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Knowledge, attitude, and practice regarding organ donation among adult population of urban Puducherry, South India

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Abstract:

BACKGROUND: India is currently having a deceased donation rate of 0.05–0.08 per million population. The National Organ and Tissue Transplant Programme have planned strategies to improve organ donation by creating awareness and capacity building. There is great need to assess the knowledge regarding organ donation among general population.

OBJECTIVE (S): Among the adult population (≥ 18 years) residing in urban slum of Puducherry to determine the knowledge, attitude, and practice regarding organ donation.

MATERIALS AND METHODS: Community-based cross-sectional study was conducted during April to May 2017 among 257 randomly selected participants in selected wards of urban Puducherry. Data regarding knowledge, attitude, and practice were collected through pretested semi-structured questionnaire.

RESULTS: Mean (standard deviation) age of the study participants was 45 (15) years and majority (57%) were female, 41% of them were educated more than secondary. Almost 90% of the study participants have heard about organ donation. However, only 28% (95% confidence interval [CI]: 22.9–33.8) had adequate knowledge regarding organ donation. 58% (95% CI: 51.5–63.5) had positive attitude toward organ donation. Practice regarding registration for organ donation was only 2.3%. Knowledge regarding organ donation was more among joint family (odds ratio [OR] = 1.86, $P = 0.02$) and middle socioeconomic status (OR = 2.40, $P = 0.01$). Positive attitude was more among those who were educated above secondary (OR = 3.47, $P = 0.001$) and less among Muslim/Christian religion (OR = 0.49, $P = 0.03$).

CONCLUSION: Less than one-third of the study population had adequate knowledge regarding organ donation. Even though more than half of them had positive attitude toward organ donation only six individuals registered for organ donation.

Keywords:

Awareness, organ transplantation, urban health

Introduction

“We make a living by what we get, but we make a life by what we give” – Winston Churchill. Organ transplantation is the most preferred treatment for many of the end-stage organ

diseases as it increases life expectancy. Besides long-term survival benefits, organ donation also improves quality of life in many circumstances (for instance, in case of cornea, skin, or bone transplantations).^[1]

As per data given by the Global Observatory on Donation and Transplantation, globally, there were around 1.2 lakh solid organs

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reported to be transplanted in 2015. This accounts for about 20.65 donations per million population. It was reported that there was an increase in trend of organ donation of about 5.8% since 2014. Yet, it was <10% of the global needs. Deceased organ donation has an advantage of decreasing this inequity. Globally, deceased organ donation rate, which is around 5.1 donations per million population makeup only one-fourth of the total organ transplantations.^[2]

In India, a total of 7715 solid organ transplantations were done in 2015 equalling a rate of 5.9 donations per million population, trailing far behind the global trend. Certainly, with 1.3 billion population, India is also lagging behind with respect to deceased organ donation with a rate of <1 per million population. The performance of Tamil Nadu, a southern state in India, deceased organ donation rate (1.3 per million population) was relatively better than the national performance (0.05–0.08 per million population). Although, India falls second in the number of live donor transplants, next only to the USA, but stands nowhere in the list of deceased donor transplantation.^[3] Recent studies report that India is in need of 260,000 organs every year, which translates to about 180,000 kidneys, 30,000 livers, and 50,000 hearts, whereas only 6000 kidneys, 1200 livers, and 15 hearts are transplanted annually.^[4]

Thus, it is clear that the primary hindrance to the organ transplantation program in India is the shortage of donor organs. There is an urgent need to identify the reasons for this wide gap between number of patients who are in need of transplantation and the availability of organs for transplantation in India.

While lack of awareness and negative attitude toward organ donation could be possible reasons for the gap between the need and availability of organs. Lack of awareness about the concept of brain death, religious attitudes, superstition related to rebirth, fear of misuse of organs, health risks due to organ donation, and lack of consensus among family members have been identified as potential barriers for successful implementation of organ donation program in India.^[5]

There is a paucity of studies assessing the community's awareness, attitude, and practices with respect to organ donation in India. Hence, this study has been undertaken to assess the knowledge, attitude, and practice regarding organ donation among adult population in the selected wards of urban Puducherry.

Materials and Methods

A community-based cross-sectional study was conducted from April to May 2017 among the adult population

residing in JIPMER Urban Health Centre (JIUHC) service area. JIUHC provides general outpatient services from 9.00 am to 4.30 pm for 6 days in a week. JIUHC caters to a population of about 9423 spread over four wards (Kurusukuppam, Vazhaikulam, Vaithikuppam, and Chinnayapuram). All the four wards were located along the coastal areas of Puducherry where fishing was the major occupation.

