

Awareness about brain death and attitude towards organ donation in a rural area of Haryana, India

Puneet Misra¹, Sumit Malhotra¹, Nitika Sharma⁴, M.C. Misra², Arti Vij³,
C.S. Pandav¹

¹Centre for Community Medicine, ²Ex Director, ³Hospital Administration (CNC), All India Institute of Medical Sciences, New Delhi, ⁴Department of Community Medicine, KCGMC, Karnal, Haryana, India

ABSTRACT

Introduction: Awareness about brain death influences organ donation behaviour of community. There is huge gap in the demand and availability of organs in India. This study was carried out with the objective of assessing awareness about brain death and attitude towards organ donation in a rural community. **Material and Methods:** A community based cross-sectional study was carried out among 1050 adults in a rural area of district Faridabad, Haryana. Data were collected through a pre-tested interview schedule and analysed using SPSS v17. **Results:** 80% of the study participants had heard about organ donation. Among them, about 40% were aware of brain death. Majority of the study participants (71.5%) were willing to donate organ irrespective of circumstances. Totally, 94.6% participants had the perspective that special facility should be there for organ donors and their families. Awareness was significantly more among men and among those educated above primary level. **Conclusion:** Knowledge about brain death is crucial in convincing people into organ donation. Hence more efforts should be made to educate and make people aware about brain death and its implications for organ donation.

Keywords: Awareness, brain death, deceased, organ donation, transplantation

Introduction

Organ donation is the donation of biological tissue or an organ of human body from a living or dead person to a living recipient in the need of transplant.^[1] Organ donation activity in any country is influenced most by the awareness about importance of organ donation and brain death in the community.^[2] Over 200,000 people are estimated to be diagnosed in India with organ failure owing to varied aetiologies. These people need transplantation as part of life saving measure.^[3] The organ donation rate from deceased donor in India in 2012 was 0.16

per million population^[3] which improved to 0.34 per million population in 2013–2014.^[4] There is a huge gap in demand and availability of organ donation in India. Though blood donation seemed to be acceptable depicted by the number of units collected in 2012–2013 (587.3/100,00 population),^[5] donation of organs after death continues to be scarce.

Various hospital based studies and studies from urban areas have assessed the knowledge and awareness regarding organ donation, barriers to organ donation, awareness on need for organ donation and knowledge regarding brain death.^[6] Across all studies, majority of the participants reported no religious prohibitions regarding organ donation. However, attitude towards organ donation varied across different religious communities. Knowledge and awareness of organ donation and brain death was variable depending upon the study population.^[6-11]

Address for correspondence: Dr. Puneet Misra,
Centre for Community Medicine, All India Institute of Medical
Sciences, New Delhi, India.
E-mail: doctormisra@gmail.com

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Brain death is diagnosis and confirmation of death based on the irreversible cessation of functioning of the entire brain, including the brainstem.^[12] Nearly 70% population of India belongs to rural areas.^[13] Various studies on organ donation and brain death have been conducted in the region of southern India. There is paucity of literature regarding organ donation and its determinants in northern parts of India and especially from rural population regarding aspects of organ donation. The present study was carried out with the objective of assessing awareness about brain death and attitude towards organ donation in a rural community setting.

Material and Methods

Study was carried out in the area catered by PHC Dayalpur which is a part of Intensive Field Practice Area of CRHSP-AIIMS, Ballabgarh, Faridabad. The area comprises of 28 villages and had a total population of 48775 in 2015 (as in annual census annual census conducted by field workers of PHC Dayalpur).

Study design

Community based cross-sectional study.

Sample size

Sample size was calculated using the formula

$$n = (1.96)^2 pq/d^2$$

From the reference study,^[8] prevalence of knowledge about brain death was taken to estimate a sample size of 940 at an absolute precision of 2%.

Assuming 10% non-response rate, the final sample size was taken as 1050.

Study population and sampling procedure

Study population comprised of persons aged more than 18 years and above and residing in villages under PHC Dayalpur for at least six months. Study participants were selected using simple random sampling from HMIS data of the population covered under PHC Dayalpur. Village wise random list of adults was made and house to house visits were conducted using Family Record Card, with the help of ASHA worker.

Study instruments

A pre-tested self-designed interview schedule was used to assess the knowledge and awareness about organ donation, barriers for organ donation and socio-demographic status of participants.

Ethical consideration

Prior ethical approval for study was obtained from the Institutional Ethics Committee, All India Institute of Medical Sciences, New Delhi vide the number IESC/T-04/03.01.2014. Eligible study population were given Participant Information Sheet (PIS) and those who gave informed consent were taken as participants in the study.

