



Myths about Organ Donation Among Community Populations from Selected Areas of Chandigarh

Pompa Mukherjee¹ & Dr. Abdul Latif²

¹*Ph.D. Research Scholar, Department of Nursing,
Shri Jagdishprasad Jhabarmal Tibrewala University, Rajasthan.*

²*Ph.D. Research Guide, Department of Nursing,
Shri Jagdishprasad Jhabarmal Tibrewala University, Rajasthan.*

Corresponding Author: Pompa Mukherjee

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Abstract:

Transplantation is the treatment of choice for organ failure; nevertheless, there is a severe shortage of organs on a global scale. We conducted a comprehensive review of qualitative research that surveyed community members' perspectives on the donation of solid organs from both living and deceased donors. This was done so that we could better guide efforts to increase the number of organs that are donated. This overview of qualitative research illustrates how seemingly intractable components such as culture and religion are frequently related to more complex issues such as distrust of the medical system, misunderstandings about religious viewpoints, and ignorance about the process for organ donation. The use of strategies that are culturally appropriate to engage minority groups, in particular by way of religious or cultural leaders, and the provision of additional, comprehensive information on the donation process and the positive impacts of doing so are two potential treatments that should be taken into account.

Keywords: Myths, Organ Donation, Community Populations and Chandigarh.

Introduction:

Even though there is a lot of enthusiasm for organ donation, there simply aren't enough healthy organs to go around. There are now close to six thousand people on the waiting list for organ transplants in the United Kingdom. Despite this, there were not enough organs to go around, and as a result, 411 people passed away in 2017 while they were on the organ donation waiting list. Donating organs has the

potential to save many lives; however, in order for this to happen, it is imperative that researchers investigate the positives and negatives of the factors that impact the decisions and actions of organ donors. In addition to the modification of national legislation, a great deal of attention has been paid, in the course of a number of studies, to the question of how to boost organ donation and the number of persons who sign up to be donors. For example,

opt-out authorization systems. Recent in-depth study was conducted with the intention of determining whether or not the possibility of future regret may be utilised as a tool to boost the number of people who register as organ donors. The scientists found that a short expected regret change resulted in a reduction in the number of confirmed organ donor registrations, which was contrary to their predictions as well as the findings of the test research and other data (1).

By conducting a survey with the control group, we were also able to study the psychological barriers to organ donation, such as a lack of confidence in the healthcare system. Education and the general mentality of the population are also recognised to be key variables that influence organ donation. Even though research has shown that the majority of people don't know much about organ donation and have incorrect assumptions, such as not knowing what brain death is, the general public claims to be aware of the organ donor shortage. This is despite the fact that the general population claims to be aware of the organ donor shortage. Because of this, there is a greater potential for erroneous information and misunderstanding, which is a significant barrier to participation. Misconceptions and mistakes are made more likely when

organ donation is portrayed in a negative light. One example of this is the sensationalist media's distortion of organ donation in popular entertainment television shows like Grey's Anatomy. People tend to accept urban tales and myths rather than give serious thought to the possibility of donating an organ since all of these factors work together to reduce the number of possible donors (2).

The following are some of the objectives of the study: The following are the four main objectives of this research: 1) to determine the extent to which inhabitants of Chandigarh are aware of organ donation; 2) to locate the obstacles that prohibit individuals from giving organs; 3) to find out how residents of Chandigarh feel about misconceptions around organ donation; and 4) to determine how residents of Chandigarh feel about donating organs in general.

Organ Donation:

Giving one's organs for transplantation is known as "organ donation," and it may take place while the donor is still alive or after death with the approval of the donor's next of kin. In organ donation, a person pledges to have part or all of their organs removed after death for the purpose of transplantation in order to help terminally ill people live longer. In light

of current developments in transplantation, organs may be donated by people of diverse ages and health statuses. Donations of organs have been made from people as old as 80 years old. However, organs and tissues that meet donation criteria are only taken from donors who have undergone a rigorous medical evaluation. Donating an organ is a legal process that may be performed on a living person or after death with the approval of the donor and/or the donor's family (Fig. a). Liver, intestinal tract, pancreas, bone, bone marrow, and kidney transplants are commonplace (3, 4).

