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A community based study on awareness of organ donation among young adults in rural areas of Puducherry

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ABSTRACT

Background: The objective of the study was to determine the knowledge, attitudes and practices regarding organ donation in a selected rural adult population in Pondicherry.

Methods: Simple random sampling was used to generate a sample of 100 in rural service areas of IGMC&RI. Face to face interview was conducted based on a pre-tested questionnaire in selected rural areas of Pondicherry. Data was analysed using SPSS v.22 and associations were tested using the Pearson's Chi square test.

Results: 66% of the participants in this survey had adequate knowledge score for organ donation. Knowledge about organ donation was significantly associated with employment status (p=0.025). Television emerged as the major source of information. Only 19% had donated an organ. All (19%) were volunteers who have donated blood.

Conclusions: Better knowledge may ultimately translate into the act of donation. Effective measures should be taken to educate people with relevant information with the involvement of media and doctors.

Keywords: Organ donation, Awareness, Rural, Pondicherry

INTRODUCTION

Organ transplantation is recognized as one of the most gripping medical advances of the century as it provides a way of giving the gift of life to patients who need them. The issue of organ donation is complex and multifactorial involving medical, legal, ethical, organizational, and social factors. ¹⁻⁴ Organ transplantation saves thousands of lives worldwide. According to WHO, globally 6600 kidney donations, 21000 liver donations and 6000 heart donations was transplanted. ⁵

Organ shortages are a global problem, but Asia lags behind much of the rest of the world. Organ donation following brain stem death is infrequent in India. The current organ donation for cadaver in India is 0.08 per million while Spain tops the list with 35 per million. There is a huge shortage of organs in India, and patients die while on the waiting list as they do not get an organ

on time. The increasing incidence of organ failure and inadequate supply has created a wide gap which has resulted in increasing number of deaths while waiting. Only 5% of all patients with end-stage kidney disease are successful in undergoing kidney transplantation.⁷ The current demand in the country for kidney transplants is 150,000; liver 200,000 and heart 150,000.⁸

Human organ donation was legalized in India since 1994 through 'The transplantation of Human Organs Act, 1994'. India has a fairly well developed corneal donation programme however donation after brain death is slow. To promote organ donation after brain death the government enacted "The Transplantation of Human Organs Act" amendment in 2011. 10

Every year, close to six lakh people die due to organ failure. Conversely, with 70 per cent of India's 1.4 lakh accident victims diagnosed as brain dead annually, the country has 80,000 potential organ donors. Yet, organs from only about 120 are retrieved, making the percentage of cadaver donations a dismal 0.08 per million of the population, according to MOHAN Foundation. On the other hand, in most developed countries, the cadaveric conversion is approximately 25% to 30%. This result in 90% of all organs for transplants coming from brain-dead donors. The greatest obstacle to organ donation is the refusal of family consent. Organ donation rates could be increased by enhancing the quality of hospital care and ensuring that the request for donation is handled in a way that meets the families informational and emotional needs.

Lack of awareness along with myths and misconceptions add to the low percentage of organ donation. Knowledge, attitudes, and behaviours are essential factors in fostering an environment that positively influences organ donation rates. ¹⁴⁻¹⁶ Globally the prevalence of knowledge of organ donation ranges from 60 to 85%, which varies between countries. ¹⁷

Most of the research evidence on organ donation is from developed countries. There is dearth of information in India. The aim of our study is to fill these gaps regarding awareness of organ donation among general public.

Objectives

- To determine the knowledge, attitudes and practices regarding organ donation among adults population in rural areas of Puducherry.
- To find the predictors of knowledge of organ donation in rural area of Pondicherry.

METHODS

Type of study: Community based cross-sectional study

Inclusion criteria

Inclusion criteria were all the young adults between the age group of 18–40 years; participants belonging to rural service areas of IGMC&RI; participants agreeing to participate and providing consent.

Exclusion criteria

Exclusion criteria were individuals less than 18 years and more than 40 years; individuals not belonging to the service areas of IGMC&RI; participants not willing to participate in the study/to give consent.

Study duration: March 2015 – July 2015.

Study area

The study was conducted in Karikalampakkam which is rural service areas of Indira Gandhi Medical College and Research Institute (IGMC & RI).

