

**ORGAN DONATION, AWARENESS, ATTITUDES AND
BELIEFS AMONG THE YOUNG ADULTS (18-30 YEARS)**

Dissertation Submitted to



The IIHMR University, Jaipur

for the partial fulfillment for the award of the degree of

Master of Business Administration (MBA)

in

Hospital and Health Management

by

MOHINI GUPTA

Under the Supervision and Guidance of

Dr. Goutam Sadhu

(Professor, in-charge School of Rural Management)

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DECLARATION BY STUDENT

I hereby declare that this dissertation title **“ORGAN DONATION, AWARENESS, ATTITUDES AND BELIEFS AMONG THE YOUNG ADULTS (18-30 YEARS)”** is the bonafide record of my original research work. I declare that it has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.



Name of Student: MOHINI GUPTA

Date: 21st June, 2022

CERTIFICATE

This is to certify that MOHINI GUPTA in partial fulfillment of the requirements for the award of the degree of MBA (Hospital and Health Management) from the IIHMR University, Jaipur has successfully completed her internship at NITI AAYOG during April 4, 2022 to July 4, 2022.

Place:
Date:

Preceptor/Head of the Organization
Name of the organization

CERTIFICATE

This is to certify that dissertation title ORGAN DONATION, AWARENESS, ATTITUDES AND BELIEFS AMONG THE YOUNG ADULTS (18-30 YEARS) is a record of the research work undertaken by Mohini Gupta in partial fulfilment of the requirements for the award of the degree of MBA (Hospital and Health Management) from the IIHMR University, Jaipur under my guidance and supervision and his/her approach to the research study has been sincere, scientific, and analytical.

Faculty Guide
IIHMR University, Jaipur

Date

School Dean
IIHMR University, Jaipur

Date

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Sincerely,

Mohini Gupta

MBA Hospital and Health Management (2nd Year)

IIHMR University, Jaipur

Date: 29th June 2022

Abstract

Organ transplantation is one of the most preferred treatments for patients with end-stage organ disease or organ failure; which has no other option left other than the transplant. There is a huge deficit among the supplies of cadaver organs that can cover needs. Young adults make up a critical link in creating sensitization about organ donation. The attitudes and beliefs of young adults can change the public opinion as they deal with a larger population within their social circle on the daily basis. The study aimed to understand the awareness, attitudes, and beliefs among young adults (18-30 years). A total of 501 respondents from Delhi, situated in North India participated in the study. A questionnaire (Google form) was circulated and used in the collection of the data. Data were analyzed using Microsoft Excel. The age of the respondents was in majority between the age group of 22-25, 52% were females, and 40% belonged to the Hindu religion. 57% of the respondents wished to donate their organs after death, 60% didn't believe that their body will be disfigured after organ donation and 60% didn't believe that they will be born without the donated organ in their rebirth if they pledged their organs. 40% of the respondents were in favor of donating the organs of their family members in the case of BSD. 38% of the respondents were in favor of receiving organs from family and cadavers, and about 47% didn't believe that organ donation is against their religion as many religious leaders have given their thoughts regarding the same. Most of the respondents disagreed with the myth that doctors wouldn't give adequate care to the patient while they were admitted and if doctors know that they had pledged their organs during their life. From the study, it can be concluded that there was a close relationship between attitudes, beliefs, and awareness among young adults. Young adults, however, had a positive impact on attitudes and beliefs toward organ donation. This study emphasizes the awareness regarding organ donation and transplantation as young adults are the connecting link between the two generations and are more active in the social circle which might help in educating a large-scale population. The study also concluded some recommendations which would lead to an increase in the number of donations and that could give life to a majority of the population. The limitations of the study include that the study needs to be done on a larger scale so that awareness of organ donation and transplantation reaches a larger part of the society. The study also gave new light on the use of advanced technology which might fill the deficiency between the demand and supply of organs.

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Abbreviations

BSD	Brain Stem Death
THOA	Transplantation of Human Organ Act
THOR	Transplantation of Human Organ Rules
NOTTO	National Organ & Tissue Transplant Organization
ROTO	Regional Organ & Tissue Transplant Organization
SOTTO	State Organ & Tissue Transplant Organization
NABL	National Accreditation Board for Testing and Calibration laboratories
V/s	Versus
N	No. of Respondents

Chapter -1

1. Introduction

Organ transplantation is the most preferred treatment for patients with end-stage organ disease. Thousands are reported dead due to organ failure annually, owing to the huge discrepancy between the number of people waiting for organ donation and the number of organs available.^[1] It is imperative that the young generation, the future donor force, comprehends the concept and importance of organ donation.^[2] There is an inadequate supply of cadaver organ to fulfill the high demand. The level of knowledge of BSD (Brain- stem death) as well as attitudes toward organ donation are very important determinants of people's willingness or otherwise to donate organs. In present scenario young adults are the critical link in creating public awareness about organ donation. Their attitudes and beliefs can influence the public opinion.^[3] The young youth is much more creative and sensitive towards the social issue hence, a small thought could create a larger impact over the society. The present scenario of organ donation is 0.52% of the population in the 2019. This study aims at understanding the awareness, attitudes, and beliefs among the young adults. Organ donation is the process of surgically removing an organ or tissue from one person (the organ donor) and placing it into another person (the recipient). Transplantation is necessary because the recipient's organ has failed or has been damaged by disease or injury.^[4] Organ transplantation is one of the great advances in modern medicine. Unfortunately, the need for organ donors is much greater than the number of people who actually donate.^[5] Due to the pandemic there is a decrease in the donation and transplantation data.

India holds 3rd place in total number of transplant globally, after USA (40,621) and China (19462). India ranks 78th position in the organ donation per million populations. Total number of organ transplants done in the country has increased from 4990 in 2013 to 12666 in 2019 (Living -10604, Deceased – 2060 and Domino- 2). Organ donation rate (No. of deceased donors per million population) in the country increased from 0.27 in the year 2013 to 0.65 in 2018, however it has dipped to 0.52 in 2019 and for Spain it is 48 per million due to its Opt-In & Opt-out policy. The following figure shows the current status of the organ wise donations, male v/s female donations and living v/s cadaver transplant. [Source – NOTTO website- <https://notto.gov.in/organreport.htm>]

