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# A Study to Assess Knowledge and Awareness about Eye Donation in Northern India

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## **Abstract**

Introduction: Corneal diseases constitute a major burden of blindness worldwide, especially in under previliged countries like India. Corneal transplantation provides a great potential for visual rehabilitation and sight restoration to those who are blind due to corneal diseases. Eye donations are dependent on the people who are willing to donate their eyes and on the relatives who honor their pledge on death of the donor. Health education is an important step to increase awareness among people about eye donation and thus raising number of eye donations annually. In view of all the above factors, a hospital based study was conducted to assess the awareness about eye donation among people attending various outpatient department in a tertiary hospital of northern India catering mainly rural population using a questionnaire.

**Methodology:** The present cross sectional study included about 475 patients attending various Outpatient department of the hospital from January 2018 to June 2018. The nature of the study was explained to the patients and a pretested semistructed questionnaire was asked to each and every patient. The questionnaire included questions regarding demographic data, age, sex, marital status, educational status, awareness about eye donation, source of awareness willingness to donate eyes and reasons to donate or not donate eyes.

**Results:** The mean age of subjects was 57 years (range 35-75 years), out of whom and 280 (58.9%) were males and 195(41.1%) were females. Out of 475, only 176 (37.1%) were literate; 188 (37%). About 232 respondents (48.8%) out of total subjects were aware of eye donation. The major source of information about corneal transplantation was T.v., magazine and other media sources (37.9%). Only 4.2% of the total subjects were aware about the fact that eye donation had to be done within 6 hours of death. The response of questionnaire was noted in all the patients.

Conclusion: Thus the data from our study suggested that there is a need to increase awareness among population about corneal transplantation by using appropriate strategies. The age group most willing to pledge eyes include 55-70 years age group. A lot has been done at the national level with the help of media but still more enforced efforts are required at the level of individual hospitals. There is need to conduct public awareness seminars/lectures during the eye donation week and putting up posters and charts regarding eye donation in wards and intensive care units.

**Keywords**: eye donation, blindness, corneal transplantation, health education.

### Introduction

Corneal diseases constitute a huge burden of visual impairment and blindness in developing countries<sup>1,2</sup>. Corneal diseases either in the form of ulcers or trauma constitutes a major cause of blindness in children and young adults<sup>3</sup>. The etiology of corneal blindness include trachoma, ulceration, vitamin A deficiency, leprosy, ophthalmia neonatorum, and ocular trauma. The current statistics labelled corneal blindness as fourth leading cause of blindness worldwide<sup>4</sup>. According to Andra Pradesh Eye Disease Study (APEDS), the prevalence of corneal blindness is 0.13% which makes it 9% of total blindness<sup>5</sup>. Corneal transplantation offers the potential for visual rehabilitation to those who are blind due to corneal diseases<sup>6</sup>.

There are about 18.7 million people in India <sup>7</sup> who are blind and out of which about 190,000 have bilateral corneal disease and 20,000 new patients join the list annually<sup>8</sup>. The first eye bank in India was started by Dr Muthiah and successfully performed first corneal transplantation in the year 1948<sup>9</sup> but even after so many years there is a considerable backlog for corneal transplantation and that is why there is need to educate the masses about corneal transplantation. The Eye Bank Association of India estimated that the current cornea procurement rate is 22,000 per year in India and a significant amount of donor corneas are not suitable for transplantation<sup>10</sup>. Depending on our current data, we would need 277,000 donor eves in order to perform 10.000 corneal transplantation per year in India<sup>11</sup>. The factors affecting corneal procurement and attitude of public towards corneal transplantation have been received attention in developed countries but not in developing countries. 12 In view of all the above factors, a hospital based study was conducted to assess the awareness about eye donation among people attending various outpatient department in a tertiary hospital of northern India catering mainly rural population using a questionnaire.

# Methodology

The present cross sectional study was conducted in a tertiary hospital of Northern India mainly catering rural population from Jan 2018 to June 2018. The study included about 475 patients attending various Outpatient department of the hospital. The nature of the study was explained to the patients and a pretested semi structed questionnaire was asked to each and every patient. The questionnaire included questions regarding demographic data, age, sex, marital status, educational status, awareness about eye donation, source of awareness willingness to donate eyes and reasons to donate or not donate eyes.

