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Knowledge, attitude, willingness, and factors influencing organ donation decision making in India

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ABSTRACT

Background: Organ donation is crucial for saving lives, but its success depends on an individual's willingness to donate, as a shortage of donor organs greatly hinders transplantation efforts. This study evaluates the general public's knowledge, attitudes, willingness, and the factors that encourage or hamper organ donation.

Methods: The study included 519 participants from Odisha, India, who completed a self-designed questionnaire assessing their knowledge, attitudes, willingness, and factors influencing organ donation. Knowledge was measured with nine items (score range: 0-9), attitudes with 12 items on a 4-point Likert scale (score range: 0-48), and willingness to donate was recorded as a binary variable (0=No; 1=Yes). Factors influencing organ donation were evaluated through multiple response questions. Logistic regression analyzed the relationship between knowledge and attitudes with willingness to donate, controlling for demographic and socioeconomic factors.

Results: The mean knowledge score on organ donation was 5.63 ± 1.22 , and the mean attitude score was 36.04 ± 4.80 . Among willing donors, the belief that organ donation benefits humanity was the most frequently reported encouragement, while family disapproval was the main barrier for those unwilling to donate. Logistic regression showed an association between attitudes (AOR=1.177; 95% CI: 1.123, 1.235) and residence (AOR=0.588; 95% CI: 0.385, 0.901) with the willingness to organ donation.

Conclusions: Attitudes were positively associated with the general public's willingness to donate organs, and increasing knowledge about the transplant process could help enhance willingness to donate organs.

Keywords: Organ transplantation, Organ donation, Knowledge, Attitude, Asia, Tissue donors

INTRODUCTION

Organ transplantation represents a remarkable achievement in medical science. It offers an extended life span, improved quality of life, and psychological and emotional benefits for patients with life-threatening organ failures. The effectiveness of organ transplantation relies on the intricate collaboration between medical professionals, patients, and support networks, and it is significantly influenced by people's readiness to donate their organs. Although organ donation is crucial, acceptance rates vary widely across countries and

regions, ranging from 31.3% to 85%.^{1,2} The International Registry for Organ Donation and Transplantation (IRODaT) reports that in 2023, Spain led in deceased organ donations with 4,938 per million population (pmp), followed by the USA at 4,804 pmp, and Portugal at 3,693 pmp. In living organ donations, Turkey ranked highest with 5,380 pmp, Saudi Arabia came second with 4,642 pmp, and Israel was third with 3,402 pmp.³ India conducts between 16,000 and 17,000 organ transplants annually, making it the leading country after the USA and China. However, in India, demand outpaces supply in transplantation rates, with only 0.65 transplants pmp.³

According to the 2023 registry from India's National Organ and Tissue Transplant Organization (NOTTO), there were 16,542 transplants, with 15,436 of these being living transplants.⁴

The gap between current organ donation rates and the demand for transplants has led to an increase in illegal activities due to insufficient regulatory oversight.⁵ To combat organ trafficking and ensure equitable distribution of organs from deceased donors, India enacted the Transplantation of Human Organs Act (THOA) in 1994, with the latest amendment in 2014. This legislation permits organ and tissue donations from both deceased and living donors, criminalizes the commercialization of organs, and recognizes brain death.⁶ Despite these strict regulations, sporadic unethical practices continue to deter donations, especially from deceased donors.

Organ failure is a major cause of serious health issues, with many patients suffering and dying due to the shortage of available organs. A single organ donation drive can save eight to ten lives by providing hearts, kidneys, pancreas, lungs, livers, intestines, hands, faces, tissues, bone marrow, and stem cells. In India, despite its significant population advantage, the rate of organ donation is very low. A person's decision to donate organs is influenced by their understanding of organ donation, their attitudes, and behaviors. It is also affected by their cultural and religious beliefs and trust in the healthcare system.^{7,8} Gender disparities in organ transplantation are notable, with more men typically receiving transplants compared to women. Conversely, women are often more likely to be organ donors than men. Women's higher representation as donors might be influenced by social expectations and personal motivations, such as donating to family members. 9 To create effective strategies for promoting organ donation, it's crucial to understand the unique context and characteristics of each population.

