

Original Research Article

## Perception of Organ Donation among adults: a community-based study in rural West Bengal, India.

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**Abstract:** There is a lack of awareness and misconception regarding organ donation among people in India. The following study was done to assess the knowledge and attitude towards organ donation of people residing in a rural community of west bengal. It was an Observational, Descriptive study of cross-sectional design conducted among people randomly selected from Amdanga Community Development Block of West Bengal using a pre-tested semi-structured schedule. Out of the total 110 participants, 102 (92%) were aware of the term organ donation. Although majority of them (66%) believed organ donation to be a noble act and should be encouraged, only 24% of the respondents agreed to donate organ if required and only 20% were willing to sign organ donor card so that their organ can be harvested for donation after death. More than half of them had fear in their mind that donated organs could be misused. Proportion of people having a 'positive attitude' towards organ donation, was higher in the age group below 55 years and in people having higher educational status and the difference was significant ( $p < 0.05$ ). Mass awareness campaign should be conducted at the local level to promote organ donation among general population to tackle the problem of huge demand-supply gap of organs in India.

**Keywords:** Knowledge, attitude, organ donation, rural, west bengal.

### INTRODUCTION

Organ donation means the process of donating organs or biological tissues to a living recipient, who is in need of a transplant. The donor may be alive, brain-dead or deceased. Living donors are able to donate a very limited number of organs or biological tissue. This list usually consists of one kidney, a lobe of lung or a part of pancreas or liver. On the other hand, transplants with deceased donors (or who are brains dead) can be of the heart, lungs, kidneys, pancreas, liver as well as tissues like the cornea and bone marrow [1]. Organ transplantation remains the only available treatment for persons with end-stage failure of solid organs and the best treatment for end-stage kidney failure, both in terms of survival and quality of life, as well as cost effectiveness compared with other replacement therapies [2].

Currently, there are 77 countries with deceased donation programs. However, there are still large differences between the countries regarding access to suitable transplantation and in the level of safety,

efficacy and quality of donation and transplantation of organs [2].

A list of countries ordered by organ donation ranking, by the International Register of Organ Donation and Transplantation, shows that Spain, France, Belgium and Italy, which all have "presumed consent" laws on organ donation, where everyone is considered as a donor unless they specify otherwise, are in the top in the top five. In contrast, the USA which practices an "opt in" consent law where their citizens provide informed agreement to donate organs in the event of their death is also among the top five, ahead of many other countries that are "opt in" [3].

In India, organ donation has been very slow to take off. The primary legislation related to organ donation and transplantation in India, named as Transplantation of Human Organs Act, was passed in 1994 and is primarily aimed at the regulation of removal, storage and transplantation of human organs for therapeutic purposes and for prevention of any kind of commercial dealings in human organs [1]. Though

the number of transplants done annually has been gradually rising, still there is a poor Organ Donation Rate of 0.26 per million in India, compared to some of the better performing countries mentioned above such as Spain's 35.3, America's 26 and Croatia's 36.5 per million respectively. At present, around 1000 livers, 5000 kidneys and around 15 hearts are transplanted annually. With a slight increase i.e 1 per million-donation rate, India would have 1,100 organ donors or 1,000 hearts, 1,100 Livers, 2,200 kidneys, 1,100 Pancreas and 2,200 Eyes. This would take care of almost all the current demands for organs [4].

In West Bengal too, organ donation is a very rare concept. Lack of awareness along with myths and misconceptions among people regarding organ donation, the concept regarding brain death and the process of organ transplantation is the main reason behind this low percentage of organ donation in our state as well as in India. As more than two-third of the total population of India lives in the rural areas, the assessment of their perception regarding organ donation is of great importance to address this huge gap between demand and supply. Very few studies have been carried out so far on this issue among the rural population of India.

With this background, this study was conducted with the following objectives of a) to assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and b) to study the association of socio-demographic factors with the knowledge and attitude towards organ donation.

## **MATERIAL AND METHODS**

**Type of study:** Observational, Descriptive study of Cross-Sectional Design.

**Study Setting:** The study was conducted in selected villages of Amdanga Community Development Block(C.D) of North 24-Paraganas district, West Bengal, India.

**Period of data collection**  
February- April 2016.

### **Sample size**

In a similar study [5] done in rural kerala, India it was found that 97% (P) of people were aware of the term 'organ donation'. Assuming this as prevalence of knowledge level, sample size was calculated taking 95% confidence level ( $Z\alpha$ ), 5% relative error (d) of 97% prevalence (P) by applying the formula ( $Z\alpha^2PQ/d^2$ ). Assuming a design effect of 2 and non-response rate of 10% the sample size was calculated to be 105. The final sample size was inflated to the nearest round figure i.e 110.