Study population

All the participants in the age bracket of 18–40 years belonging to the rural service areas of Indira Gandhi Medical College and Research Institute (IGMC & RI) was included in the study. Further simple random sampling was used to draw the samples from in rural service areas.

Sample size

A sample size of 99 was calculated assuming a prevalence of 52.8 from a previous study for knowledge, attitudes and practices of organ donation, at 95% confidence interval and a sample error of 10%. The formula used for calculation was $N=Z_{1-\alpha/2}^{2}*p*q/(d)^2$. This was rounded of to 100. A total sample of 100 adult subjects was covered.

Technique and tools

All the participants chosen was interviewed individually by using a pre-tested, structured questionnaire.

Methodology

The Dean of the college was contacted and the purpose of the study was explained to him in detail. Permission was obtained from "Institute Research Committee" and "Institution Ethical Committee" before the start of study. Initially, the questionnaire was pretested among 10 community members from another village. Pretesting was done among adults in the same age brackets, in a similar setting in another rural area to screen for potential problems in the questionnaire after which the questionnaire was finalized. The purpose of the study and the contents of the form was explained in detail to each participants selected. The detailed consent form was given individually to all the participants in the study. One to one interview was conducted by the investigator using a pretested, structured questionnaire. In case the selected participants are not available at the time of the first visit, two more visits were made to contact them personally. If after these 3 visits contact could not be established, no further attempt was made to contact them.

Questionnaire

The questionnaire comprises of identification data, sociodemographic information and knowledge, attitude and practice regarding organ donation in the community.

Knowledge, attitude and practice variables

Knowledge of the respondents was 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 were measured by enquiring about actual donation of any organ, reason for donation and whether they have signed an organ donation card.

Methods of statistical analysis to be used

Data was analyzed using SPSS version 22. Descriptive statistics, frequency, mean and standard deviation was estimated as appropriate. Chi -square test was be used to find the association between the attributes.

Ethical considerations

The study was given ethical approval by Institute Ethics Committee and Institute Research Council. All ethical requirements including confidentiality of responses and informed consent were maintained throughout the project.

RESULTS

A total of 100 individuals were approached for participation in our survey. Table 1 provides details of the socio-demographic characteristics of respondent population. Among the population studied 55% of them were in the age group of 31-40 years.

Table 1: Socio demographic characteristics of study population.

Socio demographic variables	Subcategory	Frequency (n=100)	%
Age group (in years)	18-30	45	45
	31-40	55	55
Condon	Males	51	51
Gender	Females	49	49
	Illiterate	13	13
	Primary school	18	18
Education	Middle school	46	46
Education	High school	18	18
	Diploma	1	1
	Graduate	4	4
	< 5000	27	27
	>5, 000 – 10,000	53	53
Income (in Rs.)	>10,000–50,000	16	16
	>50,000-80,000	3	3
	>Rs. 80,000	1	1
	Unemployed	63	63
	Unskilled	16	16
Occupation	Semiskilled	16	16
	Skilled	4	4
	Semi professional	1	1
	Hindu	98	98
Religion	Christian	1	1
	Muslim	1	1

Almost an equal proportion of male (51%) and females (49%) were represented in the study. 46% of the participants had completed middle school education. 53% of them belonged to income group of 5000–10,000. Majority (63%) were unemployed and 98% of the study participants were Hindu by religion.

Participants who hadn't heard of the term "Organ Donation" were not asked to answer other questions of the Organ Donation section. They were included among respondents who were not adequately knowledgeable about organ donation. These cumulative scores were based on a set of 10 questions; people achieving ≥50% score were regarded as being adequately knowledgeable

while those achieving less than 50% scores were regarded as being inadequately knowledgeable. Accordingly, 66% (66/100) of the respondents in this survey had adequate knowledge score for organ donation while 34% had inadequate knowledge.

Table 2 shows the proportion of respondents with adequate and inadequate knowledge in relation to different socio-demographic variables. For knowledge status of respondents, the following variables were subjected to chi square analysis: Only occupation was both found to have a significant association with knowledge scores of organ donation (p=0.025). Unemployed group emerged as significant predictor of knowledge status of respondents.

Table 2: Knowledge score of organ donation by socio-demographic variables.

