

# Awareness and Attitudes toward Organ Donation in Rural Puducherry, India

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## Abstract

**Background:** For many of the end-stage organ diseases, organ transplantation is the most preferred treatment. The need for the organ transplantation is higher than the availability. For the transplantation program to be successful, awareness regarding organ donation is needed and people must have a positive attitude toward donating organs. **Aim:** This study aims to assess the awareness and attitudes regarding organ donation among the rural population and to evaluate the sociodemographic factors associated with their awareness. **Subjects and Methods:** This community-based cross-sectional study was conducted among 360 people living in 4 villages of Puducherry. Face-to-face interviews were carried out using pretested questionnaire, which included the sociodemographic data. Data were entered into Excel and analyzed using Statistical Package for Social Sciences. **Results:** Of 360 participants, 88% (317/360) were aware of organ donation. Among these 317 participants, awareness was highest in the age group 18–30 years 98.8% (87/88), male 91% (147/161), higher secondary and above 100% (58/58), and Class I socioeconomic status 92% (13/14). Source of awareness about organ donation was primarily through media 83% (263/317). The majority of the participants 88% (281/317) felt that the purpose of organ donation was to save life. Most of the participants 91% (290/317) said that all healthy adults are eligible organ donors and 87% (275/317) of the participants said that monetary benefits could not be accepted for organ donation. Most of the participants 70% (223/317) were willing to donate their organs after death. Among the participants who refused to donate their organs, family refusal 57% (25/44) was the most common reason. **Conclusion:** This study shows that there is a high level of awareness about organ donation among rural people and most of the participants are willing to donate their organs.

**Keywords:** Attitude, Awareness, Organ donation, Rural Puducherry

## Introduction

Organ transplantation is the most preferred treatment for many of the end-stage organ diseases as it offers a better quality of life and has a better long-term survival benefits.<sup>[1]</sup> However, the primary hindrance to the organ transplantation program worldwide is the shortage of donor organs.<sup>[2]</sup> There is an increasing discrepancy between the number of patients on the waiting list for organ transplantation and the available

number of deceased donor organs. India is currently having a deceased donation rate of 0.05–0.08/million population compared to rates of more than 20/million in Spain, US, and France.<sup>[3]</sup> Because of this low donation rate, patients requiring transplantation wait for a long time. Patients with end-stage renal disease can be maintained on dialysis till they get the donor organ. However, patients requiring heart, lung, and liver cannot be maintained for an extended time on mechanical

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devices. Therefore, there is a great need for increasing organ donation and harnessing of donor organs. Although the public is accustomed to blood donation, there is largely a hesitation about organ donation. For the success of the organ donation program, positive attitude of the public toward organ donation and the consent by relatives for organ donation in the event of brain death are required.

In India, due to the imbalance between availability and demand, kidneys were harvested from the poor Indians by exploiting their poverty. To ban this illegal sale of organs, in the year 1994, the Government of India passed “the transplantation of human organs act.”<sup>[4]</sup> Under this act, donation of organs by deceased persons was made legal; and the transplantation between unrelated live individuals was made illegal. Nevertheless, due to lack of knowledge about the legal and procedural details of organ donation, kidneys are sold in the black, and frequently, the police uncover these illegal kidney transplant rackets.<sup>[5]</sup> Thus, there is a great need for increasing awareness about the importance of organ donation and the legal provisions related to it. An assessment of awareness and attitude toward organ donation would help to plan sensitization programs and to propagate knowledge at the community level. A study in Andhra Pradesh (a Southern state in India) reported that only 30% were aware of eye donation.<sup>[6]</sup> However, in India, there is a lack of studies on awareness and attitude of the people about solid organ donation, especially in the rural areas. The aim of this study is to assess the awareness regarding organ donation among the rural population and to assess their attitudes toward organ donation.

## Subjects and Methods

### Study setting and design

This is a community-based cross-sectional study conducted in the rural service area of Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry that includes four villages (Ramanathapuram, Thondamanatham, Thuthipet, and Pillayarkuppam). Data collection was done in January 2014. All persons aged above 18 years were included in the study.

A structured questionnaire was used to collect sociodemographic variables such as age, gender, religion, marital status, education, occupation, and income. Modified Prasad’s classification was used to categorize the socioeconomic status of the study population. The questionnaire was translated into the local language and translated back into English to ensure reliability and validity. Pretesting was done on 25 individuals, and the questionnaire was modified accordingly. The sample size was calculated using the formula  $4pq/d^2$  was 336 based on an estimated awareness ( $p$ ) of 30% from the previous study and an absolute precision ( $d$ ) of 5%. After accounting for 10% nonresponse rate, the final sample size was estimated as 360.

