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Knowledge, attitude, practice pattern and willingness for eye donation among tribal population of Northern Odisha

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Abstract---To evaluate knowledge, attitude, practice pattern and willingness of the tribal population for eye donation among patients and their relatives attending outpatient department of Ophthalmology in a tertiary health care hospital in Northern Odisha. A pretested semi-structured questionnaire on eye donation was given

to 984 persons, patients as well as their attendants were asked to select the correct answer among the multiple choices given against each question. Data was analyzed using SPSS 26 software. Out of 984 participants, 554(56.3%) were males and 430(43.6%) were females. 876(89%) participants belonged to tribal area. Among the participants only 220(22.3%) had knowledge about the nearest eye bank and eye donation center .640(65%) had prior knowledge about eye donation. Willingness for eye donation is 48% among tribals. The main reason for unwillingness among tribal population was insufficient information regarding eye donation. Multipronged strategies need to be adopted to provide sufficient information to the tribal population regarding eye donation to increase their willingness for eye donation.

Keywords---willingness, eye donation, knowledge, attitude, cornea blindness.

Introduction

36 million in the world are blind with visual acuity less than 3/60 in better eye, out of which 8 million belongs to India.[1] After cataract and glaucoma, corneal diseases are among the major causes of vision loss and blindness in the world today. In India, it is estimated that there are approximately 6.8 million people who have vision less than 6/60 in at least one eye due to corneal diseases; of these, about a million have bilateral involvement. Every year another 25,000 - 30000 join the list.[2]. The Andhra Pradesh eye disease study (APEDS) reported the prevalence of corneal blindness at 0.13%, constituting 9% of all blindness. The study observed that 95% of corneal blindness in the rural population of Andhra Pradesh, was avoidable and the avoidable causes of corneal blindness reported in the journal were keratitis in childhood, trauma, aphakic bullous keratopathy, severe astigmatism, post cataract surgery, keratitis in adulthood and traditional eye medicines.[3] Corneal blindness caused due to measles infection, Vitamin A deficiency, ophthalmia neonatorum, trachoma, ocular trauma, the use of harmful traditional eye medication remedies and congenital rubella syndrome can be completely prevented by adopting effective preventive or prophylactic measures at the community level.

Corneal transplantation being the major treatment option for restoring sight in corneal blind people, and cornea being donated only after death, this is completely dependent on people's willingness to pledge for eye donation and the willingness of their legal heirs and relatives to honor the pledge after the death of the person.[4] Because of a smaller number of cornea collection, the number of corneal transplants done in India are very less than the actual requirement. According to statistical data of NPCB, the current cornea procurement in India was 55953 cornea tissues between 1st April 2019 to 31st March 2020, only 46% were utilized for sight restoration as the rest were found not suitable for transplantation due to poor quality of collected cornea,[5]. Based on our current

ratio of suitable corneas, we would need 2,77,000 donations per year to perform 1,00,000 corneal transplantations in a year in our country.[6].

After the first successful corneal transplantation by Edward Zirm, of Czechoslovakia, cornea transplantation is now the most successful organ transplantation till date. Late Dr. Muthiah started the very first eye bank in Chennai in 1945. He performed the first corneal transplant successfully in 1948.[7] Though corneal transplantation is being performed for more than 60 years in India, still a large no of patients are waiting for corneal transplantation. Due to awareness among population for cornea donation, now there is 20-fold increase in the donor corneal tissues but still shortage of transplantable good quality corneal tissues has been the matter of concern. Reasons for not getting good transplantable corneal tissues are due to time gap between death and information to the eye bank and delay in completing legal procedures before corneal collection in case of post mortem cases. To enhance the procurement of good quality corneal tissues, awareness regarding eye donation is necessary especially among the relatives of gravely ill or injured patients in ICU, casualty, and trauma center by grief counselors. [8,9,10]. Around 10 million people die in India every year, but to our utter dismay the corneal donation does not exceed more than a few thousand.[11] The reasons for the very low number of eye donation in our country are absence of motivation among people especially tribal and rural population due to low literacy rate, social and religious myths, and many among them not aware of the requirement and benefits of cornea donation. In present scenario it is essential to enhance the awareness regarding eye donation among tribal population with support of the government and non-government organizations (NGOs). In our study we assessed the knowledge, attitude and willingness for eye donation among the patients and their relatives attending the outpatient department of ophthalmology of PRM Medical college, Baripada situated in the Northern part of Odisha having majority tribal population. Very few studies were found till date regarding the willingness of eye donation among tribal population after cornea retrieval.

