



## A STUDY OF AWARENESS OF ORGAN DONATION AMONG YOUNG ADULTS IN RURAL AREA.

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**ABSTRACT** **INTRODUCTION:** Though in India, the Transplantation of Human Organs Act was enacted in 1994, the rate of organ donation is poor (.00034%) and patients die while on the waiting list as they do not get an organ on time. The obstacle to organ donation are - refusal of family consent, lack of awareness, myths and misconceptions about it.

**OBJECTIVE:** To assess knowledge, attitude and misconceptions regarding organ donation among general public in rural area.

**METHODOLOGY:** Present cross-sectional study is carried out in 350 adults of 18 to 40 years belonging to rural area during July and August 2019. Randomly selected individual is interviewed to obtain information about their demographic characteristics, their knowledge, attitude and practice about organ donation.

**RESULTS:** Mean age of the participants was 31.1 years. All 350 participants heard about organ donation. Eligibility criteria for organ donation was known to 40.6% participants. 19.7% heard about brain death. 12.9% and 10.6% are aware about the organ donation card and legislation respectively. Mass media was the major source of information (82.6%). 34.8% participants have adequate knowledge while 39.1% have positive attitude about organ donation. Various misconceptions about organ donation were- chance to misuse donated organs (13.7%), organ donation disfigures the body (10.3%), people below 18 years cannot donate the organ (8.3%), patients with hypertension and diabetes cannot donate organs (9.4%), organ donation can be done only after death of the patient (6.9%) and religion do not allow them to donate organs (6.6%).

**CONCLUSION:** These rural people lack awareness with regard to brain-death and procedure of organ donation requiring spreading awareness for understanding of the concept of brain-death and organ donation through awareness campaign.

**KEYWORDS :** Organ Donation, Organ Transplantation, Transplantation Of Human Organs Act

### INTRODUCTION:

Organ donation is defined as an act of giving one or more organs, without compensation, for transplantation to another person<sup>[1,2]</sup>. Organ transplantation is one of the most important medical advances of the century as it provides a way of saving the life of the needy patient. The issue of organ donation is complex and multi-factorial involving medical, legal, ethical, organizational, and social factors.<sup>[3-6]</sup> Organ Transplantation is a major treatment protocol for a number of cases of end stage organ failure.<sup>[7]</sup> Organ transplantation saves thousands of lives worldwide. According to WHO, globally 6600 kidney donations, 21000 liver donations and 6000 heart donations were transplanted<sup>[8]</sup>. In spite of this, organ shortages are a global problem<sup>[9]</sup>. Asia lags behind much of the rest of the world in organ donation and transplantation. While India ranks second in the world in organ transplant surgeries by live organ donors<sup>[10]</sup>, its deceased organ donation rate is 0.08 per million populations per year<sup>[11,12]</sup> which is very low. In India, the Transplantation of Human Organs Act (THOA) was enacted in 1994<sup>[12]</sup>. Yet the rate of organ donation in India is poor (0.34 per 100 000 population) compared to developed countries<sup>[13]</sup>. There is a huge shortage of organs in India, and needy patients die while on the waiting list as they do not get an organ on time<sup>[14]</sup>. In addition, organ donation following brainstem death is infrequent in India. THOA (1994) defines brainstem death as 'the stage at which all functions of the brainstem have permanently and irreversibly ceased'<sup>[15]</sup>. However the vital organs such as heart, lungs, liver, pancreas and kidneys can be kept viable for few days if supported by artificial or mechanical support. It is during this time, the family members can humanly opt for donating the vital organs of brainstem dead person to an end stage patient who is waiting for a second chance at life.

The current demand in the country for kidney transplants is 150,000; liver 200,000 and heart 150,000<sup>[16]</sup>. The greatest obstacle to organ donation is the refusal of family consent<sup>[17]</sup>. Lack of awareness, myths and misconceptions about organ donation add to the low percentage of organ donation. Knowledge, attitudes, and behaviour are essential factors in fostering an environment that positively influences organ donation rates<sup>[18-22]</sup>. The aim of our study is to fill these gaps regarding

awareness of organ donation among young adults in general public in rural area.