### Procedure

A total of 360 participants were interviewed from four villages after obtaining verbal consent. The sample size in each village

was proportionate to the village population. In each village, houses were selected by systematic random sampling and the participants in each house were selected randomly. After obtaining informed consent from the participants, questionnaire was administered. “Awareness of organ donation” was defined as having heard of organ donation. The demographic details were recorded for all the participants. Questions regarding knowledge and attitude were administered only to those participants who have heard about organ donation.

### Statistical analysis

A continuous variable like age is expressed as mean and standard deviation (SD) as it was normally distributed. Categorical variables such as gender, socioeconomic status, educational status, and awareness on organ donation are expressed as proportions. The data were entered into Microsoft Excel 2007 and analyzed using Statistical Package for Social Sciences, version 20, 2011 (IBM Inc, Armonk, New York, USA). Chi-square test of independence was used to test the difference in proportion keeping the level of significance at 5%.

### Awareness regarding organ donation

A total of 360 subjects aged more than 18 years were interviewed. The mean (SD) age of the study participants is 42 (14) years. Among them, 88% (317/360) have heard about organ donation. The questions regarding knowledge and attitude toward organ donation were administered to these 317 participants. Awareness was the highest 98.8% (87/88) in the age group 18–30 years, male participants 91% (147/161), higher secondary and above 100% (58/58), Class 1 socioeconomic status 92% (13/14), professionals 100% (13/13), and Christians 91% (21/23). Elderly 64.7% (33/51) and uneducated participants 61.7% (50/81) had the lowest level of awareness about organ donation [Table 1]. Source of awareness on organ donation was primarily media 83% (263/317) such as newspapers and television [Figure 1]. Only one-fifth of the participants (60/317) knew someone who had donated organ.

### Reasons for organ donation

The majority 88% (281/317) of them said that the purpose of organ donation was to save life. Out of 317 participants, 87% (275/317) were aware that organs could not be donated for monetary benefits.

### Awareness regarding the eligibility and time of organ donation

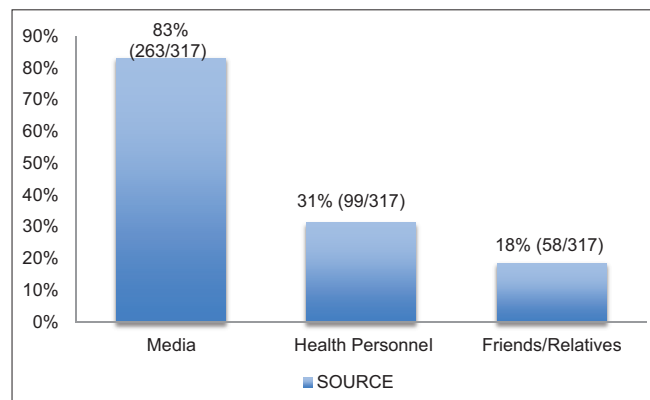
Almost 90% (290/317) of the participants are aware that all healthy adults are eligible organ donors. Majority of the participants 82.3% (261/317) felt that victims of road traffic accidents who are in the end stage of life could donate organs.

About 85% (270/317) of the participants responded that organ donation should be done immediately after death [Figure 2]. Three-fourths (72/101) of the participants who perceived that organs could be donated when alive responded that

kidneys could be donated. Among participants who perceived that organs could be donated after death, 39% (116/302) responded that all organs could be donated. Almost all the subjects felt that eyes can be donated after death, but only 3% felt that other organs such as kidneys and heart could also be donated. In cases of organ donation after death, 93% (280/302) responded that the organs could be donated to anyone in need.

### Perceived risks with organ donation

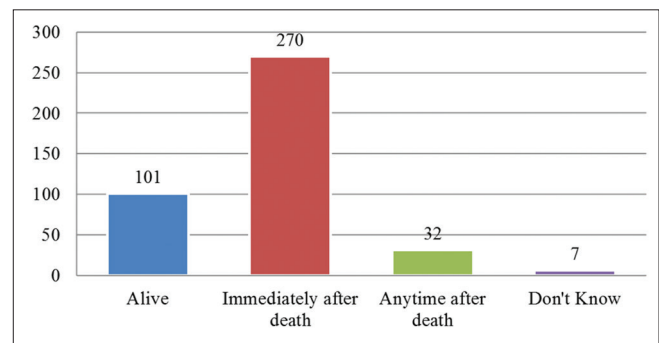
About one-fifth of the participants (61/317) felt that organ donation is associated with some risk to the donor. The most common perceived risk was weakness 48% (29/61), followed by failure of the other paired organ 39% (24/61).