Till date, numerous studies have been conducted in India assessing the knowledge and attitude toward organ donation, focusing on the general population. ^{2,10,11} At the same time, all other research is limited to medical students. ¹²⁻¹⁴ Additionally, there is a lack of research on the factors that affect and hinder decision-making about organ donation in India. This highlights a significant gap in understanding broader public views compared to the medical student demographic. The study aims to assess the knowledge, attitude, willingness, and factors encouraging and hindering organ donation among the general population in Odisha, India. Analyzing the public's knowledge and attitudes toward organ donation is essential for enhancing willingness and guiding policy and legislation to boost organ donation rates.

METHODS

The study was approved by the Institutional Ethics Committee. Before taking part in the study, participants were given a thorough explanation of the procedure, and informed consent was collected from everyone who met the criteria. As the study also included an online survey, participants who completed and submitted their responses were deemed to have implicitly consented. Additionally, participants could withdraw from the study at any point during the process. The questionnaire comprised a mix of self-developed questions and those derived from literature reviews. The questionnaire was available in both English and Odia versions.

This cross-sectional observational study was conducted between May 2024 to September 2024. The study was conducted among the residents of Bhubaneswar, Odisha, who are above 18 years of age and have heard of organ donation. The participants were excluded if they had been donors/recipients, awaiting organs transplantation for self or first-degree relatives, or firstdegree relatives have been organ donors/recipients. Adopting a convenience sampling technique, the questionnaires were distributed to the eligible participants face-to-face and online via Google Forms. The sample size was calculated using Cochran's formula [n= $(Z^2pq)/e^2$, where n = estimated sample size, Z = standard normal deviate i.e., 1.96 with a confidence level of 95%, p = proportion of individuals in the population with the characteristic of interest (knowledge, attitude, willingness to organ donation) i.e., 60%, e = desired level of precision (0.05), q = 1-p (0.04). With an addition of 10% attrition, the sample size was estimated to be 405.

The questionnaire consisted of six tools. The first tool was about socio-demographic information composed of nine items. It contained information about age, gender, residence, marital status, educational status, etc. The second tool was about the knowledge of organ donation with a true/false response option, focusing on the age limit for organ donation, the advantages and risks of donating an organ, the possibility of donating whole or part of an organ, and the timing of organ donation. Nine questions were used to evaluate knowledge about organ donation. Scores ranged from 0 to 9. The third tool was about the attitude toward organ donation, and this part concentrated on the participant's attitude toward organ donation, the role of organ donation in saving lives, donation after death, and self-evaluation on willingness to organ donation. Attitudes were assessed with 12 questions using a four-point Likert scale, using response options of strongly agree, agree, disagree, and strongly disagree. The total score of attitudes towards organ donation ranged between 12 and 48. The questionnaire was designed to feature a mix of positive and negative questions, allowing the study to prevent false-positive results due to incorrectly filled questions. The fourth tool gauged participants' willingness to donate organs by posing the question, "Are you willing to donate your organs?" This resulted in a binary response (No or Yes). Tool Five explored the factors that motivate organ donation, and Tool Six looked into the factors that inhibit it, using multiple-response questions. Participants were

given Tool Five if they indicated a willingness to donate organs in Tool Four or Tool Six if they did not. The reliability of the knowledge questionnaire was assessed using Kuder Richardson (KR21) and resulted in a score of 0.68. Meanwhile, the reliability of the attitude rating scale was evaluated with Cronbach's alpha, and the result was a score of 0.65. The reporting of the current study followed the guidelines of Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). 16

The data were analyzed using SPSS version 21 software (SPSS Inc., Chicago, United States). Categorical data were expressed in terms of frequencies and percentages. Continuous data were reported as means and standard deviations. The chi-square test was used to assess the associations between socio-demographic variables with knowledge, attitude, and willingness to organ donation, with a significance level set at a p value of 0.05 or lower. The Relative Importance Index was calculated for factors encouraging and hindering organ donation among participants willing and unwilling to donate by dividing

the number of responses for each factor by the total number of participants in each category.

RESULTS

The demographic and socioeconomic characteristics of the study participants are represented in Table 1. The participant's age ranged from 18-54 years, with a mean age of 24.59 years. Among the participants, the majority were females 346 (66.7%). The prevalence of willingness to organ donation was 71.67%. The prevalence rate of willingness to organ donation was higher among females (74.27%), people residing in urban areas (75.07%), and people with a monthly family income greater than 20,000 (74.48%). A chi-square test was performed to assess the association between socio-demographic variables and the willingness to donate organs. The results indicated that residence, religion, and monthly family income were significantly associated to the willingness to donate organs at the 0.05 level of significance (Table 1).

Table 1: Demographic characteristics.

