

## Knowledge And Perception Of Eye Donation Among Health Care Seekers In A Tertiary Care Centre In Western India

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**Abstract:** The present procurement rates of surgical grade corneas are insufficient to meet the ever increasing corneal transplantation needs in India, posing a major challenge in eliminating corneal blindness. The major reasons for this are the lack of proper knowledge and motivation in the masses. This cross sectional study was conducted to assess the awareness and knowledge of eye donation amongst patients and their attendants in a tertiary care hospital of Western India and to use this information to identify the possible interventions to increase the rates of eye donation. Two hundred and eighty two literate health care seekers were selected to answer a pretested semi-structured questionnaire in local language, during the National Eye donation Fortnight 2018. Questions were based on the socio-demographic details and assessment of the awareness and knowledge of various aspects regarding eye donation amongst the participants. The responses were analysed. Though a majority of 93.97% participants were aware that eyes can be donated, 34.75% had the misconception that eye donation can be done before death. 33.33% were not aware of National Eye donation fortnight. Only 20.57% knew of eye donation done amongst family and friends. Only 15.96% had pledged their eyes. Although the awareness was good amongst the participants in our study, the number of people who had pledged was very low, indicating a significant lack of motivation. Hence, appropriate strategies need to be developed to increase the relevant knowledge and subsequently, sensitisation and motivation for eye donation.

**Keywords:** corneal blindness, eye donation awareness, knowledge, health care seekers, strategies, motivation

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### I. Introduction

Corneal blindness is a significant public health problem, constituting a major cause of visual impairment and blindness in India. <sup>1</sup> According to the National Programme for Control of Blindness and Visual impairment (NPCB & VI) estimates, there are currently 1,20,000 corneal blind persons in the country with an addition of 25,000-30,000 new cases per year. <sup>2</sup> The burden of corneal blindness has been reported to be 0.12% (blindness defined as presenting visual acuity of < 3/60 in the better eye) by a population based study done in northern India <sup>3</sup> and 0.13%, in another study done in Andhra Pradesh. <sup>4</sup> The major causes of corneal blindness include keratitis, xerophthalmia, eye trauma, trachoma, use of harmful traditional medicines and congenital disease. <sup>5</sup> The burden of corneal blindness on the community is not just reflected by the prevalence but also by the younger age of those with it. <sup>6</sup>

Keratoplasty is an effective treatment option for many patients with corneal disease, with a high success rate in restoring sight. According to NPCB & VI statistics, the corneal procurement rate in India was 69,343 corneas during 2017-18, with a significant proportion unsuitable for corneal transplantation <sup>2</sup>. Thus there is a huge gap between the demand and supply of quality tissues.

There are two ways to overcome this backlog, one by encouraging voluntary donation and other by Hospital Cornea Retrieval Programme (HCRP) <sup>7</sup>. Voluntary eye donation is dependent on the willingness of people to donate and pledge their eyes for corneal donation as well as the consent of the family members after death. However, with the implementation of HCRP, harvesting of more number of good quality

donor corneas has become possible.<sup>8</sup> Tertiary care hospitals with Intensive care units (ICUs), Intensive Cardiac Care Units (ICCU) and trauma centres have high morbidity rates and cornea procurement rates can be higher with readily available patient investigation reports, previous treatment and other data.

Few hospital based studies have assessed the awareness and perception regarding eye donation in the patients and their attendants in different parts of the country. However, to the best of our knowledge, no such study has been done till date in the western part of India.

With this in background, the study was undertaken in the patients and their attendants in various clinics in a tertiary care hospital of Western India, with an aim to assess their awareness and knowledge of eye donation and to use this information to identify the possible interventions to increase the rates of eye donation.

## **II. Material and Methods**

The hospital based cross-sectional study was conducted in a tertiary care hospital in Western India. The study was designed and implemented by the in house Eye bank of the tertiary care hospital. A trained eye donation counsellor (EDC) working with the Eye bank under HCRP was appointed to conduct the survey.

The study was conducted in accordance with the tenets of Declaration of Helsinki.

**Study design-** Hospital based cross sectional study

**Study location-** Tertiary Care centre of Western India

**Study duration-** National Eye Donation Fortnight 2018( 25<sup>th</sup> August to 8<sup>th</sup> September)

**Sample Size calculation-** During the study period, the EDC visited the trauma centre, trauma ICU, kidney hospital and the out-patient departments of speciality clinics of Medicine and Surgery, and interviewed the patients and their attendants above 16 years of age waiting their turn outside about their willingness to participate in the survey. A total of 387 patients and their attendants were interviewed. A purposive type of sampling procedure was employed and of the 387 people, 282 willing candidates were selected.

**Subjects and selection method-** The study population was drawn from the patients and their attendants waiting outside the trauma centre, trauma ICU, kidney hospital and the out-patient departments of speciality clinics of Medicine and Surgery.

