

Original Articles

Knowledge, attitude and behaviour of the general population towards organ donation: An Indian perspective

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ABSTRACT

Background. The rate of organ donation in India is low and research on organ donation among the general population is limited. We assessed the knowledge, attitude and willingness to donate organs among the general population.

Methods. We carried out a cross-sectional descriptive study among 193 randomly selected relatives of patients (not of those seeking organ donation) attending the outpatient department at a tertiary care centre. We used a structured questionnaire to collect data through face-to-face interviews.

Results. We found that 52.8% of the participants had adequate knowledge and 67% had a positive attitude towards organ donation. While 181 (93.8%) participants were aware of and 147 (76.2%) supported organ donation, only 120 (62.2%) were willing to donate organs after death. Further, there were significant associations between age, gender, education, economic status and background of the participants with their intention to donate organs.

Conclusion. Our study advocates for public education programmes to increase awareness among the general population about the legislation related to organ donation.

Natl Med J India 2016;29:257–61

INTRODUCTION

Organ donation is defined as an act of giving one or more organs, without compensation, for transplantation to another person.¹ Although, organ donation is a personal issue, the process has medical, legal, ethical, organizational and social implications.^{2,3} Technological advances in the past few decades have enhanced the feasibility of organ transplantation, which has pushed the demand for organs. Consequently, shortage of organs has become a global concern.⁴

In India, the Transplantation of Human Organs Act (THOA) was enacted in 1994.⁵ Yet the rate of organ donation in India is

poor (0.34 per 100 000 population) compared to developed countries.⁶ In addition, organ donation following brainstem death is infrequent in India. THOA (1994) defines brainstem death as 'the stage at which all functions of the brainstem have permanently and irreversibly ceased'.⁷ Attitudes are generally influenced by social and cultural factors.⁸ Knowledge, attitude and behaviour are the key factors that influence rates of organ donation.^{9–11} Culture and religion have also been documented to affect the decision-making process of organ donation.⁸ Hence, it is crucial to assess the knowledge and attitudes of the general population towards organ donation. In India, published evidence on organ donation is mainly from studies among healthcare workers,¹² patients¹³ and college students.¹⁴ However, some research is available about organ donation among the general¹⁵ and rural populations.¹⁶ We assessed the knowledge, attitudes and willingness to donate organs among the general population.

METHODS

We carried out this cross-sectional descriptive survey among relatives of patients attending the outpatient department (OPD) at a tertiary care centre in Bengaluru. The study sample was selected by a lottery method based on the OPD registry. We included all individuals ≥ 18 years of age and those who were willing to participate. We excluded people with cognitive impairment and relatives of patients who were in need of organs for transplantation. We asked 275 people to participate in our study; of them, 82 (30%) declined due to lack of time and interest. Hence, our final sample had 193 people.

Data collection instrument

The questionnaire was in four parts. The first part consisted of items about sociodemographic details of the participants such as age, gender, education, religion, economic status, marital status and place of residence. In addition, five questions related to participants' awareness about organ donation, brain death, legislation, opinion on promotion of organ donation and sources of information about organ donation.

The second part intended to measure the knowledge level of participants about organ donation.¹⁷ This had two components. One was a list of 11 items with true/false response options in five subscales, namely general donation-related statistics (2 items), knowledge of the donation process (3 items), knowledge of what signing a donor card means (3 items), knowledge of medical suitability for donation (2 items), and knowledge of religious

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institutions' approach to donation (1 item). With one mark for every correct response, the maximum score in this component was 11. The second component of this part measured experiential knowledge of people (8 items) about organ donation and organ transplantation in three domains: (i) personal knowledge of a donor or donor family member (3 items); (ii) personal knowledge of a person on a waiting list (2 items); and (iii) personal knowledge of an organ/tissue recipient (3 items).

The third part consisted of 22 items assessed on a 5-point Likert scale that ranged from 'strongly disagree' to 'strongly agree'. These items assessed perceptions and attitudes of participants toward organ donation.¹⁷ Points ranging from 1 to 5 were given to each response such that the more positive the response, the higher the score. The range of scores for this scale was 22 to 110.

