

# Awareness knowledge and attitude regarding eye donation in Thiruvananthapuram district south India

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## Abstract

**Objective:** To study the awareness, knowledge and attitude to eye donation among the residents of Thiruvananthapuram, Kerala State, India. **Materials and Methods:** After obtaining informed consent, subjects aged 16 or above selected from the residents of Thiruvananthapuram district were asked to fill up a validated objective type questionnaire on eye donation. Data was analyzed using appropriate computer statistical software tools. **Results:** A total of 557 subjects participated in the study. The awareness of eye donation was 90.5%. The awareness was significantly less among the illiterate (63.6%) ( $p < 0.05$ ), those with monthly income less than 1000 rupees (79.3%) ( $p < 0.05$ ) and females (78.4%) ( $p < 0.05$ ). Only 70.6% were willing to donate their eyes or have already pledged their eyes. Among those who were unwilling to donate eyes, 48.2 % believed that their body would be disfigured ( $p < 0.05$ ). 25% thought that persons with cataract could not donate eyes. Audiovisual and print media were the major sources of information (58%). Government publicity measures accounted for only 1.8%. **Conclusion:** Although Thiruvananthapuram has a high level of awareness about eye donation, significant number of people are unwilling to donate their eyes mainly due to their misconceptions. To increase the availability of corneas for transplantation, more effective publicity measures are needed to properly educate the residents about eye donation.

**Keywords:** Awareness, Attitude, Eye donation, Knowledge, Thiruvananthapuram.

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## INTRODUCTION

Out of the 40 million blind persons in India, more than 2.5 million are blind from corneal. Disease<sup>1</sup>. According to the Andhra Pradesh Eye Disease Study (APEDS) findings, the prevalence of corneal blindness was 0.13% (95% CI: 0.06-0.24) and constituted 9% of all blindness<sup>2</sup>. Corneal ulcers and ocular trauma are common causes of corneal blindness<sup>3</sup> Corneal transplantation is the major treatment option for visual rehabilitation of these patients. Among the different organ donation surgeries, eye

donation has the highest transplant success rate. However there exists a severe demand-supply gap in the number of corneas available for transplantation. In 2012-13 53, 543 corneas were obtained by eye donation in India<sup>4</sup>. In spite of the high literacy rate in Kerala, only 1,758 corneas were obtained in 2012-13<sup>4</sup>. Awareness and knowledge regarding this noble deed is necessary to help the blind see this beautiful world. The objectives of this study was to analyze the awareness, knowledge and attitude towards eye donation among the residents of Thiruvananthapuram, the capital of Kerala state.

## MATERIALS AND METHODS

Cross sectional study done between January 2014 and April 2014. 557 residents of Thiruvananthapuram district aged 16 or above were selected for the study by two stage cluster sampling technique. The sample size was calculated using the formula  $n = 4pq/L^2$  where n is the sample size, p is the prevalence of awareness about eye donation in the population, q is 1-p and L is permissible error of prevalence. After obtaining informed consent, all the subjects were asked to fill up the validated

questionnaire on eye donation. All the questions were of objective type, printed in English and Malayalam. For the illiterate, the questionnaire was read out and the response noted. Awareness was defined as having heard of eye donation<sup>5</sup>. Knowledge was defined as having some understanding about eye donation<sup>5</sup>. Attitude was defined as the positive or negative view of a person towards eye donation. Files compiled on the basis of the validated questionnaire were processed and coded in a computer spreadsheet (Excel, 2007, Microsoft Corp., Redmond, WA). Univariate and multivariate regression analysis was used to determine the factors associated with awareness, knowledge, and attitude towards eye donation. Descriptive and comparative analyses were performed using computer software (SPSS, Version 16, SPSS Inc., Chicago, IL). A two-sided p value of < 0.05 was considered significant.

**OBSERVATIONS AND RESULTS**

A total of 557 subjects participated in the study. 432 subjects (77.6 %) were males. 33 subjects (5.9%) were illiterate. 163 subjects (29.3%) had a degree/diploma.

**Awareness:** The awareness of eye donation was 90.5%. The awareness was 94 % among males and 78.4% among females. ( p < 0.05 )

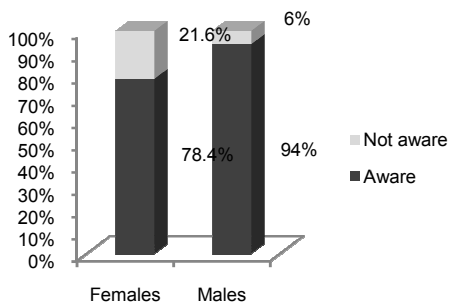


Figure 1: Awareness based on gender

Awareness was least among the illiterate (63.6 %).