### OBJECTIVES:

1. To assess the knowledge, attitudes and practice regarding organ donation among adult population in rural areas.
2. To assess the common barriers which prevent these people from volunteering for organ donation

### METHODOLOGY:

The present community based cross-sectional study is conducted in young adult in the age bracket of 18–40 years belonging to the service areas of Rural Health Training Center of Government Medical College during July and August 2019. For this study, a sample size of 344 is calculated assuming a prevalence of 52.8% from a previous study for knowledge, attitudes and practices of organ donation, at 95% confidence interval and allowable error of 10%<sup>[23]</sup>. The formula used for calculation of sample size was  $n = Z^2 (p q) / L^2$ . The calculated sample size was rounded off to 350. Thus, a total sample of 350 young adult subjects in the age group of 18 to 40 years were covered for present study. Individuals less than 18 years and more than 40 years, not belonging to the RHTC areas and not willing to give consent to participate in the study were excluded from the study.

Prior permission for the study is obtained from concerned authorities. House to house survey in the RHTC area is conducted and from each house one individual belonging to 18 to 40 years of age is randomly selected and interviewed by using pretested semi structured questionnaire after explaining the purpose of the study. First house is selected by rotating the bottle and the neck of bottle pointing the house is first house in the survey. In addition to socio-demographic information, data about Knowledge of the respondents is assessed through questions regarding meanings of the terms "organ donation", awareness of donation by living people as well as cadavers, purpose, organs which can be donated and the sources of information for their knowledge. Attitudes of the respondents regarding organ donation was determined through questions regarding opinions on issues such as the

willingness to donate organs in the future, influence of religion on attitude towards organ donation, allowance for incentive-based organ donation and factors influencing choice of recipient for future donation. Practices are measured by enquiring about actual donation of any organ, reason for donation and whether they have signed an organ donation card. In case the participant is not available at the time of home visit the participant from next house is selected till 350 participants were covered.

Data so collected was analyzed using Epi Info software. Descriptive statistics, frequency, percentage and mean was estimated as appropriate. Chi -square test was used to find the association between the attributes.

Ethical approval by Institute Ethics Committee was obtained before start of study and informed consent from participants was also be obtained.

**RESULTS:**

**Table 1: Socio demographic characteristic of study participants**

Characteristics	Frequency	Percentage
Age(Years):		
18-25	93	26.6
26-30	58	16.6
31-35	65	18.6
36-40	134	38.2
Sex:		
Male	180	51.4
Female	170	48.6
Marital Status:		
Married	283	80.9
Unmarried	67	19.1
Education:		
Illiterate	32	9.1
Primary	21	6.0
Secondary	52	14.9
Higher secondary	168	48.0
Diploma & above	77	22.0
Occupation:		
Farmer	73	20.9
Labourer	61	17.4
Shopkeeper	28	8.0
Business	28	8.0
Student	55	15.7
Housekeepers	105	30.0
Religion:		
Hindu	270	77.1
Buddhist	22	6.3
Muslim	58	16.6
Family type:		
Nuclear	123	35.1
Joint	227	64.9

Table 1 shows the demographic characteristics of participants. In the present study 26.6% participants belonged to the age group 18 to 25 years, 16.6% to 26 to 30 years, 18.6% to 31 to 35 years and 38.2% to 36 to 40 years of age group. The mean age of the participants was 31.1 years. There were 51.4 % male and 48.6% female participants. In the study 80.9% participants were married while 19.1% were unmarried. 9.1% participants were illiterate while 91.9% were literate. There were 20.9 % farmers, 17.4% labourers, 8% shopkeepers, 8% businessmen, 15.7% students and 30.0% participants were house keepers. 77.1% participants were Hindus while 16.6% were Muslim and 6.3% were Buddhist. 35.1% participants belonged to nuclear families and 64.9% to joint families.

