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Perceptions and practices related to organ donation among a rural population of Kancheepuram district, Tamil Nadu, India

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Abstract:

Background and Objectives: Organ transplantation is the ultimate treatment of choice to save patients with end-organ damage. But the scarcity of organs from live or deceased donors remains an important barrier to the successful utilization of this measure in India. Our study intends to identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India.

Methods: This study was conducted

among 100 participants from 100 households chosen by simple random sampling in a rural area of Kancheepuram district in Tamil Nadu, between February and March 2014. A pre-tested, semi-structured schedule was applied to the participants and the responses were summarised. **Results:** The response rate was 100%. Though all participants had heard about organ donation, only 86% were aware of the complete meaning. The awareness on organs which could be

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donated, related legislation was less than adequate. Ninety-seven percent participants opined that organ donation should be promoted and 71% were willing to consider organ donation in future. None of the participants have registered themselves as organ donors or have voiced their willingness to their close families.

Conclusion: Our study population had basic awareness about organ donation and

reasonably positive attitudes with regard to its promotion and willingness to donate in future. But there is a need to plan appropriate health education campaigns to equip them with accurate knowledge to enhance their attitudes and translate them into positive behaviour.

Key words: India, organ donation, perceptions, practices, rural

Introduction:

Organ transplantation is the ultimate life-line management for most organ failures and saves thousands of patients with end-organ damage worldwide.¹ With an organ donation rate of 0.08 per million population, India lags well behind other developed nations such as Spain, United States and United Kingdom.^{2,3} There is a huge shortage of organs in India with many patients facing premature death while on the waiting list. Currently the incidence of end-stage renal disease (ESRD) is 150 to 200 per million population.⁴ But only an approximate 3500 kidney transplantations are done annually as against the requirement for more than 21000 transplants.⁴ Tamil Nadu continues to lead the nation in organ donation, since the launch of the Cadaver Organ Transplantation Programme in 2008 with an organ donation rate of 1.15 per million per year.³ The progress in the organ donation rates especially the deceased organ donations in Tamil Nadu has been due to the effective public education efforts by the government and non-governmental organisations (NGOs), the efficient public-private partnership which ensures a systematic wait-listing process and fair sharing and organ allotment.^{3,4}

There is a paucity of literature assessing the public perceptions and practices with regard to organ donation in India. Available studies reveal that though majority of the participants were aware of organ donation, the knowledge related to the organs that could be donated, the process and purpose of organ donation was less than adequate.^{5,6} Guleria et al in their study reported that more than 80% had knowledge about organ donation and close to three-fourths of the study population were willing to donate organs. While this is a definitely encouraging trend, only 6% in urban and 10% in rural areas have pledged their organs for donation.⁵

Lack of awareness about organ donation and the brain-death concept, religious attitudes, superstitions related to rebirth, fear of misuse of organs and health risks, lack of consensus among family members and being unaware of their deceased relative's wishes have been identified as potential barriers for successful implementation of organ donation programme in India.⁶⁻⁸ Ample knowledge about organ donation has been associated with significantly positive attitudes.^{9,10} The objective of the current study was to evaluate the perceptions about organ donation and practices among a rural population of Kancheepuram district in Tamil Nadu as a preliminary step in planning and organising a health education programme in the community.

Materials and methods:

This was a cross-sectional, descriptive study conducted in a rural area of Kancheepuram district, during the period July 2015 to August 2015. The sample size was calculated using the formula $N = \frac{Z^2 pq}{d^2}$. Assuming at least 50% (p) of the population would be aware about organ donation and 10% absolute error (d), the sample size was calculated as 96 and approximated to 100. There were 523 households in the rural area selected. Among them 100 households were chosen by simple random sampling using computer generated random numbers. One adult member in each household was

chosen randomly for participation in the study.

After obtaining informed written consent, a pretested, standardized, semi-structured schedule prepared in the local language was administered to the participants. The schedule consisted of the following 3 sections: sociodemographic details, perceptions about organ donation classified as awareness and attitude, and practices related to organ donation. Complete confidentiality was ensured.

