



Original Research Article

A STUDY ON AWARENESS, ATTITUDES AND FACTORS IMPEDING ORGAN DONATION AMONG RURAL POPULATION IN SOUTH INDIA

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ABSTRACT

Background: The definitive treatment for end-stage organ diseases is organ transplantation, but there is huge disparity between the organ demand and its availability in India. In this study, we focused on rural population and aimed to assess the awareness, attitude and factors hindering organ donation.

Objectives

1. To assess the awareness and attitudes among rural population towards organ donation.
2. To study about various factors hindering the organ donation.
3. To evaluate differences between the various findings based on their education level and socioeconomic status.

Materials and Methods: Study design - Cross sectional study. **Type of study** - Community-based study. **Sample size** - 250 subjects. **Study population** - residents of the village near our medical college **Inclusion criteria** - Subjects of both sexes and more than 18 years. **Exclusion criteria**- Subjects less than 18 years. **Data collection:** A self-constructed semi-structured questionnaire was designed based on the website of NOTTO.^[1] (National Organ and Tissue Transplant Organization). **Statistical analysis:** Statistical analysis was performed using SPSS software. Pearson's Chi-square tests and descriptive statistics were used to find the significant associations between different factors considered in the study. Study was conducted after obtaining clearance from Institutional ethical committee. (AMCH/IEC/Proc.No.50/2023)

Results: Out of 250 participants, 84% have got information about organ donation through social media, 6% through people talking about organ donation, 5% got information at hospitals and clinics, 3% at a national blood service donation session. 99.2% of the population felt they can change their mind to unpledge, even if they have pledged their organs already. Majority (46.8%) agreed for organ donation, 3.6% disagreed, 2.4% strongly disagreed and 16.8% remained neutral.

Conclusion: People at rural communities were educated regarding the concept, types, legal issues of organ donations, and motivational messages that inspired them to donate organs. Subjects interested to donate their organs were guided to the nearest health center.

Keywords: Organ donation awareness, Attitude towards organ donation, Barriers to organ donation, Willingness to donate.

INTRODUCTION

Organ donation and transplantation is defined as a surgical process in which the patient's failing or failed organ is replaced with a healthy organ from some donor. Organ donors can be either deceased people or living individuals. According to a recent survey, there are nearly 3,00,000 patients waitlisted for an organ transplant with the hope of receiving one and to live a better life. But around 20 people are dying daily while awaiting because of the shortage of the organ transplants.

According to the OPTN, 2015, (Organ procurement of Transplant Network) the organs and tissues procured from a single donor can help with as many as eight people,^[2] yet the organs demand exceeds availability globally. In India, the organ donation rate (ODR) is only 0.80 per million population.^[3]

Transplantation of Human Organ and Tissues Act (THOA) declared by the Indian Government in 1994, states a person can pledge to donate his or her organs after their death. Various laws and amendments were given by the government from time to time in order to encourage the public to pledge their organs and tissues for donation.^[2,4]

For persons who suffer brainstem death, and not registered as organ donors, the decision of their family will be considered.^[5,6] In spite of all the efforts taken by the government, there is still a wide gap between the donor and recipient ratio. Few factors attributed to the reduced number of deceased organ donation are religion-related, cultural, various superstitious beliefs and ethical problems.^[7,8] Other possible causes which act as a barrier to the low number of donations from brain-dead patients are opposition from the family, fear, misuse of the donated organs.^[9] The chief minister of Tamil Nadu and Odisha has announced that state funerals will be held for organ donors, as a token of respect to them and also to encourage the public to pledge their organs for donation.^[10]

In order to increase the organ donation rate, it is highly necessary to study about the various factors which influence the attitudes of individuals, their family members and their thoughts on organ donation. It is also the need of the hour to increase awareness about organ donation among the various professionals of healthcare system since they play a pivotal role in the organ donation chain, and also to motivate the general population.^[11] Very meagre literature is there which were conducted among rural population regarding organ donation.^[12,13,14,15]

Hence in this study we wanted to assess the awareness, attitudes and various factors which impede organ donation among rural population of southern India and also to plan programs to sensitize and to increase knowledge about organ donation at the community level.