Types of Donation:

There are two types of organ donation (Fig. b) are as follow:

Deceased Donation:

Donations made by dead people may take several forms, including those of organs, corneas, and tissues. Deceased organ donation refers to the practise of giving an organ or a piece of an organ from a donor who has passed away to another person in order to perform a transplant. Donated corneas and tissues have the potential to not only restore eyesight but also save and recover lives. At the moment of a person's passing, organs or organ fragments may be harvested for donation in the very uncommon case that a live donation cannot be performed. This is what people refer to

as a "spoiled present." The majority of transplants use organs from donors who have passed away. For a person to be eligible to receive an expired gift after being diagnosed as having brain death, they need to be hospitalised and placed on a ventilator. Keep in mind that a fatal gift may only be given after all other attempts to preserve the patient's life have failed and after it has been determined that the patient is no longer mentally capable of living. The imbalance between the high demand for organs and the low supply is the most significant factor that gives rise to worry. It is a worry that there is a global shortage of organs, and organ donation after death is the most effective and long-term solution to this problem (5-7).

Living Donation:

Donating an organ while the recipient is still alive not only saves the life of the recipient but also the life of the person waiting for an organ, and it also provides potential transplant patients with an additional option. Patients in need of a kidney or liver transplant who are also candidates for a transplant from a living donor have a significantly increased chance of obtaining a healthy organ in a timely manner, often in less than a year. Patients who are not candidates for a transplant from a living donor have a much lower chance of receiving a

healthy organ. A person is considered to be a living donor if they provide their free and informed consent to the removal of an organ, tissue, or other part of their body while they are still alive (8). Living organ donation is beneficial not only to the recipient but also to the individual who is on the waiting list for an organ from a deceased donor. The complete absence of deceased organ donors was the impetus behind the development of the live organ donation and transplantation procedures. Giving a functioning organ to a person who is in need of one might potentially save their life. A formal registration as a donor is required in order to donate a live organ. In addition to this, the donor must get individualised care and maintain open communication channels with the transplant clinic (9).

Organs that can be Donated:

Heart:

The heart is a muscular hollow organ that is responsible for pumping blood throughout the whole body. If the heart is unable to adequately pump blood or carry out its other duties, this will result in changes to the functioning of the whole body. It's possible that some individuals may need to have their hearts replaced in order to continue living because they've suffered from heart failure, a congenital heart defect, or an infection caused by a virus. When

all previous attempts to save the patient's life via medical treatment have been unsuccessful, a heart transplant may be performed. Temporarily replacing a patient's natural heart with an artificial one may be an option while waiting for a donor heart to become available. Patients may still have heart valve replacements even if a complete heart transplant is not a viable option (7-9).

Lung:

In irreversible illnesses such as cystic fibrosis or emphysema, in which the lungs are unable to provide the body with an adequate amount of oxygen, organ transplantation is required. It is possible to transplant one lung or both lungs into a single recipient, as well as perform a transplant of only one lung (Fig. c). A significant number of people are of the opinion that smoking will prevent lung donation. Regardless of what happens, this can't be right. In intensive care, there are procedures that should be able to determine how effectively the lungs function, and the results of these procedures determine whether or not the lungs are suitable for donation (8-10).

Kidney:

When it comes to filtering out harmful substances from the bloodstream, the kidneys are a very necessary organ. The kidneys are responsible for filtering out all of the

waste products of metabolism that are floating about in the blood, which is subsequently expelled from the body in the form of urine (Fig. d). When one or both kidneys are damaged or seriously diseased, and when they are unable to filter the blood adequately, debris starts to gather in the patient's body and may cause significant injury to the body, the most frequent treatment choices are kidney donation and transplantation (10). Donating a kidney or receiving a transplanted kidney is a surgical procedure that replaces a kidney that has been destroyed or is badly sick. Dialysis is an alternate therapy option that is available to patients who suffer from chronic renal failure. Dialysis removes waste products from the circulation when the kidneys are unable to do so on their own (11).