The sample size was calculated using OpenEpi (v 3.01 updated on 2013, USA).^[6] Based on a previous study, assuming awareness regarding organ donation as 53%,^[7] absolute precision of 6%, and 5% alpha error, the minimum sample size was calculated to be 266.

All adults aged 18 years and above and their address details were obtained from the line list. The line list of adults was maintained at JIUHC, by regular yearly household survey by field staff, public health nurse, and nursing sister in-charge. Two hundred and ninety-two adults were randomly selected (keeping nonresponse rate as 10%) using this line list through simple random sampling. All the adults aged 18 years and above and residing in JIUHC service area for >6 months were included in the study. Individuals who were not able to understand and answer questionnaire were excluded from the study.

All the selected individuals were contacted through household visit and questionnaire was administered by data collectors after obtaining informed written consent. The purpose and motive of the study were explained to the participants. Six training doctors posted in urban health center were chosen as data collectors. They were sensitized regarding the objectives of the study, confidentiality of information, participant's right and informed consent, and were also trained to administer the questionnaire to the participants. Postgraduates posted in the same urban health centre supervised the data collection procedure by reviewing all questionnaires at the end of each day. If the house was locked or individual was found missing even after two consecutive visits, then that particular individual was considered as nonrespondent and subsequently excluded from the study.

Semi-structured questionnaire was used after pilot testing for about 10 individuals attending outpatient service in urban health centre. Questionnaire contained sociodemographic details of individuals such as age, gender, occupation, education, marital status, religion, type of family, and socioeconomic class. Details regarding their awareness about organ donation, source of information regarding organ donation, their attitude and willingness to donate organ in future, awareness regarding procedure and place of registration, as well

as current registration status for organ donation was also captured.

Knowledge regarding organ donation was assessed based on three domains. It included whether they have heard about organ donation or not, knowledge regarding eligibility status for organ donation, and knowledge regarding the place of registration for organ donation. Participants who were able to answer correctly for all the three domains were considered to have adequate knowledge regarding organ donation.

Attitude toward organ donation was assessed based on two domains. It included their willingness to donate organ in future and persons to whom they are willing to donate organs. Participants who answered as willing to donate organ in future as well as willing to donate to unknown members were considered to have good attitude toward organ donation. Practice of organ donation was assessed based on their current registration status for organ donation.

Statistical analysis

Data were entered using Epidata Entry 3.1 and analyzed using STATA version 12.0. Continuous variables such as age of the participants and age at which the participant registered for organ donation were summarized as mean (standard deviation [SD]) or median (interquartile range) based on their normality in distribution. Categorical variables such as gender, occupation, religion, socioeconomic class, awareness regarding organ donation, source of information and knowledge, and attitude and practice regarding registration of organ donation were summarized as frequency (percentages). Binary logistic regression (Chi-square test/Fisher exact test) was used to find the association between sociodemographic characteristics and knowledge and attitude regarding organ donation which were summarized as odds ratio (OR). $P < 0.05$ was considered statistically significant.

Results

Totally 292 individuals were contacted, out of which 257 individuals were included in the study. Out of the 35 individuals who were not included in the study, we could not contact 15 individuals as the house was locked even after two consecutive visits or change of address. Rest 20 individuals were not able to understand and respond to the questionnaire. Response rate was 88%.

The mean (SD) age in years of the study population was 44.6 (15.4). Table 1 depicts sociodemographic characteristics of the study participants. Majority 147 (57.2%) were females; 127 (49.4%) were unemployed which includes homemaker, ex-serviceman, pensioner,

Table 1: Sociodemographic characteristics of the study participants belonging to selected wards of urban Puducherry, N=257

