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# Awareness and knowledge of eye donation in patients attending eye OPD in a tertiary care hospital in north India

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#### Abstract

Introduction: Corneal opacity is the leading cause of blindness among the Indian population of the age group 0-49 years, and it is the third most prevalent cause of blindness among the age group 50 years and above. Corneal transplantation is the sole method available for restoring vision in individuals with corneal opacity. However, willingness to donate eyes depends on an individual's awareness and level of knowledge.

Aim and objectives: To assess the awareness and knowledge of eye donation in patients attending eye OPD in a tertiary care hospital in North India.

**Material and Methods:** This was a cross-sectional study, and a total of 140 participants who were  $\geq$ 18 years of age were included in this study. They were asked to participate in a questionnaire after a written informed consent was taken. The responses were recorded in a Microsoft Excel sheet and

Results: Out of the total 140 participants, 42.14% were female and 57.86% were male. The majority of the participants belonged to the age group of 30-81 years. Among these, 64% were aware of eye donation, while 36% were unaware. The most common sources of information were family members, relatives, or friends (31.1%), followed by mass media platforms such as radio and television (27.7%). Only 44% of the aware individuals were willing to donate their eyes, and 33.3% of the aware individuals correctly identified that eye donation should be done within 6 hours of death.

Conclusion: While awareness of eye donation is above average, the knowledge about eye donation was inadequate, and misconceptions persisted. Educational initiatives are needed to address these gaps. We also need to improve corneal tissue availability.

Keywords: Corneal blindness, eye donation, awareness

According to the World Health Organization, blindness is defined as a visual acuity of less than 3/60 or a notable loss of visual field in the better eye, even with the highest level of correction available. In contrast, low vision is indicated by a visual acuity that falls below 6/12 but is equal to or better than 3/60 in the better eye when optimally corrected [1]. Corneal opacity is one of the top five causes of blindness globally [2]. According to the Government of India, corneal blindness is the leading cause of blindness in 0-49 years of age group, and it is the third most prevalent cause of blindness among 50 years and above [3]. The causes of corneal blindness are ophthalmia neonatorum, non-infectious neonatorum, keratoconus, dry eye syndrome, bacterial keratitis, fungal keratitis, herpes simplex keratitis, vitamin A deficiency, ocular trauma and trachoma among others [4]. Corneal transplantation is the sole method available for restoring vision in individuals with corneal opacity [5]. In the year 2021-22, 45,294 eyeballs were procured against a target of 60,000 [6]. Every year, one lakh corneal transplantation are needed to be done to decrease the burden of corneal blindness in India.<sup>[7]</sup> With an estimated 90% of global corneal blind people residing in the country, need for more transplantable tissue is rising each year [6]. However, willingness of people to donate eyes depends on their awareness of eye donation and level of knowledge.

## **Materials and Methods**

This was a questionnaire-based, cross-sectional study which was conducted in the Outpatient Department of Ophthalmology, Christian Medical College, Ludhiana. All patients who were 18 years of age and above; who fulfilled the inclusion criteria, were included in this study. Demographic details were taken after a written informed consent was obtained. The patient was then asked to fill the questionnaire. A standardized questionnaire was used for this study [8]. The questionnaire was divided into two sections. Section 1 included questions related to awareness of eye donation, and Section 2 included questions related to knowledge on eye donation.

At the end of the completion of the questionnaire, a printed awareness pamphlet was given to the patient in the language that he/she was comfortable with.

## Sample Size

The awareness level in participants for eye donation is assumed to be 28% <sup>[9]</sup>. Therefore, the minimum sample size was calculated to be N=125, by using the formula N=Z2\*p\*(1-p)/d2, where Z=1.96, is a standard normal deviate at 95% confidence level, p=28% awareness of eye donation, and d is the margin of error (8%). In our study, there were 140 participants.

# **Statistical Analysis**

The data was entered into a Microsoft Excel sheet. Data was summarized using frequency distribution and descriptive analysis. Chi-square test or Fisher's exact test was used to find the association of categorical variables between the groups. The normality of the data was assessed through the statistical test and graphical method. Then, the normally distributed data was compared with the independent t-test. The non-normally distributed data was compared with the non-parametric test. The p-value of 0.05 was considered statistically significant. All the statistical analyses were performed using IBM SPSS (Statistical Packages for Social Sciences, version 28.0. Armonk, NY: IBM corp.).

# Results

This was a cross-sectional study conducted on a total of 140 patients who were 18 years or above attending the Ophthalmology OPD, over a period of 6 weeks.

# Age and gender distribution

The age distribution in the study shows that 13.5% patients were in the age group of 18-30 years. There were 45.71% patients in the age group of 30-60 years, and 40.71% fell in the 60-81 years age group. Thus, the majority of the participants were from the middle and elderly age groups. The gender distribution among participants was 42.14% female and 57.86% male (Table 1).