Vaniables	Group	Willingness to o	Davahaa		
Variables		(n=519) (%)	Yes (372) (%)	No (147) (%)	P value
Age (in years) 24	1.59±6.13				
Gender	Male	173 (33.3)	115 (66.47)	58 (33.52)	0.063
Gender	Female	346 (66.7)	257 (74.27)	89 (25.72)	0.003
Residence	Rural	166 (32)	107 (64.46)	59 (35.54)	0.012*
Residence	Urban	353 (68)	265 (75.07)	88 (24.93)	0.012*
	Hindu	445 (85.74)	326 (73.25)	119 (26.74)	
Religion	Muslim	17 (3.3)	12 (70.58)	5 (29.41)	0.012*
Kengion	Christian	44 (8.5)	24 (54.54)	20 (45.45)	0.012*
	Others	13 (2.5)	10 (76.92)	3 (23.07)	
Family type	Nuclear	393 (75.7)	290 (73.79)	103 (26.21)	0.059
Family type	Joint	126 (24.3)	82 (65.07)	44 (34.92)	0.039
Marital status	Single	439 (84.6)	321 (73.12)	118 (26.87)	0.087
Maritai Status	Married	80 (15.4)	51 (63.75)	29 (36.25)	0.087
Educational	Higher secondary or below	31 (6)	19 (61.29)	12 (38.70)	0.350
status	Undergraduate and above	488 (94.1)	353 (72.33)	135 (27.66)	0.550
Employment	Yes	150 (28.9)	104 (69.33)	46 (30.66)	
Employment	No	369 (71.1)	268 (72.62)	101 (27.37)	0.450
Family income	<10,000/-	42 (8.1)	26 (61.90)	16 (38.09)	
(monthly)	10,001-20,000	85 (16.4)	54 (63.53)	31 (36.47)	0.043*
(monuny)	>20,000	392 (75.5)	292 (74.48)	100 (25.51)	

^{*}Significant p<0.05

The mean score $\pm SD$ for knowledge about organ donation was 5.63 ± 1.22 out of 9. Participants willing to donate organs had a higher mean score (5.65) than those unwilling (5.59). The distribution of knowledge on willingness to organ donation is depicted in Table 2. Most participants were knowledgeable about items 5, 7, and 3, acknowledging that organs can be donated not only to

immediate family members (87%), multiple organs can be donated (96.53%), and that not everyone with a disease can donate organs (93.44%). Those willing to donate were more aware of the age regulations for organ donors (item 8) than those unwilling (95.43% vs. 88.43%). Items 3, 7, 8, and 9 were significantly associated with willingness to organ donation (Table 2).

The overall mean ±SD score for attitudes toward organ donation in this study was 36.04±4.80 out of 48. Participants who were willing to donate organs had a higher attitude score (36.99±4.54) than those who were unwilling (33.64±4.62).

Table 2: The distribution of knowledge on willingness to organ donation.

	Statement		Willingness to	■ Test		
Item		True/false	All (n=519) (%)	Yes (n=372) (%)	No (n=147) (%)	statistics#
1	Organ donation can be done by people who are alive.	True False	366 (70.52) 153 (29.47)	263 (70.69) 109 (29.30)	103 (70.06) 44 (29.93)	0.020
	Organ extraction should be	True	227 (43.73)	163 (43.81)	64 (43.53)	0.003
2	performed ONLY after brain death is determined	False	292 (56.26)	209 (56.18)	83 (56.46)	
3	Organ can be donated only to immediate family members.	True False	455 (87.66) 64 (12.33)	334 (89.78) 38 (10.21)	121 (82.31) 26 (17.68)	5.441*
	A person has not expressed their	True	398 (76.68)	292 (78.49)	106 (72.10)	2.403
4	opinion on organ donation. In such a situation, after their death, their legally competent relative can express their consent for organ donation.	False	121 (23.31)	80 (21.50)	41 (27.89)	
	Multiple organs (Kidneys, Liver, Heart, Eyes, etc.) can be donated.	True	501 (96.53)	361 (97.04)	140 (95.23)	_
5		False	18 (3.46)	11 (2.95)	7 (4.76)	1.025
6	Organ donation requires donor consent.	True	461 (88.82)	329 (88.44)	132 (89.79)	0.195
		False	58 (11.17)	43 (11.55)	15 (10.20)	
7	People with any disease can	True	34 (6.55)	17 (4.56)	17 (11.56)	8.421**
8	Organs can be donated by people of any age.	False True False	485 (93.44) 172 (33.14) 347 (66.85)	355 (95.43) 108 (29.03) 264 (70.96)	130 (88.43) 64 (43.53) 83 (56.46)	10.00**
9	Organ donors cannot claim any monetary compensation.	True False	313 (60.30) 206 (39.69)	237 (63.70) 135 (36.29)	76 (51.70) 71 (48.29)	6.348*

^{*} p<0.05, **p<0.01, Significant; # Chi-Square

Table 3: Comparison of knowledge and attitude regarding organ donation among willing and unwilling participants.