Table 1: Socio-demographic characteristics of the study population

Variable	Sex		Total (n=947) (%)
	Women	Men	
Age Group (in years)			
18-20	38	37	75 (7.9)
21-30	201	162	363 (38.3)
31-40	84	80	164 (17.3)
41-50	66	79	145 (15.3)
51-60	60	54	114 (12.0)
61 and above	30	56	86 (9.1)
Caste*			
Scheduled	67	58	125 (13.8)
Lower	30	44	74 (7.8)
Artisan	21	22	43 (4.5)
Agricultural	27	24	51 (5.4)
Prestige	84	87	171 (18.1)
Dominant	250	233	483 (51.1)
Socio-economic Status			
Upper	01	00	1 (0.1)
Upper Middle	103	91	194 (20.5)
Middle	348	345	693 (73.2)
Lower Middle	27	30	57 (6.0)
Lower	00	02	2 (0.2)
Education			
Illiterate	185	33	218 (23.0)
Can read only	2	2	4 (0.4)
Can read and write only	4	10	14 (1.5)
Primary school completed	213	101	314 (33.2)
Middle school completed	43	126	169 (17.8)
High school completed	30	175	205 (21.6)
Graduation or PG completed	2	21	23 (2.4)
Marital Status			
Single	21	63	84 (8.9)
Married	439	404	843 (89.0)
Divorced/widow/separated	19	1	20 (2.1)
Land			
No Land	200	226	426 (45.0)
<1 acre	179	123	302 (31.9)
1-5 acres	86	91	177 (18.7)
5-10 acres	6	13	19 (2.0)
>10 acres	8	15	23 (2.2)
Type of House			
Kutch House	10	10	20 (2.1)
Mixed House	74	64	138 (14.4)
Pukka House	380	387	767 (81.0)
Mansion	15	7	22 (2.3)
Religion			
Hindu	476	461	937 (98.9)
Muslim	3	7	10 (1.1)

Data analysis

Data was entered in excel sheet and analysed using SPSS v17. For quantitative data, Mean \pm SD and percentages for qualitative data were calculated. Chi square was used for measuring association wherever required. Bivariate and multivariate analysis was carried out for selected variables. A *P* value of < 0.05 was considered statistically significant.

Results

Out of the 1050 participants, 103 were excluded as either they did not respond to questions or were not found even after two visits. Finally 947 participants were interviewed and included in the study.

Among the study participants, majority of males and females were in the age group of 21–30 years. Half of the participants belonged to dominant caste (51.1%) and nearly three-fourth (73.2%) were lying in middle socio-economic status strata. Majority were married (89%) and 33.2% had completed education till primary level. Majority lived in pukka house (81%) and were Hindu (98.9%) by religion [Table 1].

Totally, 80% of the study participants had knowledge about the term ‘Organ Donation’.

Table 2 shows that more than half (61.2%) of the study participants had not heard of brain death. Among those who had heard of brain death, 57.8% considered brain haemorrhage as brain death.

Table 3 shows that majority (91.4%) of the study participants were of the opinion that it is right to donate organs from cadaver.

Table 4 shows that majority of the study participants (71.5%) would like to donate organ irrespective of circumstances. Totally, 94.6% participants had the perspective that special facility should be there for organ donors and their families. Totally, 94.7% believed that there should be a provision of facility/card on organ donation.

Majority (70.5%) participants appraised that they would donate organ to anyone in need followed by 21.5% of those who preferred to donate organ to close family members [Figure 1].

Table 5 shows that knowledge of brain death was significantly more in participants belonging to prestige/agricultural/ dominant caste, participants with no land, participants with education $\geq 6^{\text{th}}$ class and among the male participants.

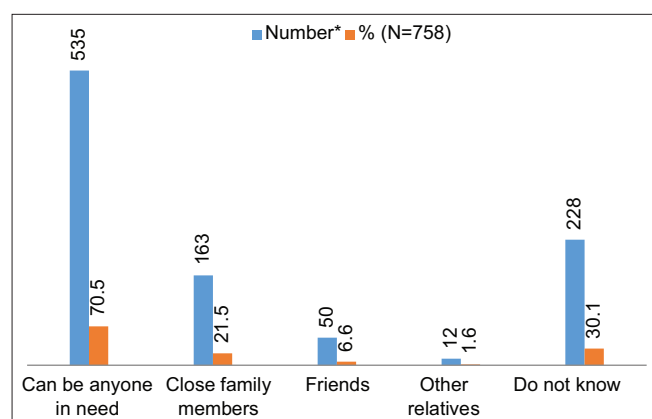


Figure 1: Preferences to whom participants would like to donate organs

On multivariate regression, awareness about brain death was significantly more among men, among those better educated ($\geq 6^{\text{th}}$ class) and among participants with no land [Table 6].

Discussion

In the present study, 947 randomly selected participants from 17 villages under CRHSP were interviewed about awareness and opinion on organ donation. In our study, it was found that 39% participants had heard of the term ‘brain death’. Among these, 57% stated that brain death occurred due to brain haemorrhage, 30% considered being in coma meant brain death. Surprisingly 13% considered psychiatric illness as brain death.