Aims and objectives

1. To assess the awareness and attitudes among rural population towards organ donation.

2. To assess various factors hindering the organ donation.
3. To evaluate differences between the various findings based on their education level and socioeconomic status.

MATERIALS AND METHODS

Study design - Cross sectional study

Type of study - Community-based study.

Sample size - 250 subjects.

Sample size calculation:

The sample size was calculated based on the primary outcome of assessing the awareness and attitudes among rural population towards organ donation. From previous study "Knowledge and Attitude towards Organ Donation in Rural Kerala",^[16] the obtained proportion was 26% and using this proportion with absolute precision of 6% and to assess the awareness and attitudes with 95% confidence interval a total sample size of 205 will be required. Considering the literacy rate of rural places of Tamil Nadu compared to the literacy rate in Kerala, we planned to include 250 subjects.

Study population

Inclusion Criteria

Subjects of all sexes, 18 years and more residing in the villages near our medical college were included in the study as participants after explaining the purpose of the study and getting written informed consent. The houses in each village were selected based on systematic random sampling and the participants were selected randomly in each house.

Exclusion Criteria

Subjects less than 18 years were excluded.

Data collection: Clearance from Institutional Ethical Committee was obtained (AMCH/IEC/Proc.No.50/2023). Data collected from mid-October to mid-December 2023. A self-constructed semi-structured questionnaire was prepared to assess the attitude, awareness and factors hindering organ donation which included three parts. The first part of the questionnaire included questions regarding sociodemographic profile of the subjects like age, gender, religion, and educational status. Modified B.G. Prasad's classification,^[17] was used to stratify people according to their socioeconomic status. The second part consists of nine questions to assess willingness, attitudes and beliefs regarding organ donation.

The third part of the questionnaire had ten dichotomous questions to assess the awareness level was used. The questionnaire was designed based on the website of NOTTO (National Organ and Tissue Transplant Organization).^[18] The questionnaire was designed both in local language as well as in the English language. The questionnaire consisted of questions which included few with the response to be yes/no and few multiple-choice questions. Few open-ended questions were also

included if the subjects had anything to mention other than the options provided in the questionnaire.

In some multiple-choice questions, the subjects had to select a single response while few questions allowed selection of multiple choices. After a brief introduction, the subjects were explained about the purpose of the study and written informed consent was obtained from all.

They were asked to fill the questionnaire. The participants were given full liberty to ask all their queries while filling the questionnaire, which was clarified by the investigator. Subjects who could read and write were asked to fill the questionnaire themselves. For illiterate participants, the investigator helped to fill the questionnaire by reading the questions out and filling the options selected by them.

Statistical Analysis: The collected data was entered in the excel sheet and statistical analysis was performed using

SPSS software, version 21. Pearson's Chi-square tests and descriptive statistics were used to find the significant associations between different factors considered in the study.

Confidentiality of the data collected was maintained.

RESULTS

The results of the study are tabulated. Table 1 shows the demographic data. Out of 250 participants 132 (52.8%) were males and 118 (47.2%) were females, 91.2% were married, 8.8% were unmarried. Majority of the study population were in the age group of 30 to 45 years (37.6%). Nearly 69.2% of the people were employed and 30.8% were unemployed. Of the study population 42% (N=105) were graduates and 58% (N=145) have done their schooling only.

The study participants were also stratified according to their socio-economic status based on Modified B.G. Prasad classification.

Most of the people (84%) have got information about organ donation through social media like television, radio, newspaper and magazines, 6% have heard through people talking about organ donation, 5% got information at hospitals and clinics, 3% at a national blood service donation session (graph 1).

Table 2 shows the frequency of different responses regarding the awareness towards organ donation, if a person has already registered with the organ donor register. 82.8% of the study population felt their organs can be donated without consent from close family and friends.