Socio-	Knowledge status of organ donation					_
demographic	Sub category	Adequate knowledge score		Inadequate knowledge score		P value
variables		Frequency (n=66)	%	Frequency (n=34)	%	1 value
Age (in years)	18-30	32	48.5	13	38.2	p=0.398
Age (iii years)	31-40	34	51.5	21	61.8	p=0.398
Gender	Male	35	53	16	47.1	
Gender	Female	31	46.9	18	52.9	p=0.674
	Illiterate	6	9.1	7	20.6	
	primary school	12	18.2	6	17.6	
Education	middle school	30	45.5	16	47.1	_
Education	high school	16	24.2	2	5.9	p=0.113
	Diploma	0	0	1	2.9	
	Graduate	2	3.0	2	5.9	
	Unemployed	41	62.1	22	64.7	
	Unskilled	9	13.6	7	20.6	
Occupation	Semiskilled	15	22.7	1	2.9	p=0.025*
Occupation	Skilled	1	1.5	3	8.8	
	Semi professional	0	0	1	2.9	
	Hindu	64	97.0	34	100	
Religion	Christian	1	1.5	0	0	n=0.501
	Muslim	1	1.5	0	0	p=0.591
	< 5000	18	27.3	9	26.5	
	>5000-20,000	34	51.5	19	55.8	
Income (in Rs.)	>10,000-20,000	12	18.2	4	11.7	
	>20,000-50,000	2	3.0	1	2.9	p=0.625
	>50,000-80,000	0	0	1	2.9	

P value <0.05 is considered as significant.

The attitude among our study population towards various aspects of organ donation is shown in Table 3.

Majority (86%) opined that organ donation is effective. One third of the respondents said that they would like to donate under special circumstances. The most important special circumstance was after death (72%). More than half of the participants (64%) said that they would give importance to age of recipients. However, only 10% of them said that organ donation can be promoted. Of the 80 people who felt that organ donation should not be promoted, almost an equal proportion said that fear of organs being wasted (27.5%) and fear of mutilation (26%). Another 29% of them said that this might lead to organ trade. All the participants (89%) opined that risk is involved in organ donation which includes body weakness (76.4%), infection (12.4%), anxiety and depression (10%). Majority, 69% of the respondents opined that cost of organ transplant need not be criteria for prescription. More than half (54%) of the participants were not sure in signing the donar card. 33.7% of them refused to sign the donor card. 30% of them were afraid of misuse all the time. 73% of them said that law should be enforced to avoid misuse. A majority (71.9%) said that ethical issues were important in organ donation.

For majority (68.5%) religion was not a hindrance for organ donation. 48 (78.7%) opined that organ donation can be done to anyone irrespective of blood relation. Majority of the participants said that they would like to donate their organs to non-smoker (86.9%) and non-alcoholic (90%) respectively. 62.3% preferred donating their organs to mentally sound person. Similarly 57.4% of them preferred their organs to be donated to physically sound persons. Only 36% of them said that they would prefer physically disabled person for donation. Majority (70.5) said that organ donation can be done for people belonging to different religion.

Table 4 shows the practice of organ donation among rural subjects. Almost (43.8%) do not know anyone who had donated any organ. Only 19% of the respondents had donated organ during their life time. All the 19% of them had donated blood were volunteers. Majority (80%) had not signed the donar card. Nearly half (49.4%) of the participants family allows organ donation.

Source of information regarding organ donation is given in Table 5. Television was the leading source of information for most people regarding organ donation. Only a minority (17.8%) of the respondents reported doctors as being their source of information.

Table 3: Attitude regarding organ donation among respondents.

