the willingness to donate organs among relatives of patients referred to emergency department was 73 percent while not all having a positive attitude towards donation (Pouragheai et al., 2015). The study in Nigeria showed the willingness to donate to be higher that is at 79 percent (Ibrahim and Randhawa, 2017). The willingness to register as an organ donor in the cities of Denver and San Francisco in the USA, was 68 percent while only 11 percent having positive perceptions towards it (Regalia et al., 2014). The attitude of young adults in the UK in a study by Coad et al. (2013) showed that the attitude of young adults towards organ donation is very low i.e.22.4 percent in the UK but high in Spain i.e. 42.2 percent.

A study was conducted by Rykhoff et al. (2010) to raise the awareness regarding organ donation among health science students in Canada and along with it to check their knowledge, attitude and beliefs for same. Out of 235 students, 86 percent were aware about organ donation while 52 percent stated family consent is important before going for organ donation. This study was quasi experimental with an educational session given to them. The post educational session result found that awareness regarding family consent increased from 52 percent to 96 percent. The student who showed willingness for donating an organ increased from 63 percent to 82 percent. However, 20 percent said they will not donate organ at all. Thus, study concludes that the educational session in curriculum helps to improve awareness of students regarding organ and tissue donation (Lei et al., 2020).

2.4 Demand -Supply Mismatch and Shortage for Organs

2.4.1 Shortage of Organs across Globe

The organ transplantation is the best treatment which has been available for years for the treatment of organ failure. However, organ availability is still not reached

that mark where people don't need to wait years together for an organ donor (National Academies of Sciences, 2017). The problem is still as big as it was in the beginning. Though many different measures have been initiated for the same and the result is still meagre. In spite of the growing literacy rate across the globe, people's thinking has not yet changed as needed. Thus, organ donation is not a problem in India alone and it has marked its global presence. Different reviews show that almost all countries suffer from the pain of organ shortage and this review has attempted to find out the intensity of the problem worldwide.

However, Gulf News and health has published survey on organ transplants which showed that in the UAE, the number of patients receiving dialysis is around 2000 and all are waiting for a kidney transplant (Gulf News, 2019). Ethics about current scenario of organ donation in Saudi Arabia and knowledge and perception of people of Saudi Arabia about organ donation stated organ failure many times have no age group and occurs even in younger age people who are not suffering with any chronic illness (Ali et al., 2013). Therefore, death happens due to the shortage of organ. In the country the death because of liver failure is around 10,000 and 50,000 die due to organ failure. About 18,000 people suffer with renal failure and among them 10 percent receive dialysis and only 4.5 percent have received transplant the rate is 5 per million population.

Statistics on organ donation in the UK reveal variations in donation rates, influenced by differences in people's attitudes, opinions, and levels of knowledge about the subject (Jones et al., 2019). That Northern Ireland is having highest organ donation rate that is 25.5 percent per million population where it was low in Scotland. According to Statistics Department of Health and Human Services in UK the number of donors available nationwide has remained stagnant over last decade starting 2016 (Govt. of UK, 2017). In 2005 there were 14,497 donors and in 2016 the numbers of donors were 14,415. Also, the number of organs received from live donors dropped by more than 16 percent. Johnston (2017) in an article in ‘The Guardian’ discusses that reluctance to talk about donation leaves families unsure of potential donors and a reluctance to donate specifies that according to NHS 450 patients died waiting for organ and currently 6414 patients were added within a week to already existing list (NHS,2021).

The statistics of Australia on organ transplant reveals1500 people waiting for organ transplant and among them 703 for kidney, 264 liver and 95 for heart transplant (Transplant Australia, 2019). The current donation rate in Australia is 18.3 donors/million. According to National Kidney Foundation (2016), USA there are currently 1,21,678 patients waiting for organ transplantation and among these 1,00,791 waits for kidney transplant. Each month the waiting list is added with 3,000 new patients and the death of such patients waiting for life saving renal transplant is almost 13 people each day. The US department of Health and Human Services in their report says in spite of high education and economic levels in the USA, organ failure is high that about 119,000 require organ transplantation (Health Resources & Services Administration, USA, 2023).

On their waiting list of organ donation 81.8 percent are require kidney transplant and 11.4 percent liver transplant. However, organ donated by living are 5990 and by deceased donor it is 24,980. About 95 percent of US adults support organ donation and still they are facing the shortage of organs. A study by Health Dept. of Canada on blood, tissue and organ donation, (Canada, 2021) specifies the need for donation of organ in Canada. As per the article over 4500 people are waiting as organ recipient and about 278 people died waiting for organ transplantation. The number of deceased organ donors has gone up by 44 percent in Canada. As stated by the European Consensus Department, condition in Europe countries is not different. Currently 40000 are waiting for kidney transplantation, mortality rate among people waiting for organ transplantation like liver, lung and heart is between 15-30 percent. Almost 400 deaths occur due to organ failure as they are waiting for transplants (Furian et al.,2024).

The problem is not only in the developed countries like USA, UK and France. The developing countries like India, Pakistan or some of the East countries, also face the problem equally. Vij (2014) states liver failure to be a major problem associated with kidney failure. People are still not familiar with concept of liver donation and therefore neither anyone from patients relative nor general public come forward for organ donation leading to 200,000 people losing their lives and around 20,000 people requiring liver transplantation while only 2,000 transplantations are being done (Betrosian et al.,2007). However, Westphal et al. (2016); Betsch et al. (2020) suggested that given the complexity of the process of liver transplantation, its time now that all

the brain-dead patients especially those whose organs are acceptable and function adequately will donate to improve the likelihood of recipient.

According to Organ Retrieval Banking Organization (ORBO) there is acute shortage of organ donors in India. The donation rate is very low at 0.1 meaning the people donating their organ is only one in ten. While requirement is quite high, around 50,000 need hearts, 200,000 require kidneys and 100,000 require liver. In spite of India having trained doctors or facility for transplantation or donation, it is the apathy of people towards it and the neglect of this by the health workers are the cause of the problem (Organ Retrieval Banking Organization, 2023).

2.4.2 Reasons for Shortage of Organs

There are various reasons associated with low rates of organ donation across the globe. A few prominent reasons highlighted in literature are classified below.

2.4.2.1 Myths on Organ Donation

It was found that various studies have on 'myths of organ donation' stated that people are mostly worried about the disfigurement of body with organ donation (Mohan foundation, 2013; Medicine, 2016; Miller et al., 2018). However, in China, it is religious beliefs and lack of knowledge on brain death is the common reasons for low organ donation in China (Wu et al.,2018; Li et al.,2019; Fan et al.,2022; Chen et al.,2023). The News Minute (2016) states the five common myths relating to organ donation were that it can only happen after death, scared donors due to misconception that doctors may not save their lives, scared about other organs being stolen, fear of family being charged for donation and religious superstitions about mutilation of body post death.

However, MOHAN Foundation (2016) specifies that it is religion that discourages organ donation in India. There is a belief that organ removal disfigures the body and affects cremation. Another myth is that only rich and famous people get organs fast while others do not. A survey carried out by Times of India (2013) showed that 28 percent of a total of 641 urban respondents believed that organ donor will not receive any lifesaving treatment and 18 percent believed that their body will not be mutilated. The awareness program arranged by Mudra Communication for Youth held in Ahmedabad on 13th August 2016, highlighted the superstitions among the people that the person donating organ will be reborn blind (Shastri, 2016). Still there is

misunderstanding among people that after donating organ the person goes to hell after death. According to Organ Retrieval Banking Organization (2023) India is facing an acute shortage of organ donors due to prevalence of myths and superstition regarding organ donation especially the deceased organ donation, the concept of brain death which is leading to wrong practices like kidney rackets and exploitation of needy and poor people.

2.4.2.2 Legal Processes

Among other factors are the legal processes involved in organ donation as discussed by Razdan et al. (2015). As there are tedious legal procedures to be followed by the donor, recipients and the institute carrying out the transplantation these processes are time-consuming leading to absenteeism from work or financial loss. The deviations from the procedures to be followed can affect the recovery of organ and will affect the organ donation. They also specified that if the procedure is carried out smoothly then the deceased person willing for organ donation will improve four times more than the current one(Gardiner et al., 2021).

2.4.2.3 Attitude of Health Care Professionals

A study carried out in Poland on the major limiting factor in organ donation from brain dead donors mainly blamed the attitude of health care professionals for a low rate of donations as the common medical practitioners are not willing to start formal diagnostic procedures once clinical signs suggest brain death, unless an organ procurement was considered. Therefore, residents were in general more willing than established specialists (Kosieradzki et al., 2014). A study by Sahi et al. (2013) support that many myths and misconceptions regarding organ donation exists as no proper guidelines are available and neither proper counselling is done before the procedure either by health team member or counsellor specially among those people who personally encountered transplant recipients and donor which affects the donation (Ralph et al., 2014).A study by Souqiyyeh and Shaheen (2006) in their study in Saudi Arabia found the attitude of doctors towards the follow up patients largely affect the rate of organ transplant. Proper medical care within reach, taking acceptance of organ transplant, well designated clinic, and proper laboratory set up to monitor the

immunosuppressive drug levels. There was also problem with availability of expertise and proper protocol for treatment and follow up patients.

2.4.2.4 Family Refusal

The opposition from family members were are also a major cause for refusal of organ donation. A study by Sorensen and Kousgaard (2017) on the important reason for lack of organ donation says that in most families the family members do not support the decision of person. As per the study among 350 neuro patients that died, the rate of organ donation was 27 percent and in second half among 270 patients that died the donation rate was 37 percent, the reason being lack of consent from next kin. A study by Little and Balamurugan (2013) carried out a cross-sectional exploratory study to assess the expected barriers for organ donation and the factors that can facilitate it. The common realization the study gave were that there was family opposition about 80 percent of the times and few of them specified about the fear about the organ donation. There were also a few facilitators for willingness as organ donor such as saving someone's life and humanity. However, association with demographic variables and educational status were positively associated with willingness for donation (Regalia et al., 2014).

According to Irving et al. (2012) several factors influence the decision to become an organ donor. These include family influences, cultural and religious beliefs, relational ties, concerns about body integrity, mistrust regarding brain death criteria (potentially leading to premature organ retrieval), limited individual knowledge, and significant reservations about the donation process. Ghorbani et al. (2011) conducted a retrospective study in Iran to assess how family refusal creates a barrier for organ donation along with other cultural and religious factors causing ignorance and obstruction. The study was carried out on individuals who wanted to donate organ but refused the same later. Among 146 families studied, common reason expressed for denial were denial and rejection of brain death criteria, fear about organ trade and unknown organ destination, religious belief that body should be intact after death, unstable family mood and fear of objection by other family members.

2.4.2.5 Medical Condition of Donor

The studies conducted by Downar et al. (2016); Shemie et al. (2017); MacDonald and Shemie (2017); Lyu and Zhang, (2017); Akdeniz et al. (2021); Carlisle

and Bagwell, (2021) highlighted the ethical dilemmas in withdrawing treatment of the critically ill patients for various reasons and organ donation. Transplantation is long duration procedure which requires strong financial support, the outcome of which is insecure. The study suggested that patients should be told about quality of life in the physical, psychological, social and spiritual aspect after transplant. Chintamani and Mrunalini (2011) mentioned many factors which affects the selection of appropriate recipient. The candidacy is determined by a variety of medical (HTP matching and tissue typing) and psychosocial factors. Those patients with diabetes and hypertension are to be considered high risk and improper selection or compromising the selection criteria may lead to failure (National Academies of Sciences, 2017).

2.4.3 Measures to Improve Organ Donation

2.4.3.1 Training to Medical Staff

According to Slabbert and Venter (2017) treatment for terminal organ failure is organ transplantation and to improve organ donation rate the donation should be routine component of end-of-life care. The study also specified that if a health department of South Africa can start the routine- referral policy document which will be best basic step to start the willingness for organ donation. It should be compulsory for all physicians to evaluate every death, for possibility of organ donation. Whereas, Ajayi et al. (2016) discussed the ethical and legal issues in renal transplantation suggested certain measures which can improve the donation such as professional bodies like doctors, nurses, social workers, program coordinator should be in leading role for organ donation. Even government can start public consultation with regard to this which will help to bring awareness among community regarding living as well as deceased person organ donation (Potter et al., 2017). According to Bharambe et al. (2015) examined the awareness on organ donation in urban areas of Pune, Maharashtra. It was suggested to use health professionals and newspapers for generating awareness regarding body and organ donation. Providing information to individuals to generate awareness will help to clarify their myths and increase understanding and motivation.

A study by Oznur et al. (2016) carried out the retrospective studies in a hospital in Turkey found that the transplantations that were performed in the hospital were possible because of effective role of coordinator during family interview. The study

suggested that for effective procurement of organ there is need to train the ICU staff for recognizing the signs of brain death, and increasing the awareness for donor care. The interview and counselling regarding the organ donation among families should be done by the trained and experienced coordinator so as to help to improve the acceptance among family for organ donation and bringing awareness in community.

According to Sobnachet al. (2016) inclusion of educational measures in South Africa for improving medical students' knowledge about brain death. A systematic review conducted by Douville et al. (2014) suggested that if we want to improve donation rates there should be practical frameworks based on sound theories. The professionals will be benefited if more rigorous evaluation method is used. For improving professional practices ensuring good knowledge and translation and appropriate organizational decision are needed. The intervention needed are educational, organizational or combination of both. To improve the knowledge, service meetings, workshops, conferences can be conducted with the use of printed documents.

A study carried by Ramadurg and Gupta (2014) assessed the impact of educational intervention on medical student knowledge he found that it helped to change attitude and improve beliefs. It was found that about 70 students consented to participate and of the sample 91 percent were Hindus and only 4.3 percent were Muslims. The students who have heard about organ donation were 95 percent. The study also revealed that while a knowledge change was observed before and after educational intervention, the awareness about the legal aspects regarding organ donation was poor. The study specified the importance of educational intervention which will be included as motivational messages for organ donation, current facts and figures, which will help to bring the change in perceptions and intentions of students towards organ donation.

2.4.3.2 Generating Awareness Among Public

Lopez et al. (2015) conducted a cross-sectional study on medical students to know whether there is association between education and acquisition of the organ donor card found that proper education should be provided to raise the donation rate and positive attitude towards donation. A study by Zamani and Abedi (2015) conducted comparative study on effective factors on consent to organ donation among families of

brain death victims in Isfahan and found that the factors which may affect the person's ability to take decision for organ donation are awareness and knowledge along with the attitude of family members. It was found that cultural background plays an important role in this (Bora and Zarghami, 2017). It was also suggestedto improve the knowledge and awareness as it will help to improve attitude of people regarding organ donation which in terms will facilitate the acceptance by family members. Kumar (2016) and Zirpe et al. (2020)specified that increased in brain death has increased in number of transplantation but in order to have significant improvement in the cadaver organ donation the steps to be taken are bringing awareness among people by providing knowledge and maintain proper protocol while caring for the donor.

A study conducted by Lespier et al. (2013) in Puberto Rico highlighted the need to incorporate educational program to increase knowledge and awareness regarding organ donation and the transplantation process. The predictors of public attitudes towards living organ donation in Kango Northern Nigeria by Iliyasu et al. (2014) had highlighted the importance of information education and communication strategies which will provide clear message on social benefits as well as on religious aspects. It will also provide bioethical guidance which will help to improve awareness and willingness (Caplan,2014).

A study conducted in Sweden regarding influence of two organ donation campaigns on knowledge and formal decision making found that 88 percent people showed willingness for organ donation after campaign. Thirty five percent showed willingness for registering and acquiring donor card. The willingness of donating organ of relative after the death had improved from 70 percent to 79 percent. This learning and teaching support showed improvement in request for organ donation which reveals that campaign was successful (Krekula, 2009).

Tong et al. (2013) suggested measures to improve the public awareness such as reimbursement for out-of-pocket expenses to be paid, provision of leave, health insurance and donor acknowledgement should be encouraged. The analysis carried out to find out the factors that are effective for consent for organ donation by families of victims suffering with brain death, suggested that the major factors affecting were

cultural backgrounds and knowledge and awareness. There is a need to improve the knowledge and awareness the attitude also improves which further leads to acceptance of family members. However, Guleria et al. (2012) analysed the trends of organ donation and awareness in Ernakulum, Kerala and stated that the need of awareness is required among people to improve donation. The legal procedure and formalities should be less problematic and be encouraging people for deceased donation. While specifying why Spain is having high rate of organ donation. According to Escobar (2012) and Striets et al. (2023) there were few reasons such as more ICU to take care of donors, positive decision to withdraw life sustaining treatment are made for less often, accepting organ donation as normal aspects of end-of-life care, the confidence and support of the general public and awareness among public through mass communication. The superstitions which are among the people needs to be fought by the religious order and incentive can be given in form of health insurance.

A study by Stefanone et al. (2010) specified the need of educational campaigns to educate and promote the population about organ donation through media. For this it is important to bring some changes in practice guidelines followed in US as well as modification in national policy regarding support provided by nurse specialist change in current information status and improvement in process of consent for tissue as well as organ donation. However, Bellomo and Zamperetti (2007) defined vital condition for organ donation gave importance to the public education and said there is no alternate measures other than education which can bring the change in knowledge. But this education should not be based on particular ideology and needs to be based on socially and morally acceptable facts and supported with appropriate information regarding the support technology used for vital organ. The most important thing is the autonomy of patient should be maintained. A study by Li et al. (2013) assessed the knowledge and attitude about deceased organ donation with classroom education. It was found that most of the educational program consisted of one or two classrooms' sessions. The result showed that educational program succeeded to increase knowledge and attitude in five studies. The success of promoting family discussions for organ donation (Rodrigue et al., 2010) was seen in seven studies thus the study concludes the promising strategy that can be utilized to improve knowledge of students for deceased organ

donation will be classroom education and also help to increase support of public for organ donation.

2.4.3.3 Targeted Teaching Programmes to Improve Organ Donation

According to Kumar et al. (2019); Janetet al. (2023), highlighted that brief educational video can positively impact individual's willingness to become organ donor (Kurleto et al., 2022). After watching videos members of the public are more likely to say they would be willing to donate organs. Whereas, Maiti and Balaji (2022) carried out a study for finding out the impact of teaching via video assistance for staff nurses on prevention of Corona virus infection. Study findings showed the difference among pre-test and post-test knowledge score which indicated that the video assisted teaching was effective.

A study carried out by Joshi (2020); Tejeshwari et al. (2022) on 60 samples to know how a structured program will be able to improve knowledge and behaviour of nursing students showed that in pre-test 51.76 percent had inadequate knowledge and about 48.3 percent had less adequate knowledge. But, the post test result showed some improvement in knowledge with 85 percent having adequate knowledge and only nine students had moderate knowledge. In case of attitude, 35 students had negative attitude in pre-test which later on turned to positive attitude in post-test. The study also reveals that effective measures are needed to educate people with proper information. A study Pauline et al. (2015) assessed the effectiveness of a structured teaching program regarding organ donation among adolescent boys in school of Chennai. The post test result showed improvement in knowledge which helped to conclude the teaching was effective. Abouna (2008) conducted a study on assessing the problems in organ donation and the possible shortages to organ shortage crisis. The study suggested that implementation of appropriate education programs to public and hospital staff appropriate utilization of marginal, acceptance of paired organ donation reward gifting for family (Cantarovich, 2004).

There were also evidences of effective targeted teaching in other medical fields too. A study to assess the effectiveness of video-assisted teaching on knowledge and practice of using metered dose inhaler with space among patients with bronchial asthma found the video teaching was effective (Pushpakala,2015). Another study to find the

effectiveness of video-assisted teaching regarding aerobic exercises and practice to maintain the blood sugar level among diabetes patients showed the teaching was effective to reduce blood sugar levels (Begum, 2015). However, Babu (2015) assessed the effectiveness of video-assisted teaching on knowledge and pre procedural anxiety level of patients undergoing mammography in Kerala. It helped them to understand the procedure and they found that it helped to reduce their anxiety through mass media. The pre-procedural anxiety level of patients was reduced after video-assisted teaching given through mass media. Abed et al. (2014) also carried out study on "video assisted patient education to modify behaviour" and found that successful behaviour modification in the treatment group shows behavioural change especially in practice or narrative presentation.

2.4.3.4 Influence Through Religious Leaders

A study by Kent and Owens (1995) study of nurse's attitude to organ donation says that nurses had conflicting attitudes towards cadaveric organ donation and the main reasons for same are religious belief and fear of disfigurement. Pasha and Albar (2006) studied the ethical challenges in organ donation in the Arab world and suggested approaches to improve it such as approval from religious leader's public opinion and views, medical expertise and existing legislation regarding donation and transplantation. The religious leaders play important role to improve the attitude of people and therefore, increasing awareness amongst them is important (Sayyed et al., 2021).

2.5 Cost of Organ Transplant

In India, there are roughly 290 deaths every day due to kidney failure (Kumar et al., 2021). Nearly 1.5 lakhs brain deaths are caused in India due to accidents, stroke (sub-arachnoids' haemorrhage) and brain tumours. Even if 5-10 percent of all brain deaths are harvested properly for organ donation, there would be no requirement for a living person to donate organs. These numbers suggest that with adequate systems in place, people succumbing to accident-prone injuries could meet a major portion of the demand (Shroff et al.,2005; MoHFW,2024). At present, private healthcare system provides 80 percent of renal replacement therapy (RRT). In India the crude and age-

adjusted incidence rates of end-stage renal disease (ESRD) is estimated to be 151 and 232 pmp, respectively (Modi and Jha, 2006). However, every year 3.25 per million population RRT are performed. The average cost of the two most commonly transplanted organs among the hospitals in which the fieldwork was conducted are: liver-₹20 to ₹25 lakhs and kidney – ₹2 to ₹4 lakhs. The government rate for a liver transplant is ₹14 lakhs, whereas most of the hospitals charge ₹6-₹10 lakhs more than the government rate (Narasimhan, 2016)

The organ transplant procedure and its maintenance are costly affair to begin with but the gains are evident when individual is able to return back to his work and lead good quality of life than that was prior to transplantation. Authors have evaluated the economics versus quality of life of the patient of transplantation (Krueger, 1989; Laupacis et al.,1996) and noted that 'offering a patient extended life without reasonable quality seems to be cruel and unusual punishment. The quality of life is an important issue but its measurement is not straightforward. However, out of the different approaches, the simplest is to state the proportion of transplant survivors who have been rehabilitated, with rehabilitation defined as the ability to return to the occupation or activity of their choice (Evans, 1986; Callahan and Paris, 2010).

Balakrishnan and Nageswaran (2020) examined the cost incurred by a hospital in Indian setting in conducting heart transplants during a 3-year period. Classifying both direct and indirect costs to the hospital, the direct costs turned out to be 40 percent of the total costs. Their estimations showed that a wide variation in direct costs ranging from ₹2,40,882 to ₹24,03,193 with a mean of ₹6,03,755. The costs were affected by duration of hospital stay, survival or death of patient and the death of patient within 7 days of surgery. According to the study, the total average cost of heart transplant procedure was ₹14, 59,000. Therefore, a 'one package fits all" seemed unrealistic as per the study.

Another cross-sectional study carried out at a public tertiary care hospital on the direct costs involved in treating chronic kidney disease (CKD) of 150 CKD patients at an outpatient department of a public tertiary care hospital showed that the annual average costs of treatment for patients on medication only and for patients on haemodialysis plus medication were ₹25,836 and ₹2, 13,144, respectively and the difference seemed to be statistically significant (Ahlawat et al., 2017). However, Ramachandran and Jha (2013) conducted a similar study by taking into account the

direct and indirect costs incurred from the time of diagnosis of the kidney disease to the transplantation. The direct expenses considered were physician fees, cost of drugs and disposables, dialysis, and expenses on investigations and hospitalization while indirect expenses in forms of travel, food, stay, and loss of income suffered by the family were included. The opportunity costs of educational dropout and financial loss were also considered. The study found direct expense accounted for two-thirds of the total expenses, while the estimated indirect expenses accounted for remaining one third. The study observed that transplant treatments are catastrophic in nature and among respondents about 54 percent, 8 percent, and 10 percent of the patient families suffered from severe, moderate, and some financial crisis respectively.

Palakuri et al. (2024) sought to estimate the financial burden of acute-on-chronic liver failure (ACLF) using cross-sectional data from 55 ACLF patients in a tertiary care hospital. The study considered and calculated direct costs that included medicines, doctor visits, investigations, procedures, treatment, direct non-medical cost that comprised of transportation, food and accommodation and indirect costs that arose due to loss of productivity by patient and care giver. The calculation revealed that the average cost of management of ACLF in India is ₹1,78,483 ± ₹83,460. As to the breakup of these costs, the direct medical costs, direct non-medical costs and indirect costs were ₹134,310 ± ₹ 62,796, ₹ 13,809 ±₹ 8455 and ₹30,364 ± ₹ 21,142, respectively.

2.6 Research Gap

The above review of literature conducted under various headings provided valuable insights of the research gaps.

a. Almost every country faces a shortage of organ donations and recognizes the urgent need to raise awareness among the general public.
b. The widespread lack of knowledge and the prevalence of myths about organ donation are significantly hindering this noble cause.
c. No one offers medical claims or incentives for donors.
d. Regardless of age, education, or profession, attitudes and knowledge about organ donation remain largely unchanged.
e. Many countries are also grappling with fraudulent activities during organ donation and transplantation, where the poor are often exploited and coerced into selling their organs to the wealthy.
f. Legal challenges surrounding organ donation are consistent across countries. The legal system, at times, appears to be manipulated to favor the rich, often with the involvement of medical professionals.

Ultimately, these reviews guided the researcher in shaping the problem statement, study objectives, methodology, video-assisted teaching, and data collection tools.

CHAPTER III
METHODOLOGY

CHAPTER III
RESEARCH METHODOLOGY

The research methods adopted and the tools used for data collection and analysis are imperative for framing the research design for a study (Mann, 2003). A research design endows with the structure for data gathering and examination (Badu et al., 2019). It involves the processes of formulation of the sample design, developing of the tools for information gathering and the process of data gathering and its examination. Thus, a well set out research design is inevitable for data collection and analysis. A detailed description of the study population is presented in this chapter and the research methodology including sample design and sample size as well as data analysis tools used are described. There are three sections in this chapter. Section I, of the chapter discusses the concept and hypotheses for the study and the sample design and process of estimation of sample size for the research. In section II, instruments of research are discussed in terms of their validity and reliability. Analysing, data using statistical tools is described in detail in Section III.

3.1 Design of the Study

3.1.1 Research Design

The research study titled "Perception and Awareness towards Organ Donation and Transplantation and Policy Suggestions: A Study of Haryana State" is based on descriptive research and cross-sectional in nature. The study tried to examine the various aspects of organ donation and transplantation in the state of Haryana. This study intends to conduct an in-depth analysis of the organ donation and transplantation process in Haryana by looking at awareness and perception levels. The study analysed the concerns of various stakeholders involved in the process of organ donation and transplantation and finally give some policy suggestions for the betterment of this process. Furthermore, it analysed the concerns of various stakeholders involved in the process of organ donation and transplantation, including donors, recipients, medical professionals and policymakers and provided actionable policy suggestions for improving the efficiency, equity and accessibility of the organ donation and transplantation process in the state.

3.1.2 Sampling Design

The study population consisted of the population in Haryana, along with a subset of patients who have had exposure to organ transplantation, including transplant recipients and patients awaiting transplants. The study participants were drawn from both the general population and individuals with organ transplant exposure in Haryana. The summary details of the sampling frame used across the state are provided in table 3.1. This list was initially compiled from records obtained from the Department of Health and Family Welfare and relevant Government of Haryana websites.

Table 3.1: District-wise Population Distribution in Haryana

District	Population (2011)	Population (2020est.)	Percentage of total population of the State(Based on 2020estimates)
Panchkula	561,293	639,874	2.21
Ambala	1,128,350	1,286,319	4.45
Hisar	1,214,205	1,384,194	4.79
Kurukshetra	964,655	1,099,707	3.81
Kaithal	1,074,304	1,224,707	4.24
Karnal	1,505,324	1,716,069	5.94
Panipat	1,205,437	1,374,198	4.75
Sonipat	1,450,001	1,653,001	5.72
Jind	1,334,152	1,520,933	5.26
Fatehabad	942,011	1,073,893	3.72
Sirsa	1,295,189	1,476,515	5.11
YamunaNagar	1,743,931	1,988,081	6.88
Bhiwani	1,634,445	1,863,267	6.45
Mewat	1,061,204	1,209,773	4.19
Jhajjar	958,405	1,092,582	3.78
Mahendragarh	922,088	1,051,180	3.64
Rewari	900,332	1,026,378	3.55
Gurgaon	1,514,432	1,726,452	5.97
Rohtak	1,089,263	1,241,760	4.30
Faridabad	1,809,733	2,063,096	7.14
Palwal	1,042,708	1,188,687	4.11

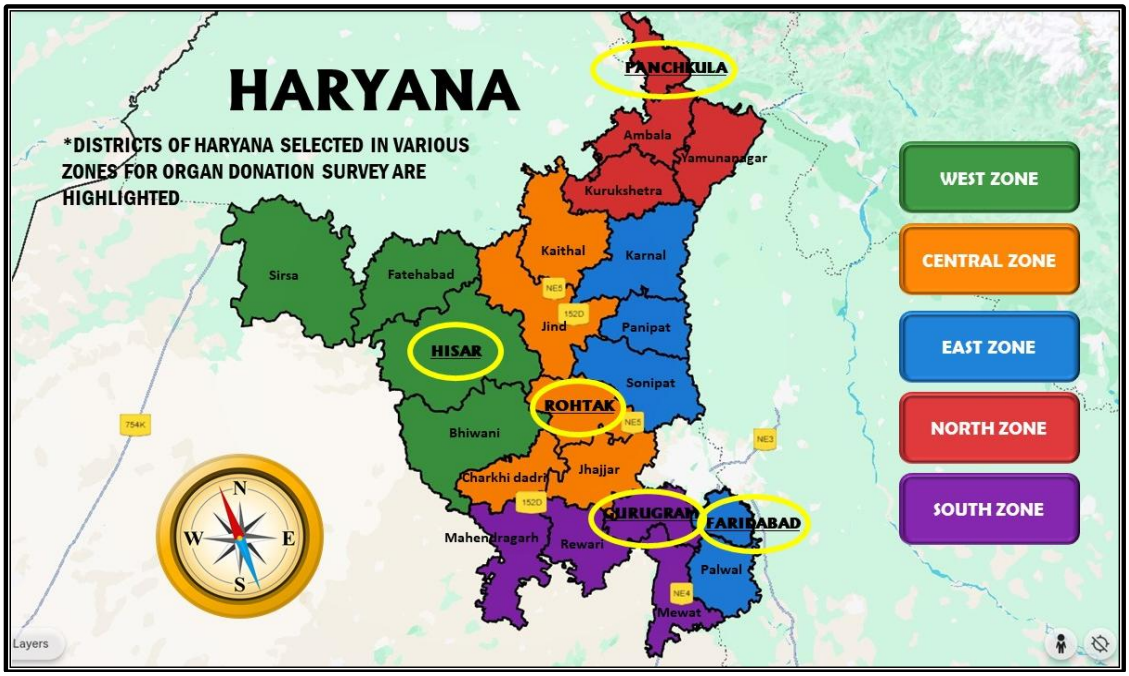
Source: Census, 2011

However, cluster sampling has been used for selection of the sample for the study. In cluster sampling, sub-groups are selected from the population such that every subgroup must have characteristics that are analogous to those of the whole sample. Including everyone from each sampled cluster may not be feasible. Therefore, sampling

individuals from within the clusters is preferred and this process is referred to as multi-stage sampling. Large and dispersed populations can be handled using this method. There may, however, be substantial differences in clusters, increasing the risk of error in the sample. Also, if the sampled clusters may not represent the entire population, it is difficult to guarantee their representativeness. Thus, to avoid bias in the work presented here in making the assessment; a complete list of clusters representing the sampling frame was gathered.

In order to understand the awareness and perceptions of organ donation program under different clusters / zones. The target population was identified in each cluster. Accordingly, the researcher collected and compiled data from respondents representing the sampling frame from each zone.

Fig 3.1 Division of Haryana in Various Zones and Selection of Districts



Source: Haryana Statistics 2000

3.1.3 Sample area and District Selection

The present study involved the state of Haryana, as itis divided into five clusters representing northern, southern, central, eastern and western zones. Furthermore, one district from each of the zones, which has at least one transplant hospital been enrolled viz., Panchkula, Gurugram, Rohtak, Faridabad and Hisar respectively has been included in the present study. Furthermore, data is collected from neighbouring towns and villages of these districts on the basis of purposive sampling. Whereas, the data from

patients for other objectives has been collected from all transplant hospitals (14 in number), which are located at only five (5) cities in Haryana i.e. Panchkula, Gurugram, Rohtak, Faridabad and Hisar; SOTTO Office in Rohtak and DGHS Office in Panchkula. The complete details of the hospitals surveyed for the collection of data has been shown in table 3.2.

Table 3.2 Surveyed Transplant Hospitals of Various Zones of Haryana

Zone	District	Hospital	Organ/s Transplanted
North	Panchkula	Alchemist Hospital	Kidney
		Command Hospital	Kidney,Liver,Cornea
		Ojas Hospital	Kidney
West	Hisar	Aadhar Hospital	Kidney
Central	Rohtak	PGIMS	Kidney
		Mann Hospital	Kidney
South	Gurugram	MedantaMedicity	Kidney,Liver,Heart,Cornea
		Artemis Hospital	Kidney,Heart,Cornea
		Paras Hospital	Kidney,Liver
		Fortis Institute	Kidney,Liver,Heart,Cornea
East	Faridabad	AIMS	Kidney,Heart
		ESIC	Kidney
		Fortis	Kidney
		Sarvodya Hospital	Kidney, Bone

Source: NOTTO (2020)

3.1.4 Sample Size Selection

As per the latest census, Haryana had a population of approximately 3 crores. According to the Ronan Conroy guide on sample sizing, a sample size of around 500 was deemed appropriate to achieve a study with 95 percent power and a margin of error of less than 5 percent for the first two objectives. The sample size from each representative district was proportionally taken based on their share of Haryana's total population.

Calculating the sample size involves determining how many observations or repeats should be included in a statistical model. While factors such as data collection costs, time, and convenience can influence the sample size, it is essential to ensure sufficient statistical power based on the standards set by the researcher. The sample size is derived using the following equation:

$$Sample\ Size\ (n) = Z^2(p)\ (1-p)\ /\ e^2$$

Where, Z= Z statistic for a level of confidence. However, a 95 percent level of confidence, the conventional Z value is 1.96. p=estimated prevalence of risk factor and e= margin error e.

Table 3.3: Sample Sizes According to Ronan Conroy Guide on Sample Sizing

Acceptable Margin of Error	Size of Population					
	Large	5000	2500	1000	500	200
+_20 percent	24	24	24	23	23	22
+_15 percent	43	42	42	41	39	35
+_10 percent	96	94	93	88	81	65
+_7.5 percent	171	165	160	146	127	92
+_05 percent	384	357	333	278	217	132
+_03 percent	1067	880	748	516	341	169

Source: The RCSI Sample size *hand book. (2021)*

Table 3.4 Prevalence and Power for Comparing a Sample with a Known Population

Difference between the prevalence	Population prevalence 50 percent		Population prevalence 25 percent		Population prevalence 10 percent	
	90 %	95 %	90 %	95 %	90 %	95 %
5%	1047	1294	825	1028	438	553
10%	259	319	214	267	122	156
15%	113	139	97	122	59	76
20%	62	76	56	70	35	46

Source: The RCSI Sample size *handbook. (2021)*

3.1.5 Distribution of Sample Size for Awareness and Perception

A sample size of 500 was selected from five representative districts: Panchkula, Gurugram, Rohtak, Faridabad and Hisar as per the above-mentioned zones. The sample was distributed according to the probability proportionate to size (PPS) of the population in each district. Based on available secondary data, Faridabad, representing 30percent of the total population in the five districts, had the largest sample size of 150. Gurugram, with 24percentof the population, was allocated a sample size of 120. Rohtakand Hisar, each accounting for around 18-19percent of the population, were assigned sample sizes of 90 and 95, respectively. Panchkula, with the smallest population share of 9 percent, was allocated a sample size of 45. Table 3.5 below shows the distribution of the sample size across the districts.

Table 3.5: Distribution of Sample Size as Probability Proportionate to Size

District	Population of District	Percent Of Total Selected Districts Population	Sample Size
Faridabad	2063096	30	150
Gurugram	1726452	24	120
Hisar	1384194	19	095
Rohtak	1241319	18	090
Panchkula	0639874	09	045

Source: Census, 2011

As of the above a total of 150 respondents were selected from Faridabad, 120 from Gurugram, 95 from Hisar, 90 from Rohtak and 45 from Panchkula on the basis of purposive sampling. Thereafter, those who are aware of the organ donation and transplantation, a further video-assisted teaching (VAT) intervention on knowledge and attitudes regarding organ donation was conducted.

3.1.6 Data Collection from Stakeholders

The organ donation and transplantation process in a state has four important stakeholders that are part of the formal structure of this process. These include:

a) Government agencies and policymakers–State Health Department officials handling Organ donation and transplantation.

b) The transplant authorized empaneled hospitals under the scheme.

c) Transplant Team members including Surgeons & Coordinators

d) The beneficiaries - patients received organ transplant (organ recipients) or are awaiting organ donation for transplant

The current research study has also conducted interviews with these different stakeholders using pre-defined and pretested questionnaire. The discussions were planned and conducted for the following sample of stakeholders in the present study as shown in table 3.6.

Table 3.6 Description of Selection of Stakeholders

	Stakeholder	Number of Interviews
1	Health Department officials handling Organ donation and transplantation	5
2	Administrators of empanelled hospital– public and private(1 each from 14 Transplant authorized Hospitals)	14
3	Transplant Team members (Surgeons & Coordinators) – (1 from each Hospital)	14
4	The beneficiaries include: • The patients who had received organ transplant(organ recipients'), 2 from each centre – total 2x 14= 28 • The patients who are awaiting organ donation for transplant, 3 from each centre – total3x14 =42,	70

Source: Authors Creation Based on Survey

In order to get diverse opinions from various stakeholders involved in the scheme through interviews to gain a deeper understanding of their concerns regarding the implementation process. By engaging these stakeholders, study captured a range of perspectives, offering a comprehensive view of the challenges and intricacies associated with the scheme's execution. This approach not only highlighted potential barriers but also provided insights into how the processes are perceived and navigated by those directly involved. As a result, the study gained a richer, more nuanced understanding of the implementation dynamics, enabling a more informed analysis of the factors that may impact the success of the scheme.

3.2. Data Sources

This section defines the approaches and measures used for the collection of data. Considering the comprehensive objectives of the study, figures were obtained from the second-hand and first-hand sources:

3.2.1 Primary Data

The primary data was analysed using structured questionnaire from 150 respondents from Faridabad, 120 from Gurugram, 95 from Hisar, 90 from Rohtak and 45 from Panchkula on the basis of purposive sampling. The questionnaire was designed

and consisted of a five-point scale (Likert Scale) and close-ended questions. The questionnaire was pre-tested before the collection of the data.

Moreover, data collection sample for this study also encompassed diverse stakeholders' group who are directly involved in or affected by organ donation and transplantation in Haryana. Thus, to give a better insights government agencies and policymakers such as officials from the State Health Department responsible for managing and regulating organ donation and transplantation were approached to provide insights into policy implementation, challenges, and strategies. The study included transplant-authorized empanelled hospitals, offering a closer look at institutional frameworks, procedures, and compliance under relevant schemes. It involved transplant team members, including surgeons and coordinators, who played a pivotal role in the operational aspects of organ retrieval, matching, and transplantation. The sample also incorporated beneficiaries, comprising patients who have undergone organ transplants (organ recipients) and those awaiting organ donation. This group has helped to provide valuable perspectives on the effectiveness, accessibility, and challenges of the organ donation process, as well as their lived experiences.

3.2.2 Secondary Data

The secondary data for study was gathered to study the demand and supply of the organ donation and transplantation was obtained from NOTTO, the central authority for all organ donations related activities in the country. It is responsible for maintaining a central registry of transplants done as well as those in waiting. It also maintains a web site to provide data on empaneled hospitals and on variables including the district coverage, geographical location, type of hospital, the waiting list of various organs for transplant

3.3 Research Instruments

3.3.1 Development of Research Instruments or Tools

The research conducted is based on both primary and secondary data. For collection of primary data from the selected sample qualitative and quantitative methods were used. The details about the qualitative and quantitative research and the development of instruments or tools for the study are discussed here under:

3.3.1.1 Quantitative Research

In quantitative research, data are collected and analysed numerically. Patterns and averages can be found, predictions can be made, causal relationships can be tested, and results can be generalized to a broader population. Quantitative research involved collection of both primary and secondary information which were compiled using Excel sheets.

3.3.2 Content Validity

The degree up to which a research instrument envelops the content which it is supposed to measure is termed as content validity. The two important aspects that are required for content validity are:

1) Assessable level of every item for describing the characteristics;
2) Combination of items that signifies every phase of the characteristics (Yaghmaie, 2009).

As there are no such mathematical and numerical analyses for knowing whether a questionnaire satisfactorily envelops every content segment or not this ultimately rests upon the decision of academicians and experts in the particular field. The content validity is a judgmental process in which there is an effort to find out whether the queries involved in the questionnaire are relevant to the domain of the research or not (Dar and Mishra, 2019). For this particular research, content validity was taken up for both the questionnaires from the various experts in the field. Majority of the experts suggested lessening the use of technical terminologies, language of the questionnaire to be simple and clear and deletion of some of the constructs which they assumed to be repetitive. A few of the constructs were also deleted from the instrument after an astute suggestion by the experts. Thus, after the execution of the suggestions as given by the professionals the language of the research questionnaire was uncomplicated, understandable, useful as well as comprehensible by the respondents for the research.

3.3.3 Pilot Study

Known also as a feasibility study, a pilot study evaluates whether a future full-scale study is feasible and evaluates the study questionnaires/tools to examine if it produces the required information correctly. The accomplishment of a pilot study does

not guarantee the triumph of a research project. While it is helpful in assessing your method and practicing the relevant methods, it does not guarantee success.

The pilot phase or pre-test of the study was conducted in one of the twenty-two (22) districts, Panchkula. A total of 40participantswere randomly selected and interviewed to carry out preliminary analysis. The wrong understandings, measurement errors and duplications were rectified and after rephrasing of words and statements as per the findings of the pilot study, the study questionnaires were finalized and used for data collection in the study.

3.3.4 Reliability Analysis

The reliability is a trait that assures the same result multiple times when a particular method is adopted. If the research techniques adopted produce the same result and are not influenced by external factors then methods are said to be reliable. According to Jaradat and Shakri (2012), "*reliability may be explained as consistency in the results when the instrument recurs again and again. If a questionnaire is put to use on the same population produces similar output, then it is said to be reliable."* According to Field (2017), "*The most reliable technique to determine reliability is the Cronbach's alpha under which the value ranges from 0-1 and it can be used to determine the reliability of dichotomous type questions, Likert scale type questions, ordinal as well as nominal scale type questions.* "To find the validity of the questionnaire, the minimum value of "Cronbach Alpha" should not be less than 0.70. If the value gets higher than the threshold limit it is assumed to be a good questionnaire for research and if the value gets lower than 0.70, it is assumed to be a less reliable research instrument. The Chronbac's alpha value of the beneficiaries' questionnaire for awareness towards Organ donation and transplantation was 0.8, thus endorsing the reliability of all constructs. The Chronbac's alpha value for the perception levels towards organ donation was 0.8785 thus certifying the reliability of all the statements in the instrument. The value of Chronbac's alpha for demand supply gap and cost benefit analysis of organ donation and transplantation in Haryana was 0.75 also certifying the reliability of statements. Hence, all the scales for the instrument were established to be reliable for research.

3.3.5 Ethical Considerations

All ethical considerations were undertaken for the research designs and practices. A special effort was taken to maintain the confidentiality of participants. Informed consent was obtained and the letter of consent included the information about the study with the objectives. Consent also included the right to refusal and maintain confidentiality of the respondents.