Liver:

The liver is the largest gland in the body and is responsible for a variety of complex metabolic activities, including assisting the body in the elimination of toxic waste and regulating the coagulation of blood. Customers who suffer from irregularities of the digestive system and metabolism, liver cirrhosis, B and C hepatitis, viral infections, as well as congenital liver and biliary problems. Transplantation is required in order to treat the aforementioned conditions effectively. It is possible to cut the single

liver into two portions and offer one to each of two worthy people who are suffering from liver damage, either in part or in its whole (12).

Pancreas:

Islet cells, which may be found in the pancreas, are responsible for the production of insulin, which helps keep the glucose levels in the body under control. Even with insulin infusions, persons with type 1 diabetes have an extremely difficult time keeping their blood sugar levels under control since their pancreas generates nearly no insulin. Patients diagnosed with type 1 diabetes, which may also lead to renal failure, make up the vast majority of recipients for pancreatic transplants done in modern medicine. As a consequence of this, the kidney from the same donor as the pancreas is often transplanted at the same time (13).

Organ Donation in India:

Each year, a growing number of patients lose their lives while on the transplant waiting list. It is estimated that there are more persons in need of an organ transplant than there are organs now available for donation. This void becomes wider since there are not enough donated organs to meet the requirements of the situation. As the population as a whole ages, and more people experience organ failure, it is projected that there will be an increased need for organ transplants. Even though

automobile collisions are the greatest cause of mortality in India, only a tiny percentage of persons who pass away in these types of occurrences are qualified to have their organs donated after they die. This is due to the fact that organs need to be harvested and transplanted as quickly as humanly feasible following the death of the donor. Patients who have suffered a stroke, severe head trauma due to an accident, or a haemorrhage and have been declared brain dead in the intensive care unit and are being kept alive by a ventilator often have their organs removed. This is done so that the patient may continue to be kept alive by the ventilator. Even though there is a scarcity of organs all across the globe, Asia is still very far behind other areas in this regard. India lags behind other nations, including those in Asia, by a substantial margin. In this area, there is an abundant supply of organs that may be donated to those in need. When someone dies suddenly or as the result of an accident, they nearly always meet the criteria necessary to be considered prospective donors. However, many patients are still having problems locating a suitable donor (14-16).

Government Organisations for Organ Donation:

National Organ and Tissue Transplant Organisation (NOTTO) has

been established in New Delhi by the Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India. These are its two divisions:

National Human Organ and Tissue Removal and Storage Network:

The 2011 THO (Amendment) Act led to the establishment of this. The National Network Division of NOTTO serves as the principal hub for networking and organising organ distribution in India. It houses the nation's official register for tissue and organ donation and transplantation. In order to facilitate transplantation in the safest and quickest manner, NOTTO has established policy guidelines and procedures at the national level for various transplant-related activities (15).

National Biomaterial Centre (National Tissue Bank):

Registration of tissue banks and tissue donation were both included in the THO (Amendment) Act of 2011. To fulfil the growing need for tissue transplantation, a national level tissue bank must be established. This comprises tasks including tissue distribution, storage, and purchase. The main reason for establishing the centre was to satisfy the demand for different tissues and to provide quality control.

Regional Organ and Tissue Transplantation Organization (ROTTTO):

It coordinates the transplant related activities within the specific regions.

State Organ and Tissue Transplant Organization (SOTTO):

The organisation coordinates all transplant related activities within the state.

Rules Governing Organ Donation and Transplantation in India:

In order to control organ donation and transplantation procedures, India approved the Transplantation of Human Organ Act (THO) in 1994.

NGOs involved in Organ Donation in India:**Gift your Organ:**

A registered charity trust, Gift Your Organ Foundation was established in February 2011. The members of the foundation thought it was their duty to solve the issue of the organ scarcity by encouraging organ donation and educating the public. The gift of an organ should be given to those who suffer from end-stage organ failure. This organisation supports life. Our lives, your lives, and once we are gone, someone else's lives. Life must continue (14, 15).