Variable	Willingness to orga	Test statistics#		
	Total (n=519)	Yes (n=372)	No (n=147)	Test statistics"
Knowledge	6 (5 to 7)	6 (5 to 6)	6 (5 to 7)	0.315
Attitude	36 (33 to 39)	37 (34 to 40)	34 (31 to 37)	7.065**

[#] Mann Whitney U Test; **p<0.01 Significant; IQR= Inter Quartile range

The Mann-Whitney U test was conducted to assess differences between willing and non-willing participants to organ donation, where the knowledge regarding organ donation was not significantly different between the groups (U=0.315, p>0.05). In contrast, attitudes towards organ donation were significantly different among the two groups (U= 7.065, p<0.01) (Table 3).

The correlation between total scores of knowledges, attitude, and willingness to organ donation was assessed using the Spearman rho test. A significant correlation was found between the total score of knowledge and the total score of attitudes (r=0.195, p<0.01), as well as between the total score of attitude and willingness to organ donation (r=0.310, p<0.01). However, there was no significant correlation between the total score of knowledge and willingness to organ donation (r=0.014, p>0.05).

Table 4: Regression analysis to identify predictors of willingness to donate organs when controlling for other confounders.

Step	Variable	OR (CI 95%)	P value	AOR	P value
1	Total score of knowledge	0.93 (0.77 to 1.07)	0.283	0.91 (0.771 to 1.078)	0.278
2	Total score of attitudes	1.169 (1.117 to 1.223)	<0.001**	1.177 (1.123 to 1.235)	<0.001**
3	Total Score of knowledge X Attitude	1.007 (1.003 to 1.010)	<0.001**	1.007 (1.003 to 1.010)	<0.001**
4	Residence	1.660 (1.114 to 2.475)	0.013*	0.588 (0.385 to 0.901)	0.014*
5	Residence X total score of attitudes	1.027 (1.017 to 1.038)	<0.001**	1.141 (1.063 to 1.226)	<0.001**

*p<0.05, **p<0.01, OR= Odds Ratio, CI= Class interval; Controlled variables in AOR are Steps 1 & 2: Gender, Residence, Family type, Education, and Occupation. Steps 3 and 4: Knowledge attitude, Gender, Residence, Family type, Education, and Occupation

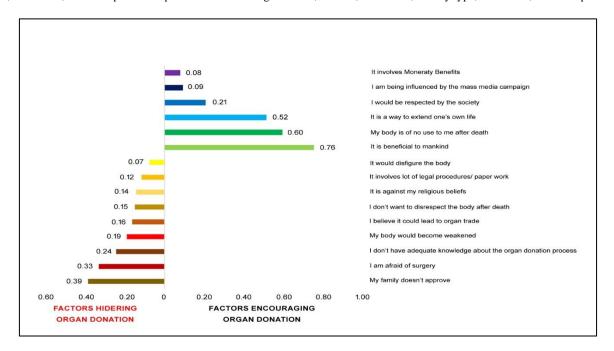


Figure 1: Relative importance index of factors encouraging and hindering organ donation.

The relative importance index was used to identify the factors encouraging and hindering organ donation, ranked from most to least significant. Among those willing to organ donation, the belief that it benefits humanity was identified as the most reported factor encouraging organ donation, followed by the view that the body is of no use after death. Among those not willing to organ donation, the most reported factor hindering organ donation was identified as disapproval from their family, followed by fear of surgery. The factors encouraging and hindering organ donation are depicted in Figure 1.

The logistic regression analysis explored the association between various factors and willingness to donate organs. The total knowledge score was not statistically significant (AOR=0.91; 95% CI: 0.77, 1.07), indicating that knowledge alone does not significantly impact willingness to donate. In contrast, total attitude scores significantly associated with willingness (AOR=1.177; 95% CI: 1.123, 1.235), suggesting that a positive attitude

strongly correlates with increased willingness to donate. When examining the interaction between total knowledge and attitude scores, a significant effect was found (AOR=1.007; 95% CI: 1.003, 1.010), indicating that combined knowledge and attitude positively influence organ donation willingness. Additionally, rural participants were 42% less likely to be willing to donate organs (AOR=0.588; 95% CI: 0.385, 0.901). The interaction between residential status and total attitude score was also significant (AOR=1.141; 95% CI: 1.063, 1.226), highlighting the importance of attitude in relation to residential status (Table 4).

