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Research article

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### A study of knowledge, attitude and behavior of urban population of National Capital Territory of Delhi (aged 15 – 45 years) about organ donation

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#### ABSTRACT

##### Aim of the study

To assess the level of knowledge, attitude and behavior of urban population of Delhi in the age group of 15 – 45 years about organ donation.

##### Material and Methods

Urban people of Delhi in the age group 15 – 45 years were targeted for the study. An already validated questionnaire was pretested for a small sample. Some changes were suggested and were incorporated in the questionnaire. Then this questionnaire was validated by the experts. Questionnaire was a structured one and included questions to assess the knowledge, attitude and the behavior of the people about Organ Donation.

##### Results

384 people were recruited for the study. Only 3.38% (n=13) were already registered as an organ donor. 52% (n=201) of the respondents were found to have average knowledge about organ donation, 35.93% (n=138) of the respondents had a good knowledge and 4% (n=15) were found with very good knowledge about organ donation. So, the knowledge of the respondents was found to be adequate. Almost all the respondents had a positive attitude towards organ donation but some respondents were concerned about some issues like body disfigurement after organ retrieval process and the possible misuse of the organs. 39.84% (n=153) of the respondents were willing to register as an organ donor and 34.11% (n=131) gave their response as “May be” but, they showed no reluctance towards registering as an organ donor.

##### Conclusion

Although respondents had adequate knowledge and positive attitude towards organ donation, still the willingness to register as organ donor was not satisfactory. Issues which are refraining people from registering as an organ donor must be addressed.

**Keywords:** Organ donation, Knowledge, Attitude, Urban people, Delhi

## INTRODUCTION

Organ donation and transplantation has proved to be a ray of hope for all the end stage life diseases [1] whose organs can no longer can take their life further. Organ donation is the act of humanity in its purest form. [2]

When the first organ transplantation was done in 1954 [3], it was thought that this transplantation will change the lives of many people who are suffering from end stage diseases [4]. But for transplantation of any organ, there should be a donor. Although, the transplantation gained lot of popularity across the world and new technological advancements have made this procedure much easier, but still a lot of people die waiting for a donor [5]. The scenario is almost same in all the countries more or less, donors list is too short and the waiting list for the transplantation has been increasing enormously [6].

According to international registry in organ donation and transplantation, in 2017, the actual deceased organ donor in USA and UK was 31.96 and 23.05 per million people respectively which is very low [7]. The deceased organ donor in India is 0.34 persons per million [7]. In America, 20 people die every day waiting for a transplant [8]. According to a survey in India every year about 5,00,000 people die because of non-availability of organs, 2,00,000 die due to liver disease, and 50,000 people die because of heart disease. [9]

The requirements for a successful transplant of an organ from a deceased donor starts with the consent of the kin of the donor, awareness and the attitude of the family members is also very important for giving the consent. There is also a provision for people to register as an organ donor with any organization or with the government [10]. Lack of knowledge and understanding about organ donations, religious attitudes, and superstitious beliefs have generated fear and because of these reasons, people refrain themselves from registering as an organ donor or giving consent for donation of organs of their loved ones [11]. Although there have been several studies which have assessed the awareness and attitudes of the people. But these studies have mainly focused the attitudes of the health care providers [12]. However, there has been lack of studies done on the perceptions of the general people towards organ donation. This study is even rarer because, it targets only a particular age group people i.e. 15 – 45 years. The young

population can easily influence the mind of their family members. Moreover, in the case of emergency situations in their families they would be the decision takers [13]. So the assessment of knowledge, attitude and behavior of young people will give us an opportunity in understanding the thought process, their knowledge, their apprehensions and beliefs.

## MATERIALS AND METHODS

This was a cross-sectional descriptive survey. The target population were all the people who are in the age group 15- 45 years in Delhi. The sample size of the survey was calculated through Cochran's formula [14]. So, the calculated sample size was calculated as 384. Non-random quota sampling technique was used to recruit participants in the survey. Groups were made on the basis of religion. Accordingly samples were recruited from each group.

### Data collection

A constructed questionnaire which was developed and validated by Singh R. et al. in 2018 [15]. which was made for the Arabic world was used. Small changes were incorporated in keeping Indian context in mind. Then the questionnaire was validated by the expert. Participants were approached through an online web based (Google forms).