All the participants were residents of different districts of Gujarat state, literate and knowing well the local Gujarati language. Literacy was defined as minimum ability to read and write one's name. Place of residence was classified as urban and rural based on existing census records.

A pretested semi-structured self administered questionnaire was developed and used in this study (developed in a pilot study conducted in 50 participants). The study was conducted during the National Eye Donation Fortnight 2018. After an informed written consent, the questionnaire in local Gujarati language was given by the EDC to the attendants. Participants' confidentiality was respected.

The data collection instrument, questionnaire was in three parts. The initial part contained questions on socio-demographic details of the participants: age, gender & place of residence. The second part contained multiple choice questions on their awareness of eye donation and the source of information. The third part had multiple choice questions testing the knowledge of the participants about the various aspects of eye donation and their pledge to donate eyes.

Microsoft Office Excel 2007 software and Medcalc software was used for statistical analysis. Patient demographics were reported as mean and standard deviation for continuous variables and percentages for categorical variables. Chi Square test was used to test significance across category and p value <0.05 was considered statistically significant.

## **III. Results**

During the study period, a total of 387 patients and their attendants were interviewed. Out of these, 282 (72.87%) attendants who consented to participation were included in the study done during the National Eye donation fortnight 2018.

The mean age of the participants was 40.06 years (SD ±16.05) with a range of 17 to 88 years. 21.98% (n= 62) were between 17- 25 years of age. 56.02% (n = 158) were from Ahmedabad district and a majority of participants were from urban area, 66.31% (n= 187). [Table-1]

**TABLE 1:** Demographic Profile of study participants (n= 282)

Characteristics	Total number	Percentage (%)
Age		
< 40	159	56.38%
>40	123	43.62%
Gender		
Males	170	60.29%
Females	112	39.71%
Residence		
Urban	187	66.31%
Rural	95	33.69%

The awareness that eyes can be donated, was found to be 93.97% (n=265), indicating that a majority of the participants knew of this noble cause. [Table-2]

**TABLE-2-** Responses assessing awareness of eye donation

Can eyes be donated?	
Yes	93.97% (n=265)
No	6.03%(n=17)
Awareness of National Eye Donation fortnight	
Yes	42.56%(n=120)
No	33.33%(n=94)
No response	24.11%(n=68)

Significant difference was noted between awareness of eye donation and the urban population ( $p < 0.001$ ) [Table-3].

**TABLE-3** Statistical analysis of relation of awareness of eye donation with different variables

Variable	Total (n=282)	Aware that eyes can be donated (n=265)	P value- Significant/ not significant	Chi square value; d.f.(degree of freedom)
Age group (years)				
<40	159	148	p value= .48 not significant	0.505;1
>40	123	117		
Gender				
Males	170	161	P= .52 Not significant	0.406;1
Females	112	104		
Residence				
urban	187	182	p<.001 extremely significant	11.02;1
rural	95	83		

Awareness was found to be more in urban population.

42.55 % (n= 120) were aware of the National Eye donation fortnight.

The major source of awareness was television in 31.91%, followed by newspaper (24.47%). [Table- 4]

**TABLE- 4 -** Source of awareness

Source of awareness	
Television	35.81% (n=101)
Newspaper	24.47% (n=69)
Family & friends	19.86% (n=56)
Others	15.25% (n=43)
No response	4.61% (n=13)

In spite of the high awareness of eye donation, only 15.96% had pledged their eyes [Table-5].

**TABLE 5-** Responses assessing knowledge of eye donation

Responses to queries%	
<b>Age for eye donation</b>	
<20 years	8.51 ( n= 24)
50 years	0.71 ( n=02)
Any age	87.59 (n=247)
No response	3.19 (n= 09)
<b>Can eyes be donated before death?</b>	
Yes	34.75 (n=98)
No	47.52 (n= 134)
No response	17.73 (n=50)
<b>Can eye donation be done if body of the deceased is at home?</b>	
Yes	49.29 (n=139)
No	29.08 (n=82)
No response	21.63 (n=61)
<b>Ideal time for eye donation after death</b>	
Within 6- 8 hours	47.87 (n=135)
Within 10-15 hours	17.37(n=49)
Within 15- 20 hours	18.09(n=51)
No response	16.67(n=47)
<b>Utilisation of eye donation</b>	
Research education	2.13(n=06)
Corneal transplantation	13.83(n=39)
Both	77.30 (n=218)
No response	6.74(n=19)
<b>Is there any commercial dealing in eye donation?</b>	
Yes	28.82 (n=70)
No	52.83(n=149)
No response	22.34(n=63)
<b>Eye donation done in friends/ family?</b>	
Yes	20.57(n=58)
No	74.11(n= 209)
No response	5.32 (n=15)
<b>Have you pledged eyes?</b>	
Yes	15.96(n=45)
No	78.36(n=221)
No response	5.68(n=16)