Narmada Kidney Foundation:

This was established in 1993. It is a non-profit organisation that assists those who have renal illness. "Life shared, life lived" serves as the foundation's guiding concept, and they believe that information is power, and that sharing knowledge will help them achieve their goal.

Amit Gupta Foundation:

This foundation was created in 2009 and is a trust that is registered under section 80G. This foundation was established in honour of Amit Gupta, who died in 2008 as a consequence of several complications after a kidney transplant and renal failure. His wife Anasuya saw first-hand the desperation, anguish, and lack of information experienced by families dealing with end-stage organ failure over the 15 years he was receiving therapy. She also saw the medical professionals and hospitals' utter powerlessness. The organisation also counsels, directs, and provides advice on nutrition, medicine, and associated expenditures to patients and families with end-stage organ failure. The majority of those in need of this guidance come from underprivileged or illiterate backgrounds, thus it is important to point them in the right direction. The confidence they get from this education often enables them to confront issues and come up with answers. Hospitals

are where this work is mainly done (16).

Shatayu:

The term "Shatayu" originates from a phrase found in ancient Indian scriptures referred to as "Shatayu Bhavah," which may be translated as "Live a hundred years." There is an organisation known as "Shatayu," and it is not for profit. This community-wide endeavour, which is supported by Ganesh Housing Corporation Limited, was conceived by and is being led by the Govindbhai C. Patel Foundation. The primary objective of Shatayu is to educate people about the importance of organ donation and, as a consequence, alter their worldviews (16, 17).

Apex Kidney Foundation:

The year 2008 marked the beginning of operations for this organisation, which was established by six individuals: five nephrologists and a philanthropist. This charity foundation works towards the prevention of kidney disorders by educating the general public and by detecting the disease in its earliest stages. Providing high-quality treatment through training both dialysis technicians and medical professionals. Contributing to the operation of charity institutions and promoting kidney donation are important goals. Providing help on both a financial and logistical level. Keeping a registration of organ

donations received in exchange in India (ASTRA).

MOTHER:

The non-profit organisation MOTHER has its headquarters in the city of Bhubaneswar. The acronym MOTHER is an abbreviation that stands for "Multi-Organ Transplantation and Human and Educational Research." This non-governmental organisation (NGO) with its headquarters in Bhubaneswar was established on December 4, 2006 with the mission of encouraging organ donation. This charity distributed free copies of a brochure titled "A Priceless Gift" to residents of Bhubaneswar and other cities throughout India to raise awareness about the importance of organ donation. MOTHER is dedicated to working with patients, clinicians, and the general population to increase awareness about organ donation in India. This is done so that THOA-1994 will be a success in India (18).

Organ Donation Process:

Organ donation and transplantation from a person who has been certified as having brain death should take place as soon as possible after brain death has been confirmed in order to guarantee that the organs are in good enough condition for transplantation and that the individual who passed away did not lose the chance to contribute. On the other hand, organ donation won't go forward if the

individual who wants to do it doesn't make his intentions clear or if the person's immediate family isn't on board with the idea (17, 18).

Donation after Brain Death:

When a patient is admitted to the hospital, the medical personnel will immediately begin doing all in their ability to try to save the patient's life. After doing a thorough assessment and a battery of tests on a patient, a physician will declare that the patient is brain dead if they are unable to bring the patient back under control. In order to proceed with the donation, the organ procurement agency has to be notified, and the family's agreement is required before we can go further. Before stabilising the patient by placing them on a ventilator and giving them intravenous fluids and drugs, the donor's permission was requested first. The patient who is ventilated has a significant number of laboratory examinations. Both the organ donors and the recipients have been tracked down and contacted. Before the ventilator is switched off, a surgical team will extract various organs and tissues from the donors while they are under general anaesthesia in an operating theatre. The exhumation of the donor's corpse, followed by painstaking sewing of the wounds.