Majority (53.2%) of the people said that their family members can just be informed and not necessary to take their permission, whereas 46.8% were against it. 79.2% of the people felt their family members should be consulted to confirm the person's wishes for organ donation, and the family can refuse the person's wish for organ donation.

If a person is not registered with the organ donor register, 96.4% of people said their organs cannot be

donated under any circumstances. All the study population felt their family members may be asked and they can decide to donate the person's organ if they wish. Moreover, all felt that the age limit for organ donation in living donors should be above 18 years of age and there is no age limit in organ donation of deceased persons.

Table 3 shows nearly 99.2% of the population felt they can change their mind to unpledge, even if they have pledged their organs already. All the people felt the donors should be screened for transmissible diseases. 66% of the study population felt that, a person who has been rejected a blood transfusion or a blood donation, can still be an organ donor whereas 34% opposed it.

74.4% of the study population opposed a person being an organ donor with an existing medical condition. 94.8% had the feeling that whole-body donation and organ donation were different. 86.4% of the study population said the dead body of the registered donor should not be used for research purposes.

Majority of the study population (89.6%) were unaware of the procedure for registering for organ donation whereas only 10.4% were aware of it.

Regarding the awareness level among the study participants, our study showed 64% had adequate awareness regarding organ donation whereas 36% had inadequate awareness.

Attitude towards organ donation has been tabulated in table 4. Majority (46.8%) agreed for organ donation, 3.6% disagreed and 2.4% strongly disagreed for organ donation and 16.8% remained neutral. 44% of the population strongly had a comfortable idea about organ donation, 3.2% strongly disagreed to this and 16% neither agreed or disagreed for organ donation and were neutral.

Among the study population, 46.8% strongly wanted to donate all their organs, if possible, whereas 2.4% strongly disagreed for organ donation, 11.6% were neutral.

Most of the people (73.2%) strongly agreed the importance of informing their wishes to donate their organs after death to their family members and few people (8%) were neutral.

Graph 2 shows the frequency of the population who had not registered their name in organ donor registry.

It also shows the various reasons for not registering.

None of the respondents have registered their name in the organ donor registry. 114 respondents cited that they were unaware about the registration procedure.

A significant proportion of respondents (103) expressed concerns about their family not approving their decision to donate organs. A smaller number of respondents (10) indicated that their cultural beliefs might prohibit organ donation. 60 of them expressed concerns about being perceived primarily as an organ donor rather than as a patient. 54 participants were unaware that there even exists a register for organ donation. 28 participants indicated that they had no point in registering because their family already knows their wishes regarding organ donation

Graph 3 shows the proportion of various reasons the respondents considered for donating their organs. 90 respondents expressed the belief that their organs would go to waste after their death if not donated. 27 of the respondents mentioned a desire for others to perceive them as extremely unselfish by donating their organs. 68 cited a sense of social responsibility as a motivation for organ donation. 54 documented replies stated that they would feel proud to donate their organs. 101 perceived to recognize the potential to improve and save the lives of others through organ donation. 35 recorded response expressed a desire to provide hope and happiness to the families of organ recipients. 56 study subjects believe that organ donation is something everyone should do. 64 responses mentioned that they may feel contented knowing they could help someone through organ donation.

No respondents selected this option, indicating a lack of consideration for reducing the donor-recipient discrepancy rate as a motivation for organ donation. Graph 4 depicts various reasons, the study subjects quoted for not willing to donate their organs. 19 respondents expressed concern that their family members might worry if they choose to donate their organs. 21 participants indicated that they are concerned hospital staff might not provide adequate

care if they are identified as organ donors. 8 of them stated a preference to keep all their organs intact for burial or cremation. 3 respondents felt that organ donation goes against their cultural beliefs. 10 respondents believed that organ donation contradicted their religious or personal beliefs. 12 respondents indicated a lack of knowledge about organ donation as a reason for their hesitance to donate. None of them expressed a preference for their organs not to be donated to individuals of different religious backgrounds.

