Original Article

Cross Sectional Study on Awareness About Eye Banking in Moradabad (India)

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Abstract

Purpose: *There has been a shortage of transplantable corneal tissue in developing countries. Assessing awareness about eye banking would help us in making effective strategies to overcome this.*

Methods: *A cross-sectional descriptive study was conducted using a standard pretested closed-ended structured questionnaire. Survey interview was conducted by an independent trained interviewer. Questionnaire had eighteen questions to assess awareness (6 questions), knowledge (6 questions) and process (6 questions) of eye donation.*

Results: *A total of 396 individuals of more than 18 years participated in this survey. A total of 269 (67.9%) participants were aware that eyes can be donated and 156 (39.4%) participants agreed to donate their eyes after their death. Of all, 251 (63.4%) were aware that family consent is needed for eye donation and 172 (43.4%) participants thought that one needs to come to an eye hospital for eye donation. Only 82 (20.7%) participants know an eye bank facility in their nearby area. Of all, 86 (21.7%) participants believed that eyes can be donated by a living person and 24 (6.1%) believed that they need to pay for eye donation.*

Conclusion: *Majority of participants know that eyes can be donated. However a low percentage of them agreed to donate their eyes after death. Awareness was low in terms of knowledge and process of eye banking. To increase awareness, innovative community based strategies to be implemented in the study area which ultimately increase cornea retrieval.*

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Keywords: *Eye Bank, Awareness, Cornea Retrieval, Eye Donation, Knowledge*

Introduction

Corneal diseases are among the major causes of vision loss and avoidable blindness globally. This has been of public health concern (both in social and economic terms) in most developing countries. According to rapid survey on avoidable blindness conducted under National Programme for Control of Blindness and Visual Impairment (NPCB&VI) during 2015-18, prevalence of blindness was 0.45%.[1] Corneal blindness had been the third main cause of blindness, accounted for 0.9% after cataract (62.6%) and refractive error (19.7%). Various community-based studies conducted in India have reported the prevalence of corneal blindness.[2-7] In developing countries effective strategies have been implemented for cataract backlog and refractive error corrections.[8] However comparatively less focus has been given to programs dealing with other causes of visual impairment such as corneal blindness.

Unlike cataract, corneal blindness also affects people of younger age, which results in a very high disability adjusted life years (DALYs) compared to cataract. A study from south India had reported that the average age of patients with blindness caused by corneal opacities was significantly lower than blindness caused by cataract.[9] Corneal transplantation has been the most important sight restoring procedure for corneal blindness. This procedure has high returns since this disease has been associated with very high DALYs. Underdeveloped eye banking infrastructure has been one of the potential barrier to corneal transplantation. India needs approximately needed 277,100 donor tissues and there has been a shortage of transplantable corneal tissue.[10] Although there are some areas in India with excellent Hospital Cornea Retrieval Programs and are able to meet the demand for corneal tissue, but in smaller towns most eye donations are still voluntary mostly depending on community participation. Public awareness about eye banking has a potential to increase eye donation which can ultimately reduce the backlog of transplantable corneal tissue. Awareness of eye banking in different population has been reported by many previous studies.[11-15]

During regular record review, it has been noticed that there has been a lot of difference between the number of patients with corneal opacities who need corneal transplant and the rate of donor tissue collection at a tertiary eye care institute in western Uttar Pradesh. In the past, the polio eradication program also faced challenges from this area due to low education, awareness and personal beliefs of the general population.[15-18] Looking at this, this community based study was conducted to assess the awareness level about eye banking among the general population residing at western Uttar Pradesh (India). These results will help us to make community based strategies which would ultimately reduce the transplantable corneal tissue backlog in the study area.

Methodology

The study was approved by CL Gupta Eye Institute Ethics Committee (ECR/1310/Inst/UP/2019) and conducted in compliance with the tenets of declaration of Helsinki. A cross sectional survey was conducted among adult participants aged more than 18 years. Study area district was divided into eight blocks. Out of these eight blocks, four blocks were randomly selected for survey. Community field workers were trained to conduct study surveys. Participants were randomly selected from the catchment area of the institute vision centers located in these blocks. Quality control system was implemented during data collection to ensure uniformity and accuracy of the data. Identified participants were invited to participate in this survey. The objective of the study was discussed with study participants and they

were requested to sign the inform consent. Participants who gave their consent were enrolled in the survey. The participants were asked to answer each question face-to-face with one trained interviewer (field worker). Each interview took approximately 20-25 minutes and was conducted at places which were comfortable to all participants. After the interview, general information about eye banking was provided by the interviewer. Pretested content validated questionnaire was developed with the help of experienced faculty and literature search. Questionnaire consists of demographic information, and questions to assess awareness about eye banking. Questionnaire had eighteen questions to assess awareness (6 questions), knowledge (6 questions) and process (6 questions) of eye donation. Questionnaire was pretested on staff working at the institute to assess its internal consistency. However the data generated during pretesting was not included in the final analysis.