3.3.6 Hypothesis of the Study

The present study is based on hypothesis that awareness and positive perception amongst the population has impact on the organ donations. If the population is aware about the organ donation, it can increase the voluntary organ donation rates and decrease the organ demand supply gap. On the basis the objectives specified in Chapter 1 and the literature review conducted in Chapter 2, the following hypothesis were framed and were examined in order to achieve the objectives of the present research.

H_{01}: There exists no significant difference in the level of awareness towards organ donation across various socio-economic variables in different regions of Haryana.

H_{02}: There exists no significant difference in the perceptions about the organ donation in different regions of Haryana.

H_{03}: There exists no significant difference in the organ demand and supply in different regions of Haryana.

SECTION III

3.4 Statistical Tools for Data Analysis

3.4.1 Methods for Data Analysis

The data was analysed using descriptive and inferential statistics and analysis has been made with the help of SPSS software. The details of various statistical tools were given as under:

3.4.1.1 Measure of Central Tendency: "*A measure of central tendency includes the mean, median, and mode. The mean (or arithmetic average) is calculated by adding up all the scores and dividing them by the number of scores. Extreme variables have a profound effect on mean".* The extreme variables have a profound effect on mean. The formula for mean is:

$$mean = \frac{\sum x}{N}$$

Whereas, x is the sum of all observations and N is the number of samples.

3.4.1.2 Standard Deviation (SD): It measures how distributed data is from the mean. There is a high degree of clustering around the mean with low standard deviation. There is a greater spread in data when the standard deviation is high. Its formula is given as:

$$SD = \sqrt{\frac{\sum(x_i - mean)^2}{N}}$$

Where, N is the population size and x_i is one sample from the population.

3.4.1.3 t-test: "t test" *compares two groups' means without needing to make multiple comparisons since there is only one p value. Statistical hypothesis tests based on t-distributions are t-tests whose statistic follows the null hypothesis's t-distribution. When a scaling parameter in the test statistic is unknown, it tends to mean the test statistic would follow a normal distribution. The student's t distribution is followed when the scaling term is estimated from data"* (Pandey & Pandey,2015). The student's t distribution is followed when the scaling term is estimated from data. Its formula is given as follows:

$$t = \frac{mean - theoretical\ value}{SD/\sqrt{n}}$$

Where, n is the variable set size.

3.4.1.4 Wilcoxon Test: "*The Wilcoxon Test is a more powerful alternative to the sign test or t-test because it considers the magnitude of the differences, but it requires this moderately strong assumption of symmetry. There are two variants of the signed-rank test, the one-sample test, which is more fundamental and, paired sample test is more practical.*

For a paired sample test, the data consists of a sample . Each data point in the sample is a pair of measurements. In the simplest case, the measurements are on an interval scale. Then they may be converted to real numbers, and the paired sample test is converted to a one-sample test by replacing each pair of numbers by its difference. In general, it must be possible to rank the differences between the pairs. This requires that the data be on an ordered metric scale, a

type of scale that carries more information than an ordinal scale but may have less than an interval scale." (Pandey & Pandey,2015)

- The Wilcoxon rank sum test can be used to test the null hypothesis that two populations have the same continuous distribution. The base assumptions necessary to employ the rank sum test is that the data are from the same population and are paired, the data can be measured on at least an interval scale, and the data were chosen randomly and independently.
- The Wilcoxon signed rank test assumes that there is information in the magnitudes and signs of the differences between paired observations. As the nonparametric equivalent of the paired student's t-test, the signed rank can be used as an alternative to the t-test when the population data does not follow a normal distribution.

The steps for arriving at a Wilcoxon signed rank test statistic, *W,* are as follows:

1. For each item in a sample of n items, obtain a difference score, D_i, between two measurements (i.e., subtract one from the other).
2. Neglect then positive or negative signs and obtain a set of n absolute differences $|D_i|$.
3. Omit difference scores of zero, giving you a set of n non-zero absolute difference scores, where $n' \leq n$. Thus, n' becomes the actual sample size.
4. Then, assign ranks R_i from 1 to n to each of the $|D_i|$ such that the smallest absolute difference score gets rank 1 and the largest gets rank n. If two or more $|D_i|$ are equal, they are each assigned the average rank of the ranks they would have been assigned individually had ties in the data not occurred.
5. Now reassign the symbol "+" or "–" to each of the n ranks R_i, depending on whether D_i was originally positive or negative.
6. The Wilcoxon test statistic W is subsequently obtained as the sum of the positive ranks.

3.4.1.5 Z-test: "Z test is a statistical test used to determine whether two population means are different when the variances are known and the sample size is large. It can also be used to compare one mean to a hypothesized value. The data must approximately fit a normal distribution, otherwise the test doesn't work. Parameters such as variance and standard deviation should be calculated for a

z-test to be performed. The z-test is also a hypothesis test in which the z-statistic follows a normal distribution. The z-test is best used for greater-than-30 samples because, under the central limit theorem, as the number of samples gets larger, the samples are considered to be approximately normally distributed. When conducting a z-test, the null and alternative hypotheses, and alpha level should be stated. The z-score, also called a test statistic, should be calculated, and the results and conclusion stated. A z-statistic, or z-score, is a number representing how many standard deviations above or below the mean population a score derived from a z-test." (Pandey & Pandey,2015)

It can be conducted as z-tests include a one-sample location test, a two-sample location test, a paired difference test, and a maximum likelihood estimate. Z-tests are closely related to t-tests, but t-tests are best performed when an experiment has a small sample size. Also, t-tests assume the standard deviation is unknown, while z-tests assume it is known. If the standard deviation of the population is unknown, the assumption of the sample variance equaling the population variance is made.

The Z-score is calculated with the formula:

$$z = (x - \mu) / \sigma$$

Where,

z = Z-score

x = the value being evaluated

μ = the mean

σ = standard deviation

3.4.1.6 Perception Scoring

"In Perception Scoring and Analysis approach, respondents' views on objective questionnaire are methodically measured and interpreted. A score ranging from 1 to 5 is assigned to each response category, which includes Strongly Disagree, Disagree, Can't Say, Agree, and Strongly Agree. The number of replies in each category is multiplied by the corresponding score to determine the mean score for each statement. These products are then added together and divided by the total number of responses" using the formula

$$\text{Mean Score} = \frac{(N_1 \times 1) + (N_2 \times 2) + (N_3 \times 3) + (N_4 \times 4) + (N_5 \times 5)}{N}$$

Where:

- N_1, N_2, N_3, N_4, N_5 represent the frequencies or counts of responses in categories 1 through 5, respectively.
- N is the total number of responses ($N = N_1 + N_2 + N_3 + N_4 + N_5$).
- The numbers 1, 2, 3, 4, and 5 are the assigned weights or scores for each category.

A mean score close to 1 indicates strong disagreement, while a score close to 5 indicates strong agreement. A score around 3 suggests neutrality or indecision. (Pandey & Pandey, 2015)

3.5 Limitations of the Study

The present study has the following limitations:

1) The study is limited to Haryana, and findings may not apply to other Indian states due to varying socioeconomic, cultural, and demographic factors.
2) As a cross-sectional study, results may not be consistent with those from a longitudinal approach.
3) Only 14 transplant centers under SOTTO were selected for convenience, which may not represent the overall transplant scenario.
4) Since the Organ Donation and Transplantation Program is centrally managed by NOTTO, caution is necessary when using these findings for national-level policy decisions.
5) The restricted geographical focus on Haryana limits the generalization of the study's findings to regions with different healthcare infrastructures.

CHAPTER IV

AWARENESS LEVEL AND KNOWLEDGE ABOUT ORGAN DONATION AND TRANSPLANTATION IN HARYANA

CHAPTER IV

AWARENESS AND KNOWLEDGE ABOUT ORGAN DONATION AND TRANSPLANTATION IN HARYANA

According to World Health Organization (2003), "Organ transplantation stands as the preferred treatment for numerous end-stage organ diseases, as it not only enhances the quality of life but also provides long-term survival benefits." However, a global shortage of organ donors remains a significant challenge. Many countries have implemented measures to increase deceased organ donations, yet disparities persist. However, organ donation and transplantation are considered as the vital components of modern healthcare systems and offers life-saving solutions for the patients suffering from such end-stage diseases related to organs. But, success of the organ transplantation and donation relies heavily on the public awareness and knowledge towards organ donation and transplantation. The awareness can play a crucial role in dissipating the prevailing myths and addressing various cultural and religious concerns of the public by fostering an encouraging attitude towards organ donation and transplantation. However, various studies have highlighted that lack of awareness and misconceptions about organ donation and transplantation process can significantly contribute to decrease donation rates among the common masses (Tong et al., 2021). Thus, understanding the level of awareness and the factors influencing knowledge about organ donation is indispensable for designing effective campaigns and strategies to bridge the gap between the organ demand and supply in the country.

Thereby, present chapter assessed the awareness of respondents about the various aspects of organ donation. Further, as part of the study, a video-assisted teaching (VAT) was conducted irrespective of their awareness of organ donation. The results obtained were presented in the subsequent sections as follows:

4.1 Demographic Characteristics of the Sample

This section deals with demographic characteristics of data related to age, gender, caste, religion, marital status, educational status, and profession of the respondents.

a) Age of Respondents

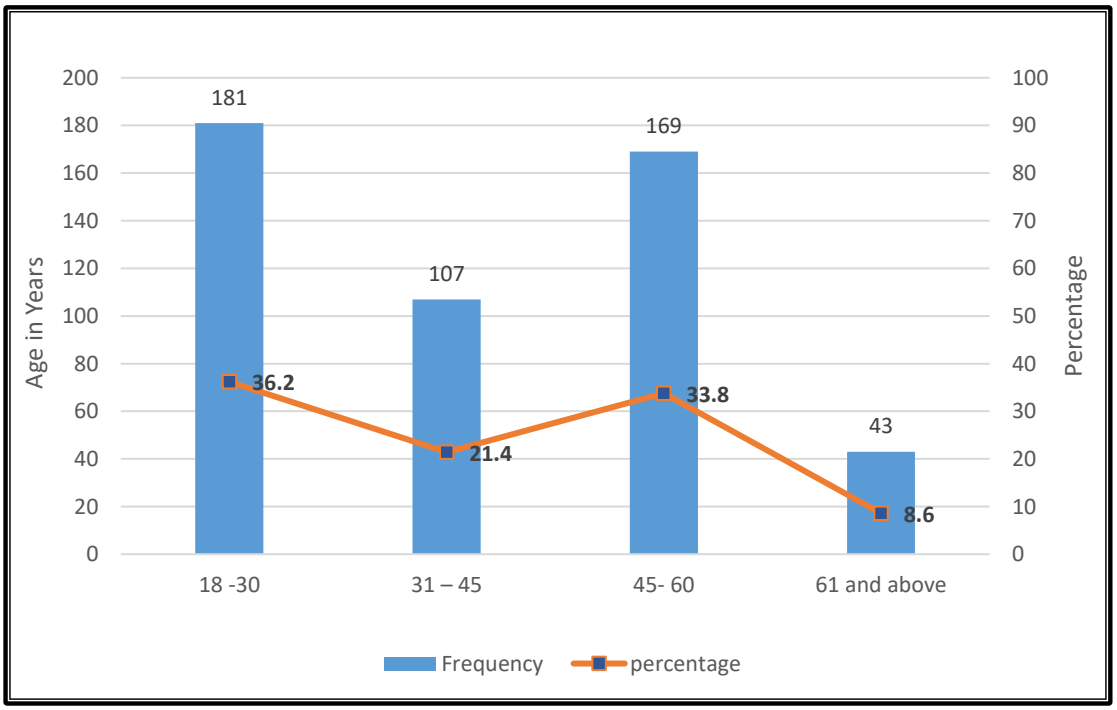
The analyses of data as presented in table 4.1 and figure 4.1 shows that among the 500 study participants, about 36 percent of them were in age group 18-30 years, a 21 percent were in age group 31-45 years, 33.8 percent of them were in 45-60 years age group and about 9 percent were above 61 years old. Thus, majority of the respondents (57 percent) were of younger age group in range 18-45 years.

Table 4.1: Distribution of the Respondents According to Age Group

Age	Frequency	Percentage
18 years -30 years	181	36.2
31 years – 45 years	107	21.4
45 years- 60 years	169	33.8
61 years and above	43	8.6
Total	500	100.0

Source: Calculations based on primary survey

Figure 4.1: Age Group of Respondents



Source: Calculations based on primary survey

b) Gender of Respondents

It can be observed from table 4.2 most of the respondents of the study were males. There were 178 females out of 500 participants that were interviewed and a 322 of them were males. Thus, participant group was male (64 percent) in the present study.

Table 4.2: Distribution of Respondents According to Gender

Gender	Frequency	Percentage
Male	322	64.4
Female	178	35.6
Total	500	100.0

Source: Calculations based on primary survey

c) Type of Residence of Respondents

The respondents were selected such that they represent both urban and rural regions as presented in table 4.3. There were about 40 percent samples that were selected from rural region and 60 percent selected from urban region. Thus, the samples consisted about were mostly urban region.

Table 4.3: Distribution of Respondents According to Type of Residence

Type of residence	Frequency	Percentage
Rural	200	40.0
Urban	300	60.0
Total	500	100.0

Source: Calculations based on primary survey

d) Caste and Religion of Respondents

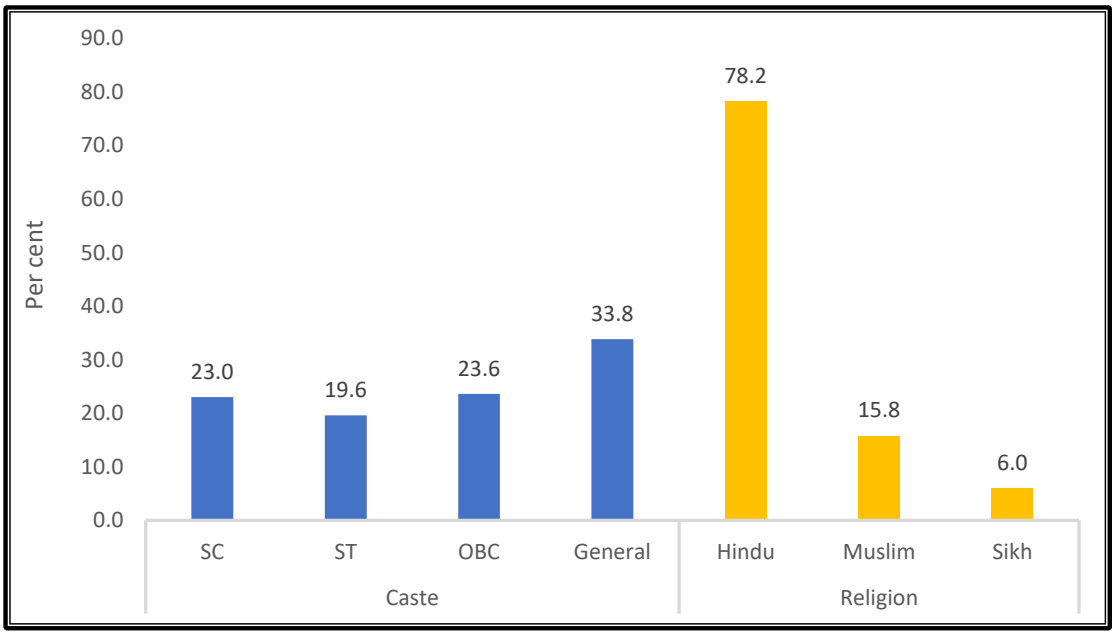
It can be observed from table 4.4 and figure 4.2 that respondents for the study were almost equally distributed between the different castes. About 23 percent belonged to SC and OBC castes each, 34 percent belonged to general category and 20 percent belonged to ST category. Therefore, sample was representative of the various social groups in society. As regards the religion followed by the respondents, it was observed that majority of respondents, that is 391 (78 percent) out of 500, belongs to Hindu religion. About 79 (16 percent) followed Islam and were Muslims and only 6 percent of them followed Sikhism.

Table 4.4: Distribution of Respondents According to Caste and Religion

Particulars		Frequency	Percentage
Caste	SC	115	23.0
	ST	98	19.6
	OBC	118	23.6
	General	169	33.8
Religion	Hindu	391	78.2
	Muslim	79	15.8
	Sikh	30	6.0
Total		500	100

Source: Calculations based on primary survey

Figure 4.2: Caste and Religion followed by Respondents



Source: Calculations based on primary survey

e) Marital Status of Respondents

It could be seen from the data in table 4.5 that 323 (64.6 percent) respondents of the study were married, 112 (22.4 percent) respondents were unmarried and 50 (10 percent) were widowed and 15 (3 percent) divorced.

Table 4.5: Distribution of Respondents According to Marital Status

Marital Status	Frequency	Percentage
Unmarried	112	22.4
Married	323	64.6
Widowed	50	10.0
Divorced	15	3.0
Total	500	100

Source: Calculations based on primary survey

f) Educational Qualification of Respondents

The table 4.6 indicates the distribution of samples of respondents according to their level of education. Majority of the respondents have completed graduation or higher education (45 percent) followed by 17.6 percent that has completed middle school and a 16 percent were diploma holders. Therefore, education levels were fairly good with majority of them being a graduate.

Table 4.6: Distribution of Respondents According to Educational Qualification

Educational Qualification	Frequency	Percentage
No formal education but can read & write	48	9.6
Middle school	88	17.6
High school	61	12.2
Intermediate	80	16.0
Graduate or higher	223	44.6
Total	500	100.0

Source: Calculations based on primary survey

g) Employment Status of Respondents

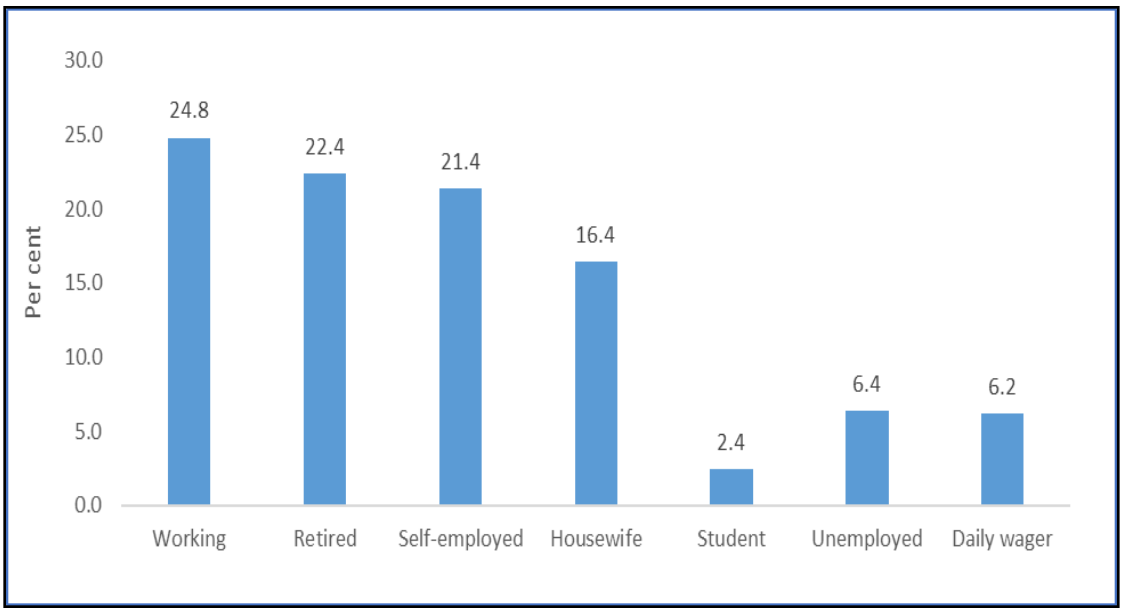
The below data table 4.7 and figure 4.3 depicts the distribution of samples as per the profession of the respondents. More than 47 percent of the respondents were not employed. Among those working, about 25 percent belonged to salaried class, 21 percent were self-employed and a 6.2 percent were daily wagers.

Table 4.7: Distribution of Respondents According to Profession

Profession	Frequency	Percentage
Salaried	124	24.8
Self Employed	107	21.4
Daily Wager	31	6.2
Retired	112	22.4
Housewife	82	16.4
Student	12	2.4
Unemployed	32	6.4
Total	500	

Source: Calculations based on primary survey

Figure 4.3: Occupation of Respondents



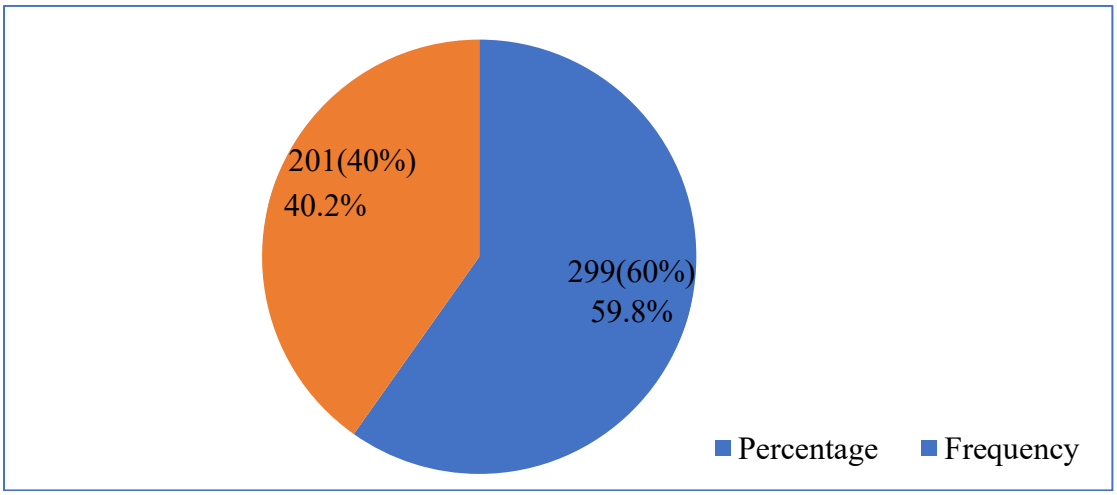
Source: Calculations based on primary survey

4.2 Awareness about Organ Donation and Transplantation

4.2.1 Awareness about Organ Donation amongst Respondents

The overall awareness about organ donation and transplantation was assessed among the 500 respondents and the results are as seen in figure 4.3. It was observed that 201 (40.2 percent) respondents out of 500 were not aware that body organs could be donated transplanted into another person. Thus, awareness level among the public about organ donation was 59.8 percent with 299 respondents out of 500 were aware about organ donation.

Figure 4.4: Awareness about Organ Donation and Transplantation



Source: Calculations based on primary survey

4.2.2 Source of Information about Donation

Amongst the 299 respondents that expressed awareness about organ donation and transplantation, questions were posed to them about their source of information. The analysis of data as presented in table 4.8 showed that the internet (25.1 percent) and social media (19.7 percent) were the prime source of information.

Table 4.8: Distribution of Respondents According to Source of Information

Source of Information	Frequency	Percentage
Newspaper	42	14.0
Television	33	11.0
Internet	75	25.1
Social media	59	19.7
Family Members	12	4.0
Hospital	54	18.1
Medical College	24	8.0
Total	299	100

Source: Calculations based on primary survey

About 18.1 percent of those aware knew about it from the hospitals and about 14 percent and 11 percent knew about it from newspaper and television respectively. However, family members had provided information to about 4 percent of those who were aware of organ donation.

4.2.3 Awareness about Live and Deceased Organ Donation

A further deep dive into the level of awareness among those who were aware of organ donation and transplantation did not show favouring results as there was lot of wrong information perceived by the public. It was depicted from table 4.9 that the awareness levels about the type of donation. Among those aware of organ donation only 42 percent were aware of organ donations made by live human beings. It was found that only 33 percent was aware of cadaver donation, that is, organ donation at death. It was found that 25 percent of the people were informed of both types of donations.

Table 4.9: Respondents Distribution as per Awareness about Kind of Organ Donation

Type of donation	Frequency	Percentage
Cadavers	99	33.1
Living humans	125	41.8
Both	75	25.1
Total	299	100

Source: Calculations based on primary survey

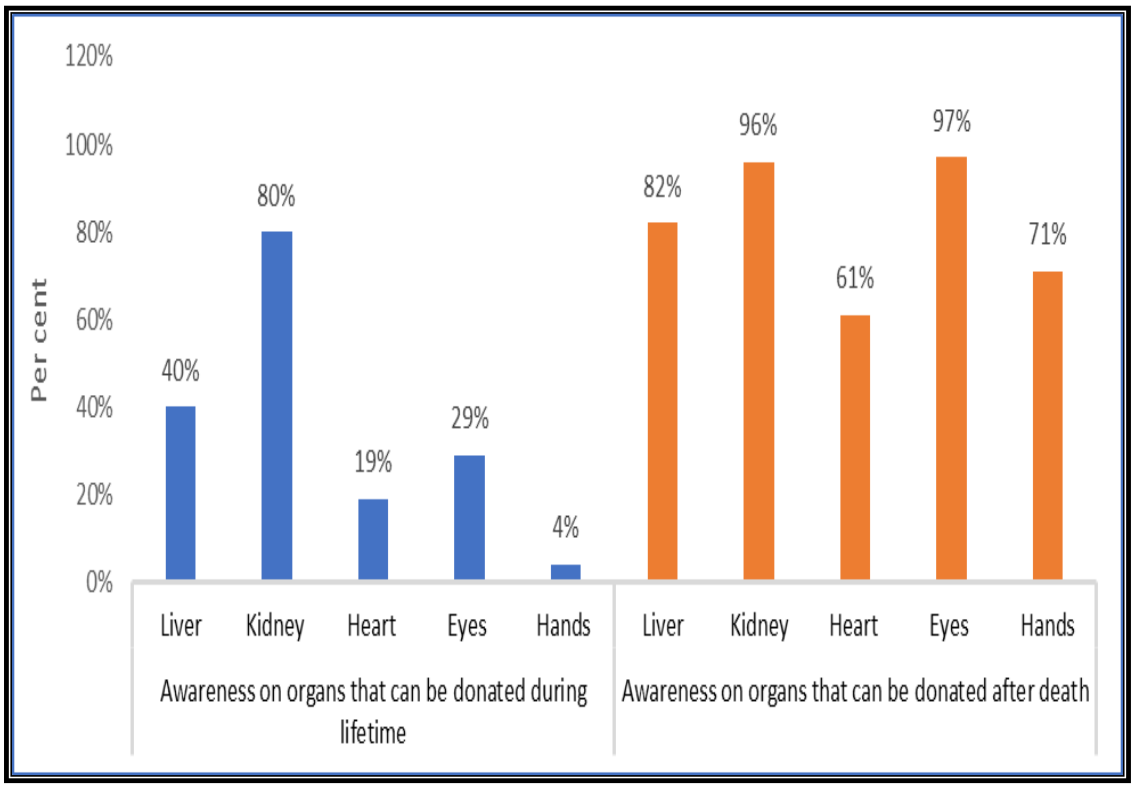
Further on examining the different organs that can be donated when alive and after death too, the public did not seem to have correct information. It can be observed from table 4.9 and figure 4.4 that the awareness levels were quite poor about live and deceased donation among people. There was about 80 percent of them aware that kidney could be donated when alive and only 40 percent was aware that liver could be donated when alive. However, most of them were aware that organs could be donated after death. Still, a few of them did not have correct information as only 82 percent, 96 percent 61 percent, 97 percent and 71 percent of them were aware of donating liver, kidney, heart, eyes and hands respectively after death.

Table 4.10: Distribution of Respondents by Awareness on Kind of Organ Donation

Kind of Donation	Organ	Aware N(%)	Not Aware N(%)
Awareness on organs that can be donated during lifetime	Liver	120(40)	179 (60)
	Kidney	239 (80)	60 (20)
	Heart	56 (19)	243(81)
	Eyes	87(29)	212 (71)
	Hands	12(04)	287 (96)
Awareness on organs that can be donated after death	Liver	244 (82)	55 (18)
	Kidney	287 (96)	12(04)
	Heart	182(61)	117(39)
	Eyes	290 (97)	09 (03)
	Hands	212 (71)	87 (29)

Source: Calculations based on primary survey

Figure 4.5: Awareness on Live and Deceased Organ Donation



Source: Calculations based on primary survey

4.2.4 Awareness on Registration and Legalities of Organ Donation

The awareness of the public on the registration for organ donation and the legalities regarding it was seen to be quite low. The data presented in table 4.11 shows that only 93 (31 percent) of the respondents knows about organ donation was aware of the process of registering as an organ donor. It was found that 275 out of 299

respondents (92 percent) were aware that the consent of parent, spouse or children is required before organ donation. While as, 57 percent of them felt the need for law concerning the governing of organ donation and transplantation, only 37.5 percent were aware that legal provisions existed for organ donation and transplantation. About 20 percent did not know if any legal processes existed for organ donation. Only 9 percent was aware that organ swapping was legal in the country and only about 41.5 percent was aware of a nearest transplant centre.

Table 4.11: Distribution of Respondents as per Awareness on Registration and Legalities of Organ Donation

S. No.	Particulars	Yes N (%)	No N (%)	Don't Know N (%)
1	Aware of the process of registering as an organ donor	93(31.1)	206 68.9)	0 (0)
2	Aware that consent of parent/spouse/children is required before organ donation and transplantation	275(92.0)	24 (8.0)	0 (0)
3	Need for law to govern the organ donation and transplantation	170(56.9)	69 (23.1)	60(20.1)
4	There exists law for organ donation and transplantation in the state at present	112 (37.5)	127(42.5)	60(20.1)
5	Aware that organ swapping is legal in the country	27(9.0)	272(91.0)	0 (0)
6	Aware of the nearest organ transplant center	124(41.5)	175(58.5)	0 (0)

Source: Calculations based on primary survey

4.2.5 Awareness on Organ Shortage and Donation

However, those who were aware of organ donation it is found that only 65 percent were aware that many people lose lives due to shortage of organs. Similar was the proportion that was aware that one donor can donate to multiple recipients. Whereas, avery few of them were aware that organ donation cannot be done by patients with chronic diseases. Only 16.7 percent were aware that organ donation cannot be done if the donor is HIV, Hepatitis B or C positive and about 27 percent were aware that organ donation cannot be done if donor has active cancer (Table 4.12).

Table 4.12: Distribution of Respondents as per Awareness of Organ Donation

S. No.	Particulars	Yes N (%)	No N (%)
1	Aware that many people lose their lives due to the shortage of organs	195 (65)	104(35)
2	Aware that one donor can donate to multiple recipients	201(67.2)	99 (32.8)
3	Aware that organ donation can't be done if the donor is HIV, Hepatitis B or C positive	51 (16.7)	249 (83.3)
4	Aware that organ donation can't be done if donor has active cancer	81 (27.1)	219 (72.9)

Source: Calculations based on primary survey

4.3 Impact of a Video-assisted Training (VAT) on Knowledge and Attitude

A video-assisted training was conducted on the respondents who have shown awareness towards organ donation. The findings from the pre-test and post-test conducted prior and after the VAT is summarized in the below mentioned sections.

4.3.1 Organ Donation Status in Family of Respondents

The data showed that none of the respondent families had registered for organ donation. Though around 10 percent of the study respondents had a family member suffering with organ failure and only 1 percent had seen/ known about organ donation in the family, out of which none of the family members of respondents from rural background ever donated an organ as shown in table 4.13.

Table 4.13: Distribution of Respondents as per Organ Donation Status in Family

S. No.	Variables	Urban	Rural
		N(%)	N (%)
1	Registered for organ donation	0 (0)	0 (0)
2	Organ failure in family	18 (12)	12 (8)
3	Organ donation in family	3 (2)	0 (0)

Source: Calculations based on primary survey

The respondents were asked about their plan for organ donation in future and the responses recorded are as presented in table 4.14. It can be well seen from the table that most of the respondents, that is about 67 percent of them in urban and 47 percent in rural, were not decided about donation of organs in future. About 22 percent of urban respondents and 31 percent rural respondents refused to be donors in future, and a 2.7 percent urban and 4 percent rural samples have not made firm decision. Thus, only 8.7

percent urban respondents and 18.7 percent rural respondents showed willingness for organ donation in future.

Table 4.14: Distribution of Respondents by Willingness for Organ Donation

Willingness for Organ Donation in Future		Urban	Rural
		N (%)	N (%)
1	Yes	13 (8.7)	28 (18.7)
2	No	33 (22)	46 (30.7)
3	Not decided	100 (66.7)	70 (46.7)
4	Not sure	4(2.7)	6 (4.0)
	Total	150	150

Source: Calculations based on primary survey

4.3.2 VAT Pre-test and Post-test Knowledge Score

A pre-test of the knowledge of the respondents on organ donation was assessed using 20 questions and responses were scored by assigning '1' to correct response and '0' otherwise. The scores obtained for all the 20 questions were aggregated and the analysis was conducted on the total scores achieved by the urban and rural groups to assess the improvements in knowledge levels. The results on the effect of the VAT on knowledge are presented in this sub-section.

Pre-test Knowledge Scores:

Table 4.14 shows the frequency and percentage of pre-test knowledge score on organ donation. On a maximum score of 20, there were 6 urban respondents who had scores less than 10 with the least scoring being 4. There were 3 respondents (2 percent) having a score 4. Six respondents each were having score 10 and 11 out of 20. About 35 percent of the respondents had obtained scores above 15 out of 20 with the maximum score obtained being 17 out of 20 (2 respondents). Among rural respondents, minimum pre-test score obtained by respondents was 4 out of 20 (2 respondents).

There were 15 respondents whose knowledge score on organ donation was less than 10 out of the maximum score of 20. About 27 percent of them (41 respondents) scored above 15 out of 20 with the maximum score obtained being 18 (by 3 respondents). This meant that there were both the categories of good knowledge and bad knowledge about organ donation among the respondents.

Post-test Knowledge Scores

On a maximum score of 20, there were 93 percent of the urban respondents who had scores more than 15 with the least scoring being 11. There were 3 respondents (2 percent) each having a score 11 and 12 and there were 5 respondents who had scores of 14. The maximum score obtained was 20 out of 20 by 4 respondents (2.7 percent). In the rural sample, there was improvement in the knowledge of rural respondents as the minimum score obtained was 11 and the majority of respondents were having scores from 14 to 19.

Table 4.15: Pre-test and Post-test Knowledge Scores Amongst Respondents

Pre-test					**Post-test**				
Score	**Urban**		**Rural**		**Score**	**Urban**		**Rural**	
	N	**%**	**N**	**%**		**N**	**%**	**N**	**%**
4	3	2.0	2	1.3	-	-	-	-	-
5	0	0	2	1.3	-	-	-	-	-
6	1	0.7	3	2	-	-	-	-	-
7	1	0.7	3	2	-	-	-	-	-
8	1	0.7	3	2	-	-	-	-	-
9	0	0	2	1.3	-	-	-	-	-
10	6	4.0	11	7.3	-	-	-	-	-
11	6	4.0	15	10	11	3	2	1	0.7
12	24	16.0	22	14.7	12	3	2	3	2
13	28	18.7	17	11.3	13	0	0	5	3.3
14	28	18.7	29	19.3	14	5	2.7	12	8
15	31	20.7	26	17.3	15	15	10	20	13.3
16	19	12.7	10	6.7	16	37	24.7	26	17.3
17	2	1.3	2	1.3	17	35	24	34	22.7
18	0	0	3	2	18	34	23.7	33	22
19	-	-	-	-	19	14	9.3	15	10
20	-	-	-	-	20	4	2.7	1	0.7
Median score	14		13		Median score	17		17	

Source: Calculations based on primary survey

This meant that there was considerable improvement in the awareness among the respondents post VAT.

4.3.3 VAT Pre-test and Post-test Attitude Level

The study assessed the impact of VAT on the attitudes of the people on organ donation. For this, 9 positively formed statements and 11 negatively formed statements were posed to the respondents prior and post the VAT. The results of the effect of the VAT on attitude levels on organ donation are presented in this sub-section. This section also compares the pre-test and post-test attitude scores of samples analysed by applying Wilcoxon Signed Rank test is a non-parametric statistical test used to assessed whether the median of a distribution differs significantly from a specified value. It tests the null hypothesis that the median of the distribution is equal to the given value. The proportion of favourable response in the pre-test and proportion of favourable response in the post-test were considered.

4.3.3.1 Pre-test and Post-test Attitude Levels in Urban Group

Table 4.16 reveals the favourable attitudes of respondents in pre-test and post-test towards nine positively formed statement regarding organ donation among the urban respondent. Around 130 (86.7percent) respondents said if an approach is made to donate organ, they will be willing to donate but, in the post-test, this increased to 142 (94.7 percent) respondents. There were 103 (68.7 percent) respondents in urban group in the pre-test who were affirmative about donating the organs of their family members while in the post-test this improved to 81.3 percent. Moreover, 64 percent of the respondents in the pre-test were not sure if their family members will support donating their organ while after the VAT the proportions feeling that their family members will support donating their organ increased to 73 percent.

In pre-test about 81.3 percent of the 150 respondents responded in favour that it is valuable to discuss organ donation with a dead patient's family members which was 93.3 percent in the post-test indicating an improvement in attitudes. Whereas, in case the respondent was declared brain dead, only 88 (58.7 percent) respondents in pre-test replied that their families will be willing for their organ donation. This increased to 69.3 percent in the post-test. On the desirability of organ donation when a patient is brain dead, only 80 (53.3 percent) respondents answered favourably which raised to 66.7 percent in post-test. Nearly 111(74 percent) respondents gave a favourable response on referring the members

of a bereaved family to a transplant team if they wish to donate their loved one's organs in the pre-test and in post-test this improved to 84.7 percent after VAT.

There were about 128 (85.3 percent) respondents in pre-test that were of the opinion that people do not come forward for organ donation because of poor knowledge which improved to 91 percent in the post-test. About 63 percent of the respondents also vouched for medical insurance being expanded to include organ transplant surgery in the pre-test assessment which rose to 88.7 percent after the VAT. It was observed that each of the nine positively formed statements saw improvements in the attitudes of the urban group to organ donation. However, Wilcoxon tests for favourable attitudes towards positively formed statements on organ donation in the urban group showed that the pre-test and post-test difference was significant for , extending medical insurance to include organ transplant surgery (p-values provided in table 4.15).

The respondents' attitude against organ donation was assessed by posing ten negatively formed statements regarding organ donation to the study respondents. Table 4.15 also reveals the favourable attitudes of respondents to organ donation in pre-test and post-test towards negatively formed statement on organ donation in the urban group. In the urban group, the attitude against organ donation was high among the respondents in pre-test. About 35 (23 percent) respondents out of 150 did not believe in keeping their body intact for life after death and about 46 (31 percent) respondents did not believe in cultural values of keeping their body intact after death. These proportions improved to 56.7percent and 40.7 percent in the post-test after VAT.

There were many of the respondents who feared the process of donation and transplantation. The data shows that only 25 (16.7 percent) respondents did not fear that their body will be disfigured by donating organ. The VAT took the proportions not fearing of body disfiguring to 24 percent. There were about 51 percent respondents that did not fear the surgical procedures which rose to 66 percent in the post-test. While only 20 percent of the respondents believed that selling an organ is a crime, there were 43 percent of them that believed there was no trafficking of organs and a 54 percent did not did not find scams in organ donation. The proportions having these beliefs improved after the VAT. About 65.3 percent respondents opined that insurance in form of money should not be given to donors and 51.3 percent respondents were not of opinion to legalizing selling of organs. Also, a 35 percent of them did not feel that there should be benefits provided to the donor. These proportions improved to 76.7 percent, 68.7 percent and 46 percent respectively.

Table 4.16: Pre-test and Post-test Attitude Amongst Urban Respondents

Sr. No	Statement	Pre-test favourable response to organ donation		Post-test favourable response to organ donation		p-value
		N	%	N	%	
Positive Statements						
1	If an approach is made to donate organ I will donate.	130	86.7	142	94.7	0.23
2	If an approach is made to donate my family member's organ, he/she will donate.	103	68.7	122	81.3	0.11
3	If an approach is made to my family members for donating my organ they will.	96	64.0	110	73.3	0.17
4	It is valuable to discuss organ donation with a dead patient's family members.	122	81.3	140	93.3	0.13
5	My family will be willing for my organ donation after me being declared brain dead.	88	58.7	104	69.3	0.11
6	Organ donation is desirable when a patient is brain dead.	80	53.3	100	66.7	0.07
7	If the members of a bereaved family would like to donate the organ of deceased. I'd refer them to transplant team.	111	74.0	127	84.7	0.16
8	People should come forward for organ donation voluntarily.	128	85.3	137	91.3	0.29
9	Medical insurance should be expanded to include organ transplant surgery.	95	63.3	133	88.7	0.006**

Sr. No	Statement	Pre-test favourable response to organ donation		Post-test favourable response to organ donation		p-value
		N	%	N	%	
Negative Statements						
1	I would like to keep my body intact for life after death.	35	23.3	85	56.7	0.00025***
2	Certain religion does not agree with organ donation or transplantation.	23	15.3	73	48.7	0.00025***
3	I have a cultural belief that my body should be kept intact after death.	46	30.7	61	40.7	0.07
4	I have fear that my body will be disfigured if I donate my organ	25	16.7	36	24.0	0.06
5	I have a fear of surgical procedures.	77	51.3	99	66.0	0.04*
6	I believe that selling of organ is not a crime.	30	20.0	106	70.7	0.00025***
7	I would not like to donate organ because of trafficking of organs	65	43.3	100	66.7	0.003**
8	There are many scams in organ donation	82	54.0	89	59.33	0.28
9	Organ donors should be paid money/ insurance	98	65.3	115	76.7	0.12
10	Selling organs should be made legalized.	77	51.3	103	68.7	0.02*
11	There should be incentives (other than money) towards donor/ donor's family for organ donation	52	34.7	69	46.0	0.04*

Source: Calculations based on primary survey

Wilcoxon test for favourable attitudes towards negatively formed statements in the urban group showed that the proportions of favourable responses have increased considerably from the pre-test to the post-test. The Wilcoxon test results indicate that the difference was highly significant at 5 percent level of for three statements and significant at 1 percent level or highly significant for four statements.

4.3.3.2 Pre-test and Post-test Attitude Levels Among Rural Respondents

However favourable attitudes of respondents in pre-test and post-test towards the nine positively formed statement regarding organ donation among the rural respondents is presented in table 4.16.In rural group it was found that around 102 (68 percent) respondents said if an approach is made to donate organ, they will be willing to donate but, in the post-test, this increased to 122 (81 percent) respondents agreeing to it. About 105 (70 percent) respondents were sure about donating the organs of their family members in the pre-test while in the post-test this improved to 74 percent. About half the respondents (54 percent) in the pre-test were confident that their family members will support donating their organ while after the VAT the proportions increased to 65 percent.

About 105 (70 percent) of the 150 respondents in pre-test responded in favour that it is valuable to discuss organ donation with a dead patient's family members and this attitude improved to 88 percent in the post-test after VAT. In cases of the respondent themselves being declared brain dead, only 57 (38 percent) respondents in pre-test replied that their families will be willing for their organ donation and this attitude improved in the VAT post-test to 58 percent. On the desirability of organ donation when a patient is brain dead, about74(49 percent) respondents answered favourably which raised to 60.7 percent in post-test. In situations where the members of a bereaved family would wish to donate their loved one's organs nearly 90 (60 percent) respondents gave a favourable response to referring the to a transplant team. In post-test this improved to 69 percent after VAT.

There were about 112 (75 percent) respondents in pre-test that were of the opinion that people do not come forward for organ donation because of poor knowledge which was felt by about 91 percent respondents in the post-test. This acknowledges the importance of strengthened IEC to improve organ donation. About 63 percent of the

respondents also vouched for medical insurance being expanded to include organ transplant surgery in the pre-test assessment which rose to 67 percent after the VAT. It was observed that, though the impact of VAT was low on the rural population as compared to the urban population, each of the nine positively formed statements saw improvements in the attitudes of the rural group to organ donation. The results of the tests conducted for examining the significance in difference between the pre-test and post-test outcomes (Wilcoxon tests) for favourable attitudes towards positively formed statements on organ donation in the rural group show significant results for three statements – (a) discuss organ donation with a dead patients family members; (b) family will be willing for my organ donation after the declaring brain death and (c) People should come forward for organ donation voluntarily (p-values provided in table 4.16).

