



KNOWLEDGE AND ATTITUDE TOWARDS ORGAN DONATION AMONGST PATIENTS' ATTENDANTS AT A TERTIARY CARE HOSPITAL IN DELHI

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ABSTRACT

Title: Knowledge and Attitude towards Organ Donation amongst Patients' Attendants at a Tertiary Care Hospital in Delhi
Context: Each year thousands of lives are lost worldwide for want of human organs. The gap between supply and demand

of human organs is constantly widening. First step towards bridging this gap would be to assess the existing knowledge of people towards organ donation and dispel myths and misconceptions surrounding it.

Aims: To assess the knowledge, attitude and willingness towards organ donation amongst patients' attendants and elicit factors determining their willingness towards organ donation.

Settings and Design: Hospital based Cross sectional study

Methods and Material: 390 attendants aged between 18 – 60 years accompanying patients to various out patients' departments were interviewed using predesigned semi-structured interview schedule.

Statistical analysis: The data was analyzed using SPSS version 20.0. Simple descriptive tabulation was done for socio-demographic variables, sources of information and attitude towards organ donation. Knowledge score was computed. To find out association between willingness for organ donation and various socio-demographic variables and level of knowledge, Chi square test or Fisher's exact test was used.

Results: Most participants were (83%) were aware that organs can be donated. Majority of subjects knew that kidney (92.3%), eye (86.4%) and liver (81.8%) can be donated but knowledge about donation of other organs was very low. None of the participants had good knowledge about organ donation. Statistically significant association was seen between age and willingness to donate. Females, those who were married and had satisfactory level of knowledge showed greater willingness for organ donation.

Conclusion: Lack of knowledge about organ donations, religious and superstitious beliefs and misconceptions are the major impediments in the way of organ donation.

KEYWORDS : organ donation, knowledge, willingness, patients' attendants

Introduction

Each year thousands of lives are lost worldwide for the want of human organs. Organ donation, the gift of life to patients with terminal failure of vital organs, requires the participation of fellow human beings and of the society in general. Organ donation is referred to as the removal of some tissue or organ from the body of a person who has recently died or from a living donor for the purpose of transplantation. Approximately 25 different organs and tissues including cornea, kidney, heart, lung, liver, pancreas, stomach, intestine, middle ear, bone, cartilage, ligaments, bone marrow, blood vessels and skin can be transplanted. People of all ages may be organ and tissue donors (1).

If we look at the current global scenario there is a huge shortfall of donated organs. Organ donation rate from brain dead patients is highest in Spain, being 32 per million population (2) whereas in USA and UK it is 22 and 14 per million population respectively. The situation in India is quite dismal with an organ donation rate of 0.16 per million population (3). In India around 5 lakh people die every year because of non availability of organs. (4).

Moreover, there has been increasing incidence of vital organ failure and inadequate supply of organs, especially from cadavers, which has created a wide gap between organ supply and organ demand. These have resulted in very long waiting times to receive an organ as well as an increasing number of deaths while waiting. Therefore, these events raise many ethical, moral and societal issues regarding supply, the methods of organ allocation and the use of living donors as volunteers including minors.(5)

Hence, this study comes at a point in time when organ donation is one of the most vigorously debated ethical biomedical issues. Against this background, our study was done to assess the knowledge and attitude of a sample of population towards organ donation and also to elicit factors which determine willingness towards organ donation.

Objective

Our objectives were to assess the knowledge and attitude of patients' attendants towards organ donation, to find out their willingness towards organ donation and to identify the factors determining willingness towards organ donation

MATERIAL & METHOD

This hospital based cross sectional study was conducted at a tertiary care health facility in Delhi from May 2016 to June 2016. Attendants aged between 18 – 60 years accompanying patients to various out patients' departments of the Hospital and consenting to participate were included in the study. Attendants whose patients were critical and required immediate hospitalization were excluded from the study. Sample size was calculated using software Epi Info version 6, taking the prevalence of 50% (in the absence of any literature from India with regard to percentage of people having correct knowledge about organ donation in the general population, we assumed the prevalence of 50% so as to obtain the maximum sample size), a confidence level of 95% and an absolute precision of 5%, the sample size came out to be 384 which was rounded off to 390.