Statistical Analysis

All analysis were performed using Statistical software IBM SPSS Statistics version 20. Descriptive statistics were obtained to determine the frequency and proportions. Mean and standard deviation was calculated for continuous variables. Summaries of descriptive statistics and group comparisons are provided, which were made using the unpaired t-test for continuous data and the chi square test for proportions.

Sample size calculation: Based on awareness percentage, p=50% i.e. 0.5, q=1-p, α=0.05, allowable error, d=5% and applying formula $Z\alpha 2pq/d2$, sample size for this survey was 384. Assuming data losses due to incomplete questionnaires, the sample size was adjusted to 400.

Results

A total of 396 individuals of more than 18 years participated in this survey. The mean age of participants was 36.1±13.6 (Range: 18-82) years. Of all participants 235 (59.3%) were male and 161 (40.7%) were female (p=0.00; one sample binomial test). Education level and occupation of study participants are presented in (Table 1). A total of 269 (67.9%; 95% CI: 63.1-72.5%) participants were aware that eyes can be donated and 156 (39.4%; 95% CI: 34.6-44.4%) participants agreed to donate their eyes after their death. Among literates, 199 (76.9%) participants were aware of eye donation as compared with 70 (51.1%) among illiterates (p=0.00, Fisher's exact test) (Figure 1). Among males, 176 (74.8%) participants were aware of eye donation as compared with 93 (57.7%) among females (p=0.002, Fisher's exact test) (Figure 2).

Table 1: Frequency Distribution of Occupation and Education of Study Participants

Occupation	Frequency	Percent
Business	139	35.1
Service	108	27.3
Not working	149	37.6
Education		
Literate	259	65.4
Illiterate	137	34.5
Total	396	100.0