Donation after Circulatory Death:

When a person dies of circulatory collapse, their heart stops beating, and as a consequence, all of their important organs also pass away. Because of this, critical organs such as the heart, lungs, kidneys, liver, and pancreas cannot be given. After the cessation of circulatory activity, some tissues such as cornea, skin, and bones may be given (19).

Myths About Organ Donation and Transplantation:

Over one hundred thousand persons in the United States are now on the transplant waiting list. It is unfortunate that many may never get the phone call informing them that a donor organ has been located. It's possible that a lot of people won't receive that second opportunity at life. There are about 17 persons who pass away in the United States every single day due to a lack of donor organs for those who are on the transplant waiting list. It's not easy to dwell on one's own mortality. Thinking about giving organs or tissue might be much more challenging than it already is. Donors of organs, however, are lifesavers (19, 20). The following are some widespread misconceptions and worries about organ donation:

Lack of Knowledge about Organ Donation:

The lack of awareness about organ donation is the primary factor

contributing to the donor shortage. According to the results of a recent poll, a significant number of individuals will become donors if they are provided with further information on organ donation.

Failing to register one's Wish to

Donate:

There are a lot of individuals who want to give their organs, but they don't register their desire to do so, and they don't talk to their families about their plan to donate.

Myths and Beliefs:

Potential donors are discouraged from registering as organ donors due to the widespread prevalence of misunderstandings regarding organ donation in the society (Fig. e).

Reasons for Shortage of Organ

Donors:

There is a significant disparity between the number of people in India who need transplants and the number of organs that are currently accessible. It is estimated that over 1.8 lakh people suffer from renal failure each year; yet, the number of kidney transplants performed each year is only approximately 6000. An estimated two million people in India lose their lives each year to liver failure or liver cancer; however, between 10 and 15 percent of these deaths may be prevented with prompt liver transplantation. Since this is the case, around 25–30 thousand liver

transplants are required on a yearly basis in India; yet, only approximately 1,500 of them are carried out. In a similar vein, over 50000 people in India are diagnosed with heart failure each year, yet only approximately 10 to 15 heart transplants are done each year in the country. In the case of the cornea, around 250,000 transplants are performed annually, although the need is just one lakh (19).

Organ Donation Myths in India:

The lack of available organs is an issue on a global scale, but Asia lags behind other continents, and India falls even more behind other Asian nations. In a country with an annual death toll of 9.5 million, there are around 500,000 fatalities that may be attributed to a lack of organ donors. In India, there are 15–18 fatalities that occur daily as a result of waiting on the transplant list; 2.5 lakh people pass away as a result of waiting for a kidney transplant; and 500,000 people pass away yearly as a result of a shortage of human organs. According to a research from the Organ Retrieval Banking Organisation (ORBO) of the All India Institute of Medical Sciences (AIIMS New Delhi, 2020), out of the 1.5 to 2 lakh kidney transplants that are needed each year, only around 8,000 transplants actually take place. Even in Delhi's NCR (National Capital Region), only 10% of patients are obtaining kidney transplants, while 90% are still

on the waiting list. This indicates that there is a very large disparity between the demand for transplants and the availability of organs. According to the findings of a research conducted by Dr. Anand Bharathan (2020), liver illnesses claim the lives of around 2,59,749 individuals in India each year. Only one thousand eight hundred liver transplants were carried out in 2018, as stated in the study. Co-morbidities, variables that impact organ donation, socio-politico-economic issues, and the inability to pay the procedure are some of the reasons why there are not more liver transplantations. This is the primary reason for the high prices charged for livers obtained from living donors in order to perform transplants. Heart transplants in India have an overall high success rate of about 85 percent. However, India needs more than 10 lakh donors in order to satisfy the criteria for heart transplantation at the national level. According to estimates, there is a need for around 15,000 heart transplants each year, but only about 250 actually take place. Only brain dead organ donors (also known as DBD) and circulatory death organ donors (also known as DCD) may donate their organs after they have passed away. Patients who are in the latter stages of organ failure and who have donated organs may be able to

benefit from medical therapy using those organs (20).