Among the various determinants, male sex, education level of $\geq 6^{\text{th}}$ standard and owing land were found to be significantly associated with awareness regarding brain death. Majority of

Table 2: Distribution of participants on the basis of awareness and understanding of ‘Brain Death’

	n	% (n=758)
Heard of Brain Death		
Yes	294	38.8
No	464	61.2
Understanding of Brain Death		
Brain haemorrhage	170	57.8
Being in coma	86	29.3
Psychiatric illness	38	12.9

Table 3: Opinion about organ donation from brain dead body/cadaver

	n	% (n=758)
Is it right to donate organs from cadaver		
Yes	693	91.4%
No	65	8.6%

Table 4: Attitude towards organ donation after death

Attitude towards donation	n	% (n=758)
Organ donation behaviour		
Definitely want to donate irrespective of circumstances	542	71.5
Think about it	154	20.3
Only donate under special circumstances	20	2.6
Never consider donating an organ	16	2.1
Health system should increase awareness about it	13	1.7
Do not know	08	1.1
Others	05	0.7
Special facility for organ donors and their family		
Yes	717	94.6
No	41	5.4
Provision of facility/card on organ donation		
Yes	718	94.7
No	06	0.8
Do not know	34	4.5

*Multiple responses

Table 5: Association of knowledge of brain death with socio-demographic variables (Bivariate Analysis)

Characteristics		Number		Odd's Ratio	95% CI	P
		Not heard	Heard			
Caste	Scheduled/Lower/Artisan	124	55	1.00		0.011
	Agricultural/Prestige/Dominant	340	239	1.658	1.10-2.27	
Land	Land present	227	171	1.00		0.0132
	No land	237	123	0.68	0.51-0.92	
Marital Status	Married/Widow/Divorced	422	256	1.00		0.092
	Single	42	38	0.67	0.42-1.06	
Education	≤5th class	294	97	1.00		<0.005
	≥6th class	170	197	3.51	2.58-4.78	
Age	≥41 years	159	96	1.00		0.65
	≤40 years	305	198	1.07	0.79-1.47	
Sex	Women	254	80	1.00		<0.005
	Men	210	214	3.23	2.36-4.43	

Table 6: Independent association of awareness about brain death with socio-demographic variables on multivariate analysis

Characteristics	Adjusted OR	95% CI	P
Caste			
Scheduled/Lower/Artisan	1.00		0.247
Agricultural/Prestige/Dominant	0.82	0.60-1.13	
Land			
Land present	1.00		<0.005
No land	0.48	0.36-0.65	
Sex			
Women	1.00		0.055
Men	1.40	0.99-2.00	
Education			
≤5 th class	1.00		<0.005
≥6 th class	3.10	2.02-4.77	

participants (91%) were of the opinion that it was right to donate from 'brain dead' body or cadaver. In the study by N Wig *et al.*^[14] among office goers, school children and villagers, it was reported that only 11% of the village population were aware about brain death. Mithra P, *et al.*^[7] in their study among the OPD attendees reported that 14.9% participants had heard brain death. Among them only 8% considered brain death equivalent to death. In the study by Alghaim SA,^[15] 30% rural participants were found to have awareness about brain death. These findings reflect a need to aware people about various aspects of brain death and its importance for organ donation.

In our study, 17% of the study participants expressed inclination to donate organs only if required by their relatives, while 56% were willing to donate to anyone in need. Balwani MR, *et al.*^[16] in their study reported that 25% and 65% of the participants were willing to donate organ to family and to anyone in need, respectively. Sam N, *et al.*^[17] in their study reported that 32.7% participants were willing to donate organs to family members and 43.6% were willing to donate to anyone in need. In the study by Saleem T, *et al.*^[18] in Pakistan, it was found that 51% participants were willing to donate to family only and about 44% were amenable to donate to anyone. The difference could

be attributed to prevalent cultural practices and religious beliefs of the study population.

In our study, 95% of the participants felt that donor card or special facility should be provided to donors and their family to facilitate organ donation. Balwani MR, *et al.*^[16] also reported that study participants felt the need to increase awareness about aspects of organ donation.

Conclusion and Recommendations

- The study pointed out that though people have heard of organ donation, but they were mostly unaware about the concept of brain death.
- Knowledge about brain death is crucial in convincing people and relatives of brain dead victims into organ donation. Primary care level can prove to be a good platform to aware communities of od and its aspects. This is because a primary care physician gets a chance to interact with general public as part of their routine activity. If they have adequate knowledge on various aspects of organ donation, they can aware the general public about the same. A prior knowledge and understanding about organ donation and brain death facilitate families to take positive decision on organ donation after death.
- Hence, more efforts should be made to educate and make people aware about brain death and its implications for organ donation. The participants considered organ donation a noble act and were willing to donate to anyone in need.

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Conflicts of interest

There are no conflicts of interest.

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