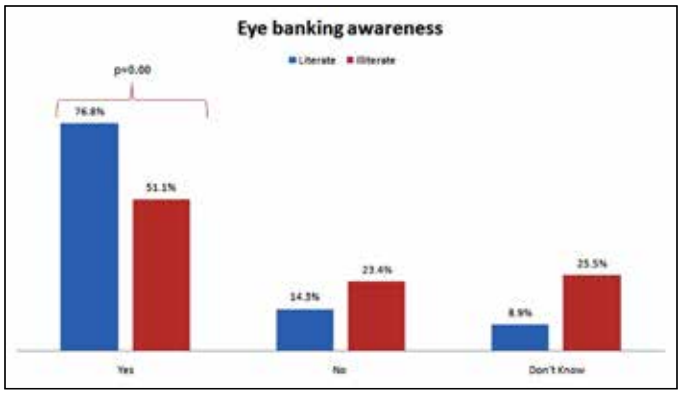

Figure 1: *Eye banking awareness distribution among literate and illiterates*

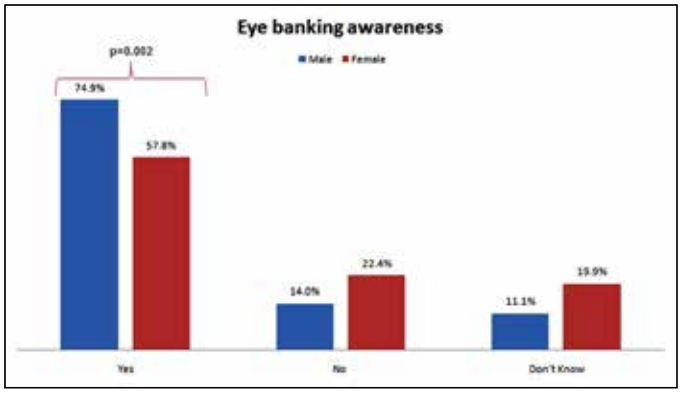

Figure 2: *Eye banking awareness distribution among male and female*

Of all, 251 (63.4%; 95% CI: 58.4-68.1%)) were aware that family consent is needed for eye donation and only 81 (20.5%; 95% CI: 16.6-24.8%) participants agreed to donate eyes of their close ones after their death. A total of 172 (43.4%; 95% CI: 38.5-48.5%) participants thought that one needed to come to an eye hospital for eye donation. Only 34 (8.6%; 95% CI: 6-11.8%) participants knew anyone who had donated his/her eyes and 30 (7.6%; 95% CI: 5.2-10.6%) participants knew someone who had undergone corneal transplantation (received donated corneal tissue). A total of 82 (20.7%; 95% CI: 16.8-25%) participants know an eye bank facility in their nearby area. Of all, 86 (21.7%; 95% CI: 17.8-26.1%) participants believed that eyes can be donated by a living person and 214 (54%; 95% CI: 49-59%) know that donated eyes can be transplanted by an ophthalmologist.

Of all participants, 42 (10.6%; 95% CI: 7.8-14.1%) believed that whole globe, 121 (30.6%; 95% CI: 26.1-35.4%) believed cornea and 5 (1.3%; 95% CI: 0.4-2.9%) sclera has been recovered during eye donation. Regarding time duration for tissue recovery, 111 (28%; 95% CI: 23.7-32.7%) participants responded that the duration was within 6 hours, 25 (6.3%; 95% CI: 4.1-9.2%) up to 10 hours, and 260 (65.6%; 95% CI: 60.7-70.3%) participants were not aware of any timeline. A total of 35 (8.8%) participants responded that donated eyes can be preserved till 3 days, 26 (6.6%; 95% CI: 6.2-12.1%) participants till 7 days, 15 (3.8%; 95% CI: 2.1-6.2%) participants till 14 days. When asked who performed the recovery, 320 (80.8%; 95% CI: 76.6-84.6%) participants said it was the doctor, 17 (4.3%; 95% CI: 2.5-6.8%) said optometrist and 40 (10.1%; 95% CI: 7.3-13.5%) said eye bank technician. Of all, 72 (18.2%; 95% CI: 14.5-22.3%) believed that the older

age group may require more than one cornea transplantation surgery. A total of 170 (42.9%; 95% CI: 38-48%) participants had not known the process to become an eye donor. Of all, 24 (6.1%; 95% CI: 3.9-8.9%) participants had the incorrect information that one needs to pay for eye donation and 151 (38.1%; 95% CI: 33.3-43.1%) participants responded that they were not aware of this. Only 39 (9.8%; 95% CI: 7.1-13.2%) participants know the correct eye bank information service toll free number. Frequency distribution of responses are presented in Table 2.

Regarding awareness about eye donation, a majority of the population surveyed were aware of eye donation. This was related to the education level of study participants. A significantly more number of participants were literate and among them significantly higher numbers were aware of eye donation as compared to illiterate participants. Also the male participants were significantly more aware compared to female participants. This relates to the education level since among the study population; significantly more number of male participants (73.6% male versus 53.4% female) were

Table 2: Frequency distribution of Occupation and Education of study participants

S.No	Questions	Yes	No	Don't Know		
Q1	Can Eye Be Donated	269(67.9%)	69 (17.4%)	58 (14.6%)		
Q2	Are you opt for eye donation after your death	156 (39.4%)	161 (40.6%)	79 (19.9%)		
Q3	Do you donate eye of your closed one after their death	81 (20.4%)	156 (39.4%)	159 (40.2%)		
Q4	Do you know anyone who has donated eyes	34 (8.5%)	362 (91.5%)	NA		
Q5	Do you know anyone who has received donated eye	30 (7.5%)	366 (92.5%)	NA		
Q6	Eyes can be donated by a living person	86 (21.7%)	224 (56.5%)	86 (21.7%)		
Q7	Donated eyes can be transplanted	214 (54.1%)	83 (20.9%)	99 (25%)		
Q8	Which part of eye will be donated	Whole Globe	Cornea	Sclera	Don't Know	
		42 (10.6%)	121 (30.5%)	5 (1.2%)	228 (57.5%)	
Q9	Time duration for eye donation	Within 6 Hrs.	Up to 10 Hrs.	Don't Know		
		42 (10.6%)	121 (30.5%)	233 (58.8%)		
Q10	How many days donated eyes can be preserved	3 Days	7 Days	14 Days	Don't Know	
		35 (8.8%)	26 (6.5%)	15 (3.7%)	320 (80.8%)	
Q11	Who takes the eyes	Ophthalmologist	Physician	Optometrist	Eye Bank Technician	Don't Know
		136 (34.3%)	27 (6.8%)	17 (4.2%)	40 (10.1%)	176 (44.2%)
Q12	Which age group can need re-transplantation	Old Age Group	Young Age Group	Don't Know		
		72 (18.2%)	130 (32.8%)	194 (48.9%)		
Q13	Is family consent is required for eye donation	251 (63.4%)	90 (22.7%)	55 (13.8%)		
Q14	Do you need to come to an eye hospital for donating eyes of deceased	172 (43.4%)	132 (33.3%)	92 (23.2%)		
Q15	Do you know your nearby eye bank	82 (20.7%)	314 (79.3%)	NA		
Q16	Do you know the process of becoming an eye donor	139 (35.1%)	257 (64.9%)	NA		
Q17	Do you have to pay for eye donation	24 (6.1%)	221 (55.8%)	151 (38.1%)		
Q18	Do you know Eye banking toll free number	39 (9.8%)	357 (90.1%)	NA		