Global Report of Transplantation:

According to study conducted by Shivaram Prasad Singh and colleagues (2019), liver transplants are the second most prevalent kind of solid organ transplantation. Despite this fact, less than 10% of the transplantation needs of the globe are currently being met at the current rate. The United States of America is the leading transplantation country in the world, according to the Global Observatory on Donation and Transplantation (GODT) (2020), with a total of 37,386 transplants, followed by India, which has a total of 10,840 transplants. But in 2019, the Organ Donation Rate (ODR) in India was just 0.52 per million people, whereas the ODR globally was 7.91 per million people (Fig. f).

Facts and Myths:

- When it comes to organ donation, factors such as religion, community, and caste are irrelevant. Anyone may give to the cause.
- It is not possible for those who are afflicted with HIV, cancer, diabetes, renal difficulties, or heart problems to donate their organs.
- It is possible to donate tissue in the event of a natural death; however, organ donation is only feasible in the event that the brain stem has died.

- In contrast to coma, brain death is a condition from which there is no chance of recovery. To determine whether or not a person has a functioning brain, the law in India requires a comprehensive battery of tests.
- People have the misconception that medical professionals will not make every effort to save a patient if they or the patient's family have given their consent for organ donation. This could not be farther from the truth. The treating physician has absolutely nothing to do with organ donation or transplantation. Every single physician always gives their very best effort for the patient.
- The donor's family will not be responsible for paying any of the fees associated with the transplantation (21).
- The donor's body will not be altered in any manner as a result of the organ donation process.
- A person who has previously said that they would donate their organs has the ability to alter their mind at any time and withdraw their consent. It is not set in stone or legally binding.
- It is a fallacy and a superstition to believe that a person who gives his organs would be reincarnated without such organs in their future

life. These beliefs are without foundation and are not real (19-21).

Current Situation and Challenges:

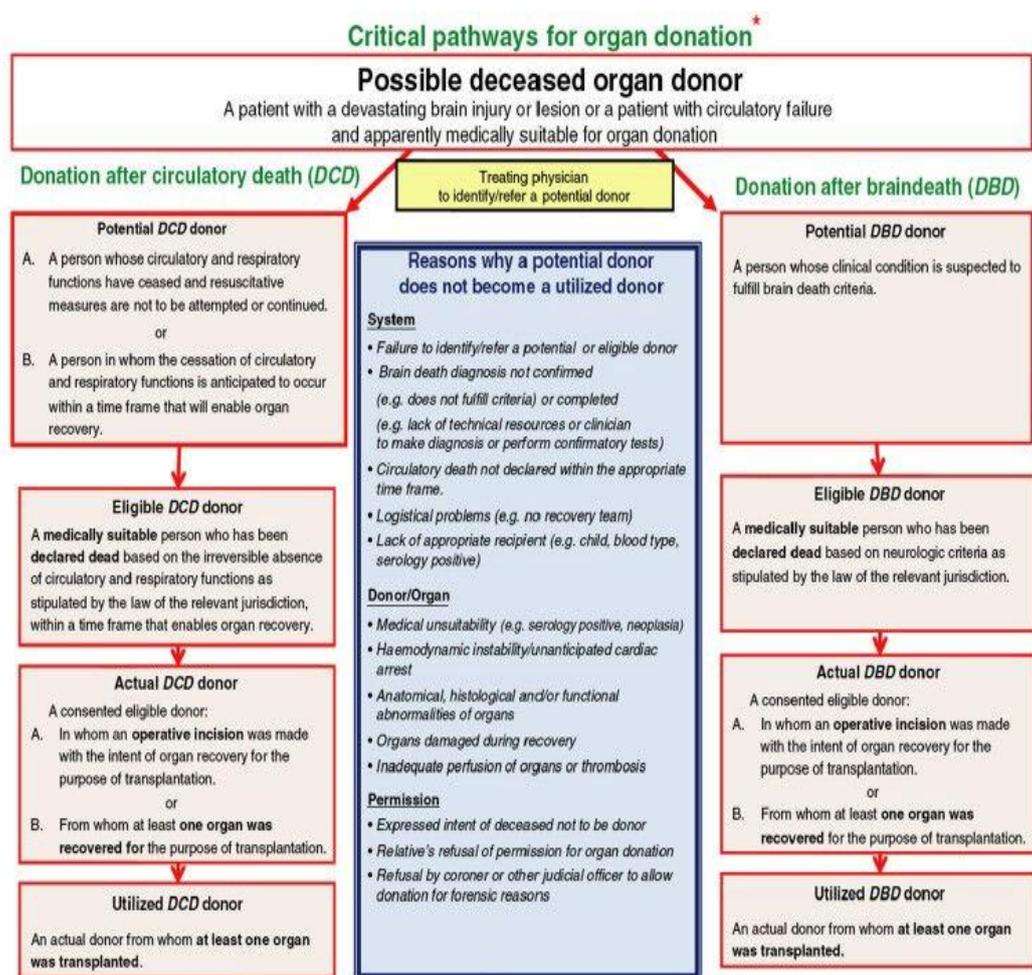
In spite of the vast variety of initiatives that have been created by Member States, the Secretariat, and other stakeholders in the twelve years following the adoption of resolution WHA63.22, there is still an apparent inadequate increase in, as well as an asymmetrical development of, transplantation all over the globe. In spite of the fact that different health care systems have different capacities and agendas, widespread national and regional obstacles nevertheless exist as a consequence of:

