

Original Article

Awareness & perceptions about organ donation among patient attendants in a tertiary-care hospital in South India: An observational study

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Background & objectives: Numerous barriers like lack of awareness, fear of misuse and sociocultural beliefs contribute towards low rates of organ donation. In 2019, India had a donation rate of only 0.52 per million. Hence, this study was undertaken to determine the awareness levels and perceptions about organ donation among patient attendants in a tertiary-care hospital in South India.

Methods: This cross-sectional study, 'passing on the torch of life', with a sample size of 110 was conducted in a tertiary care hospital from June to October 2022. Beds across were selected by simple random sampling and the attendants of patients were interviewed using a face-validated structured interview schedule. Data was analysed using SPSS v.20 using the independent sample t test and ANOVA.

Results: The majority of the participants were Hindus (62%), married (68%), living in urban areas (62%) and gainfully employed (60%). The mean awareness score was 7.86 ± 2.64 (out of 13). About 70 per cent of the participants were regarded to have adequate knowledge. The mean perception score was 67 ± 9.41 (out of 86). A total of 95 per cent of the participants supported organ donation, however only 51 per cent were willing to donate. Males, participants with higher education and income and those residing in urban areas had significantly higher awareness scores ($P < 0.05$). Multiple linear regression analysis showed that higher education levels was a predictor of increased awareness ($P = 0.036$).

Interpretation & conclusions: The majority of participants had adequate awareness, positive perceptions and supported organ donation, however, only 51 per cent were willing to donate their organs. Education levels was a significant predictor of awareness levels. A further qualitative study is recommended to explore the reasons behind the unwillingness to donate, despite strong support for organ donation.

Key words Awareness - barriers - deceased donation - living donation - organ donation - perception

Organ transplantation is a key medical milestone, yet there's a large gap between organ demand and supply in India. In 2019, India's donation rate was only 0.52 per million people, compared to 46.9 in Spain

and 36.8 in the United States of America¹. Though deceased organ donation rates in India increased from 0.27 to 0.52 per million between 2013 and 2019, these donations account for less than 20 per cent of

all organ donations (deceased and living donations)². Many potential donors are brain-dead victims of traffic accidents. In 2019 alone, there were 1,37,689 deaths nationally due to road traffic accidents and a previous study estimated around 68.7 per cent of road traffic accident victims in India to have fatal traumatic brain injuries^{3,4}. Hence, in 2019, 94,592 individuals were potential donors, yet only 715 donations occurred². Moreover, post the COVID-19 pandemic, global organ donations have declined by 17.6 per cent^{5,6}.

One of the key barriers to organ donation is the lack of awareness among the general population⁷. Other factors include sociocultural aspects such as superstitions and religious beliefs, lack of familial consent, fear of misuse and misconceptions about the organ donation process⁷⁻⁹. In terms of organizational barriers, poor levels of coordination and poor communication within the teams involved in organ donation and inadequate counselling of the key stakeholders were the key barriers. These in turn lead to the low rates of deceased donation rates seen in India. Hence it is important to assess the knowledge levels and views on organ donation to help understand the current barriers.

While there have been many Indian studies on medical professionals¹⁰, students in the healthcare profession¹¹, specific demographic groups like police personnel¹², rural communities¹³ and patients¹⁴ there is limited data on the knowledge levels and perceptions of the general public. A study done in 2016, showed that only 52.8 per cent of the general population have adequate awareness on organ donation¹⁵. Therefore, this study was undertaken to explore the current knowledge levels and perceptions about organ donation by interviewing patient attendants in a tertiary care hospital in a metropolitan city in South India using a structured interview schedule. The medical college hospital in which the study was undertaken caters to patients from various socioeconomic strata, hence the attenders of patients are likely to be a representative of the general public in the study area.

Materials & Methods

This study was conducted at the department of Anatomy, St John's Medical College, Bangalore after obtaining the ethical clearance from the Institutional Ethics Committee. Data was collected by face-to-face interview after taking written informed consent or thumbprints for illiterate individuals.