Sociodemographic characteristics	Frequency, n (%)
Age category (years)	
18-29	39 (15.1)
30-39	65 (25.4)
40-49	51 (19.8)
50-59	50 (19.5)
≥60	52 (20.2)
Gender	
Men	110 (42.8)
Women	147 (57.2)
Education status	
No formal education	51 (20.2)
Primary (1-5)	23 (9.0)
Middle (6-8)	27 (10.5)
Secondary (9-10)	50 (19.5)
Higher secondary (11-12)	28 (10.9)
Posthigher secondary (graduate and above)	78 (29.9)
Occupation	
Employed	130 (50.6)
Unemployed†	127 (49.4)
Area of residence	
Kurusukuppam	94 (36.5)
Vazhaikulam	87 (33.8)
Chinnayapuram	47 (18.2)
Vaithikuppam	29 (11.5)
Marital status	
Married	195 (75.9)
Never married	34 (13.2)
Others*	28 (10.9)
Religion	
Hindu	213 (82.9)
Christian	38 (14.8)
Muslim	6 (2.3)
Type of family	
Nuclear	137 (53.3)
Joint	73 (28.4)
Three generation	47 (18.3)
Socioeconomic class (Rupees)‡	
Lower (≤835)	50 (19.1)
Lower-middle (836-1670)	62 (24.1)
Middle (1671-2785)	47 (18.6)
Upper-middle (2786-5169)	59 (23.1)
Upper (≥5170)	39 (15.1)

†Includes homemaker, ex-servicemen, pensioners, and retired persons, *Includes widowed, separated, and divorced, ‡According to BG Prasad scale May 2016

and retired persons; 195 (75.9%) were married; and 213 (82.9%) belonged to Hindu religion. Almost one-third of the study participants, 78 (29.9%) were graduates; more than half, 137 (53.3%) belonged to nuclear family and nearly one-fourth, 62 (24.1%) belonged lower middle socioeconomic class according to modified BG Prasad classification May 2016.

Table 2 shows the knowledge regarding organ donation determined based on three domains among the study

participants. Nearly nine out of ten, 229 (89.1%) have heard about organ donation in their lifetime, but only half of them had adequate knowledge regarding eligibility status for organ donation and place of registration for organ donation, 115 (44.8%) and 152 (59.1%), respectively. Overall, 72 (28%) had adequate knowledge regarding organ donation. (95% confidence interval [CI]: 22.9–33.8)

Media was the only source of information in more than half, 130 (56.9%) of the study participants. Among those who have heard about organ donation ($n = 229$), more than half of them (130 [56.9%]) reported that media was the only source of information regarding organ donation. Majority (75 [32.3%]) believed that the eye, heart, and kidney are the organs that can be donated.

Table 3 represents attitude toward organ donation determined based on two domains among the study participants. More than half of the study participants, 151 (59%) thought about organ donation at any time in the past during their lifetime and 169 (66%) were willing to donate organ in the future. Among those who were willing for organ donation, more than three-fourth (186 [77.5%]) of them were willing to donate organ to unknown member.

Overall 60% (148) had positive attitude toward organ donation if they were willing to donate organ in future and willing to donate organs either to unknown members or to a medical college (95% CI: 51.5–63.5).

Only 6 (2.3%) were registered for organ donation. All six were registered for eye donation. The median (interquartile range) age of registration for organ donation was 23 (18–39).

Table 4 represents the association of sociodemographic characteristics with knowledge regarding organ donation. Chi-square test/Fisher exact test was used to find the association between sociodemographic characteristics and knowledge regarding organ donation. The study participants belonged to joint or three generation family (OR = 1.86) and middle socioeconomic status (OR = 2.40) were found to have more adequate knowledge regarding organ donation when compared to those belonged to nuclear family and lower socioeconomic status and also found to be statistically significant ($P < 0.05$).

The study participants of age >30 years, female gender, educated from Class 1 to Class 10, employed, and single were found to have less adequate knowledge regarding organ donation. However, these variables are not statistically significant.

Table 5 represents the association of sociodemographic characteristics with attitude toward organ donation. The

Table 2: Knowledge regarding organ donation determined based on three domains among the study participants belonging to selected wards of urban Puducherry, N=257

Knowledge regarding organ donation	Frequency, n (%)
Heard about organ donation	
Yes	229 (89.1)
No	28 (10.9)
Eligibility status for organ donation	
No idea/don't know	142 (55.2)
Living donor/brain dead patients/after death	115 (44.8)
Knowledge regarding place of registration	
No idea/don't know	105 (40.9)
Government hospital/medical college/private agency	152 (59.1)
Knowledge regarding organ donation	
Inadequate	185 (72.0)
Adequate*	72 (28.0)

*If all the three domains (heard about organ donation, eligibility status for organ donation, and place of registration) were correct, then they were considered to have adequate knowledge

Table 3: Attitude toward organ donation determined based on two domains among the study participants belonging to selected wards of urban Puducherry, N=257