- Low organizational and political commitments, including lack of national strategies for transplantation and therefore lack of significant funding, human resources or infrastructure;
- Lack of understanding of the burden of disease in order to escalate interventions for preventing end-stage organ failure;
- Inadequate legislation, ethical frameworks, regulatory oversight and governance that may allow for illegal or unethical practices such as organ trafficking or tissue commercialization;
- Limited community awareness and knowledge, as well as cultural

- resistance, regarding donation and the value of transplantation;
- Deficiencies in deceased donor identification and donation management, including low awareness and engagement among the public and health care professionals;
 - Inadequate measures for the protection of living donors from coercion and exploitation;
 - Deficient universal health coverage that excludes access to transplantation; and
 - Limited alternatives in cases of undersupply or emergencies (22).

Figures and Tables:

Figures:



*The "dead donor rule" must be respected That is, patients may only become donors after death, and the recovery of organs must not cause a donor's death

Figure (a) Critical pathways for organ donation

2 TYPES OF DONORS

Living Donor

A living donor kidney transplant is a surgery to give you a healthy kidney from someone who is still alive. This is possible because each person only needs one healthy kidney to live.



Deceased Donor

A deceased donor is someone who has just died. This person or their family members decided to donate healthy organs at the time of death in order to benefit people who need transplants.