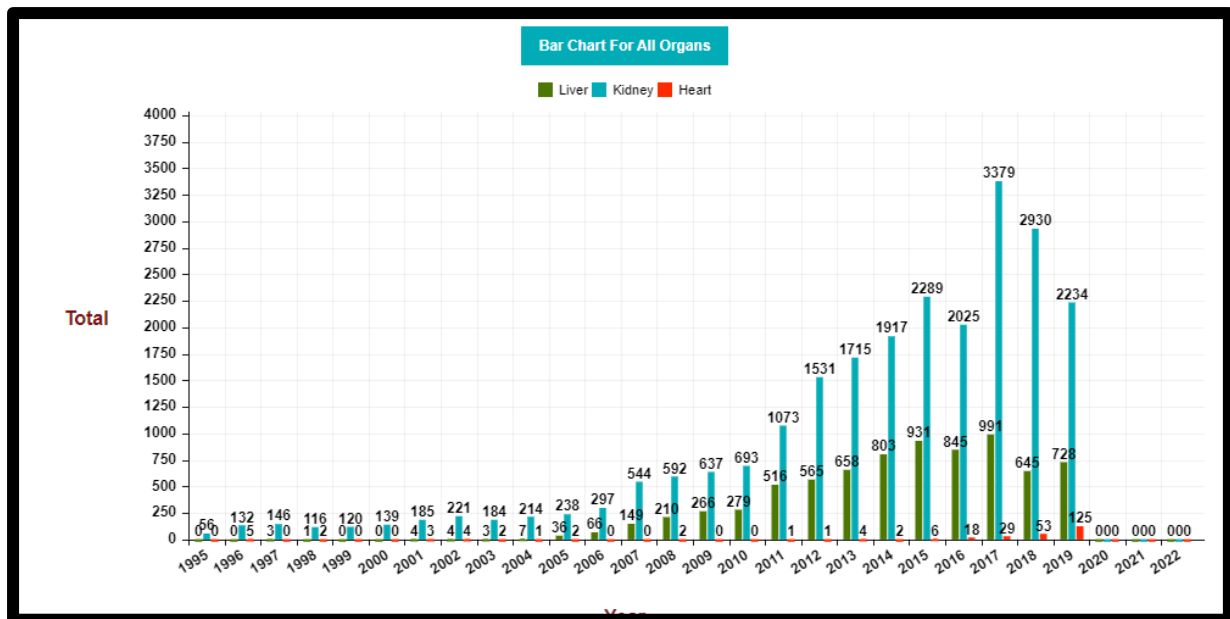


Fig 1.1- Depicts the organ wise donation from 1995-2019

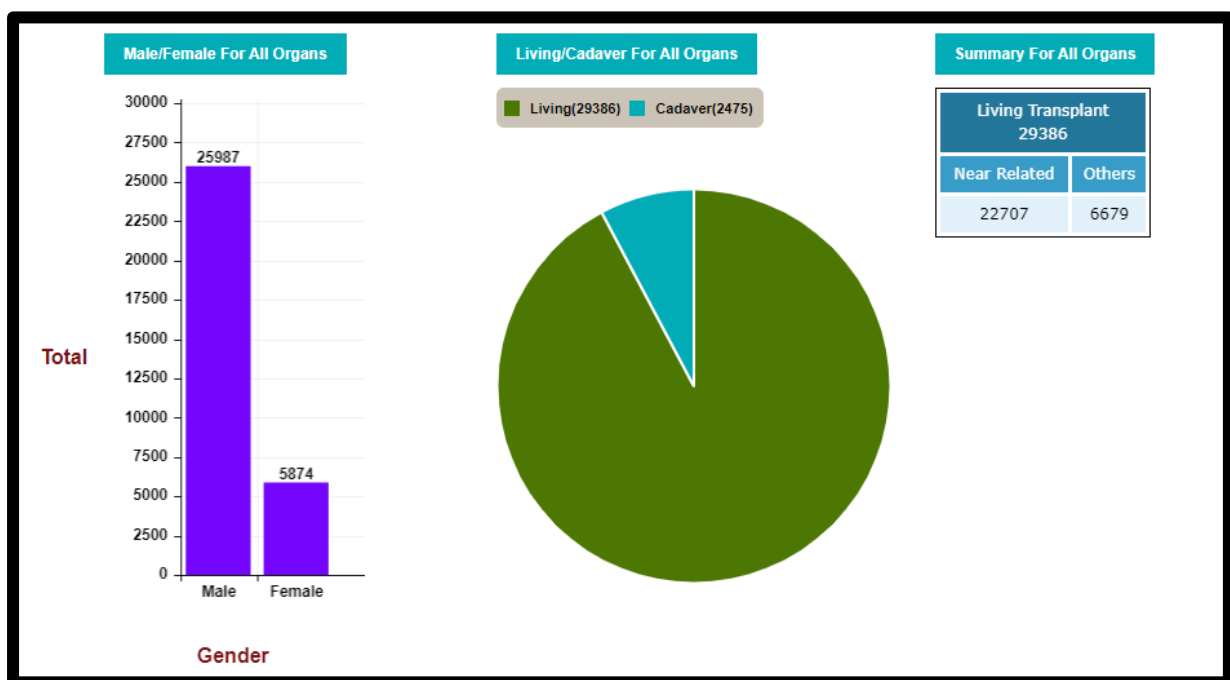


Fig 1.2- Depicts the summary of all organs transplanted

India had developed the capacity for undertaking the rare transplants for pancreas, intestine, hand, limbs, lung and uterus. Tamil Nadu and Maharashtra contribute to the maximum number of organ transplant. In the North -East region donation activities are not flourished due to the gap and no functional ROTTO (Guwahati) & SOTTOs.

To regulate the removal, storage and transplantation of human organs and tissues for the therapeutic purposes and for the prevention of commercial dealings in human organs and tissues the Transplantation of Human Organ Act (THOA) was passed in 1994 and then Transplantation of Human Organ (THO) Rules 1995 were passed and there after various amendments were done; following are the key features of the act and the rule.

THOA (Transplantation of Human Organ Act) – 1994^[6]

- Transplantation of Human organ bill, 1992 was introduced in the Lok Sabha on August 1992.
- The bill was assented by the President on 8th July 1994 and hence enacted as THOA 1994 (42 of 1994)
- It aims to regulate, storage and transplantation of human organs for therapeutic purposes.
- Main provision of the act are as follows:
 1. Concept of “Brain Stem Death” accepted-
 2. It is the stage at which all functions of the brain stem have permanently and irreversibly ceased. Only “Living related Donors” are allowed to donate organs without legal problems- “Near relatives”
 3. For unrelated donors- Permission from “Authority” required prior to surgery
 4. Regulations and registration of hospitals undertaking transplantation- “Licensing”
 5. Punishment for any commercial dealings in organs
 6. Blood and blood related products are not included in the THOA 1994.

The THOA 1994 was accepted by all the states except the Jammu & Kashmir and Andhra Pradesh (Annexure-I).

Transplantation of Human Organ Rules- 1995^[7]

The THO rules have a detailed description regarding the following points:

- Define duties of the medical practitioner

- Eligibility of the medical practitioner
- Introduction of Forms
- Composition of Authorisation Committees
- Requirement for Registration of hospital
- Conditions for Renewal of registration
- Conditions for grant of certificate of registration

Transplantation of Human Organ (Amendment) Rules- 2008^[8]

The amendments made to the THO rules of 1995 include the following:

- NABL(National Accreditation Board for Testing and Calibration laboratories) certified laboratories included in the rules
- Role of authorization committee defined to establish relationship/link/circumstances
- One state level authorization committee
- Defined Composition of authorization committee

THOA (Transplantation of Human Organ Act) Amendment – 2011^[9]

The amendments made to the THOA 1994 include the following:

- Organ Swapping legalised
 - Includes the donation of tissues
 - Penalties enhanced
 - Grandparents and Grandchildren included in the list of near relatives
 - In the absence of a neurologist or neurosurgeon following can be nominated for Brain death certification
1. An independent Surgeon or Physician
 2. An anaesthetists or Intensivist

- Makes mandatory for a doctor in an ICU to ascertain if a family wants to donate organs
- No donation from a mentally challenged person before his death

The THOA was amended in 2011 which was accepted by all states except the 9 states i.e. (Andhra Pradesh, Telangana, Arunachal Pradesh, Karnataka, Meghalaya, Mizoram, Nagaland, Tripura and Uttarakhand) – [Annexure I]

Transplantation of Human Organ (Amendment) Rules -2014^[10]

The amendments made to the THO rules of 1995 & 2008 include the following:

- Allows transplantation from the living donors and cadavers
- Form 7 included - Organ or tissue pledging & Form 10 - Brain stem death declaration
- Criteria Registration of hospitals & tissue banks and their renewal.
- Conditions and standards for grant of certificate of registration for tissue banks
- National registry regarding donors and recipient - Organ transplant, Organ donation & tissue registry

National Organ Transplant Program (2013) ^[11]

Objectives of the scheme ^[11]

- To organize an efficient mechanism for organ and tissue procurement/retrieval especially from deceased donors and their distribution for transplantation.
- To promote deceased organ and tissue donation including pledging for the same.
- To spread awareness about various aspects of organs and tissue transplantation among the public at large.
- To bridge the gap between the demand & supply of organs for transplantation.
- To establish new and strengthen the existing organ and tissue retrieval and transplant infrastructure facilities especially in public sector hospitals/institutions.
- To train required manpower for organ & tissue donation, retrieval & transplant.

- To identify/establish skill centres for training of transplant & retrieval surgeons, physicians, Anaesthetists, immunologists, Nurses, Transplant Coordinator etc. in NOTTO/ROTTTO/SOTTO/Medical Colleges/ Institutions as applicable.
- To monitor organ and tissue transplant services and bring about policy and programme corrections/ changes whenever needed.
- To establish and operationalize Digital National Organ &Tissue Donation and Transplant Registry.