The survey results indicate that 147 respondents, accounting for 58.8% of the total sample, expressed a positive attitude, while 103 respondents, constituting 41.2% of the total, conveyed a negative attitude.

When Association between demographic variables and awareness towards organ donation were done, both education level and socio-economic status does not show positive association with p value more than 0.05.

Table 5 shows association between demographic variables and awareness towards organ donation. Socio economic status of the study subjects showed positive association with p value of 0.01. Education level does not show positive association with p value more than 0.05.

Table 1: Demographic variable distribution

Variables	Categories	Count	Column N %
Gender	Male	132	52.80
	Female	118	47.20
	Others	0	0
Age(years)	18-30	47	18.8
	30-45	94	37.6
	45-60	68	27.2
	60+	41	16.4
Education	Schooling	145	58.00
	Graduate	105	42.00
Occupation	Employed	173	69.20
	Unemployed	77	30.80
Religion	Hindu	190	76.00
	Christian	41	16.40
	Muslim	19	7.60
	Others	0	0
Marital Status	Married	228	91.20
	Unmarried	22	8.80
Socio Economic Status	I	72	28.8
	II	57	22.8
	III	42	16.8
	IV	55	22
	V	24	9.6

Table 2: Awareness towards organ donation regarding the roles of friends and family and age limit of living and deceased donor

		TRUE	n (%)	FALSE	n (%)
1	If a person is already registered with the organ donor register				
A	The person's organs are donated even without consent from close family and/or friends	207	82.80	43	17.20
B	Close family or friends are just informed that the person's organs will be donated, but need not take their permission	133	53.20	117	46.80
C	Close family and or friends are consulted to confirm the person's wishes and they have a choice to refuse if they want to.	198	79.20	52	20.80
2	If a person is not registered with the organ donor register				
A	Their organs cannot be donated under any circumstances	9	3.60	241	96.40
B	Their close family and or friends may be asked and they can decide to donate the person's organs if they wish	250	100	0	0

3	What is the age limit for organ donation				
A	In living donors, they should be above 18 years of age	250	100	0	0
B	In organ donation of deceased persons there is no age	250	100	0	0

Table 3: Awareness regarding pledging and unpledging the organs, selection of donors and registration procedure

S.no		Yes	n (%)	No	n (%)
1	Can you change your mind to unpledge even if you have pledged your organs already?	248	99.2	2	0.8
2	Do the donors be screened for any transmissible disease?	250	100	0	0
3	Can a person be an organ donor, if a person has been rejected a blood transfusion, donate blood?	165	66	85	34
4	Can a person be a donor with an existing medical condition?	64	25.6	186	74.4
5	Does whole body donation and organ donation are same?	13	5.2	237	94.8
6	Can the dead body of the registered donor be used for research purposes?	34	13.6	216	86.4
7	Are you aware of the procedure to register your organs for donation?	26	10.4	224	89.6

Table 4: Attitude towards organ donation willingness and informing their wish to friends or relatives

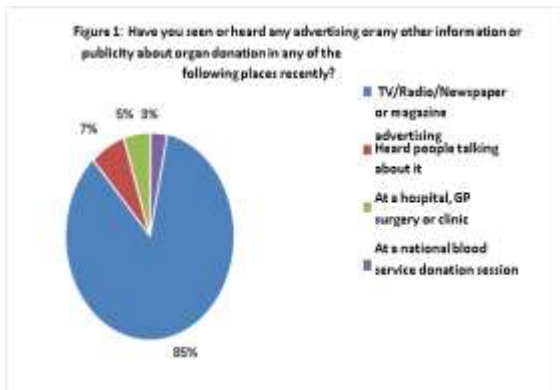
S. No		Strongly agree		Strongly disagree N (n%)		
		N (n%)	Agree N (n%)	Neutral N (n%)	Disagree N (n%)	
1	I support organ donation	117 (46.8)	76 (30.4)	42 (16.8)	9 (3.60)	6 (2.4)
2	I am comfortable with the idea about donating my organs	110 (44)	81 (32.4)	40 (16)	11 (4.4)	8 (3.2)
3	I want to donate all my organs, if possible	117 (46.8)	90 (36)	29 (11.6)	8 (3.2)	6 (2.4)
4	Is it important to inform your wishes about donating your organs to your close friends or relatives after death?	183 (73.2)	47 (18.8)	20 (8)	0	0