The respondents' attitude against organ donation among rural respondents was assessed by posing ten negatively formed statements regarding organ donation to the study respondents. The analysis of data provided in Table 4.16 also shows the favourable attitudes of respondents to organ donation in pre-test and post-test towards negatively formed statement on organ donation in the rural group. It was observed that the overall attitude against organ donation was high among the respondents in pre-test. Only about 30 (20 percent) respondents out of 150 did not believe in keeping their body intact for life after death. A VAT improved these proportions to 50 percent and 37.7 percent respectively. There fear of body getting disfigured due to the process of donation and transplantation was observed among majority of the respondents in the rural group. Data showed that only 25 (16.7 percent) respondents did not fear that their body will be disfigured by donating organ which improved to 28 percent in post-test after VAT. There were just about 38 percent respondents that did not fear the surgical procedures and this improved to 55 percent in the post-test. On the malpractices in the organ donation process, only about 23 percent of the respondents believed that selling an organ is a crime, there were 42 percent of them that believed there was no trafficking of organs and a 53 percent did not did not find scams in organ donation. The proportions having these beliefs improved to 47 percent, 64 percent and 51 percent respectively after the VAT. There were unfavourable responses among the urban group towards compensating the donors. Only about 45 percent respondents opined that money should not be given to donors. 47 percent of them did not feel that there should be benefits provided to the donor. These proportions improved significantly in the post-test.

Table 4.17: Pre-test and Post-test Attitude Amongst Rural Respondents

S. No.	Statements	Pre-test favourable response to organ donation		Post-test favourable response to organ donation		p-value
		N	%	N	%	
Positive Statements						
1	If an approach is made to donate organ I will donate.	102	68.0	122	81.3	0.09
2	If an approach is made to donate my family member's organ, he/she will donate.	105	70.0	111	74.0	0.34
3	If an approach is made to my family members for donating my organ they will.	81	54.0	97	64.7	0.12
4	It is valuable to discuss organ donation with a dead patient's family members.	105	70.0	132	88.0	0.03*
5	My family will be willing for my organ donation after the declaring brain death.	57	38.0	87	58.0	0.006**
6	Organ donation is desirable when a patient is brain dead.	74	49.3	91	60.7	0.09
7	If the members of a bereaved family would like to donate their loved one's organ I'd like to actually refer them to transplant team.	90	60.0	104	69.3	0.16
8	People should come forward for organ donation voluntarily.	112	74.7	139	92.7	0.04*
9	Medical insurance should be expanded to include organ transplant surgery.	95	63.3	133	88.7	0.006**

S. No.	Statements	Pre-test favourable response to organ donation		Post-test favourable response to organ donation		p-value
		N	%	N	%	
Negative Statements						
1	I would like to keep my body intact for life after death.	30	20.0	75	50.0	0.00025***
2	Certain religion does not agree with organ donation or transplantation.	17	11.0	68	45.3	0.00025***
3	I have a cultural belief that my body should be kept intact after death.	28	18.0	56	37.3	0.00097***
4	I have fear that my body will be disfigured if I donate my organ	25	16.7	42	28.0	0.01*
5	I have a fear of surgical procedures.	57	38.0	83	55.3	0.01*
6	I believe that selling of organ is not a crime.	34	22.7	70	46.7	0.0003***
7	I would not like to donate organ because of trafficking of organs	63	42.0	96	64.0	0.006**
8	There are many scams in organ donation	80	53.3	77	51.3	0.4
9	Organ donors should be paid through money/ insurance	67	44.7	105	70.0	0.0015**
10	Selling organs should be made legalized.	68	45.3	100	66.7	0.007**
11	There should be incentives (other than money) towards donor/ donor's family for organ donation	70	47.0	96	64.0	0.02*

Source: Calculations based on primary survey

The Wilcoxon tests for favourable attitudes towards negatively formed statements in the rural group are shown with their p-values in table 4.16. It is observed that the proportions of favourable responses have increased considerably from the pre-

test to the post-test. The Wilcoxon test results indicate that the difference was highly significant for 10 out of the 11 statements. This indicated the highest impact of the VAT The above analysis has assessed that the pre-test and post-test assessments of knowledge, after video assisted teaching, revealed that generating awareness significantly improves the knowledge on organ donation which can promote organ donation. Similarly, the assessment of the attitude levels using positively framed and negatively framed statements in pre-test and post-test showed that the attitude levels improved too. However, extent of improvement of the attitudes was low especially in rural areas. The study highlights the need for targeted policy interventions to promote organ donation. First, there is a significant gap in awareness, particularly in rural areas, which calls for region-specific and culturally sensitive awareness campaigns. These could include video-assisted teaching, community outreach, and collaboration with local influencers to effectively spread information. Additionally, since changing attitudes toward organ donation is challenging, policies should focus on sustained and repeated efforts. Educational programs in schools, healthcare centres, and communities could help reinforce positive attitudes over time. Furthermore, none of the respondents were registered as organ donors, suggesting a need for easier access to organ donation registration through healthcare facilities and digital platforms. Special focus should also be placed on rural populations, ensuring that interventions address local beliefs and misconceptions.

CHAPTER V

PERCEPTION LEVELS ABOUT ORGAN DONATION AND TRANSPLANTATION HARYANA

CHAPTER V

PERCEPTION LEVEL ABOUT ORGAN DONATION AND TRANSPLANTATION IN HARYANA

The perception of organ donation and transplantation varies widely across different communities, shaped by cultural beliefs, personal experiences, and societal attitudes (Varshney et al., 2023). While many view organ donation as a noble act that saves lives, misconceptions and lack of awareness often hinder broader acceptance. The factors such as religious beliefs, myths about the body after death, and mistrust in the medical system can influence individuals' willingness to participate in organ donation. Education and public awareness campaigns play a critical role in addressing these barriers, highlighting the transformative impact of organ donation, and fostering a supportive attitude towards it. Understanding the nuances of public perception is vital for developing effective policies and interventions to increase organ donation rates and ensure equitable access to transplantation. Many urban people have myths about receiving organs from different families and post-death rituals indicating their negative attitude towards organ donation mainly due to lack of awareness (Chen et al., 2019).

The rural areas are in a worse condition than urban areas. The rural population are ignorant and illiterate and health care workers and the doctors who work in the rural areas are considered to be indigenous or to be from ayurveda or homeopathy (Barik and Thorat, 2015). There is no access to super specialists in rural areas. Rural areas have government-run programmes for non-communicable diseases such as diabetes and hypertension. The organ failure due to these health conditions is becoming more common in rural areas, while there are no existing facilities. Due to the fact that rural people are illiterate, lack awareness and lack medical facilities, they are in a dire situation (Greiner and Knebel, 2019). However, to increase the organ donation activities at national level, first we have to promote and increase social acceptance of organ donation from ground level. The rumours, myths and misunderstandings about organ donation and transplantation are many (Dasgupta et al., 2014). The purpose of this chapter is to investigate the perceptions of the respondents towards organ donation and transplantation.

5.1 Perception Level towards Organ Donation and Transplantation

The opinions of sampled respondents about organ donation and transplantation are shown in this table 5.1. The respondents score each item on a five-point Likert scale indicating how much they agree or disagree.

Table 5.1: Perception about Organ Donation and Transplantation

S. No	Statements	Strongly Disagree N (%)	Disagree N (%)	Can't Say N (%)	Agree N (%)	Strongly Agree (%)
1	Organ donation and transplantation is safe and successful process for both donor and the beneficiary.	24(8)	144(48)	120(40)	12 (4)	0(0)
2	Organ donation and transplantation should be promoted in the state.	0 (0)	21(7)	120(40)	123(41)	36(12)
3	Religion opposes organ donation and transplantation.	12(4)	36(12)	84(28)	123(41)	45(15)
4	It is important for a person to have all of the body parts when they are deceased.	3(1)	57(19)	121(40.5)	76 (25.5)	42 (14)
5	A traditional funeral cannot be held for a deceased donor.	3(1)	57(19)	108 (36)	131(44)	0(0)
6	I will be born deformed, if I donate my organs in this life.	0(0)	60(20)	117(39)	122(41)	0(0)
7	If my life is in danger, I would accept an organ transplant.	6 (2)	39 (13)	96 (32)	152 (51)	6 (2)
8	Health risks are associated with organ donation.	12(4)	66 (22)	111 (37.2)	113 (37.8)	0(0)
9	I am willing to donate my organs.	12(4)	36(12)	66(22)	152 (51)	33 (11)
10	It is important to discuss the willingness to donate organs with the family members.	0(0)	48(16)	120 (40)	161 (54)	0(0)
11	I will donate my organ to my family member / relatives.	0 (0)	0(0)	93 (31)	158(53)	48 (16)
12	I will donate my organ to anyone in need.	21 (7)	78 (26)	120 (40)	81 (27)	0(0)
13	I will support my kin if he/she decides to be a organ donor.	36 (12)	72 (24)	111 (37)	76 (25.4)	5 (1.6)
14	I will convince or promote organ donation and transplantation with my friends / relatives.	0(0)	90 (30)	120 (40)	63 (21)	27 (9)
15	Organs can be bought and sold in the black market	0(0)	27(9)	111(37)	150(50)	12(4)

Source: Calculations based on primary survey

A sizeable fraction of respondents (48 percent) disagreed, 40 percent were unsure (can't say) and 4 percent believed that organ donation and transplantation are safe and successful procedures for both the donor and the recipient. This suggests a broad lack of trust in these methods' efficacy and safety. Nonetheless, sentiments are more favourable when it comes to the state's promotion of organ donation and transplantation, with 41 percent agreeing and 12 percent strongly agreeing that it should be done. This shows that, despite safety concerns, there is a significant amount of support for organ donation activities. The perceptions seem to be greatly influenced by religious beliefs. It was found that 41 percent of respondents concur and 15 percent strongly concur that religion is against organ transplantation and donation; 28 percent are unsure. This demonstrates a widespread perception that religious factors provide a barrier. Furthermore, 25.5 percent of respondents agreed that it is necessary to have all body parts after one dies and 40.5 percent of respondents were doubtful. These results may indicate that there is cultural or religious value to maintaining one's bodily integrity after death.

There are several common misunderstandings about organ donation as it was observed that 41 percent of respondents agreed with the assertion that they would be born damaged if they donate their organs, while 39 percent expressed uncertainty. This suggests that more education is required regarding the realities of organ donation. Health risks are another issue; 37.8 percent of respondents agreed and 37.2 percent disagreed that there is a link between health hazards and organ donation, indicating concern about potential detrimental effects on health. Regarding individual acts, 51 percent of participants concur that they would accept an organ transplant if their life were in jeopardy, demonstrating a pragmatic acceptance of transplantation under dire circumstances. On the other hand, only 51 percent of respondents agreed to donate their organs, while 22 percent of respondents were unsure. This suggests a cautious but significant readiness to donate.

However, 54 percent respondents considered it as important to talk about organ contribution among family members, demonstrating a strong preference for include family in such important decisions. It was 40 percent, however, are still unsure,

suggesting a possible communication or understanding gap on the significance of these conversations. It was found that 53 percent of respondents agreed to donate to family members, compared to 27 percent who were willing to donate to anyone in need, indicating that respondents have a larger preference for donating organs to family members. This choice demonstrates how decisions about organ donation are influenced by family. There is some support for family members choosing to donate their organs; 37 percent are unsure and 25.4 percent agree, indicating a modest level of support.

The responses to the promotion of organ donation among friends and family are not uniform; thirty percent disapprove and forty percent are unsure.

The concerns regarding the illegal organ trade are also prevalent; 50 percent of respondents believe that organs can be purchased and sold illegally, demonstrating a high level of lack of knowledge and anxiety around this issue.

5.2 Perception Scoring

The respondent's views on organ donation and transplantation are methodically measured and interpreted using the perception scoring and analysis approach. A score ranging from 1 to 5 is assigned to each response category, which includes strongly disagree, disagree, can't say, agree, and strongly agree. The number of replies in each category is multiplied by the corresponding score to determine the mean score for each statement. A mean score closes to 1 indicates strong disagreement, while a score closes to 5 indicates strong agreement. On the basis of the above table 5.2, it has been inferred that organ donation and transplantation is a safe process for donor as well as recipient (mean score=2.40). The comparatively low mean score indicates a high degree of scepticism or ambiguity about the safety and efficacy of organ transplantation and donation among people in Haryana. This impression draws attention to possible misunderstandings or ignorance of the developments in medical practices and safety measures related to organ transplantation. However, raising trust and desire to engage in organ donation programmes may be achieved by addressing these worries with factual information and educational initiatives.

Table 5.2: Mean Score of Views on Organ Donation and Transplantation

S. No.	Statement	Mean Score
1	Organ donation and transplantation is safe process for donor as well as recipient	2.40
2	Organ donation and transplantation should be promoted in the state	3.58
3	Religion opposes organ donation and transplantation	3.51
4	A person should have all the body parts when they are deceased	3.32
5	A traditional funeral cannot be held for a deceased donor	3.23
6	I will be born deformed, if I donate my organs in this life	3.21
7	If my life is in danger, I would accept an organ transplant	3.38
8	Health risks are associated with organ donation	3.07
9	I am willing to donate my organs	3.52
10	Willingness to donate organs should be discussed with family	3.38
11	I will donate my organ to my family member / relatives	3.85
12	I will donate my organ to anyone in need	2.87
13	I will support my kin if he/she decides to be an organ donor	2.79
14	I will promote organ donation amongst my friends / relatives	3.09
15	Organs can be bought and sold in the black market	3.49
	Overall Perception Score	**3.19**

Source: Calculations based on primary survey

Whereas, organ donation and transplantation should be promoted in the state has a mean score of 3.58. This statement demonstrates a favourable attitude towards organ donation promotion in Haryana, as indicated by a mean score greater than 3.5. It emphasises how respondents understood the value and advantages of promoting awareness and encouraging involvement in organ donation campaigns. This positive view implies receptivity to public health initiatives and regulations meant to boost organ donation rates, which may enhance patient outcomes for transplant recipients.

However, religion opposes organ donation and transplantation has a mean score of 3.51. The high mean score indicates a widespread perception among respondents that transplantation and organ donation could be hampered by religious beliefs. This view emphasises how important cultural and religious beliefs are in influencing attitudes towards healthcare decisions in the state of Haryana. By addressing these issues with culturally aware methods and including religious authorities, it may be possible to dispel myths and advance a more educated discussion regarding the morality of organ donation in relation to religion.

It is important for a person to have all of the body parts when they are deceased has a mean score of 3.32. This moderate score suggests that respondents place a personal or cultural emphasis on maintaining bodily integrity after death. One's willingness to participate in organ donation programmes may be impacted by opinions regarding organ donation, which may be influenced by the belief that maintaining the body intact is crucial. This perception gap could be closed by educating the public about the life saving potential of organ donations and its conformity with honourable burial customs.

It has been observed that a traditional funeral cannot be held for a deceased donor has a mean score of 3.23. As with the preceding sentence, the average score raises questions regarding how organ donation and customary funeral practices might coexist. This view emphasises how important it is to communicate respectfully and with cultural awareness in order to help people understand and accept organ donation. However, giving examples of how organ donation and customary funeral customs might coexist should allay fears and promote more accepting views towards donation.

I will be born deformed if I donate my organs in this life has a mean score of 3.21. This claim highlights a common misunderstanding or superstition that affects respondents' opinions on organ donation. The moderate score suggests that specific educational initiatives are required to debunk misconceptions and false information on the effects of organ donation. Giving donors and recipients accurate information about how organ donation affects them both may allay concerns and promote well-informed donation decision-making.

The mean score of if my life is in danger, I would accept an organ transplant is 3.38. With a score above 3, this statement indicates a general willingness among respondents to consider accepting an organ transplant in a life-threatening situation. In order to promote widespread support for organ donation programmes, it may be necessary to provide balanced education about all facets of organ transplantation. This pragmatic approach to healthcare decisions may highlight potential differences in attitudes between those who are eager to donate and receive organs.

Health risks are associated with organ donation and have a mean score of 3.07. The respondents' concerns about possible health hazards related to organ donation are indicated by the moderate mean score. The potential donors may feel less afraid and

have more faith in the process if these worries are allayed with accurate information about the safety and protocols of organ donation. Reassuring people about the safety of becoming donors can involve highlighting the stringent medical standards and screening procedures involved in the process.

I am willing to donate my organs (mean score - 3.52). This statement, with a mean score above 3.5, suggests that respondents have a generally positive attitude towards organ donation. It implies a readiness to contemplate organ donation, indicating a possible openness to donation solicitations and campaigns meant to boost donor registrations. By promoting this optimistic outlook by public awareness campaigns and legislative backing, it may be possible to turn willingness into action and raise the number of organ donors in Haryana.

The question “It is important to discuss the willingness to donate organs with family” has a mean score of 3.38. The score indicates that respondents are aware of the significance of family conversations when making decisions about organ donation. This demonstrates how family support and communication influence people's views and actions towards organ donation. In order to ensure informed judgements and boost support for donation among loved ones, it can be helpful to encourage open communication about organ donation preferences within families.

The mean score is 3.85 for “I will donate my organ to my family member/relatives”. This indicates that respondents have a strong sense of familial duty and are willing to offer their organs to their family members. This emphasises how important familial ties and selfless reasons are when making decisions about organ donation. To further promote organ donation among close-knit communities, it is recommended to fortify support networks within families and address the practical and emotional obstacles associated with intra-family organ donation.

The statement “I will donate my organ to anyone in need” has a mean score of 2.87. When compared to donating to family members, the lower score indicates that respondents are less inclined to give their organs voluntarily to anyone in need. This draws attention to any preferences or reluctances about more general organ donation procedures that can be resolved by public awareness and education campaigns. More

inclusive donation practices might be encouraged by educating people about the advantages of selfless organ donation and dispelling common misconceptions.

The statement “I will support my kin if he/she decides to be an organ donor” has a mean score of 2.79. This statement has a lower mean score, indicating that respondents may not be fully supportive of their family member’s decisions to donate their organs, or they may be hesitant. Building a supportive atmosphere for prospective donors can help them feel more at ease and confident in their choices. This can be achieved by encouraging supportive familial attitudes and addressing donation-related issues.

“I will convince or promote organ donation and transplantation with my friends / relatives” has a mean score of 3.09. This moderate score shows that respondents are willing to advocate for organ donation and have conversations about it with their social circle. It draws attention to the possible contribution that social networks and peer pressure might have in fostering favourable attitudes and actions towards organ donation. Using social media platforms for advocacy and education can boost the effect of public awareness campaigns and inspire community support for charitable giving.

The question if “Organs can be bought and sold in the black market “has a mean score of 3.49. This statement indicates that respondents are aware of unlawful practices related to organ trafficking, as indicated by a score greater than 3.5. Potential donors' mistrust and misunderstandings may be lessened by addressing ethical questions and maintaining openness in the organ donation procedures. Building legal frameworks and highlighting the moral underpinnings of organ donation are two ways to promote moral donation practices and build trust.

The mean score of “overall perception” is 3.19 and it means the respondent have average attitudes on organ donation and transplantation in Haryana. It suggests a somewhat optimistic viewpoint that is restrained by ethical, religious, and cultural factors that affect people’s view to decide about organ donation. Improving organ donation rates in the region requires addressing myths and raising awareness.

Table 5.3: Grouped Mean Scores of Perception

Category	Statements Included	Mean Score
Safety and Benefits	1, 8	2.74
Promotion and Willingness	2, 9, 10, 14,	3.39
Religious and Cultural Beliefs	3, 4, 5, 6	3.32
Personal Action and Acceptance	7, 11, 12, 13	3.22
Legal Concerns	15	3.49

Source: Calculations based on primary survey
Note: The grouping and naming of categories in the table are based on thematic similarities among the statements regarding organ donation perception.

5.3 Perception Analysis

5.3.1 Safety and Benefits

Statement 1 named as organ donation and transplantation is a safe and successful process for both donor and the beneficiary and statement 8 as health risks are associated with organ donation are included in this group. The perceptions regarding the efficacy and safety of organ donation and transplantation are the main subject of this category. The concerns regarding risks and results for both donors and receivers are addressed in statement 1, which express opinion regarding the process's overall success and safety. The concerns regarding possible health hazards connected to organ donation are emphasized in statement 8, which may have an impact on decisions regarding donation safety.

The divergent opinion regarding organ donation and transplantation are evident among respondents in Haryana in the perception of safety and benefits category. While accepting the overall benefits for both donors and receivers the mean score of 2.74 indicates significant scepticism regarding the safety and health implications of organ donation. This shows that in order to address concerns about improvements in transplantation operations and medical safety regulations, specific education efforts are needed. Such programs may boost trust and willingness to join in donation programs by clearing up misconceptions and emphasizing the benefits of organ donation. This could lead to an improvement in healthcare outcomes through a higher transplantation rate.

5.3.2 Promotion and Willingness

Statement 2 (organ donation and transplantation should be promoted in the state), 9 (I am willing to donate my organs), 10 (It is important to discuss the willingness to donate organs with the family members), and 14 (I will convince or promote organ donation and transplantation with my friends / relatives) are included in this category. This category includes beliefs and plans for encouraging and taking part in organ donation. The second statement advocates for the advancement of organ donation programs in the local or state level. The willingness to donate one's own organs and the significance of family conversations in donation decisions are indicated in statements 9 and 10. Intentions to promote organ donation within social circles are highlighted in statement 14, demonstrating proactive engagement in raising awareness and participation in donation.

With a mean score of 3.39, promotion and willingness category demonstrate a favourable attitude towards supporting and taking part in organ donation programs in Haryana. This suggests both a strong community endorsement of organ donation and an individual's readiness to donate organs. The high score highlights an openness to policy initiatives and awareness efforts that aim to improve donor registrations and provide fair access to life-saving organ transplants. This good mood can be leveraged by promoting this proactive approach through ongoing lobbying and educational initiatives, which may result in increased donor rates and better healthcare outcomes for transplant patients in the area.

5.3.3 Religious and Cultural Beliefs

Statement 3 (religion opposes organ donation and transplantation), 4 (It is important for a person to have all of the body parts when they are deceased), 5 (A traditional funeral cannot be held for a deceased donor), and 6 (I will be born deformed, if I donate my organs in this life) are included in this group. This topic deals with attitudes about organ donation that are shaped by cultural and religious convictions. The concerns regarding religious opposition to organ donation are reflected in statement 3, which may have an impact on decisions and perceptions of the compatibility of donation with cultural or religious beliefs. Statements 4 and 5 highlight traditional funeral customs and views regarding the value of maintaining one's physical integrity, which may have an impact on one's views towards organ donation. Statement 6

discusses myths or superstitions regarding the possible outcomes of organ donation, taking into account cultural values and how they affect decisions to donate.

The respondents from Haryana exhibited a considerable degree of effect from religious and cultural elements on their perceptions of organ donation in the religious and cultural beliefs category, as indicated by their mean score of 3.32. This area brings to light issues with religious objections to organ donation, views on the integrity of the body and the suitability of donation in light of customs surrounding funerals. It is imperative to address these misconceptions by engaging with community and religious leaders and providing information that is sensitive to cultural differences. The stakeholders can encourage acceptance and support for donation programs while promoting a more inclusive understanding of organ donation that respects multiple cultural and religious perspectives by promoting informed discussions and busting myths.

5.3.4 Personal Action and Acceptance

Statement 7 (if my life is in danger, I would accept an organ transplant), 11 (I will donate my organ to my family member / relatives), 12 (I will donate my organ to anyone in need) and 13 (I will support my kin if he/she decides to be an organ donor) are included in this category. This category focuses on individual organ donation related behaviours, choices, and acceptance. Statement 7 indicates a willingness to consider medical interventions involving organ transplants and represents the individual's acceptance of organ transplantation in life-threatening circumstances. Altruistic motivations and individual decisions regarding donation are indicated by statements 11 and 12, which emphasized intents and willingness to donate organs to family members or anybody in need. The support for family member’s decisions to donate their organs is covered in statement 13, which reflects perspectives about donation decisions and familial dynamics.

With a mean score of 3.22, the personal action and acceptance category shows that respondents in Haryana have a balanced viewpoint regarding their own decisions and activities related to organ donation. This category represents support for family members' decisions to become organ donors, acceptance of organ transplantation in dire circumstances and readiness to donate organs to loved ones or anybody in need. Further increasing donation rates and creating a positive atmosphere for organ transplantation can be accomplished by bolstering support systems within families, attending to

practical issues, and encouraging altruistic motives. This well-rounded perspective highlights chances to support and encourage organ donation as a family and individual commitment to saving lives.

5.3.5 Legal Concerns

Statement 15 (organs can be bought and sold in the black market) is there in this category. This category addresses concerns about illegal practices related to organ donation. The statement 15 expresses awareness of or opinions regarding the illegal organ trade, emphasizing worries about the moral ramifications and openness of the organ donation procedure.

A high mean score of 3.49 in the legal concerns category indicates that respondents in Haryana are very concerned about illegal organ trafficking methods. This category mostly represents knowledge of and apprehension about the moral ramifications and government regulation of organ donation procedures. It is crucial to address these issues by putting in place strong regulatory frameworks, open donation procedures and strict enforcement mechanisms. The stakeholders can protect patient welfare, uphold integrity in healthcare procedures and promote a fair and equitable organ donation system that puts patient safety and ethical considerations first by guaranteeing ethical standards and preserving public faith in organ donation efforts.

It was observed from the above discussion that there was a noticeable lack of confidence regarding the safety and health concerns connected with organ donation yet, overall attitudes for promotion and desire to donate were cautiously open. This study found that cultural and religious influences had a considerable impact on attitudes. Many respondents believed that religious teachings prohibit organ donation and that physical integrity should be respected after death. Individuals had a comparatively high propensity to donate, particularly within families. The willingness to donate to non-family members was lower, underscoring the significance of familial relationships in decision-making. There was a high degree of mistrust which emphasized the necessity of ethical and transparent organ donation procedures. This is especially true when it comes to the possibility of organ sales on the black market. The results highlight the necessity of focused educational campaigns to dispel myths, highlight the advantages and security of organ donation and involve religious and community leaders in order to harmonize organ donation with cultural and religious beliefs.

CHAPTER VI

DEMAND-SUPPLY GAP IN ORGAN DONATION AND TRANSPLANTATION IN HARYANA

CHAPTER VI

DEMAND-SUPPLY GAP IN ORGAN DONATION AND TRANSPLANTATION IN HARYANA

Organ transplant as a curative medical technique gained public acceptance in India with the Transplantation of Human Organs Act (THOA), 1994 which facilitated the lives of organ failure patients and safeguard the interest of the organ donors. The act envisaged both living donations and cadaver/deceased donations and for the first-time recognized brain death as a positive case for organ retrieval leading to solid organ transplants. However, despite additions of the cadaver organ donation in the THOA, deceased organ donation program has not been popular among the masses in the country and hence, the number of organ donors have not increased over the years, still posing a dismal state (Nallusamy et al., 2018; Srivastava and Mani, 2018; Kute et al., 2020; Kute et al., 2021).

The countries like Spain, Iran, and Iraq have successfully bridged the gap between demand and supply of transplantable organs through legislative measures. These countries have implemented laws that allow for "presumed consent" and have actively engaged transplant coordinators in intensive care units (ICUs). As a result, they have been able to mitigate the shortage of donor organs and improve transplantation rates. The present study has used secondary data to examine the depth of the demand-supply gap in the market in the country and especially in Haryana. Further, this chapter has findings from interactions with the transplant patients to get a realistic picture of the demand-supply gap for organs and the issues faced. The data collected (primary and secondary) has been classified, analysed and presented under three sections , on the basis of the objective of the study as such as magnitude of demand for organs, magnitude of supply for organs and demand-supply gap in organ donation and transplantation.

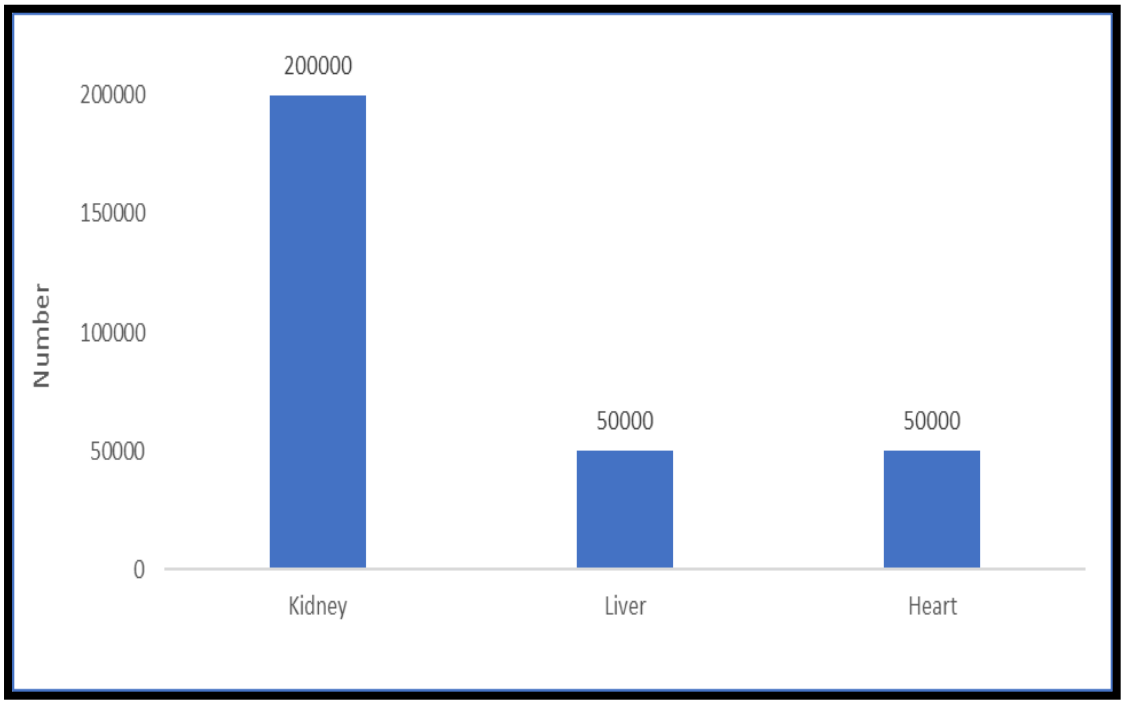
6.1 Magnitude of Demand for Organs

6.1.1 Need for Organs in India

The market for demand and supply of organs is characterized by specific features that are highly backed by ethical concerns. The failure of an organ which may include kidney, liver, heart, pancreas, lung or others creates a demand for organs for

transplantation. Therefore, the demand basically originates from ailing patients with a damaged or failing organ, which requires a surgical operation for replacement of the damaged organ with a functioning one. According to the NOTTO statistics, there is an estimated need of about 2, 00,000 kidneys, about 40,000-50,000 liver and 50,000 heart per year in India (NOTTO, 2023) as shown in figure 6.1.

Figure 6.1: Need of Organs for Transplantation in India

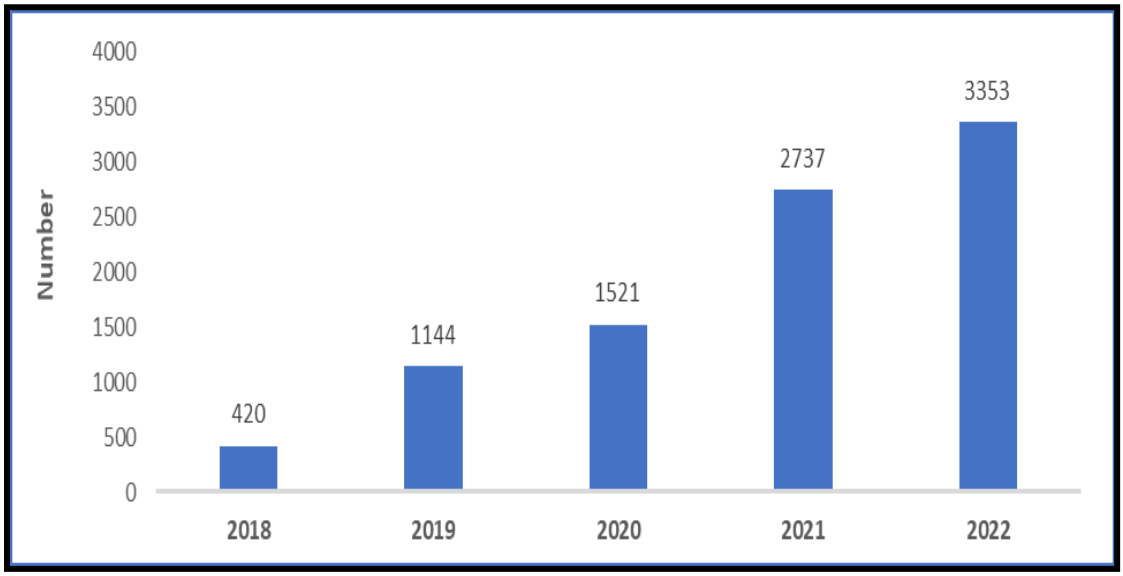


Source: NOTTO, 2023

6.1.2 Need of Organs for Transplantation in Haryana

There has been an alarming increase in the need for organs in Haryana, as deciphered by NOTTO. The need for organs in the state skyrocketed from 46 in 2018 to 420 in 2019 which was a whopping 813 percent increase in the need. The trend continued with a need of 1,144 organs in 2020 and the number rising to 1,521 in 2021 and 2,737 in 2022. The state has continued to see a hike in the number of people awaiting organ transplants this year with a 22 percent hike to 3,353 in 2023 as shown in figure 6.2. Of these patients in Haryana in 2023, maximum of them (2,613) were awaiting donation of kidney, followed by liver (555), heart (88), lungs (42) and intestine (6) (NOTTO, 2023) as shown in figure 6.3.

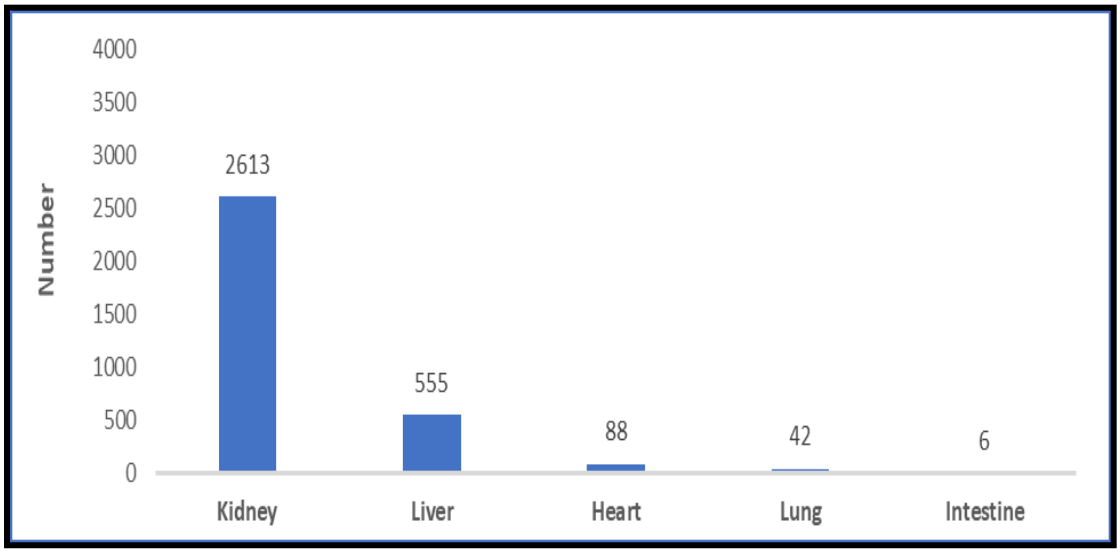
Figure 6.2: Year-wise Patients Waiting for Transplant in Haryana



Source: NOTTO, 2023

Figure 6.3 shows that the longest waiting times in hospitals are for kidney transplants, followed by liver, heart, lung, and intestine transplants. This may be due to due to high demand from prevalent kidney disease, compatibility requirements, availability from living donors and the cost-effectiveness of transplantation over dialysis.

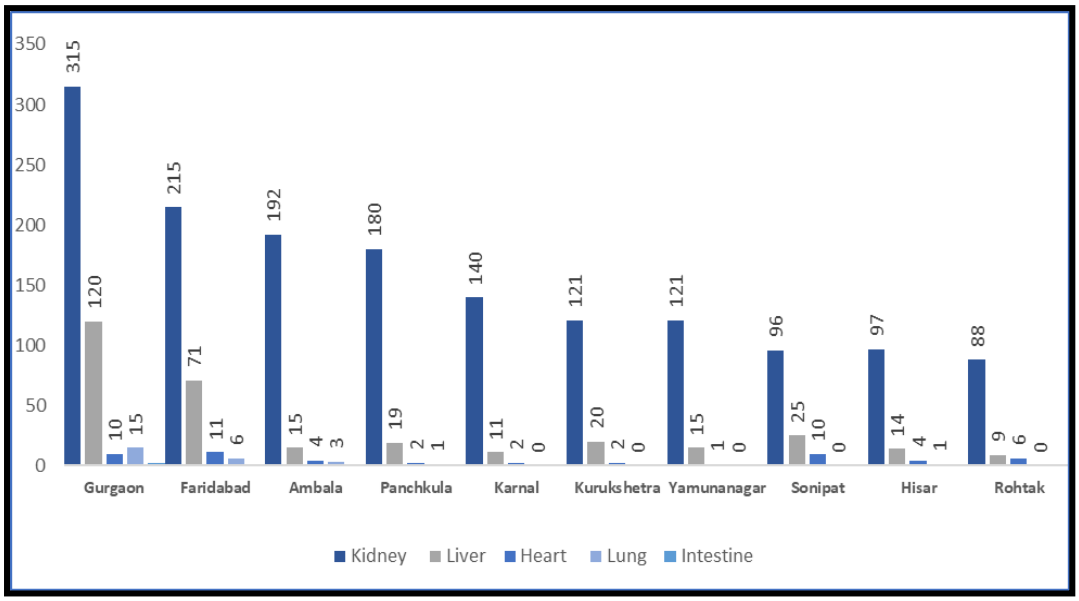
Figure 6.3: Patients Waiting for Transplant by Category of Organs in Haryana



Source: NOTTO, 2023

A further look at the available disaggregated state level data as shown in figure 6.4 indicates that there is huge variation in the demand for organs across the districts of Haryana. The top ten districts having high patient waiting list for organs shows Gurgaon to have the highest numbers followed by Faridabad, Ambala and Panchkula.

Figure 6.4: Districts with High Patients Waiting List for Organs in Haryana



Source: NOTTO, 2023

6.2 Magnitude of Supply for Organs

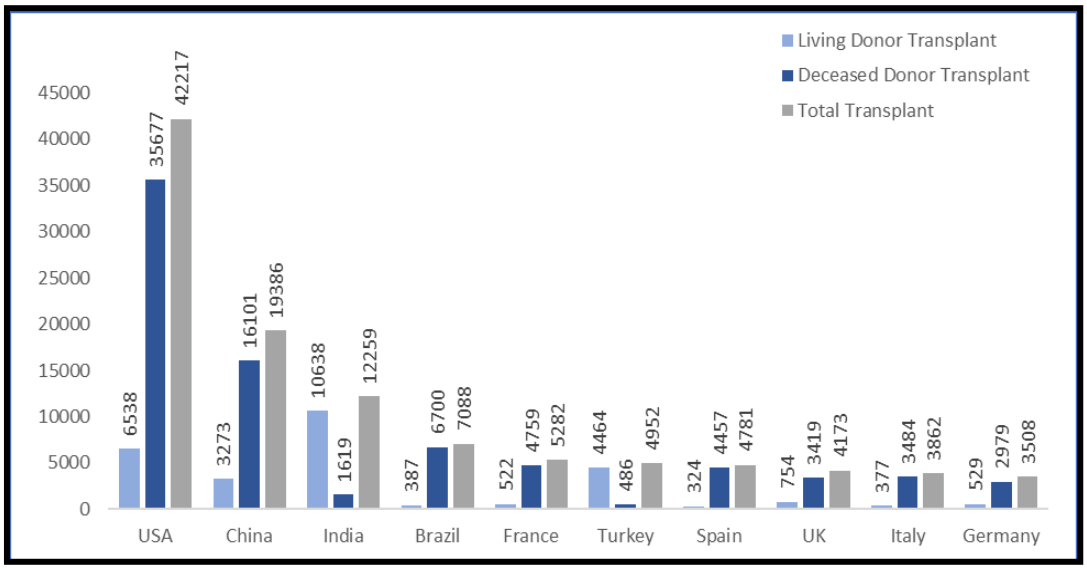
The supply for the organs, on the other hand, is peculiar in nature as the supply in the market is driven by altruism. The organ donor here donates an organ to a stranger, prioritizing the recipient's health over their own potential risks. Therefore, a donor acts out of their desire to help or benefit other individual(s) expecting nothing in return. This demarcates the nature of supply for organs in the market. The organ donation is a gift of an organ to a person with an end stage organ disease who needs a transplant. The donated organ can be from a deceased person (known as cadaveric donor) or a living donor. A deceased donor (cadaver) can donate multiple organ and tissues after (brain-stem/cardiac) death after consent of a near relative or a person in lawful possession of the body. Each cadaver can support six transplants and give life to about six people. Living donors legally includes immediate blood relations, non-near relatives and swap donors (swapping of donors between two pairs of near relatives, when donor of first pair matches with the second recipient and donor of second pair matches with the first recipient).The Transplantation of Human Organs Act (THOA) passed in 1994 and

amended in 2011 provides a system to regulate removal, storage and transplantation of human organs for therapeutic purposes and for prevention of commercial dealings in human organs.

6.2.1 Situation of Global Supply of Organs

An analysis of the living donors, deceased donors and total transplants in specific countries present a diverse picture. It was found that countries like USA and China have high number of total transplants. The supply for organs seems to be weak in India compared to these countries owing to variety of factors, primarily the lack of awareness (as discussed in previous chapter) and myths about organ donation (discussed in the subsequent chapter). As observed in figure 6.5 below, India is at the third highest position in the world, standing next to USA and China in total organ transplants in a year. However, a fact that is observed is that the deceased donor transplant is quite low in India. This indicates low levels of deceased donor in the country that drastically affects the supply for organs.

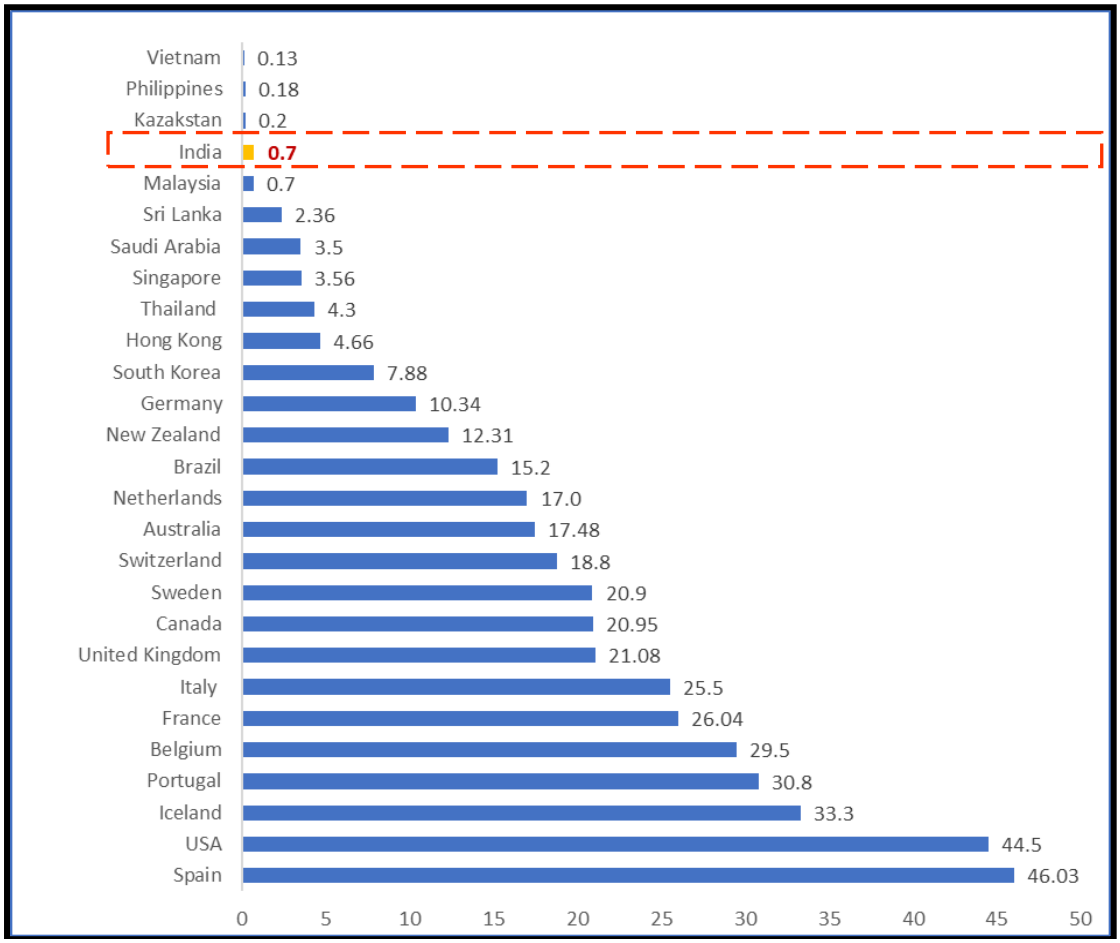
Figure 6.5: Country-wise Living Donor, Deceased Donor and Total Transplants



Source: Global Observatory on Donation and Transplant (GODT), 2021

The deceased or cadaveric organ donation is not widely accepted in India for various superstitions and religious reasons. This pushes India to a very low position among world countries in terms of deceased organ donation per million population (pmp). India has just about 0.7 pmp deceased organ donation rate in 2022 which is quite low as compared to 44 pmp in USA and 46 pmp in Spain as shown in figure 6.6.