## **Sample Design and method of data collection**

Amdanga C.D block has four primary health centres including Amdanga Block PHC. In the first stage, one village was randomly selected from each of these four PHC areas. Then in each village number of households was calculated according to probability proportionate to size and thus total 110 households were selected from these four villages. Households were chosen by simple random sampling in each of the villages and the data was collected interviewing the head or decision maker of that household. The respondent was briefed about the study objectives and his/her informed consent was taken.

The data was collected with the help of a pre-designed pre-tested semi-structured schedule. Before adapting the schedule review of some relevant literature on this topic was carried out in order to select some statements related to respondents' knowledge and attitudes. The schedule was then corrected and validated by the experts of the Institute and later translated in Bengali. This schedule had two sections. The first section consisted of socio-demographic characteristics of the respondent. The second part consisted questionnaire on knowledge and attitude of the respondent regarding organ donation. The last ten questions were scored (0-5) on a Five-point Likert scale ranging from strongly disagree-1 to strongly agree-5 except item no 2,3,5,8 and 9(which were inversely rated as strongly disagree-5 to strongly agree-1). The higher the total scores for this section, the more positive the attitude of the participant towards organ donation. Participants who hadn't heard of the term "Organ Donation" were not asked to answer other questions of the second i.e Organ Donation section.

## **Statistical analysis**

Data entry was made in excel software in codes and analysis was done by SPSS software (version 16 for windows). Descriptive statistical analysis was used to characterize the data. Association with the factors was tested for significance using chi-square test and  $p < 0.05$  was considered as statistically significant.

## **RESULTS**

### **Socio-Demographic**

Among the 110 participants, 79(72%) were male and 31(28%) were female. Most of them (28%) belonged to the age group of 45-54 years. Majority of the participants were Muslim(54%) and belonged to scheduled caste category(40%). Most of them had their education level upto primary. The participants mainly(70%) belonged to joint family and most of them were from Class IV socio-economic status(43%) followed by class V(31%)[table 1].

**Table-1: Socio-demographic characteristics of the participants(n=110)**

Character		Number	Percentage
Sex	Male	79	71.8
	Female	31	28.2
Age	35-44	23	20.9
	45-54	31	28.1
	55-64	30	27.2
	65+	26	23.6
Mean age in years	Male/Female	53.3/58	--
Religion	Muslim	59	53.6
	Hindu	51	46.4
Caste	General	31	28.1
	Scheduled caste	44	40.0
	Scheduled tribe	04	03.6
	OBC	31	28.1
Marital status	Married	72	65.4
	Currently Single	38	34.6
Family type	Nuclear	32	29.1
	Joint	78	70.9
Education	Illiterate	18	16.3
	Upto Primary	40	36.3
	Upto Secondary	26	23.6
	Higher-secondary	17	15.4
	Graduate	09	08.1
Occupation	Currently Unemployed	07	06.3
	Currently Employed	75	68.1
	Home-maker	28	25.6
Socio-Economic Scale(Modified Prasad)	Class V	34	30.9
	Class IV	48	43.6
	Class III	22	20.0
	Class II	04	03.6
	Class I	02	01.8

### Organ Donation perception

Out of the 110 participants, 76(96%) male and 26(84%) female i.e total 102 (92.7%) were aware of the term organ donation and thus were eligible for participation in the second section of the schedule. Out of them, only 15% knew that it can be donated both before and after death(table 2). Predominant source of information regarding organ donation was friends/family or neighbour(52%) followed by hospital staffs(20%) and electronic media(8%). Only few (4%) of them knew that apart from kidneys organs like part of the liver, lung, pancreas etc also can be donated by a living person. Almost 70% of them were not aware of any legislation regarding organ donation. Only 4% of the respondents knew someone who had donated organ or having an organ donor card. 66% of the participants believed organ donation to be a noble act and should be

encouraged(table 3). But more than half of them(58%) had fear in their mind that donated organs could be misused. Only 24% of the respondents agreed to donate organ if required and only 20% were willing to sign organ donor card so that their organ can be harvested for donation after death. Only 31% of them stated that they would support their kin if they decide to donate organ. Majority of the study participants(52%) believed that grief counselling of relatives by the hospital staffs may be successful in procuring organs in case of death in hospitals. In this study it was found that only 42% of the respondents had a positive attitude towards organ donation(table 4). People having a positive attitude was significantly higher in the groups aged between 35-54years and having educational status above higher secondary level ( $p < 0.05$ )(table 5).