The fourth part of the questionnaire measured participants' willingness to donate organs. Intent to sign the card was measured on a 5-point scale developed by Skumanich and Kintsfather¹⁸ (1: I will definitely sign the card; 2: I will probably sign the card; 3: I am unsure as to whether or not I will sign it; 4: I will probably not sign it; and 5: I will definitely not sign it). A sixth item was added to identify participants who had already signed an organ donation card.¹⁹

Data collection

We piloted the questionnaire among a group ($n=20$) of participants and we found that the study was feasible. The primary author collected the data through a face-to-face interview, in a private room at the treatment facilities where the participants were recruited. It took approximately 45–50 minutes to complete the structured questionnaire.

Ethical considerations

The ethics committee of the hospital approved the study protocol. The researchers approached the participants and briefly explained the purpose of the study. Written consent was obtained from the participants and they were given the freedom to quit the study at any time. Participants' confidentiality was respected.

Data analysis

Before analysis, negatively worded items were reverse coded. Descriptive (frequency, percentage, mean and standard deviation) and inferential (chi-square test) statistics were used to interpret the data. Statistical significance was considered at $p<0.05$.

RESULTS

Of the 193 people interviewed, 103 (53.4%) were men. The majority of participants were between 25 and 40 years (36.3%) with a mean (SD) age of 44.1 (1.55) years (Table I). The majority were married (85.5%), Hindus (60.1%) and from an urban background (56%). While most of them (93.8%) were aware of organ donation, only 5.7% had heard about the organ donation law (Table II). With regard to organ donation statistics, the majority of people were not aware about the demand of organs for transplants (100, 51.8%) and that people on the waiting list for transplant die every day because of non-availability of organs (130, 67.4%). Participants possessed better knowledge about the process of organ donation as the majority approved that organ and tissue donation does not disfigure the body, so an open casket funeral is possible (161, 83.4%) and said that selling organs is illegal in India (168, 87%). A majority of the participants were aware that people can specify on a donor card about the organs and

tissues they wanted to donate (146, 75.6%), and donors can change their mind about organ donation after signing the donor card (137, 71%). More than half the participants (101, 52.3%) agreed that religious people do not oppose organ and tissue donation. However, the mean (SD) knowledge score (5.81 [1.84]) showed that only 52.8% of participants had adequate knowledge about organ donation. Regarding experiential knowledge, more participants were familiar with people who were on dialysis (130, 67.4%) and had a corneal transplant (69, 35.8%).

Over three-fourths of the people supported organ donation (147, 76.2%) and 120 were willing to donate organs after death (62.2%). The majority of people (106, 54.9%) recognized the importance of discussing their wishes related to organ donation with their family and disagreed that their religion taught against organ donation (136, 70.5%). The mean (SD) attitude score (73.6 [5.52]) indicated a positive attitude among the study population. Seventy-nine participants (40.1%) were willing to sign an organ donation card but only 1 among them had signed an organ donation card (Table III).

There was a significant association between sociodemographic variables and participants' willingness to sign an organ donation

TABLE I. Characteristics of the sample

| Variable | Group | Frequency (%) |
|--|----------------------|---------------|
| Age (years) | <25 | 23 (11.9) |
| | 25–40 | 70 (36.3) |
| | 41–55 | 53 (27.5) |
| | 56–70 | 36 (18.7) |
| | >70 | 11 (5.7) |
| Sex | Male | 103 (53.4) |
| | Female | 90 (46.6) |
| Education | Illiterate | 36 (18.7) |
| | Primary education | 55 (28.5) |
| | Secondary education | 35 (18.1) |
| | Pre-university | 20 (10.4) |
| | Degree and above | 47 (24.4) |
| Marital status | Unmarried | 28 (14.5) |
| | Married | 165 (85.5) |
| Religion | Hindu | 116 (60.1) |
| | Muslim | 56 (29) |
| | Christian | 21 (10.9) |
| Residence | Rural | 85 (44) |
| | Urban | 108 (56) |
| Income (₹) | <3000 | 72 (37.1) |
| | 3001–6000 | 59 (30.4) |
| | 6001–9000 | 7 (3.6) |
| | >9000 | 55 (28.4) |
| Heard about organ donation | Yes | 181 (93.8) |
| | No | 12 (6.2) |
| Know the meaning of brain death | Yes | 9 (4.7) |
| | No | 184 (95.3) |
| Source of information about organ donation | Television | 135 (69.9) |
| | Newspapers | 66 (34.2) |
| | Posters | 2 (1.0) |
| | Healthcare providers | 40 (20.7) |
| | Family | 35 (18.1) |
| | Friends | 63 (32.6) |
| Promotion of organ donation | Yes | 184 (95.3) |
| | No | 9 (4.7) |
| Heard about organ donation law | Yes | 11 (5.7) |
| | No | 182 (94.3) |

card. More number of participants below 40 years (55, 68.7%) were willing to sign the organ donation card ($p<0.001$). While 60