Figure 6.6: Deceased Organ Donation Rate (per million population) in World

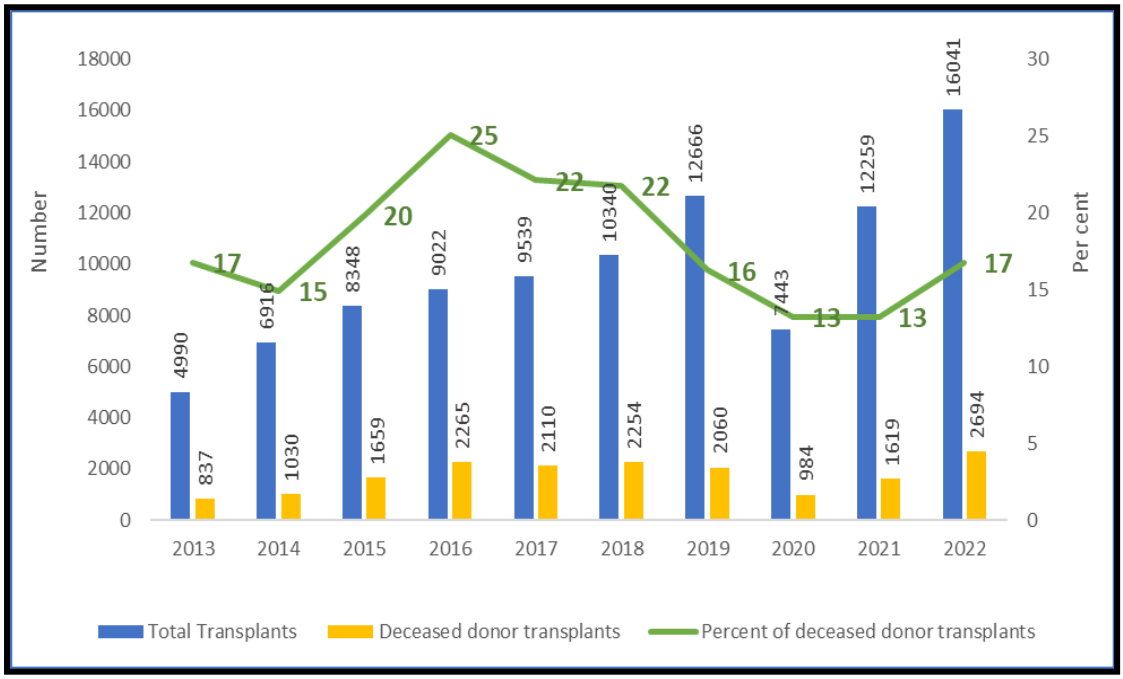


Source: International Registry on Organ Donation and Transplant (IRODaT), 2022

6.2.2 Situation of Supply of Organs in India

The deceased donor organ transplant tends to be low and the proportions have remained sticky over the decade. The deceased donor transplant reduced during the COVID years (2019-21) and is regaining the momentum after 2021. As could be observed in figure 6.7, the proportion of deceased donor transplants was 17 percent in 2013 and has increased over years to 25 percent in 2016. During COVID, the proportion of deceased donor transplants reduced to 13 percent in years 2020 and 2021 and has again increased to 17 percent in 2022. Hence, above 80 percent of the organ transplants in India are living donor transplants.

Figure 6.7 Trends in the Proportion of Deceased Donor Transplants in India



Source: NOTTO, 2023

6.2.3 Gender Disparity in Organ Transplant

An evident gender disparity is persistent in the organ donation and transplantation sphere in the country (Kute, Chauhan and Meshram, 2024). According to Global Database on Donation and Transplantation (GODT) data revealed that gender disparity existed in over 60 countries in the year 2017 and usually in range 30-40 percent females. A study published in Experimental and Clinical Transplantation Journal in 2021 analysed organ transplants in 2021, found that 80 percent of the living donors are women indicating that 80 percent of the organ recipients are men. This meant that most of the living donors were mothers, sisters and wives as men happen to be the breadwinners for the family. Whereas, men do not come forward to donate when the wife or mother or sister is ailing.

6.2.4 Situation of Supply of Organs in Haryana

As observed in the previous sub-section, Haryana state has a predominant demand for kidney and liver. There are about 14 hospitals listed under the SOTTO Haryana for kidney and liver transplantation of which are mainly located in Panchkula, Hisar and Rohtak. A large number of transplant hospitals of Haryana are located it its 2 cities of NCR region mainly, Faridabad (7) and Gurgaon (6). The co- location to

national capital region and easy connectivity to the rest of country may be the main reason of it. Despite this, the state lags far behind in terms of organ donation and transplantation. The state faces a huge shortage of supply with only about 5 percent of the demand met through donors that are majorly donating to their own kin.

Haryana is amongst the poorest performers in the country in terms of cadaver organ retrieval to the extent that they do not even have the record of number of brain-dead patients each year. As per the government records, state registers an average of about 5000 accidental deaths each year. Each cadaver can give a lease of life to six people, but hardly 1 percent of organ retrieval was reported from among them in the state. While it is easier to blame the misconception of unwillingness to donate, there are real challenges that the state faces in terms of cadaver organ retrieval.

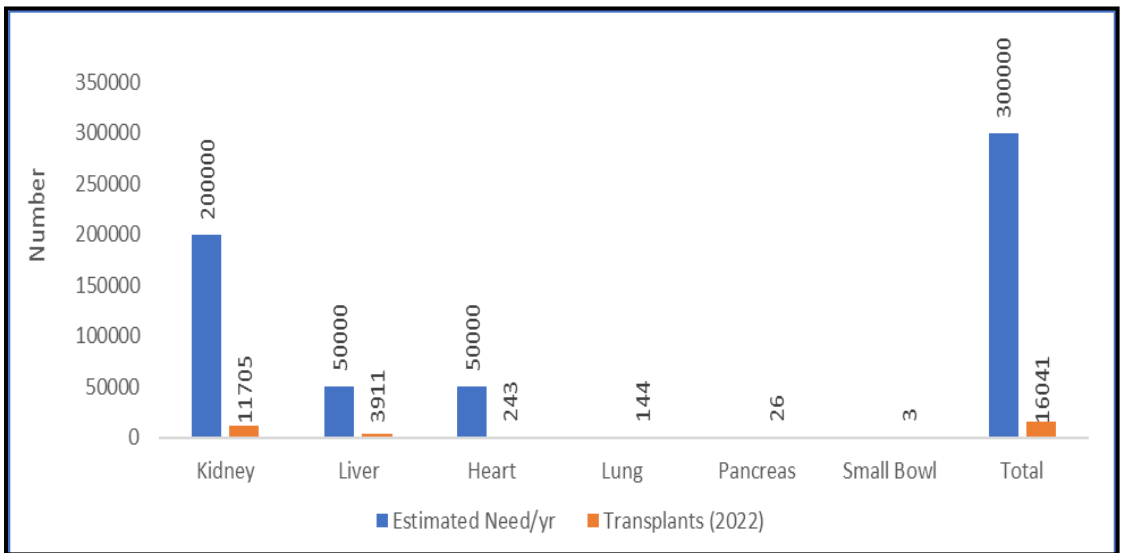
i. Firstly, there are no mechanisms in the hospitals to identify and certify brain death.
ii. Secondly, staff is not trained for effective communication to the relatives of the brain-dead person about the option of saving lives by donating organs of their loved one.
iii. Thirdly, there is lack of trained professionals or the required equipment in government hospitals for carrying out cadaver organ retrieval and also no seamless network between public and private hospitals for transferring potential donor cadavers on time to retrieve organs.

6.3 Demand-Supply Gap in Organ Donation and Transplant

6.3.1 Estimated Need for Organs against Actual Transplants in India

There is a "huge gap" in the demand and supply of human organs and tissues for transplant in the country. As per the NOTTO estimates, every year over five lakh Indians die from waiting for an organ. While annually there is a demand for 2 lakh kidneys, only 11,705 gets a kidney transplant. About 50,000 await liver transplants against an availability of just about 3,900 and about 30,000 require heart transplants against an availability of only 100 as shown in figure 6.8. It is understood that majority of the donors were living donors who were kin and cadaver donations were very meagre. This situation is despite the constitution of the NOTTO in 2014 which acts as the nodal networking agency for coordinating procurement, allocation and distribution of organs in the country.

Figure 6.8: Estimated Need for Organs and the Actual Transplants in India



Source: NOTTO, 2023

The central government constituted NOTTO, for coordinating all activities and networking for procurement and distribution of organs and tissues and maintaining registry of organs and tissues donation and transplantation in the country. The Government of India, DGHS implements the National Organ Transplant Programme for carrying out the activities as per amendment act, training of manpower and promotion of organ donation from deceased persons. Despite these initiatives, the perpetual problem of shortage of organs has led to an ever-increasing demand supply gap. Living donation alone cannot fulfil the requirement as certain organs like heart cannot be taken from living person. The country sees around 1.5 lakh deaths from road traffic accidents every year, of which about 70 percent are declared brain dead and are potential donors. This is about 1,05,000 potential donors who can support nearly 6,30,000 transplants.

However, this gets into a huge waste due to a variety of reasons ranging from:

i. Unwilling families
ii. Lack of knowledge of hospital staff about patient being BSD (Brain stem dead)
iii. Religious beliefs of patient's family
iv. Police intervention as in medico-legal case

However, several states have designed meticulous systems for organ transplant as listed below:

i. Jeevandan Program in Andhra Pradesh
ii. Zonal Coordination Committee of Karnataka for Transplantation in Karnataka
iii. Zonal Transplant Coordination Committee in Mumbai and Nagpur in Maharashtra
iv. 'Mritha Sanjeevani' - Kerala Network for Organ Sharing in Kerala
v. MOHAN foundation in Delhi-NCR and Chandigarh
vi. Rajasthan Network for Organ Sharing in Rajasthan.

Every state is expected to have a SOTTO (State Organ and Tissue Transplant Organization), but only a few have taken focused steps to address the challenges. Despite these efforts, significant progress is still needed to fully tackle the issue and establish a robust organ donation framework nationwide.

6.3.2 Estimated Need for Organs against Actual Transplants in Haryana

6.3.2.1 Demand-Supply Gap for Organs in Haryana

The situation in Haryana is more alarming with a huge demand-supply gap experienced every year in organ transplantation. The state lags far behind in terms of organ donation when compared with other states like Tamil Nadu, Telangana and Maharashtra. Currently, state government has introduced the multi-pronged mass movement/campaign on organ donation 'Donate Organs, Save Lives' in four districts-Gurugram, Faridabad, Rohtak and Panchkula where private hospitals are equipped for transplantation. This campaign has been directly monitored by the chief minister office and imbibes a ray of hope in improving organ donation in the state.

As per government records the state approximately faces a need for about 3,000 transplants every year against which it managed to secure only approximately 100 donors/transplants. However, majority of the donations were those donated to own kin, that is, kidney transplants. This system of altruistic supply has consistently failed to yield an adequate number of organs for transplantation. The number of organs donated annually under this policy has fallen short of the number of organs desired by potential transplant recipients. The expected waiting times are now measured in years rather than months, and many patients will die because a suitable donor organ cannot be found in

time. The organ shortage, which has persisted for so long, is rapidly growing worse and is now approaching crisis proportions.

The state is one of the poorest performers in terms of cadaver organ retrieval. The situation is worse with the state not having the record of number of brain-dead patients each year. Every year Haryana registers an average of 5000 traffic accident deaths, but hardly 1 percent of organ retrievals were reported from these prospective donors. The state stands 100 percent short of its potential transplants. It was found that 50 percent cadaver retrieval could sufficiently cater to the yearly need in the state. The lack of knowledge among hospital staff to identify brain death; lack of initiative among staff to inform relatives of the option of organ donation; lack of infrastructure at the hospitals for organ retrieval; lack of organized records and network for facilitating transfer of retrieved organs for transplant; and the misconception and myths of donation leading to unwillingness to donate among the general public have been hurdles in organ donations.

6.3.2.2 Stakeholders Awareness of the Demand-Supply Gap

In order to understand if the various stakeholders of the organ donation process , the patients - both those who had a transplant and those expecting a transplant , the government officials involved with the SOTTO, the administrators of transplant hospitals and the transplant team members , were aware of the demand-supply gap in organ transplantation , their views on the aspect were recorded on a five-point Likert scale such as ‘strongly disagree’, ‘disagree’, ‘moderate’, ‘agree’ and ‘strongly disagree’. It was observed from table 6.1, that majority of the participants, agreed (58 percent) and 23 percent ‘strongly agreed’, on the demand and supply gap for organ donation in the country. It was observed that almost all the stakeholders agreed that there existed a demand supply gap between the organs required and those available. Only around 7 percent of the patients ‘disagreed’ that there was any demand-supply gap in availability of organs for transplant; these may be of that category, which would have got their organ for transplant relatively in a shorter period of time with minimal wait period. It was also observed that none of the category of stakeholders’ ‘strongly disagreed ‘about the existence of demand supply gap of organ availability.

Table 6.1: Stakeholders' Views on Demand and Supply Gap for Organ Donation

Stakeholders	Strongly Disagree N(%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly Agree N (%)
Transplant Patients (N=70)	0(0)	5(7)	12(17)	49(70)	4(6)
Govt. Officials (N=05)	0(0)	0(0)	0 (0)	2(40)	3(60)
Hospital Administrators (N=14)	0(0)	0(0)	0(0)	4(30)	10(70)
Transplant Team (N=14)	0(0)	0(0)	3(22)	4(28)	7(50)
Total	0(0)	5(5)	15(14)	59(58)	24(23)

Source: Calculations based on primary survey

6.3.2.3 Stakeholders Opinion on Compensating the Donors

An important fact that emerged from the present study was that though there was good understanding of the existent gap in the demand and supply for organs among patients, they were ignorant of some of the regulatory aspects related to organ donation like payment of monetary compensation to the organ donors. The regulatory environment is to be tightened for organ donation due to the specific nature of the act of donation. An organ donation is considered as a gift to the recipient made out of benevolence by the donor.

The opinion of the patients taken on the payment of monetary compensation to the donor was majorly in support to the donor. Given the medical condition they are in, the resulting chaos undergone and the agony of waiting for a donor made about 77 percent of the patients agree or strongly agree with the aspect of providing monetary compensation to the donor though it may be against the law/act as mentioned in table 6.2. They felt this can promote more organ donation to reduce the supply gap as well as compensate the donor for the medical expenses they encountered in the process. Amongst all categories of stakeholders, majority were in favour of monetary compensation in lieu of organ donation. This may be due to frustration developing in huge demand and supply gap or the waiting period for various transplants. The Govt Officials and the transplant team members were the only categories where majority did not support for the monetary compensation in lieu of donated organs. However,

ensuring ethical processes in such compensations is difficult for governments, both at the centre and state levels. Though, there are instances where the governments are adopting strategies for honouring the deceased donors and compensating their families/relatives with money as the one initiated by the Odisha Government with compensation of ₹5 lakh and a state honour award to the relatives of deceased donor (Govt. of Odisha 2024; Tathya, 2024). It may be, compensation only for the deceased organ donations, will be the way forward in motivating people to donate organs of their dead relatives.

Table 6.2: Stakeholders' Opinion on Provision of Monetary Compensation

Stakeholders	Strongly Disagree N (%)	Disagree N (%)	Moderate N (%)	Agree N (%)	Strongly Agree N (%)
Transplant Patients (N=70)	0(0)	5(7.5)	11(15)	49(70)	5(7.5)
Govt. Officials (N=05)	1(20)	2(40)	1(20)	1(20)	0(0)
Hospital Administrators (N=14)	0(0)	3(22)	2(14)	7(50)	2(14)
Transplant Team (N=14)	2(14)	6(44)	2(13)	4(19)	0(0)
Total	3(3)	16(15)	15(14)	61(60)	8(8)

Source: Calculations based on primary survey

6.3.2.4 Stakeholders' Opinion on Factors Affecting Supply of Donated Organs

However, discussion with the various stakeholders seeking their awareness on the factors affecting supply of donated organs revealed that they were in affirmation of the fact that societal factors were the major determinants of the supply of donated organs as depicted in table 6.3. About 45 percent of the respondents believed that ethics had a major role to play in the supply of organs which is followed by the religion with 30 percent of them believing so. It was found that 20 percent stated of consent as the barrier to supply and a 5 percent of them specified that races of the people also determine supply of organs.

Table 6.3: Stakeholders' Opinion on Factors Affecting Supply of Donated Organs

Factors Affecting Supply	Proportion of Stakeholders N (%)
Ethics	46(45)
Consent	21(20)
Race	05(5)
Religion	31(30)
Total	103(100)

Source: Calculations based on primary survey

6.3.2.5 Stakeholders' Opinion on Reasons for Shortage of Donated Organs

The stakeholders' opinions on various reasons for shortage of donated organs were asked to understand their awareness of the supply issues in Haryana. It was found that about half of them (50 percent) brought out the fact that social taboos were the main reason for the shortage. In addition, lack of awareness was stated by 30 percent of the stakeholders as the main reasons for shortage in the organ supply and 20 percent suggested the lack of donor registrations to be that cause.

Table 6.4: Stakeholders' Opinion on Reasons for Lesser Organ Donations

Reasons for shortage of organ supply	Proportion of patients N (%)
Lack of donor registrations	20(20)
Social taboos	52(50)
Lack of awareness	31(30)
Total	103(100)

Source: Calculations based on primary survey

6.3.2.6 Stakeholders' Opinion on Reducing the Demand-Supply Gap

On the basis of response on the measures for reducing the demand-supply gap it was found that the patients hinted that the shortage could be overcome by increasing public awareness, broadening the pool of potential cadaver donors and by redesigning the ethical framework. The desire to ease out laws and ethical framework was mostly seen amongst the patients, hospital administrators and transplant team members whereas Govt. officials were not at all in favour of it. Stakeholders even agreed for monetary compensation in lieu of organ donation. The various opinions on measures to reduce organ demand supply gap, that emerged are summarized below.

a) Increase Public Awareness

However, generating awareness about organ donation amongst masses is inevitable for successfully motivating people for organ donation. About 40 percent of the patients agreed that increasing public awareness towards organ donation will reduce the demand-supply gap. Moreover, from an economic perspective, increasing organ donation rates could reduce healthcare costs associated with prolonged treatments, as timely transplants can lead to quicker recoveries and lower long-term medical expenses.

b) Easing the Laws/ Rule and Redesigning the Ethical Framework

It was depicted in table 6.5 that 60 percent of the stakeholders agreed and 11 percent strongly agreed that the demand-supply gap can be reduced by easing the rules/laws. It was found that 11 percent of the stakeholders moderately agreed on the same. There were 18 percent of the respondents that disagreed with easing of law for reducing demand-supply gap. It was interesting to note that almost none of the govt officials were in favour of redesigning of the ethical framework or easing out laws for improving the demand-supply gap.

Table 6.5: Stakeholders' Opinion on Easing Laws for Organ Donation

Stakeholders	Strongly Disagree N(%)	Disagree N(%)	Neutral N(%)	Agree N(%)	Strongly Agree N(%)
Transplant Patients (N=70)	0(0)	12(18)	8(11)	42(60)	8(11)
Govt. Officials (N=05)	1(20)	3(60)	1(20)	0(0)	0(0)
Hospital Administrators (N=14)	0(0)	1(8)	2(14)	10(70)	1(8)
Transplant Team (N=14)	0(0)	2(14)	2(13)	9(64)	1(8)
Total	1(1)	18(17)	13(11)	61(60)	10(11)

Source: Calculations based on primary survey

c) Broaden Pool of Potential Cadaver Donors

The responses of the patients reveal that about 34 percent agreed that they believed there was adequate cadaveric organ harvesting happening in the country and only a meagre 3 percent strongly agreed on this aspect. There were about 7 percent of them that moderately agreed that cadaver donations were adequate while 60 percent of them disagreed with the adequacy of cadaver donations as presented in table 6.6.

Table 6.6: Stakeholders' Opinion on Adequacy of Cadaver Donations

Stakeholders	Strongly Disagree N(%)	Disagree N(%)	Neutral N(%)	Agree N(%)	Strongly Agree N(%)
Transplant Patients (N=70)	0(0)	35(50)	4(06)	28(40)	3(04)
Govt. Officials (N=05)	2(40)	3(60)	0(0)	0(0)	0(0)
Hospital Administrators (N=14)	0(0)	10(72)	2(14)	2(14)	0(0)
Transplant Team (N=14)	1(07)	09(65)	2(14)	2(14)	0(0)
Total	3(3)	57(56)	08(07)	32(31)	3(3)

Source: Calculations based on primary survey

d) Legalizing Organ Harvesting from Unclaimed Cadavers

However, it was observed that almost 71 percent agreed that legalizing organ harvesting from unclaimed cadavers should be done to improve the organ donor pool and decrease the demand supply gap, out of which about 13 percent of total strongly agreed. There was 11 percent who moderately agreed on this aspect and 18 percent of them disagreed to legalize organ harvesting from unclaimed cadavers to improve organ donor pool.

However, it was observed from the above discussion that in Haryana, demand for organs surged dramatically by 813 percent from 2018 to 2019, continuing to grow at an alarming rate. The primary need is for kidney donations, followed by liver, heart, lungs, and intestines with patients awaiting transplants across cities like Gurgaon, Faridabad, Ambala, and Panchkula. However, the supply side faces significant challenges. Despite having 14 hospitals equipped for organ transplantation, only about 5 percent of demand is met, with most donations coming from living relatives. The cadaveric organ donation remains low, constituting just 1 percent of accidental fatalities due to systemic issues, including insufficient hospital protocols for certifying brain death, lack of communication with families, and a shortage of trained personnel and specialized equipment.

Table 6.7: Stakeholders' Opinion on Legalizing Organ Harvesting from Unclaimed Cadavers

Stakeholders	Strongly Disagree N(%)	Disagree N(%)	Moderate N(%)	Agree N(%)	Strongly Agree N(%)
Transplant Patients (N=70)	0(0)	14(20)	6(09)	42(60)	8(11)
Govt. Officials (N=05)	0(0)	0(0)	2(20)	3(60)	0(0)
Hospital Administrators (N=14)	0(0)	2(14)	1(08)	10(70)	1(08)
Transplant Team (N=14)	0(0)	3(20)	2(13)	04(30)	5(37)
Total	0(0)	19(18)	11(11)	59(58)	14(13)

Source: Calculations based on primary survey

The supply-demand imbalance creates a critical market inefficiency. With supply constrained by barriers such as family reluctance, religious beliefs, and complex legal procedures, patients facing life-threatening conditions are left without viable options. Some patients advocate for financial incentives to donors, viewing it as a necessary intervention to address the gap. This suggestion arises from a rational attempt to stimulate supply through monetary compensation, which could lower opportunity costs for potential donors or their families. Economically, addressing these barriers could improve the supply chain for organs. Proposed solutions include increasing public awareness, simplifying donation regulations, revisiting ethical frameworks, expanding the cadaver donor pool, and considering the legalization of organ retrieval from unclaimed cadavers. These strategies aim to reduce the demand-supply gap, enhance market functionality, and ultimately improve health outcomes across Haryana.

CHAPTER VII

COSTS AND BENEFITS OF ORGAN DONATION AND TRANSPLANTATION IN HARYANA

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The journey towards organ transplantation is burdened with uncertainties and an escalating financial implication. The costs associated with this treatment are considerable, with expenses primarily borne by patients who have limited insurance coverage (Balakrishnan and Nageshwaran, 2020). Due to the seriousness of the illness, the financial strain is often overlooked by the individual, caregivers, and society as a whole (Palakuri et al., 2024). In resource-constrained countries, cost of medical treatment places a significant burden on citizens, often resulting in catastrophic financial consequences (Chugh and Jha, 1996; Dhankar et al., 2021). These factors encompass the frequency of hospital visits, duration of hospital stay, costs associated with diagnostic and therapeutic procedures, as well as any additional therapies and critical interventions required (Ramachandran and Jha, 2013; Palakuri et al., 2024). These constitute the direct costs associated with organ transplantation. The indirect costs include expenses related to transportation, food and accommodation for both the patient and caregivers (Clarke et al., 2006). Even more distressing are the financial setbacks faced by patients due to missed workdays resulting from hospital visits for diagnosis, treatment and transplantation. In addition, patients are often accompanied by multiple caregivers, leading to further absences from studies or work, which in turn contribute to economic losses (Ramachandran and Jha, 2013; Ahlawat et al., 2015).

Healthcare reimbursement for transplant patients is accessible only to a minority, majority of citizens of which the self-employed or unorganized sector workers in particular requires to bear out of pocket expenses to cover healthcare related costs, who often seek care in public sector hospitals, where the government provides subsidized treatment. (Ramachandran and Jha, 2013). Many seek care in public sector hospitals where the government provides subsidized treatment, though they still must pay for drugs and disposables (Ramachandran and Jha, 2013). Whereas, limited slots and long queues in public hospitals often compel patients to opt for private hospitals or

centres, where the costs are exorbitant, further increasing the financial burden (Chugh and Jha, 1996; Jha, 2004).

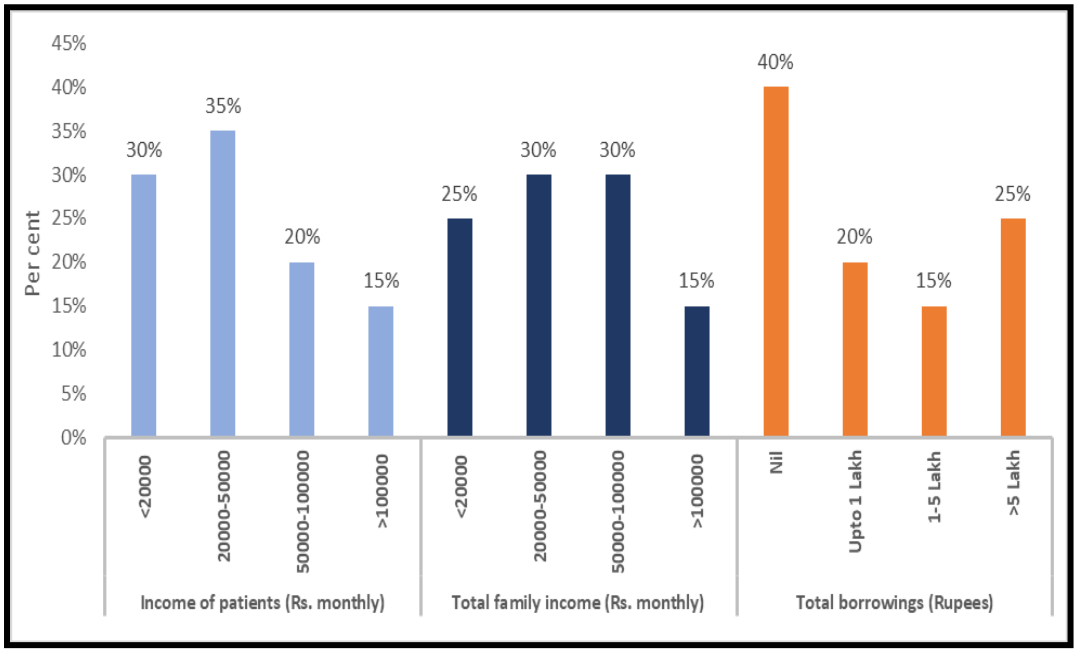
In this chapter an attempt has been made to examine the costs incurred by patients (organ recipients) who had undergone organ transplant throughout their whole episode of diagnosis, treatment and transplant. These patients were asked about the details of their economic conditions; their type of illness (organ failure); the services accessed; the direct costs incurred by them in form of cost of diagnosis and hospital visits, cost of organ transplant and hospital stay, the medical bills after organ transplant, costs borne for the accompanying person(s) and indirect costs or opportunity costs of job loss/ man work hour days lost by the patient and their caregivers due to the ailment and treatment. The patients were also asked to rate their quality of life prior to transplant and after transplant for understanding the extent the transplant has benefitted them.

7.1 Economic Status of Organ Transplant Patients

An attempt was made to examine the economic capacity of the patients in the study; the economic status of the patients was examined by collecting information on their household income and debt levels. It was observed that (figure 7.1) among the sample size of 70 (patients who already got organ transplant done and those awaiting transplant), 21 (30 percent) patients were from income bracket <₹20,000 per month. 25 patients (35 percent) were earning in ₹20,000-₹50,000 bracket per month and about 14 (20 percent) and 10 (15 percent) of them were having jobs/businesses earning in ₹50,000-₹1,00,000 and >₹1,00,000 per month respectively.

The data on total family income of the patient's households showed that 31 (45percent) households had incomes >₹50,000 while 18(25 percent) were in the <₹25,000 income bracket and 21(30 percent) were in bracket ₹20,000-₹50,000. It could also be seen that about 42 (60 percent) of the households held debts. It was observed that 18 (25 percent) of the patient households held debt >₹5 Lakh and 10 (15 percent) had debts in range ₹1-₹5 lakh and 12 (20 percent) had debts upto₹1 lakh as mentioned in figure 7.1.

Figure 7.1: Income and Debt Status of Patient Households



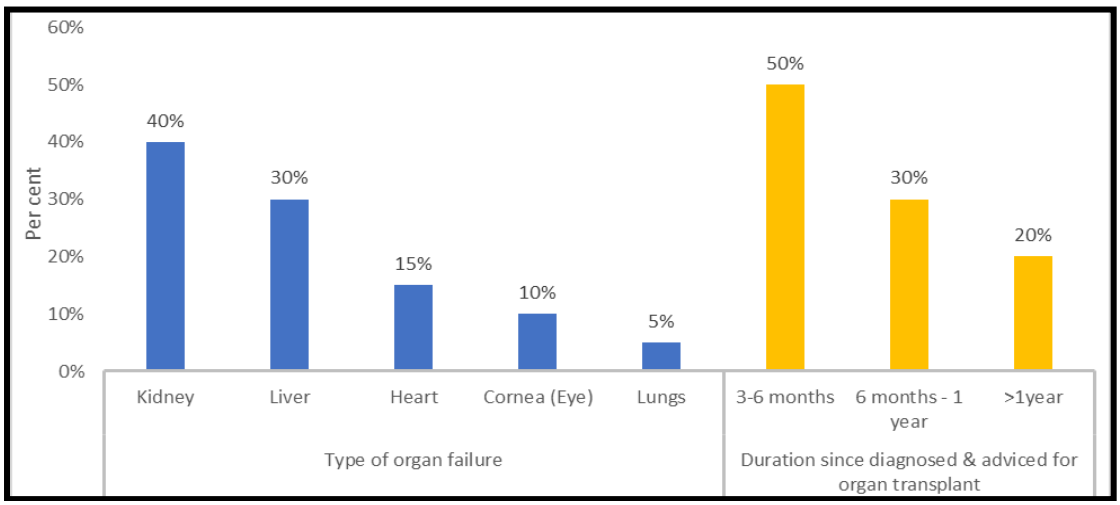
Source: Calculations based on primary survey

7.2 Type of Illnesses and Services Availed

The patients interviewed in the study have undergone kidney, liver, heart, eye and lung transplants. It can be observed from figure 7.2 that majority (49 out of 70) of them have got their kidney (28- 40 percent) and liver (21- 30 percent) transplants. Only10 (15 percent) of them had undergone heart transplant, (may be because of rare availability of heart for transplant and expertise available for successful outcome), 7 (10 percent) of our survey population has undergone eye transplant and only 4 (5 percent) lung transplant. This indicates that the costs borne by the patients also varied as per the type of organ transplant undergone.

It was also observed from data that the waiting time for receiving an organ transplant was more than 6 months and up to 1 year in the case of 30 percent of the patients and more than a year in case of 20 percent of the patients. Hence, about 50 percent of the patients were battling the diseases for more than 6 months and awaiting transplants which could have worsened their quality of life due to an increased number of hospital visits, for diagnoses and treatment and an increased financial burden from the hospitalizations and medications. Added to these could be their loss of workdays and the resulting loss of pay that could have worsened their economic status.

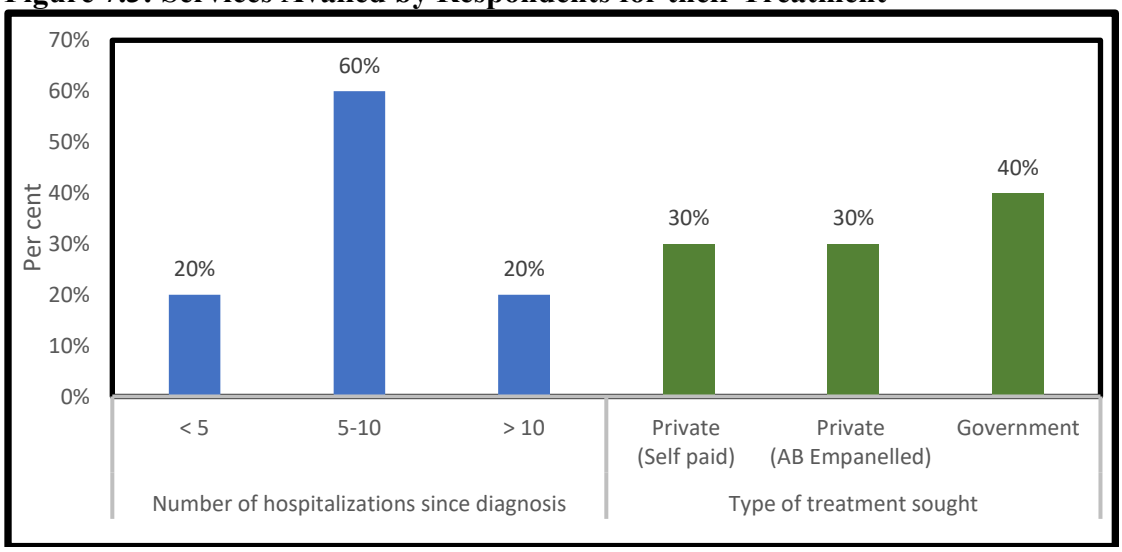
Figure 7.2: Types of Organ Failure and Waiting Period for Organ Transplant



Source: Calculations based on primary survey

The study participants planned their organ transplant services or treatment either at private or public hospitals. As per the information shown in figure 7.3, 24 (40 percent) of the patients had availed the services from a public hospital. The remaining 36 (60 percent) had accessed services at private hospitals which composed of 18 (30 percent) from hospitals empanelled under Ayushman Bharat Scheme and another 18 (30 percent) self-paid for the service at the private hospital. The organ transplant package is a recent addition to the ambit of the Ayushman Bharat Scheme. Hence, unless guided appropriately, lack of awareness about the scheme forced people to pay medical expenses from their pocket which seemed to have increased their financial burden.

Figure 7.3: Services Availed by Respondents for their Treatment



Source: Calculations based on primary survey

7.3 Costs of Organ Transplant

On the basis of the above discussion, it was observed that majority of the patients interviewed for the cost analysis on the basis of their experiences for kidney (40 percent) and liver (30 percent) transplants. The cost factor increased with the increasing wait period for donation of the required organ. The wait was more for the major critical organs like heart and lungs and which cannot be donated by a living person. Hence, an attempt was made in the study to analyse the costs for transplant for the other organs. The previous sub-section indicates several variable cost factors that needs to be accounted while calculation of the costs. The present study considers the following factors while calculation of the costs of organ transplants:

a) Organ type

b) Number of hospital visits and hospitalizations for diagnoses and treatment purposes

c) Type of service availed - public/private (OOP)/private (AB)

d) Loss of workdays and the resulting loss of pay

Among the above factors includes direct costs and indirect costs that would be borne by the patient/individual and therefore while calculation of the costs these were separated out for clarity of the analysis.

7.3.1 Direct Cost

The direct cost includes the costs incurred by the patients in form of cost of diagnosis and hospital visits including travel, food and accommodation, cost of organ transplant and hospital stay, medical bills after organ transplant, and the costs borne for the accommodation and food of accompanying person(s).

a) Cost of Diagnosis, Hospital Visits and Treatment

However, prior to diagnosis and post-diagnosis for treatment, patient has to visit the hospital/doctor multiple times. On an average the patients have visited hospital for about five times for diagnosis and treatment. These visits include direct costs in the form of costs towards transportation, doctor fee, diagnostic tests, medications, procedures and hospitalizations.

b) Cost of Transplant Procedure

The major costs incurred by organ transplant patients are associated with the organ transplant procedure itself. The organ does not involve a cost as per the law in India, but

the procedure is expensive as it requires major investments in trained workforce as well as the supportive technology and the other infrastructure. These demand huge investments for which there are not many public/government hospitals being registered as organ transplant centres and gives way for a dominant private sector. The state of Tamil Nadu, which is pioneer in organ transplantation in the country, has only 8 government hospitals registered as organ transplant centres and the situation in remaining states are still worse.

The wide variations are observed in the costs of availing the procedure in the public and private sector. A kidney transplant procedure would cost about ₹5-₹10 lakh in India (in Haryana as well) in the private sector and about ₹5 lakh in the public sector in India. A liver or heart transplant may cost in the range of ₹18-₹25 lakh in private sector and about ₹15 lakh in the public sector. In Haryana, only diagnosis and treatment costs are considered as there are no public hospitals conducting transplants. The patients get the procedure done in a private setup and revert to the public hospitals for continued treatments and follow-up.

Recently, with the addition of the transplant procedure in the Ayushman Bharat Scheme which provides upto₹5 lakh cover per family on the healthcare costs through a network of public and private hospitals, costs of transplants tend to be still lower in the public sector. However, lack of awareness about the scheme has forced people to pay medical expenses out-of-pocket most of the time.

c) Cost of Post-Operation Medical Expenses

Following an organ transplant procedure, it is essential for the patient to maintain their immunity lifelong to avoid any complications. The post-operative medication would cost about ₹30,000-₹40,000 per month. This may turn out to be expenditure for lifetime.

7.3.2 Indirect Cost

The indirect cost is basically the opportunity costs incurred due to not attending office/work during the course of the treatment and transplant. Apart from the economic losses incurred by the patient due to loss of work, this component also includes the opportunity costs incurred by the caregivers by way of not attending classes or work.

a) Loss of Workdays

A major opportunity cost is incurred by the patients as they tend to lose their jobs and income due to making frequent visits to the hospital at every stage – pre, during and post-transplant procedure for diagnoses, treatment, transplant procedure and monthly follow ups after the procedure. The discussions with the patients in the study revealed that

during diagnosis and treatment before transplant about 45 percent have missed up to 10 workdays per month and 50 percent missed 10-20 days of workdays per month.

However, during the process of organ transplant, about 20 percent of the patients missed about 3 months of workdays, about 50 percent of them missed 3-6 months of workdays and a 30 percent even missed more than 6 months of workdays. This stay in hospital has affected jobs and incomes of about 55 percent of the patients and about 45 percent were able to manage their jobs as they were either government employees or they were businessmen who had the support system in their families to manage their businesses. Even after undergoing the transplant procedure, these patients informed of losing about 5 workdays per month for follow up visits. These job losses and income losses are a major indirect cost to the patient and their families due to the organ transplant procedure undergone.

b) Loss of Workdays of Caretaker

Along with their own job and income losses patients also tend to incur another major indirect cost by way of loss of jobs and incomes of their caretakers who accompany them right from pre-transplant diagnosis and treatment, during transplant procedure and during post-transplant phase and additionally caretaking at home. As discussed with the patients, it is understood that the person accompanying them during diagnosis and treatment and took care of them at home missed up to 15 days of work per month. During the transplant procedure undergone, on an average there were two persons stayed with them in the hospital during hospitalizations for treatment and transplant procedures. The persons accompanying were away from work for about 20-30 days during the transplant procedure of hospital stay and home care. The cost of boarding and lodging of the accompanying person was an additional indirect cost that had to be borne by the patient and this was in the range of ₹50,000-₹1,00,000 as discussed with the patients.

Considering the above aspects as assumptions, direct and indirect cost for major types of organ transplants – kidney, liver and heart were calculated which is as shown in table 7.1.

Table 7. 1: Average Direct and Indirect Costs of Organ Transplantation in Haryana

Costs of Organ Transplant	Description	Organ Type								
		Kidney			Liver			Heart		
		Public	Private	Private Empanelled	Public	Private	Private Empanelled	Public	Private	Private Empanelled
Direct Costs										
Fee paid on each visit for diagnosis	(average 5 visits)		5000	500		5000	500		5000	500
Transportation cost from your home to doctor's chamber for each visit for diagnosis	(average 5 visits)	2500	4000	2500	2500	4000	2500	5000	10000	5000
Total cost of Consultation, diagnostic tests & Medications	(average 5 visits)	5000	15000	10000	5000	25000	15000	5000	25000	10000
Expenses on treatment of organ failure (incl. travel, hospitalization, food &medicines) per month prior to transplant	(avg. 5 months waiting time considered for transplant)	30000	150000	45000	50000	150000	60000	30000	150000	75000
Total hospital bill for organ transplantation	Expenses on your treatment of organ failure (incl. travel, hospitalization, food &medicines) for transplant	No Public Hosp doing Transplant in Haryana	800000	200000	No Public Hosp doing Transplant in Haryana	2500000	1500000	No Public Hosp doing Transplant in Haryana	3500000	2500000
Expenses on medicines post organ transplant	Average follow up for 12 months	Transplant Medicine NA	200000	100000	Transplant Medicine NA	300000	100000	Transplant Medicine NA	300000	100000

Costs of Organ Transplant	Description	Organ Type								
		Kidney			Liver			Heart		
		Public	Private	Private Empanelled	Public	Private	Private Empanelled	Public	Private	Private Empanelled
Indirect Costs										
Days of work per month missed for diagnosis & taking treatment of organ failure (of patient)	15 days per month (Average 1500 per day)	22500	22500	22500	22500	22500	22500	22500	22500	22500
Days out of work (of patient) during the process of organ transplantation, before returning to work	5 months (Average 45000 per month/ 1500 per day)	225000	225000	225000	225000	225000	225000	225000	225000	225000
Days of work per month, missed after taking organ transplant for follow up	5 days per month @1500 per day for 12 month follow up	90000	90000	90000	90000	90000	90000	90000	90000	90000
Days of work per month, caregiver/ accompanying person missed during diagnosis & treatment of organ failure	15 days per month (Average 30000 per month)	15000	15000	15000	15000	15000	15000	15000	15000	15000
Days the accompanying person was away from work for the organ transplant	20 days per month * 5 = 100 days	No Public Hosp doing Transplant in Haryana	100000	100000	No Public Hosp doing Transplant in Haryana	100000	100000	No Public Hosp doing Transplant in Haryana	100000	100000
Cost of boarding & lodging for the	75000		75000	75000		75000	75000		75000	75000

Costs of Organ Transplant	Description	Organ Type								
		Kidney			Liver			Heart		
		Public	Private	Private Empanelled	Public	Private	Private Empanelled	Public	Private	Private Empanelled
accompanying person during organ transplant										
Days of work per month caregiver missed after organ transplant for FU	5 days per month; follow up of 12 months	60000	60000	60000	60000	60000	60000	60000	60000	60000
Total cost incurred		*4.50 L	16.60L	9.45L	*4.70L	35.70L	22.65L	*5.55L	45.80L	32.80L

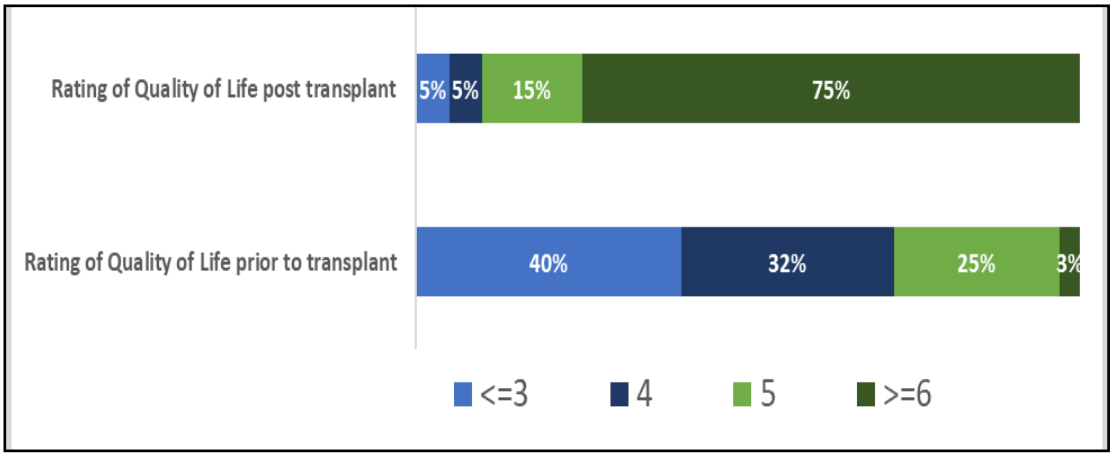
Source: Calculations based on Primary Survey

** No Public Hospital under SOTTO Haryana is doing Organ Transplant.*
***Gurugram& Faridabad Hospitals, doing Transplants are directly under NOTTO.*
**** Cost (in ₹) shown is for the visits to hospital prior to Transplant, Transplant cost will be added extra @ Kidney – 3L, Liver 10L & Heart 20L.*
All costs shown are approximate expenditures.