**Figure 1:** Source of information\* about organ donation among those who were aware about it (n = 317). \*Multiple responses

### Willingness to donate organs

Nearly, 70% of participants (223/317) were willing to donate their organs after death and 78% (247/317) were willing to donate the organs of their deceased relative. There was no gender differential in the willingness to donate organs. Around two-thirds of the subjects (199/317) were willing to sign up for donor card and one-thirds (65/223) were ready to donate multiple organs (eyes, heart, kidney). Almost all the willing subjects were keen on eye donation. Among the participants who refused to donate their organs (94/317), family objection 57% (25/44) was the most common reason. Risks to donor 20% (9/44), “do not want to be cut open” 16% (7/44), religious beliefs 4.5% (2/44), and possible misuse of donated organs were the other reasons.



**Figure 2:** Awareness\* regarding time of organ donation among those who were aware about organ donation (n = 317). \*Multiple responses

**Table 1: Sociodemographic characteristics and awareness about organ donation in the study population**

Characteristic	Total (n=360)	Number of participants aware# (%) (n=317)	Number of participants unaware# (%) (n=43)	$\chi^2$	P
Age group (years)					
18-30	88	87 (98.9)	1 (1.1)	49.6	<0.001
31-45	134	128 (95.5)	6 (4.4)		
46-60	87	69 (79.3)	18 (20.6)		
>60	51	33 (64.7)	18 (35)		
Sex					
Male	161	147 (91.3)	14 (8.6)	2.9	0.09
Female	199	170 (85.4)	29 (14.5)		
Level of education					
Uneducated	81	50 (61.7)	31 (38.2)	78.6	<0.001
Middle school	44	36 (81.8)	8 (18)		
High school	177	173 (97.7)	4 (2.2)		
Higher secondary and above	58	58 (100)	0		
Occupation					
Homemaker	149	124 (83.2)	25 (16.7)	16.1	0.01
Student	17	17 (100)	0		
Unemployed	14	10 (71)	4 (28.5)		
Unskilled	88	77 (87.5)	11 (12.5)		
Skilled	43	41 (95.3)	2 (4.6)		
Clerk, shopkeepers, farmers	36	35 (97.2)	1 (2.7)		
Professionals	13	13 (100)	0		
Total	360	317 (88.1)	43 (11.9)		

#Row percentage

## Discussion

We aimed to assess the attitude and awareness regarding organ donation in a selected adult population in Puducherry, South India. The analysis of collected data yielded interesting findings. Majority of the study participants have heard about organ donation. Media was the major source of information about organ donation, similar to the earlier studies done in Bengaluru<sup>[7]</sup> and Kerala.<sup>[8]</sup> In 2008, a doctor couple from the neighboring city of Chennai in Tamil Nadu, situated 145 km from Puducherry, donated the heart, liver, and kidneys and eyes of their teenage son who had died in a road traffic accident. The donated organs saved the lives of six other persons from various states of India. This generous act was widely publicized in the print and visual media. Following this incident, the concept of “organ donation” became familiar among the general public in this part of the country.<sup>[9]</sup> This may be a reason for the high level of awareness about organ donation in this study. However, we observed that the awareness was not uniform across the study population. Awareness was highest among those belonging to higher socioeconomic status and the students, 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.<sup>[10]</sup>

The fact that organs have to be harvested immediately after death is known to most of the participants. This will prevent them from wasting precious time to harvest organs in case of death of a donor. Another encouraging finding is that 72% of the participants were willing to donate their organs and were ready to sign the donor card. This is much higher than the 30% willingness reported from a similar survey in Nigeria.<sup>[11]</sup> Willingness to donate eyes was much higher than the willingness to donate other solid organs. This may be because the participants knew someone who had done eye donation, but there was no case of other solid organ donation from these villages before this study period. This unfamiliarity might be a cause for the differential willingness between eye and other solid organ donation.

The medical students in Bengaluru city<sup>[7]</sup> and the office goers in urban New Delhi,<sup>[12]</sup> have responded that religious beliefs were the least common reason for refusal to organ donation. Our study also shows that religious beliefs of the people did not hinder their decision to donate organs. However, the objection by family members was the most common reason that prevents them from donating organs. This underlines the importance of involving family members in decision-making regarding organ donation. The majority of participants were aware that organs could not be donated for monetary benefit and it should be done only on humanitarian basis to someone in need of organs. This awareness about the legal provisions of organ donation will prevent them from getting exploited by the illegal organ trade. However, the awareness regarding cadaveric kidney donation was very low which is a matter of concern.

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 information in this study was obtained through face-to-face interview using a questionnaire. Hence, there is a possibility of respondent bias while collecting data. 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.

## Conclusion

In this study population, there is high level of awareness about eye and kidney donation, but the awareness about other organ donation is poor. The awareness about eligible donors and the timing of organ donation is also high. Almost all the subjects were willing for eye donation, while two-thirds were unwilling to donate solid organs due to perceived risks and family pressure. 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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## Conflicts of interest

There are no conflicts of interest.

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