DISCUSSION

The number of organ donations in India has significantly increased in recent years, yet the demand remains unmet, posing a major challenge to saving lives. This study represents the most recent survey of public knowledge, attitude, and willingness to donate organs in

Bhubaneswar, India. Additionally, the article offers valuable insights into the factors that influence and impede organ donation.

Gender impacts a person's decision to donate organs, with men—often being the primary earners—potentially being more hesitant to donate, while women's decisions are significantly influenced by their parents and spouses.¹⁷ To eliminate gender disparities in organ donation, increased public education and clearer communication about posthumous wishes are essential. Addressing societal expectations, challenging traditional gender roles, and raising awareness are key to creating a more equitable organ transplantation system.¹⁷ Younger adults, those from higher socioeconomic backgrounds, and individuals with more education showed greater willingness to donate organs.¹⁸ Our study also found that married individuals were less willing to donate organs, aligning with Xiaojing, and Yan's findings but contradicting Shuchi, and Zubairu results. 19-22 This relationship warrants further investigation.

This study found that greater knowledge about organ donation did not correlate with a higher willingness to donate, consistent with findings from research in Australia, and Korea. 23,24 However, it differs from research conducted in the United Kingdom, and China. 19,25 These differences may stem from variations in how knowledge is measured (content and number of questions), as well as cultural and country-specific factors like traditional values, religious beliefs, compensation methods, and institutional trust. Further research is needed to explore the link between knowledge and willingness to donate. In this study, the average knowledge score was 5.63±1.22 out of 9 questions, suggesting that increasing awareness about organ transplantation could boost willingness to donate in India.

Our study, consistent with other research, found a positive correlation between attitude and willingness to donate organs. Increasing public awareness and shifting attitudes about organ donation can enhance donation rates. Narrative medicine, known for improving doctor-patient interactions, is particularly useful in addressing complex issues like organ donation and can help clarify misunderstandings among family members. In particularly members.

The majority of participants (71.7%) showed a willingness to donate organs, closely matching the 70% willingness rate found in Balajee's study.²⁸ Our study, consistent with findings from Syria and Saudi Arabia identified helping others as the primary motivation for organ donation.^{29,30} Individuals prioritize their safety and believe the body is of no value after death, which makes organ donation a simple choice. The critical motivators for organ donation were the belief in saving lives, the view that the body is of no use after death, the potential to extend life, and the desire to set a positive example for others.³¹

This study found that decisions about organ donation are shaped by a range of complex social factors beyond mere knowledge. The study also identified knowledge gaps, fear, and family disapproval as major barriers to organ donation. Fear and mistrust have long impacted decision-making, yet research has not thoroughly explored how fear affects organ donation, its sources, or how to address it. This fear may stem from reports of illegal organ trade or other concerns, but the reasons behind it remain underexplored. The social state of the socia

Raising public awareness about the possibility of organ donation is a key first step in improving donation rates. Organ donation procedures should be structured to manage communication timing, environments, and methods to alleviate the stress, pain, and pressure experienced by families during the process. Thoughtful planning, a calm approach, a comfortable and private environment, and the presence of skilled requestors all help to boost organ donation rates. Studies reveal that families are more inclined to make adverse decisions when healthcare professionals do not communicate empathetically and sensitively and when there is a lack of trust in the care given to their relatives. 33,34

Organ donation is becoming a significant public health issue due to the growing disparity between the need for organs and the actual number of donations. This problem exists not only in India but also in developed countries. Misconceptions and cultural beliefs about organ donation need to be tackled through awareness campaigns. Primary healthcare workers, who are often the first point of contact in the community, should be involved in these campaigns. Additionally, the organ donation registration process should be simplified and made accessible at the most basic levels of health care.

CONCLUSION

The study indicates that participants are open to organ donation. However, there is a significant shortage of available organs for transplantation in India. To address this, it's crucial to educate the public about organ donation, including its process, risks, and potential outcomes, while addressing fears and misconceptions. This effort should involve healthcare professionals, media, religious leaders, and politicians to enhance patient outcomes.

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