Materials and Method

We carried out this cross-sectional descriptive survey between 1st September 2019 to 31st December 2019 among 984 patients and their relatives attending the outpatient department (OPD) of Ophthalmology. Our study population consists of people of more than 18 years of age and those who were willing to participate in the study. People with cognitive impairment and relatives of patients who were in need of corneas for transplantation were excluded from the study. 1040 eligible participants were approached to participate in the study, of which 56 declined due to lack of time and interest. A structured questionnaire was used to elicit response. Interviewers trained for this study explained the questions to the participants in local language and noted their responses. Data collection instrument i.e., the questionnaire was divided into four parts. The first part consists of items about socio demographic details of the participants such as age, gender, religion, education, economic status, and place of residence. The second part of the questionnaire was intended to measure the knowledge level of

participants about eye donation and their source of information where from they came to know regarding eye donation. The third part consists of questions regarding their attitude towards eye donation, their willingness and unwillingness to donate.[12] The participants willing to donate eyes were given pledge forms to take signatures of their legal heirs and to submit them in eye bank after duly filling it up. The ethical core committee of the medical college approved the study protocol. Written consent was obtained from all the participants participated in the study and confidentiality was respected. Descriptive (frequency, percentage, mean and standard deviation) and inferential (chi-square test) statistics were used to interpret the data. SPSS version 26 was used for statistical analysis. P values of <0.001 were considered as significant.

Results

Table 1
Demographic profile of study participants (n=984)

Characteristics	Total no	Percentage (%)
Age		
<40	429	43.5
≥40	555	56.4
Gender		
Male	554	56.3
Female	430	43.6
Education		
Higher secondary pass	384	39
Literate(Below tenth class)	503	51.1
Illiterate	97	9.8
Location		
Urban	96	9.7
Tribal	876	89
Rural	12	1.2
Religion		
Hindu	973	98.8
Muslim	11	1.1

A total of 984 subjects participated in this study. The mean age was 41.73 ± 14.05 years with a range of 18 to 81 years. Out of 984 participants, 554(56.3%) were males and 430(43.6%) were females. 876 (89%) participants belonged to tribal area, 96 (9.7%) belonged to urban and 12(1.2%) were from rural area. Majority of population belonged to Hindu community 973(98.8%) and 11(1.1%) were Muslim. 887(90.2%) participants were literate, among them 384 (39%) had passed higher secondary education while 97(9.8%) were illiterate. (Table 1)

Table 2
Responses to the questionnaire on eye donation

Response of the participants	Total number of respondents who gave positive response	Percentage (%) of respondents who gave positive response
Persons who knew about eye donation after death	640	65.0
Ideal time to remove eyes (Within 6hours of death)	546	55.4
Persons bearing spectacles, post cataract surgery, hypertensive, diabetic can donate eyes	325	33.0
Anterior most transparent part of the eye is called Cornea	479	48.6
Only cornea is collected	533	54.1
Eye donation is to restore vision in corneal blindness only	470	47.7
Cornea retrieval takes ~30 minutes	380	38.6
No disfigurement of face because artificial prosthesis given	601	61.0
Persons with septicaemia, hepatitis B, HIV positive, Rabies cannot donate eyes	473	48.0
No monetary benefit to donor family	636	64.6
For eye donation one has to contact eye bank & knowledge regarding nearest eye bank or eye collection centre.	220	22.3

In our study we found that out of 984 participants, 640(65%) had knowledge about eye donation after death. 546(55.4%) knew that ideal time to remove eyes was within 6 hours of death. 325(33.0%) had knowledge regarding who all can donate their eyes. 479(48.6%) knew that only cornea was the part the eye which is being collected for eye donation. 470(47.7%) knew the purpose of eye donation and that it is done to restore vision in corneal blind people only. 601(61%) had knowledge that there will be no disfigurement of face of the donor after eye donation and 383(39%) participants had the misconception of disfigurement of face after eye donation. Only 220(22.3%) had knowledge about the nearest eye bank or eye donation center and how to contact them. (Table 2).

Table 3
Different sources of information regarding eye donation

Source of awareness	Total (n=640)	Percentage (%)
Newspaper	164	25.6
Tv/internet/radio	211	32.9
Wall paints/posters/pamphlets	132	20.6
Friends/relatives/neighbours	133	20.7

Among all, 640(65%) participants had prior knowledge about eye donation. Regarding their sources of information, Tv/internet/radio (n=211,32.9%) was the commonest source followed by newspaper, friends, relatives, and neighbors and from posters and pamphlets. (Table 3)

Table 4
Factors associated with willingness to donate eyes

Characteristics	Total (n=984)	Willing donation (n=510)	Percentage (%)	p-value
Age				
<40	429	290	67.5	<0.0001
≥40	555	220	39.6	
Gender				
Male	554	310	55.9	0.003
Female	430	200	46.5	
Education				
higher secondary	384	295	76.8	<0.0001
Below 10th	503	190	37.7	
Illiterate	97	25	25.7	
Locality				
Urban	96	85	88.5	<0.0001
Tribal	876	421	48.0	
Rural	12	4	33.3	

We studied the association of age, gender, educational status and locality of participants with willingness for eye donation. Out of 510(51.8%) participants who were willing to donate their eyes, 290(67.5%) were below 40 years age, 310(55.9%) were males, 295(76.8%) passed higher education. We found strong association of willingness to donate eyes among people below 40 years age in comparison to people above 40 years($p<0.0001$), among people with higher education level in comparison to people with low education status or illiterate($p<0.0001$), willingness is more in urban population 88.5% were willing to donate their eyes after death in comparison to tribal people only 48% were willing to donate their eyes after death($p<0.0001$). No strong association was found in willingness to eye donation among males and females (Table 4)

