

## Original Research Article

# SOCIO-DEMOGRAPHIC CHARACTERISTICS AND PLEDGE RATES FOR EYE DONATION IN OUTREACH SCREENING CAMP PARTICIPANTS

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Received : 10/01/2025  
Received in revised form : 03/03/2025  
Accepted : 18/03/2025

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DOI: 10.70034/ijmedph.2025.1.324

Source of Support: Nil,  
Conflict of Interest: None declared

Int J Med Pub Health  
2025; 15 (1); 1732-1736

**ABSTRACT**

**Background:** Corneal diseases constitute a significant cause of visual impairment and blindness in the developing world. At present the major treatment option for restoring sight in those who have corneal blindness is by corneal transplantation. The only source of the cornea is from donor corneas through eye donation, thus sight restoration is largely dependent on voluntary eye donation by suitable donors. **Aim:** To educate people at outreach screening camps regarding eye donation, assess the pledge rates and study the socio-demographic characteristics of people pledging eyes.

**Materials and Methods:** A cross-sectional study was conducted in outreach screening camps of our tertiary care centre. The total number of participants who attended these camps, people attending ophthalmology screening, the number of people willing to pledge their eyes and their socio-demographic parameters were noted after educating them on eye donation.

**Results:** Of the 1433 camp participants, ophthalmology screening was done on 647, and 136 pledged their eyes. Of the 21.02% of the participants who pledged their eyes, 31.0% were in the age group 44-56, 56.0% were males and 44.0% were females, with 90.0% being literate, 82.0% married, 93.0% following Hinduism, 71.0% belonging to nuclear family type and 64.0% with a family monthly income of >6573 INR.

**Conclusion:** Socio-demographic characteristics influence pledge rates. Strategies to improve pledge rates can be planned accordingly with a resultant increase in eye donation to meet the requirement for corneal transplant.

**Keywords:** Outreach screening camps, eye donation, pledge rate, socio-demographic parameters.

**INTRODUCTION**

Corneal diseases constitute a significant cause of visual impairment and blindness in the developing world. The major causes of corneal blindness globally include trachoma, corneal ulceration following xerophthalmia due to vitamin-A deficiency, ophthalmia neonatorum, use of harmful traditional eye medicines, onchocerciasis, leprosy and ocular trauma.<sup>[1]</sup> At present visual rehabilitation by corneal transplantation remains a major treatment option for restoring sight in those who have corneal

blindness though strategies to prevent corneal blindness are likely to be more cost-effective.<sup>[2]</sup>

Despite the large proportion of corneal blindness, eye banking in India is still nascent. Corneal transplantation surgery which offers the potential for sight restoration is largely dependent on voluntary eye donation by suitable donors.<sup>[3]</sup> A sizeable proportion of the urban population is aware of eye donation, however, in rural India, failure to pledge eyes could be due to a lack of knowledge of the purpose of eye donation and a negative attitude among the general population.

Outreach Services are a critical function of primary health care which serves to expand the reach and coverage of health services to the most vulnerable populations to be connected to and avail the basic medical facilities. Urbanization is one of the most significant demographic trends of the 21st century. Unplanned and rapid urbanization has led to massive growth in the number of urban poor population. Despite the supposed proximity of the urban poor to health facilities their access to them is severely restricted. Ineffective outreach and weak referral systems also limit the access of urban poor to healthcare services.<sup>[4]</sup>

The lack of awareness becomes a major obstacle to convince and obtain consent for eye donation.<sup>[5]</sup> Thus, the need of the hour is to educate common people and enhance their awareness about eye donation to increase the procurement of cornea.

This study attempted to educate the people attending outreach screening camps regarding eye donation, in turn positively influencing them to pledge their eyes. The objective of this study was to educate the general population on eye donation and estimate the people pledging their eyes in outreach screening camps; and to study the socio-demographic characteristics of people pledging their eyes. This would help to plan strategies that increase the

pledging of eyes, in turn increasing the rate of eye donations to meet the requirement for corneal transplant.

## MATERIALS AND METHODS

A descriptive cross-sectional study was conducted among people who attended outreach screening camps organized by our tertiary care centre for a period of 1 year. The study was conducted by the Declaration of Helsinki. The distance of outreach screening camps from our tertiary care centre ranged from 2 km to 141.2 km.

At every outreach screening camp, an educational talk on eye donation was given to the camp participants followed by the distribution of educational handouts with matter printed in English as well as the local language i.e. Kannada regarding eye donation. The total number of people attending camp, people attending ophthalmology screening and people pledging eyes was noted.

The socio-demographic parameters including age, gender, level of literacy, occupation, family type, religion, marital status, and economic status according to BG Prasad classification 2018,<sup>[6]</sup> of people willing to pledge eyes were documented.