A predesigned semi-structured interview schedule was used for the study comprising of socio-demographic details of the participants like age, sex, marital status, socioeconomic status, religion, category, place of current and permanent residence, questions pertaining to their knowledge and attitude about organ donation, sources of this information and their willingness for organ donation in future.

Participants for this study were selected using convenience sampling technique from the registration area and waiting area for the patients at the hospital. Those who consented to participate were interviewed personally by the investigator using a semi-structured schedule. Selecting the participants from the registration area and common waiting area of the hospital made it possible to include attendants accompanying patients with varied illnesses. The data collection was continued till the required sample size (390) was obtained.

Statistical analysis: The data was analyzed using SPSS version 20.0. Simple descriptive tabulation was done for the socio-demographic variables, sources of information regarding organ donation, perception and attitude towards organ donation. Knowledge score was computed. There were 7 items in the questionnaire to assess knowledge about organ donation. Each item pertaining to correct knowledge was given a score ranging from 0 to 2. Hence the total score ranged from 0 to 14. A scale was developed to assess the level of knowledge of the participants as follows:

Total Score Level of knowledge

- <6 Poor
- 6– 10 Satisfactory
- > 10 Good

To find out the association between willingness for organ donation and various socio-demographic variables and the level of knowledge, Chi square test or Fisher’s exact test, as applicable, was used for categorical variables. For the purpose of this analysis age was dichotomized as 18 – 30 years and 30 – 60 years, level of knowledge as poor and satisfactory (as none of our subjects had good knowledge) and socio-economic status as middle and lower (none of our study subjects belonged to the upper class). P-value <0.05 was considered as statistically significant result.

Results Table 1: Socio-demographic characteristics of the study participants (n=390)

S. No.	Variable	Number (%)
1.	Age (years)	
	18 – 30	138 (35.5%)
	30 – 45	197 (50.4%)
	45 – 60	55 (14.1%)
2.	Sex	
	Male	316 (81.1%)
	Female	74 (18.9%)
3.	Religion	
	Hindu	370 (94.9%)
	Muslim	13 (3.3%)
	Sikh	2 (0.5%)
	Christian	2 (0.5%)
	Others	3 (0.8%)
4.	Category	
	SC	28 (7.1%)
	ST	20 (5.2%)
	OBC	45 (11.5%)
	General	297 (76.2%)
5.	Marital status	
	Married	200 (51.3%)
	Unmarried	190 (48.7%)
6.	Socioeconomic status	
	Upper	0 (0%)
	Upper middle	107 (27.4%)
	Lower middle	95 (24.4%)
	Upper lower	157 (40.3%)
	Lower	31 (7.9%)
7.	Place of residence (current)	
	Delhi	279 (71.5%)
	Outside Delhi	111 (28.5%)
8.	Place of residence (permanent)	
	Delhi	248 (63.6%)
	Outside Delhi	142 (36.4%)

Table 1 shows the socio-demographic characteristics of the study participants. Nearly half of the subjects belonged to the age group of 30 – 45 years with the mean age of the participants being 41.9 years. Majority of the subjects were males (81%) and approximately one – half of them were married. Most of the participants were Hindu by religion (94.5%) and belonged to the general category (76.2%). About half of the study subjects belonged to the middle socioeconomic class (52%), closely followed by the lower class (48%). None of our subjects were in the upper socioeconomic class.

Table 2 shows the knowledge of the participants regarding various aspects of organ donation. Majority of the subjects (83%) were aware of the fact that organs can be donated to the life of a person. However, only around one – fifths of the participants (20.3%) had correct knowledge that organs can be donated both during life as well as after death. Most of the participants (64%) thought the organs can only be donated during life. A vast majority of subjects knew that kidney (92.3%), eye (86.4%) and liver (81.8%) can be donated but knowledge about donation of other organs was very low ranging from 2.6% for bones and pancreas to 8.5% for lungs. Most of the participants

(87.2%) had correct knowledge that organs could not be sold although knowledge about brain death was very low amongst the participants and only around 11% knew about brain death. Similarly awareness about a parliamentary law regulating organ donation and organ donation card was very poor with only 12.3% and 13.3% of the subjects being aware about them respectively. However, almost 86% of the subjects expressed their willingness to carry an organ donor card.