Discussion

Significantly more male participants were included in this study. Probably because when field workers visited the family, the male of that family being the decision maker in most cases in rural India, preferred to answer the questionnaire. Preponderance of male participants has also been reported in a recent survey on awareness about eye banking by Acharya et al and Lal et al.[19,20]

literate. This also points out the need to educate the large illiterate population by alternative means of publicity than printed materials .This corroborates with the results of survey conducted by Acharya et al, where 88.45% of study population heard about eye donation.[19] They also reported no correlation between eye donation and its prior knowledge.[19] Although they have not relate this finding to the education level of their study participants. Higher education level in the developed countries had been found related to consent

of families for eye donation of their deceased relatives.[12] The awareness level of our study is higher to the previously reported studies.[11,21-23] This can be explained by the large scale publicity by a highly active volunteer group supporting the eye bank in the study area.

Although a high awareness level has been reported in the study still only 40% of the study population agreed for eye donation after their death and further only 20% of them agreed to donate eyes of their close relatives. This was due to their personal or religious beliefs about eye donation. This reflects that only awareness of an individual is not enough for eye donation, their personal beliefs prevail over their awareness level while making a decision on eye donation. Innovative community based strategies must be adopted to overcome this barrier to eye donation in the study area. Involving and educating religious leaders about eye donations and impact of their religious beliefs on this can be one of them.

Regarding knowledge about eye donation; 70% of the study population did not know which part of eye is retrieved during eye donation. Many study participants believed that the whole globe is removed during retrieval and this may cause deformity to the deceased body. This has been the most important barrier to eye donation. Acharya et al also reported that the concern that deceased body should remain intact and the fear that body would not be treated properly during eye donation accounted for refusals in approximately 30% of their study population.[19] More clarity in information regarding corneal retrieval should be provided though different programs so that general population becomes aware that in most modern eye banks now only corneoscleral rim retrieval is done during eye donation and this will not cause deformity to the deceased body. Only few (28%) knew the correct timelines within which eye donation can be performed which was again a cause of concern because the window of opportunity for decision making is less in warm climatic conditions and precious tissue may be lost if the eye bank is informed late.
Regarding the process of eye donation; significantly more participants were aware that family consent is a regulatory requirement before eye donation. But approximately half of the study population believed that cornea retrieval (eye donation) has to be performed at an eye hospital and few of them believed that a living individual can also donate their eyes. Half of the study population had been not aware of the process of becoming an eye donor. Significantly lower numbers of participants know their nearby eye banking facilities. Some of them believed that they needed to pay for eye donation. Only few participants know the eye banking toll free number of eye bank help lines. These factors also become a barrier to voluntary eye donation. Even if an individual opts for eye donation of his deceased relative these factors become barriers to eye donation. Extensive awareness campaigns (print/electronic/media) about eye donation and its process are needed in the study area to address these barriers. Although, according to a previous study conducted by Acharya et al, the most common source of information about eye banking was through healthcare facilities and relatives followed by mass media, brochures and social gathering.[19] Lal et al reported significantly higher percentage of medical and nursing students had received information through media campaigns as compared to information received from hospital itself.[20] Door to door education by field workers or through ASHA workers can be another strategy to deal with these barriers.

In conclusion, simple publicity by print media is not effective in creating correct awareness about eye donation in rural and semi urban India unless more innovative strategies involving religious leaders and community health workers are developed to reach out to the illiterate population.

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