Strategies [\[11\]](#)

- Advocacy for promoting organ and tissue donation and carrying out various IEC activities for increasing awareness among the general public and stake holders.
 - Encouraging individuals to register their willingness to be a donor after death.
 - Enforcement of ‘mandatory declaration of Brain Stem Death and required request.
 - Develop National, Regional and State Network for organ and tissue removal, storage, allocation and transplantation.
 - Capacity building of personnel involved in Organ & Tissue Donation and Transplantation.
 - To establish new skills centres for training transplant surgeons, physicians and immunologists etc. in NOTTO and certain medical colleges in the country
 - Establish and maintain a national registry of organ and tissue donation and transplantation.
 - To train in organ donation and transplantation data management in NOTTO. A post-doctoral fellowship course to be started in NOTTO.
 - M.Ch/Post-Doctoral Fellowship in Hand surgery and Transplant to be started in NOTTO in collaboration with VMMC and AIIMS Trauma centre
 - Develop requisite infrastructure for organ and tissue donation and transplantation activities at various levels.
 - Developing an effective transport system for rapid and safe transportation of organs and tissues within and across the cities (surface, metro, Train and air transport including security etc.)
 - Providing support system for Living donors in form of Insurance support etc.
 - Help organising a robust support system to ensure optimal graft outcomes (in form of immunosuppressant drugs for ill affording and adequate timely medical support)

Institutional Framework for the smooth functioning of organ donation, awareness and transplantation [12]

National human organs and tissue removal and storage network 1 NOTTO, 5 ROTTO and 16 SOTTOs and 638 transplant/retrieval/tissue banks.

National - 1 NOTTO^[12]	Regional 5	State Level -16
	ROTTTO- NORTH (Chandigarh)	Uttar Pradesh- SGPGIMS Lucknow
		Rajasthan- SMS Jaipur
		Haryana- PBDSPGIMS Rohtak
		Jammu & Kashmir - GMC Jammu
		Punjab- GMC, Patiala
		Himachal Pradesh- IGMC, Shimla
	ROTTTO- NE (Guwahati)	Guwahati Medical College, Guwahati
	ROTTTO- South (Chennai)	Kerala- GMC Thiruvananthapuram
		Andhra Pradesh- Jeevandan AP
		Pondicherry- IGGGH and PGI
	ROTTTO- West (Mumbai)	Goa-GMC Bambolim
		Gujarat- IKDRC Ahmedabad
		Madhya Pradesh- MGMMC Indore
		Dada & Nagar Haveli- Shri Vinoba Bhave Civil Hospital
	ROTTTO- East (Kolkata)	Bihar- IGIMS Patna
		Jharkhand- RIMS, Ranchi
		Odisha - SCBMC Cuttack

National Organ and Tissue Transplant Organization (NOTTO) [13]

It is a National level organization set up under Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India located at 4th and 5th Floor of Institute of Pathology (ICMR) building in Safdarjung Hospital New Delhi. It has following two divisions:

- "National Human Organ and Tissue Removal and Storage Network"
- "National Biomaterial Centre".

"National Human Organ and Tissue Removal and Storage Network" [13]

This has been mandated as per the Transplantation of Human Organs (Amendment) Act 2011. The network will be established initially for Delhi and gradually expanded to include other States and Regions of the country. Thus, this division of the NOTTO is the nodal networking agency for Delhi and shall network for Procurement Allocation and Distribution of Organs and Tissues in Delhi.

Function/Activities [13]

National Network division of NOTTO would function as apex centre for All India activities of coordination and networking for procurement and distribution of Organs and Tissues and registry of Organs and Tissues Donation and Transplantation in the country. The following activities would be undertaken to facilitate Organ Transplantation in the safest way in shortest possible time and to collect data to develop and publish National registry:-

At National Level [13]

- Lay down policy guidelines and protocols for various functions.
- Network with similar regional and state level organizations.
- All registry data from States and Regions would be compiled and published.
- Creating awareness, promotion of organ donation and transplantation activities.
- Co-ordination from procurement of organs and tissues to transplantation when organ is allocated outside the region.

- Dissemination of information to all concerned organizations, hospitals and individuals.
- Monitoring of transplantation activities in the Regions and States and maintaining data-bank in this regard.
- To assist in data management for organ transplant surveillance & organ transplant and Organ Donor registry.
- Consultancy support on the legal and non-legal aspects of donation and transplantation.
- Coordinate and organize trainings for various cadres of workers.

For Delhi and NCR ^[13]

- Maintaining the waiting list of terminally ill patients requiring transplants.
- Networking with transplant centres, retrieval centres and tissue banks.
- Co-ordination for all activities required for procurement of organs and tissues including medico legal aspects.
- Matching of recipients with donors.
- Allocation, Transportation, Storage and Distribution of Organs and Tissues within Delhi and National Capital Territory region.
- Post-transplant patients & living donor follow-up for assessment of graft rejection, survival rates etc.
- Awareness, Advocacy and Training workshops and other activities for promotion of organ donation.

National Biomaterial Centre (National Tissue Bank) ^[13]

The Transplantation of Human Organs (Amendment) Act 2011 has included the component of tissue donation and registration of tissue Banks. It becomes imperative under the changed circumstances to establish National level Tissue Bank to fulfil the demands of tissue transplantation including activities for procurement, storage and fulfil distribution of biomaterials.

The main thrust & objective of establishing the centre is to fill up the gap between ‘Demand’ and ‘Supply’ as well as ‘Quality Assurance’ in the availability of various tissues.

The centre will take care of the following Tissue allografts:-

- Bone and bone products e.g. deep frozen bone allograft, freeze dried bone allograft, dowel allograft, AAA Bone, duramater, facialata, fresh frozen human amniotic membrane, high temperature treated board cadaveric joints like knees, hips and shoulders, cadaveric cranium bone graft, loose bone fragment, different types of bovine allograft, used in orthodontics
- Skin graft
- Cornea
- Heart valves and vessels

Other tissues shall be gradually included.

Activities^[13]

- Coordination for tissue procurement and distribution
- Donor Tissue Screening
- Removal of Tissues and Storage
- Preservations of Tissue
- Laboratory screening of Tissues
- Tissue Tracking
- Sterilization
- Records maintenance, Data Protection and Confidentiality
- Quality Management in tissues
- Patient Information on tissues
- Development of Guidelines, Protocols and Standard Operating Procedures
- Trainings
- Assisting as per requirement in registration of other Tissue Banks

The primary hindrance to a successful deceased donor organ transplantation program is the extreme shortage of donor organs. The cadaver organ donation program in India is still in its infancy and is hindered by the lack of adequate awareness about the criteria and guidelines for declaration of brain-death, among doctors.^[34] Although the public is accustomed to the idea of donating blood, donation of organs after death continues to be a problem.^[10] There is a great need for increasing awareness about organ transplantation and organ donation among the general public, beginning with the health-care professionals who in turn, can motivate the

public. Educating health-care professionals about organ donation process appears to be an important factor in maximizing the benefits from the limited organ donor pool. ^[34] Increasing the donor pool is an important public health issue. The major factor which contributes to the limited availability of donor organs is the lack of knowledge about the legal and procedural details of organ donation. Health-care professionals are considered to be the critical links in the organ procurement process because they are the first individuals to establish relationship with the potential donors' family and to have the opportunity to raise the option of donation in case the patient is BSD.

An assessment of knowledge, attitudes and beliefs of young adults towards organ donation would help to plan sensitization and increase awareness programs among the young adults and hence propagate knowledge among their social circle.

This is a cross sectional study on organ donation with specific emphasis of awareness, attitudes and beliefs among the young adults of the Delhi, India.

The objectives of the present study included the following:

1. To assess the attitude of the young adults over the organ donation.
2. To assess the factors creating reluctance towards the organ donation among the young adults.
3. To assess the awareness of the young adults over the organ donation.
4. To assess the beliefs of the young adults over the organ donation.

Operational Definitions:

Cadaver Donor: Cadaveric donation comprises organ donation—that is, taking organs (heart, lungs, kidneys, liver, pancreas) from brain dead people, as well as tissue donation, meaning taking tissues (skin, corneas, tendons, bone) from brain dead as well as heart dead people.

Cadaver organ: Cadaver organs are heart, lungs, kidneys, liver, pancreas which are taken from brain dead people.

Living Donor: The living related donor can be a family member, such as a parent, child, brother or sister, spouse, grandparents, grandchildren etc.