**Table 2. Respondent's knowledge about organ donation and transplantation.**

Knowledge	No. of participants	Percentage
Heard about organ donation	350	100.0
Know whom should be contacted for organ donation	132	37.7
Eligibility status for organ donation (Living donor/brain dead patients/after death)	142	40.6
Know types of organs that can be donated (at least three)	310	88.6
Know someone who had donated or received transplantation	23	6.6
Have heard about brain death	69	19.7
Have heard about organ donation card	45	12.9

Aware about legislation for organ donation	37	10.6
Knows cadaveric organ donation	316	90.3

In the present study all 350 participants have heard about the term 'organ donation. Majority of them knew about blood donation and kidney donation. 88.6% participants knew about the various (at least three) organs- kidney, lung, liver, heart, retina, blood etc. that can be donated. None of these respondents knew about skin, small intestine, veins, ligaments or tendon donation. 37.7% participants knew about to whom should be contacted for organ donation i.e. either signing the authorized organ and tissue donation forms (form no 7 as per THOA) available in medical institutions or by signing up with website www.notto.nic.in. Eligibility criteria for organ donation was known to 40.6% participants. Only 6.6 % participants knew the individuals from their community who donated their organs that to about eye donation, blood donation and kidney donation. 19.7% participants heard about brain death.12.9% and 10.6% participants were aware about the organ donation card and legislation about organ donation respectively. 316(90.3%) participants knew about cadaveric organ donation. (Table 2)

**Table 3. Respondents' source of knowledge about organ donation and transplantation.**

Source of knowledge	No. of respondents	Percentage
Television	155	44.3
Internet	47	13.4
News paper	71	20.3
Posters	38	10.9
Health providers	70	20.0
Friends/ relatives	57	16.3

Source of information regarding organ donation is given in Table 3. Television was the leading source of information for most people regarding organ donation in 44.3% participants followed by newspaper 20.3% and health care providers i.e. in 20.0% participants. Posters in 10.9%, internet in 13.4% and friends/relatives 16.3% also played a good source of information. Mass media i.e. television, internet, newspaper and posters was the major source of information about organ donation i.e. 82.6% participants received knowledge about organ donation from various mass media.

**Table 4: Attitude toward organ donation among the study participants**

Attitude	Number of participants	Percentage
Willingness to donate organ in future	192	54.6
Want to discuss with family members about organ donation	61	17.4
Not willing to donate organ/ tissue	97	27.2
Willing to donate to only own family members/relatives	55	15.7
Willing to donate to unknown members	137	39.1
Registered for organ donation	7	2.0

Table 4 represents attitude toward organ donation in participants. 54.6% of the study participants showed their willingness about organ donation in future while 17.4% participants wanted to discuss about organ donation with their family members before deciding organ donation.

27.7% participants refused to donate organ/tissues. Reasons given by them for their unwillingness to donate organ/tissue were-'engaged in hard labour work', 'their low socioeconomic condition', 'fear of organ donation processes, 'only earning member in the family' etc. Among those 192 respondents who were willing for organ donation, 55 (28.6%) were willing to donate organ to their family members or relatives while 137 (71.4%) participants were willing to donate organs to unknown needy patients also. Only 7 (2.0%) were registered for organ donation. All seven were registered for blood donation. During the survey the participants were counseled for organ donation after the interview was over. Of 350 participants 267 (76.78%) participants signed the organ donation forms.

Participants are considered to have adequate knowledge if they heard about organ donation and knew about eligibility status for organ donation, and place of registration. Similarly, participants are considered to have positive attitude for organ donation if they are

willing to donate organ in future and willing to donate organs to unknown members. In the present study 122 (34.8%) participants had adequate knowledge about organ donation while 137 (39.1%) participants had positive attitude for organ donation.