Table 2: Response of participants regarding knowledge about organ donation (n=390)

S. No.	Knowledge about organ donation	Response Number (%)
1.	Aware that organ can be donated to save life of a person	323 (82.8%)
	Yes	67 (17.2%)
	No	
2.	When can organs be donated?	250 (64.1%)
	During life	61 (15.6%)
	After death	79 (20.3%)
	Both	
3.	Which organs can be donated?	337 (86.4%)
	Eye	23 (5.9%)
	Skin	33 (8.5%)
	Lungs	10 (2.6%)
	Pancreas	360 (92.3%)
	Kidney	10 (2.6%)
	Bones	319 (81.8%)
	Liver	
4.	Can we sell our organs?	18 (4.6%)
	Yes	340 (87.2%)
	No	32 (8.2%)
	Not sure	
5.	Have you heard of brain death?	44 (11.3%)
	Yes	346 (88.7%)
	No	
6.	Aware about parliamentary law which regulates organ donation in India?	48 (12.3%)
	Yes	342 (87.7%)
	No	
7.	Do you know about an organ donor card?	52 (13.3%)
	Yes	338 (86.7%)
	No	

Table 3: Level of Knowledge of the participants about organ donation (n=390)

S. No.	Level of Knowledge	Number (%)
1.	Poor	298 (76.5%)
2.	Satisfactory	92 (23.5%)
3.	Good	0

Table 3 shows the level of knowledge of the participants about various aspects of organ donation. Nearly three – fourths of the subjects had poor knowledge. Satisfactory level of knowledge was seen in only around 23% of the subjects. None of our study subjects had good knowledge about organ donation.

When asked about the sources of information about organ donation, majority of the participants (90%) had known about it through multiple sources. Television and newspaper as an exclusive source of information was reported by a very small proportion of participants (4%).

Attitude of the participants towards organ donation was also assessed. Less than 15% of the participants expressed their willingness to donate organs whereas a great majority (78%) was not willing for it and 7.4% of the participants were not sure of the same. However, of the 57 subjects who expressed willingness to donate organs, only 44 of them were ready to register as donors and one of them was already registered as a donor. Although 12 subjects showed willingness towards organ donation yet were not ready to register as a donor. About one – fifth (21.3%) the participants showed willingness to donate only if they knew that it was for the family or friends.

Table 4: Perception of the participants about organ donation (n=390)

S. NO.	Participants' Perception	Response		
		Agree Number (%)	Disagree Number (%)	Don't know Number (%)
1.	Giving organs take lot of time	48(12.3%)	75(19.2%)	267(68.5%)
2.	Giving organ is risk for my life	192(49.4%)	69(17.7%)	129(32.9%)
3.	Being organ donor is a private matter	92(23.5%)	82(21.1%)	216(55.4%)
4.	Being signed up as organ donor I would get better facilities in hospital	213(54.6%)	88(22.6%)	89(22.8%)
5.	You get paid as organ donor	43(10.9%)	121(30.9%)	226(57.2%)
6.	You can choose which parts to donate	304(77.9%)	18(4.6%)	68(17.5%)
7.	Everyone is a donor unless they sign up to say no	33(8.4%)	300(76.9%)	57(14.7%)
8.	Families have right to overrule your wishes regarding donation	143(36.7%)	140(35.9%)	107(27.4%)
9.	There is shortage of organ among ethnic groups	344(87.8%)	1(0.3%)	45(11.9%)
10.	You have to die in hospital to donate organ	47(12%)	293(75.2%)	50(12.8%)

Table 4 shows the perception of the participants about organ donation. More than 10% of the subjects agreed that organ donation takes a lot of time while majority of them (68.5%) did not know about it. Nearly half of the subjects (49.2%) agreed that giving organs would be a risk for his life. About one – fourth of the participants of the participants thought that being an organ donor is a private affair. More than half of the subjects felt that being an organ donor would entitle them to better facilities in the hospital. However, only around 10% of them thought that one gets paid as an organ donor. More than three- fourths of them felt that one can choose which organs to donate. Majority of the subjects disagreed that one is an organ donor unless they sign up to say no.