N- Frequency of the study population, n% - percentage of study population

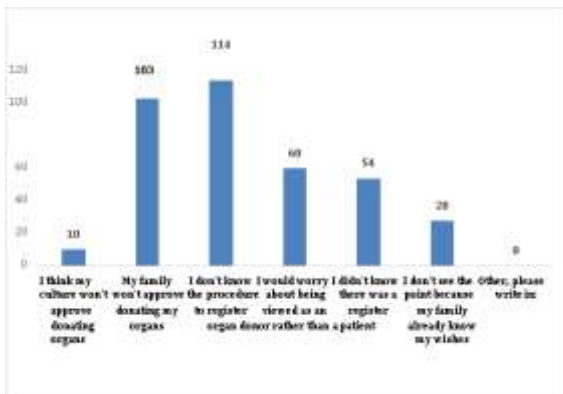
Table 5: Association between demographic variables and attitude

Variables	Positive Attitude		Negative Attitude		p value
	Count	Column N %	Count	Column N %	
Education					
Schooling	92	62.59	53	51.46	0.079
Graduate	55	37.41	50	48.54	
Socio Economic Status					
I	62	42.18	10	9.71	<0.001
II	38	25.85	19	18.45	
III	6	4.08	36	34.95	
IV	30	20.41	25	24.27	
V	11	7.48	13	12.62	

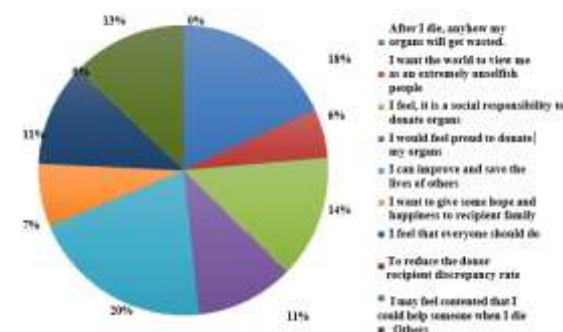
DISCUSSION



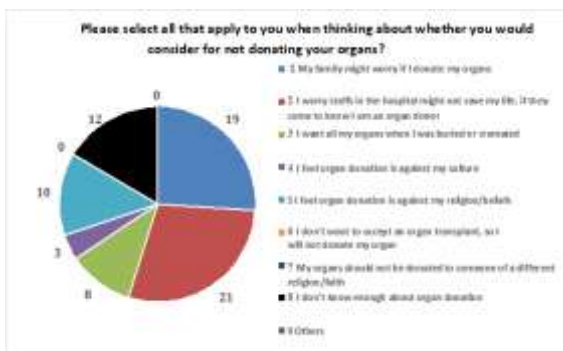
Graph 1: Sources from where the subjects got information about organ donation



Graph 2: The reasons, for not registering in the organ donor register



Graph 3: Showing proportions of various reasons, the respondents considered for donating their organs



Graph 4: Please select all that apply to you when thinking about whether you would consider for not donating your organs?

We aimed to assess awareness, attitudes and factors impeding organ donation among rural population in South India. Regarding awareness on organ donation, our study was compared with the study in general population of Haryana, India by Anurag Garg,^[19] and study by Manish R Balwani,^[20] in Ahmedabad city of Gujarat, India. 64% of the participants in our study were aware about organ donation which is comparatively little higher than study by Dr Anurag which was 59.4% In a study by Manish R Balwani,^[20] 86% were aware of the term organ donation which was significantly higher than our study results. Death have occurred while waiting for a suitable organ donor. The incidence of deaths can be reduced by increasing the awareness on organ donation. In this digital world, social media plays a pivotal role in increasing awareness and encouraging people to donate organs. It enlightens the need and significance of organ donation in saving one's life.