7.4 Benefits of Organ Transplant

Even though the costs of organ transplant were quite high for the participants to bear for their lifetime, when the patients were asked to rate their quality of life on a scale of 1-10 prior and post organ transplant, about 75 percent of them rated their quality of life to be equal or above 6. There were about 25 percent of that did not find the quality of life so good, that is, they rated their quality of life to be less than or equal to 5 as shown in figure 7.4.

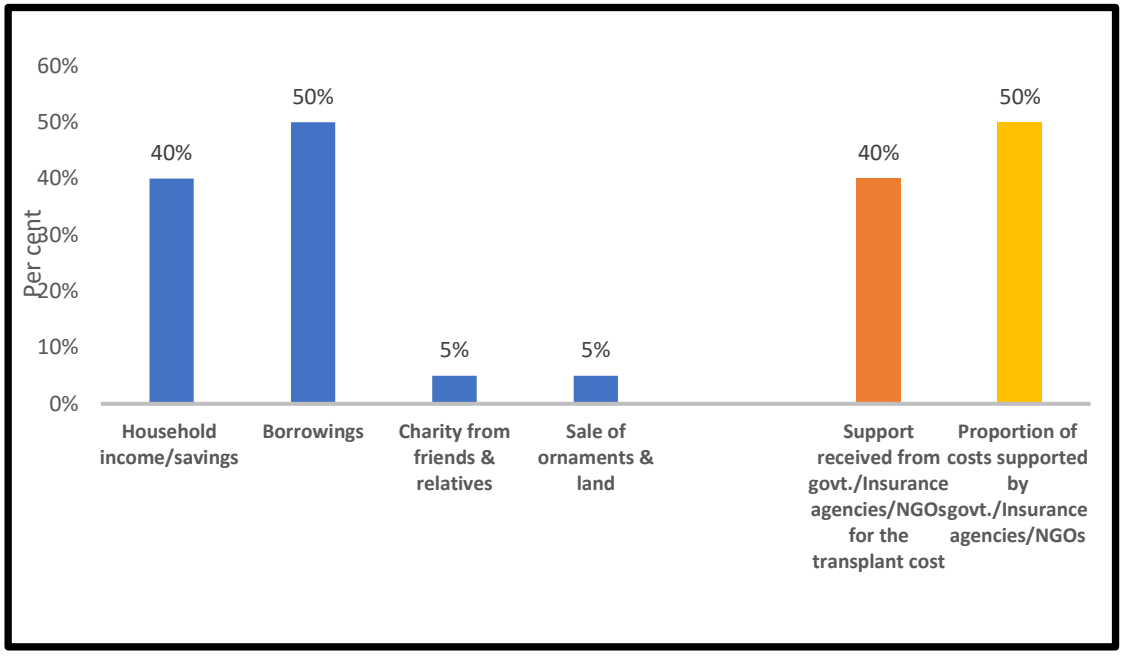
Figure 7.4: Rating of Quality of Life (on a scale of 1-10) Prior and Post Organ Transplant among Recipients



Source: Calculations based on Primary Survey

A look at the source of financing for the huge transplant costs incurred during hospitalization shows that most of them (above 50 percent) have depended on borrowed finances for their treatment. It was found that about 40 percent have relied on their household income and savings, while a 5 percent each had meted out the expenditure from charity done by friends and relatives and through sale of ornaments or land. Only about 40 percent of the patients have received support from government, insurance agencies, NGOs etc. It was observed that among those who received support it was observed that not all of the expenditures were supported as only 50 percent of the costs/expenses were met by these agencies as shown in figure 7.5. This explains the heavy debt burdens that have bundled up for the patient to settle along with their increased cost of living due to expensive medications and food requirements to maintain their health.

Figure 7.5: Source of Finance for the Transplant Costs Incurred during Hospitalization



Source: Calculations based on Primary Survey

On the basis of the above discussion, it was found that the costs associated with organ transplants reveals significant financial strain on patients, with over 60 percent of them in a low-income bracket and a similar percentage already burdened by debt. A substantial number of these patients underwent kidney or liver transplants, with a smaller portion receiving heart, eye, or lung transplants. However, around 60 percent accessed transplantation services in private hospitals, either self-paid or through Ayushman Bharat empanelled facilities. However, as Haryana lacks public hospitals that perform transplants, about 40 percent of patients still relied on public hospitals for pre- and post-transplant care, highlighting a fragmented access to healthcare resources. The healthcare access is underscored by the stark cost differences between private self-funded hospitals and Ayushman Bharat empanelled facilities, with private hospitals imposing much higher direct and indirect expenses. Although Ayushman Bharat theoretically provides coverage for organ transplants, few respondents took advantage of this scheme, likely due to limited awareness or accessibility barriers. While a high cost of transplants imposes a considerable burden on patients, leading to increased debt

and financial insecurity, the procedure offers a substantial return in terms of enhanced quality of life and longevity. Whereas, an increase in medication expenses post-transplant further compounds the economic hardship, suggesting a need for policy intervention. Expanding awareness and improving accessibility to financial assistance programs, such as Ayushman Bharat, could help alleviate some of the economic strain and make lifesaving transplants more accessible to low-income populations. This approach aligns with the broader goals of health economics, emphasizing cost-effective access to essential healthcare and improving economic resilience among vulnerable groups.

CHAPTER VIII

STAKEHOLDERS' CONCERNS REGARDING ORGAN DONATION IN HARYANA

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The issues around organ donation have two dimensions such as demand and supply (Herdman and Potts, 1997). The two direct stakeholders concerning organ donation therefore, are the patients awaiting organ transplant and donors of organs. However, a direct connection between both these stakeholders though naturally starts existing and is inevitable, they cannot perform the act of organ donation or receive the organ on their own. The patient is bound by the physician/specialist's diagnosis and treatment even before awaiting the transplant and dependent on the physician/specialist and hospital/medical care for receiving of the organ (Vanholder et al., 2021). Similarly, donor is bound by their family perceptions and opinions, legal provisions for transplant and the institutional setup that exists for coordination and networking for procurement and distribution of organs and tissues at the national and state levels (Irving et al., 2012; Nadeem & Taqi, 2023).

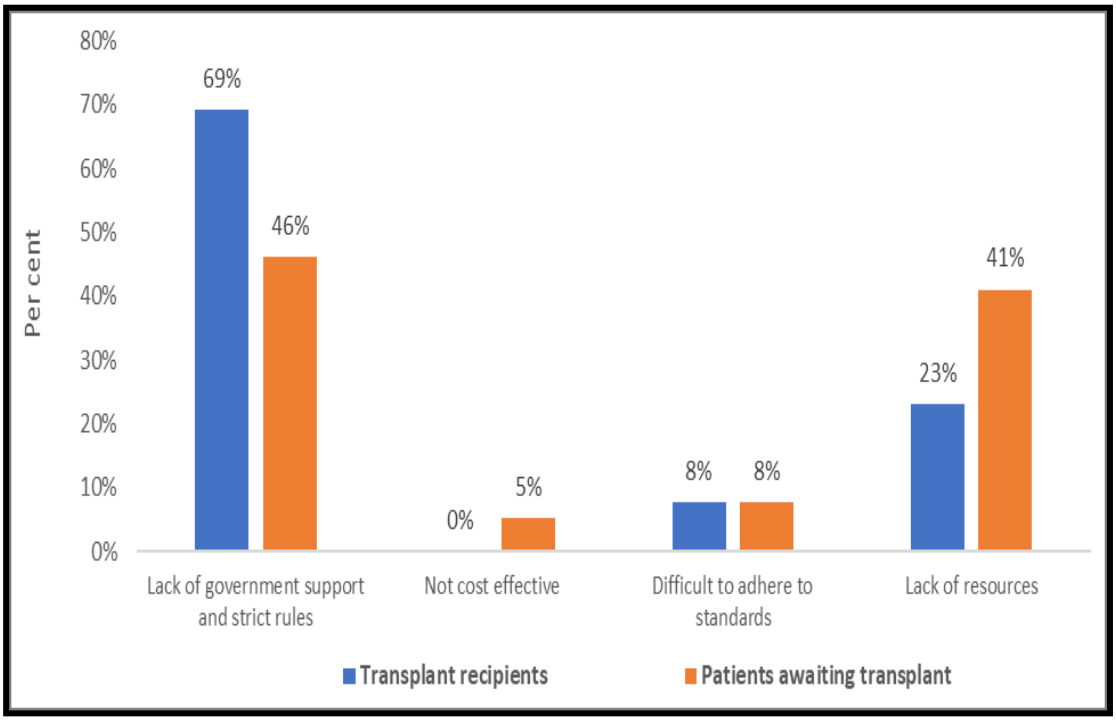
Thereby, present chapter depicts the key findings from key informant interviews (KIIs) that how organ donation can be improved in the state. The interviews and discussions were carefully planned and conducted with various key stakeholder groups, including transplant recipients, patients currently on waiting lists for transplants, and donor families. Additionally, hospital administrators, members of the transplant team (surgeons and coordinators), and representatives from the State Organ and Tissue Transplant Organization (SOTTO) were engaged to gain diverse perspectives and in sights. The discussions included their views on the demand supply gap for organs, their views on the need for active government participation and its probable roles and responsibilities and the kind of governance initiatives.

8.1 Respondents Perspective of Demand and Supply of Organs

The perspective on the demand for organs was examined in the study by interviewing two types of patients, organ recipients and patients waiting for a transplant. Most of them informed that they have encountered issues in accessing their

treatments for a transplant as there were lesser number of hospitals registered as organ transplant centres. The respondents, both that received a transplant and those awaiting transplant, felt that the reasons for this were mainly the lack of government support and stricter rules for organ donation and transplant and the lack of sufficient resources as shown in figure 8.1.

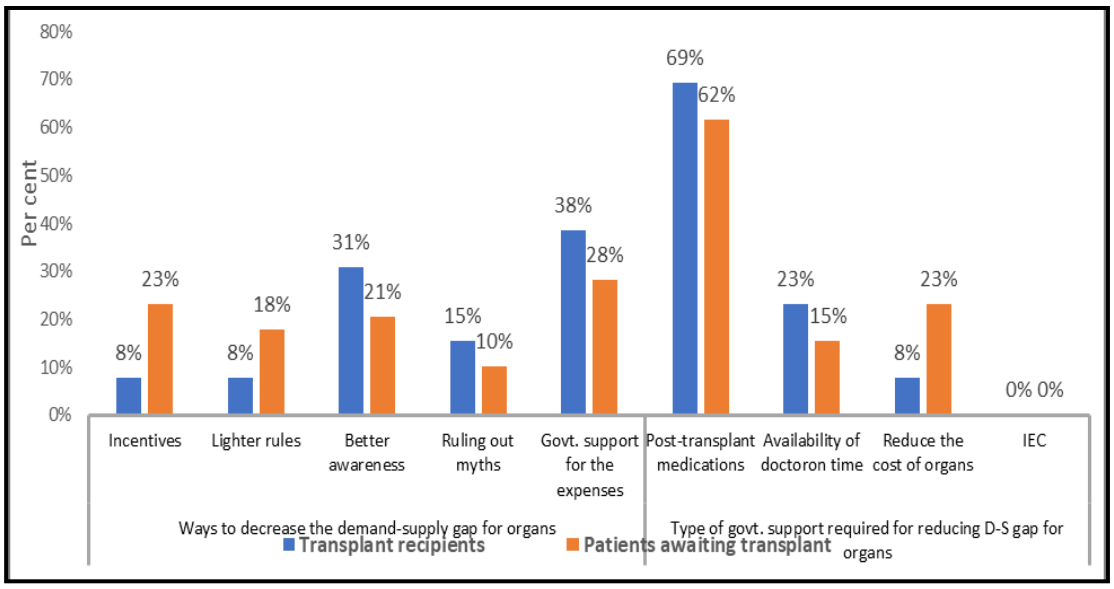
Figure 8.1: Reasons Stated by Respondents for Less Number of Transplant Centres



Source: Calculations based on Primary Survey

As stated by an organ recipient, "There are very few hospitals that engage in an organ transplant and treatment. This is because the government does not provide necessary support mechanisms to these hospitals. The rules for donation and transplant are also very strict that the hospitals find it difficult to adhere to the rules and standards". The patients were annoyed by the huge demand-supply gap and the wait time for organ transplant and suggested government support for the transplant expenses. Furthermore, with regards to the type of support required from the government for reducing the demand-supply gap, the recipients were of the opinion that government should ensure availability of the doctors concerned on time and support with the post-transplant medications as they seemed to be unaffordable to them as shown in figure 8.2.

Figure 8.2: Respondents' Opinion on Reducing the Demand-Supply Gap



Source: Calculations based on Primary Survey

A respondent who had organ transplant done stated that, "*The cost of medicines after the transplantation treatment is very high that I still incur debts to meet it. I will not be able to go to work for another few months and during this time the government should support with some subsidy or schemes, at least for three months till we get back to routine work and start earning*". The respondent awaiting treatment demanded the government for reduction in the cost of organ transplant procedure and for providing post-transplant medications. "*I am awaiting a kidney transplant and the cost quoted to me is too high that I cannot afford it. I had to miss a chance and had to postpone it for future availability hoping it would be available at lower rate. This dismal situation of the availability of organs for transplant, makes my life even more miserable*" – Respondent awaiting transplant.

However, among the respondent who had organ transplant increasing incidence of vital organ failure and the inadequate supply of organs seemed to be of greatest concerns. However, prior to the transplant these organ recipients had to wait quite long time with a reduced quality of life. As could be observed in figure 8.3, only patients undergone cornea transplant were able to receive a transplant in less than 1 month. The waiting time for heart transplants were always longer mostly more than a year. Most of the recipients of liver transplant have waited 6 months to more than a year while the kidney transplant recipients have mostly waited 1 month to a year for the transplant.

Table 8.1: Wait Time of Respondents for Different Organs in Haryana

Organ	Respondents	Waiting Period			
		< 1 Month	1-6 Month	6-12 Months	>1 Year
Liver	Organ Recipient	-	-	12	10
	Waiting for Organ	-	5	22	12
Kidney	Organ Recipient	-	13	10	03
	Waiting for Organ	-	18	14	05
Cornea	Organ Recipient	10	10	06	-
Heart	Organ Recipient	-	-	-	5
	Waiting for Organ	-	-	-	8

Source: SOTTO Haryana, 2023

Regarding the benefit of the organ transplant is concerned, about 85 percent of the recipients felt their life expectancy is increased after organ transplant. While none of the recipients stated no improvement, there were 15 percent of them who could not say about the increase in life expectancy. Also, 92 percent of them stated that they have been able to carry out their pending responsibilities after organ transplant. None of them denied this fact except for 8 percent of them who did not comment on carrying out their pending responsibilities after organ transplant as depicted in figure 8.3.

Figure 8.3: Opinion on the Benefits of Undergoing Organ Transplant

Figure 8.3.a: Increase in Life Expectancy after Organ Transplant

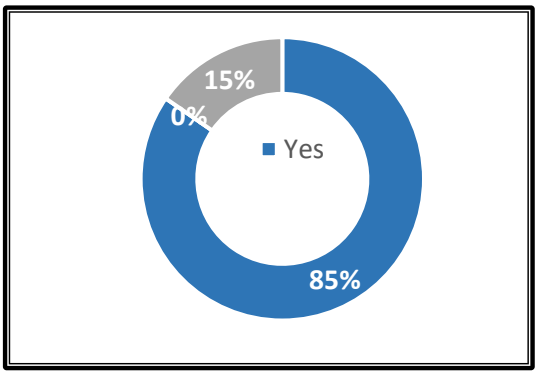
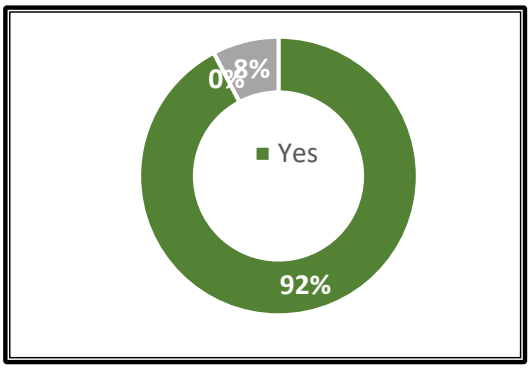


Figure 8.3b: Ability to Carry out Responsibilities after Organ Transplant



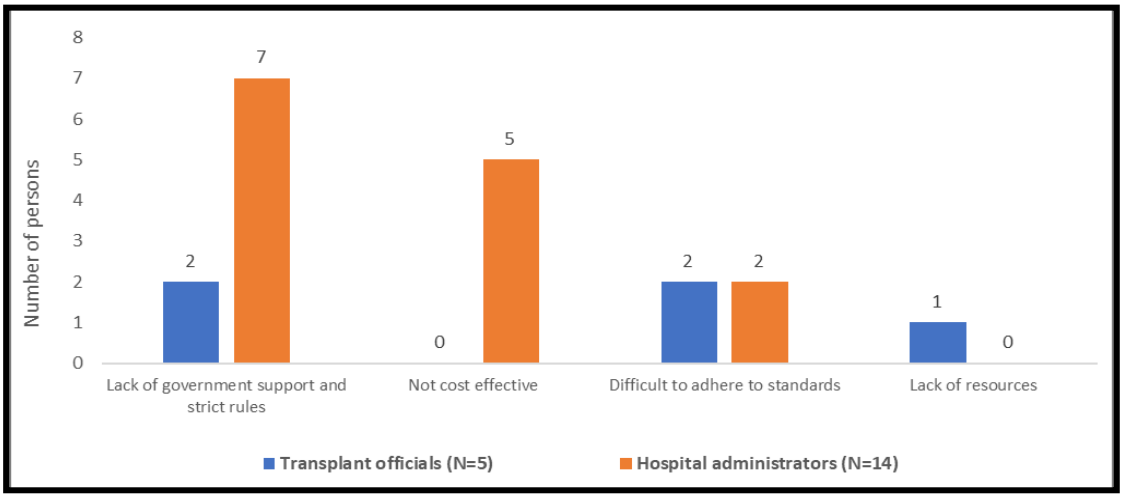
Source: Calculations based on Primary Survey

In spite of the above, the organ recipients face severe issues on the economic front. Majority of the interviewed recipients being kidney and liver or lung patients, they have taken about 3-6 months to get back to their job and re-start their earnings. To many of them, the financial burden has increased after their transplant as the care required after the treatment has increased their cost of living drastically. There was prevailing myth about the deteriorating health of donors after donation of organs. Also, they raised issues about inability of the donor to choose the receiver in case of deceased donors which they thought mainly were the drawbacks of organ donation.

8.2 Demand and Supply Dynamics in Organ Donation

The provider perspective on the legalities and the demand and supply of organ donation captured in the study through interviews of the SOTTO officials and administrators in transplant hospitals brought out that there were not many transplant centres registered in the state due to lack of government support and strict rules and also due to difficulty in adherence to standards. The hospital administrators have felt that transplant procedures are not cost effective and hence hospitals do not opt for registering for it as shown in figure 8.5.

Figure 8.4: Reasons Stated by Officials for Less Registration of Organ Transplant Centres

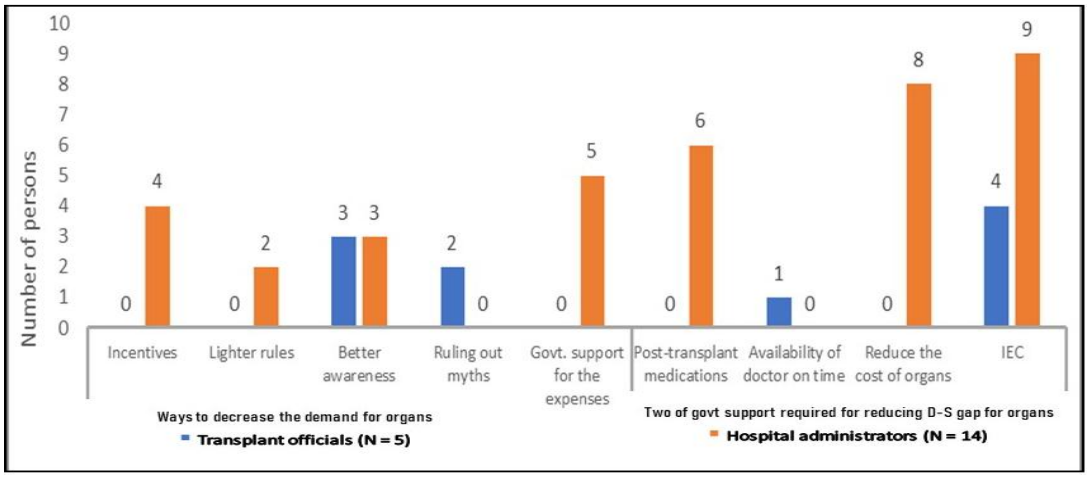


Source: Calculations based on Primary Survey

As per the government officials there has to be intense focus on creating better awareness and ruling out the myths in order to decrease the demand-supply gap for organs. In addition to creating awareness the hospital administrators also vouch for

government support for expenses and providing incentives to donors to decrease demand-supply gap. Since the organ donation is not a well-accepted fact in the society, there is a requirement for government involvement for intense information, education and communication (IEC) activities to promote organ donation activities in the state as per the officials at the government and the hospitals as depicted in figure 8.6.

Figure 8.5: Officials' Opinion on Reducing the Demand-Supply Gap for Organs



Source: Calculations based on Primary Survey

The IEC activities are expected to encourage organ donation in the public. "*There is always a huge mis-match in numbers of recipients or those awaiting transplants and the numbers of organ donors in the country. Actually, this wide gap between the supply and demand could be controlled only by a complete change of mindsets of the society about organ donation. It is considered as social taboo by many communities and religion. For this to change, mass campaigning for organ donation is essential across the nation. We need to find the best medium to reach the masses and convey the message effectively and encourage more donors.*" – said a respondent who was transplant official.

All the transplant officials interviewed in the study were of the opinion that there is adequate participation of the government in organ donation. While, about half of the transplant hospital administrators interviewed, disagreed of the adequacy of the participation of government in organ transplant activities. Both the transplant officials and the hospital administrators were of the unanimous opinion that the THOA rules are inadequate and did need further amendments. The SOTTO officials also were very

hopeful in positive outcome in demand supply ratio with the 'Organ Donation Pledge' drive undertaken by the government. "*The present organ donation pledge drive undertaken by Government of India will definitely help to motivate people to come forward for organ donation. With Prime Minister, himself mentioning the issue on his address to the nation, in MANN KI BAAT, the myths & misconception about organ donation are going to be addressed"* told a respondent who was hospital administrator.

As reiterated by the officials and administrators in the study, there is a huge shortage of organs available for transplant. However, a more pressing issue is that there is huge gender disparity in the market for organ donation. "*While above 80 percent of the kidney transplant recipients are men, when a woman develops kidney failure its hard to find a male donor among the relatives. Usually for women, their sister or mother or daughter donates kidney and never a husband comes forward to do so"*, told a transplant official.

While the hospital administrators were positive about the hospital being adequately equipped for organ donation, the transplant officials disagreed to this fact. Similarly, their opinions differed on the government support to patients for medications after organ donation. The transplant officials were of the opinion that the government should not supply the medications after organ donation, whereas many of the hospital administrators felt the government has a responsibility of supplying necessary medication to the donors. However, on a different note, majority of both the hospital officials and administrators disapproved of the existence of fraudulent practices in organ donation. Though the officials said that the present-day Government has taken encouraging steps to promote organ transplantation and has even linked the Ayushman Bharat Scheme to make the process of organ transplantation easier and affordable for the masses.

8.3 Improving Organ Donation in Haryana

The opinion of stakeholder groups was sought initially on improving organ donation in Haryana. There was consensus across all groups that there was an urgent requirement to improve public awareness regarding organ donation in order to increase

organ availability and donation rates in Haryana. Most agreed that it is imperative to give people the correct and accurate information.

8.3.1 Normalising organ donation

"There is a huge wait list of patients for organ transplant but the donors are not coming forward for donation even after the death. A huge of patients die waiting for an organ donor to donate organs to them" told a respondent who was SOTTO official. All stakeholders agreed that the best way for improving organ donation was to break down the societal stigma associated with organ donation. This could only be accomplished via public information campaigns (IEC campaigns) to educate the public, with a special emphasis on the younger generation. Most stakeholders predicted that normalising organ donation would lead to more communication among families about donation and reducing misinformation about the donation procedure.

However, both state transplant officials and transplant hospital representatives were in affirmation of the need for intense IEC activities for promotion and improvement of organ donation levels in the state. While the state officials agreed that the state government participation in organ donation activities are adequate, only few of the hospital administrators agreed to above as shown in table 8.2.

Table 8.2: Opinion of Stakeholders on Adequacy of IEC Activities for Promotion of Organ Donation in Haryana

Particulars	Type of official	Strongly Disagree N(%)	Disagree N(%)	Neutral N(%)	Agree N(%)	Strongly Agree N(%)	Cannot say N(%)
Intense IEC activities needed for promotion of OD activities in state	State transplant officials	-	-	-	5(100)	-	-
	Hospital administrators	-	-	2(14)	12(86)	-	-
	Transplant Team	-	-	-	2(14)	12(86)	-
IEC activities will improve OD among general population	State transplant officials	-		2(40)	3(60)	-	-
	Hospital administrators	-			14(100)	-	-
	Transplant Team	-	-	-	4(28)	10(70)	-
Govt. participation in OD is adequate	State transplant officials				5(100)		
	Hospital administrators		5(35)	3(22)	6(43)		
	Transplant Team		6(43)	2(14)	6(43)		

Source: Calculations based on Primary Survey

During meetings with government officials and managers from transplant institutions, it was discovered that donation rates were greater in nations like as Canada and Spain than in India. This was attributable to the fact that organ donation was a common cultural practice in these nations. As a result, these stakeholders believed it was critical to educate the public, particularly the younger generation, about the need of adopting organ donation as a cultural norm in the future. Individuals disagreed among groups on how they thought the younger generation might be educated or the best medium for reaching out to the public and younger generation, with some believing this should be included as a topic in the school curriculum. Others thought a variety of social media aimed at the younger generation would be more acceptable. Some felt that organ donation should be discussed with secondary school students, while others believed that elementary school students may be contacted. Another way to engage the younger generation, according to several groups, is to approach them before they begin applying for provisional driving licenses, which is a strategy used to register on the NHS Organ Donor Register (ODR) in the United Kingdom.

Most agreed that children and/or young people should be taken care of with sensitivity, allowing for the dispelling of all misconceptions and the resolution of all queries / concerns, which should be freely discussed and answered. Immediate benefits of teaching the younger age include promoting knowledge of the many ways to register for organ donation, encouraging registrations, and inspiring family discussions about donation desires. "*Showing motivating movies for organ donation to the younger generation as well as the patients or relatives waiting in OPDs & ICU, will definitely work to create awareness and change the perception towards organ donation"* told a hospital administrator.

"The youth of today idolizes the celebrities; In case few of our celebrities can come forward to motivate the masses about organ donation, that definitely is going to have a forceful impact" was told by a respondent who was a SOTTO Official.

"*The gap in demand and supply for organs is fuelled by multiple factors. Foremost of these factors are the lack of awareness and the also the myths surrounding them. There are also factors like incentives to those donating and the government support for the expenses, but these are secondary*" told a transplant official.

However, hospital administrators felt that better incentives and government support for the expenses are important to reduce the demand supply gap. "*The government needs to actively involve in the process of organ donation/transplant through creating appropriate incentives to the donor which may encourage more donation and keep up supply momentum. Even on the demand side there are a lot of poor or middle class that require donation and are unable to meet the cost of the transplant. The government needs to support them with the expenses. This can drastically reduce the gap in the demand and supply*" told a hospital administrator. The participants of the recipient interviews were largely in support of instituting the government support for the transplant expenses and creating more awareness for reducing the demand-supply gap as shown in table 8.3. There was a strong opinion among the officials that the THOA rules need further amendments. The state government officials disagreed on the need for government support for medications after organ transplant, while the hospital administrators were in support of the same.

Table 8.3: Opinion of State and Hospital Officials on the Participation of Government in Organ Donation

Particulars	Type of official	Strongly Disagree N(%)	Disagree N(%)	Moderate (%)	Agree N(%)	Strongly Agree N(%)	Cannot Say N(%)
The THOA rules need further amendments	State transplant officials		1(20)		4(80)		
	Hospital administrators		3(22)	9(64)	2(14)		
	Transplant Team		1(7)	10(71)	3(22)		
Government should supply medications after organ donation	State transplant officials		5(100)				
	Hospital administrators			3(22)	11(78)		
	Transplant Team		7(50)	5(43)	1(7)		

Source: Calculations based on Primary Survey

The officials also called out for special awareness initiatives for dispelling the myths. "*I had to sell my land for this treatment. I have also to borrow money from friends and also at high interest rates. Now I am on rest due to my kidney transplant and not able to work and this has increased my financial burden. It would be nice if the government can make some provisions for some support for the expenses*" told a respondent who was organ recipient. The interviews with patients that were awaiting

transplant highlighted the need for government support for transplant expenses, appropriate incentives to donors, relaxation of rules for transplant and also better awareness among public, as means of reducing the gap.

The organ donation incentive videos should be shown in the ICU relative waiting room since the majority of transplant coordinators believe that making such a decision when in crisis or concerned about losing a loved one is more difficult, especially if the request for consent is unexpected. Normalising organ donation in Haryana was viewed as a crucial step in preparing potential donor families before they are asked to provide consent to donation. There was widespread agreement that normalising organ donation and breaking down death taboos would result in higher rates of consent and more lives saved.

8.3.2 Provide Correct Information and Dispel Myths

There was a common feeling among stakeholders that knowledge about organ donation among the general public is generally low and needs to be improved. *"The distress or urgency is only felt once a person himself or his near or dear one requires an organ for transplant"* said a leading transplant surgeon when asked about awareness and perception about organ donation amongst general public. The majority of transplant coordinators then believed that proper information about organ donation needed to be dispelled in order to educate the public. It was observed that misunderstandings about organ donation make it more difficult for people to decide whether or not they want to donate, which raises the possibility that they won't consent. The following is information compiled from discussion groups that stakeholders felt it was important for the public to know:

a) Organ Transplantation as a treatment for failed organs is a boon of modern medical science that can save the cost of treatment of the patient (in comparison to treating those waiting for a transplant) and add quality years to patient's life.

b) The number of people waiting on a transplant is high and there are a number of lives that can be saved or improved from one person donating their organs as a single brain-dead person can donate organs which can save at least six (6) lives.

c) Children who require a transplant are likely to need more than one transplant in their lifetime as each transplant will help these patients to enhance their life by few years.

d) The length of time people can wait for an organ cannot be endless – there is not an endless supply of organs. Many patients die in the intervening period, waiting for some donor to donate his/her organs.

e) With the increasing life spans, there are more chances that more and more people are likely to need an organ in a wish to defy death but if, someone is willing to accept an organ then he/she should sign the Donor Pledge register.

f) Family consent is required after death before donation occurs.

g) The treatment of the body after organ retrieval has taken place is done with utmost sensitivity and in a respectful manner.

h) The range of organs/tissue that can be used for transplantation should be explained through IEC activities, posters and videos. How different organs are used, especially the cornea should be included in school curriculum to enhance awareness about organ donation and transplantation.

i) Transplant coordinators reiterated the importance of dispelling myths or addressing negative beliefs about donation.

j) Some of the myths or beliefs which were cited as reasons for potential donor families to decline to give consent to donation, included:

i. Signing the organ donation pledge meant that your patient will be given poor quality treatment so that his organs could be taken for transplantation.

ii. Signing the organ donation pledge means that life support treatment could be withdrawn early, in a haste to remove organs.

iii. Organ retrieval means the body will be butchered /mutilated.

iv. Only young people can/should donate organs, whereas, actually one can donate organs until 80 years of age.

v. People are still alive when the decision about donation is made in cases of donation following brain death (donation is actually only considered when all treatment options are exhausted and the person has died).

vi. Religious myths and misconceptions which need to address like the heart/eyes are part of the soul and if donated, one may be born without them in next birth.

vii. Transplants are only for adults and children may not need organs.

viii. Religious myths that a person will suffer next birth if he/she has donated organs.

8.3.3 Other Suggestions

The infrastructure available at the hospitals seemed to be inadequate to the state transplant officials. However, hospital administrators seemed to disagree to this fact. However, majority of the government and the hospital officials disagreed of the fraudulent practices prevalent in organ donation as depicted in table 8.4.

Table 8.4: Opinion of Stakeholders on Infrastructure Availability and Fraudulent Practices in Organ donation

Particulars	Type of official	Strongly Disagree N(%)	Disagree N(%)	Neutral N(%)	Agree N(%)	Strongly Agree N(%)	Cannot say N(%)
Hospitals are adequately equipped for organ donation	State transplant officials	-	3(60)	2(40)		-	-
	Hospital administrators	-	-	-	14(100)	-	-
	Transplant Team	-	2(14)	2(14)	10(72)	-	-
Fraudulent practices are prevalent in organ donation	State transplant officials	-	4(80)	1(20)		-	-
	Hospital administrators	-	12(86)	-	2(14)	-	-
	Transplant Team	4(28)	10(72)	-	-	-	-

Source: Calculations based on Primary Survey

In order to cope with the increase in transplant operations assumed to result from improving organ donation, transplant officials (SOTTO) said that it is necessary to improve infrastructure within private and government transplant centres. One of the SOTTO official told that "O*ut of 50 hospitals which applied for Transplant Centre accreditation, only 14 could clear the various norms during inspection by the approving authorities".* This included making more resources available to help cope with more retrieval. Such resources included:

a) Improving facilities in ICUs to ensure they are comfortable and provide potential donor families with privacy and soothing ambience to get over their grief and may become willing for organ donation.

b) Having more specialized staff, like trained transplant coordinators to deal with donation.

c) Special earmarked area for counseling of relatives in each ICU.

d) Increasing capacity (theatres, ICU beds, staffing).

e) Quicker access to retrieval teams in case accreditation is to the hospitals with infrastructure but no transplant teams.

However, many were keen that registering for pledging for organ donation should be made easier. Whilst there are many ways to sign, there was some confusion about where and how to sign. As a means of raising awareness, many felt the organ pledging should have more identifiable branding or visibility (badge or the donor card could be introduced).

Whereas, SOTTO officials felt that it would be beneficial for the doctors to register patients who wish for donation at routine appointments. Many hospital officials felt that contact points with patients and relatives such as emergency departments, inpatient/outpatient appointments, etc. are ideal places to make people aware about donation.

Many a times the potential donor families do not consent to donation, as they did not know their loved one's wishes, whether he/she wanted to donate organs or not. Consequently, most transplant coordinators felt that the organ donation pledge card should include the signature/contact details of the next of kin, with whom the person signing has discussed his/her wishes. The requirement of providing another person's contact information could act as a way for individuals to initiate the conversation about donation.

In addition to making registration easier, some transplant coordinators and hospital officials felt that the process to check the details held with NOTTO and national organ pledge registry should be made easier as many times the next of kin do not know about the wishes of the deceased. SOTTO officials, ICU staff and transplant coordinators in particular felt that support for organ donation from key religions leaders would be useful to dispel myths and making public to understand the concept of organ donation from their spiritual and religious point of view.

Almost all the stakeholders, in unison, were of the view that some incentives should be attached to organ donation. The relatives of organ donor family wanted a special priority card issued by govt. for their sacrifice as given to various sports person. Another innovative suggestion given by one donor family was that they wanted a special promise/card by the government, guaranteeing them a 'priority treatment', in case, in future they ever require an organ for transplant.

8.4 Public Information Campaign: Support and Key Messages

There is much felt need for IEC campaign, to be conducted in Haryana for mass awareness. There is general consensus for IEC which needs to be well funded and sustainable. "*To reduce the demand and supply gap for organ donation the message of organ donation needs to reach the masses. There is a need for strong support from the government to step up and be the central player in the IEC campaigns*" told a transplant official.

8.4.1 Central Dogma

The donors as well as recipients should imbibe the need for IEC activities. The central dogma of such campaigns is to make organ donation a cultural norm. Sustained awareness about the concept of organ donation and transplantation will people assimilate the essence of the issue and which will further motivate people towards more donations, which will in turn reduce the demand supply gap of organs. Certain measures suggested by stakeholders to augment the efficacy of IEC are:

a) Popular public figures promoting organ donors as role models for the society by means of public campaign.

b) Misconception, religious beliefs, myths and orthodox practices are a common reason for families of potential donors not giving consent for organ donation in Haryana. They often feel that donation is against the wishes of the brain-dead donor. Adequate counseling by professionals involving the entire family often results in a positive outcome and this generally waves off the psychological burden from the family, further reducing the distress of losing their loved ones. It also ensures that the individual's donation wishes are honored. Additionally, other points of consensus are as follows:

i. Mass awareness regarding organ donation pledging

ii. Sensitizing people to consider the fact that they might need such a donation in future and hence they should pledge their own organs

iii. Providing facts and figures (e.g. recipient wait list)

iv. True nature of process involved in donation

v. Dispel the myths and misbelieve

8.4.2 The Way Ahead

The IEC strongly feels that true facts and figures are to be projected to the public- for example, the number of lives that can be touched by a single donor. The campaign should also focus upon benefits to donor families with respect to the recipients. Narrating personal experiences of recipients and donor families and focusing on change in quality of life following donation was considered a viable approach for mass motivation. The benefits to recipients are obvious, following a successful transplantation; but personal experiences are likely to add depth. Benefits to the donor families are generally less well known to public. There is an immense sense of pride amongst donor families due to the perpetual feeling in knowing the positive impact their loved one had on the lives of the recipients and their families. SOTTO members felt that the key to success was to involve local popular public figures, to disseminate the message as it was envisaged that the impact would be sustainable and well assimilated like the Government Road Safety advertisements.

8.5 Donor Registration System

Registration systems aim to maximise organs availability. Since the implementations of the Task force Report 2008, mandatory availability of transplant coordinators into all ICUs in Haryana has made a positive impact on the donor status. Transplant coordinators are an invaluable asset in liaising with potential donor families and working passionately for maximizing consent for donation. Donor family feedback speaks volumes about transplant coordinators having a deep positive impact in their decision making. However, donor families and recipients are still of the opinion that the involvement of the government is inadequate and more efforts need to be exercised to further streamline the process, including relaxation in health care rules and health insurances.

8.5.1 Soft Opt-Out/ Presumed Consent Option

THOA rules govern organ transplant program in our country, which follows an "OPT IN" approach. But this approach is often more of a hindrance rather than facilitation. The idea of introducing a soft opt-out/presumed consent registration system was the only idea that resulted in differences amongst stakeholders. The support for the

proposed option of soft opt-out/presumed consent registration system was highest among the health care providers and some patients on wait list. However, a section of stakeholders was in disagreement with the proposed changes of a soft opt-out system in Haryana. Notably, the greatest hesitations were voiced by those who work closely or directly with potential donors and their families. One of the respondent, who worked as transplant coordinator told *"The people of our state are not mentally prepared to adapt to the soft opt out legislation. There will be a large hue and cry in the society as people of Haryana are sentimentally labile and have lots of religious myths associated with a complete body going for cremation, to be able bodied in the next birth"*.

8.5.2 Advantages of Soft Opt-Out/Presumed Consent

Despite the concerns raised by stakeholders, it was felt that soft opt-out/presumed consent legislation can bring about a cultural change for people of Haryana encouraging altruistic behaviour among the masses. A legislative change could possibly result in an increase in the number of potential donors and therefore organs available for transplantation as it appeals to ambivalent individuals, including unclaimed bodies or the destitute. It was perceived that change to soft opt-out/presumed consent will make it easier for transplant coordinators and the ICU staff to facilitate potential donor families by reducing decision-making burden. One of the SOTTO official suggested that "*The change in registration system to 'soft opt-out' or presumed consent, should start with the unclaimed bodies, destitute or the people whose medical expenses are completely paid by the state"*.

8.5.3 Concerns Regarding Soft Opt-Out/Presumed Consent

There are a number of risks associated with the introduction of soft opt-out/presumed consent system if it is not implemented cautiously. If the legislation is not promulgated carefully, it could result in reduction in the number of donors and increase the risk of potential donor families not consenting.

8.5.3.1 Medical Distrust

It was noted that particularly by medical staff that people have lost faith and respect towards members of the medical profession over recent years. As such, the public are increasingly likely to question the judgement of medical staff. This has been

confounded by newspaper reports of misinformation about hospitals retaining tissue and other body following demise of an individual. Adding to this is insufficient knowledge available in the social media. ICU staff and transplant coordinators were concerned that the introduction of soft opt-out/presumed consent could ultimately lead to more conflict amongst health care providers and potential donor families. Obtaining consent from families in a highly emotionally charged situation is an extremely complex and labile issue and often leads to conflict within family members. There was a general concern about public perception that in order to have a positive outcome, focus of the medical staff will be on harvesting organs viz a viz, the emotional issues which families have in accepting brain death, may exacerbate difficulties associated with accepting end of life status and withdrawal of therapy, which may, in turn, result in denial of consent. Furthermore, there are ethical concerns intertwined with end-of-life care and conflict of interest pertaining to patient care and death, particularly while dealing with donors with cardiac or brain death. There is a possibility that soft opt-out/presumed consent would result in further dissatisfaction. Some stakeholders, SOTTO officials and hospital administrators feared possibility of heightened litigation and negative media publicity resulting from first complaint by a donor family who may have had the slightest perception that their loved one wasn't given appropriate honour and care. This could have devastating consequences on the credibility of the very idea of organ donation.

8.5.3.2 Consent by Family

The family's conviction for donation and mutual consent amongst all members was perceived to be the most fundamental issue in augmenting organ donation rates in Haryana. In the opt-in system, potential donor's families are approached to seek consent when medically appropriate. In the event of implementation of soft opt-out/presumed consent system, it is difficult to predict if this would still be the scenario, as some staff feared that they would feel reluctant to approach a family whose loved ones had opted out. Consequently, pool of potential donor families could reduce sizably.