Study area, design and population: This cross-sectional study was conducted from May to November 2022 at a 1,350-bed tertiary care hospital in Bangalore, Karnataka. The study population were attendants of inpatients, aged 18 yr or older, interviewed using a pre-validated schedule. The study excluded individuals with cognitive impairments and attendants in the Intensive Trauma Units or Intensive Care Units, emergency, and COVID wards.

Sample size: The sample size was calculated by using the formula

$$n = \frac{(Z_{\alpha})^2 \times p \times q}{d^2}$$

Where n was the sample size and Z_{α} was 1.96. The estimated prevalence, p was taken as 52.8 from a previous study done in India that showed 52.8 per cent of the participants had adequate knowledge about organ donation¹⁵. Subsequently, q ($100 - p$) was taken as 47.2 along with a desired level of precision (d) of 10 per cent. Hence, the sample size was calculated to be 96, which was rounded off to 100. After allowing for 10 per cent of the interviews to be incomplete, the final sample size was estimated to be 110.

Sampling plan: A simple random sampling method was used. Bed numbers meeting the inclusion and exclusion criteria were mapped, and 875 beds were identified as part of the sampling frame. Random numbers generated by SPSS v.20 selected the beds, and the attendant of the chosen bed was interviewed. If the attendant did not consent or the bed was empty, the next available bed in sequence was selected.

Study tool: The study used a pretested, face-validated interview schedule. It was validated by five experts working in community medicine, forensic medicine, medical social work, and medical humanities. It consisted of three sections (A, B, and C) with questions based on two previous studies done in India and the US respectively^{15,16}. The two studies were chosen for their comprehensive questionnaires. The tool aimed to collect data about the variables of interest: knowledge and perceptions of organ donation (the dependent variables) and the sociodemographic factors (the independent variables). The tool was translated into five local languages (Kannada, Hindi, Telugu, Malayalam, Tamil) and back-translated for accuracy.

Table I. Sources of awareness

Source	<i>f</i> (n=100)
Mass media	79
Discussion with a family member/friend	36
Information provided by medical personnel	23
Social media	23
Health awareness camp	16
Personal experience or involvement	8
Billboard or poster	8
Schools and textbooks	1

It was pretested with 15 patient attendants. The study tool has been included as a supplementary material.

Section A: Sociodemographic details: There were 11 questions on sociodemographic details such as age, gender, religion, educational background, economic status and place of residence.

Section B: Awareness on organ donation: This section included 13 questions to assess awareness: eight on general organ donation and five on donation laws. Each correct answer earned one point, with a maximum score of 13. A score of ≥ 50 per cent indicated adequate awareness of organ donation.

Section C: Attitude on organ donation: Section C consisted of 26 questions focused on participants' willingness to donate organs and their perspectives on organ donation. Most questions had responses recorded using a 5-point Likert scale. There was one open-ended question (question 16) to explore reasons for unwillingness. All questions except question 15 was scored out of 5 while question 15 scored out of 1. Questions 2-4, 9-12, and 16 were excluded from final scoring, they were kept to better understand perceptions. Hence, this led to a total score of 86 points, with higher scores indicating more positive attitudes. All negatively worded items were reverse-coded before analysis.

Data analysis: The data collected was entered into a MS Excel sheet, then analysed using the Statistical Package for Social Sciences (IBM Corp., Armonk, NY, USA) v.20¹⁷. Participants scoring ≥ 50 per cent of the score range of the section B were regarded to have adequate knowledge or awareness. Awareness and perception scores obtained from sections B and C, respectively were the primary outcome variables. The secondary

objective of the association of awareness levels with sociodemographic variables was assessed using the independent sample t test and ANOVA. Multiple linear regression was done to estimate associations if any between sociodemographic variables and the previously stated outcome variable. A *P* value of <0.05 was considered as significant. Additionally, thematic analysis was done on a question in section C to find reasons behind unwillingness to donate.

Results

Out of 110 patient attendants interviewed, nine interviews were incomplete, and one withdrew consent, leaving 100 participants for analysis. The participants included 55 females and 45 males, with ages ranging from 19 to 66 yr (mean age 35.1 ± 10.8). Most were Hindus (62%), married (68%), living in urban areas (62%), and employed (60%).