Chapter -2

2. Review of literature

S. No.	Author	Place	Study setting	Study Design	No. of Participant	Age-group	Method of data collection	Findings
1.	H. Jung 2013 ^[16]	Europe	Medical students	Cross-sectional	140	Mean age 20 years	Self-Administered Questionnaire	The study shows that the emotional and moral factors were the main factors that affected the organ donation.
2.	Salman T Gauher & et.al ^[15] 2013	UK based Indian & Pakistani students	Medical & Non-medical students	Cross-sectional	—	18-30	9 focused groups and 8 semi-structured interviews	6 factors influencing organ donation are Religion, awareness towards organ donation, cultural factors, and myths prevailing towards the donors, and influence of family as their consent is important.
3.	Hasan H	Pakistan	Medical	Cross-	450	18-25	Structured	Insufficient

	& et.al. 2019 ^[20]		students	sectional			Questionnaire	overall knowledge about organ donation
4.	Misra Puneet & et.al. ^[19] 2021	Faridabad, Haryana	Adults of rural area	cross-sectional	1050	—	Pre-tested self-designed interview	The study depicts that the knowledge regarding the brain death is the governing factor to convince people for the organ donation
5.	Usha Bapat & et.al. ^[10] 2010	Saudi Arabia	Postgraduate medical student	Cross-sectional	143	27-29	Structured Questionnaire	The study shows a statistical significant correlation between attitudes, beliefs and demographics
6.	Laysa Ghanta & et.al. ^[11] 2022	Chennai	Medical students	Cross-sectional	500	18-25	Structured Questionnaire	1. Emotional and moral factors affected the organ donation the most
7.	Sami Akbulut & et.al. ^[12] 2022	Turkey	School teacher	Cross-sectional	2400	-	Structured questionnaire	The teacher at the school has an insufficient

								knowledge and attitudes toward organ donation.
8.	Marie Louise Uwiringabiywe & et. al. ^[13] 2021	University of Rwanda	Nursing Students	Cross-sectional	179	20-49	Structured Questionnaire	From the study it shows that the kidney donation and other organ donation to be incorporated in the curriculum of the nurses so that they have a better mindset and training regarding the organ donation.
9.	Hakeem & et.al. ^[14] 2021	South India	Healthcare professionals	Cross-sectional	996	20-35	Structured Questionnaire	The major factor which governs for the poor donation rates in the India is the religious misconception and other myths prevailing against the organ

								donation.
10.	Shanmukh Kamble & et. al. [15] 2021	Karnataka	Medical students	Cross-sectional	339	Young Indians	Structured Questionnaire	The present stats of the organ donation show that there is shortage of organs in India that is neither psychological nor cultural.

Chapter -3

3. Methodology/ materials and methods

Delhi: Delhi, or the National Capital Territory (NCT) of India, is a large metropolitan area in India. Delhi is the fifth most populous city in the world and the largest city in India area-wise. Delhi has an estimated 2016 population of 18.6 million. The NCT and its urban area are granted the special status of National Capital Region, and this NCR includes neighboring cities of Baghpat, Alwar, Sonapat, Gurgaon, Ghaziabad, Faridabad, Greater Noida, Noida, and nearby towns. The NCR has an estimated population of 24 million, exceeding the Delhi population of 17.8 million in 2014. Delhi has a rapidly growing population, which was near 16.7 million in 2011. Delhi covers a large area, totaling around 1,484 square kilometers. The city has a population density of 29,259.12 people per square mile, which is one of the highest in the world. [\[32\]\[33\]](#)

The young adults of the different colleges of Delhi which belong to the age group of 18-30 years were listed and those consenting to participate were studied. A total of 501 students participated in this cross sectional study. The study has the Inclusion criteria i.e. Adults aged between 18-30 years and Exclusion criteria i.e. individual that opted out of the study. A specially designed self-administered questionnaire consisting of demographic profile and items covering awareness, attitudes, and beliefs towards organ donation was prepared and distributed through the Google forms. The respondents had to indicate their responses as

either yes/no/maybe. Topics related to personal willingness to donate or receive an organ for transplantation, and objections to donation, religious and other beliefs towards donation were studied. [34] The duration of the study was between 8-12 weeks. The completion of the research along with final report would last by 12 week. The data was collected through the Google (survey) form were analyzed using the Microsoft Excel. The sampling for the collected data was done with Simple Random sampling as it ensures the individual elements in the universe and gives an equal chance of being chosen.

Chapter-4

4. Results & Discussions

The study population consisted of 600 respondents of whom, 501 participated in the study. There was a near equal distribution between genders. It was found from the study that more than half (52%) of the respondents were female whereas about 48% were male and 0.2% population preferred not say (figure-4.1).

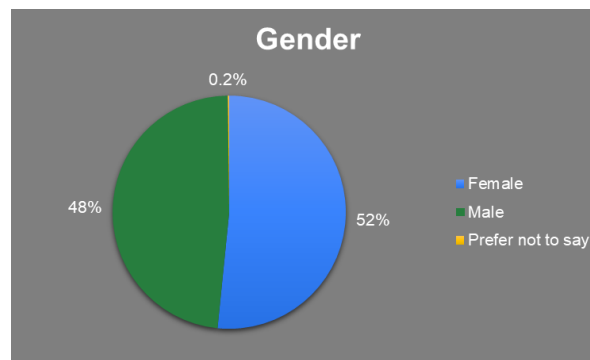


Fig 4.1- Gender of the Respondents (N= 501)

The maximum concentration was found to be in the age-group of 20-25 years (figure-4.2).

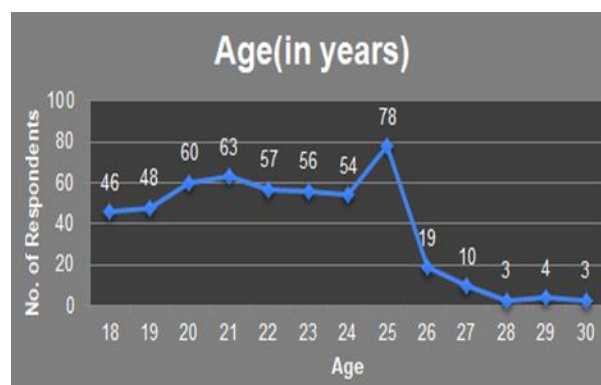


Fig 4.2- Age of the respondents (N= 501)

It was found from the analysis that 12 percent belonged to Christian religion, 39 percent belonged to Hindu religion, 17 percent belonged to Muslim religion, 16 percent belonged to Sikh religion among all 15 percent of the population prefer not to disclose their religion.

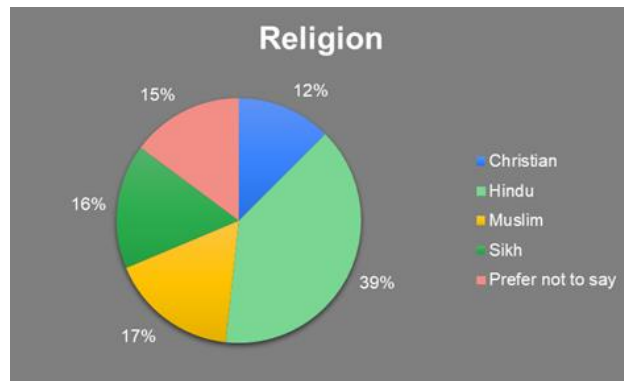


Fig 4.3- Religion of the respondents (N= 501)

Figure 4.4 shows that 56.2% were aware of live and cadaver donation whereas 42.2% of the respondents know that organs can be donated only by the cadaver donation.

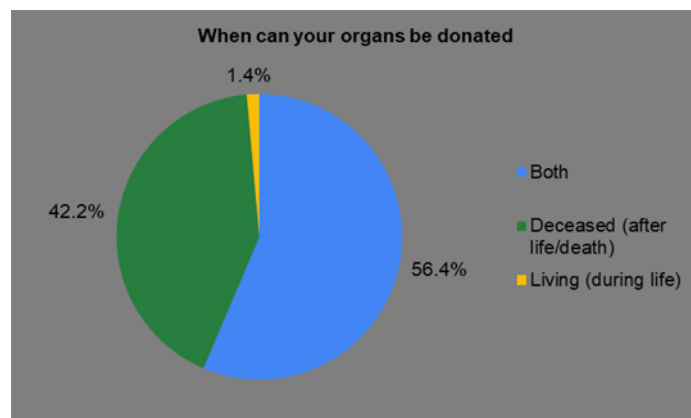


Fig 4.4- When can the organs be donated (N= 501)

As shown in the [figure 4.5] it was found that the 65 percent of the respondents were aware about that the organs can be donated to save another person's life whereas 35 percent weren't aware of the same and 0.4 % said it might be possible.