The stakeholders were sceptical that the organ donation pledge (ODP) would not be acceptable to masses in the soft opt-out/presumed consent system. They were also of the opinion that people who are ambivalent about organ donation would be unlikely to be actively seeking for an 'opt-out' register. In contrast, SOTTO officials and patients on the wait list felt that those who are unwilling for donation would be raising objections against donation in a soft opt-out/presumed consent system.

Transplant coordinators, donor families and some recipients perceived that a soft opt-out/presumed consent system reduces the likelihood of individuals discussing their donation wishes. However, it was also felt that signing the ODP is a proactive declaration of last wishes which may stimulate conversation amongst family members. It has been realised that soft opt-out/presumed consent is a difficult concept to comprehend. Presumed consent might cause complications and can lead to emotional turmoil amongst family members and transplant coordinators. Their concern was that a lack of adequate understanding regarding consent system, confounded with grief, would increase the likelihood of refusals while simultaneously contributing to feelings of distrust towards the medical system. The ODP is definitely a positive aid towards initiating a conversation regarding donation. It is a sober and emotional way of communication about donation wishes. However, the situation may be viewed in a way that the family's loved one did not actively make a decision not to donate, making the choice more difficult for them.

8.5.3.3 Inadequate Comprehension of the Idea that Donation is a Gift

The moot idea that donation is a gift of life, holds strongly for many. Donor families identified a sense of pride in the fact that donation being a gift that their loved one had offered to others. Recipients and those on the wait list also acknowledged the importance of the idea that donation is a supreme gift. However, it was psychologically difficult for some recipients to cope with the idea of integration of someone else's bodily parts into their lives and this was further imploded with the sense that someone had to die in order to help them carry on with their lives.

8.5.3.4 Perplexity of Situation

It was thought that changing the registration system to soft opt-out/presumed consent would cause confusion and non-acceptance among the general public. "*At the end of the day it's not about the staff, it's about the donor family and opt out makes it more difficult for the family to come to a decision. They are confused"* commented a transplant coordinator.

There are concerns that public may not understand the soft opt-out/presumed consent system, methods of its implementation, if the system has already been changed, how the organs will be handled, process of registering an objection, and how conflicts between various registration systems would be resolved. The hard work, done over the years to increase awareness, may get undone by this public confusion/ misconception and this may result in higher rates of refusal. It was perceived that between the discussions and the implementation of the proposed changes, there possibly will be reduced numbers of pledges and compliances to organ donation.

8.5.3.5 Undue Mileage

Majority of stakeholders perceived that introducing new legislation of soft opt-out/presumed consent may culminate into politicians taking undue mileage out of it. This may lead to indifference amongst the public about organ donation. Such individuals may consider otherwise to the option of donation, as the idea may antagonise them. There was also the danger of political turnover of the issue and generation of the false sense that mortal remains being 'state owned' which may not affiliate with a section of the people of Haryana.

8.5.4 Changing Opinions

Some stakeholders raised concerns about the changing attitude of public towards organ donation in view of the proposed legislative changes. The introduction of soft opt-out/presumed consent led to changes in attitudes, which were noted during joint discussions regarding concerns associated with change in legislation. A transplant coordinator told *"I was initially in agreement of the proposed changes but my outlook changed when I further pondered about the implications and were more cautious about soft opt-out/presumed consent".*

This change in attitude gave a subtle hint on medical distrust, with many feeling that they needed further evidence for effectiveness of this system, before the changes to be implemented. Some recommended that soft opt-out/presumed consent legislation can be introduced in other states like Tamil Nadu or Rajasthan where donation rates are high; its implications can be assessed before the system being changed in Haryana, after assessing its impact in those states. However, SOTTO officials and hospital administrators discussed the interpretation of the efficacy of soft opt-out/presumed consent system in other countries. Some reflected upon the example of Spain as a model of success for the soft opt-out/presumed consent system. However, other stakeholders (especially transplant coordinators) highlighted that donation in Spain was higher due to structural and cultural differences.

Spanish people have a higher level of trust in their medical system and organ donation is an acceptable cultural norm in their society. Such discussions led many stakeholders to conclude that soft opt-out/presumed consent legislation alone may not be able to bridge the organ demand and supply gap, for transplantation unless other changes are implemented. It has been agreed upon by all stakeholders, that organ donation rates can significantly be augmented by increasing public awareness, change of legislation and mass education.

The discussions with the stakeholders regarding the essence of organ donation, which included SOTTO officials, hospital administrators, ICU staff and transplant officials, the donor families and the patients (both recipients and those awaiting transplant), threw light on strategies for IEC and the detriments causing transition from ‘opt-in’ to ‘soft opt-out’ approach. The stakeholders unanimously supported the idea of aggressive IEC campaign, adequately funded and sustainable, to be conducted in the state. This was viewed as a means of realizing organ donation a cultural norm. Much of scepticism was seen on the proposal for transition of the legalities for organ donation from the present ‘opt-in’ approach to a ‘soft opt-out’ approach. Despite the hindrances, both increased awareness as well as change in legislation is the only way forward to ensure better donation rates and decrease in the demand supply gap.

CHAPTER IX

CONCLUSION AND POLICY RECOMMENDATIONS

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The pace of technological advancement is phenomenal across the globe. Technological advancements are reaching new horizon in the field diagnostics and therapeutics too (Thimbleby, 2022). However, there is a surge in the incidence of lifestyle diseases like coronary heart disease, diabetes and hypertension etc. (Jamison et al., 2006). Such diseases can cause end organ damage like as renal failure, liver failure and cardiac failure (Xanthopouloset al., 2018). Replacing irreversibly damaged organs with transplanted organs is one of the treatment options available which gives a new lease of life to patients (Cascalho and Platt, 2006). The diseased people have a chance of surviving with a good quality of life, but for the availability of organs (Grinyo, 2013). The data from GODT shows that 12,666 organ transplants were carried out in India in 2019 after the United States and China. In view of India's population in spite of these encouraging numbers, India stands far behind USA (8 transplants pmp as compared to more than 100 transplants pmp in the USA). The maximum of transplants were kidneys from live donors and out of which only one fifth were from deceased donors and the donation rate remains as low as below1 percent per million in India.

WHO has made an appeal to all nations of the world to become self-sufficient in organ transplantation, both by decreasing life style diseases and by increasing the availability of organs. To bridge the gap between demand and supply, government and citizens must make more concerted efforts for the societal acceptance of organ donation (Sun, 2014). Social influencers should also be roped into this task along with health care workers (Cotrau et al., 2019). Living as well as deceased donors can donate kidneys, livers, and other organs, but only deceased donors can donate heart and cornea. In India, donation rate of merely 1 donation per million deceased Indians is unfortunate (Sarveswaran et al., 2018). The number of live donor transplants occurring in India is second only to the United States, but our country doesn't rank anywhere in the list of deceased donor transplants (Asia, 2024). The situation is fairly grim owing to the fact that Haryana is one of the states in the North India with lowest rate of organ donation (Vincent et al., 2022). Such discrepancies may be due to misinformed perceptions and lack of awareness (Carola et al., 2023).

9.1 Major Findings

The major findings of the present study have been presented objective wise as follows:

9.1.1 Awareness about Organ Donation and Transplantation

The overall awareness about organ donation and transplantation was assessed among 500 respondents and it was observed that 201 (40 percent) respondents out of 500 were not aware that body organs could be donated transplanted into another person. Thus, awareness level among the public about organ donation was 60 percent with 299 respondents out of 500 saying 'Yes' to the question. Among the 299 respondents that expressed awareness about organ donation and transplantation, questions were posed to them about their source of information about it. The analysis of data showed that the internet (25 percent) and social media (19.7 percent) were the prime source of information among the public. About 18 percent of those aware knew about it from the hospitals and about 14 percent and 11 percent knew about it from newspaper and television respectively. The family members have provided information to about 4 percent of those that were aware of organ donation.

A further deep dive into the level of awareness among those who were aware of organ donation and transplantation did not show favouring results as there was lot of wrong information perceived by the public. Among those aware of organ donation only 42 percent were aware of organ donations made by live human beings. It was observed that 33 percent were aware of cadaver donation, that is, organ donation at death. The correct information was available to about 25 percent of the people who were informed of both types of donations. The awareness of the public on the registration for organ donation and the legalities regarding it was seen to be quite low. It was found that 92 percent were aware that the consent of parent, spouse or children is required before organ donation. While, 57 percent of them felt the need for law concerning the governing of organ donation and transplantation, only 37.5 percent were aware that the legal provisions existed for organ donation and transplantation in the state. About 20 percent did not know if any legal processes existed for organ donation. Only 9 percent was aware that organ swapping was legal in the country and only about 41.5 percent was aware of a nearest transplant centre.

Even among those who were aware of organ donation it is found that only 65 percent were aware that many people lose lives due to shortage of organs. Similar, was the proportion that was aware that one donor can donate to multiple recipients. The video-assisted training conducted on 300 participants found that were chosen random irrespective of their awareness levels about organ donation had been instrumental in proving that strengthening of IEC would improve awareness and attitude toward organ donation and would lead to increase in organ donation. However, around86.7 percent of the respondents mentioned that if an approach is made to donate organ they will be willing to donate but in the post-test this increased to 142 (94.7 percent) respondents. There were 103 (68.7 percent) respondents in urban group in the pre-test who were affirmative about donating the organs of their family members while in the post-test this improved to 81.3 percent. More than half the respondents (64 percent) in the pre-test were not sure if their family members will support donating their organ while after the VAT the proportions feeling that their family members will support donating their organ increased to 73 percent.

The study observed that none of the respondent families both in rural and urban have registered for organ donation neither have donated an organ nor had a family member suffering with organ failure. It was found that 60 percent of the respondents were aware that the body organs could be donated and transplanted into another person indicating a huge gap in the awareness of organ donation. Further, a video-assisted teaching (VAT) of the respondents on organ donation was conducted among 300 respondents (150 urban and 150 rural) to assess its impact on the improvement in awareness and attitudes of the respondents. A comparison of the pre-test and post-test assessments of knowledge revealed that generating awareness significantly improves the knowledge on organ donation which can promote organ donation. Similarly, the assessment of the attitude levels using positively framed and negatively framed statements among urban and rural respondents in pre-test and post-test showed that the attitude levels improved too. However, extent of improvement of the attitudes was low especially in rural areas. The Wilcoxon test for proving the significance of the differences between pre-test and post-test indicated few of the differences to be highly significant. This indicated that the changing of attitudes is possible, but difficult, and requires multiple awareness initiatives on targeted groups for it to be impactful.

9.1.2 Perception Level about Organ Donation and Transplantation

The organ donation is a critical medical procedure that can save lives by providing organs to individuals suffering from end-stage organ diseases. Despite its importance, perception and awareness of organ donation vary significantly across different regions. In Haryana, a state in northern India, the perception of organ donation is influenced by various factors, including cultural beliefs, religious views, and the level of awareness among the general population.

A sizeable fraction of respondents (48 percent) disagree, 40 percent are unsure, and 4 percent believe that organ donation and transplantation are safe and successful procedures for both the donor and the recipient. This suggests a broad lack of trust in these methods' efficacy and safety. Nonetheless, sentiments are more favourable when it comes to the state's promotion of organ donation and transplantation, with 41 percent agreeing and 12 percent strongly agreeing that it should be done. This shows that, despite safety concerns, there is a significant amount of support for organ donation activities. The perceptions seem to be greatly influenced by religious beliefs. It was roughly 41 percent of respondents concur, 15 percent strongly concur that religion is against organ transplantation and donation and 28 percent are unsure. This demonstrates a widespread perception that religious factors provide a barrier. Furthermore, 25.5 percent of respondents agreed that it is necessary to have all body parts after one die and while 40.5 percent of respondents were doubtful. These results may indicate that there is cultural or religious value to maintaining one's bodily integrity after death.

There are several common misunderstandings about organ donation; 41 percent of respondents agreed with the assertion that they would be born damaged if they donate their organs, while 39 percent expressed uncertainty. This suggests that more education is required regarding the realities of organ donation. The health risks are another issue; 37.8 percent of respondents agreed and 37.2 percent disagreed that there is a link between health hazards and organ donation, indicating concern about potential detrimental effects on health. Regarding individual acts, 51 percent of participants concur that they would accept an organ transplant if their life were in jeopardy, demonstrating a pragmatic acceptance of transplantation under dire circumstances. On the other hand, only 51 percent of respondents agreed to donate their organs, while 22

percent of respondents were unsure. This suggests a cautious but significant readiness to donate. It was found that 54 percent of respondents agreed that it is important to talk about organ donation with family members, demonstrating a strong preference for include family in such important decisions. It was 40 percent, however, were still unsure, suggesting a possible communication or understanding gap on the significance of these conversations.

It was found 53 percent of respondents agreed to donate to family members, compared to 27 percent who were willing to donate to anyone in need, indicating that respondents have a larger preference for donating organs to family members. This choice demonstrates how decisions about organ donation were influenced by family. There is some support for family members choosing to donate their organs; 37 percent were unsure and 25.4 percent agree, indicating a modest level of support. The responses to the promotion of organ donation among friends and family were not uniform; thirty percent disapproved and forty percent were unsure. The concerns regarding the illegal organ trade were also prevalent; 50 percent of respondents believed that organs could be purchased and sold illegally, demonstrating a high level of lack of knowledge and anxiety around this issue.

The perceptions of organ donation and transplantation in Haryana were analysed and the results had shown a complicated interaction between legal awareness, cultural and religious beliefs, personal willingness and safety concerns. With a mean score of 2.74, there was a noticeable lack of confidence regarding the safety and health concerns connected with organ donation; yet, the mean score of 3.39 for promotion and desire to donate indicates that overall attitudes were cautiously open. A mean score of 3.32 in this category indicates that cultural and religious influences had a considerable impact on attitudes. Many respondents believed that religious teachings prohibit organ donation and that physical integrity should be respected after death. Individuals had a comparatively high propensity to donate, particularly within families; yet, the willingness to donate to non-family members was lower, underscoring the significance of familial relationships in decision-making. The legal issues received a mean score of 3.49 suggesting a high degree of mistrust and emphasizing the necessity of ethical and transparent organ donation procedures. This is especially true when it comes to the possibility of organ sales on the black market. Overall, results highlighted the necessity

of focused educational campaigns to dispel myths, highlight the advantages and security of organ donation, and involve religious and community leaders in order to harmonize organ donation with cultural and religious beliefs. The area may improve public trust and promote participation in organ donation programs by addressing these complex issues and creating a supportive atmosphere. This will ultimately improve the care that transplant recipients receive.

9.1.3 Demand-Supply Gap in Organ Donation and Transplantation in Haryana

Despite additions of the cadaver organ donation in THOA, organ donation after death from dead body has not gained popularity among the masses in the country and hence the number of organ donors have not increased over the years, still posing a dismal state, leading to huge demand and supply gap (Nallusamy et al., 2018; Srivastava and Mani, 2018; Kute et al., 2020; Kute et al., 2021). The failure of an organ which may include kidney, liver, heart, pancreas, lung or others creates a demand for organs for transplantation. Therefore, demand basically originates from ailing patients with a damaged or failing organ, which requires a surgical operation for replacement of the damaged organ with a functioning one. According to NOTTO statistics, there is an estimated need of about 2,00,000 kidneys, about 40,000-50,000 liver and 50,000 heart per year in India (NOTTO, 2023).

The present study has used secondary data to examine the demand and supply gap in the market in the country and especially in Haryana. The study has findings from interactions with the transplant patients to get a realistic picture of the demand-supply gap for organs and the issues faced. In Haryana state, there has been an alarming increase in the need for organs as deciphered by NOTTO. The need for organs in the state skyrocketed from 46 in 2018 to 420 in 2019 which was a whopping 813 percent increase in the need. The available data indicated that there is huge variation in the demand for organs across the districts of Haryana. The top ten districts having high patient waiting list for organs shows Gurgaon to have the highest numbers followed by Faridabad, Ambala and Panchkula. Haryana state has a predominant demand for kidney and liver. There are about 14 hospitals listed under the SOTTO Haryana for kidney and liver transplantation of which are mainly located in Panchkula, Hisar and Rohtak. Despite this, the state lags far behind in terms of organ donation and

transplantation. The state faces a huge shortage of supply with only about 5 percent of the demand met through donors that are majorly donating to their own kin.

Haryana is amongst the poorest performers in the country in terms of cadaver organ retrieval to the extent that they do not even have the record of number of brain-dead patients each year, in spite of an average of about 5000 accidental deaths each year. In order to understand if the patients, both those having had a transplant treatment and those expecting a transplant treatment, were aware of the demand-supply gap in organ transplantation, their agreement on the aspect were recorded on a five-point Likert scale. The analysis of survey results has shown that majority of the respondents found that is about 71 percent 'agree' and 7 percent 'strongly agree', agreed on the demand and supply gap for organ donation in the country.

An important fact that emerged from the present study was that though there was good understanding of the existent gap in the demand and supply for organs among patients, they were ignorant of some of the regulatory aspects related to organ donation like payment of monetary compensation to the organ donors. Given the medical condition they are in, the resulting chaos undergone and the agony of waiting for a donor made about 77 percent of the patients agree or strongly agree with the aspect of providing monetary compensation to the donor though it may be against the law/act. However, majority were in affirmation of the fact that societal factors were the major determinants of the supply of donated organs. Whereas, 45 percent of the respondents believed that ethics had a major role to play in the supply of organs which is followed by religion, social taboos and particular races of the people. On posing questions on the measures for reducing the demand-supply gap, the patients hinted that the shortages could be overcome by increasing public awareness on organ donation, broadening the pool of potential cadaver donors, redesigning the ethical framework easing the laws/rules for donation and legalizing organ harvesting from unclaimed cadavers.

9.1.4 Cost and Benefits of Organ Donation and Transplantation in Haryana

The journey toward organ transplantation is fraught with numerous uncertainties and the escalating financial burden of medical care. The patients and their families grappling with this life-threatening predicament and burden can be overwhelming. In resource-constrained nations, the cost of medical treatment places an overwhelming financial burden on citizens, often resulting in catastrophic consequences.

These factors encompass not only the direct costs due to frequency of hospital visits, the duration of hospital stay, the costs associated with diagnostic and therapeutic procedures, as well as any additional therapies and critical interventions required; but the indirect costs which include expenses related to transportation, food, and accommodation for both the patient and caregivers. Even more distressing are the financial setbacks faced by patients due to missed workdays resulting from hospital visits for diagnosis, treatment, and transplantation. In addition, patients are often accompanied by multiple caregivers, leading to further absences from studies or work, which in turn contributes to economic losses.

In the present study to understand the economic status of the patients was examined using their household income and debt level. The majority were earning <₹50000/- per month and were under debts due to the rising cost of treatment. The costs borne by the patients varied as per the type of organ transplant undergone. It was also observed from data that waiting time for receiving an organ transplant was more than 6 months and up to 1 year in the case of 30 percent of the patients and more than a year in case of 20 percent of the patients. Hence, about 50 percent of the patients were battling the diseases for more than 6 months and awaiting transplants which could have worsened their quality of life due to an increased number of hospital visits and hospitalizations for diagnoses and treatment and an increased financial burden from the hospitalizations and medications. This could be their loss of workdays and the resulting loss of pay that could have worsened their economic status.

Majority of patients in the study had accessed services at private hospitals which composed of hospitals empanelled under Ayushman Bharat Scheme as well as self-paid services at the private hospital. The organ transplant package is a recent addition to the ambit of the Ayushman Bharat Scheme. Hence, unless guided appropriately, lack of

awareness about the scheme forced people to pay medical expenses from their pocket which seemed to have increased their financial burden. Even, though the costs of organ transplant were quite high for the participants to bear for their lifetime, when the patients were asked to rate their quality of life on a scale of 1-10 prior and post organ transplant, about 75 percent of them rated their quality of life to be equal or above average while only 25 percent of those did not find the quality of life so good or improved as compared to pre transplant. Most of the patients were under heavy debt burdens that had bundled up for the patient to settle along with their increased cost of living due to expensive medications and food requirements to maintain their health.

Haryana did not have public hospitals conducting transplants about 40 percent of the patients were dependent on the public hospitals for diagnosis, treatment and follow-up services after transplantation. The cost calculated considering the direct and indirect costs showed that the cost of taking a transplant in private hospital was much higher than that in private empanelled hospitals.

9.1.5 Stakeholders' Concerns Regarding Organ Donation in Haryana

The different stakeholders concerning organ donation are the patients awaiting organ transplant and the donors of organs. However, act of organ donation or receive the organ cannot be done on their own. The patient is bound by the physician/specialist's diagnosis and treatment even before awaiting the transplant and dependent on the physician/specialist and hospital/medical care for receiving of the organ. Similarly, donor is bound by their family perceptions and opinions, legal provisions for transplant and the institutional setup that exists for coordination and networking for procurement and distribution of organs and tissues at the national and state levels. The present study conducted key informant interviews (KIIs) to seek stakeholders' views and ideas on the methods to improve organ donation in Haryana. The interviews and discussions were conducted with transplant recipients, patients on waiting lists, donor families, hospital administrators, transplant coordinators, and State Health Officials entrusted with Organ Transplantation (SOTTO).

The discussions included their views on the demand supply gap for organs, their views on the need for active government participation and its probable roles and responsibilities and the kind of governance initiatives, their support for information campaigns & IEC activities and also their views on legislation about presumed consent.

The perspective on the demand for organs was examined in the study by interviewing two types of patients - organ recipients and patients waiting for a transplant. Most of them informed that they have encountered issues in accessing their treatments for a transplant as there was a smaller number of hospitals registered as organ transplant centres. The main reason for above was thought to be, the lack of government support and resources as well as the stricter rules for organ donation and transplant.

It was observed that increasing incidence of vital organ failure and the inadequate supply of organs seemed to be of greatest concern regarding organ transplant. Prior to the transplant these organ recipients had to wait quite long time with a reduced quality of life. As regards the benefits of the organ transplant undergone and about 85 percent of the recipients felt their life expectancy is increased after organ transplant. While none of the recipients stated no improvement, there were 15 percent of them who could not say about the increase in life expectancy. It was found that 92 percent of them stated that they have been able to carry out their pending responsibilities after organ transplant. At the same time, organ recipients face severe issues on the economic front. Majority of the interviewed recipients being kidney and liver or lung patients had taken about 3-6 months to get back to their job and re-start their earnings. Whereas, financial burden has increased after their transplant as the care required after the treatment has increased their cost of living drastically.

The provider perspective on the legalities and the demand and supply of organ donation captured in the study through interviews of the SOTTO officials and administrators in transplant hospitals brought out that there were not many transplant centres registered in the state due to lack of government support and strict rules and also due to difficulty in adherence to standards. As per the government officials there has to be intense focus on creating better awareness and ruling out the myths in order to decrease the demand and supply gap for organs. In addition to creating awareness, hospital administrators also vouch for government support for expenses and providing incentives to donors to decrease demand-supply gap. The transplant officials were of the opinion that the government should not supply the medications after organ donation, whereas many of the hospital administrators felt the government has a responsibility of supplying necessary medication to the donors. However, on a different note, majority of both the hospital officials and administrators disapproved of the existence of

fraudulent practices in organ donation. Most of the officials were of the view that the government has taken encouraging steps to promote organ transplantation and has made the process easier and affordable by linking it with public health insurance scheme - Ayushman Bharat Scheme. Majority of the government and the hospital officials disagreed of the fraudulent practices prevalent in organ donation. Almost all stakeholders agreed that the way to improve organ donation was to break the taboo surrounding the topic of death and organ donation. This could be achieved by doing public information campaigns (IEC campaigns) regularly, to educate the public, especially the younger generation.

9.2 Policy Recommendations

The various policy recommendations suggested on the basis of the empirical findings and has been mentioned as follows:

1) The study has shown that a significant gap in awareness especially in rural areas, calls for region-specific, culturally sensitive campaigns, such as video-assisted teaching and community outreach. These campaigns should collaborate with local or village level influencers to address misconceptions and raise awareness about organ donation.
2) The present study has suggested to change the attitude and perceptions which is challenging and thus it is suggested to devise policies which emphasized sustained and repeated educational efforts. This can be achieved through programs in schools, healthcare centers and even communities to reinforce positive attitudes toward organ donation over time.
3) The study found that none of the respondents have been registered as organ donors. Thereby, it is suggested that policies should promote easier access to organ donation registration via healthcare facilities and digital platforms, with a focus on increasing outreach in rural areas to encourage more participation.
4) The policies should focus on educational initiatives to remove widespread myths, alleviate safety concerns, and increase awareness about the legal and ethical aspects of organ donation. These campaigns should highlight the safety measures in place to ensure donor protection.

5) Since cultural and religious beliefs significantly influence attitudes toward organ donation, engaging religious and community leaders in awareness programs can help align donation practices with local beliefs, making it more acceptable and encouraging broader participation.

6) To combat mistrust and fears about illegal organ sales, policies must ensure transparency in the organ donation process. Thus, strengthening legal frameworks and ethical oversight will build public confidence in the system, promoting a more supportive environment for organ donation.

7) On the basis of the findings, it can be concluded that there is a need to strengthen the public awareness campaigns on organ donation and need to simplify laws to encourage cadaver donations and promote ethical practices to address the demand-supply gap in the country.

8) It was observed that a huge financial burden has been involved thus need is to bring more public hospitals with transplant services and it can enhance affordability and support unclaimed cadaver utilization to reduce patient financial burden.

9) There is a need to simplify the laws and need to encourage cadaver donations and promote ethical practices to address the demand supply gaps. Even, grass root organizations can be involved to guide and encourage the public about the organ donation.

10) There is a need to develop targeted financial aid programs and streamline insurance coverage for transplant related expenses to alleviate direct and indirect economic hardships on patients and caregivers as it was identified that even the indirect cost posed a huge financial burden on the respondents.

11) The study suggested the need to promote presumed consent legislation and also need to introduce family counselling programs to encourage organ donation while addressing societal concerns and perceptions about death and donation.

12) There is a need to introduce financial incentives for organ donors and provide government-funded post-transplant care to alleviate the economic burdens on patients and promote donation participation.

9.3 Scope of Further Research

The following are the scope of future studies:

a) Compare awareness and perceptions of organ transplantation in Haryana with other states to highlight the regional differences.

b) Conducting a longitudinal study to understand changes in awareness and attitudes over time as policies and campaigns evolve.

c) Investigating the differences in perception and awareness between rural and urban populations within Haryana.

d) Assessing the effectiveness of awareness campaigns and educational interventions in improving the organ donation knowledge across different demographics.

e) Exploring the role of religious and cultural beliefs in shaping attitudes towards organ transplantation to create more tailored outreach efforts.

REFERENCES

REFERENCES

Abbasi, M., Kiani, M., Ahmadi, M., & Salehi, B. (2018). Knowledge and Ethical Issues in Organ Transplantation and Organ Donation: Perspectives from Iranian Health Personnel. *Annals of Transplantation*, *23*, 292–299. doi: 10.12659/AOT.908615

Abouna, G. M. (2008). Organ Shortage crisis: Problems and Possible Solutions. *Transplantation Proceedings*, *40*(1), 34–38.https://doi.org/10.1016/ j.transproceed.2007.11.067

Abraham, G., Vijayan, M., Gopalakrishnan, N., Shroff, S., Amalorpavanathan, J., Yuvaraj, A., Nair, S., &Sundarrajan, S. (2016). State of deceased donor transplantation in India: A model for developing countries around the world. *World Journal of Transplantation*, *6*(2), 331–335.doi: 10.5500/wjt.v6.i2.331

Abu Abed, M., Himmel, W., Vormfelde, S., &Koschack, J. (2014). Video-assisted patient education to modify behavior: A systematic review. *Patient Education and Counseling*, *97*(1), 16–22. https://doi.org/10.1016/j.pec.2014.06.015

Acharya, M., Farooqui, J., Dave, A., Chaku, D., Ganguly, K., Das, A., & Mathur, U. (2019). Eye donation in north India: Trends, awareness, influences and barriers. *Indian Journal of Ophthalmology*, *67*(10), 1570.doi: 10.4103/ ijo.IJO_2151_18.

Adair, A., & Wigmore, S. J. (2011). Paid Organ Donation: the Case Against. *Annals of the Royal College of Surgeons of England*, *93*(3), 191–192. doi: 10.1308/147870811X565061a

Agata Anna Wykrota, Weinstein, I., Hamon, L., Daas, L., Flockerzi, E., Shady Sufo, & Seitz, B. (2022). Correction to: Approval rates for corneal donation and the origin of donor tissue for transplantation at a university-based tertiary referral center with corneal subspecialization hosting a LIONS Eye Bank. *BMC Ophthalmology*, *22*(1). 1-12. doi: 10.1186/s12886-022-02263-8.

Aguilera, V., Oya Andacoglu, Francoz, C., Berlakovich, G., Pai, S.-L., Adelmann, D., Ghosh, S., Lunsford, K. E., Montenovo, M. I., Mrzljak, A., Scalera, I., Xie, Q., Becchetti, C., Berenguer, M., & Nazia Selzner. (2022). Gender and Racial Disparity Among Liver Transplantation Professionals: Report of a Global Survey. *Transplant International*, *35*, 10506. https://doi.org/10.3389/ ti.2022.10506

Ahlawat, R., Kumar, V., Gupta, A. K., Sharma, R. K., Minz, M., & Jha, V. (2013). Attitude and knowledge of healthcare workers in critical areas towards deceased organ donation in a public sector hospital in India. *The National medical journal of India*, *26*(6), 322–326.

Ahlawat, R., Tiwari, P., & D'Cruz, S. (2017). Direct Cost for Treating Chronic Kidney Disease at an Outpatient Setting of a Tertiary Hospital: Evidence from a Cross-Sectional Study. *Value in Health Regional Issues*, *12*, 36–40. https://doi.org/10.1016/j.vhri.2016.10.003.

Ajayi, S., Raji, Y., & Salako, B. (2016). Ethical and legal issues in renal transplantation in Nigeria. *Saudi Journal of Kidney Diseases and Transplantation*, *27*(1), 125. https://doi.org/10.4103/1319-2442.174146

Akbulut, S., Ozer, A., Gokce, A., Demyati, K., Saritas, H., & Yilmaz, S. (2020). Attitudes, awareness, and knowledge levels of the Turkish adult population toward organ donation: Study of a nationwide survey. *World Journal of Clinical Cases*, *8*(11), 2235–2245. https://doi.org/10.12998/wjcc.v8.i11.2235

Akdeniz, M., Yardımcı, B., &Kavukcu, E. (2021). Ethical considerations at the end-of-life care. *SAGE open medicine*, *9*, 20503121211000918. https://doi.org/ 10.1177/20503121211000918

Al-Bar, M. A., &Chamsi-Pasha, H. (2015). Contemporary Bioethics. *PubMed*. https://doi.org/10.1007/978-3-319-18428-9

Aldhafar, A., & Arafa, S. (2017). Knowledge and Awareness of Organ Donation and Brain Death among the Population in Al-Ahsa, Saudi Arabia. *Journal of Advances in Medicine and Medical Research*, *23*(1), 1–6. https://doi.org/ 10.9734/jammr/2017/34843

Alghamdi, A., Abdulmalak Abdullah Alsaleh, Omar Abdulaziz Alfozan, Qutob, R., Abdullah Alaryni, Bukhari, A., Hakami, O. A., Bassam Abdulaziz Alhusaini, Saad Abdullah Alzmamy, Fadhah Saud Alhudayris, Lama khalidAlshuaibi, Al-Enazi, A. M., Lama Alhosaini, Najd Khalid Aljarba, & Shahad Alshammari. (2023). Awareness, Attitude, and Beliefs Regarding Organ Donation Among the General Public in Saudi Arabia. *International Journal of General Medicine*, *Volume 16*, 4973–4989. https://doi.org/10.2147/ijgm. s434589

Ali, N. F., Qureshi, A., Jilani, B. N., & Zehra, N. (2013). Knowledge and ethical perception regarding organ donation among medical students. *BMC Medical Ethics*, *14*, 1-7. https://doi.org/10.1186/1472-6939-14-38

AlKhawari, F. S., Stimson, G. V., & Warrens, A. N. (2005). Attitudes Toward Transplantation in U.K. Muslim Indo-Asians in West London. *American Journal of Transplantation*, *5*(6), 1326–1331. https://doi.org/10.1111/j.1600-6143.2005.00814.x

Alok Atreya, Priska Bastola, Bhandari, S., Samata Nepal, &Prawesh Singh Bhandari. (2023). Brain Death and Organ Transplantation in Nepal: Navigating Cultural, Legal, and Ethical Landscapes. *Transplant International*, *36, 11882*. https://doi.org/10.3389/ti.2023.11882

Alvaro, E. M., Siegel, J. T., Turcotte, D., Lisha, N., Crano, W. D., & Dominick, A. (2008). Living Kidney Donation among Hispanics: A Qualitative Examination of Barriers and Opportunities. *Progress in Transplantation*, *18*(4), 243–250. https://doi.org/10.1177/152692480801800406

Ambagtsheer, F., Annema, C., Forsythe, J., Jansen, N., & Paredes-Zapata, D. (2024). Ethical and Legal Aspects of Organ Donation and Transplantation. *Transplant International*, *37*, 13011. https://doi.org/10.3389/ti.2024.13011

Ambagtsheer, F., Bunnik, E., Pengel, L. H., Reinders, M. E., Elias, J. J., Lacetera, N., & Macis, M. (2024). Public Opinions on Removing Disincentives and Introducing Incentives for Organ Donation: Proposing a European Research Agenda. *Transplant International*, *37*, 12483. https://doi.org/10.3389/ti.20 24 .12483.

Ambiga, K., & Brita Jane, J. (2016). A study to assess the attitude on organ donation among paramedical workers among paramedical workers at SRM General Hospital, Kattankulathur, Kancheepuram Distt. *International Journal of Pharmacy and Biological Sciences*, *6*(1), 168–171.

Andorno, R. (2005). The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law. *Journal of International Biotechnology Law*, *2*(4). 133-143. https://doi.org/10.1515/jibl.2005.2.4.133

Annadurai, K., Manik, K., & Ramasamy, J. (2013). A study on knowledge, attitude and practices about organ donation among college students in Chennai, Tamilnadu.

Progress in Health Sciences, *3*(2), 59–65. https://doi.org/ 10.18203/2394-6040.ijcmph20192328

Arogundade, F. A. (2013). Kidney transplantation in a low-resource setting: Nigeria experience. *Kidney International Supplements*, *3*(2), 241–245. https://doi.org/ 10.1038/kisup.2013.23

Ashraf, O., Ali, S., li, S. A. A., Ali, H., Alam, M., Ali, A., & Ali, T. M. (2005). Attitude Toward Organ Donation: A Survey in Pakistan. *Artificial Organs*, *29*(11), 899–905. https://doi.org/10.1111/j.1525-1594.2005.00153.x

Ashwin, A., Cherukuri, S. D., & Rammohan, A. (2024). The psychology, legality, ethics and medical aspects of organ donation by minors. *Transplantation Reviews*, *38*(2), 100832. https://doi.org/10.1016/j.trre.2024.100832

Asia. (2024). Organ transplantation in India: needs a bigger push. *The Lancet Regional Health - Europe*, *21*, 100366–100366. https://doi.org/10.1016/ j.lansea.2 024.100366

Babiker, A., El Husseini, M., Al Nemri, A., Al Frayh, A., Al Juryyan, N., Faki, M. O., Assiri, A., Al Saadi, M., Shaikh, F., & Al Zamil, F. (2014). Health care professional development: Working as a team to improve patient care. *Sudanese Journal of Paediatrics*, *14*(2), 9–16. http://www.ncbi.nlm.ni h.gov/ pmc/articles/PMC4949805/

Badu, E., O'Brien, A. P., & Mitchell, R. (2019). An integrative review on methodological considerations in mental health research–design, sampling, data collection procedure and quality assurance. *Archives of Public Health*, *77*, 1-15. https://doi.org/10.1186/s13690-019-0363-z

Balakrishnan, K., & Nageswaran, C. (2020). Cost analysis of 163 consecutive heart transplant operationsin an Indian setting. *Indian Journal of Thoracic and Cardiovascular Surgery*, *36*(S2), 200–209. https://doi.org/10.1007/s12055-020-00996-z

Balwani, M. R., Kute, V. B., Patel, H., Shah, P. R., Goswami, J., Ghule, P., Shah, M., Gattani, V., & Trivedi, H. L. (2015). Awareness and beliefs towards organ

donation in chronic kidney disease patients in western India. *Journal of nephropharmacology*, *4*(2), 57–60.

Barik, D., & Thorat, A. (2015). Issues of Unequal Access to Public Health in India. *Frontiers in Public Health*, *3*(245). https://doi.org/10.3389/fpubh.2015.00245

Bathija, G., Ananthesh, B. G., & Bant, D. (2017). Study to Assess Knowledge and Attitude towards Organ Donation among Interns and Post Graduates of a Medical College in Karnataka, India. *National Journal of Community Medicin Volume*, *8*(5), 5–2017. https://njcmindia.com/index.php/file/article/download/698/492

Begum, K. (2015). A Study to assess the effectiveness of video assisted teaching regarding aerobic exercises and practice to maintain the blood glucose level among diabetes in crescent hospital, Alathur, Palakkad. *IOSR Journal of Nursing and Health Science*, *4*(1), 44–50. https://doi.org/10.9790/1959-04134450

Bellomo, R., &Zamperetti, N. (2007). Defining the vital condition for organ donation. *Philosophy, Ethics, and Humanities in Medicine*, *2*(1), 27. https://doi.org/10.1186/1747-5341-2-27

Benavides López, X., Figueroa Bohorquez, D. M., Pérez, H. C., Serna Escobar, D. P., Alzate, J. P., & Lozano Marquez, E. (2015). Association between education about organ transplantation aimed at medical students and the acquisition of the organ donor card. A cross-sectional study. *Revista de La Facultad de Medicina*, *62*(4), 571–578. https://doi.org/10.15446/revfacmed.v62n4.45544

Betrosian, A. P., Agarwal, B., &Douzinas, E. E. (2007). Acute renal dysfunction in liver diseases. *World journal of gastroenterology*, *13*(42), 5552–5559. https://doi.org/10.3748/wjg.v13.i42.5552

Betsch, C., Schmid-Küpke, N. K., Otten, L., & von Hirschhausen, E. (2020). Increasing the willingness to participate in organ donation through humorous health communication: (Quasi-) experimental evidence. *PLOS ONE*, *15*(11), e0241208. https://doi.org/10.1371/journal.pone.0241208

Beyar, R. (2011). Challenges in Organ Transplantation. *Rambam Maimonides Medical Journal*, *2*(2). https://doi.org/10.5041/rmmj.10049

Bharambe, V. K., Rathod, H., & Angadi, K. (2016). Knowledge and Attitude Regarding Organ Donation among Medical Students. *BANTAO Journal*, *14*(1), 34–40. https://doi.org/10.1515/bj-2016-0008

Bhardwaj, A., Mirski, M. A., & Ulatowski, J. A. (2014). *Handbook of Neurocritical Care* (A. Picard, Ed.). Wealth Management Apollo.DOI: 10.1093/bja/aeh630

Bhengu, B. R., & Uys, H. H. M. (2004). Organ donation and transplantation within the Zulu culture. *Curationis*, *27*(3). https://doi.org/10.4102/curationis. v27i3.995

Bilgel, H., Bilgel, N., Okan, N., Kilicturgay, S., Ozen, Y., & Korun, N. (1991). Public attitudes toward organ donation. *Transplant International*, *4*(4), 243–245. https://doi.org/10.1007/bf00649112

Bilgel, H., Sadikoglu, G., &Bilgel, N. (2006). Knowledge and attitudes about organ donation among medical students. *Transplantationsmedizin*, *18*(2), 91.

Bilgel, H., Sadikoglu, G., Goktas, O., &Bilgel, N. (2004). A survey of the public attitudes towards organ donation in a Turkish community and of the changes that have taken place in the last 12 years. *Transplant International*, *17*(3), 126–130. https://doi.org/10.1007/s00147-003-0680-5

Bosakhar, B. Y., Al-Mesailekh, Z. A., Al-Farhan, S. A., Arab, D. A., Al-Tawheid, N. A., Al-Ali, N. F., & Mitra, A. K. (2017). Predictors of Knowledge and Attitude Regarding Organ Donation in Kuwait. *IMC Journal of Medical Science*, *10*(1), 1–9. https://doi.org/10.3329/imcjms.v10i1.31099

Breitbart, W. (2017). Existential guilt and the fear of death. *Palliative and Supportive Care*, *15*(5), 509–512. https://doi.org/10.1017/s1478951517000797

Brown, R. S. (2008). Live Donors in Liver Transplantation. *Gastroenterology*, *134*(6), 1802–1813. https://doi.org/10.1053/j.gastro.2008.02.092

Buckley, T. A. (2000). The shortage of solid organs for transplantation in Hong Kong: part of a worldwide problem. *Hong Kong Medical Journal*, *6*(4), 399–408. PMID: 11177162.

Callahan, M. B., & Paris, W. (2009). Post-Transplant Employment and its Relationship to Physical Status in Kidney Transplant Recipients. *Journal of Nephrology Social Work*, *31*.

Canada, H. (2021, December 14). *Organ donation and transplantation collaborative*. Www.canada.ca.https://www.canada.ca/en/health-canada/services/healthy-living/blood-organ-tissue-donation/organ-tissue/transplantation-collaborative. html

Cantarovich F. (2004). The role of education in increasing organ donation. *Annals of transplantation*, *9*(1), 39–42.

Cantarovich, F. (2014). Education and Organ Donation. Potential Role of School Programs. *Transplantation*, *98*, 838. https://doi.org/10.1097/00007890-20140 7151-02862

Caplan, A. (2014). Bioethics of Organ Transplantation. *Cold Spring Harbor Perspectives in Medicine*, *4*(3). https://doi.org/10.1101/cshperspect.a015685

Carola, V., Morale, C., Vincenzo, C., Cecchi, V., Errico, L., & Nicolais, G. (2023). Organ donation: psychosocial factors of the decision-making process. *Organ Donation: Psychosocial Factors of the Decision-Making Process*, *14*. https://doi.org/10.3389/fpsyg.2023.1111328

Cascalho, M., & Platt, J. L. (2006). The Future of Organ Replacement: Needs, Potential Applications, and Obstacles to Application. *Transplantation Proceedings*, *38*(2), 362–364. https://doi.org/10.1016/j.transproceed.2005. 12.055

Caulfield, T., Duijst, W., Bos, M., Chassis, I., Codreanu, I., Danovitch, G., Gill, J., Ivanovski, N., & Shin, M. (2016). Trafficking in Human Beings for the Purpose of Organ Removal and the Ethical and Legal Obligations of Healthcare Providers. *Transplantation Direct*, *2*(2), e60. https://doi.org/ 10.1097/txd.0000000000000566

Chandrasekaran, S., Chandrasekaran, V., Nandi, D., Setty, R. S., Srinivasan, O., & Kaur, K. N. (2022). Assessment of Awareness Level Regarding Organ Donation among Healthcare Professionals and Students in India. *Indian Journal of Critical Care Medicine*, *27*(1), 57–63. https://doi.org/10.5005/jp-journals-10071-24387.