**Table 5: Demographic characteristics of the participants and adequate knowledge in them.**

Demographic characteristics	Have adequate knowledge (%)	Do not have adequate knowledge (%)	Total	Chi sq.value P- value
Age: 18-30 years	51 (33.8)	100 (66.2)	151 (100)	0.13
31-40 years	71 (35.7)	128 (64.3)	199 (100)	P>0.05
Sex: Male	78 (43.3)	102 (56.7)	180 (100)	11.72
Female	44 (25.9)	126 (74.1)	170 (100)	P<0.05
Marital status: Married	110 (38.9)	173 (61.1)	283 (100)	10.48
Unmarried	12 (17.9)	55 (82.1)	67 (100)	P<0.05
Education: Illiterate	14 (43.7)	18 (56.3)	32 (100)	1.22
Literate	108 (33.9)	210 (66.1)	318 (100)	P>0.05
Religion: Hindu + Buddhist	117 (40.1)	175 (59.9)	292 (100)	20.71
Muslim	5 (8.6)	53 (91.4)	58 (100)	P<0.05
Family type: Nuclear	67 (54.4)	56 (45.5)	123 (100)	32.13
Joint	55 (24.2)	172 (75.8)	227 (100)	P<0.05

Table 5 shows association of demographic characteristics with adequate knowledge about organ donation. In the present study more male (43.3%) and married respondents (38.9%) had adequate knowledge about organ donation as compared to female and unmarried

respondents. Similarly, more respondents belonging to Hindu and Buddhists (40.1%) and belonging to joint families (54.4%) had adequate knowledge about organ donation. These differences are statistically significant (p<0.05)

**Table 6: Demographic characteristics of the participants and positive attitude about organ donation in them.**

Demographic characteristics	Have positive attitude (%)	Do not have positive attitude (%)	Total	Chi sq. Value P- value
Age 18-30 years	58 (38.4)	93 (61.6)	151 (100)	0.06
31-40 years	79 (39.7)	120 (60.3)	199 (100)	P>0.05
Sex Male	86 (47.8)	94 (52.2)	180 (100)	11.6
Female	51 (30.0)	119 (70.0)	170 (100)	P<0.05
Marital status: Married	121 (42.8)	162 (57.2)	283 (100)	8.1
Unmarried	16 (23.9)	51 (76.1)	67 (100)	P<0.05
Education Illiterate	13 (40.6)	19 (59.4)	32 (100)	0.03
Literate	124 (38.9)	194 (61.1)	318 (100)	P>0.05
Religion Hindu + Boudh	125 (42.8)	167 (57.2)	292 (100)	9.93
Muslim	12 (20.7)	46 (79.3)	58 (100)	P<0.05
Family type Nuclear	74 (60.2)	49 (39.8)	123 (100)	35.17
Joint	63 (27.7)	164 (72.3)	227 (100)	P<0.05

From table 6 it is found that more male respondents, married respondents, respondents belonging to Hindu and Buddhist religion and respondents belonging to nuclear families had positive attitude as compared to their counterparts. These differences are statistically significant (p<0.05).

**Table 7: Misconceptions about organ donation**

Statements	Number of participants	Percentage
Organs can be sold or misused by hospital authority	48	13.7
Organ donation after brain death is disfigures the dead body	36	10.3
There are age limits in organ donation	27	7.7
Person below 18 years cannot donate organ.	29	8.3
People with diabetes and hypertension should not donate organs	33	9.4
There religious norms prevents from organ donation	23	6.6
Organs can be donated only after death	24	6.9

In spite of having some knowledge about organ donation in 350 participants, various misconceptions about organ donation were also prevalent in them.

Table 7 shows that 13.7% respondents thought that there is a chance to misuse the donated organs. 10.3% participants thought that organ donation disfigures the body. 8.3% participants thought that people below 18 years cannot donate the organ. 9.4% opined that patients with hypertension and diabetes cannot donate organs. 6.9% said that organ donation can be done only after death of the patient. 6.6% participants believed that religion do not allow them to donation organs.