Data entry and analysis was performed using Microsoft Office Excel 2007. Descriptive statistics were expressed as frequency and percentages.

Results:

A total of 100 people participated in the study. More than 50% were of 31-50 years age group, and 60% were females. 42%

passed higher secondary or above. 42% were unskilled labour & 35% homemaker. Most of the respondents (96%) were married. (Table-1)

Table 1: Socio demographic profile of the participants (N=100)

| Variable | Frequency (%) |
|----------------------------|----------------------|
| Age group | |
| Less than 30 years | 24 (24) |
| 31 to 50 years | 57 (57) |
| More than 50 years | 19 (19) |
| Sex distribution | |
| Males | 40 (40) |
| Females | 60 (60) |
| Educational status | |
| Illiterate | 8 (8) |
| Primary | 18 (18) |
| Middle | 32 (32) |
| Higher secondary | 36 (36) |
| Diploma | 6 (6) |
| Occupational status | |
| Student | 3 (3) |
| Home makers | 35 (35) |
| Semiskilled | 20 (20) |
| Unskilled | 42 (42) |
| Marital status | |
| Single | 4 (4) |
| Married | 96 (96) |

*Percentage within parentheses

All the participants (100%) had heard about organ donation. Television was the main source of information for 86 participants (86%). Other sources reported were newspapers (11, 11%), friends and relatives (23, 23%).

86% had idea about the meaning of organ donation. Most of the respondents said that it was done for saving lives. Majority of them (91% & 87% respectively) said that eyes & kidneys can be donated. 88% said that individual should give consent for live donation

Table 2: Awareness on organ donation among the participants (N=100)

| Question | Frequency* |
|---|-------------------|
| Meaning of organ donation (Frequency of participants with correct answer) | 86 (86) |
| Why is organ donation done?* | |
| To save lives | 96 (96) |
| For monetary benefits | 10 (10) |
| Sympathy | 1 (1) |
| Do not know | 4 (4) |
| What are the organs that can be donated?* | |
| Eyes | 91 (91) |
| Kidney | 89 (89) |
| Heart | 11 (11) |
| Liver | 1 (1) |
| Could you pledge your organs for donation after death, when you are alive? | |
| Yes | 21 (21) |
| No | 56 (56) |
| Do not know | 23 (23) |
| Who should give consent for live donation? | |
| Individual donor | 88 (88) |
| Family | 9 (9) |
| Do not know | 3 (3) |
| Who should give consent for organ donation after death? | |
| Family | 74 (74) |
| None | 26 (26) |
| Are you aware of any legislation to regulate organ donation and transplantaion in India? | |
| No | 100 (100) |

*Percentage within parentheses

**Multiple responses obtained

Twenty-one participants replied in the affirmative when asked if organs could be pledged for donation when alive and all of them were aware about eye donation only. None of them were aware that they could sign up as organ donor when alive. (Table 2)

Most of the respondents thought that organ donation should be promoted and 60% said no risk following organ donation. Seventy one respondents have positive attitude towards organ donation.(Table-3)

Table 3: Attitude of participants towards organ donation (N=100)

| Questions | Frequency* |
|--|------------|
| Do you think organ donation should be promoted? | |
| Yes | 97 (97) |
| Do you believe that organ donation is associated with any risks? If Yes, specify.** | |
| None | 60 (60) |
| Body weakness | 11 (11) |
| Future self need | 20 (20) |
| Fear of misuse | 38 (38) |
| Do not know | 9 (9) |
| What are the factors you would prefer to consider in a recipient? | |
| None | 69 (69) |
| Relationship with donor (close relative) | 22 (22) |
| Character of the recipient (good character) | 2 (2) |
| Age of the recipient (younger age group) | 2 (2) |
| Do not know | 5 (5) |
| Would you be willing to accept an organ if required in future? | |
| Yes | 61 (61) |
| No | 23 (23) |
| Do not know | 16 (16) |
| Would you be willing to convince a family for donating organs of their dead relative? | |
| Yes | 36 (36) |

| | |
|---|---------|
| No | 63 (63) |
| Do not know | 1 (1) |
| Would you be willing to donate organs in future? | |
| Yes | 71 (71) |
| No | 9 (9) |
| Will think about it | 19 (19) |
| Do not know | 1 (1) |