(54.1%) of the women were unsure, majority (50, 62.5%) of men were in favour of signing an organ donation card ($p<0.03$). Participants with lower education ($p<0.001$), those from a lower socioeconomic status ($p<0.001$) and rural background ($p<0.05$) were unsure about signing the organ donation card. A majority of participants (59, 67.8%) with poor knowledge were unsure ($p<0.02$) of signing an organ donation card (Tables IV and V).

TABLE II. Participants' knowledge about organ donation

| Item | True (%) | False (%) |
|---|-------------|------------|
| <i>General donation-related statistics</i> | | |
| 1. For most organs, the demand for transplants is higher than the availability | 93 (48.2) | 100 (51.8) |
| 2. People on the waiting list for a transplant die every day because not enough organs are available | 63 (32.6) | 130 (67.4) |
| <i>Knowledge of the donation process</i> | | |
| 1. Organ and tissue donation disfigures the body so an open casket funeral is not possible | 32 (16.6) | 161 (83.4) |
| 2. Indians wait longer for kidney transplants | 116 (60.1) | 77 (39.9) |
| 3. It is illegal to sell organs in India | 168 (87) | 25 (13) |
| <i>Knowledge of what signing a donor card means</i> | | |
| 1. A person can specify on a donor card what organs and tissues they want to donate | 146 (75.6) | 47 (24.4) |
| 2. Next of kin must give permission for donation to occur even if I sign a donor card | 63 (32.5) | 130 (67.4) |
| 3. Once a person has signed a donor card they cannot change their mind about organ donation | 56 (29) | 137 (71) |
| <i>Knowledge of how medical suitability for donation is determined</i> | | |
| 1. Anyone can decide to be a donor regardless of their age or medical condition | 80 (41.5) | 113 (58.5) |
| 2. Signing a donor card will not change the medical treatment I receive to save my life at the hospital | 136 (70.5) | 57 (29.5) |
| <i>Knowledge of religious institutions' objections to donation</i> | | |
| 1. Most religious people oppose organ and tissue donation | 92 (47.7) | 101 (52.3) |
| Mean (SD) overall knowledge* | 5.81 (1.84) | |

* Maximum score was 11

DISCUSSION

We aimed to assess knowledge and attitude of the general population towards organ donation. The results show that the majority of participants had heard about organ donation and had a positive attitude towards organ donation. However, only 1 participant had signed an organ donation card. We also explored the experiential knowledge of the participants related to organ donation and found a significant association between sociodemographic variables and willingness to sign an organ donation card.

The majority (93.8%) of participants in our study were aware of organ donation and these findings are similar to those of previous studies.^{13,14,16} In line with previous research,^{14, 20-23} we also found that television and newspapers were the major sources of information on organ donation. Similar to previous studies,^{14,24} in the current study merely 20.7% of the participants received

TABLE IV. Association between knowledge level and willingness to donate organs

| Donor card | Knowledge level | | p value |
|---------------------|----------------------|-----------------------|---------|
| | Poor n=87 (45.1%) | Good n=106 (54.9%) | |
| Willing to sign | 27 (31) | 53 (50) | 0.029* |
| Unsure | 59 (67.8) | 52 (49.1) | |
| Not willing to sign | 1 (0.9) | 1 (0.9) | |