Significant difference was seen between the pledging and the participants' age and residence. The rate of pledging was more with increase in the age and the urban residence of the participants. [Table-6]

**TABLE 6-** Statistical analysis of relation of pledging of eyes to different variables

Variable	Total (n=282)	Pledged eyes (n=45)	P value- Significant/ not significant	Chi Square test ; d.f.
<b>Age group (years)</b>				
<40	159	14	P<.001 extremely significant	36.28;1
>40	123	31		
<b>Gender</b>				
Males	170	26	p value=.71	0.13;1
Females	112	19	Not significant	
<b>Residence</b>				
Urban	187	37	p value= .01	6.07;1
Rural	95	08	p<0.02 significant	

#### **IV. Discussion:**

In our study, 93.97% participants were aware that eyes can be donated, which is similar to a study conducted by Ronanki et al in South India, where the awareness was found to be 93%<sup>9</sup>. It is high as compared to the study conducted by Khan et al (86%) and another study by Marathe et al (78%), both done in the population of central India<sup>10,11</sup>. The awareness was low in a study conducted by Priyadarshini et al, in the adult population of southern India and another study done by Panigrahi in eastern India.<sup>12,13</sup> The high level of awareness in our study can be attributed to a literate, predominantly urban population and Gujarat's inherent rich tradition of philanthropy and pioneering work in eye donation and eye banking.

Most respondents in our study, reported learning about eye donation through mass media like television (35.81%) and newspapers (24.47%), which is similar to other studies.<sup>9,10,11,12,13</sup> This suggests maximizing this as a possible outlet for future public health campaigns for propagation of the cause of eye donation.

To address the gap between the demand and supply of the donor eyes and to create awareness among people regarding eye donation and related issues, the NPCB and VI celebrates the National Eye Donation Fortnight (25<sup>th</sup> August to 8<sup>th</sup> September) every year in India.<sup>8</sup> Our study assessed the awareness of National Eye donation fortnight amongst the participants and found it to be only 42.56%. This has not been assessed in any other similar studies previously done. It indicates that more efforts should be made to use this occasion to propagate the noble message of eye donation. Aggressive action plans can be designed to organize massive public educational campaigns in different forms in hospitals as well as various public places during this period.

34.75% had the misconception that eye donation can be done before death, which was found to be more (47%) in another study by Khan et al. whereas lower (2.8%) in the study by Prabhu<sup>10,14</sup>.

47.87% knew that the ideal time for eye donation is within 6 to 8 hours of death, somewhat similar to findings of Marathe et al (44.7%) and more than study done by Priyadarshini et al (4.34%).<sup>11,12</sup> 35.46% participants did not know when to ideally donate eyes, suggesting that a large number of donor eyes may not be available at an optimal time which can compromise the quality of the donor corneas for transplantation.

A sizeable proportion (77.30%) of population knew that the donated eyes are used for corneal transplantation as well as research. This suggests that a majority were knowing how the donated eyes are used and the potential of sight restoration through corneal transplantation.

Even if the deceased is a pledged donor, the consent of the family members is essential for executing enucleation at the time of death. Thus, ultimately it is the family of the potential donor who must be positively influenced to enhance eye donation rates. In our study, only 20.57% knew of eye donation done amongst family and friends. This is quite low and indirectly highlights the existing ignorance of eye donation and the low eye donation to pledge ratios in the community.

52.83% opined that there is no commercial dealing involved in the noble act of eye donation, which is more than that found in study by Prabhu (41.8%).<sup>14</sup>

Only 15.96% had pledged their eyes, indicating a significant lack of motivation in spite of high awareness among the participants. A study by Marathe et al (2.8%) and Dandona et al (1.9%) also had a very low number of participants pledging eyes<sup>10,15</sup>, suggesting that there is enough potential to obtain more corneas for transplantation by working on improving this.

To conclude, this study highlights that each health care seeker is not only a potential eye donor but also a potential motivator of eye donation. Encouraging and educating this group of population can help to spread the message of eye donation in the society.

Although the awareness was good amongst the participants in our study, the number of people who had pledged was very low, indicating a lack of motivation. Hence, appropriate strategies need to be developed to increase the relevant knowledge and subsequently, motivation for eye donation. Targeting the aspects in which the knowledge is found to be low and organizing public awareness campaigns highlighting the need of eye donation and dispelling the myths of the masses should be done. Wider practice of grief counselling, publicity of success stories of corneal transplant recipients, targeted hospital cornea retrieval programme, use of mass media, round the year promotional campaigns in the community, schools and colleges can help.

## V. Limitation

Study subjects were patients and their attendants in hospital and were predominantly an urban population. Hence, their knowledge and awareness can't be generalized. Perceived reasons for not pledging eyes or non-willingness for eye donation needs to be evaluated.

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