The mean awareness score was 7.86 ± 2.64 (out of 13). Seventy per cent ($n=70$) had adequate knowledge, while 30 per cent ($n=30$) had inadequate knowledge. Ninety-five per cent had heard of organ donation, with mass media being the primary source of awareness for 79 per cent of participants (Table I).

Most participants were aware of key organ donation laws: 73 per cent knew organ trade was illegal, 69 per cent recognized the family's final decision, and 53 per cent were aware of the existence of an organ donation law. However, awareness of organ donor cards was low, with only 19 per cent familiar with the concept and 34 per cent believing it was possible to change one's mind after registering as a donor. The mean score for questions on organ donation laws was 2.5 out of 5. The results of awareness have been summarised in table II.

The mean perception score on organ donation was 67 ± 9.41 (out of 86). For 16 of the 17 five point Likert scale questions, the median score was above 3.5 (Table III). About 95 per cent of participants supported organ donation. In terms of willingness, 51 per cent were willing to donate, 35 per cent were unsure, and 14 per cent were unwilling. The reasons for unwillingness were thematically analysed and presented in figure.

The likelihood of organ donation was dependent on the relationship between individuals. The median score decreased from a score of 5 for a family member to four for a friend and to 2 for an unknown person. A large majority of participants were more likely to donate the organs of their family members if they knew

Table II. Awareness regarding organ donation

Sl. no	Question	Correct response	Participants with correct response (Score=1)	Participants with incorrect response (Score=0)
1.	Heard of term 'organ donation'	-	95	5
2.	Can organs be donated to save lives	-	98	2
3.	When can organs be donated (while alive/after death)	Both	52	48
4.	Any age limit to receive an organ	No	60	40
5.	Any age limit to donate an organ	No	60	40
6.	Awareness on brain death	-	60	40
7.	What organs can be donated	-*	49	51
8.	Need for organs greater than availability	Yes	64	36
9.	Awareness of the organ donor card	-	19	81
10.	Possibility of change after indicating to be a donor	Yes	34	66
11.	Final decision of deceased organ donation depends on	Family members	69	31
12.	Is it Legal to sell/buy organs	No	73	27
13.	Is there a law to regulate organ donation	Yes (THOTA)	53	47

*The organs that can be donated include heart, liver, kidneys, intestines, lungs, pancreas and the donatable tissues include the cornea, heart valves, skin and bones

their family's wishes (91%) compared to those who did not know (54%).

A significant majority (74%) believed that choosing to be an organ donor would not affect a doctors' efforts to save their lives. A lesser proportion (60%) believed that there will be no misuse of donated organs. Most participants (61%) believed that both the rich and the poor have an equal chance for organ donation. The response to the Likert scale questions have been summarised in table III.

To understand the factors behind organ donation awareness, the various sociodemographic factors were subjected to bivariate analysis using the independent sample t-test or one-way ANOVA (Table IV). The variables of gender ($P=0.037$), education ($P<0.001$), per capita income ($P=0.014$) and locality ($P=0.04$) were significant with respect to the awareness score.

To understand the true predictors of awareness levels, the variables with a P value less than 0.05 were selected for multiple linear regression. The regression [$F(4,95)=6.25$; $R^2=0.208$] was run to predict the awareness levels from gender, education, per capita income and locality. Only the education level was a

statistically significant predictor ($P=0.036$) of organ donation awareness levels.

Discussion

The results of the study show that most participants had adequate awareness about organ donation and had a positive perception towards it. A previous study done on the general public in 2016 in an urban area in India¹⁵ estimated an awareness of 52.8 per cent. The increased rate of awareness in this study could be due to increased publicity in mass media. Participants had conveyed that media (like movies, news reports) in the last decade started spreading awareness on the topic. However, the awareness levels still remain less as compared to studies done globally in countries like the USA and Saudi Arabia which showed an awareness level of around 86 per cent and 90 per cent, respectively^{18,19}. In line with previous studies done both in India and globally²⁰⁻²², mass media was attributed as the main source of awareness. Additionally, only 23 per cent attributed their knowledge to healthcare personnel. This is consistent with previous studies done in India^{15,23}, and highlights the need to increase medical sources of awareness. With respect to the laws

