

Perceptions and Attitudes Towards Organ Donation Among People Seeking Healthcare in Tertiary Care Centers of Coastal South India

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ABSTRACT

Background: Organ transplantation is the most preferred treatment modality for end-stage organ diseases. The need for the transplants is higher than the availability. Prerequisites for the success of transplantation program include awareness and positive attitudes.

Aim: To assess the perceptions and attitudes of the people seeking health care in tertiary care centers towards organ donation in Mangalore, India.

Settings and Design: This cross-sectional study included 863 people seeking general healthcare as outpatients.

Materials and Methods: Face to face interviews were carried out using pretested tools which included the socio demographic data. Data was analyzed using Statistical Package for Social Sciences version 11.5.

Results: Overall, 59.6% participants showed the willingness to donate organs. Females (64.1%) and participants from upper socio economic status (62.7%) had higher willingness rates for organ donations. Hindus (63.6%) and Christians (63.3%) had higher willingness rates for organ donations than Muslims (38.2%). Also, 23.7% participants showed willingness to donate eyes and 33.6% wished to donate any organ after death. Most of the participants (67%) were aware that money should not be accepted for donating organs, and 58.1% were aware that it is an offence to accept any benefit for organ donations. Forty percent participants had perceived risks associated with organ donation. Regarding donor cards, 42.3% of the participants knew about it and 3.7% already possessed it.

Conclusion: It is apparent from the study that though there was high level of awareness about organ donation, a high proportion of the participants did not have positive attitudes towards organ donation.

Key words: Attitude, Awareness, Organ donation, Perceptions, South India

INTRODUCTION

Organ transplantation is the most preferred treatment modality for end-stage organ disease and organ failures.^[1] Many organs such as cornea, kidney, and liver are commonly

transplanted to human recipients. However, the need for the transplants is high and the gap between organs available for transplantation and the number of patients waiting for a transplant is widening globally. Similar to the developed countries,^[2] a situation exists in India where there is a chronic shortage of organs available for transplantation.^[3] This shortage is primarily attributed to a limited number of organ donations in our country. A study from India, done in the last decade has shown that less than 50% were willing to consider organ donation.^[4] The patients on palliative care can serve as source of organs and tissues. However, the systems and pre-requisites for successful organ donation among them are lacking.^[5]

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The prerequisites for the success of a transplantation program include awareness, positive attitude of the public toward organ donation and consent by relatives for organ donation in the event of brain death.^[4] Lack of knowledge and understanding about organ donations, religious attitudes, and superstitious beliefs have generated fear and mistrust in the minds of the common man and, especially, the terminally ill patients.^[3,5] Studies have been done on Medical and Nursing students towards their perceptions and attitudes about organ donation and to enhance their motivation towards the same.^[4] However, there is a lack of studies done on the terminally ill patients and the general public with regards to their perceptions and attitudes about organ donation.^[3] The present study was carried out to seek an insight into the awareness and attitudes towards organ donation and to evaluate the factors associated with the same among the people seeking health care in the tertiary care centers of Coastal South India.

MATERIALS AND METHODS

This hospital based cross sectional study was conducted in three selected tertiary care centers in the Coastal city of Mangalore; a fast developing region with high literacy rate, located in Southern part of Karnataka State.^[6] People seeking healthcare as outpatients for general health reasons in the selected centers constituted of the study participants. The participants were not known cases of any chronic or major illnesses and were attending the health centers mainly for respiratory, gastro intestinal, and other general symptoms. The sample size for the study was estimated to be 863; by considering the assumed awareness about organ donation among people attending the tertiary care centers as 50%, relative precision 7%, Confidence Interval of 95%, and 10% non-response error.

