

**PERCEPTION AND AWARENESS ABOUT EYE DONATION IN HEALTH-CARE PROVIDERS IN CENTRAL INDIA: CHALLENGES AND SOLUTIONS**Rekha Khandelwal<sup>1</sup>, Payal Katre<sup>2</sup>**HOW TO CITE THIS ARTICLE:**

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**ABSTRACT:** Corneal transplantation can restore sight in patients of corneal blindness but the number of transplants done in India is far less than needed. The active participation of paramedical staff in the eye donation programme can increase the number of donors. The purpose of this study was to evaluate awareness and knowledge about eye donation in medical and paramedical staff working in a tertiary care hospital of Central India. **METHODS:** A cross-sectional observational study was done at a tertiary care hospital attached to a medical college. A pre-tested, open-ended questionnaire on eye donation was designed to collect information from 300 health-care providers chosen by random sampling method. The data was analyzed using SPSS version 11.0 software. **RESULTS:** Out of 300 subjects, 143 (47.66%) were males and 157 (52.33%) were females. It was observed majority of the participants (91%) had heard about eye donation but the knowledge about ideal time of eye donation and corneal transplantation was poor. Sixty-five percent quoted that lack of awareness about eye donation in masses was as an important reason for not donating eyes. **CONCLUSION:** The medical and paramedical staff should be trained regarding this noble gesture so as to improve the corneal transplantation rates and thereby reduce the burden of corneal blindness in our country.

**KEYWORDS:** Eye donation, Corneal transplantation, Health care providers.

**INTRODUCTION:** Corneal diseases constitute a significant cause of visual impairment and blindness globally. It accounts for 20-30% of all blindness in the developing countries.<sup>1</sup> Previous studies have reported various causes of corneal blindness like, unjustified use of steroids for treating red eyes,<sup>2</sup> ocular trauma,<sup>3</sup> corneal ulceration<sup>4</sup> and use of traditional eye medicines.<sup>5</sup> In India, the prevalence of corneal blindness in India was found to be 0.13% (95% CI: 0.06-0.24) and accounts for 9% of all blindness. The Andhra Pradesh Eye Disease Study (APEDS) estimated that 1, 200 people per million population are blind (<3/60) from corneal pathology in India.<sup>6</sup> Recently, blindness rates of 3.6% (95%CI: 3.3-3.9) were reported by a rapid assessment method in Indian population and 6.5% of which was due to corneal opacities leading to visual impairment and blindness. The study also estimated that, approximately 40 million people were blind in India in 2007 and 2.5 million were blind from corneal pathology.<sup>7</sup>

Corneal blindness can be prevented by prompt primary and secondary level care, which is also cost-effective. But in those who already develops corneal scar, surgical management is the only option for restoration of vision. The first corneal transplant surgery in India was done in 1948 by Late Muthiah who also started first eye bank in India.<sup>8</sup> Corneal transplant not only provides an opportunity for improved vision in patients with poor visual function, but can act as a

## ORIGINAL ARTICLE

treatment for symptomatic relief of many corneal diseases. According to the Eye Bank Association of India (EBAI), the current cornea procurement rate is only 49,000 per year and significant donor corneas are unsuitable for transplantation.<sup>9</sup> There is a need of 2,77,000 donor eyes to perform 1,00,000 corneal transplants in a year as per the current rate of requirement.<sup>10</sup>

Previous reports suggest that training of the health care workers can significantly increase the numbers of eye donation.<sup>11</sup> If the health care providers are trained, they can influence the relatives for eye donation even if the eyes were not pledged before death. This will have positive impact on the eye donation rates in India. But, the first step is to understand their current knowledge and attitude towards eye donation so this study was undertaken. This study was designed to evaluate the awareness of nursing staff, medical students, medical staff, doctors in training and paramedical staff towards eye donation and their willingness to pledge eyes.