### The questionnaire included 4 sections

1. Section A: this part consisted of items related to demography. Age, gender, religion and education were asked. Two more items were added, awareness about organ donation and source of information about organ donation.
2. Section B: This part of items intended to measure knowledge level of the participants about organ donation. Questionnaire consisted of items about organ donation and transplant law, awareness about organ donor card, the age at which one can register as an organ donor, when can the organs be donated, what organs can be donated after death, awareness of difference between brain death and coma, do their religion allow organ donation and if they have discussed about organ donation with their religious leaders. Correct responses were given scores accordingly.
3. Section C: this part consisted of 11 items with 5-point Likert scale [16] that ranged from

“strongly disagree” to “strongly agree” to assess participants’ attitudes toward organ donation. Points ranging from 1 to 5 were given to each response such that the more the positive the response, the higher the score.

- Section D: this part of the questionnaire measured participants’ willingness to register as an organ donor. 3 more items were added including willingness to motivate others to register, discussion about organ donation with social groups and if they would donate organs of their loved ones.

### Ethical consideration

This research study was cleared by Delhi Pharmaceutical Sciences and Research University – Biomedical Human Research Ethical Committee (DPSRU-BREC/2019/A/003). Moreover, all the participants were given the informed consent form and the purpose of the study was told. They were given freedom to not to submit the responses. Participants’ confidentiality was maintained. Responses were anonymous.

### Statistical Analysis

Sample size was checked by Epi Info Software. Descriptive analysis was done by Ms Excel. Descriptive analysis including frequency, percentage, mean and standard deviation were used.

### RESULTS

The sample of the present study consisted of 384 individuals of age group 15- 45 years. The sample consisted of 59.64% (n=229) male and 40.36% (n=155) female. 33.85 % ( n=130) were from age group 15- 25 years. 40.10% (n=154) were from age group 25- 35 years. 26.05 % ( n=100) were from age group 35- 45 years. Majority of the sample 80.20 % (308) were Hindus,

12.76 % (49) were Muslims, 4.42 % (17) belonged to Sikhism. All the participants heard about the organ donation. Majority of the participants acknowledged that television (38.80%) and social networking sites (22.40%) were the main source of information about organ donation. (Table 1)

**Table 1: Characteristics of the sample**

Variables	Number of responses	Percentage (%)
Age (in years)		
15 – 25	130	33.85
25 – 35	154	40.10
35 – 45	100	26.05
Gender		
Male	229	59.64
Female	155	40.36
Education		
Senior secondary and above	33	8.59
Graduate	166	43.22
Post graduate and above	185	48.12
Religion		
Hinduism	308	80.20
Islam	49	12.76
Christianity	4	1.04
Sikhism	17	4.42
Jainism	5	1.30
Other	1	0.26
Heard about organ donation		
Yes	384	100
No	00	
Source of information about organ donation		
Television		
Newspaper		

Health- care providers	149	38.80
Family/ friends	58	15.10
Social networking sites	63	16.41
	28	7.29
	86	22.40

Table 2 denotes the level of knowledge about organ donation among the participants. Only 36.20% (139) were about the parliamentary that governs the organ and transplant activities in India. 40.36% (155) knew about the organ donor card. 76.82% gave the correct response to when the organs can be donated. 66.67% knew the correct age at which a person can register as an organ donor. 80.47% of the participants didn't know how to register as an organ donor. Only

28.64% knew the difference between brain death and coma. 35.45% of the participants considered brain death and coma as same. 60.94% of the people knew if their religion allowed organ donation or not but only 14.84% discussed about organ donation with their religious leaders. Only 21.61% of the participants knew that intestines can be donated after death. Only 26.30% knew that pancreas can be donated after death.