## DISCUSSION:

Organ and tissue transplantation has become an integral part of health care services in every nation. It saves lives, increases life expectancy, improves quality of life and has cost benefits for community. In recent years, the cost of transplantation has become significantly lower, and organ transplantation is one of the most effective lifesaving procedures [24]. Rapid advancement in research pertaining to transplantation of organs and tissues have however, failed to meet the increasing demand for donor organs resulting in severe shortage of donor organs [25].

Even though almost all the respondents had heard about organ donation, we found that only 54.6% participants were willing to donate their organs under any circumstances. However only 2% participants registered for organ donation before the conduct of survey and that to for blood donation. During the survey the participants were counseled for organ donation after the interview was over. Of 350 participants 267 (76.28%) participants signed the organ donation forms. In present study only 19.7% participants knew about concept of brain death and aware of organ donation after brain death. India ranked 2<sup>nd</sup> in live organ donations in the world [10]. Awareness of concept of brain death and its importance for organ donation was extremely low in people and very few were aware about legal aspects of brain death in India [25]. Bharambe V et al also reported that only 7.3% knew that in India a brain death person is legally accepted as dead and 14.6% were aware of organ donation following brain death [26]. This needs to create awareness among these rural people about brain death which involves loss of brain function permanently and irreversibly and use of vital organ such as heart, lungs, liver, pancreas and kidneys of such deceased person for transplantation to the end stage patients. Though THOA was enacted in India in 1994, yet in the present study only 10.6% respondents were aware about the legislation related to organ donation. Similar findings were also observed by Annadurai K et al [14], Pouraghaei M [27] and Coelho JC et al [28].

17.4% participants said that they will think about organ donation after discussion with their family members. 27.7% participants are unwilling to donate their organs, even blood to the needy people. This required consistent counselling of these people about organ donation

which will help to change their attitude for organ donation and also help to remove any fear about donation procedure.

In present study Mass media i.e. television, internet, newspaper and posters was found to be the major source of information about organ donation, similar to the earlier studies<sup>[7,29-32]</sup>. It is a disappointing trend to note that only 20.0% people had heard about organ donation, through a health care worker. Alghanim found that 90% of the respondents in their study reported that contribution of health care providers as a source of information was 'none' or little<sup>[33]</sup>. Similar observations were also reported by Kaistha Madhvi et al<sup>[34]</sup>. Comparing our results with the previous study done in Pakistan, it is clear that television, print media and doctors fall in the same order of frequency with regards to being sources of information for organ donation.<sup>[22]</sup>

Greater emphasis should be paid on spreading awareness and understanding of the concept of brain death and organ donation through various mass media.

Efforts should be made to increase the participation of health care providers in creating awareness of organ donation in the general population. As a first step, the medical curriculum should increase health care worker's awareness of the organ shortage problem and how it can be effectively addressed.<sup>[35]</sup>

in turn these health care workers and other mass media will help to spread awareness about organ donation in the community.

### CONCLUSION:

This study was conducted with an aim to know about the community level knowledge, attitude and practice regarding organ and body donation. It was observed that adequate knowledge of organ donation was present in 122 (38.60%) and, the knowledge was significantly high in male literate participants belonging to Hindu and Buddhists. Though in majority of participants, the source of knowledge being mass media, there is still a lack of awareness with regard to brain-death and also most of them are not aware about the procedure, facts, organs that can be donated. Larger emphases are needed to put on spreading awareness for understanding the concept of brain-death and organ donation.<sup>[36]</sup> The communication gap between patients and doctors should be bridged for the generation of a more favorable attitude towards organ donation in the population. This needs to be addressed through awareness campaigns in the community and also popularize during their contact with the health system.<sup>19</sup>

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