Table III. Perceptions regarding organ donation

Sl. no	Question	Strongly agree/agree	Neutral	Strongly disagree/disagree	Median perception score (out of 5)
1.	How do you feel about the donation of organs?	95	5	0	5
2.	Willingness to donate your organs after death?*	66	22	12	4
3.	Likelihood of donation to a family member?*	83	11	6	5
4.	Likelihood of donation to a friend?*	53	25	22	4
5.	Likelihood to an unknown person?*	23	19	58	2
6.	If you didn't know your family member's wishes, likelihood to donate organs upon their death?*	54	19	27	4
7.	If you knew your family member wanted to donate organs, likelihood to donate organs upon their death?	91	7	2	5
8.	Organ donation should be promoted	91	6	3	5
9.	It is important for a person's body to have all of its parts when buried/cremated	16	17	67	4
10.	It is possible to have a regular funeral service following organ donation	88	2	10	5
11.	Organ donation is against your religion.	11	6	83	5
12.	Every year, thousands of people die due to a lack of donated organs	75	17	8	5
13.	Annually, the need for organs is less than its availability.	32	13	55	4
14.	A poor person and rich person has equal chance of getting an organ transplant.	61	1	38	4.5
15.	If you indicate you intend to be a donor, doctors will be less likely to try to save your life.	13	13	74	4.5
16.	Doctors and hospitals will use organs as they are intended to be used.	60	29	11	4
17.	People who donate a family member's organs after death pay extra medical bills.	9	25	66	4

*For these questions, the term likely/unlikely was used instead of agree/disagree for the Likert scale. Note: The median perception score was the score given after reverse coding negatively worded items

regarding organ donation, there is increased awareness as compared to previous studies done on medical students in India^{20,24}. However, awareness of the organ donor card was low, with only 20 per cent being aware. Hence, media campaigns should focus on promoting donor cards.

In terms of perceptions, there was a positive perception in general. Similar to a previous study on the general public in India¹⁵, the majority (95 per cent) supported organ donation. Participants were also more likely to donate the organs of their family members if they knew their family's wishes. This is consistent with a systematic review done by Vincent *et al*⁹, which revealed that even though a number of individuals were willing to donate their organs, a large proportion never expressed their wish to donate their organs to

their family due to the discomfort associated with the conversation, hence this remained a barrier to donate. Additionally, family members may hesitate to make a decision on donating the organs of a deceased loved one due to emotional stress. Hence public campaigns should encourage people to discuss their donation-related wishes with their family and friends.

The likelihood of donating organs was also dependent on the relation between the donor and recipient. This is in line with the findings of studies done in both Pakistan and China on perceptions regarding organ donation which show that family members and relatives are the preferred potential recipients compared to other groups for living transplants^{25,26}.

In this study, about half of the participants were willing to donate their organs, which is slightly lower

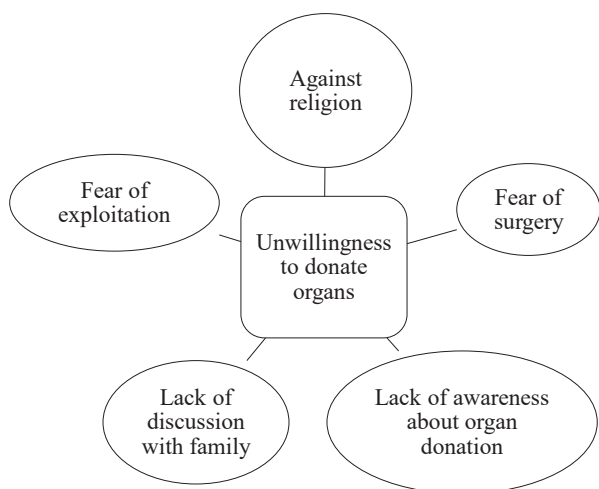


Figure. Reasons behind unwillingness to donate organs.

than a previous study on the general public in India¹⁵. Reasons for unwillingness included fear of exploitation, religious beliefs, lack of awareness, and lack of discussion; these were consistent with a systematic review done in 2022 on organ donation barriers⁹. These issues need to be addressed by both governmental and non-governmental organizations. Moreover, although 95 per cent of participants supported organ donation, only 51 per cent were willing to donate. Further qualitative studies can be done on groups such as family members who declined organ donation to provide insights into this gap and find strategies to tackle it. Additionally, interventional studies on ways to motivate individuals to donate organs would be beneficial.