## **Educational Background**

Participants from various educational backgrounds were recruited for the study and were classified according to the modified Kuppuswamy scale [10]. The educational background ranged from being illiterate to having attained a postgraduate degree. The majority were below the level of intermediate or post-high school diploma (77.1%). A few participants were graduates or degree holders (7.8%), (Figure 1). The result comparing educational background

with awareness of eye donation is statistically significant (p<0.001).

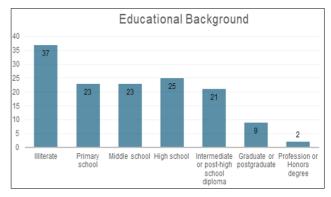


Fig 1: Educational Background

# Awareness of eye donation

Amongst the total participants, 64.3% were aware of eye donation while 35.7% were unaware (Fig 2). Among 64.3% of participants who were aware, the educational background was mostly from middle school and above.

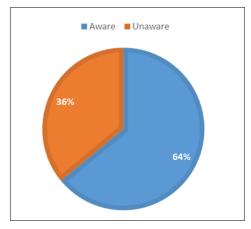


Fig 2: Awareness of eye donation

# **Duration of knowledge**

It was found that among those who were aware, 86.8% had heard about eye donation more than five years ago, while 13.2% had heard about eye donation in the last 1-5 years (Table 2).

#### **Source of information**

The most common sources of information were family members/relatives/friends (31.11%), and mass media platforms such as radio and television (27.77%). Health workers accounted as the information source in 14.4% cases, and educational institutions were cited by 14.4% of respondents. Very few participants mentioned "other sources", suggesting a relatively limited role of online media and social campaigns in this population. (Table 3)

# Awareness regarding eye donation sourced by a now-deceased person

Only 33% of the aware individuals, personally knew someone who had donated their eyes after death. This low percentage further highlights the rarity of eye donation in practice (Fig 3).

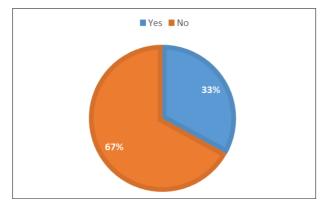


Fig 3: Awareness regarding eye donation sourced by a nowdeceased person

# Willingness for eye donation

Out of 90 participants who were aware of eye donation, only 40 participants expressed a willingness to donate their eyes after death. This demonstrates a striking gap between awareness and willingness. Of the 40 participants who were willing to donate their eyes, 62.5% were females. This result is statistically significant (p<0.0002) (Table 4).

# Eligibility for eye donation

Knowledge regarding eligibility criteria for eye donation was also limited. Only 35 participants (38.5%) correctly responded that anyone, irrespective of age could donate their eyes. Many participants harbored misconceptions such as: 33% believed that donors must not have undergone cataract surgery, a small fraction thought that spectacle wearers could not donate (3.3%), 1.1% indicated that only those below the age of 50 years could donate eyes and 3.3% indicated that those without a history of any chronic illness could donate eyes. Of the total 90 participants, 16.6% had no knowledge about any eligibility regarding eye donation (Fig 4).

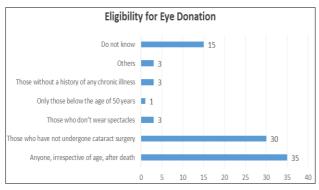


Fig 4: Eligibility for eye donation

# Willingness to disclose eye donation intentions to relatives

The total number of participants who were willing to donate their eyes, 17.5 % were hesitant to inform their family members regarding their wish to donate their eyes, while 82.5% were comfortable in informing their family members regarding their wish. This indicates that there is still some reluctance present in society regarding making a decision for eye donation and informing someone. (Table 5)

**Reason for not donating eyes:** Among those unwilling to donate, personal reasons were cited by 92%. A few

participants gave the reason as religious beliefs (4%) or concerns about post-mortem facial disfigurement (4%) (Table 5).

# When to donate eyes after death

The participants' understanding of when eyes should ideally be donated to maintain tissue viability was limited. Only Thirty (33.3%) correctly identified that eye donation must be done within 6 hours of death. Notably, twenty-eight (31.1%) admitted that they did not know about the timing for eye donation, while two (2.2%) incorrectly believed that eye donation is possible even after 24 hours of death. Thus, although general awareness exists, detailed knowledge about critical aspects like when to donate eyes remains inadequate (Table 5).

Among the participants, 7.7% had the misconception that eyes can be donated before death whereas, 81.8% of the participants had good knowledge about eye donation (Table 5).

## **Discussion**

The importance of awareness and knowledge about corneal transplantation amongst the Indian population cannot be stressed upon enough due to the huge gap between the requirement and the number of corneal donations. Our findings demonstrate that although the majority of the participants (64%) had heard about eye donation, only 44.4% of them were willing to donate their eyes posthumously. This is comparable to a study done by Singh et al in an urban slum area of Delhi, wherein 65.72% participants were aware of eye donation while 34.28% were unaware of it. Only 28% of the total participants were willing to donate their eyes [8]. Similarly, in another study conducted by Krishnaiah et al in a rural population of Andhra Pradesh, 20.87% of the eligible participants were aware about eye donation and 01% of the eligible participants were willing to donate their eyes [9].