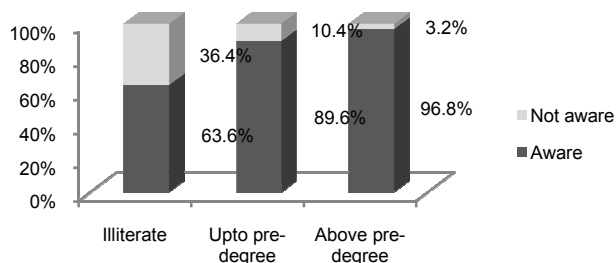


Figure 2: Awareness based on literacy

Awareness least among those with monthly income less than rupees 1000 (79.3%) (p<0.05)

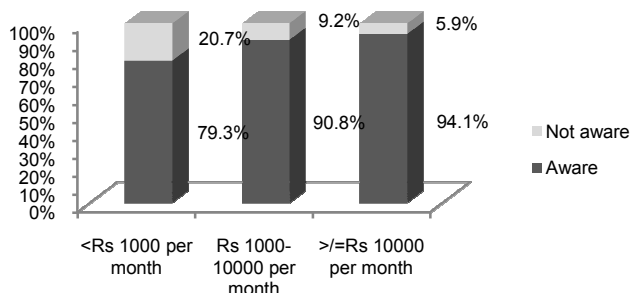


Figure 3: Awareness based on income

**Knowledge**

79.5% knew that eyes had to be removed within 6 hours of death for donation.

Table 1: Within how many hours after death should eyes be removed for donation?

Response	Frequency	Percentage
6 hours	443	79.5%
1 day	101	18.1%
1 week	2	0.4%
1 month	2	0.4%
Any time	9	1.6%

33.4% thought that donated eyes were used to replace the whole of another eye.

Table 2: What people think the donated eye is used for

To replace whole of another eye	33.4%
To replace part of another eye	57.1%
For teaching medical students	3.6%
Don't know	2.5%
Others	3.4%

207 subjects (37.2%) did not know that eyes could be pledged for donation during life. 404 subjects (72.5%) knew the fact that eyes could be removed for donation from a person who has not pledged his eyes after his death if his relatives give consent for eye donation. 284 subjects (51%) did not know that eyes are not be taken for donation from the body of a live person. 210 subjects (37.7%) thought that buying/ selling of eyes was possible. 139 subjects (25%) did not know that persons with cataract could donate eyes.106 subjects (19%) did not know that persons with spectacles could donate eyes and 126 subjects (22.6%) did not know that persons with diabetes or hypertension could donate eyes. 161 subjects (28.9%) thought that eyes could be removed from a donor only in a hospital. 126 subjects (22.6%) did not know that the request for eye donation could not be refused. 197 subjects (35.4%) thought that all blindness could be cured

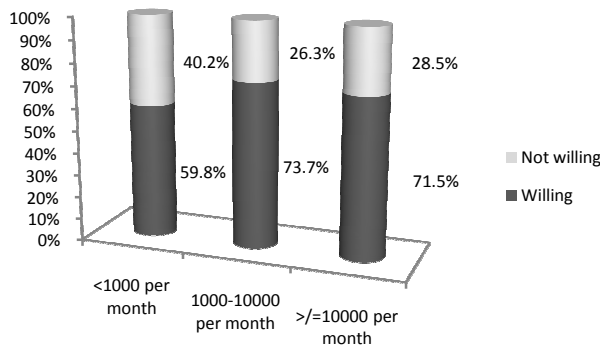
by eye transplantation. 186 subjects (33.4%) thought the identity of the recipient of the eye was revealed to the donor’s family. Though 476 subjects (85.5%) knew that facilities were available in Thiruvananthapuram for eye donation, 182 (38.2%) did not know the phone number of the hospital to contact for eye donation ( $p < 0.05$ ). 430 subjects (77.2%) knew that there is a shortage of donated eyes in India. 88 subjects (15.8%) thought that eyes of an HIV positive patient can be used for transplantation and 85 (15.3%) thought that eyes of a patient with rabies can be used for transplantation. 282 subjects (50.6%) did not know that eye donation involved removal of the whole eye. Media (television/radio/newspapers) was the major source of information (58 %) about eye donation. Government publicity measures accounted for only 1.8% of information source.