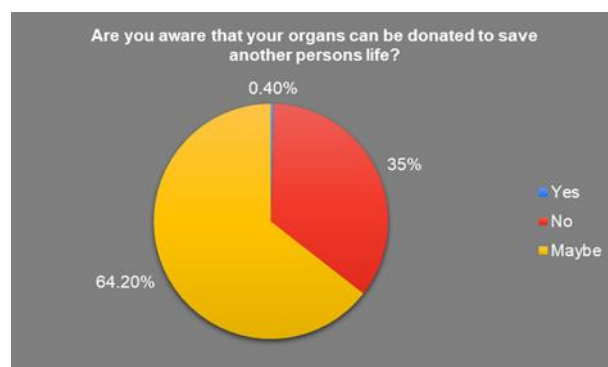


Fig 4.5- Awareness regarding your organs that can be donated to save another person's life (N= 501)

As shown in [figure 4.6] 59% of the respondents have a relative whose organs have been

donated whereas 42% of the respondent's doesn't has any relatives whose organs have been donated.

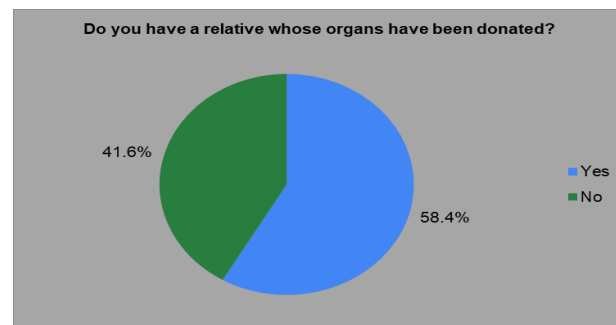


Fig 4.6- Awareness regarding the organ donation among the family (N= 501)

As shown in [figure 4.7] 42% of the population doesn't has any near relative who has undergone any organ transplantation whereas 32% of the respondents have their close relative who has gone under the tiring process of the organ transplantation and 27% doesn't have any related information.

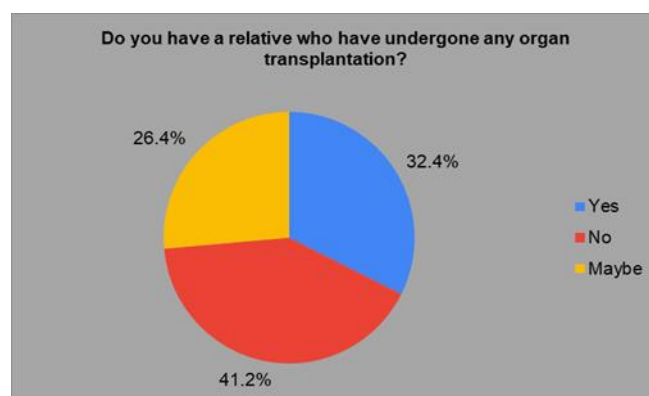


Fig 4.7- Awareness of organ transplantation among relatives (N= 501)

As shown in [figure 4.8] 53% of the respondents know how to pledge their organ whereas 47% of the respondents don't know how to pledge their organs.

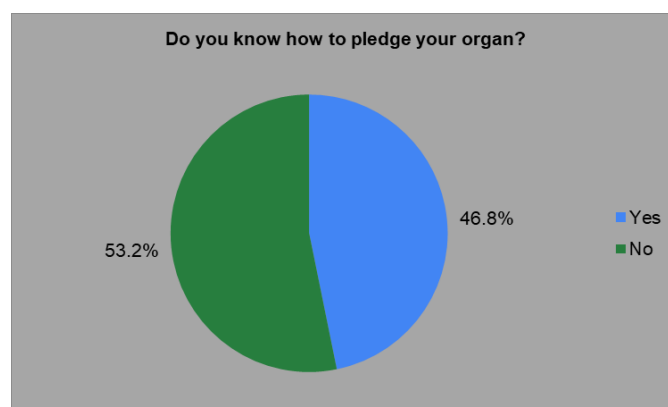


Fig 4.8- Awareness to pledge your organ (N= 501)

As shown in [figure 4.9] 57% of the respondent has knowledge of the brain death and the cadaver donation whereas 43% of the respondent's doesn't has any pre-requisite knowledge of the brain death.

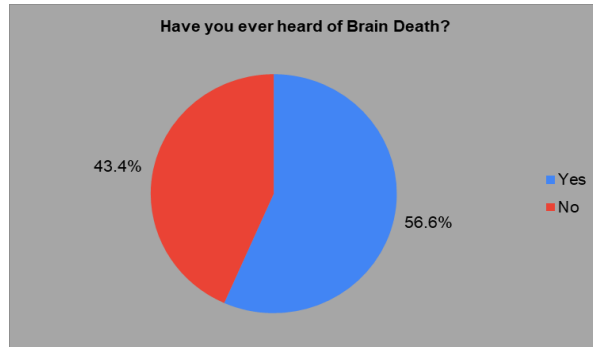


Fig 4.9- Knowledge of the brain death (N= 501)

As shown in [figure 4.10] 53% of the respondents were aware of the organ donation law in India i.e. THOA 1994 & amended 2011 whereas 47% of the respondents weren't aware of the law.

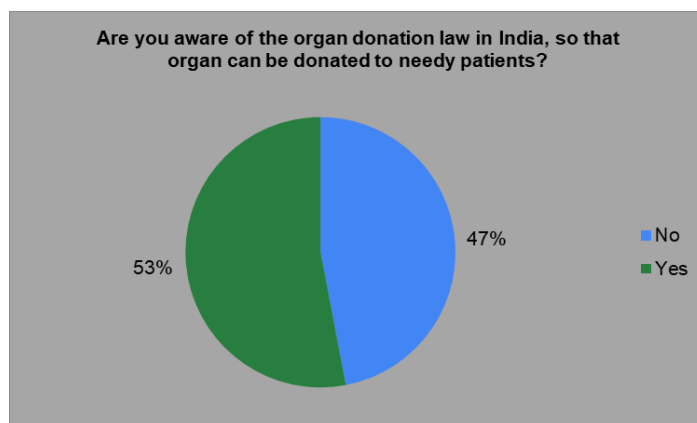


Fig 4.10- Knowledge of the THOA 1994 (N= 501)

As shown in [figure 4.11] 52% of the respondents know about the organ donor card whereas 48% of the respondent's doesn't have any idea about the organ donor card.

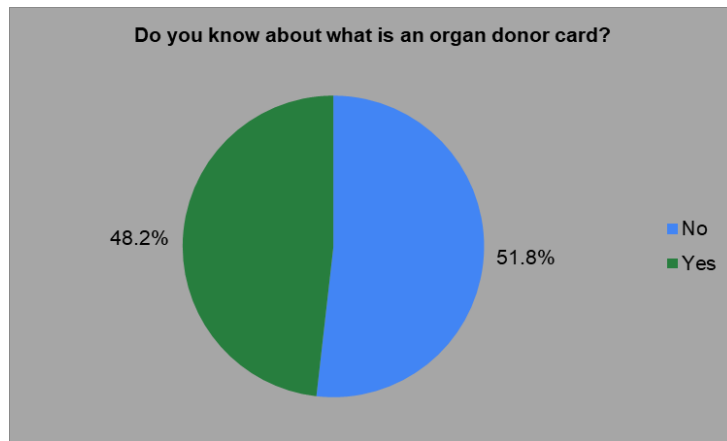


Fig 4.11- Organ donor card (N= 501)

As shown in [figure 4.12] 64% of the respondents feel comfortable to think or talk about the organ donation whereas 36% of the respondents feel hesitant to talk about the same.