**Table-2: Knowledge of the study subjects regarding organ donation (n=102)**

Variable	Statements	Male(n=76) (No/%)	Female(n=26) (No/%)	Both sexes(n=102) (No/%)	
<b>1. Organ donation means removal of organs from</b>	Dead body only	17(22.3)	6(23.0)	23(22.5)	
	Living person only	41(53.9)	12(46.1)	53(51.9)	
	Both Dead body or Living person	14(18.4)	2(7.6)	16(15.6)	
	Dont know	4(5.2)	6(23.0)	10(9.8)	
<b>2. Which of the following organs can be donated by a living person?</b>	kidney only	57(75.0)	17(65.3)	74(72.5)	
	Kidney,Liver,Lung,Pancreas	02(2.6)	2(7.6)	4(3.9)	
	Dont know	17(22.3)	7(26.9)	24(23.5)	
<b>3. Which of the following organs can be removed for donation from a dead body</b>	Eyes only	11(14.4)	5(19.2)	16(15.6)	
	Eyes and kidney only	49(64.4)	14(53.8)	63(61.7)	
	Eyes,Kidney,Liver,Heart,Lung,Pancreas	6(7.8)	1(3.8)	7(6.8)	
	Dont know	10(13.1)	6(23.0)	16(15.6)	
<b>4. Consent for organ donation of a living person to be taken from</b>	Self	61(80.2)	22(84.6)	83(81.3)	
	Spouse	10(13.1)	3(11.5)	13(12.7)	
	Any close relatives	0	0	0	
	Dont know	5(6.5)	1(3.8)	6(5.8)	
<b>5. Consent for organ donation after death</b>	Spouse	42(55.2)	7(26.9)	49(48.0)	
	Any close relative	8(10.5)	1(3.8)	9(8.8)	
	Dont know	26(34.2)	18(69.2)	44(43.1)	
<b>6. To whom organs can be donated</b>	Only Spouse	21(27.6)	6(23.0)	27(26.4)	
	Only family member	18(23.6)	12(46.1)	30(29.4)	
	Any one	31(40.7)	3(11.5)	34(33.3)	
	Don't know	6(7.8)	5(19.2)	11(10.7)	
<b>7. Is there any legislation regarding organ donation in India</b>	Yes	19(25.0)	2(7.6)	21(20.5)	
	No	8(10.5)	1(3.8)	9(8.8)	
	Don't know	49(64.4)	23(88.4)	72(70.5)	
<b>8. Do you know about organ donor card</b>	Yes	3(3.9)	1(3.8)	4(3.9)	
	No	73(96.0)	25(96.1)	98(96.1)	
<b>9. Do you know anyone who has donated organ or has organ donor card</b>	None	73(96.0)	25(96.1)	98(96.1)	
	Yes	Family	2(2.6)	1(3.9)	3(2.9)
		Friend	1(1.3)	-	1(0.9)
		Other	-	-	-
<b>10. Do you know anyone who has received transplantation</b>	None	74(97.3)	25(96.1)	99(97.0)	
	Yes	Family	2(2.7)	1(3.9)	3(2.9)
		Friend	-	-	-
		Others	-	-	-

**Table-3: The Statement and responses to them – participants’ view (n=102)**

SL No	Item	Strongly Disagree No/ %	Disagree No/ %	Neutral/ Can’t say No/ %	Agree No/ %	Strongly Agree No/ %
1	Organ donation is a noble work and it is a pleasure to help the people in need and should be encouraged.	6(5.8)	14(13.7)	14(13.7)	42(41.1)	26(25.5)
2	One can pledge for organ donation for the purpose of obtaining money.	19(18.6)	24(23.5)	16(15.6)	33(32.3)	10(9.8)
3	My religion stops me to donate organs living or dead.	17(16.6)	32(31.3)	12(11.7)	29(28.4)	12(11.7)
4	Blind religious belief and lack of awareness is an important obstacle in organ donation.	9(8.8)	21(20.5)	10(9.8)	38(37.2)	24(23.5)
5	I believe there is a danger that donated organs could be misused, abused or misappropriated.	7(6.8)	16(15.6)	19(18.6)	49(48.0)	11(10.7)
6	I am willing to donate an organ if required.	17(16.6)	37(36.2)	23(22.5)	19(18.6)	6(5.8)
7	I am willing to sign an organ donor card so that my organs can be harvested for donation after my death.	27(26.4)	35(34.3)	19(18.6)	12(11.7)	9(8.8)
8	I will not support the kin if they decide to donate organ.	11(10.7)	21(20.5)	21(20.5)	26(25.5)	23(22.5)
9	Organ donation after death should never be made mandatory.	9(8.8)	22(21.5)	19(18.6)	30(29.4)	22(21.5)
10	Grief counselling of relatives by hospital staff may be successful in procuring organs in case of death in hospitals	9(8.8)	16(15.6)	23(22.5)	33(32.3)	21(20.5)