Only about half of the participants believed there would be no misuse of organs and that organ allocation

Table IV. Association between knowledge scores and sociodemographic variable

Variable	Categories	n=100	Mean knowledge score ± SD	P value
Gender	Male	45	8.47±2.57	0.037*
	Female	55	7.36±2.60	
Age (yr)	<30	36	8.39±2.48	0.123
	30-45	46	7.85±2.29	
	>45	18	6.83±3.50	
Religion ^	Hindu	62	7.46±2.63	0.166
	Christian	21	8.33±2.90	
	Muslim	16	8.69±2.18	
Education	Grade 12 or below	51	6.88±2.67	<0.001**
	Undergraduate/ Postgraduate degree	49	8.80±2.20	
Marital status	Single	32	8.59±2.50	0.056
	Married	68	7.51±2.65	
Occupation	Gainfully employed	60	7.77±2.73	0.670
	Not gainfully employed	40	8.00±2.52	
Works in healthcare profession	Yes	13	7.77±2.68	0.895
	No	87	7.87±2.64	
Per Capita Income	0-5000	45	7.00±2.76	0.014*
	5001-10000	27	8.15±2.52	
	10001-15000	12	9.25±1.91	
	15001 and greater	16	8.75±2.24	
Locality	Urban	62	8.45±2.53	0.040*
	Rural	38	6.89±2.54	

*P**<0.05, **<0.001. ^While analysing religion, the category of ‘no religion’ with just one response was excluded. SD, standard deviation

is not influenced by financial status. In reality, organ donation is not based on wealth or social status. The fear of misuse remains a barrier to organ donation, which could be addressed through increased transparency in organ transplant allocation methods and by raising awareness about the regulatory bodies in place.

Our study showed that gender, education levels, per capita income and locality showed statistical significance with respect to knowledge levels. Gender differences could have been noted as women have lower literacy rates in India as compared to men²⁷. However, multiple linear regression analysis showed that only education was a factor associated with awareness levels. This is in line with a study done in Pakistan, however it additionally included per capita income as a predictor of awareness levels²⁵.

The study's implications are relevant for both hospital administration and policymakers. Hospital administrations can play a key role in promoting organ donation awareness among the general public and address barriers such as mistrust in the system. At the policy level, adopting an 'opt-out' system, like those in Spain and Singapore, where individuals are automatically considered organ donors, could potentially improve donation rates compared to the current 'opt-in' system in India^{28,29}.

The study had a robust methodology which included usage of a validated study tool, selection of attendants through simple random sampling and administration of the interview schedule in the first language of the participants. Attendants were interviewed from both the private and general ward to ensure a representation of various socio-economic strata. However, the limitations include that the sample size was quite small. Moreover, the sample size was estimated for the primary objective and therefore it may have been underpowered for subgroup analysis done as the secondary objective.

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Supplementary material

Interview schedule

Section A - Sociodemographic details

Section B - Awareness about organ donation

Section C - Attitude about organ donation

Section A - Sociodemographic details

1. Bed no–
2. Gender–M/F
3. Age–
4. Religion–Hindu/Muslim/Christian/Jain/Sikh/No religion
5. Highest education level–illiterate/less than grade 10/grade 10/HS graduate/Vocational training college /college graduate/post-graduate
6. Current marital status–Single/Married/Divorced
7. Occupation–student/unemployed/housewife/self-employed/salaried/retired
8. Do you work in the healthcare profession–Yes/No
9. No. Of individuals at home–
10. Monthly household income–
11. Locality–Urban/Rural