Attitudinal variables	Responses	Frequency (n)	%
	Yes	86	86
Effective	No	3	3
(n=100)	Don't' know	11	11
Attitude	Never consider donating an organ	8	9
	Think about it	27	30
	Only like to donate under special circumstances	29	33
(n=89)	Definitely want to donate irrespective of		
	circumstances	25	28
	Accident	5	18
Special circumstances	After death	21	72
(n=29)	If needed	1	3
	Depending on need	2	7
	Relation to the person	13	15
~	Age of recipient	57	64
Greatest importance	Religion of recipient	17	19
(n=89)	Health status of recipient	1	1
	None of the above	1	1
Promoted	Yes	9	10.1
(n=89)	No	80	89.9
	Fear that organs could be wasted	22	27.5
	Would not want to be mutilated	21	26
Reasons for not promoting	Religious belief	2	2.5
(n=80)	Family parents refusal	9	11
	Harmful for the donor	3	4
	Can lead to organ trade/ violation of rights	23	29
Any risks	Yes	89	100
(n=89)	No	0	0
	Infection	11	12.4
What are the risk	Bodily weakness	68	76.4
(n=89)	Anxiety & depression	9	10.1
	None of the above	1	1.1
Cost	Yes	20	22.5
(n=89)	No	69	77.5
	Yes	9	10.1
Sign donor card	No	30	33.7
(n=89)	Not Sure	48	54
()	Need more information	2	2.2
	Very effective	65	73.0
How effective	Effective rest of time	8	9.0
(n=89)	Partially effective	7	7.9
(12 05)	Not very effective	9	10.1
	Never	36	40.4
Afraid of misuse	Sometimes	15	16.9
(n=89)	Most of the time	11	12.4
(11-05)	All the times	27	30.3
Need for law	Yes	65	73
	No	17	19.1
(n=89)	Don't know	7	7.9
	Very important	64	71.9
Ethical issues	Important to some degree	13	14.6
(n=89)	Not important	12	13.5
	Yes	61	68.5
Does religion allows	Yes No		
(n=89)	No Don't know	11 17	12.4 19.1
	LIVIN T KNOW	1 /	

Continued.

Attitudinal variables	Responses	Frequency (n)	0/0
Relations	Family members	6	9.8
	Stranger	0	0
	Friends	3	4.9
(n=61)	Colleagues	2	3.3
	Anyone	48	78.7
	Others	2	3.3
Smoker	Smoker	1	1.6
Smoker (n=61)	Non smoker	53	86.9
(11-01)	Don't know	7	11.5
Drinker	Drinker	0	0
(n=61)	Non drinker	55	90.2
(11-01)	Don't know	6	9.8
	Young person ≤30 yrs	40	65.6
Age	Middle aged 30–50 yrs	15	24.6
(n=61)	Elderly persons >50 yrs	4	6.6
	Don't know	2	3.2
Mentally retarded	Mentally retarded	19	31.1
(n=61)	Mentally sound	38	62.3
(H=01)	Don't know	4	6.6
Physically disabled (n=61)	Physically disabled	22	36
	Physically sound	35	57.4
	Don't know	4	6.6
Religion	Person belonging to some religion	8	13.1
(n=61)	Person belonging to different religion	43	70.5
(11-01)	Don't know	10	16.4

Table 4: Practice of organ donation among rural subjects.

Practice	Sub category	Frequency (n)	%
V	Family member	9	10.1
	Friend	18	20.2
Know anyone	No one	39	43.8
	Others	23	25.9
Have you donated	Yes	17	19.1
	No	72	80.9
Which organ	Blood	17	19.1
	NA	72	80.9
Reason	Volunteer	17	19.1
	NA	72	80.9
Have you signed	Yes	9	10.1
	No	80	89.9
Family allow	Likely	44	49.4
	Possible	5	5.6
	Unlikely	13	14.6
	Never	15	16.9
	Don't know	12	13.5

Table 5: Sources of information of organ donation.

Sources of information	Frequency (n=140)	Percentage (%)
Heard from a doctor	25	17.8
Internet	14	10
TV	52	37.1
Radio	7	5.0
Newspapers	21	15.0
Friends/colleagues	10	7.1
Others	11	7.8

^{*}Multiple responses

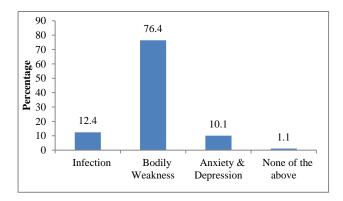


Figure 1: Reasons for not donation.

With regards to knowledge regarding the various risks associated with organ donation bodily weakness (76.4%) and infection (12.4%) were the two leading causes chosen by the respondents to be associated with organ donation as shown in Figure 1.

DISCUSSION

We aimed to study the knowledge, attitudes and practices regarding organ donation in a selected adult population of Pondicherry. Our analysis of the collected data revealed interesting findings.