Three Tertiary care centers were chosen using Simple Random Sampling (lottery method). After obtaining the clearance from Institutional Ethics Committee (IEC) of Kasturba Medical College, Mangalore, the selected tertiary care centers were visited for data collection. The data collection was done for 2 months between August and September, 2010. The participants were selected using convenience sampling and informed consent was obtained from them. A face-to-face interview was done using a pretested interview schedule. This interview schedule was developed in consultation with the experts in the field of palliative care and was pretested and validated. The interviews were conducted during the Outpatient Department timings in the selected health care centers. The socio economic status was classified based on the Modified Kuppaswamy scale.^[7] The socio economic classes were merged for the purpose of analysis as Upper and Lower. The interview schedule included questions to assess subject's

awareness on organ donation, related laws, willingness to donate organs after death and otherwise; the reasons for not willing to donate and possession of organ donor card. The collected data was analyzed using Statistical Package for Social Sciences (SPSS) version 11.5. For statistical analyses to compare the awareness and attitudes across the different categories of the study participants, Chi square (χ^2) test was performed to test the significance of each group. $P < 0.05$ was considered as statistically significant.

RESULTS

A total of 863 participants were included in the study. The majority (62.2%) of the participants were males. The overall literacy rate of the participants was high and most of the participants (62.8%) belonged to upper socio economic classes. All of the participants had heard about organ donations. Regarding attitude towards organ donation, 59.6% of the participants ($n = 514$) expressed their willingness to donate organs while 349 participants did not show any willingness for any kind of organ donation. The socio demographic profile of the participants and their willingness to donate organs is shown in Table 1. The

Table 1: Socio demographic characteristics of the study population who showed willingness to donate organs ($n=514$) amongst the total study population ($n=863$)

| Characteristic | Total (n) | Willingness to donate n (%) |
|-----------------------|-----------|------------------------------|
| Age group (years) | | |
| <20 | 73 | 45 (61.6) |
| 20-40 | 456 | 297 (65.1) |
| 40-60 | 235 | 129 (54.9) |
| >60 | 99 | 43 (43.4) |
| | | $\chi^2=18.8, df=3, P<0.001$ |
| Gender | | |
| Male | 537 | 305 (56.8) |
| Female | 326 | 209 (64.1) |
| | | $\chi^2=4.5, df=1, P=0.034$ |
| Socio economic status | | |
| Upper | 542 | 340 (62.7) |
| Lower | 321 | 174 (54.2) |
| | | $\chi^2=6.1, df=1, P=0.014$ |
| Education | | |
| <High school | 133 | 73 (54.9) |
| >High school | 730 | 441 (60.4) |
| | | $\chi^2=1.4, df=1, P=0.14$ |
| Religion | | |
| Hindu | 580 | 369 (63.6) |
| Muslim | 136 | 52 (38.2) |
| Christian | 147 | 93 (63.3) |
| | | $\chi^2=30.5, df=2, P<0.001$ |

willingness to donate organs in general was highest among the 20-40 years age group. The willingness to donate organs was higher among females than males (64.1 v/s 56.8%), and participants from upper than lower socio economic status (62.7% v/s 54.2%). The differences across the age groups ($P < 0.001$), gender ($P = 0.034$) and socio-economic status ($P = 0.014$) were found to be statistically significant. It was observed that the willingness to donate organs was higher among Hindus and Christians than Muslims and the difference was found to be statistically significant ($P < 0.001$). No significant differences were observed for willingness to donate organs in relation to educational status.

As shown in Table 2, 94.7% of the participants were aware about both living and after death organ donations. The majority of the participants (75.2%) thought that organs can be donated to anybody at will (75.2%). Regarding accepting monetary or other benefits for donating organs, 67% believed that money shouldn't be accepted for organ donations. More than half of the participants (58.1%) were aware that it is an offence in law to accept monetary or other benefits for organ donation. However, less than one-third of the respondents ($n = 253$, 29.3%) had heard about the Transplantation of Human Organs Act, the Indian law pertaining to organ donation and transplantation.

As shown in Table 3, out of the 823 people who were aware about living organ donation, 330 people (40%) believed that there are risks associated with organ donation. Among the perceived health risks, infection, and weakness were the most common (73.6%), followed by kidney failure (17.3%), psychological problems (6.7%), infertility (1.5%), and pain (0.9%). Majority of the study population (84.6%) said they would accept an organ from a donor, if required in future, and 83.2% of the respondents said they would extend support if anyone in their family decides to become an organ donor.

Overall, 365 participants (42.3%) knew about donor card. Among the people who knew about the donor card, 47.4% were aware that permission is sought from relatives before organs are recovered even if the deceased person had a donor card. A total of 14.9% respondents had heard about brain death and 81.4% of them were aware that it is an accepted criterion of death in India.