In order to find out the factors affecting willingness of a person to donate organs we studied the association between various socio-demographic variables, level of knowledge and the willingness to donate. Statistically significant association was seen between age and willingness to donate with participants in the age group of 18 – 30 years showing higher willingness as compared to those above 30 yrs. (p value = 0.03). Females and those who were married showed greater willingness to donate in our study as compared to males and unmarried subjects and this difference was also statistically significant (P = 0.01 and 0.04 respectively). However, the association between socioeconomic status and the willingness to donate organs was found to be statistically non significant (p = 0.66). Level of knowledge was found to be significantly associated with the willingness to donate, subjects with satisfactory knowledge showed greater willingness as compared to those with poor knowledge (p = 0.001).

Discussion

Organ and tissue transplant is an integral part of management of end stage organ failure. Findings of our study reveals that majority of the subjects (83%) were aware of the fact that organs can be donated to save the life of a person. Similar findings were reported in a study conducted by Bharambe et al in Pune, to assess the knowledge and attitude of people living in an urban city towards organ donation, which showed that 78% of the participants were aware of the concept of organ donation (7). The reason for similar findings in both these studies could be due to similar settings in which these studies were conducted, both being done in hospitals of urban areas amongst the patients' attendants.

However, only around one – fifths of the participants (20.3%) in our study had correct knowledge that organs can be donated both during life as well as after death. Most of the participants (64%) thought the organs can only be donated during life. The study done in Pune showed

that 39% of the respondents clearly stated that they had no idea regarding who can be an organ donor, although, 24.4% did report of being aware of live organ donation, 31.7% believed that organ donation is carried out after cardiac death, and only 14.6% were aware of organ donation following brain-death (7). A study conducted in Mangalore, India, by Mithra et al also observed that 94.7% of the participants were aware about both living and after death organ donations (8). This high awareness level among subjects from Mangalore could be because of the high literacy level in Mangalore. In a study by Payghan et al amongst medical students in Karnataka showed the awareness about live donors as follows: 62.9% knew about live kidney donation, 31.8% and 5.3% knew about live liver and pancreas donation (6).

A vast majority of subjects in our study knew that kidney (92.3%), eye (86.4%) and liver (81.8%) can be donated but knowledge about donation of other organs was very low ranging from 2.6% for bones and pancreas to 8.5% for lungs. The findings of our study was consistent with the Pune study which had also revealed that 53.7%, 78% and 19.5% were aware about kidney, eye and liver donations respectively. 17.1% were aware of body and lung donation each. Awareness of donation of other organs was found to be in the range of 4.9% to 14.6% (7). High level of awareness was reported about organs which could be donated by the study by Payghan et al: 97.65% for kidney, 80.88% knew about cornea and liver donation and nearly one – third of the participants were aware about lung and pancreas donation. These results were likely as the study was done amongst the medical students who are expected to have better knowledge about organ donation as compared to the general population (6).

Most of the participants (87.2%) of our study had correct knowledge that organs could not be sold although knowledge about brain death was very low amongst the participants and only around 11% knew about brain death. Similarly awareness about a parliamentary law regulating organ donation and organ donation card was very poor with only 12.3% and 13.3% of the subjects being aware about them respectively. The study by Mithra et al in Mangalore showed that regarding accepting monetary or other benefits for donating organs, 67% of their participants believed that money shouldn't be accepted for organ donations. More than half of the participants (58.1%) were aware that it is an offence in law to accept monetary or other benefits for organ donation. However, less than one-third of the respondents (n = 253, 29.3%) had heard about the Transplantation of Human Organs Act, the Indian law pertaining to organ donation and transplantation (8). These findings are much better as compared to our study, the probable reason once again being better literacy level of their participants. Similarly the study amongst medical students by Payghan et al showed much better awareness about brain death (52.65%) as can be expected (6).

The assessment of level of knowledge of the participants about various aspects of organ donation in our study showed that nearly three – fourths of the subjects had poor knowledge. Satisfactory level of knowledge was seen in only around 23% of the subjects. None of our study subjects had good knowledge about organ donation but the study by Payghan et al on medical students reported findings contrary to our study with nearly 12% of the students having very good knowledge about organ donation, 75.29% having good knowledge and only around 13% of the students had poor knowledge level (6). These findings definitely call for an urgent action with regard to awareness generation about organ donation in the population.

When enquired about the sources of information about organ donation, majority of the participants (90%) had known about it through multiple sources. Television and newspaper as an exclusive source of information was reported by a very small proportion of participants (4%). However, most of other studies have reported television as the commonest source of information about organ donation (5-10).