Figure (b) Types of organ donation

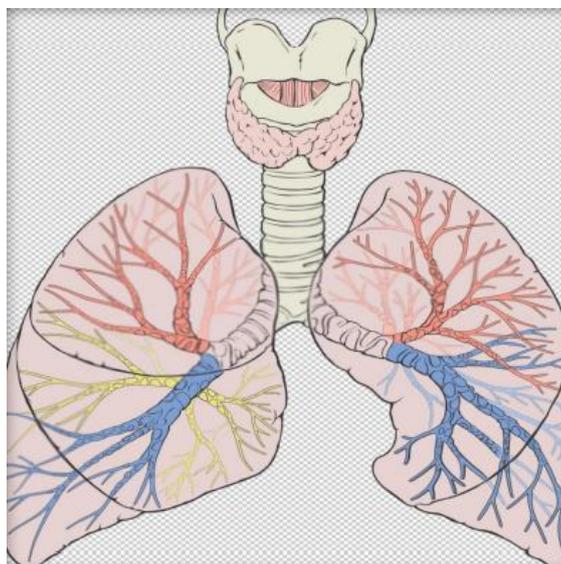


Figure (c) Human Lungs

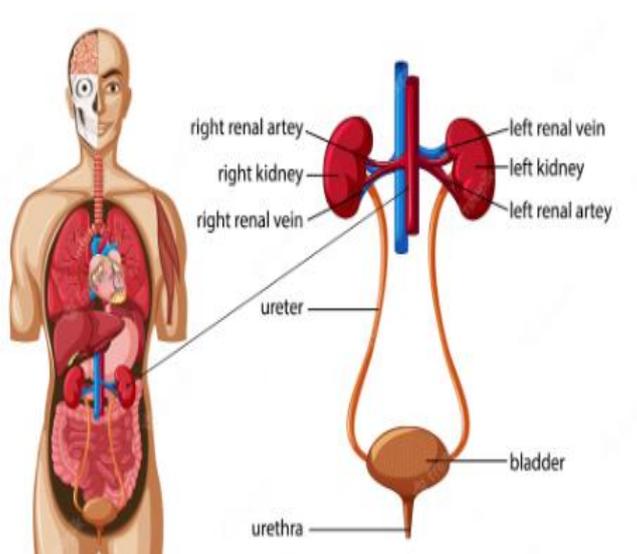


Figure (d) Human Kidneys

MYTHS	FACTS
I am too old to donate my organs	There is no age limit for donating the organs as long as your organs are fit and healthy
I am suffering from disease that's why I can't donate	Donation of organs has nothing to do with your old suffering with a disease until and unless doctors examines you and takes the decision
I am afraid if the doctor comes to know that I am registered to donate my organs so being patient he may not look after me well	The doctor who is looking after you as his/her patient he/she has no role to play in connection with your organ donation decision. The donation of organ comes in context only after the patient has been declared brain dead.
My religion does not allow me to donate organs	All religions promote organ donation because giving life to others through donation of organs is the supreme donation for anyone. All Dharamgurus irrespective of any religion support organ donation.
After organ donation body becomes deformed for the last rites and rituals	Harvesting of organs is done only by professionally skilled surgeons and the body is very meticulously stitched and with great honor is handed over to the family members and there are no hurdles in performing the last rituals of the body.
What are the expenses in getting registered and how one can do it	No expense is incurred in getting Registration done for Organ Donation, contact MFJCF office or at given mobile numbers or one can even register through our website www.mfjcfnavjeevan.org

Figure (e) Myths and facts of organ donation

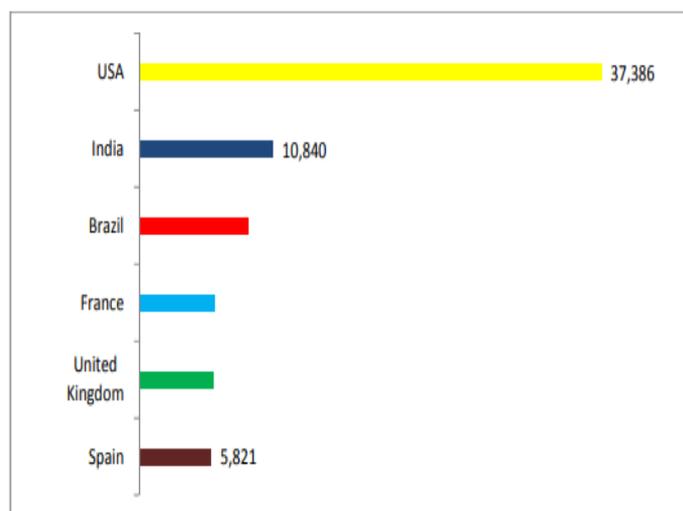


Figure (f) Global observatory Transplantation Organization (GODT) 2020 Report Transplant Sum: Kidney, Heart, Lung, Pancreas and Small Bowe

Summary and Conclusion:

At the local level, there should be mass awareness programmes done in order to improve the understanding and

attitude of the general population towards organ donation. This would result in an increase in societal acceptability and a decrease in fear.

People should be encouraged to donate their organs when they pass away, and they should let their loved ones know if this is something they want to do with their bodies (22). They need to be made aware of the fact that organ donation is the most selfless act one can engage in since it has the potential to offer someone a second shot at life and to put a smile on the faces of many others.

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