*Percentage within parentheses

**Multiple responses obtained

Table 4 shows the organ donation related practices among the participants who were positive in their awareness and attitude on the related aspects of organ donation, but

no one was found doing practices regarding it, but a family member of one of the participant has donated their kidney to their sibling

Table 4: Organ donation related behaviour among the participants

| Questions | Yes Frequency (%) | No Frequency (%) |
|--|----------------------|---------------------|
| Have you registered yourself for organ donation in a registry or have you got yourself an organ donor card? (n=21)* | 0 (0) | 21 (100) |
| Have you ever convinced any of your friends or relatives to donate organs of their deceased relative? (n=36)** | 0 (0) | 36 (100) |
| Have you discussed your willingness to donate your organs with your family members? (n=71)*** | 0 (0) | 71 (100) |

* Table 2: 21 participants replied in affirmative, when asked if organs could be pledged when alive.

** Table 3: 36 participants were willing to convince a family to donate the organs of their deceased relative.

*** Table 3: 71 participants were willing to donate organs.

Discussion:

Despite the increasing trend of organ donation rates in India, there is a severe disparity between the demand and availability of organs. This calls for the need for promoting positive perceptions among people.⁴

All 100 participants had heard about organ donation which could be attributed to the facts that 92% of the population were literate and exposed to various mass media messages on organ donation. Television was the main source of information followed by newspapers, friends and relatives. None of them had gained their knowledge from health personnel. This could be compared with the study by Saleem et al where television and print media were the main sources of information in the same order of frequency.¹¹ Similar trends was also noted in an Indian population by Mithra P et al where close to 80% of the population learnt about organ donation from media and less than 4% obtained any information from doctors and health camps.¹² Sander SL et al also reveal that health care providers were infrequently reported sources of information.¹³ This points to the fact that organ donation is a rarely discussed issue in routine health care settings and health campaigns. The reported lack of information from doctors

or other health personnel could be due to the fact that majority of hospital visits occur for medical illness when the people might not be receptive to promotional messages related to organ donation. This also reveals that all the information received by the participants had been one-way and limited and their misconceptions if any have not been explained by an authorised person.

Eighty-six percent of the participants had correct knowledge about organ donation and were aware that organs for donation come from both live and deceased donors. This is consistent with the figures reported by Manojan KK et al in Kerala and Mithra et al in Mangalore (94.7%) and is encouraging.^{6,12} Ninety-six percent were of the opinion that organ donation is done to save lives, compared to 60% as reported by Saleem et al, while 10% thought that organ donation is being done only for monetary benefits.¹¹ When questioned about the organs which could be donated, a higher proportion of study participants knew about donation of eyes (91%) and kidney (89%). This is similar to that reported by Saleem et al, Manojan et al and Mithra P et al where the awareness was highest for kidney followed by eye donation.^{6,11,12} Very few knew that heart (11%) and liver (1%) could be used in organ donation. None of them were aware

about other organs which can be donated by a living or deceased donor. Similar findings have been revealed by Manojan et al.⁶

Only 21% of the participants were aware that they could pledge their organs while they are alive for use after death. The knowledge with regard to obtaining consent for live or deceased donor organ donation was similar to that reported by Saleem et al.¹¹ In the study by Saleem et al 76% of the participants felt that the right to consent lies with the individual in a live donation and 52.8% felt the closest family should decide in deceased organ donation as in our study.¹¹