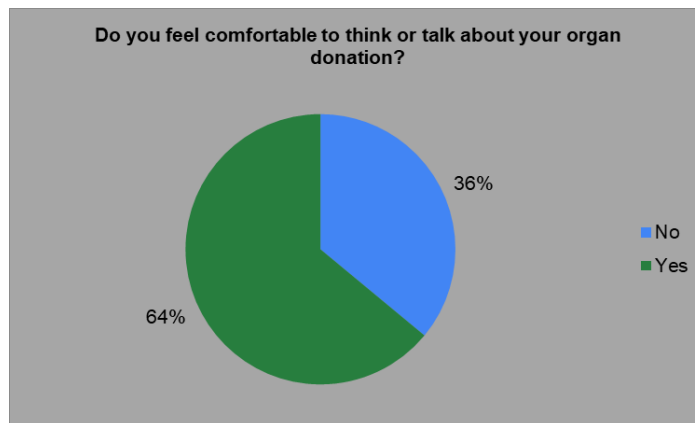


Fig- 4.12 Attitude towards organ donation (N= 501)

As shown in [figure 4.13] 50% of the respondents believe that they are willing to educate your social circle about significance of the organ donation whereas 22% don't feel comfortable for the same and about 29% of the respondents believe that they might think when the situation is important.

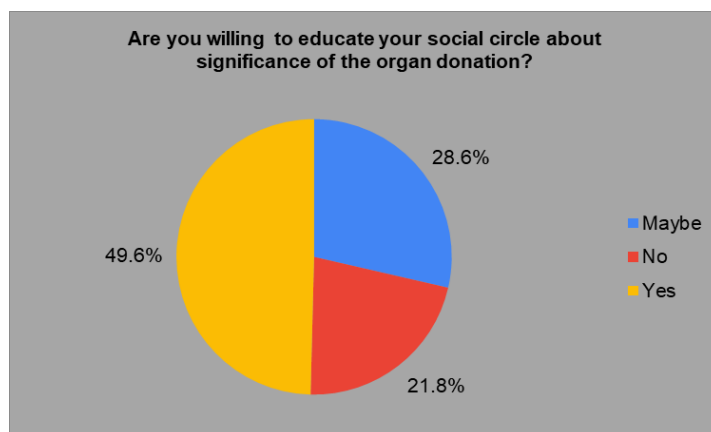


Fig 4.13- Education of social circle about organ donation (N= 501)

As shown in [figure 4.14] 36% of the respondents have a belief and are willing to donate their family member's organ whereas 29% of the respondents are not comfortable about donating the same and about 36% of the respondents will think about it when the need/situation arises.

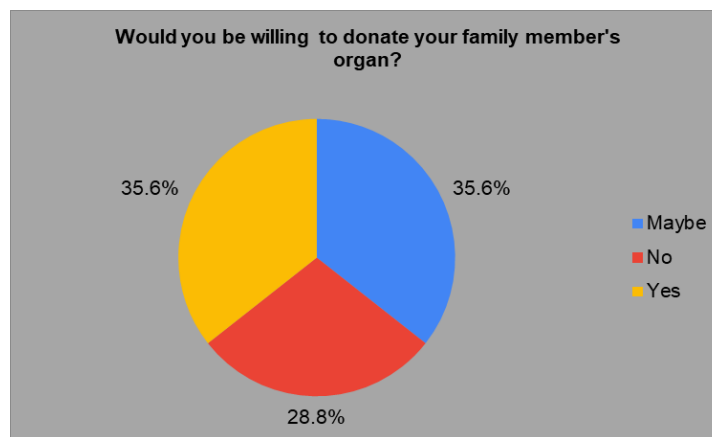


Fig 4.14- Willingness to donate family member's organ (N= 501)

As shown in [figure 4.15] 47% of the respondent's belief that their religion agree with the organ donation or the transplantation and 26 % has an opposite belief whereas about 28% of the respondents have a mixed belief.

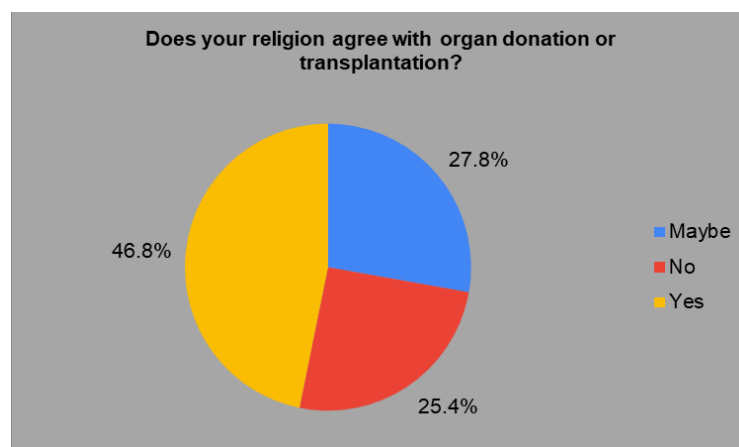


Fig 4.15- Belief in religion over organ donation and transplantation (N= 501)

As shown in [figure 4.16] 60% of the population believes that the organ should be donated to the person of the same religion and state and about 40% of the population doesn't go by the same belief.

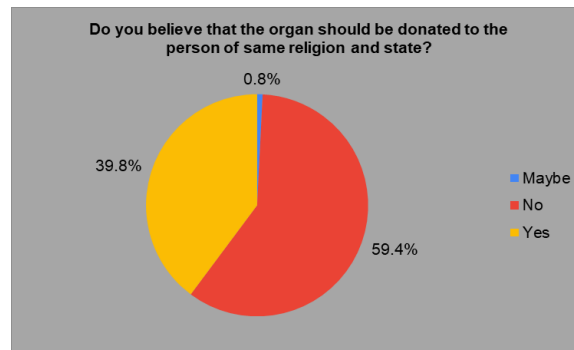


Fig 4.16- Belief regarding the organ donatio to the same religion and same state (N= 501)

As shown in [figure 4.17] 57% of the population believes that their body should be cremated with the full rituals without any removal of the organ and about 43% of the population contradict the thoughts of the other and are in support of the same.

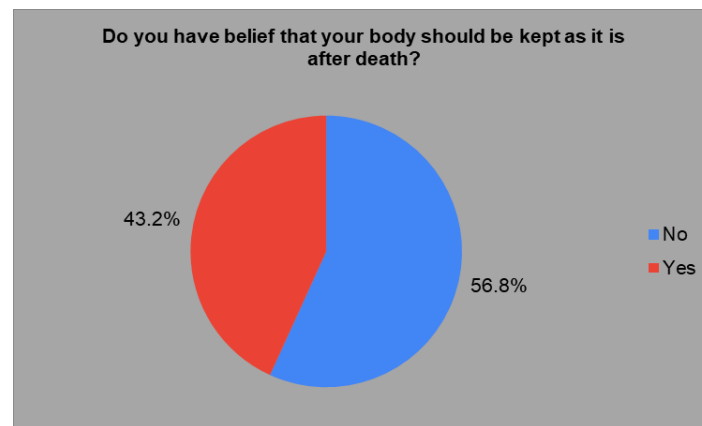


Fig 4.17- Belief regarding the body after the death (N= 501)

As shown in [figure 4.18] 60% of the respondents fear that their body will be disfigured if they donate their organs whereas for the 40% of the respondent this fear wasn't seen to be prevalent.

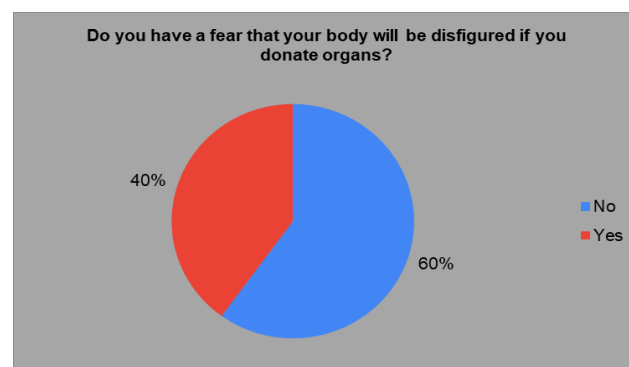


Fig 4.18- Fear of donation after death (N= 501)

As shown in [figure 4.19] 57% of the respondents have already signed as an organ donor where as 43% of the respondents are still to sign up.