**MATERIAL AND METHODS:** After Institutional Ethics Committee (IEC) approval, a brief structured, open-ended questionnaire was distributed to collect information about subject's perception and awareness regarding eye donation. This observational study was undertaken between May-June 2014 at a tertiary care hospital attached to a medical college. Respondents for this study were randomly selected from the residents, interns, paramedical staff, medical students, nursing students and nursing staff. Thirty percentage of the subjects from each stratum were included in the study and were subjected to a validated questionnaire. Residents from ophthalmology department did not participate in the study. The questionnaire included demographic profile of the participant, their awareness about different organ donation, magnitude of corneal blindness in India, time of eye donation, various reasons perceived by them for donating and not donating eye and their personal attitude towards this. Awareness was defined as having heard of eye donation. Knowledge was defined in terms of understanding that donated eye is used to replace cornea of another eye. All the subjects who had heard about eye donation were asked about their willingness to pledge eyes for donation.

The data was analyzed using non-parametric tests (Mann-Whitney, Kruskal-Wallis test). The significance of association between factors was evaluated using Chi-square test. All the analysis was performed using SPSS ver 11.0 software.

### RESULTS:

Total 300 medical and paramedical staff participated in the study. There were 143 males (47.66%) and 157 females (52.33%). There was no significant difference in the distribution of male and female participants in the study. The age distribution of the participants is shown in table 1.

Age (years)	Male	Female	Total %
15-25	23 (16.08%)	26 (16.56%)	49 (26.33%)
26-35	41 (28.67%)	37 (23.56%)	78 (26%)
36-45	37 (25.87%)	40 (25.47%)	77 (25.67%)
46-55	30 (20.97%)	31 (19.74%)	61 (20.33%)
56-65	12 (8.3%)	23 (14.64%)	35 (11.67%)
Total	143 (47.66%)	157 (52.33%)	300

**Table 1: Demographic profile of the participants**

## ORIGINAL ARTICLE

It was observed that the study subjects were aware about organ donations. Majority of the participants (91%) had knowledge that eyes can be donated after death. Knowledge about organ donation like heart, liver, kidney transplantation and eye is shown in table 2.

Organs	Residents (n=50)	Interns (n=50)	Paramed ical staff (n=50)	Medical students (n=50)	Nursing student s (n=50)	Nursing staff (n=50)	Total participants (n=300)
Heart	47(94%)	50(100%)	30 (60%)	30 (60%)	37 (74%)	36 (72%)	230(76.66%)
Liver	50(100%)	49(98%)	33 (66%)	19 (38%)	14 (28%)	23 (46%)	188(62.66%)
Kidney	49(98%)	50(100%)	42 (84%)	40 (80%)	40 (80%)	45 (90%)	266(88.66%)
Lung	44(88%)	46(92%)	12 (24%)	7 (14%)	6 (12%)	8(16%)	123(41%)
Brain	3(6%)	0 (0% )	4 (2%)	3 (6%)	4 (2%)	2 (4%)	16(5.33%)
Eye	50(100%)	50(100%)	46 (92%)	41 (82%)	39 (78%)	47 (94%)	273(91%)

Table 2: Frequency distribution of knowledge about organ donation

It was observed that 262 (87.33%) participants knew that eyes can be donated after death and 190 (63.33%) knew about ideal time of eye donation as shown in table 3.

Responses	Residents (n=50)	Interns (n=50)	Paramedical staff (n=50)	Medical students (n=50)	Nursing students (n=50)	Nursing staff (n=50)	Total participants (n=300)
Eye can be donated after death	49(98%)	45(90%)	44 (88%)	38(76%)	41(82%)	45(90%)	262(87.33%)
Ideal time for donating eye is within six hours	39(78%)	39(78%)	34 (68%)	22(44%)	26(52%)	30(60%)	190(63.33%)
Donated eye is transplanted within 3 days	17(34%)	21(42%)	8 (16%)	12(24%)	16(32%)	12(24%)	86(28.66%)
No disfigurement	35(70%)	30(60%)	12 (24%)	22(44%)	13(26%)	20(40%)	132 (44%)
No delay in religious rites	42(84%)	43(86%)	38 (76%)	30(60%)	28(56%)	35(70%)	216 (72%)

Table 3: Frequency distribution of knowledge about ideal time and procedure on eye donation

The commonest source of information on eye donation was newspaper in 248 (82.66%), followed by seminars and lectures, health exhibition and documentary/movie as shown in table 4.

Source	Residents (n=50)	Interns (n=50)	Paramed ical staff (n=50)	Medical students (n=50)	Nursing students (n=50)	Nursing staff (n=50)	Total participants (n=300)
Newspaper	49(98%)	50(100%)	38(76%)	35(70%)	38(76%)	38(76%)	248(82.66%)
Seminars and lectures	47(94%)	50(100%)	35(70%)	34(68%)	33(66%)	30(60%)	229(76.33%)
Health Exhibition	31(62%)	36(72%)	17(34%)	24(46%)	31(62%)	29(58%)	168(56%)
Documentary /movie	37(74%)	32(64%)	26(52%)	21(42%)	20(40%)	28(56%)	164(54.66%)

Table 4: Frequency distribution about common sources of information on eye donation

## ORIGINAL ARTICLE

Regarding various reasons quoted by the participants for not donating eyes, lack of awareness was found to be the main reason in 197(65.67%) and other quoted reasons were objections from family members, myths about eye donations and religious restrictions as shown in table 5.

Reasons	Residents (n=50)	Interns (n=50)	Paramedical staff (n=50)	Medical students (n=50)	Nursing students (n=50)	Nursing staff (n=50)	Total participants (n=300)
Lack of awareness	36(72%)	44(88%)	32(64%)	26(52%)	28(56%)	31(62%)	197(65.67%)
Objection by family members	9 (18%)	5 (10%)	5 (10%)	12(24%)	11(22%)	14(28%)	56(18.67%)
Myths about eye donation	2 (4%)	1 (2%)	8 (16%)	8(16%)	6(12%)	3 (6%)	28(9.33%)
Religious restriction	3 (6%)	0	5(10%)	4(8%)	4(8%)	2 (4%)	18 (6%)
Eye donation delays funeral procedure	0	0	0	0	1(2%)	0	1 (0.33%)

**Table 5: Awareness and frequency distribution of various reasons for not donating eyes**

Out of 300 participants 224 (74.66%) had positive attitude toward eye donation and 205 (68.33%) wanted to donate eyes to anyone who is needy since it is a noble gesture as shown in Table 6.

	Residents (n=50)	Interns (n=50)	Paramedical staff (n=50)	Medical students (n=50)	Nursing students (n=50)	Nursing staff (n=50)	Total participants (n=300)
Willing to donate eye	47(94%)	40(80%)	35(70%)	37(74%)	34(68%)	31(62%)	224(74.66%)
To a family member only	2(4%)	0	2(4%)	4(8%)	2(4%)	0	10(3.34%)
To a person known to you	4(8%)	2(4%)	1(2%)	0	2(4%)	0	9(3%)
To anyone who is needy	41(82%)	38(76%)	32(64%)	33(66%)	30(60%)	31(62%)	205(68.33%)
Eye donation is noble gesture	45(90%)	43(86%)	41(82%)	36(72%)	40(80%)	39(78%)	244(81.34%)

**Table 6: Attitude regarding eye donation**

## ORIGINAL ARTICLE

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**DISCUSSION:** Corneal transplantation is the most successful of all organs transplant procedures, yet the current corneal procurement rates are inadequate to meet the transplantation needs in India. In the present study, out of 300 medical and para-medical staff, 91% were aware about eye donation. The eye donation awareness was highest as compared to other organ donation like heart (76.66%), liver (62.66%), kidney (88.66%), lung (41%), and brain (5.33%). In another study carried out among the hospital staff, 97% of them had good knowledge about transplantation of various human organs.<sup>12</sup>

In this study, although 87.33% had knowledge about eye donation after death, ideal time of eye donation after death was known only to 66.33%, which is an important aspect of eye donation procedure. Our results are comparable to a similar study conducted in 395 paramedical staff reported that 317(80.5%) were aware of eye donation, 312(80%) knew that the cornea is used for eye donation and 294(76%) knew that the ideal time for eye donation is within six hours of death.<sup>13</sup> In a study done by Gupta et al, 96.8% of nursing students were aware that eyes could be donated after death but only 38.2% knew about the ideal time of donation after death.<sup>11</sup> In a study done for medical students in Delhi, 99.4% were aware that eyes could be donated after death but 44.1% had knowledge related to ideal time of donation.<sup>14</sup> Another study in medical and non-medical students reported that 79.6% knew that eyes are donated after death and 63.3% knew about the ideal time of donation.<sup>15</sup>

In our study the awareness related to ideal time of eye donation was better as compared to previously published studies because we also included residents and interns in our study. The timing of eye donation is vital, as it may not be ideal to utilize eyes that are donated later than six hours after death for optical purpose. Lack of awareness related to time of eye donation after death could be another possible barrier to eye donation.

In this study, half of the participants were aware that eye donation does not cause disfigurement but awareness about it was significantly less in paramedical staff as compared to interns and residents. Most of the participants knew that there is no delay in religious rites and funeral procedure due to it however they were less aware of the fact that the eyes are transplanted within three days of eye donation. Newspaper was found to be the primary source of eye donation information as per 82.66%. In a study reported earlier, 46.3% of paramedical staff got information related to eye-donation awareness through publicity campaigns and mass media.<sup>12,16,17</sup> Mass communication in the form of television, health exhibition and documentary/movie seems to be underutilized which can have a positive impact on the number of eye donations.

Although consent for eye donation expressed before death of the donor is mandatory but if such consent is not available, eye donation is possible with the consent from other family members. It is crucial to spread this message in the masses for eye donation awareness. In our study, only 28% were aware that consent can be given by other family members. Another study reported, only 44.3% of relatives during post mortem gave consent for eye donation after intensive counseling.<sup>17</sup> A recently published article on eye donation awareness among stakeholders in South India reported 82% of the donors had not pledged for eye donation. This also conveys that majority of the donations can be successfully initiated by the family members regardless of pledging.<sup>18</sup>

## ORIGINAL ARTICLE

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In order to increase eye donations, it is very important to train the medical staff, nurses and counselors for motivating “the next of the kin” for eye donation whenever there is the death or accident. According to our study, 65.67% feel that lack of awareness is the main reason for low rates of eye donations. Other reasons quoted by us and previously published studies were objections raised by the family members, disfigurement of the body, delay in religious rites.<sup>9,19</sup>

Attitude towards eye donation was found to be positive in health-care workers of this study. More than two-thirds (81.34%) were willing to pledge and were ready to donate their eyes to anyone who is needy. A study done for final year medical students reported 83% were willing to pledge their eyes<sup>15</sup> and yet another study published that 64.5% of optometry students were willing for eye donation.<sup>20</sup> In contrast to this, a study on medical students in Nigeria published that 79.4% were aware about eye donation but 66.4% were not ready to pledge their eyes.<sup>21</sup> Many medical students lack sufficient knowledge about important aspects of eye donation and corneal transplantation hence are hesitant to pledge their eyes for eye donation. Targeting medical students in eye donation campaigns will help in spreading the message of eye donation during their training years. These students will always be then, supportive for eye banks even if they pursue any specialty in future.

Various eye donation studies have reported that the main reason behind eye donation was humanity and happiness people get in helping blind people see through the donated eyes.<sup>11</sup> Strategies, which were effective in other parts of the world, may be tried in India to improve eye donations. For example, in USA the Presumed Consent Law was introduced in 1975. This concept has legal sanction, where, even if the dead person has not registered, consent is presumed and eyes can be removed as required. This legislation has led to a manifold increase in the availability of corneal tissue.<sup>22</sup> In India we do not have such legislation; the government should introduce the concept of “presumed consent” to increase eye donations. Such legislation would emphasize the government’s commitment to the cause of eye donation. Another area of legislation is the “required request law” wherein it becomes mandatory for all health care staff institution coming into contact with grieving families to make a request for eye donation.

There is a great need to educate masses, as they are an important part of our society. If they are educated about the preventive and curative aspects of corneal blindness, they can spread the message among their friends and family members, thus acting as important motivators. It is also essential to remove their misconception regarding eye donation.<sup>23</sup> It is essential to understand the current knowledge about eye donation in the society to take appropriate measures to improve it. The present study revealed that medical and paramedical staffs were well aware about eye donation and most of them were inclined to pledge for eye donation. Data from our study suggests that the knowledge regarding the place of eye donation, time limit to collect the cornea and whom to contact and when to contact are still not known clearly. The health-care providers could be actively involved as volunteers in eye donation movements and they can act as counselors for eye donors. The positive attitude towards eye donation is very important for making this project successful and cure corneal blindness.

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## ORIGINAL ARTICLE

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