Ninety-seven percent of the participants supported promotion of organ donation. This is substantially higher than that reported by Saleem et al (56.8%) in Pakistan and Shahbazian et al (75%) in Iran.^{11,14} The high proportion in our study is similar to the trends in rural Kerala as reported by Guleria et al.⁵ Sixty percent of the participants thought there was no specific risk associated with organ donation. Future self-need for organs and subsequent non-availability was identified to be a main risk associated with organ donation and a cause of fear and reluctance by 20% of the participants. Similar participant perceptions were also reported

by Saleem et al, Mithra P et al and Mohamed E et al.^{11,12,15}

When the participants were enquired about the factors they would consider important in a recipient, following responses were obtained: none specific (69%), relationship with the donor (22%), character of the recipient (2%), age of the recipient (2%), do not know (5%). These preferences were broader as compared to the specific preferences reported by Saleem et al where participants preferred close family members, non-smokers, non-alcoholics, younger persons, same religion, mentally sound people and those not physically disabled as their organ recipients.¹¹ Such preference towards family members and relatives were also reported among a Nigerian population by El-Shoubaki H et al and Illiyasu Z et al.^{16,17} These preferences could be explained as a normal response of thought that their organs should benefit the people they love and other deserving recipients.

Only 36% were willing to convince a family to donate the organs of their deceased relative. Although this could be expected in a conservative society in rural India it is definitely a matter of concern in a population where 86% participants had correct knowledge about organ donation and 97% supported promotion of organ donation. This shows that though they

support the concept they were not eager enough to involve themselves in promotion of organ donation. Seventy-one percent were willing to donate their organs in the future and 19% were willing to consider the option. This was comparable to the proportions reported by Guleria et al (78%) in rural Kerala, Shahbazian H et al and Saleem et al (62%) in Pakistan and much higher than that reported by Manojan et al and Odusanya et al (30%).^{5,6,11,15,18}

Table 4 of the results reveal that the positive perceptions have not resulted in adequately positive practices. None of those who were aware about organ donor cards have signed up themselves. None of those willing to donate have discussed their opinion to their close families. This is in contrast to the study by Guleria et al where 10% of their rural study population are registered organ donors and Mithra P et al where 3.7% of the participants already possessed a donor card.^{5,12} This passive trend in behaviour could be owing to the fact that this population has not been exposed to formal health education sessions on organ donation and if empowered with appropriate knowledge, this population could be motivated to become registered organ donors and spread the message on organ donation. Saub EJ et al has reported that talking with

a physician or health personnel on organ donation positively motivates them to donate organs.¹⁹

Our study has its limitations. Being a baseline survey it does not provide an extensive coverage of the knowledge and attitude aspects of the study population on organ donation. The perceptions of the populations have not been compared based on the sociodemographic characteristics. Despite that it provides useful information on the issues to be focussed in planning and organising health education sessions on organ donation. Such community-based surveys and subsequent information, education and communication sessions will aid in identifying the obstacles and opportunities and achieve uniformly high organ donation and transplantation rates in the state and the nation.

Our study points to the need to equip the community with appropriate knowledge so that they are encouraged to take informed decisions at times of need. Sufficient knowledge and attitude has been shown to be positively associated with willingness and commitment towards organ donation.¹³ The perceptions among this population has been shown to be similar to that reported by various authors from India and other parts of the world bringing into focus the common issues to be dealt with in improving organ donation practices.

Periodic public education programmes by experts could be organised in community settings to stress the purpose and potential of organ donation. The importance of organ donation and related information should be imparted as part of school and

college curriculum, driving school training and pre-employment training in factories and industries. Self-help groups should be involved in spreading the message and motivating the population to become potential organ donors.

Conclusion:

Our study shows that majority of the participants knew the exact meaning of organ donation, were positive about promotion of organ donation and were willing to donate their organs in future. In spite of this positive trend, many participants had perceived health risks and fears with regard to organ donation and were not aware of various other aspects of organ donation such as availability of

legislation, voluntary registration for organ donation. Our study stresses the need for educational interventions regarding organ donation at the community level to enhance voluntary or informed organ donation practices. The findings of this study would help in identifying the issues to be focussed while planning awareness campaigns in this community and similar communities elsewhere.