Regarding awareness about various organs that can be donated after death, 99.5% of the participants ($n = 859$) were aware about corneal transplantations, 98.1% about kidney ($n = 847$), 45.3% about liver ($n = 391$), 52.3% about heart ($n = 451$), and 22% about lung transplantations ($n = 190$). Among the 863 respondents,

3.7% participants already possessed a donor card. In the remaining participants who did not possess a donor card ($n = 831$), nearly one-third ($n = 304$) were willing to sign up for the donor card. While a large number of participants ($n = 349$) were not willing or undecided towards organ donations, 224 participants wished to donate only their eyes after death, and 290 participants wished to donate any organ required after their death. While 18.1% participants hadn't decided about donating organs as yet, 22.3% said they wouldn't consider organ donation at all [Table 4]. Among the 823 (95.4%) participants who were aware about living organ donation, 82.6% ($n = 680$) believed

Table 2: Awareness among the participants regarding organ donation and its legal aspects

| Characteristic | Response | No. (%) |
|--|----------------------------|------------|
| When can one donate organs? ($n=863$) | Only when alive | 06 (00.7) |
| | Only after death | 40 (04.6) |
| | When alive and after death | 817 (94.7) |
| To whom can one donate organs when alive, legally? ($n=823$) | Only near relatives | 179 (21.7) |
| | Anybody at will | 619 (75.2) |
| | Don't know | 25 (03.0) |
| Can one accept monetary or any other benefits for donating one's organs? ($n=823$) | Yes | 224 (27.2) |
| | No | 551 (67.0) |
| | Don't know | 48 (05.8) |
| Is it an offence in law to accept monetary/other benefits for organ donations? ($n=823$) | Yes | 478 (58.1) |
| | No | 149 (18.1) |
| | Don't know | 196 (23.8) |

Table 3: Perceptions and attitudes regarding organ donation among the study participants

| Characteristic | Responses | | |
|--|-------------|------------|--------------------|
| | Yes no. (%) | No no. (%) | Don't know no. (%) |
| Health risks are associated with organ donations ($n=823$) | 330 (40.0) | 387 (47.1) | 106 (12.9) |
| Recipient have risk following organ transplantation ($n=863$) | 271 (31.4) | 407 (47.2) | 185 (21.4) |
| Readiness to accept an organ if required ($n=863$) | 730 (84.6) | 26 (03.0) | 107 (12.4) |
| Supporting the kin if they decide to become an organ donor ($n=863$) | 718 (83.2) | 62 (07.2) | 83 (09.6) |

Table 4: Possession and willingness to possess the organ donor card among the study participants ($n=863$)

| Characteristic | Response | No. (%) |
|---|--------------------------------------|------------|
| Possession of a donor card | Yes | 32 (03.7) |
| | No | 831 (96.3) |
| Willingness to sign up for the donor card | Yes | 304 (35.2) |
| | No/Not now | 559 (64.8) |
| Organs likely to be donated after death | Don't want to donate/Not decided yet | 349 (40.4) |
| | Only eyes | 224 (25.9) |
| | All the organs | 290 (33.7) |

kidney was the only organ which could be donated when a person is alive, 7.2% ($n = 59$) were aware that single kidney, a part of the liver and bone marrow could be donated when alive and the rest did not specify any organ.

Majority of the study participants ($n = 594$, 68.8%) responded that major source of their information regarding organ donation was through the media including television, radio and print media. Family and friends were the source of information in 10% of the study population ($n = 86$). The rest of them had heard about organ donation from books ($n = 50$, 5.8%), doctors ($n = 20$, 2.3%) and camps held to spread education regarding organ donation ($n = 12$, 1.4%).