Chen, X., Orom, H., Hay, J. L., Waters, E. A., Schofield, E., Li, Y., & Kiviniemi, M. T. (2019). Differences in Rural and Urban Health Information Access and Use. *The Journal of Rural Health*, *35*(3), 405–417. https://doi.org/10.1111/ jrh.12335

Chen, X., Wei, W., & Ai, W. (2023). Organ donation: Key factors influencing the younger generation's decision-making in China. *Frontiers in Public Health*, *11*. https://doi.org/10.3389/fpubh.2023.1052875

Choi, Y., Lee, S., Lee, Y., Min Hyun Cho, Ihn, K., Kyung Chul Yoon, Kang, J.-M., Seong Heon Kim, HeeGyung Kang, & Yi, N.-J. (2023). Changes in Awareness Toward Minor's Organ Donation Through Structured Information; Survey. *Transplant International*, *36*.://doi.org/10.3389/ti.2023.10795

Chotkan, K. A., Mensink, J. W., Pol, R. A., Van Der Kaaij, N. P., Beenen, L. F. M., Nijboer, W. N., Schaefer, B., Alwayn, I. P. J., & Braat, A. E. (2022). Radiological Screening Methods in Deceased Organ Donation: An Overview of Guidelines Worldwide. *Transplant International*, *35*, 10289. https://doi.org/10.3389/ti.2022.10289

Chugh, K. S., & Jha, V. (1996). Commerce in transplantation in Third World countries. *Kidney International*, *49*(5), 1181–1186. https://doi.org/10.1038/ ki.1996.171

Clarke, K. S., Klarenbach, S., Vlaicu, S., Yang, R. C., & Garg, A. X. (2006). The direct and indirect economic costs incurred by living kidney donors—a systematic review. *Nephrology Dialysis Transplantation*, *21*(7), 1952–1960. https://doi.org/10.1093/ndt/gfl069

Coad, L., Carter, N., & Ling, J. (2013). Attitudes of young adults from the UK towards organ donation and transplantation. *Transplantation Research*, *2*(1), 9. https://doi.org/10.1186/2047-1440-2-9

Conroy, R. (2016). *The RCSI Sample size handbook*. https://www.beaumontethics.ie/ docs/application/samplesize2021.pdf

Conroy, R. M. (2021). *The RCSI Sample size handbook.* Beaumont Hospital ethics committee. (Original work published 2016)

Cotrau, P., Hodosan, V., Vladu, A., Daina, C., Daina, L. G., & Pantis, C. (2019). Ethical, Socio-Cultural and Religious Issues in Organ Donation. *Mædica*, *14*(1), 12–14. https://doi.org/10.26574/maedica.2019.14.1.1

Council of Europe. (2014). *Oviedo Convention and Its Protocols*. Bioethics. https://www.coe.int/en/web/bioethics/oviedo-convention

Dalal, A. R. (2019). Philosophy of Organ Donation: Review of Ethical Facets. *World Journal of Transplantation*, *5*(2), 44. https://doi.org/10.5500/wjt.v5.i2.44

Daniel, S. (2019). A Descriptive Study to Assess the Perception towards Organ Donation among the Students in a Selected University of New Delhi.

International Journal of Nursing & Midwifery Research, *05*(04), 8–12. https://doi.org/10.24321/2455.9318.201840

Dar, I. A., & Mishra, M. (2019). Internationalisation of SMEs: development and validation of a multi-dimensional measurement scale. *International Journal of Entrepreneurship and Small Business*, *38*(4), 507. https://doi.org/10.1504/ijesb.2019.104140

Dasgupta, A., Shahbabu, B., Sarkar, K., Sarkar, I., Das, S., Das, M., Head, & Resident, J. (2014). ISSN 2347-954X (Print) Perception of Organ Donation among Adults: A Community Based Study in an Urban Community of West Bengal. *Scholars Journal of Applied Medical Sciences (SJAMS)*, *2*(6A), 2016–2021. https://doi.org/10.36347/sjams.2014.v02i06.015

Davis, C., & Randhawa, G. (2004). ???Don???t Know Enough about It!???: Awareness and Attitudes Toward Organ Donation and Transplantation among the Black Caribbean and Black African Population in Lambeth, Southwark, and Lewisham, United Kingdom. *Transplantation*, *78*(3), 420–425. https://doi.org/10.1097/01.tp.0000128341.81362.0f

De Groot, J., Vernooij-Dassen, M., de Vries, A., Hoedemaekers, C., Hoitsma, A., Smeets, W., & van Leeuwen, E. (2014). Intensive care staff, the donation request and relatives' satisfaction with the decision: a focus group study. *BMC Anesthesiology*, *14*(1). https://doi.org/10.1186/1471-2253-14-52

De Jongh, D., Massey, E. K., Cronin, A. J., Schermer, M. H. N., &Bunnik, E. M. (2022). Early-Phase Clinical Trials of Bio-Artificial Organ Technology: A Systematic Review of Ethical Issues. *Transplant International*, *35*. https://doi.org/10.3389/ti.2022.10751

Delmonico, F. (2011). The Science and Social Necessity of Deceased Organ Donation. *Rambam Maimonides Medical Journal*, *2*(2). https://doi.org/10.5041/rmmj.10048

DeRoos, L. J., Marrero, W. J., Tapper, E. B., Sonnenday, C. J., Lavieri, M. S., Hutton, D. W., & Parikh, N. D. (2019). Estimated Association Between Organ Availability and Presumed Consent in Solid Organ Transplant. *JAMA Network Open*, *2*(10), e1912431. https://doi.org/10.1001/jamanetworkopen.2019.12431

Dhankhar, A., Kumari, R., &Bahurupi, Y. (2021). Out-of-Pocket, Catastrophic Health Expenditure and Distress Financing on Non-Communicable Diseases in India:

A Systematic Review with Meta-Analysis. *Asian Pacific Journal of Cancer Prevention*, *22*(3), 671–680. https://doi.org/10.31557/apjcp. 2021.22.3.671

Dopelt, K., Siton, L., Harrison, T., & Davidovitch, N. (2022). Revisiting the Relationship between Altruism and Organ Donation: Insights from Israel. *International Journal of Environmental Research and Public Health*, *19*(12), 7404. https://doi.org/10.3390/ijerph19127404

Douville, F., Godin, G., &Vézina-Im, L.-A. (2014). Organ and tissue donation in clinical settings: a systematic review of the impact of interventions aimed at health professionals. *Transplantation Research*, *3*(1). https://doi.org/10.1186/ 2047-1440-3-8

Durur, F., & Akbulut, Y. (2017). Turkiye'de organ naklineyonelikpolitikalarindegerlenderilmesi. *Business & Management Studies: An International Journal*, *5*(3), 570–585. https://doi.org/10.15295/bmij.v5i3.150.

Epel, E. S., Crosswell, A. D., Mayer, S. E., Prather, A. A., Slavich, G. M., Puterman, E., & Mendes, W. B. (2018). More than a feeling: A unified view of stress measurement for population science. *Frontiers in Neuroendocrinology*, *49*(1), 146–169. https://doi.org/10.1016/j.yfrne.2018.03.001

Escoto, M., Issa, F., Cayouette, F., Consolo, H., Chaudhury, P., Dhanani, S., Jiang, W., Oniscu, G. C., Murphy, N., Rockell, K., Weiss, M. J., &Dieudé, M. (2023). Research and Innovation in Organ Donation: Recommendations From an International Consensus Forum. *Transplantation Direct*, *9*(5). https://journals.lww.com/transplantationdirect/fulltext/2023/05000/research_and_innovation_in_organ_donation_.16.aspx

Escudero, D., Otero, J., Menéndez de León, B., & Perez-Basterrechea, M. (2017). Organ Donation and Elective Ventilation: A Necessary Strategy. *BioMed Research International*, *2017*, 1–6. https://doi.org/10.1155/2017/7518375

Etheredge, H. R. (2021). Assessing Global Organ Donation Policies: Opt-In vs Opt-Out. *Risk Management and Healthcare Policy*, *14*(14), 1985–1998. https://doi.org/10.2147/rmhp.s270234

Evans, D. (2007). Seeking an ethical and legal way of procuring transplantable organs from the dying without further attempts to redefine human death. *Philosophy,*

Ethics, and Humanities in Medicine, *2*(1), 11. https://doi.org/10.1186/1747-5341-2-11

Evans,R.W. (1986). Coverage and reimbursement for heart transplantation. *International Journal of Technology Assessment in Health Care*, *2*(3), 425-449. https://doi.org/10.1017/S0266462300002543

Exley, C., Sim, J., Reid, N., Jackson, S., & West, N. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: A pilot study. *Social Science & Medicine*, *43*(1), 23–28. https://doi.org/10.1016/0277-9536(95)00320-7

Fahrenwald, N. L., Belitz, C., & Keckler, A. (2010). Outcome Evaluation of "Sharing the Gift of Life": An Organ and Tissue Donation Educational Program for American Indians. *American Journal of Transplantation*, *10*(6), 1453–1459. https://doi.org/10.1111/j.16006143.2010.03120.x

Fan, X., Li, M., Rolker, H., Li, Y., Du, J., Wang, D., & Li, E. (2022). Knowledge, attitudes and willingness to organ donation among the general public: a cross-sectional survey in China. *BMC Public Health*, *22*(1). https://doi.org/10.1186/s12889-022-13173-1

Febrero, B., Ríos, A., Martínez-Alarcón, L., López-Navas, A., Sánchez, J., Ramis, G., Ramírez, P., & Parrilla, P. (2013). Knowledge of the Brain Death Concept Among Adolescents in Southeast Spain. *Transplantation Proceedings*, *45*(10), 3586–3588. https://doi.org/10.1016/j.transproceed.2013.10.014

Feld, J., Sherbin, P., & Cole, E. (1998). Barriers to Organ Donation in the Jewish Community. *Journal of Transplant Coordination*, *8*(1), 19–24. https://doi.org/10.1177/090591999800800105

Field, A. (2017). *Discovering Statistics Using IBM SPSS Statistics*. SAGE.

Ganesh, R., Sam, N., Indrapriyadarshini, V., Jeyamarthan, S., & Nandhini, C. (2018). Awareness, knowledge, and attitude regarding organ donation among final year students of medical, Dental, Engineering, and Arts and Science Colleges in Thiruvallur and Chennai City, India. *Indian Journal of Transplantation*, *12*(1), 25. https://doi.org/10.4103/ijot.ijot_60_17

Gardiner, D., McGee, A., & Shaw, D. (2021). Two fundamental ethical and legal rules for deceased organ donation. *BJA Education*, *21*(8). https://doi.org/10.1016/j.bjae.2021.03.003

Garg, A., Varshney, S., Kansra, P., &Perumallapalli, A. (2022). Awareness, attitude, and perception toward organ donation in general population of Haryana, India. *Indian Journal of Transplantation*, *16*(2), 158. https://doi.org/10.4103/ijot.ijot_104_21

Gates, S., Lall, R., Quinn, T., Deakin, C. D., Cooke, M. W., Horton, J., Lamb, S. E., Slowther, A.-M., Woollard, M., Carson, A., Smyth, M., Wilson, K., Parcell, G., Rosser, A., Whitfield, R., Williams, A., Jones, R., Pocock, H., Brock, N., & Black, J. J. (2017). Prehospital randomised assessment of a mechanical compression device in out-of-hospital cardiac arrest (PARAMEDIC): a pragmatic, cluster randomised trial and economic evaluation. *Health Technology Assessment*, *21*(11), 1–176. https://doi.org/10.3310/hta21110

Ghorbani, F., Khoddami-Vishteh, H. R., Ghobadi, O., Shafaghi, S., Louyeh, A. R., &Najafizadeh, K. (2011). Causes of family refusal for organ donation. *Transplantation Proceedings*, *43*(2), 405–406. https://doi.org/10.1016/j.transproceed.2011.01.03

Global Observatory on Donation and Transplantation. (2021). *Global Observatory on Donation and Transplantation*. GODT. https://www.transplant-observatory.org/

Global organ donation and transplantation: Challenges and opportunities. (2020). *Journal of Transplantation*.

Gopalakrishnan, S. (2012). A Public Health Perspective of Road Traffic Accidents. *Journal of Family Medicine and Primary Care*, *1*(2), 144. https://doi.org/10.4103/2249-4863.104987

Government of India. (2011). *Census of India | Office of the Registrar General & Census Commissioner, India*. Library of Congress, Washington, D.C. 20540 USA. https://www.loc.gov/item/lcwaN0017959

Government of UAE. (2024). *Hayat Organ Donation Program*. Ministry of Health and Prevention - UAE. https://mohap.gov.ae/en/hayat

Govil, D., Patil, V., Todi, S., Gurav, S., Pandit, R. A., Zirpe, K. G., Kulkarni, A. P., Karnath, S., Abhram, B., Gupta, A., Bhatacharya, P., &Samavedan, S. (2017). Management of potential organ donor: Indian Society of Critical Care

Medicine: Position statement. *Indian Journal of Critical Care Medicine*, *21*(5), 303–316. https://doi.org/10.4103/ijccm.ijccm_160_17

Govt of India. (2011). *Census of India Website : Office of the Registrar General & Census Commissioner, India*. Censusindia.gov.in. https://www.censusindia .gov.in/

Govt of UK. (2017). *Public service productivity: healthcare, England - Office for National Statistics*. Ons.gov.uk. https://www.ons.gov.uk/economy/economic outputandproductivity/publicservicesproductivity/articles/publicservicesproductivityestimateshealthcare/financialyearending2017

Gracious, N., & Jose, V. R. (2020). Certification of brain stem death in India: Medico-Legal perspectives. *Amrita Journal of Medicine*, *16*(2), 71-76. https://doi.org/10.4103/amjm.amjm_11_20.

Greiner, A. C., & Knebel, E. (2019). *Challenges Facing the Health System and Implications for Educational Reform*. Nih.gov; National Academies Press (US). https://www.ncbi.nlm.nih.gov/books/NBK221522/

Grinyó, J. M. (2013). Why is organ transplantation clinically important?. *Cold Spring Harbor perspectives in medicine*, *3*(6), a014985. https://doi.org/10.1101/cshpe rs pect.a014985

GS Adithyan, M. Mariappan, & Nayana, K. B. (2017). A study on knowledge and attitude about organ donation among medical students in Kerala. *Indian Journal 0f Transplantation*, *11*(3),133-137. https://doi.org/10.4103/ijot. ijot_49_17

Guleria, K., Singh, A., Kumar, B., Agrawal, P., & Agrawal, S. (2012). Trends of organ donation and awareness in Ernakulam, Kerala. *BMC Proceedings*, *6*(S4), 1-1. https://doi.org/10.1186/1753-6561-6-s4-p48

Gulf News. (2019, February). *UAE paves the way in saving lives*. Gulfnews.com; Gulf News. https://gulfnews.com/opinion/editorials/uae-paves-the-way-in-saving-lives-1.61796584

Gupta, A., Jain, S., Jain, T., & Gupta, K. (2009). Awareness and perception regarding eye donation in students of a nursing college in Bangalore. *Indian Journal of Community Medicine*, *34*(2), 122. https://doi.org/10.4103/0970-0218.51235

Gupta, S., Sahay, M., Ramachandran, B., Kumar, A., Gursahani, R., Sharma, A., Pandit, R., Shroff, S., Simha, S., Zirpe, K. G., Kute, V. B., Navin, S., Seth, A. K.,

Mohanka, R., Gokhale, A. G., Balakrishnan, K., Mirza, D., Mehta, D., Dhital, K., & Sundaram, R. (2022). Organ Donation after Circulatory Determination of Death in India: A Joint Position Paper. *Indian Journal of Critical Care Medicine*, *26*(4), 423–440. https://doi.org/10.5005/jp-journals-10071-24198

Haberal, M., Cantarovich, M., Muller, E., Fung, J. J., Sarwal, M., Tullius, S. G., & Ascher, N. (2019). Call for an End to Unethical Transplant Practices. *Transplantation*, *103*(4), 647. https://doi.org/10.1097/tp.0000000000002607

Hai, T. B.., Eastlund, T., Chien, L. A., Duc, P. T., Giang, T. H., Hoa, N. T., Viet, P. H., & Trung, D. Q. (1999). Willingness to donate organs and tissues in vietnam. *Journal of Transplant Coordination*, *9*, 57–63. https://doi.org/10.1177/090591999900900109

Hair, J., Anderson, R., Black, B., & Babin, B. (2016). *Multivariate Data Analysis* (7th ed.). Pearson College Division.

Health Resources & Services Administration, USA. (2023, October). *Organ Donation Statistics*. Www.organdonor.gov; Health Resources & Services Administration. https://www.organdonor.gov/learn/organ-donation-statistics.

Iacobucci, G. (2020). Organ donation: England will have "opt-out" system from May 2020. *BMJ*, m752. https://doi.org/10.1136/bmj.m752

Ibrahim, M., & Randhawa, G. (2017). Knowledge, Attitudes, and Behavior of Nigerian Students Toward Organ Donation. *Transplantation Proceedings*, *49*(8), 1691–1697. https://doi.org/10.1016/j.transproceed.2017.04.011.

Iliyasu, Z., Abubakar, I., Lawan, U., Abubakar, M., & Adamu, B. (2014). Predictors of public attitude toward living organ donation in Kano, northern Nigeria. *Saudi Journal of Kidney Diseases and Transplantation*, *25*(1), 196. https://doi.org/10.4103/1319-2442.124577

Irving, M. J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, R. D., Craig, J. C., Wong, G., & Howard, K. (2011). Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation*, *27*(6), 2526–2533. https://doi.org/10.1093/ndt/gfr683

Jamison, D. T. (2006). *Disease and mortality in Sub-Saharan Africa* (D. Jamison, R. Feachem, M. Makgoba, E. Bos, F. Baingana, K. Hofman, & K. Rogo, Eds.; 2nd Edn). World Bank.

Janahi, F. K., Al Rais, A., Al Rukhaimi, M., Khamis, A. H., & Hickey, D. (2018). Public Awareness of Knowledge, Belief, and Attitude Regarding Organ Donation and Organ Transplantation: A National Survey From the United Arab Emirates. *Transplantation Proceedings*, *50*(10), 2932–2938. https://doi.org/10.1016/j.transproceed.2018.08.006

Janet Rose, B. GOWRI, M.Sc., (N, & R. JAMUNARANI, M.Sc (N). Ph.D. (2023). A Study to Assess the Effectiveness of Video-Assisted Teaching Programmes on Knowledge and Attitude Regarding Organ Donation among Non-Health Professional Students a Selected College, Hosur. *International Journal of Medical Science and Clinical Research Studies*, *03*(03). https://doi.org/10.47191/ijmscrs/v3-i3-33

Jansen, N. E., Williment, C., Haase-Kromwijk, B. J. J. M., & Gardiner, D. (2022). Changing to an opt out system for organ donation—reflections from England and Netherlands. *Transplant International*, *35*, 10466. https://doi.org/10.3389/ti.2022.10466

Jaradat, A. A., & AL-Shakri, K. S. (2012). Marketing Research, Goals, Problems and Objectives. *Journal of Information, Intelligence and Knowledge*, *4*(2), 85-94.

Jha, V. (2004). Paid transplants in India: the grim reality. *Nephrology Dialysis Transplantation*, *19*(3), 541–543. https://doi.org/10.1093/ndt/gfg576

Johnston, C. (2017, September 4). *Shortage of organ donations led to 457 deaths last year, says NHS*. The Guardian; The Guardian. https://www.theguardian.com/society/2017/sep/04/silence-transplants-deadly-organs-shortage-nhs

Johnston-Webber, C., Mah, J., Streit, S., Apostolos Prionas, Wharton, G., Mossialos, E., & Vassilios Papalois. (2023). *A conceptual framework for evaluating national organ donation and transplantation programs*. *36*. https://doi.org/10.3389/ti.2023.11006

Jones, C. P., Papadopoulos, C., & Randhawa, G. (2019). Who's opting-in? A demographic analysis of the U.K. NHS Organ Donor Register. *PLOS ONE*, *14*(1), e0209161. https://doi.org/10.1371/journal.pone.0209161

Joshi, N. (2020). Evaluate the effectiveness of Structured Teaching Programme on knowledge and skill regarding basic cardiac life support among basic B.Sc. (N) 1st year Students. *Asian Journal of Nursing Education and Research*, *10*(4), 396–400. https://doi.org/10.5958/2349-2996.2020.00084.1

Kang, H. (2013). The prevention and handling of the missing data. *Korean Journal of Anesthesiology*, *64*(5), 402–406. https://doi.org/10.4097/kjae.2013.64.5.402

Kent, B., & Owens, R. Glynn. (1995). Conflicting attitudes to corneal and organ donation: a study of nurses' attitudes to organ donation. *International Journal of Nursing Studies*, *32*(5), 484–492. https://doi.org/10.1016/0020-7489(95)00009-m

Kiani, Z., Simbar, M., Hajian, S., &Zayeri, F. (2020). Development and psychometric evaluation of a quality of life questionnaire for infertile women: a mixed method study. *Reproductive Health*, *17*(1). https://doi.org/10.1186/s 12978-020-00988-7

Kosieradzki, M., Jakubowska-Winecka, A., Feliksiak, M., Kawalec, I., Zawilinska, E., Danielewicz, R., Czerwinski, J., Malkowski, P., &Rowiński, W. (2014). Attitude of Healthcare Professionals: A Major Limiting Factor in Organ Donation from Brain-Dead Donors. *Journal of Transplantation*, *2014*, 1–6. https://doi.org/10.1155/2014/296912

Krekula, L. G., Malenicka, S., Linder, M., &Tibell, A. (2009). From words to action - influence of two organ donation campaigns on knowledge and formal decision making. *Clinical Transplantation*, *23*(3), 343–350. https://doi.org/10.1111/j.1399-0012.2008.00919.x

Krishnan, N., Kaur, S., Rana, D., Kathania, D., Thakur, G., & Kaur, G. (2015). Knowledge, Attitude and Perception Regarding Organ Donation among the Nursing Students. *Journal of Postgraduate Medicine, Education and Research*, *49*(3), 105–110. https://doi.org/10.5005/jp-journals-10028-1157

Krueger, H. (1989). Economic analysis of solid organ transplantation: a review for policy makers. *Health Policy*, *13*(1), 1–17. https://doi.org/10.1016/0168-8510(89)90107-3

Kumar, L. (2016). Brain death and care of the organ donor. *Journal of Anaesthesiology Clinical Pharmacology*, *32*(2), 146. https://doi.org/10.4103/ 0970-9185.168266

Kumar, S., Bagaria, S., Sonia, M., & Kumar Khandelwal, K. (2019). Role of video assisted teaching in counselling to make decision for organ donation. *International Journal on Integrated Education*, *2*(6), 145–148. https://doi.org/10.31149/ijie.v2i6.225

Kumar, V., Yadav, A. K., Sethi, J., Ghosh, A., Sahay, M., Prasad, N., Varughese, S., Parameswaran, S., Gopalakrishnan, N., Kaur, P., Modi, G. K., Kamboj, K., Kundu, M., Sood, V., Inamdar, N., Jaryal, A., Vikrant, S., Nayak, S., Singh, S., & Gang, S. (2021). The Indian Chronic Kidney Disease (ICKD) study: baseline characteristics. *Clinical Kidney Journal*, *15*(1), 60–69. https://doi.org/10.1093/ckj/sfab149

Kurleto, P., Tomaszek, L., Milaniak, I., & Wioletta Mędrzycka-Dąbrowska. (2022). Factors Associated with the Willingness to Become a Living Kidney Donor: A National Cross-Sectional Study. *International Journal of Environmental Health and Public Research,19*(3), 1313–1313. https://doi.org/10.3390/ijerph19031313

Larijani, B., Zahedi, F., & Taheri, E. (2006). Deceased and Living Organ Donation in Iran. *American Journal of Transplantation*, *6*(6), 1493–1493. https://doi.org /10.1111/j.1600-6143.2006.01327.x

Laupacis, A., Keown, P., Pus, N., Krueger, H., Ferguson, B., Wong, C., & Muirhead, N. (1996). A study of the quality of life and cost-utility of renal transplantation. *Kidney International*, *50*(1), 235–242. https://doi.org/10.10 38/ki.1996.307

Lei, L., Lin, L., Deng, J., Dong, H., & Luo, Y. (2020). Developing an organ donation curriculum for Medical undergraduates in China based on theory of planned behavior: a Delphi method study. *Annals of transplantation*, *25*, e922809-1. https://doi.org/10.12659/aot.922809

Levy, M. (2018). State incentives to promote organ donation: honoring the principles of reciprocity and solidarity inherent in the gift relationship. *Journal of Law and the Biosciences*, *5*(2), 398–435. https://doi.org/10.1093/jlb/lsy009.

Lewis, A., Koukoura, A., Tsianos, G.-I., Gargavanis, A. A., Nielsen, A. A., & Vassiliadis, E. (2020). Organ donation in the US and Europe: The supply vs demand imbalance. *Transplantation Reviews*, *35*(2), 100585. https://doi.org/10.1016/j.trre.2020.100585

Lewis, J., & Gardiner, D. (2023). Ethical and legal issues associated with organ donation and transplantation. *Surgery (Oxford)*, *41*(9), 552–558. https://doi.org/10.1016/j.mpsur.2023.06.010

Li, A. H.-T., Rosenblum, A. M., Nevis, I. F., & Garg, A. X. (2013). Adolescent classroom education on knowledge and attitudes about deceased organ donation: A systematic review. *Pediatric Transplantation*, *17*(2), 119–128. https://doi.org/10.1111/petr.12045

Li, M. T., Hillyer, G. C., Husain, S. A., & Mohan, S. (2019). Cultural barriers to organ donation among Chinese and Korean individuals in the United States: a systematic review. *Transplant International*, *32*(10), 1001–1018. https://doi.org/10.1111/tri.13439

Lin, S. S., Rich, L., Pal, J. D., & Sade, R. M. (2012). Prisoners on Death Row Should Be Accepted as Organ Donors. *The Annals of Thoracic Surgery*, *93*(6), 1773–1779. https://doi.org/10.1016/j.athoracsur.2012.03.003

Little Flower, J. R., & Balamurugan E. (2013). A Study on Public Intention to Donate Organ: Perceived Barriers and Facilitators. *British Journal of Medical Practitioners*, *6*(4), 636.

Lucrezia Furian, Oriol Bestard, Budde, K., Cozzi, E., Diekmann, F., Nizam Mamode, Maarten Naesens, Liset H. M. Pengel, Soren Schwartz Sorensen, Fabio Vistoli, & Olivier Thaunat. (2024). European Consensus on the Management of Sensitized Kidney Transplant Recipients: A Delphi Study. *Transplant International*, *37*, 12475. https://doi.org/10.3389/ti.2024.12475

Lyu, C., & Zhang, L. (2018). Who decides in withdrawal of treatment in a critical care setting? A case study on ethical dilemma. *International Journal of Nursing Sciences*, *5*(3), 310–314. https://doi.org/10.1016/j.ijnss.2018.06.004

MacDonald, S. I., &Shemie, S. D. (2017). Ethical Challenges and the Donation Physician Specialist. *Transplantation*, *101*, S27–S40. https://doi.org/10.1097/tp.0000000000001697

Maiti, D., & Balaji, M. S. (2022). Statement of the Problem: A Study to Evaluate the Effectiveness of Video Assisted Teaching (VAT) on Knowledge Regarding Prevention of Corona Virus Among Staff Nurses Working in AH & RC, BG

Nagara, Karnataka. *International Journal of Nursing Education*, *14*(3), 56-62. https://doi.org/10.37506/ijone.v14i3.18351

Mann, C. J. (2003). Observational research methods. Research design II: cohort, cross sectional, and case-control studies. *Emergency Medicine Journal*, *20*(1), 54–60. https://doi.org/10.1136/emj.20.1.54

Marcus, K., Berner, D., Hadaya, K., & Hurst, S. (2023). Anonymity in Kidney Paired Donation: A Systematic Review of Reasons. *Transplant International*, *36*. https://doi.org/10.3389/ti.2023.10913

Marqués-Lespier, J. M., Ortiz-Vega, N. M., Sánchez, M. C., Sánchez, M. C., Soto-Avilés, O. E., & Torres, E. A. (2013). Knowledge of and attitudes toward organ donation: a survey of medical students in Puerto Rico. *Puerto Rico health sciences journal*, *32*(4), 187–193.

Martin, D. E., Harris, D. C. H., Jha, V., Segantini, L., Demme, R. A., Le, T. H., McCann, L., Sands, J. M., Vong, G., Wolpe, P. R., Fontana, M., London, G. M., Vanderhaegen, B., Vanholder, R., Martin, D. E., Harris, D. C. H., Jha, V., Segantini, L., Demme, R. A., & Le, T. H. (2020). Ethical challenges in nephrology: a call for action. *Nature Reviews Nephrology*, *16*(10), 603–613. https://doi.org/10.1038/s41581-020-0295-4

Martín-Escobar, E. (2012). Importancia de loscuidadosintensivosen la donación y eltrasplante de órganos. *Revista Brasileira de TerapiaIntensiva*, *24*(4), 316–317. https://doi.org/10.1590/s0103-507x2012000400002

Matesanz, R., Domínguez-Gil, B., Coll, E., Mahíllo, B., &Marazuela, R. (2017). How Spain Reached 40 Deceased Organ Donors per Million Population. *American Journal of Transplantation*, *17*(6), 1447–1454. https://doi.org/10.1111/ajt.14104

Merlin Babu, R. (2015). Effectiveness of Video Assisted Teaching (VAT) on Knowledge and Pre Procedural Anxiety Level of Patients Undergoing Mammography AIMS, Kochi. *Journal of Cancer Prevention & Current Research*, *3*(5). 350-356. https://doi.org/10.15406/jcpcr.2015.03.00096

Mihály, S., Smudla, A., Dominguez-Gil, B., Pérez, A., Procaccio, F., Cozzi, E.,...& Manara, A. (2023). Approaching the families of potential deceased organ donors: an overview of regulations and practices in Council of Europe Member

States. *Transplant International*, *36*, 11498..https://doi.org/ 10.3389/ ti.2023.11498

Milaap. (2024, July 28). *Organ Transplant Scams In India: How To Avoid Them and Stay Safe*. Free Crowdfunding for India | #1 Fundraising Website in India | Milaap. https://pages.milaap.org/2024/07/29/organ-transplant-scams-in-india-how-to-avoid-them-and-stay-safe/

Miller, J., Currie, S., & O'Carroll, R. E. (2018). "What if I'm not dead?" - Myth-busting and organ donation. *British Journal of Health Psychology*, *24*(1), 141–158. https://doi.org/10.1111/bjhp.12344

Miller, J., Currie, S., McGregor, L. M., & O'Carroll, R. E. (2020). "It's like being conscripted, one volunteer is better than 10 pressed men": A qualitative study into the views of people who plan to opt-out of organ donation. *British Journal of Health Psychology*, *25*(2), 257–274. https://doi.org/10.1111 /bjhp.12406

Milross, L., Brown, C., Gladkis, L., Downes, K., Goodwin, M., Madden, S.,...& Gardiner, D. (2022). Comparing deceased organ donation performance in two countries that use different Metrics: comparing apples with apples. *Transplant International*, *35*, 10461. https://doi.org/10.3389/ti.2022.10461

Mithra, P., Ravindra, P., Unnikrishnan, B., Rekha, T., Kanchan, T., Kumar, N., Papanna, M., Kulkarni, V., Holla, R., &Divyavaraprasad, K. (2013). Perceptions and attitudes towards organ donation among people seeking healthcare in tertiary care centers of coastal south India. *Indian Journal of Palliative Care*, *19*(2), 83. https://doi.org/10.4103/0973-1075.116701

Modi, G. K., & Jha, V. (2006). The incidence of end-stage renal disease in India: A population-based study. *Kidney International*, *70*(12), 2131–2133. https://doi.org/10.1038/sj.ki.5001958

Mohan Foundation (2014). *Organ Donation in Tamil Nadu*. Mohanfoundation.org. https://www.mohanfoundation.org/organ-donation-transplant-resources/organ-donation-in-tamil-nadu.asp

Mohan Foundation. (2013). *Myths, Misconceptions and the Reality of Organ Donation*. Mohanfoundation.org. https://www.mohanfoundation.org/organ-donation-transplant-resources/Myths-Misconceptions-and-the-Reality-of-Organ-Donation.asp

Molina-Pérez, A., Rodríguez-Arias, D., & Delgado, J. (2022). Differential impact of opt-in, opt-out policies on deceased organ donation rates: a mixed conceptual and empirical study. *BMJ Open*, *12*(9), e057107. https://doi.org/10.1136/bmjopen-2021-057107

Mostafazadeh-Bora, M., &Zarghami, A. (2017). The Crucial Role of Cultural and Religious Beliefs on Organ Transplantation. *International Journal of Organ Transplantation Medicine*, *8*(1), 54. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5347408/

Mrs. Janet Rose, Mrs. B. Gowri, M.Sc., (N), & Dr. Mrs. R. Jamunarani, M.Sc (N). Ph.D. (2023). A Study to Assess the Effectiveness of Video-Assisted Teaching Programmes on Knowledge and Attitude Regarding Organ Donation among Non-Health Professional Students at Selected College, Hosur. *International Journal of Medical Science and Clinical Research Studies*, *03*(03). https://doi.org/10.47191/ijmscrs/v3-i3-33

Muco, E., Yarrarapu, S. N. S., Douedi, H., & Burns, B. (2023, July 24). *Tissue and Organ Donation*. PubMed; StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK557431/

Nadeem Ahmad Khan, & Tajdar Husain Khan. (2023). Organ donation: Demand and supply. *IntechOpenEBooks*. https://doi.org/10.5772/intechopen.108153

Nadeem, A. K., & Taqi, T. K. (2023). Organ Donation : Demand & Supply. In G. Tsulfas (Ed.), *Current Challenges and Advances in Organ Donation and Transplantation* (pp. 0–144). Intech Open. ISBN 978-1-83768-005-4

Narasimhan, G. (2016). Living donor liver transplantation in India. *PubMed*, *5*(2), 127–132. https://doi.org/10.3978/j.issn.2304-3881.2015.09.01

Narsis, Dr. I. (2022). Exploratory Factor Analysis on Bancassurance Attributes. *International Journal of Management and Humanities*, *9*(1), 12–18. https://doi.org/10.35940/ijmh.l1523.099122

Nasar Alwahaibi, Anas Al Wahaibi, & Mohammed Al Abri. (2023). Knowledge and attitude about organ donation and transplantation among omani university students. *Knowledge and Attitude about Organ Donation and Transplantation among Omani University Students*, *11*. https://doi.org/10.3389/fpubh.2023.1115531

Nath, A., Shalini, MartinaA. J., & Mathur, P. (2021). Health systems challenges and opportunities in tackling non-communicable diseases in rural areas of India. *The National Medical Journal of India*, *34*(1), 29. https://doi.org/ 10.4103/0970-258x.32366

Nathalie van Dijk, Shaw, D., Shemie, S. D., Wiebe, K., Walther van Mook, & Bollen, J. (2023). Directed Organ Donation After Euthanasia. *Transplant International*, *36*. 11259. https://doi.org/10.3389/ti.2023.11259

National Academics of Sciences. (2017). *Opportunities for Organ Donor Intervention Research* (J. F. Childress, S. Domnitz, & C. T. Liverman, Eds.). National Academies Press. https://doi.org/10.17226/24884

National Academics of Sciences. (2022). *Realizing the Promise of Equity in the Organ Transplantation System* (K. W. Kizer, R. A. English, & M. Hackmann, Eds.). National Academies Press. https://doi.org/10.17226/26364

Nayak, V. C., & Nayak, S. (2023). An empirical investigation on the impact of attitudes towards organ donation in India. *F1000Research*, *12*, 463–463. https://doi.org/10.12688/f1000research.131652.2

Nelson, V., Manojan, K., Raja, R., Beevi, N., & Jose, R. (2018). Knowledge and Attitude towards Organ Donation in Rural Kerala Knowledge and Attitude towards Organ Donation in Rural Kerala. *Academic Medical Journal of India*, *II*(I). https://doi.org/10.4103/0973-

NHS. (2021). *Organ donation achieved three quarters of its normal activity last year despite global pandemic*. NHS Organ Donation. https://www.organdonation.nhs.uk/get-involved/news/organ-donation-achieved-three-quarters-of-its-normal-activity-last-year-despite-global-pandemic/

NOTTO, MoHFW. (2024). *National Organ & Tissue Transplant Organization Government of India Ministry of Health & Family Welfare Directorate General of Health Services (Report) National Symposium on Legal and Ethical Aspects of Organ Donation and Transplantation On*.

NOTTO. (2023). *Guidelines.* Notto.gov.in. https://notto.gov.in/guidelines.htm

OPTN. (2015). *Ethics - Living Non-Directed Organ Donation - OPTN*. Optn.transplant.hrsa.gov. https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/living-non-directed-organ-donation/

Organ Retrieval Banking Organization (2023). *Home - Organ Retrieval Banking Organization*. Retrieved from https://orbo.org.in/

Palakuri S, Chandra, A., Prakash, S., Manish Manrai, J. Muthukrishnan, Srivastava, S., & Saurabh Dawra. (2024). A cross-sectional study to estimate the cost of managing patients with acute on chronic liver failure at a tertiary care centre. *Medical Journal Armed Forces India/MJAFI*. https://doi.org/10.1016/j.mjafi.2024.02.003

Pan, X.-T., Ji-Ma, Liu, W., Bai, Z.-C., Dai, Z.-F., Huang, J.-T., & Lin, J.-F. (2021). Investigation and Strategic Analysis of Family Barriers to Organ Donation in China. *Transplantation Proceedings*, *53*(2), 513–519. https://doi.org/10.1016/j.transproceed.2020.09.017

Pandey, P., & Pandey, M. M. (2015). Research Methodology : Tools and Techniques. Bridge Centre. (Original work published 2015)

Panwar, R., Pal, S., Dash, N. R., Sahni, P., Vij, A., & Misra, M. C. (2016). Why are we Poor Organ Donors: A Survey Focusing on Attitudes of the Lay Public From Northern India. *Journal of Clinical and Experimental Hepatology*, *6*(2), 81–86. https://doi.org/10.1016/j.jceh.2016.04.001

Pasha, H. chashmi, & Albar, M. (2014). Kidney transplantation: Ethical challenges in the Arab world. *Saudi Journal of Kidney Diseases and Transplantation*, *25*(3), 489. https://doi.org/10.4103/1319-2442.132148

Pathi, B., Jain, S., Singh, A. S., Singh, S., Kunder, H., & Singh, K. (2015). Beliefs and barriers for organ donation and influence of educational intervention of dental students - A Questionnaire study. *Journal of Indian Association of Public Health Dentistry*, *13*(1), 58–62.

Pauline, S., Priya, S., & Hemavathy, V. (2007). A Study to Assess the Effectiveness of Structured Teaching Programme Regarding Organ Donation among Adolescent Boys in Selected School, Chennai. *International Journal of Innovative Research in Science, Engineering and Technology (an ISO*, *4*(4). https://doi.org/10.15680/IJIRSET.2015.0404109

Penn Medicine. (2019). *Organ Donation Myths, Debunked – Penn Medicine*. Pennmedicine.org. https://www.pennmedicine.org/updates/blogs/transplant-update/2019/march/myths-about-organ-donation

Petrini, C., Riva, L., Floridia, G., &Mannelli, C. (2020). Anonymity and Organ Donation: Ethical and Policy Implications After the Opinion Released by the Italian Committee for Bioethics. *Transplantation Proceedings*, *52*(5), 1525–1527. https://doi.org/10.1016/j.transproceed.2020.01.079

Poreddi, V., Sunitha, T., Thimmaiah, R., & Math, S. (2017). Gender differences in perceptions and attitudes of general population towards organ donation: An Indian perspective. *Saudi Journal of Kidney Diseases and Transplantation*, *28*(3), 599. https://doi.org/10.4103/1319-2442.206460

Potter, J. E., Herkes, R. G., Perry, L., Elliott, R. M., Aneman, A., Brieva, J. L., Cavazzoni, E., Cheng, A. T. H., O'Leary, M. J., Seppelt, I. M., &Gebski, V. (2017). COMmunication with Families regarding Organ and Tissue donation after death in intensive care (COMFORT): protocol for an intervention study. *BMC Health Services Research*, *17*(1). https://doi.org/10.1186/s12913-016-1964-7

Potts, J. T., Herdman, R., & Institute of Medicine. (1997). *Non-Heart-Beating Organ Transplantation: Medical and Ethical Issues in Procurement.* National Academies Press. https://nap.nationalacademies.org/catalog/6036.html ISBN: 0-309-59310-7, 104 pages

Pouraghaei Mahmood, Tagizadieh, M., Tagizadieh, A., Payman Moharamzadeh, Samaneh Esfahanian, & Kavous Shahsavari Nia. (2015). Knowledge and Attitude Regarding Organ Donation among Relatives of Patients Referred to the Emergency Department. *Emergency*, *3*(1), 33. http://www.ncbi.nlm.nih.gov/pmc/articles/pmc4614608/

Pushpkala, S., &Chako, A. (2015). Effectiveness of video assisted teaching on knowledge and practice of using metered dose inhaler with spacer among Patients with bronchial asthma. *Quest Journals Journal of Research in Humanities and Social Science*, *3*(6), 2321–9467.