In our study we found that there was no correlation between age distribution and awareness of eye donation. This corresponds with the findings of Singh  $et\ al\ ^{[8]}$ .

We also observed that awareness was higher among individuals with better educational qualifications. Participants who had middle school education and above demonstrated significantly better awareness than those with lower education levels (p<0.001). This trend is corroborated by Singh et al, who noted a similar positive association between literacy and awareness regarding eye donation [8]. These findings reinforce the need for educational interventions, particularly targeted at the illiterate or semiliterate populations, wherein awareness programs regarding eye donation can be organized. In schools, for students, teachers and staff, printed awareness pamphlets can be given along with talks, so that they can share the knowledge about eye donation with their parents and relatives.

Notably, the majority of individuals in our study, reported learning about eye donation more than five years ago. They had acquired the knowledge mostly from family/friends/relatives (31.1%), along with mass media (27.7%), serving as the main sources of information. These findings are similar to the study conducted by Singh *et al* and Pallerla *et al*, wherein most participants had heard about eye donation through radio and television [8,11]. Health workers and educational institutions accounted for only 14.4% each, indicating that organized healthcare and

academic systems are underutilized in promoting eye donation. This underlines the need to integrate eye donation awareness programs into community outreach and school-based health education.

Though the general awareness was relatively high, detailed knowledge about eye donation was inadequate. Only onethird (33.3%) of the participants (who were aware about eye donation) correctly identified the optimal post-mortem interval for eye donation (0-6 hours). A considerable proportion (7.7%) incorrectly believed that eyes can be donated before death, and 11% did not know the correct timing. Misconceptions were also evident in knowledge about donor eligibility, as 33.3% incorrectly believed that prior cataract surgery disqualifies a donor. Similar knowledge gaps have been observed in a study conducted by Singh et al wherein, only 595 participants of the total 2004 participants had good to excellent knowledge about eye donation [8]. In a study conducted by Pallerla et al in Andhra Pradesh, 49.3% of the total participants were aware about the ideal time to donate their eyes thus indicating, that knowledge about eye donation in South India is probably more than in North India [11].

Personal reasons (92%) was the predominant barrier amongst those unwilling to donate, while only a minority cited religious beliefs or concerns about post-mortem appearance. Furthermore, 17.5% of participants willing to donate, reported hesitation in discussing their decision with family members. These findings are consistent with other studies, wherein myths regarding eye donation were prevalent and participants were hesitant to donate their eyes because of religious reasons or issues related to disfigurement of the body [8,9,11]. These findings suggested that, beyond knowledge deficits, social and emotional barriers significantly influence willingness to donate.

As our study involved a tertiary care hospital population, it captures a broader sociodemographic spectrum and reveals actionable insights into both systemic and psychosocial barriers. However, in rural areas, for improving the awareness and knowledge about eye donation, the authorities should print pamphlets regarding corneal donation, that is, the basic concept printed in the regional language, Hindi, and English, so that the patients and relatives can access them. In the case of illiterate population, community-based awareness programs should be conducted, so that knowledge and awareness regarding eye donation can be increased and number of volunteers for eye donation can be increased.

Table 1: Demographics

	Categories	Percentage	Number
Age (in years)	18-30	13.6%	19
	30-60	45.7%	64
	60-81	40.7%	57
	Total	100%	140
Gender	Male	57.86%	81
	Female	42.14%	59
_	Total	100%	140

Table 2: Duration of knowledge

Categories	In the last year	0
Ŭ	In the last 1-5 years	13.2%
	5 years back	86.8%

Table 3: Source of Information

Source of information	Number	Percentage
Family Members/Relatives/Friends	28	31.1
Health Workers	13	14.4
News	9	10
Other sources	2	2.2
Radio/Television	25	27.7
Education Institution	13	14.4
Total	90	100

Table 4: Willingness for eye donation

Willingness to donate eyes	Number	Male	Female
No	50	36	14
Yes	40	15	25
Total	90	51	39

Table 5: Information regarding eye donation

Timing of eye donation	Percentage	
1.When to donate eyes		
After death	81.3%	
Before death	7.7%	
Don't know	11%	
2.When to donate eyes after death		
0-6 hours	33.3%	
6-24 hours	33.3%	
It is possible to donate even after 24 hours	2.2%	
Do not know	31.1%	
3. Willingness to inform family members regarding eye donation		
Yes	82.5%	
No	17.5%	
4.Reason for not donating eyes		
Personal reasons	92%	
Religious belief	4%	
Post-mortem facial disfigurement	4%	

#### Conclusion

This study demonstrates that though awareness of eye donation among patients attending a tertiary care hospital in North India is above average, substantial deficiencies persist in their knowledge and willingness to donate eyes. These findings highlight the urgent need for structured, community-based educational initiatives and integration of eye donation counseling within healthcare services to address informational gaps and improve corneal tissue availability in India.

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