Attitude toward organ donation	Frequency, n (%)
Thought of organ donation at any time in the past	$n=257$
Yes	151 (58.8)
No	106 (41.2)
Willingness to donate organ in future	$n=257$
Willing*	169 (65.8)
Want to discuss with family members	63 (24.5)
Don't know to take decision	8 (3.1)
Not willing	17 (6.6)
Persons to whom they are willing to donate	$n=240$
Unknown members*	186 (77.5)
Own family members/relatives	48 (20.0)
Medical college*	6 (2.5)
Attitude towards organ donation	$n=257$
Positive attitude†	148 (57.6)
Negative attitude	109 (42.4)

*Considered for determining attitude toward organ donation, †If both (willing to donate organ in future, willing to donate organs either to unknown members or to a medical college) were present, then they were considered to have positive attitude

study participants educated 11th standard and above were found to have more positive attitude for organ donation (OR = 3.47) when compared to those who did not have any formal education. The study participants belonged to Muslim/Christian religion were found to have less positive attitude for organ donation (OR = 0.49) when compared to those who belonged Hindu religion and also found to be statistically significant ($P < 0.05$).

The study participants of age >30 years and female gender were found to have less positive attitude toward organ donation. However, these variables are not statistically significant.

Table 4: Association of sociodemographic characteristics with knowledge regarding organ donation determined based on three domains among the study participants belonging to selected wards of urban Puducherry, N=257

Sociodemographic characteristics	Adequate knowledge regarding organ donation (n=72), n (%)	OR	95% CI	P
Age category (years)				
≤30	17 (37.8)	Reference	Reference	-
31 and above	55 (25.9)	0.58	0.29–1.13	0.10
Gender				
Men	31 (28.2)	Reference	Reference	-
Women	41 (27.9)	0.99	0.57–1.71	0.96
Education status				
No formal education	14 (26.9)	Reference	Reference	-
1–10	24 (24.0)	0.86	0.40–1.84	0.69
11 and above	34 (32.4)	1.15	0.62–2.71	0.48
Occupation				
Employed	34 (26.2)	0.83	0.48–1.43	0.50
Unemployed†	38 (29.9)	Reference	Reference	-
Marital status				
Married	58 (29.7)	Reference	Reference	-
Single*	14 (22.6)	0.69	0.35–1.35	0.27
Religion				
Hindu	60 (28.2)	Reference	Reference	-
Christian/Muslim	12 (27.3)	0.96	0.46–1.98	0.90
Type of family				
Nuclear	31 (22.3)	Reference	Reference	-
Joint/three generation	41 (34.8)	1.86	1.07–3.22	0.02
Socioeconomic status (class)				
Lower and lower-middle	23 (20.5)	Reference	Reference	-
Middle	18 (38.3)	2.40	1.14–5.06	0.01
Upper-middle and upper	31 (31.6)	1.79	0.96–3.35	0.06

†Includes homemaker, ex-servicemen, pensioners, and retired persons, *Includes never married, widowed, separated, and divorced. OR=Odds ratio, CI=Confidence interval

Discussion

This cross-sectional study on organ donation which was done among the adult population of urban Puducherry reported that 28% (95% CI: 22.9–33.8) had adequate knowledge and 57.6% (95% CI: 51.5–63.5) had positive attitude toward organ donation. Practice of organ donation was also assessed among the study participants based on their registration status for organ donation. It was found that 2.3% were registered for organ donation. Adequate knowledge regarding organ donation was observed to be more among those who belonged to the age group of ≤30 years, male gender, educated up to higher secondary and above, Hindu religion, joint family type, and middle socioeconomic status. However, only family type and socioeconomic status were found to have statistically significant association. Similar findings were found regarding the attitude toward organ donation; participants belonging to the educational status up to higher secondary and above and joint family type were found to have significant positive attitude toward organ donation.

Studies from different parts of the country have assessed knowledge and attitude toward organ donation using

various domains.^[7-10] However, we could not find any community-based study reporting adequacy of the knowledge regarding organ donation among general population. However, there were studies which reported adequacy of knowledge among health-care professionals such as doctors, nurses, undergraduate, and postgraduate medical students.^[11-17]

In our study, we found that 89% have heard about the term organ donation. Similar results were found in studies done in Kanchipuram (86%), Ahmedabad (86%), and Maharashtra (78%).^[5,18,19] Studies done in Kerala showed that almost all the participants have heard about organ donation. Higher awareness regarding the term organ donation among our study population can be attributed to the higher educational status of the participants.