**Table 2: Organ donation knowledge among urban people of Delhi**

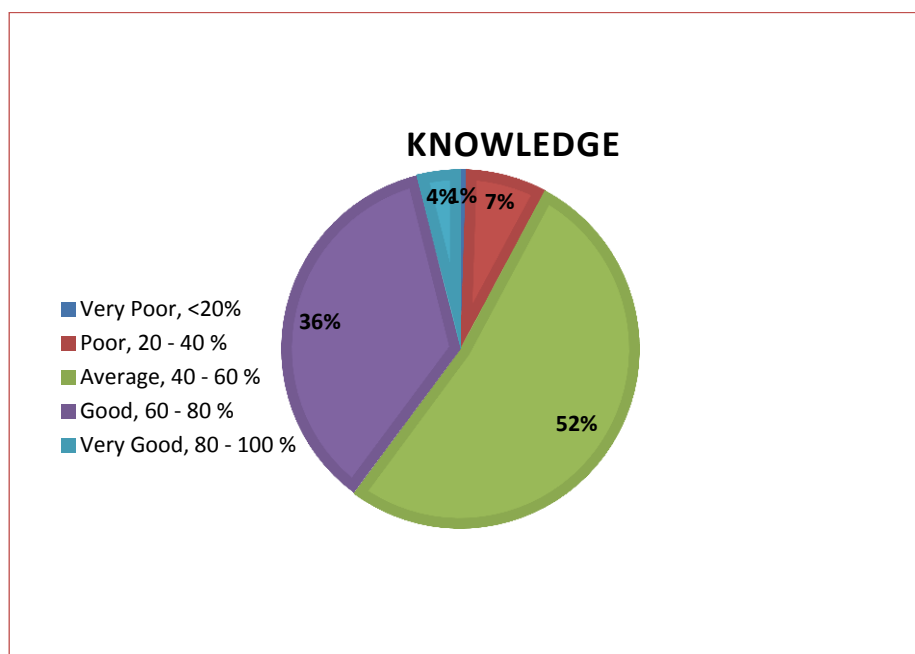
Questionnaire domains/items	Number of positive/correct responses	Percentage
<b>Knowledge</b>		
1. Are you aware of the parliamentary law that governs all organ and transplant activities in India?	139	36.20
2. Do you know what an organ donor card is?	155	40.36
3. When can the organs be donated?	295	76.82
4. At what age can an individual register for organ donation?	256	66.67
5. Do you know how to register as an organ donor?	75	19.53
6. Do you know the difference between coma and brain death?	110	28.64
7. Does your religion allow organ donation?	234	60.94
8. Have you discussed about organ donation with your religious leaders?	57	14.84
9. Can these organs be donated after death?		
Kidneys	382	99.48
Heart	273	71.09
Liver	295	76.82
Lungs	178	46.35
Pancreas	101	26.30
Intestines	83	21.61
Cornea	283	73.70
Skin	162	42.19
Bone Marrow	300	78.12
Bone	173	45.05

**Table 3: The number of respondents (total) in different grades of knowledge**

Grades	Knowledge	
	Percent	Number of respondents
Very poor	<20%	02(1%)
Poor	20 – 40 %	28 (7%)
Average	40 – 60 %	201(52%)
Good	60 – 80 %	138(36%)
Very good	80 – 100 %	15(4%)

Table 3 shows that the knowledge of 52% of the participants was found to be average, 36% had good

knowledge and 4% had very good knowledge about organ donation.



**Figure 1: Respondents in different grades of knowledge**

Table 4 describes participants’ responses to organ donation attitude questionnaire. Majority of the participants (n=281, 73.18%) considered organ donation a good thing and agreed that it should be promoted. 87.24% (n=335) of the participants agreed that organ donation can save somebody’s life.

35.67% of the participants were concerned about the body disfigurement after organ retrieval. 61.71% of the participants were worried about the possible misuse of the organs. 57.81% of the participants agreed that government should provide financial help to those families who donate organs.

**Table 4: Attitude of the people towards organ donation**

Questions	Strongly Agree (SA)	Agree (A)	Neutral(N)	Disagree (D)	Strongly Disagree (SD)	SA+A	SD+D
Do you agree that organ transplant is safe	70 (18.23%)	211 (54.95%)	84 (21.87%)	15 (3.91%)	4 (1.04%)	281 (73.18%)	19 (4.95%)
Do you agree that organ donation is an act of humanity and will be	76 (19.80%)	190 (49.48%)	93 (24.22%)	16 (4.17%)	9 (2.34%)	266 (69.28%)	25 (6.51%)