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References:

1. Abouna GM. The humanitarian aspects of organ transplantation. *Transplant Int.* 2001;14(2):117–123.
2. India moves to contain organ donation havoc. *Canadian Medical Association Journal*, 2012; 184(8):E387-388
3. TN continues to lead in organ donation. *The Hindu* dated August 8, 2013. Accessed from <http://www.thehindu.com/news/national/tamil-nadu/tn-continues-to-lead-in-organ->

- [donation/article5000427.ece](#)
Accessed on September 19, 2014
4. Organ transplant Act notified. The Hindu, dated January 18, 2014. Accessed from <http://www.thehindu.com/todays-paper/tp-national/organs-transplant-act-notified/article5588655.ece>
Accessed on September 19, 2014
 5. Guleria K, Singh AK, Kumar B, Agrawal P, Agrawal S. Trends in organ donation and awareness in Ernakulam, Kerala. BMC. Proceedings. 2012; 6 (Supplement 4): 48
 6. Manojan KK, Raja RA, Nelson V, Beevi N, Jose R. Knowledge and attitude towards organ donation in rural Kerala. Academic Medical Journal of India. 2014; 5(2): 25-7
 7. Veerappan I. Deceased donor kidney transplantation in India. Health Sciences 2012; 1(2): 1-8
 8. Singh P, Kumar A, Sharma RK. Factors influencing refusal by relatives of brain-dead patients to give consent for organ donation: experience at a transplant centre. Journal of Indian Medical Association. 2004; 102 (11): 630,632,643
 9. Gross T, Martinoli S, Spagnoli G, Badia F, Malacrida R. Attitudes and behaviour of Young European adults towards the donation of organs- a call for better information. American Journal of Transplantation 2001; 1: 74-81
 10. Ashraf O, Ali S, Li SAA, Ali H, Alam M, Ali A, Ali TM. Attitude toward organ donation: A survey in Pakistan. Artificial Organs. 2005; 29(11): 899-905
 11. Saleem T, Ishaque S, Habib N, Hussain SS, Jawed A, Khan AA, Ahmad MI, Iftikhar MO, Mughal HP, Jehan I. Knowledge, attitudes and practices survey on organ donation among a select adult population of Pakistan. BMC Medical Ethics 2009; 10(5): 1-12
 12. Mithra P, Ravindra P, Unnikrishnan B, Rekha T, Kanchan T, Kumar N, Papanna M, Kulkarni V, Holla R, Divyavaraprasad K. Perceptions and attitudes towards organ donation among people seeking health care in tertiary care centres of coastal South India. Indian

- Journal of Palliative care. 2013; 19(2): 83-87
13. Sander SL, Miller BK. Public knowledge and attitudes regarding organ and tissue donation: an analysis of the northwest Ohio community. Patient education and counselling. 2005; 58(2): 154-163
14. Shahbazian H, Dibaei A, Barfi M. Public attitudes toward cadaveric organ donation- A survey in Ahwaz. Urology Journal. 2006; 3(4): 234-239
15. Mohamed E, Guella A. Public awareness survey about organ donation and transplantation. Transplantation Proceedings. 2013; 45(10): 3469-71
16. El-Shoubaki H, Bener A. Public knowledge and attitudes toward organ donation and transplantation: A cross-cultural study. Transplantation Proceedings. 2005; 37(5): 1993-1997
17. Illiyasu Z, Abubakar IS, Lawan UM, Abubakar M, Adamu B. Predictors of public attitude toward living organ donation in Kano, Northern Nigeria. Saudi J Kidney Dis Transpl. 2014; 25(1): 196-205
18. Odusanya OO, Ladipo CO. Organ donation: Knowledge, attitudes and practices in Lagos, Nigeria. Artificial organs. 2006; 30(8): 626-629
19. Saub EJ, Shapiro J, Radecki S: Do patients want to talk to their physicians about organ donation? Attitudes and knowledge about organ donation: a study of Orange County, California residents. J Community Health, 1998; 23:407-17