Section B - Awareness about organ donation

1. A- Have you ever heard of the term ‘Organ Donation’?
 - Yes
 - NoB– If yes, how have you heard of it.(Open Ended)
 - Discussion with a family member or friend.
 - Information provided by a medical professional
 - Information provided by a member of your religious organization
 - Personal experience or involvement with organ, eye or tissue donation
 - A billboard or a poster in a public place
 - Mass media (TV, radio, newspaper, internet)
 - A community activity, such as a health awareness camp
 - Social media such as Facebook, Instagram, YouTube, WhatsApp
 - Other source:
 - If mass media which one? TV/RADIO/NEWS/Internet
2. Can organs be donated to save someone’s life?
 - Yes
 - No
 - Don’t know
3. When can organs be donated?
 - While alive
 - After death
 - Both
 - Don’t know
4. Is there an age limit (upper or lower) to receive a donated organ?
 - Yes
 - No
 - Don’t Know

5. Is there an age limit (upper or lower) to donate an organ after death?
 - Yes
 - No
 - Don't Know
6. Are you aware of the term 'brain death?'
 - Yes
 - No
7. What organs/tissues can be donated after brain death? (*open ended question*)
8. Is the need for organs greater than the availability?
 - Yes
 - No
 - Don't know
9. Do you know what is an organ donor card?
 - Yes
 - No
 - Don't Know
10. Can we change our mind after signing up to be an organ donor?
 - Yes
 - No
 - Don't know
11. In India, after death what does the final decision of organ donation depend on?
 - Possession of an organ donor card
 - Decision of the hospital
 - The decision of family members
 - The decision of friends
 - Don't know
12. Is it legal to sell/buy an organ (like kidney) in India?
 - Yes
 - No
 - Don't know
13. Is there a government law to regulate organ donation?
 - Yes
 - No
 - Don't know

Section C—Attitude about organ donation

1. How do you feel about the donation of organs for transplantation?
 - Strongly support
 - Support
 - Neutral
 - Oppose
 - Strongly oppose
2. Have you ever donated an organ or a part of an organ?
 - Yes
 - No
3. Are you waiting an organ transplant?
 - Yes
 - No
4. Do you know anybody who has donated/received an organ?
 - Yes
 - No

5. Would you be willing to donate your organs after death?
 - Definitely yes
 - Probably yes
 - Neutral
 - Probably no
 - Definitely no
6. Assuming you are medically stable, how likely would you be to donate an organ while alive to a family member?
 - Highly likely
 - Likely
 - Neutral
 - Unlikely
 - Highly unlikely
7. Assuming you are medically stable, how likely would you be to donate an organ while alive to a friend?
 - Highly likely
 - Likely
 - Neutral
 - Unlikely
 - Highly unlikely
8. Assuming you are medically stable, how likely would you be to donate an organ while alive to an unknown person?
 - Highly likely
 - Likely
 - Neutral
 - Unlikely
 - Highly unlikely
9. If you believe in the cycle of rebirths, do you believe you will be reborn without an organ?
 - Yes
 - No
 - No, I don't believe in it.
10. Have you discussed with a member of your family your wish to or not to donate your organs after your death?
 - Yes; I want them to donate
 - Yes; I don't want them to donate
 - No discussion
11. Do you know the wishes of your immediate family members regarding organ donation?
 - Yes
 - No
12. If you didn't know your family member's wishes, how likely would you be to donate his or her organs upon their death?
 - Highly likely
 - Likely
 - Neutral
 - Unlikely
 - Highly unlikely
13. If you knew your family member's wishes, how likely would you be to donate his or her organs upon their death?
 - Highly likely
 - Likely
 - Neutral
 - Unlikely
 - Highly unlikely

14. Will you be willing to sign up as an organ donor?

- Yes
- No
- Not sure
- Already hold an organ donor card

15. If no, why do you not want to donate? (open ended question)

For each of the statements, please state your views:

16. Organ donation should be promoted

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

17. Organ donation disfigures the body

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

18. It is important for a person's body to have all of its parts when buried/cremated.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

19. It is possible to have a regular funeral service following organ donation.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

20. Organ donation is against your religion.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

21. Every year, thousands of people die due to a lack of donated organs for transplantation.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

22. Annually, the need for organs is less than its availability.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

23. Given equal need, a poor person has equal chance as a rich person of getting an organ transplant.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

24. If you indicate you intend to be a donor, doctors will be less likely to try to save your life.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

25. Doctors and hospitals will use organs as they are intended to be used.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

26. People who donate a family member's organs after death pay extra medical bills.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree