

## ORIGINAL ARTICLE

### AWARENESS OF EYE DONATION IN POPULATION OF CENTRAL INDIA

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**ABSTRACT:** Corneal problems cause a significant proportion of blindness in India. Once corneal opacity is established, restoration of their vision is possible only through transplantation of cornea from donated eyes. Eye donations are dependent on people willing to pledge their eyes. **PURPOSE:** To determine "awareness of eye donation" and knowledge regarding eye donation and factors affecting in an adult population of northern India. **METHODS:** 550 Subjects who accompanied patients attending four ophthalmic clinics were interviewed using structured questionnaire. The information was collected about socio demographic profile, awareness of eye donation, knowledge about its various aspects and pledge to donate eye, reasons for donating or not donating eyes and sources of information. Data analyzed using SPSS software, Chi square test was used to test significance across category and p value <0.05 was considered statistically significant. **RESULTS:** Out 550 subjects 44.2% were in 18-35 years and 55.8 % were >35 yrs old. Majority was Hindu (76.73%) and males (71.64%). 78% subjects were aware of eye donation. The major source of awareness was AV aids (89%). Awareness was found to be high as age and education increases, in males, and in urban population. Significant difference (p<.05) was found between awareness and various variables except religion. 27% knew that relative can make pledge, only cornea is transplanted is known to 25.2%, 44.7% were aware about ideal time of eye removal and only 12 (2.8%) had pledged their eyes. 250(58.3%) subjects were aware but not willing to pledge their eyes or relatives eyes. Need more information to decide (79.2%), perceived objection by family members (52%) and religious reason (38.8%) were cited as major factors for not willing to pledge eyes. Nobility (76%) and pleasure (17.9%) was the main motivational force stated for willingness to donate eyes. **CONCLUSION:** There is good level of awareness in urban population still very less subjects is willing to pledge eyes major factor being insufficient knowledge. Targeting on aspects in which knowledge was found to be low might help to increase eye donation.

**KEYWORDS:** Eye donation, corneal blindness, awareness, Central India.

**INTRODUCTION:** Corneal problems cause a significant proportion of blindness in the developing world, including India.<sup>1,2</sup> As per the survey conducted by Ministry of Health and Family Welfare in the year 2007 "Rapid Assessment of Avoidable Blindness in India" corneal blindness constitutes 1% of total blindness in India.<sup>3</sup> The major causes of corneal blindness include trachoma, corneal ulceration following xerophthalmia due to vitamin A deficiency, ophthalmia neonatorum, and the use of harmful traditional medicines, onchocerciasis, leprosy, and ocular trauma.<sup>2,4</sup> In India, the total number of overall treatable corneal blindness is about 3.1 million; children constituting 35% of the burden. There is further addition of 40,000 to 50,000 corneal blind persons every year. Once corneal opacity is established, restoration of their vision is possible only through transplantation of cornea from donated eyes. Currently, in India the collection is ~22 thousand eyes a year,<sup>3</sup> which are negligible to the requirement. Overwhelming the situation, a significant proportion of donor corneas are unsuitable for corneal transplantation.<sup>5</sup>

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Eye donation is an act of donating one's eyes after his/her death. Only corneal blinds can be benefitted through this process no other blinds. Eye donations are dependent on people willing to pledge their eyes for donation and on relatives to honor that pledge upon the death of the person. Though there is continuous progress in eye donations over last few years still there is a huge gap between demand and supply.

To address this gap and to create awareness among community regarding eye donation and related issues, NPCB celebrates the Eye Donation Fortnight every year from 25<sup>th</sup> August to 8<sup>th</sup> September. To increase procurement of corneas, raising the level of public education on eye donation is an important first step. Soliciting for actual eye donation at the time of death is a necessary and accepted practice.<sup>6</sup> Though the factors affecting procurement of corneas and the public attitude towards eye donation have recently received attention in the developed world,<sup>7</sup> not much has been published from the developing world. This study assessed awareness of eye donation, willingness to pledge eyes and factors affecting it in an urban population in northern India.

**MATERIAL AND METHODS:** The study was conducted in Rewa city over a period of 3 months (November to January 2010). The calculated sample size for the study was 550 based on awareness of general population as 40% with relative precision of 10% for confidence interval 95%. The study was conducted among accompanied persons of patients visiting ophthalmic clinics of Rewa city. 4 clinics were selected by convenience sampling out of them 2 were peripheral catering population residing in remote areas of the city.

Purpose and the nature of the study were explained to the concerned doctor and prior permission was obtained before conducting study. All accompanied persons of age group 18 years and above were selected as study population. Purpose of the study was explained and confidentiality assured to the study subjects. Only those who gave informed verbal consent were included in the study. Data collection was terminated after obtaining the required sample size. The information was collected using structured pretested questionnaire which was administered to the participants. Questionnaire was translated into Hindi and local language and administered by the paramedical personnel.

Questionnaire contained information pertaining to socio demographic profile, awareness of eye donation, knowledge about its various aspects and pledge to donate eye reasons for donating and not donating eyes and sources of information. Only those subjects who were aware of eye donation were asked about their willingness to pledge eyes for donation. Data was analyzed using SPSS Version 11.5 software package. Chi square test was used to test significance across category and p value <0.05 was considered statistically significant. Ethics: The study was carried according to the ethical guidelines for biomedical research on human subjects (2000).

**RESULTS:** Out of 550 subjects interviewed in Rewa city 44.2% were > 18-35 yrs and 55.2 % were >35 yrs old. Majority were hindu (76.73%) and males (71.64%). 78% subjects were aware of eye donation. (Table-1) The source of information being TV and AV aids for 89% subjects followed by health personnel and health facility (23.1%). (Table-2) Significant difference (p<.05) was found between awareness of eye donation and various variables except religion. Awareness was found to be high as age and education increases, in males, and in urban population. (Table-1). Questions were asked regarding willingness procedure and other aspects of eye donation to only those subjects who were aware. 82% know that eye can be donated only after death.

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Relatives can pledge for eye donation of deceased person was known to only 27%. 81.6% knew that whole eyeball is removed from deceased but only 25.2% thought that only cornea is transplanted. Though 60% subjects agreed that there is shortage of eye donors, 38.9% were willing to donate eyes and only 12 (2.8%) had pledged their eyes. place where to contact for making pledge was known to more than half (55%) of the subjects (Table-3) 250 (58.3%) subjects were aware but not willing to pledge their eyes or relatives eyes. Need more information to decide (79.2%), perceived objection by family members (52%) and religious reason (38.8%) were cited as major factors for not willing to pledge eyes. (Table-4) Nobility (76%) and pleasure (17.9%) was the main motivational force stated for willingness to donate eyes. (Table-5)

**DISCUSSION:** Corneal transplantation offers the potential for sight restoration to those who are blind from corneal diseases. This, however, is dependent on people willing to pledge their eyes for donation, and relatives willing to honour that pledge upon the death of the person. In this study, 78% were aware of eye donation major source being mass media to spread information. However 60% agreed that there is shortage of eye donors still 38.9% are willing to donate eyes. Only 2.8% pledged their eyes. Another study in the urban population observed that 73.8% were aware of eye donations and only 44.9% were willing to pledge their eyes.<sup>5</sup>

In a study among south Indian population 50.7% subjects were aware of eye donation.<sup>8</sup> Awareness and knowledge is found to be more with increase in age, education level and urban population. Similar findings were observed in other studies.<sup>8,9</sup> In our study males were more aware and having more knowledge for eye donation. This finding is different from many studies where females are found to be more aware as compared to males.<sup>8,9</sup> Negligible proportion of the study subjects identifies or know about persons who have received or donated eyes. This indirectly throws a light about prevailing practices of eye donation in the community.

Prime reason cited for not wishing to donate eyes was they need more information followed by objection by the family members. Similar reasons was also reported in other studies.<sup>5,10</sup> Knowledge about ideal time for donation, part that is cornea used for transplantation and relatives can make a pledge is poor. These findings are more or less similar to other study.<sup>8</sup> Just more than half of the subjects were aware of place to contact for making pledge. The timing of eye donation is important, it may not be ideal to utilize eyes that are donated later than 6 hours after death for optical purposes.

The low proportion of people who are aware of the optimal time to donate eyes despite awareness of eye donations suggests that a large proportion of donated eyes may not become available at an optimal time. Also a sizeable proportion of the population is not aware of how donated eyes are used, and possibly do not understand the potential for sight restoration that corneal transplantation offers. Knowledge about various aspects of eye donation plays a critical role in increasing the rate of eye donation. Lack of these essential knowledge and facts could be possible barriers to eye donation in many who are willing to pledge their eyes.

Many potential donors may be missed if they fail to approach place or whom to contact about eye donation and if they lack sufficient knowledge about ideal time for eye donation after death of the donors. The perceived reason for not donating eyes need to be considered while creating awareness about eye donation in the community. Mass media played a critical role in creating awareness in this study. This is similar to other studies.<sup>8,9,10</sup> Role of mass media in creating awareness in well documented in various nation health programs.

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As far as knowledge and motivation is concerned it is better dealt with interpersonal communication and group approach. Various studies done in medical and nursing students depict good level of knowledge about eye donation.<sup>11-13</sup> Medical students and nursing students must be actively involved as volunteers in the programs generating awareness and knowledge in the community.<sup>14</sup> For motivation, active counseling can be effective even in families who do not have prior knowledge of eye donation. Mandatory consent for donation expressed before the death of the donor should ideally form the basis for eye donation.

However, in the case of unavailability of such consent, consent from adult family members of the deceased donor should be obtained for eye donation. In a study done on the responses of relatives of post-mortem cases, it was revealed that out of the potential post-mortem donors, only 44.3% of relatives of such cases gave consent for donation after intensive counseling.<sup>10</sup> To conclude, the study revealed good level of awareness in urban population still very less subjects are willing to pledge eyes major factor being insufficient knowledge on their part to translate into procurement and donations. Targeting on aspects in which knowledge was found to be low and utilization of medical and paramedical staff in eye donation campaign might help to increase eye donation.

**LIMITATIONS OF STUDY:** Study subjects were the attendants of ophthalmic patients and they might have more knowledge about eye donation. So the finding of the study cannot be generalized to the general population.

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**CONFLICT OF INTEREST:** None declared.

**FUNDING:** None.

**ETHICAL APPROVAL:** Not required.

Variable	Total (n=550)	Aware (n=429) 78%	P value, significant/not significant	Chi square value, df	RR, 95% CI
<b>Age group</b>					
18-35 yrs	243, 44.2	179, 73.66	.0374, significant	4.331,1	.90,.82-.99
> 35 yrs	307, 55.8	250, 81.4			
<b>Gender</b>					
Male	394, 71.6	321, 81.5	<.0001, extremely significant	38.59,1	1.38, 1.2-1.54
Female	156, 28.4	108, 69.2			
<b>Education</b>					
upto 5 <sup>th</sup>	364, 66.2	269, 73.9	.0017, very significant	9.84,1	.86,.79-.93

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>5 <sup>th</sup> ,12 <sup>th</sup> and graduates and above	186, 33.8	160, 86			
<b>Religion</b>					
Hindu	422, 76.7	329, 78	.96, not significant	.0015,1	.1,.89-1.10
Others	128, 23.3	100, 78.1			
<b>Residence</b>					
Rural	148, 26.9	103, 69.6	.0056, very significant	7.6, 1	.86,.76-.96
Urban	402,73.1	326, 81.1			

**Table1: Depicts Sociodemographic profile and association with awareness of eye donation**

Doctor / health staff/health facility	99 (23.1%)
Family member/friend/relative/ neighbor or other person(IPC)	45 (10.5%)
TV, or other AV aids	382 (89%)
Books, magazines, leaflet, poster	42(9.8%)
Lecture, group discussion, seminar	30(7%)

**Table2: Source of information about eye donation\* (n=429)**

\*Multiple responses

Eyes can be donated only after death	352 82%
Ideal time for donating eyes is within 6 hrs after death	193 44.7%
Whole eyeball is removed from deceased person	350 81.6%
Only cornea is transplanted	108 25.2%
Eyes can be removed at home	154 35.9%
Relatives can pledge for eye donation of deceased person	116 27.0%
Immediate Measure to Be Taken After Death to Preserve Eyes	158 36.8%
One Donor Can Give Vision to 2 Blind	286 66.7%
Knows a person who has donated eyes	05 1.2%
Knows someone who has received a donated eye	04 0.93%
Knows contact person/ helpline/place for making pledge	236 55.0%
Knows of shortage of eye donation in India	258 60.1%
Willing to donate eyes	167 38.9%
Already pledged to donate	12 2.8%

**Table3: Responses to the questionnaire on eye donation (n= 429)**

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Noble work	136(76%)
Pleasure to help blind person	32(17.9%)
influenced by reading article/person	11(6.1%)

**Table 4: Perceived reason for willingness to donate eyes and already pledged eyes (n=179)**

Fear of deformity of the body after death	30 (12%)
born blind in the next birth	13 (5.2%)
Due to religious reasons	97 (38.8%)
Eyes will be rendered unsuitable because of an eye problem, systemic disease, ill health	67 (26.8%)
No faith in health system	25 (10%)
Need more information to decide	198 (79.2%)
Dislike separation of body part	27 (10.8%)
Family members do not allow	130 (52%)

**Table 5: perceived reasons for not wishing to donate eyes\* (n=250)**

\*Multiple responses

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