In our study, 82.8% learned about organ donation from media, TV, newspapers and radio, depicting media being an integral part in creating awareness among people about organ donation which was significantly higher compared with study by Dr. Anurag Garg.

About 48% of the participant in Manish R Balwani study states that the major source of information was medical fraternity and about 21% became aware through print and electronic media and rest 31% of the participant through friends and classmates perspective and attitude towards organ donation vary among individuals and influenced by various factors, including cultural, religious, and personal beliefs, etc. Regarding willingness to donate organs, 82.8% of the participants in our study were willing to donate their organs after death, this figure is three times greater than Dr Anurag's study results for the same (34). In another study by KL Balajee et al,^[21] conducted in rural Puducherry. (36), it was said that most of the participants (70%) were willing to donate their organs after death. Contrastingly in another study by Manish R Balwan,^[20] about 34% of male participants responded that they would donate organ while only 17% female were willing to donate their organs.

When the reasons for unwillingness to donate their organs were discussed, 33 participants cited that staffs in the hospital would not save their life if they come to know that they are an organ donor. Also, almost equal proportion state that their families to worry if they donate their organs.

Contrastingly reasons for unwillingness in Dr. Anurag's,^[19] study was religious belief.

In a study conducted in Guwahati's educational institute, which enlightens the awareness and participation level in organ donation, particularly in India's north-eastern region.^[22]

Despite 79.17% of participants being aware of organ donation, actual involvement remains low,

with none of them having donated organs and nobody actively signed up for organ donation, which indicated that there is a gap between awareness and proactive involvement. 30% of the participants wanted all their organs buried or cremated, and 4% of the participants thought it's against their culture. In our study 49.5% were unaware of the procedure to register, which was a major impediment to registration for organ donation. In about 44.9% of the participant families, disapproval was an impacting factor in registering organ donation. In the study conducted in Guwahati's institute, about 12.5% of the participants religious beliefs were a potential barrier to organ donation, and about 51.67% recognized a lack of awareness among the general population as a major factor.

In our study, socio-economic status and attitude showed a significant association (i.e. p value is < 0.05) whereas the education level does not show significant association with both awareness and attitude towards organ donation. In study conducted by KL Balajee et al. awareness towards organ donation was positively associated with the subjects of higher socioeconomic status and the student's group, while found to be very low among the unemployed and uneducated.

Guleria K, Singh AK, et al,^[23] in their study conducted in Ernakulam, there was no significant association between income and occupation on the level of awareness.

CONCLUSION

The results of this study shed light on various aspects of awareness, attitudes, and perceptions regarding organ donation among the surveyed population. The demographic data highlights a diverse group of variations, with a significant proportion falling into the categories of married and employed.

The major information source about organ donation was through mass media channels, indicating the importance of effective communication strategies in raising awareness. Regarding attitudes towards organ donation, a substantial portion of respondents expressed support for organ donation and a willingness to donate their organs if possible. However, notable concerns emerged, including worries about family approval, cultural and religious beliefs, and perceived risks associated with being identified as an organ donor in healthcare settings.

Despite being willing to donate organs, the majority had not registered in the organ donor registry, for reasons ranging from cultural and familial concerns to a lack of awareness about the registration process. In spite of these concerns, many recognized the importance of organ donation in saving lives and bringing hope to families.

Overall, these findings emphasize the need for comprehensive educational campaigns tailored to diverse cultural and religious backgrounds, as well as improved access to registration processes, to enhance

awareness and encourage greater participation in organ donation initiatives. By addressing misconceptions and cultural barriers, it is possible to foster a more supportive environment for organ donation, ultimately contributing to the alleviation of organ shortages and the improvement of transplant outcomes.

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