DISCUSSION

All the study participants had heard about organ donations which could be attributed to the high literacy and education rate (82.2%) in Mangalore.^[6] Significant role of media being the source of the information regarding organ donation is consistent with the results obtained in the study conducted in Bangalore.^[8] Our study showed that 94.7% participants were aware about both living and cadaveric organ donations, which was similar to that reported in the earlier study from Bangalore.^[8] Better awareness regarding cadaveric/deceased donation could be a result of the popularization of corneal donation after death in the media and various Non-Governmental Organizations. In India, the potential for deceased donation is high due to the high number of fatal road traffic accidents and this pool for organ donations is yet to be tapped. This stresses on the need to assess the awareness and willingness for organ donation among the terminally ill.^[4]

Regarding attitude towards organ donation, the majority of the participants expressed their willingness to donate organs. Our observations are similar to those reported in a previous study,^[9] where 53% participants had a positive attitude towards organ donation. Our study observed that the willingness to donate organs was different across the religions and the findings were similar to the study done in Chennai.^[10] The lower willingness towards organ donation/non-willingness to donate organs among some religions was primarily attributed to religious beliefs by more than one-third of the respondents. Our observations in this regard are further supported by the research conducted in Pakistan,^[11] where religious beliefs were found as a major factor deterring many people from expressing a motivation to donate.

Out of the 194 people, who were not willing to consider living organ donation, 30.9% of the people cited religious

reasons as the reason for not willing to donate. Among the people who did not wish to donate after death (194), 39.8% cited the reason that they did not want their body to be cut open/organs taken out from their body after their demise followed by religious reasons and family refusal. This observation was in line with that of a study done in Saudi Arabia,^[12] which showed that worries about receiving inadequate healthcare after donation, lack of family support, and lack of information about organ donation were the primary reasons for lack of willingness to donate. Considering the observations of the present study, it is apparent that even in educated group of people, there is hesitancy towards organ donation.

Considering the variation across the education status, it was observed that higher awareness and willingness to donate organs were observed among people who were more educated. This observation is similar to the observation made in the study from Pakistan,^[11] where awareness of organ donation correlated well with education, and socio-economic status while motivation to donate in turn was associated with the awareness of organ donation. Similarly, a study from Turkey^[13] has reported that education and training had significant positive effect on the motivation for organ donation.

The awareness about Transplantation of Human Organs Act was low among our study participants as compared to the study done in Delhi,^[9] where 51% of the respondents were aware about the Act. Thus, spreading awareness regarding the Act that laid down the guidelines for organ transplantation in India becomes quintessential in the study region to eliminate organ trade. Nearly, one-third of the participants who did not possess a donor card, were willing to sign up for the donor card. Lack of facilities and awareness might be the withholding factors from possessing the card as reflected in the previous study.^[8] Eye donation was more widely accepted among the participants; similar findings were noted by the studies done elsewhere,^[3] however, there has been a limited growth in acceptance of donation of other organs. Lack of information regarding the donations of other organs could be a factor contributing to the lesser acceptance of other solid organ donations. The participants willing to donate their organs after death were registered as per the criteria laid by the Zonal Coordination Committee of Karnataka (ZCCK) for transplantation^[14] and their donor cards were given to them.

Therefore, addressing the concerns regarding the risks to the organ donors is required to encourage organ donation among the terminally ill and those who are on palliative treatment. The information in this regard is

limited. As per the previous qualitative study done in the United Kingdom,^[5] the observed organ donation rate among the palliative care patients was low. This could arise as a result of insufficient communication from the healthcare providers, misconceptions among the patients or the reluctance from the next to kin. Thus, the palliative patients should also be made aware about the significance of living and cadaveric organ donations and they need to be made a part of the discussion and decision making team for this purpose.

CONCLUSIONS

This study is one of the few studies in a developing country like India that has assessed the attitudes and determinants of attitudes regarding organ donation among the people. There was high level of awareness about various aspects of organ donation, except for the medico-legal aspects. However, a high proportion of the participants did not have positive attitudes towards donating or receiving organs when such occasion arises. The negative attitude towards organ donation was driven by religious beliefs and perceived risks to the donor. The reasons of unwillingness need to be looked into carefully and dealt with to increase acceptability towards organ donation in our country. Thus there is a need for culturally sensitive communication technologies to remove the various misconceptions in the minds of the public regarding organ donation along with increasing the access to the organ donation services.

Though the present study explores the perceptions and attitudes of general population towards organ donation, it is also important to study the perceptions and attitudes of terminally ill patients towards organ donation as they can be the potential donors in most number of cases. This calls for a future in-depth assessment of awareness and attitudes of palliative care patients towards organ donation.

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