TABLE III. Participants' attitude towards organ donation

| Item | Agree/strongly agree | Disagree/strongly disagree | Neutral |
|--|----------------------|----------------------------|-----------|
| I believe in afterlife | 156 (80.8) | 22 (11.4) | 15 (7.8) |
| I support organ donation | 147 (76.1) | 7 (3.7) | 39 (20.2) |
| I would agree to an organ transplant if my life were in danger without one | 92 (47.6) | 19 (9.9) | 82 (42.5) |
| I am willing to have organs donated after my death | 120 (62.2) | 73 (37.9) | — |
| It is important to discuss my wishes for after my death with my family | 106 (54.9) | 31 (16.1) | 56 (29) |
| I have discussed my wishes for after my death with my family | 153 (79.2) | 16 (8.3) | 24 (12.4) |
| If needed, I would receive an organ from a person of a different race than myself | 165 (85.4) | 2 (1.0) | 26 (13.5) |
| I would be willing to donate an organ to a person of a different race than myself | 136 (70.5) | 12 (6.3) | 45 (23.3) |
| I have been taught that organ donation is against my religion | 16 (8.3) | 136 (70.5) | 41 (21.2) |
| I think that organ donation is a safe and effective practice | 106 (54.9) | 5 (2.6) | 82 (42.5) |
| I think that organ donation disfigures the body | 51 (26.4) | 83 (43) | 59 (30.6) |
| I trust that doctors and hospitals use donated organs as they are intended to be used | 114 (59.1) | 30 (15.5) | 49 (25.4) |
| I think that doctors would try hard to save my life whether or not I plan to be an organ donor | 163 (84.4) | 30 (15.5) | — |
| In general, I think that organ donation is a good thing | 122 (63.2) | 4 (2.1) | 67 (34.7) |
| Organ donation is consistent with my moral values and beliefs | 77 (39.9) | 36 (18.6) | 80 (41.5) |
| It is important for a person's body to have all of its parts when buried | 68 (35.2) | 104 (52.3) | 24 (12.4) |
| It is impossible to have a regular funeral service after organ donation | 39 (20.2) | 96 (49.8) | 58 (30.1) |
| People who choose to donate a family member's organs pay extra medical bills | 30 (15.6) | 98 (50.7) | 65 (33.7) |
| Organs for transplant can be bought and sold in India | 139 (72) | 21 (10.9) | 33 (17.1) |
| Organ donation allows for something positive to come out of a person's death | 69 (35.7) | 45 (23.3) | 79 (40.9) |
| Most people who receive transplants gain additional years of healthy life | 70 (36.2) | 44 (22.8) | 79 (40.9) |
| Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant | 95 (49.2) | 52 (27) | 46 (23.8) |
| Mean (SD) attitude score* | | 73.6 (5.52) | |

* Maximum score was 110

TABLE V. Relationship between willingness to sign the organ donation (OD) card and sociodemographic variables

| Variable | Group | Willing to sign the OD card n=80 (41.5%) | | Unsure n=111 (57.5%) | | Not willing to sign OD card n=2 (1%) | | p value |
|----------------|-----------------------------|---|------|-------------------------|------|---|-----|---------|
| | | | | | | | | |
| Age (years) | <25 | 14 | 17.5 | 9 | 8.1 | 0 | 0 | <0.001* |
| | 25-40 | 41 | 51.2 | 29 | 26.1 | 0 | 0 | |
| | 41-55 | 17 | 21.2 | 35 | 31.5 | 1 | 50 | |
| | 56-70 | 8 | 10 | 27 | 24.3 | 1 | 50 | |
| | >70 | 0 | 0 | 11 | 9.9 | 0 | 0 | |
| Sex | Male | 50 | 62.5 | 51 | 45.9 | 2 | 100 | 0.03* |
| | Female | 30 | 37.5 | 60 | 54.1 | 0 | 0 | |
| Education | Illiterate | 14 | 17.5 | 28 | 25.2 | 0 | 0 | <0.001* |
| | Primary/secondary education | 21 | 26.2 | 51 | 45.9 | 0 | 0 | |
| | Plus two/diploma | 14 | 17.5 | 11 | 9.9 | 0 | 0 | |
| | Degree and above | 31 | 38.8 | 21 | 18.9 | 2 | 100 | |
| Marital status | Unmarried | 14 | 17.5 | 14 | 12.6 | 0 | 0 | 0.53 |
| | Married | 66 | 82.5 | 97 | 87.4 | 2 | 100 | |
| Religion | Hindu | 47 | 58.8 | 68 | 61.3 | 1 | 50 | 0.40 |
| | Muslim | 23 | 28.8 | 33 | 29.7 | 0 | 0 | |
| | Christian | 10 | 12.5 | 10 | 9 | 1 | 50 | |
| Residence | Rural | 27 | 33.8 | 57 | 51.4 | 1 | 50 | 0.05* |
| | Urban | 53 | 66.2 | 54 | 48.6 | 1 | 50 | |
| Income (₹) | <3000 | 31 | 38.8 | 41 | 36.9 | 0 | 0 | <0.001* |
| | 3001-6000 | 15 | 18.8 | 44 | 39.6 | 0 | 0 | |
| | 6001-9000 | 0 | 0 | 7 | 6.3 | 0 | 0 | |
| | >9000 | 34 | 42.5 | 19 | 17.1 | 0 | 100 | |