Our study showed a slightly lower prevalence of adequate knowledge (66%) regarding organ donation when compared to 88% have heard about organ donation in another study. Similarly a study done in Pakistan, 65.5% reported adequate knowledge. That A study done in Lagos, Nigeria also reported that 60% respondents were aware of organ donation. This difference can be explained on the basis of two reasons. Firstly, this could be because of the difference in the study population; ours being the community study while the previous survey was done among patients. Secondly, different knowledge variables have been used in our study as compared to the previous study for the assessment of knowledge status of respondents with regards to organ donation.

We also observed that the awareness was not uniform across the study population. Only occupation was significantly associated with knowledge levels. In another study awareness was highest among those belonging to higher socioeconomic status and lowest among the uneducated and unemployed. These findings are in contrast to a study in Ernakulam where income and occupation had no influence on the level of awareness. In contrast to the previous Pakistani study which showed a significant association of the willingness to donate with gender. A study from Nigeria showed that the willingness to donate an organ was significantly associated with younger age, but not with gender. 20

Another important finding was that only 9% of them were willing to sign a donar card, in contrast to findings from other studies. ^{19,22} Our study findings are different

from data from other developing countries like Nigeria where only 30% of the respondents expressed a willingness to donate in one survey. ²⁰ In a study from Ohio, over 96% of respondents expressed favourable attitudes toward donation. ²³

Our study also shows that religious beliefs of the people did not hinder their decision to donate organs which was similar to the findings from other studies. ^{19,24,25} In this study, only 44% of them said that their family are likely to allow organ donation. The objection by family members was the most common reason that prevents them from donating organs. ¹⁹ This underlines the importance of involving family members in decision-making regarding organ donation.

In our study, 48% of individuals were willing to donate an organ to anyone. Comparing findings from other studies, where 51% respondents mentioned that they would like to donate their organs to family members. These percentages are comparable to data obtained in studies from neighbouring countries like China were 49.8% respondents indicated they are willing to be living organ donors. Sixty two percent individuals designated relatives as their most probable recipients. A study from Qatar reported that the majority of subjects preferred donating organs to their close relatives and friends.

In our study the matter of concern is that majority of them were against the promotion of organ donation. This is lower compared to other studies 57% and 87% were in favor of organ donation and its promotion in the future. ^{22,28} We can explain this difference on the basis of the reservation some people might have in view of the recent mushrooming growth of organ trade and trafficking in the country. The negativity projected by the image of organ trade can have a detrimental effect even on the organ donation for altruistic purposes because it weakens the confidence of the people in the transparency and authenticity of the process.

In our study, 73% of the people expressed the need for effective legislation to govern organ donation practices. This awareness about the legal provisions of organ donation will prevent them from getting exploited by the illegal organ trade. Effective legislation is indeed important to regulate the future practices related to organ transplantation in the country; the lack of which has allowed organ trade to spawn in recent years However, 89% of the respondents said that risks are involved if they donate their organs. Among the risks majority of them reported bodily weakness in and infections were the major risks involved in organ donation.

Media was the major source of information about organ donation, similar to the earlier studies. ^{19,24,29} It is a disappointing trend to note that only 17.8% people had heard about organ donation, through a doctor. 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. Efforts to judiciously increase the participation of doctors in the process should start at the root level. As a first step, the medical curriculum should increase medical students' awareness of the organ shortage problem and how it can be effectively addressed. 30

At the end of the survey, information regarding the procedure for organ donation was provided to all the participants. Those participants who were willing to donate organs were guided to the nearest health facility. The strength of the study is that this is a community-based study and one of the few studies in India that have assessed the awareness and attitudes regarding organ donation among the people in rural community.

Limitations

We have used a quantitative tool to assess knowledge, attitudes and practices in our survey. This approach may pose some methodological problems in the procurement of all necessary information for this study. Nevertheless, this study forms an important baseline document for future studies and a qualitative tool can be employed in further studies to gauge in-depth information.

CONCLUSION

Measures should be taken to educate people with relevant information, including the benefits of organ donation and possible risks as well so that people can make informed choices in the future. The result of this research indicates that there is need for more intensified interdisciplinary discussion and information to prepare the general population about organ donation.

Television, newspapers and doctors can be used as efficient sources of information. The communication gap between patients and doctors should be bridged for the generation of a more favourable attitude towards organ donation in the population. This needs to be addressed through awareness campaigns in the community and also popularized during their contact with the health system.

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