Ralph, A., Chapman, J. R., Gillis, J., Craig, J. C., Butow, P., Howard, K., Irving, M., Sutanto, B., & Tong, A. (2014). Family Perspectives on Deceased Organ Donation: Thematic Synthesis of Qualitative Studies. *American Journal of Transplantation*, *14*(4), 923–935. https://doi.org/10.1111/ajt.12660

Ramachandran, R., & Jha, V. (2013). Kidney Transplantation Is Associated with Catastrophic Out of Pocket Expenditure in India. *PLoS ONE*, *8*(7), e67812. https://doi.org/10.1371/journal.pone.0067812

Ramadurg, U. Y., & Gupta, A. (2014). Impact of an educational intervention on increasing the knowledge and changing the attitude and beliefs towards organ donation among medical students. *Journal of clinical and diagnostic research: JCDR*, *8*(5), JC05. https://doi.org/10.7860/jcdr/2014/6594.4347

Razdan, M., Degenholtz, H. B., Kahn, J. M., & Driessen, J. (2015). Breakdown in the Organ Donation Process and Its Effect on Organ Availability. *Journal of Transplantation*, *2015*, 1–8. https://doi.org/10.1155/2015/831501

Regalia, K., Zheng, P., Sillau, S., Aggarwal, A., Bellevue, O., Fix, O. K., Prinz, J., Dunn, S., & Biggins, S. W. (2014). Demographic Factors Affect Willingness to Register as an Organ Donor More Than a Personal Relationship with a Transplant Candidate. *Digestive Diseases and Sciences*, *59*(7), 1386–1391. https://doi.org/10.1007/s10620-014-3053-

Ríos, A., Martínez-Alarcón, L., López-Navas, A., Sánchez, J., Guzmán, D., Febrero, B., Ramis, G., Ramírez, P., & Parrilla, P. (2011). Knowledge of the Concept of Brain Death in the British and Irish Population Resident in Southeast Spain. *Transplantation Proceedings*, *43*(3), 692–694. https://doi.org/10.1016/ j.transproceed.2011.02.037

Robichaux, C. M., & Clark, A. P. (2006). Practice of Expert Critical Care Nurses in Situations of Prognostic Conflict at the End of Life. *American Journal of Critical Care*, *15*(5), 480–491. https://doi.org/10.4037/ajcc2006.15.5.480

Rodrigue, J. R., Cornell, D. L., & Howard, R. J. (2008). The Instability of Organ Donation Decisions by Next-of-Kin and Factors That Predict It. *American Journal of Transplantation*, *8*(12), 2661–2667. https://doi.org/10.1111/j.1600-6143.2008.02429.x

Rodrigue, J. R., Cornell, D. L., Krouse, J., & Howard, R. J. (2010). Family initiated discussions about organ donation at the time of death. *Clinical Transplantation*, *24*(4), 493–499. https://doi.org/10.1111/j.1399-0012.2009. 01096.x

Rughini, C., Vulpe, S.-N., Flaherty, M. G., & Vasile, S. (2022). Vaccination, life expectancy, and trust: Patterns of COVID-19 and measles vaccination rates

around the world. *Public Health*, *210*. https://doi.org/10.1016/j.puhe.2022.06.027

Rykhoff, M. E., Coupland, C., Dionne, J., Fudge, B., Gayle, C., Ortner, T.-L., Quilang, K., Savu, G., Sawany, F., & Wrobleska, M. (2010). A clinical group's attempt to raise awareness of organ and tissue donation. *Progress in Transplantation (Aliso Viejo, Calif.)*, *20*(1), 33–39. https://doi.org/10.7182/prtr.20.1.g72751q64l63g7w5

S. T. MasoumianHoseini, Manzari, Z., & I. Khaleghi. (2015). ICU Nurses' Knowledge, Attitude, and Practice Towards their Role in the Organ Donation Process from Brain-Dead Patients and Factors Influencing it in Iran. *International Journal of Organ Transplantation Medicine*, *6*(3), 105. http://www.ncbi.nlm.nih.gov/pmc/articles/pmc4545304/

Sade, R. M. (2011). Brain death, Cardiac death, and the Dead donor rule. *Journal of the South Carolina Medical Association (1975)*, *107*(4), 146. http://www.ncbi.nlm.nih.gov/pmc/articles/pmc3372912/

Sahi, M., Kanvinde, H., & S. Kavitha. (2013). Myths, Misconceptions and the Reality of Organ Donation. *Organ Donation & Transplant Resources.* Mohan Foundation. https://www.mohanfoundation.org/organ-donation-transplant-resources/Myths-Misconceptions-and-the-Reality-of-Organ-Donation.asp

Saidi, R. F., & S. K. Hejazii Kenari. (2014). Challenges of Organ Shortage for Transplantation: Solutions and Opportunities. *International Journal of Organ Transplantation Medicine*, *5*(3), 87. http://www.ncbi.nlm.nih.gov/pmc/articles/pmc4149736/

Saikia, B., Tamuli, R., & Sarmah, S. (2019). Organ donation – "attitude and awareness among undergraduates and postgraduates of North-East India." *Journal of Family Medicine and Primary Care*, *8*(1), 130. https://doi.org/10.4103/jfmpc.jfmpc_206_18

Sarveswaran, G., Sakthivel, M. N., Krishnamoorthy, Y., Arivarasan, Y., & Ramakrishnan, J. (2018). Knowledge, attitude, and practice regarding organ donation among adult population of urban Puducherry, South India. *Journal of Education and Health Promotion*, *7*, 117. https://doi.org/10.4103/jehp.jehp_44_18

Saxena, D., Trivedi, P., Bhavsar, P., Memon, F., Thaker, A., Chaudhary, C., Sandul Yasobant, Singhal, D., & Sanjay Zodpey. (2023). Challenges and Motivators to Organ Donation: A Qualitative Exploratory Study in Gujarat, India. *International Journal of General Medicine*, *Volume 16*(16), 151–159. https://doi.org/10.2147/ijgm.s393240

Sayyed, A. A. K., Pratinidhi, S. A., D'Souza, D. S. J., &Dhanmane, S. T. (2021). A study of religious beliefs affecting organ donation & influence of educational intervention in western Maharashtra. *International Journal of Clinical Biochemistry and Research*, *8*(2), 109–114. https://doi.org/10.18231/j.ijcbr.2021.024

Selvanathan, C., Famure, O., Batoy, B., Cocco, A., So, S., Breckbill, K., Meliton, G., Norgate, A., Kim, S. J., & Ng, V. L. (2021). Engaging high school students about organ donation and transplantation: an evaluation of the High School Outreach Initiative (HSOI) program. *Pediatric Transplantation*, *25*(4). https://doi.org/10.1111/petr.1398

Shah, B., & Shah, S. (2018). Legal aspects of transplantation in India. *Indian Journal of Transplantation*, *12*(3), 169. https://doi.org/10.4103/ijot.ijot_43_18

Shah, R.., Patel, A.., Ramanuj, V.., & Solanki, N.. (2015). Knowledge And Attitudes About Organ Donation Among Commerce College Students. *National Journal of Community Medicine*, *6*(04), 533–535. Retrieved from https://njcmindia.com/index.php/file/article/view/1272

Shastri, P. (2016, August 13). *Organ donation: Young soldiers ready to shoulder campaign*. The Times of India; Times Of India. https://timesofindia.indiatimes.com/city/ahmedabad/organ-donation-young-soldiers-ready-to-shoulder-campaign/articleshow/53680569.cms

Shaw, R. M., & Webb, R. (2014). Multiple Meanings of "Gift" and its Value for Organ Donation. *Qualitative Health Research*, *25*(5), 600–611. https://doi.org/10.1177/1049732314553853

Shrivastav, V., Murugan, Y., Gandhi, R., Nagda, J., Shrivastav, V., Murugan, Y., Gandhi, R., & Nagda, J. (2024). Knowledge, Attitudes, and Practices Regarding Organ Donation Among Medical Students in India: A Mixed Methods Study. *Cureus*, *16*(3). https://doi.org/10.7759/cureus.56136

Shroff, S. (2009). Legal and ethical aspects of organ donation and transplantation. *Indian Journal of Urology*, *25*(3), 348. https://doi.org/10.4103/0970-1591.56203

Shroff, S. (2016). Current trends in kidney transplantation in India. *Indian Journal of Urology : IJU : Journal of the Urological Society of India*, *32*(3), 173–174. https://doi.org/10.4103/0970-1591.185092

Shroff, S., & Gill, J. S. (2021). Bold policy changes are needed to meet the need for organ transplantation in India. *American Journal of Transplantation*. https://doi.org/10.1111/ajt.16537

Shroff, S., Navin, S., Abraham, G., Rajan, P. S., Suresh, S., Rao, S., & Thomas, P. (2003). Cadaver organ donation and transplantation-an Indian perspective. *Transplantation Proceedings*, *35*(1), 15–17. https://doi.org/10.1016/s0041-1345(02)03907-6

Shroff, S., Thyagarajan, I., Hemal Kanvinde, & Sahi, M. (2022). Organ donation and the medicolegal aspects: A process analysis study of the Indian States - Observational study. *Indian Journal of Transplantation*, *16*(2), 184–184. https://doi.org/10.4103/ijot.ijot_59_21

Siminoff, L. A., Agyemang, A. A., & Traino, H. M. (2013). Consent to Organ Donation: A Review. *Progress in Transplantation*, *23*(1), 99–104. https://doi.org/10.7182/pit2013801

Siminoff, L. A., Traino, H. M., &Genderson, M. W. (2015). Communicating Effectively About Organ Donation. *Transplantation Direct*, *1*(2), 1–9. https://doi.org/10.1097/txd.0000000000000513

Sireci, S. G. (1998). The Construct of Content Validity. *Social Indicators Research*, *45*(1/3), 83–117. https://doi.org/10.1023/a:1006985528729

Sobnach, S., Wiese, K. R., Tselanyane, M. E., Borkum, M., Kahn, D., &Segobin, R. (2016). Medical Students' Knowledge About Brain Death: A South African Contribution. *Transplantation Proceedings*, *48*(6), 1904–1906. https://doi.org/10.1016/j.transproceed.2016.04.010

Somaili, M., Masmali, A., Haqawi, I., Al-Hulaibi, M., AlHabji, A. A., Salami, A., Ageel, A. A., Sultan, Y., Alhazemi, A., Moharg, F., Almansour, O., & Ahmed, A. E. (2022) Knowledge and Attitude Toward Organ Donation Among the

Adult Population in Jazan, Saudi Arabia. *Cureus*. https://doi.org/10.7759/cureus.27002

Sørensen, P., & Kousgaard, S. J. (2017). Barriers toward organ donation in a Danish University Hospital. *Acta Anaesthesiologica Scandinavica*, *61*(3), 322–327. https://doi.org/10.1111/aas.12853

Souqiyyeh, M. Z., & Shaheen, F. A. (2006). Attitude of physicians towards the follow-up of renal transplant patients: a questionnaire survey in Saudi Arabia. *Saudi journal of kidney diseases and transplantation : an official publication of the Saudi Center for Organ Transplantation, Saudi Arabia*, *17*(2), 159–167.

Stefanone, M., Anker, A. E., Evans, M., & Feeley, T. H. (2012). Click to "Like" Organ Donation: The Use of Online Media to Promote Organ Donor Registration. *Progress in Transplantation*, *22*(2), 168–174. https://doi.org/10.7182/pit2012931

Streit, S., Johnston-Webber, C., Mah, J., Apostolos Prionas, Wharton, G., Casanova, D., Mossialos, E., & Vassilios Papalois. (2023). Ten Lessons From the Spanish Model of Organ Donation and Transplantation. *Ten Lessons from the Spanish Model of Organ Donation and Transplantation*, *36*(36). 11009. https://doi.org/10.3389/ti.2023.11009

Subitha, L., Balajee, K., & Ramachandran, N. (2016). Awareness and attitudes toward organ donation in rural Puducherry, India. *Annals of Medical and Health Sciences Research*, *6*(5), 286. https://doi.org/10.4103/amhsr.amhsr_63_15

Sugumar, J., Padhyegurjar, M., &Padhyegurjar, S. (2017). An interventional study on knowledge and attitude regarding organ donation among medical students. *International Journal of Medical Science and Public Health*, *6*(2), 1. https://doi.org/10.5455/ijmsph.2017.19082016631

Sun, H.-J.. (2014). A study on the development of public campaign messages for organ donation promotion in Korea. *Health Promotion International*, *30*(4), 903–918. https://doi.org/10.1093/heapro/dau023

Surender Palakuri, Chandra, A., Prakash, S., Manish Manrai, J. Muthukrishnan, Srivastava, S., & Saurabh Dawra. (2024). A cross-sectional study to estimate the cost of managing patients with acute on chronic liver failure at a tertiary care

centre. *Medical Journal Armed Forces India/MJAFI*. https://doi.org/10.1016/j.mjafi.2024.02.003

Survey system. (2016). *Sampling size - Creative Research Systems*. Surveysystem.com. https://www.surveysystem.com/ssclac.htm

Tanna, H., Patel, H., Patel, P., Patel, G., & Kumar, D. (2023). Knowledge and Attitude Toward Organ Donation Among Interns and Residents in a Tertiary Care Hospital in Gujarat, India. *Cureus*, *15*(8). https://doi.org/ 10.7759/cureus.43797

Taş, F., Selçuk Tosun, A., & Akgül Gündoğdu, N. (2021). The Effect of Islamic Belief and Spiritual Well-being on Organ Donation in Turkey: A Descriptive-Relational Study. *Journal of Religion and Health*, *61*(3), 2121–2140. https://doi.org/10.1007/s10943-021-01252-3

Tathya Correspondent. (2024, February 15). *State Honor For Organ Donors*. Tathya. https://tathya.in/state-honor-for-organ-donors/

Tejeshwari, B., Monachan, M., Tomy, T., Akiya, T., & Author, C. (2022). Effectiveness of structured teaching programme on knowledge regarding challenges of online classes among nursing students at a selected Nursing college, Bangalore. *Asian Pacific Journal of Nursing*, *2022*(1), 57–61.

The News Minute. (2016, August 13). *Five myths related to organ donation busted*. The News Minute; The News Minute. https://www.thenewsminute.com/news/five-myths-related-organ-donation-busted-48167

Thimbleby, H. (2022). Technology and the Future of Healthcare. *Journal of Public Health Research*, *2*(3), 28. NCBI. https://doi.org/10.4081/jphr.2013.e28

Thomas, M., &Klapdor, M. (2008). Parliament of Australia Department of Parliamentary Services Parliamentary Library Information, analysis and advice for the Parliament The future of organ donation in Australia: moving beyond the “gift of life” *Executive summary*.

Timar, J., Bleil, M., Daly, T., Koomar, S., Hasz, R., & Nathan, H. (2021). Successful strategies to increase organ donation: The gift of life donor program Philadelphia model. *Indian Journal of Thoracic and Cardiovascular Surgery*, *37*(3). https://doi.org/10.1007/s12055-021-01219-9

Tong, A., Chapman, J. R., Wong, G., Josephson, M. A., & Craig, J. C. (2013). Public Awareness and Attitudes to Living Organ Donation. *Transplantation Journal*, *96*(5), 429–437. https://doi.org/10.1097/tp.0b013e31829282ac

Transplant Australia. (2019). *Statistics - Transplant Australia*. Transplant Australia. https://transplant.org.au/statistics/

Tsulfas, G. (2023). Current Challenges and Advances in Organ Donation and Transplantation. In *IntechOpen eBooks*. IntechOpen. https://doi.org/ 10.5772/intechopen.102229

University of Oxford. (1586). *Academic journals*. OUP Academic. https://academic. oup.com

UNOS. (2020). *Theological perspective on organ and tissue donation*. UNOS. https://unos.org/transplant/facts/theological-perspective-on-organ-and-tissue-donation

Van Dijk, G., van Bruchem-Visser, R., & de Beaufort, I. (2018). Organ donation after euthanasia, morally acceptable under strict procedural safeguards. *Clinical Transplantation*, *32*(8), e13294. https://doi.org/10.1111/ctr.13294

Vanholder, R., Domínguez-Gil, B., Busic, M., Cortez-Pinto, H., Craig, J. C., Jager, K. J., Mahillo, B., Stel, V. S., Valentin, M. O., Zoccali, C., &Oniscu, G. C. (2021). Organ donation and transplantation: a multi-stakeholder call to action. *Nature reviews. Nephrology*, *17*(8), 554–568. https://doi.org/10.1038 /s41581-021-00425-3

Varshney, S., Kansra, P., & Garg, A. (2023). Policy Suggestions for Transplantation of Organs in India: Use of Blockchain Technology to Manage Organ Donation. *Indian Journal of Transplantation*, *17*(3), 339. https://doi.org/1 0.4103/ijot.ijot_7_23

Vasanthi, R. (2020, December). Why NOTTO? The national organ and tissue transplant organisation and why it is crucial to regulate organ donation and transplantation in India. In *Transplantation Proceedings* (Vol. 52, No. 10, pp. 2930-2933). Elsevier. https://doi.org/10.1016/j.transproceed.2020.04.1824

Vij, A. (2014, August 6). *World Organ Donation Day 2014: Why India still faces extreme shortage of organ donors? | TheHealthSite.com*. TheHealthSite.

https://www.thehealthsite.com/news/world-organ-donation-day-2014-why-india-still-faces-extreme-shortage-of-organ-donors-192833/

Vinay, K., Beena, N., Sachin, K., & Praveen, S. (2016). Changes in Knowledge and attitude among Medical students towards Organ Donation and Transplantation. *International Journal of Anatomy and Research*, *4*(3.3), 2873–2877. https://doi.org/10.16965/ijar.2016.359

Vincent, B. P., Randhawa, G., & Cook, E. (2022). Barriers towards deceased organ donation among Indians living globally: an integrative systematic review using narrative synthesis. *BMJ Open*, *12*(5), e056094. https://doi.org/10.1136/bmjopen-2021-056094

Walton, P., Pérez-Blanco, A., Beed, S., Glazier, A., Ferreira, D., Kingdon, J., Jordison, K., & Weiss, M. J. (2023). Organ and Tissue Donation Consent Model and Intent to Donate Registries: Recommendations From an International Consensus Forum. *Transplant Direct,9*(5), e1416–e1416. https://doi.org/10.1097/txd.0000000000001416

Wang, X. (2018). Bioartificial Organ Manufacturing Technologies. *Cell Transplantation*, *28*(1), 5–17. https://doi.org/10.1177/0963689718809918

Weimar, W., Bos, M. A., & J. J. V. Busschbach. (2014). *Ethical, Legal, and Psychosocial Aspects of Transplantation* (pp. 310–316). Pabst Science Publishers. www.ciando.com

Westphal, G. A., Garcia, V. D., Souza, R. L. de, Franke, C. A., Vieira, K. D., Birckholz, V. R. Z., Machado, M. C., Almeida, E. R. B. de, Machado, F. O., Sardinha, L. A. da C., Wanzuita, R., Silvado, C. E. S., Costa, G., Braatz, V., Caldeira Filho, M., Furtado, R., Tannous, L. A., Albuquerque, A. G. N. de, Abdala, E., & Gonçalves, A. R. R. (2016). Guidelines for the assessment and acceptance of potential brain-dead organ donors. *Revista Brasileira de TerapiaIntensiva*, *28*(3). 220-255. https://doi.org/10.5935/0103-507x.20160049

World Health Organization. (2009, March 26). *Human organ and tissue transplantation.*https://apps.who.int/gb/ebwha/pdf_files/A62/A62_15-en.pdf

Wu, Y., Elliott, R., Li, L., Yang, T., Bai, Y., & Ma, W. (2018). Cadaveric organ donation in China. *Medicine*, *97*(10), e9951. https://doi.org/10.1097/md.0000000000009951

Xanthopoulos, A., Starling, R. C., Kitai, T., &Triposkiadis, F. (2019). Heart Failure and Liver Disease. *JACC: Heart Failure*, *7*(2), 87–97. https://doi.org/10.1016/j.jchf.2018.10.007

Yadla, M. (2021). Transplantation of human organs act: Act of transplantation – Time to act on the act! - Narrative review. *Indian Journal of Transplantation*, *15*(3), 260. https://doi.org/10.4103/ijot.ijot_19_19

Yousefi, H., Roshani, A., & Nazari, F. (2014). Experiences of the families concerning organ donation of a family member with brain death. *Iranian Journal of Nursing and Midwifery Research*, *19*(3), 323-33. https://pubmed. ncbi.nlm.nih. gov/24949074

Zachary, A. A., &Leffell, M. S. (2016). HLA mismatching strategies for solid organ transplantation–a balancing act. *Frontiers in immunology*, *7*, 575. https://doi.org/10.3389/fimmu.2016.00575

Zamani, Fereshte & Abedi, Hydar. (2014). A comparative study on effective factors on consent to organ donation among families of brain death victims in Isfahan, 2013. *Journal of Emergency Practice and Trauma*. *1(1).* 13-18 https://sid.ir/paper/347717/en

Zirpe, K. G., Suryawanshi, P., Gurav, S., Deshmukh, A., Pote, P., Tungenwar, A., & Malhotra, R. (2020). Increase in Cadaver Organ Donation Rate at a Tertiary Care Hospital: 23 Years of Experience. *Indian Journal of Critical Care Medicine : Peer-Reviewed, Official Publication of Indian Society of Critical Care Medicine*, *24*(9), 804–808. https://doi.org/10.5005/jp-journals-10071-23578

Zubkov, A. Y., &Wijdicks, E. F. (2010). Brain death and organ donation. *Handbook of Neurocritical Care: Second Edition*, 533-539. https://doi.org/10.1007/978-1-4419-6842-5_34

APPENDICES

QUESTIONNAIRE

ANNEXURE I

S. No. | | | |

Dear Sir/ Madam,

I am a research scholar of Mittal School of Business, Lovely Professional University. I am conducting research on "Perception and Awareness towards Organ Donation and Transplantation and Policy Suggestions: A Study of Haryana State"

Kindly spare your valuable time to give your response to the various questions mentioned in the questionnaire. The responses given by you will be kept confidential and your participation will be appreciated.

Research Scholar
Dr. Shyamli Varshney

SECTION I

Section I: Socio-Demographic Profile of the Respondents

S. No	Question	Category	Response
1	Gender	Male Female	
2	Age	18 years -30 years 31 years – 45 years 45 years- 60 years 61 years and above	
3	Educational Qualification	No formal education Primary school Middle school Secondary school Senior secondary school Graduation & above	
4	Employment Status	Salaried Self-employed Daily wager Retired Housewife Student Unemployed	
5	Residence Type	Urban Rural	
6	Religion	Hindu=1 Muslim=2 Sikh=3	
7	Caste	General Other Backward Class Scheduled Tribe Scheduled Caste	
8	Marital Status	Unmarried Married Widowed Divorced	
9	District	Panchkula Mewat Faridabad Gurugram Yamuna Nagar	

SECTION II

Section II (a): Awareness about Organ Donation Process

S. No	Question	Category	Response
1.	Are you aware about Organ donation	Yes No	
2.	Source of Awareness	Newspaper Television Internet Social Media Family Members Hospital Medical College	

Section II (b): Extent of Awareness about Organ Donation Amongst General Public

S. No	Question	Category	Response
1.	Donated Organs are taken from whom	Cadavers Living humans Both None	
2.	Which Organs can be donated during lifetime?	Liver Kidney Heart Eyes Hands	
3.	Which Organs can be donated after death?	Liver Kidney Heart Eyes Hands	

Section II (c): Extent of Awareness on Registration and Legalities of Organ Donation

S. No	Question	Response		
		Yes	No	Don't know
1.	Are you aware of the process of registering as an organ donor?			
2.	Are you aware that consent of parent/spouse/children is required before organ donation and transplantation?			
3.	Do you agree for need of law to govern the organ donation and transplantation?			
4.	Are you aware that there exists a law for organ donation and transplantation in the state at present?			
5.	Are you aware that organ swapping is legal in the country?			
6.	Are you aware of the nearest organ transplant centre?			

Section II (d) : Extent of Awareness on Shortage of Organs for Donation

S. No	Question	Response		
		Yes	No	Don't know
1.	Aware that many people lose their lives due to the shortage of organs			
2.	Aware that one donor can donate to multiple recipients			
3.	Aware that organ donation can't be done if the donor is HIV, Hepatitis B or C positive			
4.	Aware that organ donation can't be done if donor has active cancer			

Section III (b): Extent of Organ Donation Status in Family

S. No	Question	Yes	No
1.	Is anyone from your family registered for organ donation?		
2.	Is anyone from your family suffering from organ failure?		
3.	Has anyone in your family done Organ donation?		
4.	Do you intend to register to pledge for organ donation?		
5	Are you aware that there is shortage of organs for transplantation?		

Section III (c): To Test Impact of Video Assisted Teaching (VAT) on Knowledge and Attitude about Organ Donation

S. No	Question	Response		
		Yes	No	Don't know
1.	If an approach is made to donate organ I will donate.			
2.	If an approach is made to donate my family member's organ, he/she will donate.			
3.	If an approach is made to my family members for donating my organ they will.			
4.	It is valuable to discuss organ donation with a dead patient's family members.			
5.	My family will be willing for my organ donation after the declaring brain death.			
6.	Organ donation is desirable when a patient is brain dead.			
7.	If the members of a bereaved family would like to donate their loved one's organ I'd like to actually refer them to transplant team.			

8.	People should come forward for organ donation voluntarily.			
9.	Medical insurance should be expanded to include organ transplant surgery.			
10.	I would like to keep my body intact for life after death.			
11.	Certain religion does not agree with organ donation or transplantation.			
12.	I have a cultural belief that my body should be kept intact after death.			
13.	I have fear that my body will be disfigured if I donate my organ			
14.	I have a fear of surgical procedures.			
15.	I believe that selling of organ is not a crime.			
16.	I would not like to donate organ because of trafficking of organs			
17.	There are many scams in organ donation			
18.	Organ donors should be paid through money/ insurance			
19.	Selling organs should be made legalized.			
20.	There should be incentives (other than money) towards donor/ donor's family for organ donation			

SECTION IV

Section IV: Perception about Organ Donation and Transplantation

Sr. No.	Questions	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
1.	Organ donation and transplantation is safe and successful process for both donor and the beneficiary					
2.	Organ donation and transplantation should be promoted in the state.					
3.	Religion opposes organ donation and transplantation.					
4.	It is important for a person to have all of the body parts when they are deceased.					
5.	A traditional funeral cannot be held for a deceased donor.					
6	I will be born deformed, if I donate my organs in this life.					
7	If my life is in danger, I would accept an organ transplant.					
8	Health risks are associated with organ donation.					
9	I am willing to donate my organs.					
10	It is important to discuss the willingness to donate organs with the family members.					
11	I will donate my organ to my family member / relatives.					
12	I will donate my organ to anyone in need.					
13	I will support my kin if he/she decides to be an organ donor.					
14	I will convince or promote organ donation and transplantation with my friends / relatives.					
15	Organs can be bought /sold in black market					

ANNEXURE II

S. No. | | | |

Dear Sir/ Madam,

I am a research scholar of Mittal School of Business, Lovely Professional University.

I am conducting research on "Perception and Awareness towards Organ Donation and Transplantation and Policy Suggestions: A Study of Haryana State"

Kindly spare your valuable time to give your response to the various questions mentioned in the questionnaire. The responses given by you will be kept confidential and your participation will be appreciated.

Research Scholar
Dr. Shyamli Varshney

SECTION I

Section I (a): Stakeholders Opinion on Reasons for Shortage of Organs for Transplantation and Factors Affecting Consent for Organ Donation

S. No	Question	Category	Response
1	In which capacity are you are associated with organ donation	Government official Hospital administrator Transplant Team Member Patient (Translant recipient or waiting for organ transplant)	
2	In your opinion what are the reasons for people not coming forward for organ donation	Ethics Religion Race Consent of all family members	
3	In your opinion what are the reasons for short supply of organs for transplantation by means of organ donation	Lack of Awareness Lack of registration Social Taboos	

Section I (b): Stakeholders Opinion on Demand Supply Gap of Organs

S.No	Question	Strongly Disagree (1)	Disagree (2)	Moderate (3)	Agree (4)	Strongly Agree (5)
1	There is a demand supply gap in organ donation					
2	Demand supply gap can be reduced by ease of rule					
3	There is adequate cadaveric harvesting of organs in our country					
4	Organ harvestingfromunclaimed cadaversshould belegalizedafterrequisite testing					
5	Monetary incentives should be given toorgan donors					

SECTION VI

Section VI(a): Patients Survey on Various Concerns Regarding Organ Donation (Only for Respondents, who have received Organ transplant or are awaiting Transplant)

S. No	Question	Category	Response
1.	What is your average monthly income	< ₹20000/- =1 ₹20000-₹50000 =2 ₹50000- ₹1,00,000=3 >₹1,00,000=4	
2.	What is average monthly income of your whole family?	< ₹20000/- =1 ₹ 20000-₹ 50000 =2 ₹50000- ₹1,00,000=3 >₹1,00,000=4	
3	How much money have you borrowed for your treatment?	Nil Upto ₹1 lakh ₹1-₹5 lakh >₹5 lakh	
4.	What was/is the source of expenditure for your treatment and transplant ?	Own savings Sale of Ornament/Land Borrowing (Loan) Charity from friends /Relatives Charity from Govt /NGO	
5.	How long you had to wait / have been waiting for organ transplant since diagnosis ?	0-6 months 6 months – 1 year > 1 years	
6.	You have been advised for transplant of which organ	Liver Kidney Cornea Heart Lung	
7.	How many times you have been admitted in hospital for your current illness	< 5 times 5-10 times >10 times	
8.	What kind of hospital you got admitted for treatment?	Private Private (Insurance Empanelled) Govt. Hospital	

9.	In your opinion, why there are less number of transplant centers in Haryana?	Lack of resources Lack of govt support Not profitable Difficult to adhere to standards	
10.	What are the ways to increase organ supply for transplant ?	Increase awareness Relaxation in rules Give incentives to Donors Govt. should support expenses on transplant treatment Efforts to break various myths =5	
11.	What kind of govt. support is required to reduce demand supply gap of organs ?	Increase awareness Give incentives to donors Govt. should reduce cost of transplant treatment Govt should provide free medicines after transplant Govt should ensure better availability of doctors	
12.	Do you expect an increase in life span after organ transplant?	Yes No Cant Say	
13.	Do you expect to carry out your pending responsibilities after transplant?	Yes No Cant Say	
14.	On a scale of 1- 10, (1 being low & 10 being good), how will you rate your quality of life after transplant		
15.	On a scale of 1- 10, (1 being low & 10 being good), how will you rate your quality of life before the transplant		

Section VI (b): Stakeholders' Survey on Various Concerns Regarding Organ Donation
(Only for Government Officials, Hospital Administrators and Transplant Team Members)

S. No	Question	Category	Response
1.	In your opinion, why there are less number of transplant centers in Haryana?	Lack of resources Lack of Govt support Not Profitable Difficult to adhere to standards	
2.	What are the ways to increase organ supply for transplant ?	Increase awareness Relaxation in rules Give incentives to Donors Govt. Should support expenses on transplant treatment Efforts to break various myths	
3.	What kind of govt. support is required to reduce demand supply gap of organs ?	Increase awareness Give incentives to Donors Govt. should reduce cost of transplant treatment Govt should provide free medicines after Transplant Govt should ensure better availability of Doctors	

Section VI(b): Stakeholders' Concerns and Suggestions Regarding IEC Activities to Increase Organ Donation

(Only for Government Officials, Hospital Administrators and Transplant Team)

S.No	Question	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
1.	Intense IEC activities needed for promotion of organ donation activities in state					
2.	IEC activities will improve organ donation in society					
3.	Government participation in promoting organ donation is adequate					
4.	The THOA rules need further amendments					
5.	Government should supply medications after organ donation					
6.	Hospitals are adequately equipped for organ donation					
7.	Fraudulent practices are prevalent in organ donation					

PUBLICATIONS

Original Article

Effect of Video Assisted Teaching (VAT) on Awareness, Knowledge and Attitude towards Organ Donation and Transplantation in a North Indian State

Shyamli Varshney, Parikshit Sanyal[1], Anurag Garg[2*], Pooja Kansra[3]

ASMO, O/o Director General Health Services, [1]Department of Pathology, Command Hospital, [2]Department of Anaesthesiology, Command Hospital, Chandimandir, Haryana, [3]Department of Economis, Mittal School of Business, Lovely Professional University, Phagwara, Punjab, India

Abstract

Introduction: Video-assisted teaching (VAT) is an effective means of intervention in motivating toward a particular medico-social goal. We evaluated the efficacy of a VAT intervention in caregivers of patients at a polyclinic in Haryana, India. **Objectives:** To asses efficacy of VAT in changing attitude towards organ donation. **Method:** One hundred and fifty participants each from rural and urban backgrounds were chosen randomly. A standard set of questions consisting of 9 positively framed and 11 negatively framed questions was prepared. The participants were subjected to an initial evaluation with the questionnaire, followed by VAT, after which the same questionnaire was repeated. **Results:** An increase in favorable responses was noted post-VAT, both in urban and rural populations. In particular, the favorable response to negatively framed questions improved significantly after the VAT, as seen after a Z-test for paired proportions before and after VAT. **Conclusion:** The findings of the present study suggest that VAT might be a useful adjunct in motivational sessions for organ donation, especially in removing negative prejudice toward organ donation.

Keywords: Attitude, awareness, knowledge, organ transplant, video-assisted teaching

Introduction

More than 15,000 solid organ transplants were carried out in India in the year 2023,[1] which is still below 1 donor per million population.[2] Knowledge, attitude, and practice remain the principal barrier to transplant programs across India.[3,4] Although the awareness of organ transplant as a viable treatment strategy has been on the rise, there is still an alarming lack of knowledge regarding brain death, both in urban and rural population.[4,5] For this reason, majority of organ donations in India are still directed donations toward a family member, and deceased donors are only a small fraction of all donations (1619 out of 12,259 in 2021[6]). Various socioeconomic factors, such as age, gender, religion, type of family, and income, have been found to be associated with difference in transplant awareness.[3]

The importance of effective communication in transplant awareness programs is well established.[7] The efficacy of video tutorials on attitude toward transplantation has been assessed by several studies in the past; the study by Molmenti *et al.* reported a significant gain in transplant intent (odds ratio 1.70) following video tutorials in New York city residents.[8] Similar findings were reported by Selvanathan *et al.* on high school students.[9] However, no such study is reported on the complex Indian society, where apart from education, the religious and cultural outlook also shape the attitude toward transplantation.

The objective of the present study was to assess the knowledge and attitude among urban people of Haryana and rural people of Haryana (RPH) before and after video-assisted teaching (VAT) as well as to find out the association of knowledge and attitude among urban people and RPH regarding organ donation with selected demographic variable.

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Brief Communication

Policy Suggestions for Transplantation of Organs in India: Use of Blockchain Technology to Manage Organ Donation

Shyamli Varshney, Pooja Kansra[1], Anurag Garg[2]*

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Abstract

One of the most honorable acts of humanity is the donation of an organ or organs to save the lives of patients with severe diseases that necessitate organ replacement. Organs can be donated by people who are alive as well as dead. India has seen a noteworthy upsurge in organ donation following the death of the brain in recent years. There are various legal, clinical, ethical, and technical constraints implicated in the current organ donation and transplantation systems in terms of registering recipients, matching donors with recipients, removing organs, delivering organs, and transplanting organs. An end-to-end system is essential to ensure an impartial and competent organ donation and transplantation process. Use of blockchain technology in order to better manage organ donation and allocation can be one of the most efficient ways to remedy this situation. The article proposes blockchain-based solution to ensure complete decentralization, security, traceability, privacy, and trustworthiness in the donation and transplantation of organs. By performing confidentiality, safety, and privacy analyses and linking our projected resolution with the prevailing one, we evaluate the performance of the suggested solution. Adopting the above-mentioned measures will lead to the creation of block chain platforms or hyper ledger fabric frameworks, streamlining organ donation and allocation processes, which will benefit India as it moves toward the digital future in health care.

Keywords: Blockchain technology, organ donation, transplant, Transplantation of Human Organ Act

Introduction

One of the most honorable acts of humanity is the donation of an organ or organs to save the lives of patients with severe diseases that necessitate organ replacement. Organs can be donated by people who are alive and well, and organs which will not negatively affect their health, such as kidney, part of the liver, or bone marrow. Apart from this, organs can also be donated after an individual's death, whether cardiac death or brain death.

Until the enforcement of, the Transplantation of Human Organ Act (THOA) in 1994, India was the most common source of organ trade in the world. Although there has been a gradual decline with the enactment of the legislation, there is still a looming threat from the illegal underground market. There is a need for a fundamental change in the way that the Indian organ network is operated to ensure its sustainability.

In order to better manage organ donation and allocation, using blockchain technology can be one of the most efficient ways to remedy this situation.

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Figure 1 shows the procedure for the system of organ donation.

Literature Survey

Immediately finding a recipient and securely transferring the organ after it has become available is the utmost critical aspect of organ donation. It was possible to implement machine-to-machine communication in which all of these devices communicated lacking any human intervention, resulting in a faster response time.

As part of this service, users are provided with conveniences as well as transactional services. It is already being used in some

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Original Article

Awareness, Attitude, and Perception toward Organ Donation in General Population of Haryana, India

Shyamli Varshney, Pooja Kansra[1], Aditya Perumallapalli[2], Anurag Garg[2]*

General Health Services, Panchkula, Haryana, [1]Mittal School of Business, Lovely Professional University, Phagwara, Punjab, [2]Department of Anaesthesia, Army Hospital (Research and Referral), New Delhi, India

Abstract

Introduction: Organ donation is defined as an act of giving one or more organs, without compensation, for transplantation to another person the shortage of organ donation remains one of the biggest barriers globally to the organ transplantation process. The state of Haryana has in the recent past grown leaps ahead in terms of medical tourism, but according to recent data by the MOHAN Foundation, Haryana is among the poorest performers in organ donation, more specifically cadaveric organ donation. This study aimed to assess the attitudes and awareness of organ donation in the general population of Haryana and to find out the barrier to the low organ donation numbers in the state. **Materials and Methods:** This study was a community-based cross-sectional study carried out among the general population of Haryana. A questionnaire was administered to 500 randomly selected people above the age of 18 in the chosen population. The data were coded and analyzed using Microsoft Excel and SPSS software. **Results:** A large number, 40.6% (203/500), of the participants in the survey were unaware of the term "organ donation." Only 24.5% (72/293) of participants were able to correctly identify that "organ donation" was possible from both cadavers and living human beings. 98.6% (289/293) of the participants of the survey were unaware of any legislation regarding organ donation. A dismal 27.3% (80/293) of participants were willing to donate their organs after death. Of those unwilling, 60.1% (128/213) reported that they did not want to donate because of their religion. Of those willing to donate, 28.7% (23/80) reported that they would only donate to a person of the same religion. **Conclusion:** The overall levels of awareness about the organ donation and acute shortage of organ donors in Haryana as well as awareness about the prevalent low rates themselves remain low. There are various religious biases leading to negative attitude toward organ donation.

Keywords: Attitudes, awareness, organ donation, perception, transplantation

Introduction

Organ donation is defined as an act of giving one or more organs, without compensation, for transplantation to another person.[1] It is the most preferred treatment for many of end-stage organ diseases as it offers a better quality of life and has better long-term survival benefits.[2] It can help give a new lease of life to many and yet it is a complex multifactorial issue. Organ donation can widely be divided into live organ donation: when the organ is retrieved from a healthy living person, who is a near relative, and deceased organ donation: when the organ is retrieved from a person declared brain stem dead. In India, the rules for organ donation were laid down under the Transplantation of Human Organs Act, enacted in 1994. Under this act, donation of organs by deceased persons was made legal; and the transplantation between unrelated live individuals was made illegal.[3]

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The shortage of organ donation remains one of the biggest barriers globally to the organ transplantation process, but India lags far behind the western world. Despite the 1.5 lakh annual accident victims in India who are diagnosed as brain stem dead, the organ donation rate is a dismal 0.86 per million population. The total number of deceased donors in India in 2020 was only 1105.[4]

The state of Haryana has in the recent past grown leaps ahead in terms of medical tourism, but according to recent data by the

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Original Article

Financial Implications of Organ Transplant and Advantages of Covering it in Ayushman Bharat

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Abstract

Introduction: Organ transplantation imposes a growing financial burden on patients who require medical care, which was not accounted for in the Ayushman Bharat Pradhan Mantri Jan Arogya Yojna (AB—PMJAY) till 2024. Fewer chronic organ failure patients opted for Organ Transplant in view of financial constraints. **Methods:** A qualitative study employing focused group discussions was carried out across 14 transplant hospitals in Haryana, targeting individuals with experience in organ transplantation. Additionally, in-depth interviews were conducted to evaluate the costs and benefits of the procedure, along with the complexities and challenges associated with it. **Results:** Nearly 50% of patients had been battling their condition for over six months while awaiting a transplant. Additionally, post-organ transplant, 70% of recipients reported their quality of life as equal to or above average. Our study also found that 40% of patients received treatment in public hospitals, whereas 60% relied on borrowed finances to cover their medical expenses. **Conclusion:** It is essential for the government to introduce programs that strengthen healthcare, extend life expectancy, and enable beneficiaries to fulfill their responsibilities effectively. Recently, the organ transplant package has been incorporated into the Ayushman Bharat Scheme. With proper execution, this initiative can help individuals manage their medical expenses and alleviate financial burdens.

Keywords: Ayushman Bharat, below poverty line (bpl), financial burden, organ transplantation, healthcare accessibility, medical expenses

Introduction

In our country, the majority of patients requiring organ transplants are unable to afford the substantial expenses associated with the procedure.[1] Transplant costs are primarily borne by patients, many of whom have limited insurance coverage.[2,3] According to the National Health Accounts Report (2019–2020), Out-of-pocket-expenditure (OOPE) account for 47.1% of India's total healthcare spending, significantly surpassing the global average of 18.12%. This financial burden disproportionately affects individuals in the lowest wealth bracket, as highlighted by National Sample Survey Office data from the 2017 to 2018 rounds.

To address this, India launched the Ayushman Bharat program in 2018, aiming to provide universal health coverage to over 10.74 crore underprivileged families.[4,5] The scheme offers insurance coverage of up to ₹5 lakh per family per year for secondary and tertiary care hospitalization. Designed for portability, cashless transactions, and paperless services, Ayushman Bharat ensures seamless healthcare access through a network of impaneled hospitals. A significant enhancement is its coverage of transplant costs, directly reducing financial strain and potentially preventing families from falling into economic hardship.[5-7]

In addition, the Government of India introduced two major health initiatives to tackle the issue of high OOPE among low-income and marginalized populations:

1. Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana
2. Ayushman Bharat Digital Mission.

Despite these efforts, OOPE continues to account for nearly 70% of healthcare spending in India, leaving a large

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Original Article

Cost–benefit Analysis of Introducing Organ Transplant in the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana

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Abstract

Introduction: Solid organ transplantation causes an escalating financial burden of medical care, which was not included in the AyushmanBharat – Pradhan Mantri Jan Arogya Yojna (AB-PMJAY), leading to a lesser number of patients opting for organ transplant, especially from lower socioeconomic strata (below poverty line) population. **Methods:** A qualitative study based on focused group discussion was conducted across 14 transplant hospitals in Haryana, focusing on individuals with exposure to organ transplantation. In-depth interviews were conducted to assess the costs and benefits of organ transplantation, along with the associated challenges and intricacies. The study provided a deeper and more nuanced understanding of the implementation dynamics and cost factors that may influence the success of the transplant process. **Results:** Postorgan transplant, approximately 75% of recipients rated their quality of life as equal to or above average. **Discussion:** It is imperative for the government to launch initiatives that provide better medical care, enhance longevity, and enable recipients to fulfill their responsibilities effectively. The organ transplant package is a recent addition to the ambit of the AB scheme. If executed properly, this initiative has the potential to assist individuals in handling their healthcare costs and reduce their financial strain. **Conclusion:** The inclusion of Organ Transplantation in AyushmanBharat – Pradhan Mantri Jan Arogya Yojna (AB-PMJAY)is a landmark decision in India's quest for health equity ensuring that lifesaving treatments are not just a privilege for the affluent but a right for all citizens.

Keywords: Ayushman Bharat, below poverty line, cost–benefit analysis, organ transplantation, out-of-pocket expenditure

Introduction

The world is becoming more technologically advanced in every field, including health and medicine. People are becoming aware of different diseases and their treatments,[1] thereby increasing the longevity and life expectancy. Treatment for many nontreatable conditions has now become a realistic possibility. Solid organ transplantation has advanced over the past decade to the point at which it is now a realistic form of treatment for the irreversible failure of many vital organs. While organ transplantation is becoming increasingly successful, the cost of the procedures is still very high.[2] Solid organ transplant activities are largely driven by the private sector in the country. Majority of patients requiring transplant cannot pay Out Of Pocket Expenditure(OOPE) for long-term medical costs of transplant.[3]

Launched in 2018, Ayushman Bharat (AB) aims to provide universal health coverage. It targets over 10.74 crore underprivileged families, offering them an insurance cover of up to Rs. 5 lakh per family per year for secondary and tertiary care hospitalization. The scheme's design focuses on portability and cashless and paperless services, making healthcare accessible across a network of empaneled hospitals.[4] The integration of organ transplantation into

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TRANSPLANTATION OF ORGANS AND THE USE OF BLOCK-CHAIN TECHNOLOGY TO MANAGE ORGAN DONATION

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Abstract

There are various legal, clinical, ethical, and technical constraints implicated in the current organ donation and transplantation systems in terms of registering recipients, matching donors with recipients, removing organs, delivering organs, and transplanting organs. An end-to-end system is essential to ensure a impartial and competent organ donation and transplantation process. The paper proposes a private Ethereum blockchain-based solution to ensure complete decentralization, security, traceability, privacy, and trustworthiness in the donation and transplantation of organs. By performing confidentiality, safety, and privacy analyses and linking our projected resolution with the prevailing one, we evaluate the performance of the suggested solution.

Introduction

India has seen a noteworthy upsurge in organ donation following the death of the brain in recent years. The offering of organs is a culpable offence in the event of brain death. After cerebrum death was acknowledged, it became possible to begin kidney transplants, as well as heart, liver, and lung transplants. One of the most honorable acts of humanity is the donation of an organ or organs in order to save the lives of patients with true diseases that necessitate organ replacement. The moment the body gets infested with disease, urgent organs, such as the kidney, the lungs, the heart, the pancreas, the liver, and the digestive tract, turn out to be non-functional, thereby making life despicable, and generally leading to the demise of the individual. It is possible for anyone to become infected. Life can be saved by making an organ donation. In the 1950s, organ transplantation became a reality and saved thousands of lives, as well as improved the quality of life for individuals suffering from long-term illnesses. According to the circumstances of the giver, they may be living, dead, or, in the case of certain nations, brain-dead. Donations must be made by people who are alive and well, and organs which will not negatively distress their health are accepted, like kidneys, livers, lungs, and bone marrow. It is not necessary to have a maximum or minimum age limit to donate an organ,

विषयः– Regarding permission for my PHD Thesis topic "Perception and Awareness towards Organ Donation and Transplantation and Policy suggestion: A study of Haryana State"

क्या अधीक्षक पी0एम0 शाखा उपरोक्त विषय की ओर ध्यान देने की कृपा करेगें ?

2 उन्हे सूचित किया जाता है कि सरकार के पत्र कमांक 13/21/2018–2एच. बी.। दिनांक 28.08.2018 द्वारा डा0 श्यामली वारसने, चिकित्सा अधिकारी कार्यालय महानिदेशक स्वास्थ्य सेवाएं, हरियाणा को Lovely Professional University, Jalandhar से पार्ट टाईम पीएचडी डिग्री करने की अनुमति प्रदान की है। उन्हे डा0 श्यामली वारसने, चिकित्सा अधिकारी के प्रतिवेदन दिनांक 23.07.2020 की प्रति भेजते हुए लिखा जाता है कि इस अधिकारी को उसकी पीएचडी की थीसिस पूरी करने के लिए उनकी शाखा में उपलब्ध विषयवर्णित मामले से सबंधित डाटा या मामले से सबंधित पंजीकृत सस्थानों से जो भी डाटा चाहिए होगा, उपलब्ध करवाने की कृपा करें।

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इसकी एक प्रति डा0 श्यामली वारसने, चिकित्सा अधिकारी कार्यालय महानिदेशक स्वास्थ्य सेवाएं, हरियाणा को उसके आवेदन पत्र दिनांक 23.07.2020 के संदर्भ में सूचनार्थ एंव आवश्यक कार्यवाही हेतु भेजी जाती है।

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