## RESULTS

**Table 1: Number of participants screened and pledged in eleven outreach screening camps and their distances from tertiary care centres conducted over 12 months**

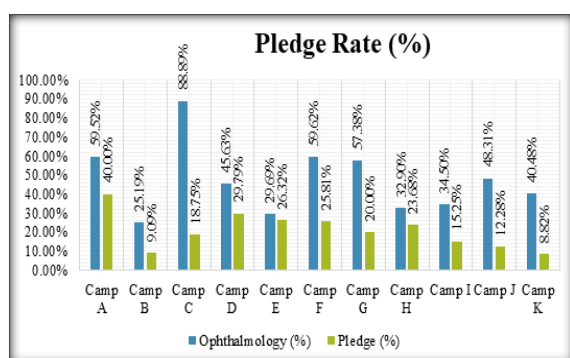
Place	Total Participants	Ophthalmology Attendants	Pledge	Distance from the tertiary centre (km)
Camp A	126	75	30	6.2
Camp B	131	33	3	37
Camp C	144	128	24	11.3
Camp D	103	47	14	3.9
Camp E	128	38	10	2
Camp F	52	31	8	23
Camp G	61	35	7	141.2
Camp H	231	76	18	60.8
Camp I	171	59	9	82.6
Camp J	118	57	7	30.1
Camp K	168	68	6	56.0
<b>Total</b>	<b>1433</b>	<b>647</b>	<b>136</b>	

**Table 2: Socio-demographic characteristics Gender-wise distribution**

Characteristics		Gender			
		Male		Female	
		Male (%)	Male (N)	Female (%)	Female (N)
Age (years)	18-30	6.67%	9	6.67%	9
	31-43	14.81%	20	13.33%	18
	44-56	17.04%	23	14.07%	19
	57-69	14.07%	19	6.67%	9
	>70	3.70%	5	2.96%	4
Literacy Status	Literate	52.59%	72	37.04%	50
	Illiterate	3.70%	5	6.67%	9
Educational Status	No Formal Education	1.48%	2	4.44%	6
	Primary School	9.63%	13	5.93%	8
	High School	22.96%	31	15.56%	21
	College / University	8.89%	12	8.89%	12
	Graduate / Postgraduate	13.33%	18	8.89%	12

<b>Marital Status</b>	Single	8.15%	11	6.67%	9
	Married	48.15%	65	34.07%	46
	Divorced	0.00%	0	0.00%	0
	Widow / Widower	0.00%	0	2.96%	4
<b>Religion</b>	Hinduism	51.11%	70	41.48%	56
	Christianity	2.22%	3	0.74%	1
	Islam	0.74%	1	1.48%	2
	Others	2.22%	3	0.00%	0
<b>Occupation</b>	Skilled Worker	11.11%	15	20.74%	28
	Unskilled Worker	9.63%	13	5.19%	7
	Retired	17.04%	23	9.63%	13
	Clerical / Shop Owner / Farmer	4.44%	6	0.00%	0
	Semi Profession	5.19%	7	2.96%	4
	Profession	8.89%	12	5.19%	7
<b>Family Monthly Income</b>	<= 985	0.00%	0	0.00%	0
	986-1971	0.74%	1	0.74%	1
	1972-3286	1.48%	2	4.44%	6
	3287-6573	14.81%	20	14.07%	19
	>6573	39.26%	53	24.44%	33
<b>Family Type</b>	Joint	14.81%	20	14.07%	19
	Nuclear	41.48%	56	29.63%	40

From the eleven outreach screening camps, ranging from 2 km to 141.2 km from our tertiary care centre, attended by a total of 1433 participants, ophthalmology screening was done for 647 people and 136 participants pledged their eyes. (Table 1, Figure 1). Of the 21.02% of the participants who pledged their eyes, the socio-demographic characteristics were tabulated. 31.0% were in the age group 44-56, 56.0% were males, with 90.0% being literate, 71.0% belonged to nuclear family type, 93.0% following Hinduism, 82.0% married and 64.0% with a family monthly income of > 6573 INR (Table 2).



**Figure 1: Pledge rates (%) in eleven outreach screening camps**

## DISCUSSION

Voluntary eye donation is the source of cornea for transplantation surgeries. It is possible to meet the demand only when there is heightened awareness and willingness among suitable donors not only in urban but also in remote and rural places. Data from this study done at outreach screening camps showed that 45.15% of the participants attended ophthalmology screening of which only 21.02% were willing to pledge their eyes despite initially educating them regarding eye donation. Various studies show better awareness than

willingness as observed by Yew et al. in Singapore where awareness was 80.7% and willingness 67%,<sup>[8]</sup> and in the study by Bhandary S et al awareness was 69% and willingness 34.42%.<sup>[3]</sup> Observations of Krishnaiah S et al study showed 30.7% of the Indian population was aware of eye donation but only 0.1% of them had pledged their eyes.<sup>[1]</sup> The study by Patil R et al concluded that although the awareness was good in the population, the quantum of people who pledged eyes was very low.<sup>[5]</sup> Only 1% of the total number who pledge their eyes donate them.<sup>[9]</sup> In addition, there is no direct relationship between pledging for eye donation and the actual collection of donated eyes. Time elapsed between the pledging of eyes and procurement of cornea following death may also play a role in the definite underutilization of the potential to obtain corneas. To a great extent, revealing the donor status among family members and close relatives can be a factor in improving the corneal procurement rates.