Regarding the domain eligibility status for organ donation, we have found that almost half of the study participants were aware that both living donor and deceased can donate organs. Similar results were reported in studies done in Ahmedabad, where more than half were aware about eligibility status regarding organ donation.^[18] However, contrast findings were

Table 5: Association of sociodemographic characteristics with attitude toward organ donation determined based on two domains among the study participants belonging to selected wards of urban Puducherry, N=257

Sociodemographic characteristics	Positive attitude toward organ donation (n=148), n (%)	OR	95% CI	P
Age category (years)				
≤30	30 (66.7)	Reference	Reference	-
31 and above	118 (55.7)	0.63	0.32–1.23	0.18
Gender				
Men	65 (59.1)	Reference	Reference	-
Women	83 (56.5)	0.90	0.54–1.48	0.67
Education status				
No formal education	23 (44.2)	Reference	Reference	-
1-10	48 (48.0)	1.16	0.59–2.28	0.66
11 and above	77 (73.3)	3.47	1.73–6.97	0.001
Occupation				
Employed	80 (61.5)	1.39	0.85–2.28	0.20
Unemployed*	68 (53.5)	Reference	Reference	-
Marital status				
Married	111 (56.9)	Reference	Reference	-
Single*	37 (59.7)	1.12	0.63–2.00	0.70
Religion				
Hindu	129 (60.6)	Reference	Reference	-
Christian/Muslim	19 (43.2)	0.49	0.26–0.95	0.03
Type of family				
Nuclear	77 (55.4)	Reference	Reference	-
Joint/three generation	71 (60.2)	1.22	0.74–2.00	0.44
Socioeconomic status (class)				
Lower and lower-middle	61 (54.5)	Reference	Reference	-
Middle	26 (55.3)	1.04	0.52–2.05	0.92
Upper-middle and upper	61 (62.2)	1.38	0.79–2.39	0.25

*Includes homemaker, ex-servicemen, pensioners, and retired persons, *Includes never married, widowed, separated, and divorced. OR=Odds ratio, CI=Confidence interval

found in studies done in West Bengal were only 15.6% had knowledge about eligibility criteria.^[10] These contrast findings can be attributed to the socioeconomic and cultural differences between the study populations.

The current study found that more than half of the study participants had positive attitude toward organ donation. In contrast, studies done in Kerala (26%) and West Bengal (42%) reported lesser proportion had positive attitude toward organ donation.^[7,10] This difference in attitude can be attributed to the religious beliefs among Muslim population which has been reported in the previous studies.^[20,21] Since most of our study population belonged to Hindu religion, attitude toward organ donation was better.

Practice of registration for organ donation was found to be poor among the study population. The findings were even worse in studies done in Kanchipuram and Ahmedabad where none of the participants were registered for organ donation.^[5,18] Lack of knowledge regarding the necessity of registration for organ donation was the main contributor for poor registration status.

Limitations of the study were cross-sectional nature of the study which makes precludes the association

between awareness regarding organ donation and sociodemographic factors. Reasons for lower practice of registration for organ donation could have been explored more.

In spite of these limitations, the current study has certain strengths also. Reporting the adequacy of knowledge and nature of attitude toward organ donation was one of the important strengths of the study. This being a community-based study makes the generalizability to general population. Good response rate was also an added strength to the study.

Organ donation is emerging as a topic of public health importance as a result of ever-increasing gap between the need and actual status of donation. This inequity is prevailing not only in India but also among the developed countries. Major reason for the existing inequity can be attributed to lack of awareness regarding organ donation among the general population. In the current study, we have found that even among those who were aware about the organ donation, practice of registration was poor. This might be because the health professionals acted as a source of information for less the 10% of the study population. Involvement of health professionals plays a vital role in developing

the trust and motivating the community to register for organ donation.

There might be certain misconceptions and sociocultural beliefs regarding organ donation which needs to be addressed through “awareness campaigns.” Involvement of primary health-care workers in such campaigns is important as Primary Health Centre is the first point of care and closer to the community. As the procedure for registration of organ donation is cumbersome, simplification of the process and availability of registration facility at lowest possible level of health care need to be done. Further study to explore the reasons or hindering factors in registration of organ donation is required.

Conclusion

Less than one-third of the study population had adequate knowledge regarding organ donation. Individuals belonging to middle socioeconomic status and joint family type had higher chance to have adequate knowledge. Even though more than half of them had positive attitude toward organ donation, only six individuals registered for organ donation. Awareness campaigns with registration facility can be conducted in community and primary health-care facility on regular basis to promote organ donation.

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Conflicts of interest

There are no conflicts of interest.

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