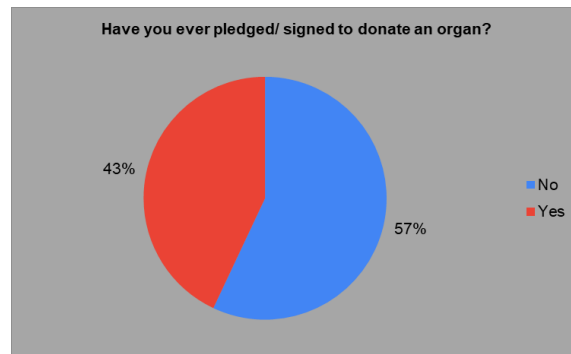


Fig 4.19 Organ Pledging (N= 501)

As shown in [figure 4.20] 36% of the respondents are willing to sign up for the organ donation after giving answers to the survey whereas 30% of the population still aren't willing to donate their organ and about 34% of the respondents still needs some time to think over the signing up of the organ donation form.

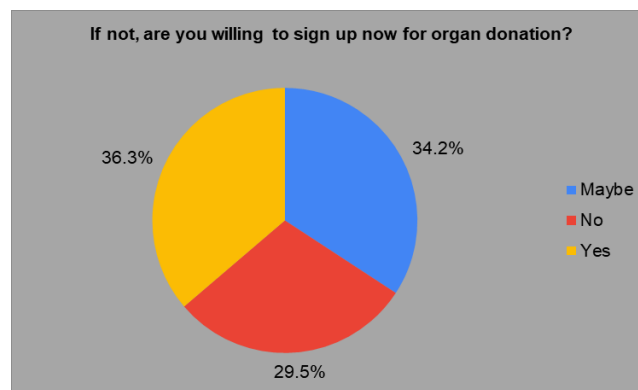


Fig 4.20- Willing to Sign up for organ donation (N= 501)

Co-relation	Age (years)	Are you aware that your organs can be donated to save a other persons life?	Do you have a relative whose organs have been donated?	Do you have a relative who have undergone any organ transplantation?	Do you know how to pledge your organ ?	Have you ever heard of brain death?	Are you aware of the organ donation law in India, so that organ can be donated to needy patients?	Do you know about what is an organ donor card?	Do you feel comfortable to think or talk about your organ donation?	Are you willing to educate your social circle about significance of the organ donation?	Would you be willing to donate your family member's organ?	Does your religion agree with organ donation or transplantation?	Do you believe that the organ should be donated to the person of same religion and state?	Do you have belief that your body should be kept as it is after death?	Do you have a fear that your body will be disfigured if you donate organs?	Have you ever pledged/ signed to donate an organ?	If now, are you willing to sign up now for organ donation?
Age (years)	1																
Are you aware that your organs can be donated to save a other persons life?	0.152246	1															
Do you have a relative whose organs have been donated?	-0.00977	-0.16535	1														
Do you have a relative who have undergone any organ transplantation?	0.021212	-0.08026	0.204687	1													
Do you know how to pledge your organ ?	0.030414	-0.00645	0.067854	0.024118	1												
Have you ever heard of brain death?	0.247923	0.120484	-0.03871	0.011278	0.09255	1											
Are you aware of the organ donation law in India, so that organ can be donated to needy patients?	0.058224	0.115934	-0.01008	0.026886	0.120624	0.121359	1										
Do you know about what is an organ donor card?	0.024856	-0.04777	-0.00208	0.059149	0.078516	0.0371	0.098401	1									
Do you feel comfortable to think or talk about your organ donation?	0.188959	0.143926	-0.11936	-0.02386	0.006346	0.175536	0.036733	0.006337	1								
Are you willing to educate your social circle about significance of the organ donation?	0.191805	0.181762	-0.09064	-0.14831	-0.07965	0.142306	0.116694	0.043742	0.135671	1							
Would you be willing to donate your family member's organ?	0.058823	-0.03726	0.058914	0.029703	-0.03931	0.069545	0.072476	0.026783	0.131227	0.081136	1						
Does your religion agree with organ donation or transplantation?	0.110733	0.123504	-0.07599	-0.01555	0.028212	0.182415	0.048025	0.033787	0.202415	0.167837	0.022569	1					
Do you believe that the organ should be donated to the person of same religion and state?	-0.22218	-0.16839	0.059818	0.065689	0.082967	-0.12064	-0.08571	-0.04839	-0.0967	-0.23457	-0.02427	-0.14848	1				
Do you have belief that your body should be kept as it is after death?	-0.10876	-0.20778	0.099477	0.060528	0.000712	-0.14057	0.004207	0.015256	-0.17866	-0.11415	0.000877	-0.08972	0.099246	1			
Do you have a fear that your body will be disfigured if you donate organs?	-0.15189	-0.12262	0.056322	0.001745	0.004909	-0.10049	-0.0409	-0.01144	-0.10206	-0.10778	-0.01876	-0.20945	0.153463	0.079119	1		
Have you ever pledged/ signed to donate an organ?	-0.02202	-0.22777	0.119335	0.054727	0.069789	-0.08713	-0.03197	0.002991	-0.09763	-0.16677	0.020755	-0.09408	0.185118	0.164086	0.090708	1	
Are you willing to sign up now for organ donation?	0.019049	0.051864	0.048816	0.099393	0.009385	0.048353	-0.05542	0.00451	0.081365	0.062354	0.088998	0.073984	-0.00123	-0.04528	-0.07334	0.056542	1

Fig 4.21- Depicts the correlation between the age and the awareness, attitude, and belief (N= 501)

As shown in the (figure 4.21) it can see that there is positive correlation between the age of the young adults and the awareness, attitude and the belief of the respondents. The age group of the young adults shows a negative correlation with the fact that the organ needs to be donated in the same religion and within the same state

donor organs resulting in severe shortage of donor organs. The magnitude of organ retrieval for the execution of a successful deceased donor program is heavily dependent upon the level of knowledge and attitudes of the young youth.^[10] The attitude of young youth effects on increasing organ donation and transplantation, as they occupy a unique position between older generation and the younger generation.

Awareness regarding organ donation

A large majority of subjects were aware of organ donation and cadaver donation. The major source of information was through media, mainly television, radio and newspaper, PM speech on the organ donation in Maan Ki Baat etc. The concept of cadaver and living donation was understood by the majority of the study population. These findings are similar to a study, which concluded that there is a poor understanding of the concept of brain-death and organ donation even among the medical students.^[10] The present study group comprised of the young adults from the colleges of Delhi and it is obvious that education about organ donation is lacking in the curriculum at the undergraduate and the postgraduate levels. Incorporating this in the syllabus will help in improving awareness about organ donation as well as clarifying the various doubts among the students and also their families.

Fifty six percent of the respondents had heard about donating of organs after death with the family consent. It was observed from this study that the majority of the respondents were willing to pledge their organs after filling structured questionnaire. The reasons cited by them for not willing to pledge their organs in the beginning of the study were "there had been no opportunity or chance as yet so that they think about pledging their organ; a need for family consent for pledging the organ and are not comfortable in having conversation with their parents/ family regarding the same; there is no information available at the open forum onto which people are willing to discuss; there is a weird feeling when you talk about death and then about the organ donation; not yet written a will also there needs to be an advanced directive/living will in place which can be accessed by the family so that the last wish of the person is kept in mind; not given a commitment so far to the better half and parents sometimes say talk to your better half over the organ donation; some of the religious persons had willed for the community through their speeches and talk". Perhaps there need to be increased social and cultural awareness about organ donation in the community that could ease out the confusion; doubts, superstitions and misconceptions in the minds of the public and especially in the minds of the youths, taking help of the social media onto which the

youth is more active would increase the awareness among the society.

The barriers for not donating organs could be because of a number of reasons. The religious beliefs like the body should be cremated without disfigurement, "a person could be born without those organs if it is donated after death", and due to this superstitions persistent in our society, these influence the social and cultural factors, attitudes, educational status and the fear of being declared dead prematurely if a donor card is signed and many myths regarding the healthcare professionals are prevalent in the society.