Less than 15% of the participants of our study expressed their willingness to donate organs whereas a great majority (78%) was not willing for it. Contrary to our study, the study by Mithra et al in Karnataka reported that while about 40% of the participants were unwilling for organ donation, a substantial proportion expressed their willingness towards donation(8). Study on medical students reported much higher willingness towards organ donation, 68.82% expressing willingness to become organ donors in future as against only 8.24% who did not wish to become donors(6). Several other studies have

reported varied levels of willingness towards organ donation suggesting that there may be a multitude of factors which determines a person's willingness towards donation. However, a finding common to most of these studies is the fact that people showed higher willingness for donation if it was meant for their relatives and friends (6 – 10).

Amongst the factors affecting willingness of a person to donate organs, our study found statistically significant association between age, sex, marital status and level of knowledge, with participants of younger age, female sex, married and those with satisfactory level of knowledge showing higher level of willingness. However the willingness to donate was not significantly associated with socio-economic status in our study. The findings of our study are in line with the study by Mithra et al in Karnataka which also showed willingness to donate to be statistically significantly associated with age, sex, socio-economic status and religion (8). In a study by Khan et al in Faisalabad, Pakistan significant association was seen between age, sex and socioeconomic status (5).

Conclusions

Although organ transplantation is the most preferred treatment modality for end-stage organ disease and organ failures, the gap between organs available for transplantation and the number of patients waiting for a transplant is widening globally. The prerequisites for the success of a transplantation program include awareness, positive attitude of the public toward organ donation and consent by relatives for organ donation in the event of brain death. Lack of knowledge and understanding about organ donations, religious and superstitious beliefs and misconceptions are the major impediments in the way of organ donation.

Recommendations

The above mentioned study provides baseline information about the level of knowledge and attitude of the people towards organ donation and also helps to elicit the factors influencing it which would go a long way in designing suitable intervention strategies like awareness generation campaigns to dispel myths and misconceptions which surround organ donation and transplantation, acquaint the masses regarding health facilities where such services are available etc. This can then be followed by creating an enabling environment for promoting organ donation with infrastructure for organ retrieval, storage and transplantation and strict enforcement of the legislation for regulating the same. These measures are likely to increase the number of people willing to donate organs.

References

1. <http://www.who.int/mediacentre/news/releases/2007/pr12/en/http://science.howstuffworks.com/environmental/life/humanbiology/organ-donation1.htm>
2. Acute Organ Donation Crisis in India. www.examiner.com/article/acuteorgan-donation-crisis-india-1;2013
3. Public Affairs, (Parliamentary and Access Branch) Common wealth Department of Health and Family Services. National Health and Medical Research Council. Donating organs after death: Ethical issues; Ethical issues in organ donation, Discussion paper no.1
4. www.giftyourorgan.org/whydonate-your-organ.html; Gift your organ- about organ donation.
5. Nahida Khan, Zahid Masood, Nadia Tufail, Hina Shoukat, KTA Ashraf et al knowledge and attitude of people towards organ donation. JUMDC Vol. 2; 2, Jul-Dec 2011, pg: 15 – 21
6. Paygan B, Kadam S, Furmeen S Organ donation : Awareness and perception about organ donation. Journal of pharmaceutical and scientific innovation
7. Vaishaly K., Rathod H, Paranjape V.M., Kanaskar N. Shevade S. , Survase K. et al. Awareness regarding body and organ donation amongst the population of an urban city in India. Nitte University Journal of Health Science. 2015 December , Vol. 5; No.4: 249-251
8. Prasanna Mithra, Prithvishree Ravindra, B Unnikrishnan, T Rekha, Tanuj Kanchan, Nithin Kumar et al; Perceptions and Attitudes Towards Organ Donation Among People Seeking Healthcare in Tertiary Care Centers of Coastal South India; Indian J Palliat Care. 2013 May-Aug; 19(2): 83–87.
9. J. R. Rodrigue, D. L. Cornell, and R. J. Howard Organ Donation Decision: Comparison of Donor and Nondonor Families; Am J Transplant. 2006 Jan; 6(1): 190–198
10. Gortmaker SL , Beasley CL , Brigham LE , Franz HG , Garrison RN , Lucas BA et al. Organ donor potential and performance: size and nature of the organ donor shortfall. Research Support, U.S. Government. Critical Care Medicine. 1996, 24(3):432-439