A study by Asha Bellad et al found adult members of joint families had better knowledge regarding eye donation compared to those in nuclear families. However, this study showed a pledge rate of 71.11% in nuclear families and 28.88% in joint families.<sup>[10]</sup> A study by Tandon also concluded that major reasons for not donating eyes included refusal to discuss the issue and dissuasion by distant relatives, legal problems, and religious beliefs.<sup>[11]</sup> The present study had similar responses from the participants for their unwillingness in addition to permission from family members and fear of disfigurement.

A study by Krishnaiah S et al said females were less willing to pledge eyes (28.7%) as compared to males (36.6%).<sup>[1]</sup> In the present study, 44% of females were willing to donate eyes. Bhandary S et al said unwillingness among females may be because of their family ties and the necessity to seek permission from the family members before pledging their eyes.<sup>[3]</sup> Hayward et al. have shown that women were more concerned about the

transmission of diseases or personality following organ donation.<sup>[9]</sup>

Krishnaiah S et al said people in the older age group (60-69 years) were more willing to donate eyes compared to the younger age group.<sup>[1]</sup> However, in this study data showed age group of 44-56 years had the highest pledge rate (31%) followed closely by the age group of 31-43years (28%). This could be attributed to the initial sensitization in the camp by way of educational talk that was well taken by individuals in the younger age group as well.

The study by Tandon showed that prior knowledge of eye donation, literacy, and socioeconomic status did not influence willingness for eye donation.<sup>[11]</sup>

The present study however showed 90% of the people who pledged eyes were literate of whom a maximum (38%) had a high school education. The higher socioeconomic status (family income >6573 per month) group had the maximum number of people (68%) pledging their eyes.

According to Patil R et al employed persons were significantly more (59.8%) aware of the correct timing to donate eyes. Regarding other facts about eye donation, no significant difference was found among different occupational groups.<sup>[5]</sup> However, the present study found a maximum pledge rate (32%) among skilled workers followed by retired individuals (25%).

In a secular country such as India, it is important to take into consideration the division and segregation of the society based on religion and caste.<sup>[1]</sup> In the present study, it was found that Hindus (94%) were more willing to pledge their eyes than other religious communities which is similar to the Singh A. et al study.<sup>[12]</sup> Studies show that there was poor awareness about the “Fatwa” regarding organ donation, passed by the Muslim Law Council in 1995. This lack of awareness has led to the fear of doing something against religion by donating organs to the population.<sup>[13]</sup> The reasons for the unwillingness could have been culture-specific issues arguing against donation including a sense of the sacredness of the body, belief that it is important to have an intact body after passing away and fear of illegal trade in organs and the poor would suffer.<sup>[3]</sup>

A study by Gogate and associates reported better influence from religious and community leaders in terms of motivating people to eye donation and increasing their knowledge.<sup>[14]</sup> The social system, customs, religious preaching, and personal values affect the acceptance of eye donation in communities and are difficult to modify.<sup>[13]</sup>

Grief counselling of relatives by hospital medical staff following the death in the hospitals has been successful in procuring organs.<sup>[15]</sup> Even if the deceased is a pledged donor, the consent of family members is important 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.<sup>[1]</sup>

Educating students in all fields about eye donation is the need of the hour, particularly those in the

medical profession, to enable the younger generation to act as future motivators for enhancing eye donation rates.<sup>[16]</sup>

Strategies that have worked well in other parts of the world may be useful here too. For example, in the USA the Presumed Consent Law was introduced in 1975. This concept has legal sanction, where, if the dead person has not registered any objection to donating while alive, consent is presumed and eyes can be removed as required. This legislation has led to a manifold increase in the availability of corneal tissue. In India, we do not yet have such legislation.<sup>[17]</sup>

Another area of legislation is the “required request law” wherein it becomes mandatory for all healthcare staff institutions coming into contact with bereaved families to request eye donation. This requires legal sanction.<sup>[1]</sup>

In the long term, the optimum public health approach would be to reduce the occurrence of corneal blindness with effective preventive strategies, but in the short term, the main way to deal with corneal blindness is to procure more corneas for transplantation. Ophthalmologists, general physicians, non-governmental organizations (NGOs), medical students and especially religious leaders should be motivated to work in unison to educate and motivate people to donate eyes. Grass root-level work is important to remove the various myths related to eye donation and to sensitize the community toward corneal blindness and its associated spectra of morbidity. It is very important for the involvement of governmental and non-governmental organizations in training the hospital medical staff, nurses and counsellors in approaching and positively motivating the community for eye donation before and at the time of death.

## CONCLUSION

To increase procurement of corneas, improving public awareness at outreach screening camps regarding eye donation is an important step. Socio-demographic characteristics like literacy level, adults in the 44-56 years age group, employment, better family income, nuclear family and liberal religious beliefs positively influence pledge rates for eye donation. Accordingly, strategies should be planned to improve pledge rates, in turn increasing the rate of eye donations to meet the requirement for corneal transplants.

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