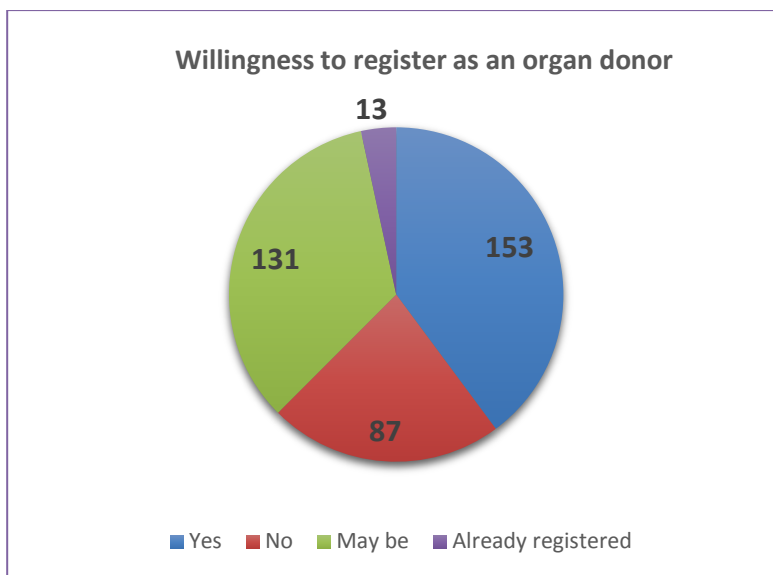
rewarded by God							
Do you agree your organs will not be misused after retrieval	84 (21.87%)	153 (39.84%)	103 (26.82%)	38 (9.89%)	6 (1.56%)	237 (61.71%)	44 (11.45%)
Do you agree that you will support if a person in your family register as an organ donor	141 (36.72%)	81 (21.09%)	98 (25.52%)	52 (13.54%)	12 (3.12%)	222 (57.81%)	64 (16.66%)
Do you agree that registering as an organ donor will save somebody's life	216 (56.25%)	119 (30.99%)	39 (10.16%)	4 (1.04%)	6 (1.56%)	335 (87.24%)	10 (2.6%)
Will you be registering as an organ donor, if your family would have no objection in allowing donation of your organs after your death.	131 (34.11%)	127 (33.07%)	71 (18.49%)	45 (11.72%)	10 (2.60%)	258 (67.18%)	55 (14.32%)
Will you be registering as an organ donor, if you knew more about organ transplant and how it is done	119 (30.99%)	114 (29.69%)	105 (27.34%)	38 (9.89%)	8 (2.08%)	233 (60.68%)	46 (11.97%)
Will you be registering as an organ donor, if more information was available about the viewpoint of your religion with regard to organ donation	83 (21.61%)	155 (40.36%)	113 (29.43%)	24 (6.25%)	9 (2.34%)	238 (61.97%)	33 (8.59%)
Will you be registering as an organ donor, if you knew where and how you could register	14 (3.64%)	123 (32.03%)	174 (45.31%)	61 (15.89%)	12 (3.12%)	137 (35.67%)	73 (19.01%)
Will you be registering as an organ donor, if you saw public appeal for organ donation by media or in the press	11 (2.86%)	138 (35.94%)	115 (29.95%)	108 (28.12%)	12 (3.12%)	149 (38.80%)	120 (31.24%)
Do you agree that doctors will try hard to save person's life whether the person has pledged or not for organ donation	87 (22.66%)	208 (54.17%)	64 (16.67%)	20 (5.21%)	5 (1.30%)	295 (76.83%)	25 (6.51%)
MEAN	93.82	147.18	93.81	38.27	8.45	241	46.73

Table 5 describes the willingness to register as an organ donor. 39.84 % ( n=153) of the participants were willing to register as an organ donor. Merely 3.39 % ( n=13) were already registered as an organ donor. 34.11% ( n=131) of the participants were in the category of “May be”, means they have not decided whether they will register or not.

Table 6 compares the willingness to register in male and females. 41.93% Females were willing to register as an organ donor. On the other hand, only 38.43% of the males were willing to register. So, the willingness was found to be higher in females.