### **Results**

We asked questionnaire 475 subjects attending various outpatient department of our hospital between Jan 2018 to June 2018. The mean age of subjects was 57 years (range 35 - 75 years), out of whom and 280 (58.9%) were males and 195(41.1%) were females. Out of 475, only 176 (37.1%) were literate; 188 (37%). Table 1 described various demographic characteristics of subjects included in our study. About 232 respondents (48.8%) out of total subjects were aware of eye donation. The major source of information about corneal transplantation was T.V., magazine and other media sources (37.9%) as described in table no.2. Only 4.2% of the total subjects were aware about the fact that eye donation had to be done within 6 hours of death. (table no.4). The response of the questionnaire has been described in table no.3

**Table No.1** Demographic Data about Respondents

AGE (IN YEARS)	TOTAL NO. (%AGE)
35-45	152 (32%)
46-60	228 (48%)
>60	95 (20%)
GENDER	
MALE	280 (58.9%)
FEMALE	195 (41.1%)
LITERACY	
ILLITRATE	299 (62.9%)
LITRATE	176 (37.1%)
RESIDENCE	
RURAL	275 (57.9%)
URBAN	200 (42.1%)

**Table No.2** Source of Awareness about Eye Donation among 232 Subjects

SOURCE	TOTAL NO. (%AGE)
T.V.,MAGAZINES &OTHER MEDIA	88 (37.9%)
NEIGHBOURS, FAMILY & RELATIVES	44 (18.9%)
PUBLICITY CAMPAIGNS	76 (32.7%)
OTHERS	24 (10.5%)
TOTAL	232 (100%)

**Table No.3** Questionnaire Response about Eye Donation

RESPONSE	TOTAL NO. (%AGE)
> CAN EYES BE	,
DONATED	
YES	342 (72%)
NO	14 (2.9%)
NO RESPONSE	119 (25.1%)
> EYES CAN BE DONATED ONLY AFTER DEATH	
YES	266 (56%)
NO	114 (24%)
NO RESPONSE	95 (20%)
> ONLY CORNEA IS USED FOR TRANPLANTATION	200 (42.1%)
OR WHOLE EYEBALL IS USED FOR TRANSPLANTATION	275 (57.9%)
> DONOR'S EYE CAN BE PRESERVED	
YES	228 (48%)
NO	152 (32%)
NO RESPONSE	95 (20%
> WILLING FOR EYE DONATION	
YES	356 (74.9%)
NO	76 (16%)
NO RESPONSE	43 (9.1%)
> ALREADY PLEDGED FOR EYE DONATION	
YES	21 (4.4%)
NO	350 (73.7%)
NO RESPONSE	104 (21.9%)

**Table No.4** Awareness about Optimal time for Eye Donation

TIME	TOTAL NO. (%AGE)
AFTER DEATH	175 (36.8%)
WITHIN 6 HRS OF DEATH	20 (4.2%)
NO IDEA	199 (41.9%)
NO ANSWER	81 (17.1%)

### **Discussion**

Every where a significant proportion of corneal blindness adds to the social and economic burden. There are about 190,000 persons blind from bilateral corneal disease in India<sup>13</sup> and another 20,000 new cases join the existing backlog anually<sup>8</sup>. Corneal transplantation offers a great

potential for visual rehabilitation to those who are blind due to corneal involvement. However it depends on the willingness of the people to pledge their eyes for eye donation. Our study showed that there is under utilization of the sources to obtain corneas as in our study 48.8% of subjects were aware about eye donation but only 4.4% had pledged their eyes for donation. To increase the level of awareness of our community on corneal transplantation, more health education about eye donation, eye diseases is required along with motivation of family members of sick and diseased patients to pledge for eye donation. Even though females were aware of eye donation but still they were willing to pledge eyes less than that of males. The awareness and willingness for eye donation was found to be higher in subjects above 55 years of age. There was no significant association between socioeconomic status and willingness to pledge for eye donation. Despite a good number of rural population being aware about eye donation, inability to pledge eyes for donation was due to lack of knowledge about significance of eye donation. The need of the hour is to provide detailed information about when to donate eyes, how to pledge for eye donation, discussion with family members, providing donor card and informing about optimal timing for corneal transplantation. Educating students particularly those in medical colleges about corneal transplantation so that they can motivate the younger generation for enhancing eye donation rates. 14 Following deaths of patients, the hospital staff counseling the grieving relatives have been successful in procuring organs 15,16. Even if a pledged donor die, family consent is a must at the time of death. Some of studies showed that training of hospital staff about eye donation is associated with significantly higher rate of eye donation.<sup>17</sup> Thus, it is important to involve the hospital staff, nurses and counselors motivating the relatives of diseases whenever there is a death. In 1975, in USA, a law was passed as Presumed consent law according to which if a dead person has not raised any

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objection to donate when alive, consent is presumed and eyes can be removed. This has led to increased availability of cornea<sup>18</sup>. Such legislation should be introduced in India to increase corneal transplantation. There is a great need to take appropriate strategies to increase the knowledge and awareness about eye donation, to encourage the population to pledge for eye donation and enhance eye donation.

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