**Table 3: Sources of information**

TV/ Radio/ Newspapers/ Magazines	58%
Doctor	20.5%
Eye Camp	19.6%
Friend/ Relative	0.1%
Govt. publicity measures	1.8%

**Attitude**

546 subjects (98 %) felt that eye donation should be promoted. However only 393 subjects (70.6%) were willing to donate their eyes or had already pledged their eyes. The major reason for wanting to donate eyes was the desire to help the visually challenged (85.5%). The willingness to donate eyes was lowest among those with income less than rupees 1000 per month (59.8%) ( $p < 0.05$ ) and in females.



**Figure 4: Distribution of willingness to donate eyes based on income**

48.2 % of those who were unwilling to donate eyes believed that body would be disfigured following eye donation ( $p < 0.05$ ).

**Table 4: Reasons for people not donating eyes**

Feels body is disfigured	48.2%
Unsuitable due to age or health problems	26.8%
Religious beliefs	1.2%
Lack of knowledge about eye donation	4.9%
Others	18.9%

**DISCUSSION**

The awareness about eye donation among the residents in Thiruvananthapuram district is high (90.5%) compared to the 55.4 % in Delhi, 50.7 % in Tamil Nadu<sup>6</sup>, 32.9 % in rural Andhra Pradesh<sup>7</sup>, 69 % awareness in Singapore<sup>8</sup> and Melaka Malaysia<sup>9</sup>. The high literacy rate of 93 % among the residents in this capital district of Kerala has contributed to this high awareness. The awareness about eye donation was significantly less among the illiterate (63.6%), those with monthly income less than rupees 1000 (79.3%) and in females (78.4 %). Most residents (85.5%) knew that facilities for eye donation were available in Thiruvananthapuram. 28.9 % thought that eyes could be removed from a donor only in a hospital and 25% thought that people with cataract could not donate eyes. 22.6% did not know that persons with diabetes or hypertension could donate eyes. 19% did not know that persons with spectacles could donate eyes. Venkata Ramana Ronanki *et al*<sup>10</sup> found that 50 % stakeholders in Srikakulam district Andhra Pradesh did not know that current spectacle users could donate their eyes. The willingness to donate eyes in Thiruvananthapuram was 70.6% compared to the 82 % willingness among the stakeholders in Srikakulam district, Andhra Pradesh<sup>10</sup>. The most common reason (85.5 %) for donating corneas was to give sight to another blind person. Gupta A *et al*<sup>11</sup> also found a similar percentage (85.6 %) in their study among nursing students in Bangalore. The lower willingness to donate eyes among females compared to males in Thiruvananthapuram, is similar to findings got by Krishnaiah S *et al*<sup>7</sup>. Willingness to donate eyes was least among those with low income. However Tandon R *et al*<sup>12</sup> found in their study that literacy and socio economic status did not influence the willingness for eye donation. 48.2 % of those who were unwilling to donate eyes believed that their body would be disfigured by it. Venkata Ramana Ronanki *et al*<sup>10</sup> found that reasons listed for unwillingness to donate eyes include objection by family members (3.4%), dislike of separating eyes from the body (0.8%), health problems (2.8%) and religious restriction (0.6%). Verble M *et al*<sup>13</sup> in their study found that some of the causes for unwillingness to donate include wanting to bury the whole body ( 8%), concerns about age and prior health ( 7 % ) and incompatibility with religion or culture ( 7 %). Media was the major

source of information about eye donation (58%) but alarmingly Government publicity measures only accounted for 1.8 % of sources of information. This highlights the need for a better awareness campaign by the Government to spread knowledge and remove misconceptions regarding eye donation. According to the 2011 census, 27,881 residents died in Thiruvananthapuram district in 2010<sup>14</sup>. However only 22 residents (0.00079 %) donated their eyes in 2010 after death. This very low actual eye donation rate in spite of the high awareness rate is due to the misconceptions and lack of proper knowledge regarding various aspects of eye donation. A concerted effort is needed by Government, private and voluntary agencies to increase the actual eye donation rate. Gogate *et al*<sup>15</sup> had mentioned about creating catalysts at community level (medical practitioners who certify the death, priests who come to pray at time of death) who will act as grief counselors. 38.2% of the residents in Thiruvananthapuram did not know the phone number of the hospital to contact for eye donation. Prominent display boards with contact phone details and information regarding eye donation should be set up at existing eye collection centres and community gathering places.

## CONCLUSIONS

The residents in Thiruvananthapuram have a high awareness regarding eye donation. However the actual eye donation rate per year is very low due to misunderstandings in their knowledge and their unwillingness for eye donation. To provide the gift of sight to all corneal blind patients, more efforts are needed by the Government and grief counselors to dispel these misunderstandings and to increase their willingness to donate eyes.

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