**Table 5: Willingness to register as an organ donor**

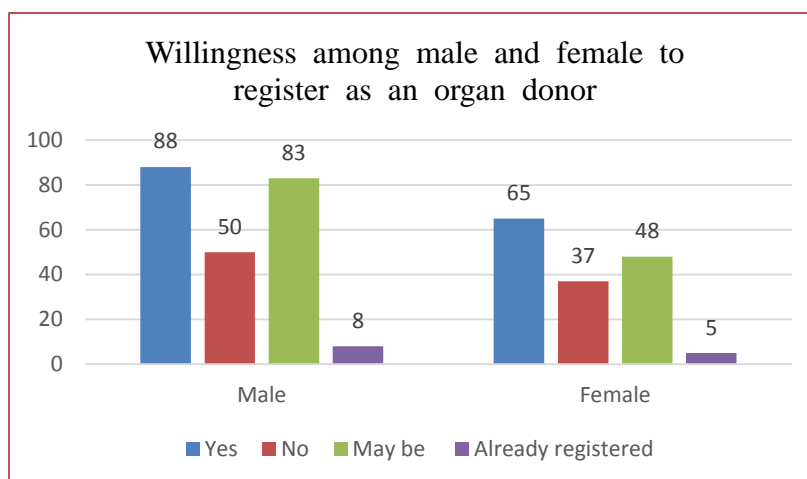
Responses	Frequency	Percentage
Yes	153	39.84%
No	87	22.66%
May be	131	34.11%
Already registered	13	3.39%
Total	384	100.00%



**Figure 2: Willingness to register as an organ donor**

**Table 6: Comparison between male and female about willingness to register as an organ donor**

Responses	Male (n=229)	Female (n= 155)
Yes	88(38.43%)	65(41.93%)
No	50(21.83%)	37(23.87%)
May be	83(36.24%)	48(30.97%)
Already registered	8(3.49%)	5(3.23%)



**Figure 3: Comparison between male and female about willingness to register as an organ donor.**



## DISCUSSION

All the participants of the study were aware about the organ donation. This could be attributed to the fact that all the people were educated and Delhi being a metropolitan city, people here are exposed to all kinds of media, hence everybody heard about organ donation. This is in line with the study previously done in Delhi [17]. Most important source of information has turned out to be television and social networking sites which is in line with the study done in tertiary care centers of south India [18]. 76.82% of the participants knew about both the living and the deceased donation which is consistent with the study done in Bangalore [19]. 66.67% of the participants knew when a person can register as an organ donor, this may be due to the fact that in India, the minimum age to register for voter card, driving license, marriage age for female is 18 years so, it is suspected that people must have extrapolated this information for organ donation as well. So, this need to be further explored if they actually knew. Only 19.53% of the participants knew how to register as an organ donor. It proves the lack of information about the registering on the media. Hence, there is a need to disseminate this information through different source of media. 60.94% of participants knew whether their religion allows organ donation or not which could be attributed to the fact that majority of the participants were graduate and above so, may be they were conscious about their religion as well. But only 14.84% of the participants have talked about organ donation with their religious leaders. Even those people who don't know about the allowance of organ donation in their religion they also have not talked about this with their religious leaders. This is an important insight which can help in increasing awareness about organ donation by engaging the religious leaders and involving them for clearing the misbeliefs attributed to religion. Majority of the participants knew which organs can be donated after death. But only 26.30% knew that pancreas can be donated and only 21.61% knew that intestines can be donated after death. This can be attributed to low popularization of these transplants in the media.

73.70% participants knew corneal transplants, 78.12% knew bone marrow transplants, 71.09% knew these organs can be donated which may be due to the fact that these transplants are popularized in the media especially in Indian television and film industry.

Regarding attitudes most of the people (78.4%) have positive attitude towards organ donation, which is consistent with the previous study [20]. But some people were concerned about the possible misuse of the organs and body disfigurement of the body after organ retrieval. These issues should be addressed through an enlightenment program or awareness campaign [21] which can clear misconceptions about these organ donation.

Regarding willingness, 39.84% of the participants were willing to register as an organ donor. But, 34.11% of the participants were not sure if they are willing or not. But, it is evident that these people are not absolutely unwilling to register but they need the counselling and persuasions to help them decide and make them willing to register as an organ donor. So, the efforts should be directed towards these people to increase the organ donation rate. This can be done by identifying their concerns and reservations and addressing them by a Targeted Educational Program. Females were more willing to register with 41.93% than males (38.43%) which is consistent with the previous research [22]. Merely 3.39% (13) of the participants were already registered as an organ donor.

Therefore, addressing the concerns regarding the risks to the organ donors is required to encourage organ donation among the general people. There is a need for awareness program through media communications which can address these issues and concerns with utmost sensitivity. They will help clearing the misconceptions and misbeliefs about the organ donation.

## Acknowledgment

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