information through healthcare providers such as doctors and nurses. Most importantly, only 4.7% of the individuals knew about the meaning of brain death. A recent retrospective case record analysis of over 5 years revealed that of 205 patients diagnosed to be brain dead, organs were donated only in 10 (5%) cases.²⁵ Hence, governmental and non-governmental agencies should take an active part in creating awareness about brain death among the general population. THOA was enacted in 1995, yet only 5.7% of the participants were aware about legislation related to organ donation. These findings were comparable to the studies which showed that 13.9% and 14.1% of participants were aware of legislation related to organ donation.^{14,23,26} Nearly all (95.3%) the participants in our study were in favour of organ donation.

In our study, 52.8% of participants had adequate knowledge about organ donation. These findings were comparable to a previous study that showed 41.5% of participants had knowledge about organ donation.²⁷ The majority of participants in our study opined that organ donation does not disfigure the body so an open casket funeral is possible. Interestingly, this is different from earlier studies that found maintaining body integrity after death to be the most common reason for unwillingness to donate organs.²⁸ Similar to developed countries,²⁹ there is a shortage of organs in India, and many patients die while on the waiting list due to the shortage of organs.¹⁴ In general, after signing the organ donation card it will be given to the donor²² and in case the donor changes their mind about donating organs, they can tear up the organ donation card.²² The majority (71%) of participants in our study believed that they cannot change their mind once they have signed the organ donation card. Hence, these issues need to be addressed when planning public education programmes. Nearly half the sample thought that various religions oppose organ and tissue donation. These findings were similar to the documented literature which showed that religious beliefs were the major barrier for organ donation.^{22,27,30}

Evidence in the literature indicates that personal experience about organ donation contributes to the knowledge of individuals³¹ and subsequently organ donation rates. Traditionally in India, the family takes care of its members even when they are sick. Hence, the consent of the next of kin is mandatory for organ donation from a deceased donor.¹² Further, 54.9% of participants felt that after their death it is important to know their family's wishes. In a recent study, 83% of people thought that family/spouse should have the right to make a decision for organ donation.¹⁴ Thus, a positive attitude towards organ donation is necessary among family members.³² Nonetheless, a majority of them in our study were enthusiastic to either donate or receive organs.³³ Earlier studies indicate that trust in the medical system positively influences peoples' attitude towards organ donation.³⁴ For example, fear of premature declaration of death and improper use of organs were the key reasons that hindered organ donation.³⁵ However, illegal organ donation and misuse of organs are the main reasons for the low rate of organ donation in India.⁵ Similar to previous studies, 72% of individuals opined that organs for transplant can be bought and sold in India and this can be a major barrier to organ donation.¹⁵ Similar to a recent study,²³ the majority of participants in our study had a positive attitude towards organ donation. Though 93.8% of participants were aware of and supported organ donation, only 62.2% of participants were willing to sign an organ donation card. Hence, there is an urgent need to identify factors that influence such an attitude. Governmental and non-governmental agencies should clarify issues related to signing organ donation cards. In line with previous research,³⁷⁻³⁹ our study also showed significant associations between age, gender, education, economic status, and background of the participants with intentions to donate the organs. We found that men (62.5%) were more willing to donate their organs than women (37.5%); these findings complement the documented literature.^{14,22,37} Similar to our study, Azkan and Yilmaz found that those who are young

and with higher education had more positive attitudes towards donating organs.³⁰ Similarly, participants with adequate knowledge were more willing to sign the organ donation card.^{31,38}

Limitations

Our study has limitations of a cross-sectional design and a small sample that consisted of patient's relatives. This makes it difficult to generalize the findings. Therefore, future studies should include larger samples and qualitative studies such as focus group discussions for an in-depth understanding of the issues. However, we studied a random sample with participants from various backgrounds, which is a strength of this study.

Conclusion

Our study highlights that though a majority of participants were aware of and supported organ donation, only two-thirds were willing to sign an organ donation card. The majority of participants were unaware of the legislation and the process of organ donation. Our study showed the importance of the media in creating awareness about organ donation among the general population.

We suggest that the government should also strengthen the infrastructure of hospitals to maintain potential brainstem dead donors.

ACKNOWLEDGEMENTS

We thank all the participants for their valuable contribution.

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