Responses related to attitudes towards organ donation

A majority of respondents i.e. sixty four percent were willing to donate their organs and small percentage i.e. thirty six percent of the respondents were not willing. The most common reasons cited were: there were too many hassles with regard to the procedure; some of them felt they would decide when the appropriate time arose and at the time of emergency. Although the respondents were young adults and some of them were still hesitant towards taking decision of their life hence, they might not have felt comfortable discussing or even thinking about death and donation. The thought towards willingness to donate the organs of their family members in the event of an unexpected death and, if they could decide about organ donation, more than half the subjects were willing to donate and other's wanted to go with the will of their family member . About twenty eight percent of the respondents were not willing mainly because of reasons such as "they thought it could add on to the survivors' sorrow; they also had to consider the will of the other family members' wishes; they alone don't have the right to decide for other family members; the deceased persons/ the family member should have expressed their intention of donating their organs after their death." Community involvement and participation in organ donation campaigns can reduce the fear and ambiguity among the family members taking the decision to donate their family members' organs to give a gift of life for someone else family. Additionally, they can also have the community sanction for donation and lastly few have a thought that the attention to the family member will be less if the healthcare professionals get to know about the organ donation.

In this study, majority were willing to donate an organ from the family and cadaver, while twenty nine percent were not willing. In a similar study, it was reported that most respondents would be willing to take some form of transplanted organ or tissue if it was needed to

maintain life. ^[16]

Culture and religion play much less prohibitive part in determining the level of organ donation. There is a desire to be aware of the religious stances so that people can make a more informed decision. None of the religions object to organ donation in principle although in some, there is varying thought. ^[15] Fifty percent of the respondents agreed that religion does permit donation. Cultural and religious leaders to become part of the organ donation campaign to increase the organ donation rate.

Strength of the study:

- The study's result will help in formulating proper strategies which could prioritize awareness among the youth and hence further to the society.
- The citizens of India will be more aware regarding the organ donation and its related aspects to their family and society

Limitations of the study:

- The study was conducted to a confined population. If we wanted to increase the donation rate the study is needed to be conducted on the larger population.

Chapter-6

6. Recommendation

The following are the recommendations which I could depict after the study are as under:

1. Promotion of the stem cell preservation of the child at the time of the birth.
2. Link NOTTO website on home page of all ministries
3. Inclusion of donor status on all departmental ID and smart cards (Aadhar card, Pan Card, Voter Id, etc.)
4. Increasing the visibility through the hoarding/ posters which are designed by the

NOTTO to be setup in the metro, roads and highways etc.

5. Red cross/organ India/ Lions/Rotary clubs to be involved for promotion
6. Promotion of organ donation during the conferences held at the ministry level, college, schools etc.
7. Organ donation messages on the post offices to be setup on the hoarding or on the passbook.
8. Dissemination of organ donation messages while phone is getting connected as was done during the time of COVID-19
9. CSR related activities to be done in the private sectors as done in some organizations for the blood donation
10. Promotion by the religious leaders/ yoga guru's (e.g. - Ramdev baba, Sadguru, Brahmakumari etc.)
11. Involvement of youth womens- Anganwadi centres/ mahila mandal/ panchayats
12. Concession to donor families in railways
13. Messages to be printed on all the tickets i.e. railway, airways etc.
14. Inclusion of the chapter on organ donation in school and colleges.
15. IEC activity to be done by NOTTO/ROTTTO/SOTTO on the crematoriums & burial grounds (permanent)
16. Ads break to be given in the TV, YouTube, Radio etc. which is to be channelized on the periodic basis.

Chapter-7

7. Conclusion

In conclusion, our questionnaire study suggests that majority of the respondents were aware of organ donation mainly through their research or through the word of mouth and they are aware of the concept of organ donation. They however had positive attitudes and beliefs towards organ donation. This study emphasizes the need for incorporating the topic of deceased organ donation into the school and medical curriculum. This study emphasizes on the awareness regarding the organ donation and transplantation as young adults are the

connecting link of the two generation and are more active on the social circle which might help in educating a large scale of population.

Ethical considerations:

The permission of all the research participants will be taken into consideration. The dignity of the research participants will come at first. Consent will be taken from all the respondents and given a will to withdraw anytime in between the process. All the respondents will be treated equally and will be told about the fair distribution of the risks and the benefits of the research. Privacy of all the respondents will be at utmost priority. The study was approved by the college ethical committee. Permission was obtained from all the heads of the departments. The respondents were assured about the confidentiality and ethical principles that would be followed, and the background and purpose of the study were explained before the questionnaires were distributed.

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Annexure I

Regional Organ and Tissue Transplant Organization (ROTHO)	States & UTs Under Regional Organ and Tissue Transplant Organization (ROTHO)	THOA Act Yes/No	1994 law OR 2011 Amendment followed
ROTHO WEST	1. Maharashtra	1.Yes	

King Edward Memorial Hospital, Mumbai	2. Gujarat 3. Goa 4. UTs of Dadra and Nagar Haveli,-Daman, Diu 5. Madhya Pradesh 6. Chhattisgarh	2.Yes 3.Yes 4.Yes 5.Yes 6.Yes	1.2011 2.2011 3.2011 4.2011 5.1994 6.1994
ROTT SOUTH Madras Medical College, Chennai	1. Tamil Nadu 2. Kerala 3. Andhra Pradesh 4. Telangana 5. Karnataka 6. Pondicherry(UTs) 7. Andaman and Nicobar(UTs) 8. Lakshadweep (UTs)	1.Yes 2.Yes 3.Yes 4.Yes 5.Yes 6.Yes 7.Yes 8.Yes	1.2011 2.2011 3.2011 4.2011 5.1994 6.2011 7.2011 8.2011
ROTT EAST Institute of Post Graduate Medical Education and Research, Kolkata	1. West Bengal 2. Jharkhand 3. Sikkim 4. Bihar 5. Odisha	1.Yes 2.Yes 3.Yes 4.Yes 5.Yes	1.2011 2.2011 3.2011 4.2011 5.2011
ROTT NORTH Post Graduate Institute of Medical Education & Research, Chandigarh	1. Punjab 2. Haryana 3. Himachal Pradesh 4. Jammu & Kashmir 5. Chandigarh (UTs) 6. Rajasthan 7. Uttarakhand 8. Uttar Pradesh 9. Ladakh (UT)	1.Yes 2.Yes 3.Yes 4. Yes (J&K act) 5.Yes 6.Yes 7.Yes 8.Yes	1.2011 2.2011 3.2011 4.1997 5.1994 6.2011 7.1994 8.2011
ROTT NORTH-EAST Guwahati Medical College	1. Assam 2. Meghalaya 3. Arunachal Pradesh 4. Manipur 5. Nagaland 6. Mizoram 7. Tripura	1.Yes 2.Yes 3.Yes 4.Yes 5.Yes 6.Yes 7.Yes	1.2011 2.1994 3.1994 4.2011 5.1994 6.2011 7.1994
NOTTO Delhi	Delhi (UTs)	Yes	2011

Annexure II

Organ donation, awareness, attitudes and beliefs among young adults (18-30)

* Required

1. Gender*

- Female
- Male
- Other
- Prefer not to say

2. Age (years)*

3. Religion*

- Hindu
- Muslim
- Sikh
- Christian
- Prefer not to say

4. Are you aware that your organs can be donated to save another persons life?*

- Yes
- No
- Maybe

5. When can your organs be donated?*

- Living (during life)
- Deceased (after life/death)
- Both

6. Do you have a relative whose organs have been donated?*

- Yes
- No

7. Do you have a relative who have undergone any organ transplantation?*

- Yes
- No
- Maybe

8. Do you know how to pledge your organ?*

- Yes
- No

9. Have you ever heard of brain death?*

- Yes
- No

10. Are you aware of the organ donation law in India, so that organ can be donated to needy patients?*

- Yes
- No

11. Do you know about what is an organ donor card?*

- Yes
- No

12. Do you feel comfortable to think or talk about your organ donation?*

- Yes
- No

13. Are you willing to educate your social circle about significance of the organ donation?*

- Yes
- No
- Maybe

14. Would you be willing to donate your family member's organ?*

- Yes
- No
- Maybe

15. Does your religion agree with organ donation or transplantation?*

- Yes
- No
- Maybe

16. Do you believe that the organ should be donated to the person of same religion and state?*

- Yes
- No
- Maybe

17. Do you have belief that your body should be kept as it is after death?*

- Yes
- No

18. Do you have a fear that your body will be disfigured if you donate organs?*

- Yes
- No

19. Have you ever pledged/ signed to donate an organ?*

- Yes
- No

20. If not, are you willing to sign up now for organ donation?

- Yes
- No
- Maybe