**Table-4: Distribution of participants according to Attitude scores attained (n=102)**

Attitude score on Likert Scale			No	Percentage
	Scores Higher than 50%	‘Positive attitude’	43	42.1
Scores Below 50%	‘Negative attitude’	59	57.9	

**Table-5: Distribution of participants according to attitude and socio-demographic characteristics**

Characteristics		Positive attitude(n=43) No(%)	Negative attitude(n=59) No(%)	‘p’ value
Sex	Male(n=76)	32(42.1)	44(57.9)	p > 0.05
	Female(n=26)	11(42.3)	15(57.7)	
Age	35-54(n=50)	27(54)	23(46)	p < 0.05
	55 and above(n=52)	16(30.7)	36(69.3)	
Religion	Muslim(n=55)	24(43.6)	31(56.4)	p > 0.05
	Hindu(n=47)	19(40.4)	28(59.6)	
Education	Below Higher Secondary(n=76)	27(35.5)	49(64.5)	p < 0.05
	Higher Secondary and above(n=26)	16(61.5)	10(38.5)	
SES	Below Class III(n=75)	29(38.6)	46(61.4)	p > 0.05
	Class III and above(n=27)	14(51.8)	13(48.2)	

**DISCUSSION**

The magnitude of organ retrieval for a successful deceased donor program is highly dependent upon the level of knowledge and attitudes of general population regarding organ donation. This study was aimed to find out the prevalent knowledge and attitude

regarding this in a rural community of West bengal.. Some interesting facts came out after the analysis.

In this study, it was found that almost 92% of the study subjects were aware of the term ‘organ donation’. This finding was similar to a study done in rural kerala [5] where 97% of the people were aware

about this term. In another study conducted in an urban community of west bengal [6] it was found that only 84% of the participants knew this term. For most of them, members of family/friend or neighbours were the main source of knowledge regarding organ donation, whereas in the urban study mentioned above media was the predominant source. In this study only 16% knew that organs can be donated by both living and dead donors which is less than studies conducted in Karachi (23%) [7] and in urban west bengal (38%). Moreover this study revealed that only 4% of the participants knew that apart from eyes or kidneys organs like heart,liver,pancreas,bone marrow etc also can be donated which is far less than findings from the study done in urban west bengal and among college students in chennai (26%) [8]. 70% of the people did not know about any law regarding organ donation which was again very low as compared to some other studies. As per the attitude of the participants is concerned, only 24% of the respondents opined positively on willingness on organ donation and only 20% were ready to sign an organ donor card to pledge their organs after death. Again much higher percentage of people expressed their willingness to donate organs in some other studies e.g in west bengal 35.5% were willing to donate. Whereas, in study done in rural kerala 47% and in karachi study 62% of the respondents were willing to donate an organ. This willingness to donate organs was even more high in some studies done on participants having higher educational background e.g in medical students of karnataka (69%) [9] and post graduate medical students in Bangalore(89%) [10].

So it is evident that level of motivation regarding organ donation was very low in this rural study area. A study done in California [11] revealed that speaking to a physician about organ donation has a positive influence on the likelihood to donate an organ. The average residents of the rural areas of West Bengal are not well informed about the growing issues of organ donation. The opinions of the people in this survey can help shape future policies regarding organ donation. This study comes at a point in time when organ donation is an actively debated medical issue in India. Therefore, this is an timely and relevant research. Better awareness in organ donation and its various aspects can improve the motivation to donate.

## **CONCLUSION**

Mass awareness campaigns should be planned at the local level to improve the knowledge and attitude of the people regarding organ donation. The staffs from the primary health centers and sub-centers also have a role to play for promotion of this and to increase the social acceptance among people.

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