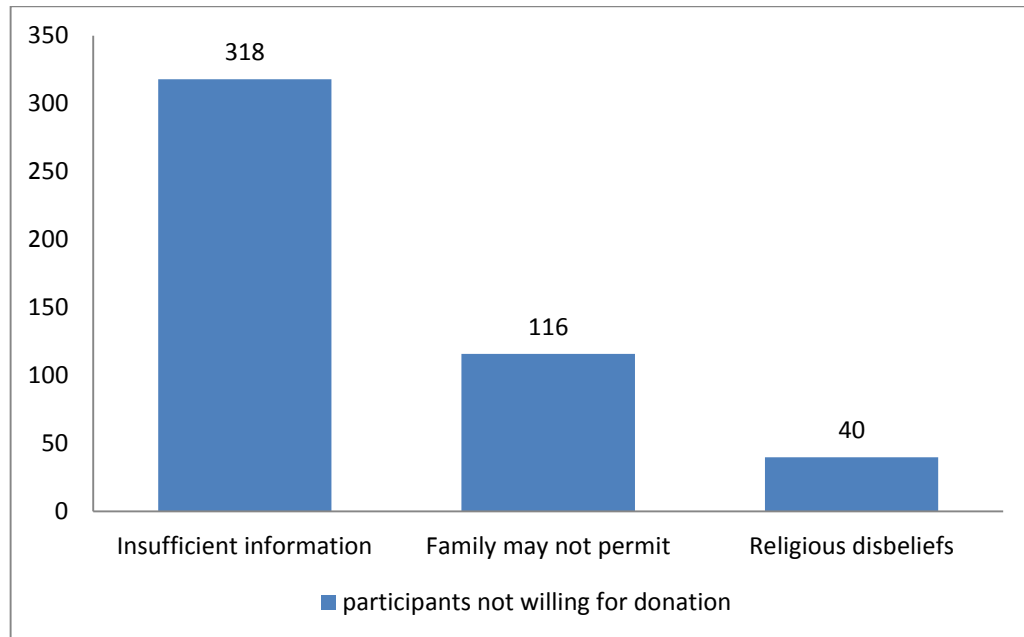


Figure 1. Reasons for unwillingness of participants for eye donation

474(48.1%) participants had no willingness for eye donation, most common reason for their unwillingness was insufficient knowledge regarding eye donation 318 (67%), the other reason was dissuasion by family members 116 (24.4%) and next reason being religious disbeliefs 40(8.4%). (Figure 1).

Discussion

We studied various factors on which the willingness for eye donation depends upon, in a predominantly tribal populated part of the country. In our study 65%(n=640) participants were aware about eye donation after death which is lower in comparison to studies by Ronaki et al (80.3%), Bhandary et al (88%) Marthe et al (80.3%) [12,13,14], but similar to studies by George et al (49%) and Shrivastava et al (53.4%) [15,16]. In our study, 55.4 %(n=546) knew the ideal time limit of eye donation, which is 6 hours after death, similar to several other studies, [6,14,17] whereas, few other studies by Bhandarey et al (88%), and George et al (79.5%) [13,15] reported higher percentage of awareness regarding the time limit. Public should be aware of the time limit for eye donation after death, so as to make them prompt in their process of eye donation which could ensure retrieval of good quality corneal tissues.

54.1%(n=533) of our participants knew that eye donation was removal of cornea (the anterior transparent portion of the eye), which is similar to the observation made by Ronaki et al(54.9%) [12] 61 % (n=601) were of the notion that eye donation did not cause disfigurement because artificial prosthesis being put after retrieval of cornea, similar observations made by Ronaki et al and Bhandaray et al. [2,13]. Other studies by Patil et al (39%) [6] and Lawlor et

al[18]reported lower awareness among people about disfigurement of face after cornea retrieval.

33%(n=325) knew that persons wearing spectacles, diabetics, hypertensive, and post cataract surgery can donate their eyes, which is similar to the study by Ronaki et al (45.4%).[12]. In our study 22.3% (n=220) respondents had knowledge about the nearest eye bank and whom they have to contact for eye donation, which is quite low in comparison to the study conducted by Ronaki et al (57.5%)[12]. Our study revealed 67.5% (n=290) respondents aged below 40 years were willing to donate their eyes, similar to the studies by Patil et al (77.6%), Gupta et al (80%) and Singh et al(87.2%).[6,19,20] while Tandon et al[21]and Yew et al[22] reported lower willingness in their studies. Higher willingness in the younger age group in our study was probably due to presence of more educated people in this age group and because of impact of mass media and internet use upon them. 55.9 %(n=310) male participants were willing to donate their eyes, whereas only 46.5%(n=200) females were willing for the same, similar observations made by Priyadarshini et al, Patil et al, Ronaki et al, Marathe et al and Shinde et al.[4,6,12,13,23], whereas no such association with gender was found by Srivastava et al. [16].

Lower willingness among females may be due to low level of literacy among females due to lackluster attitude of the tribal population for girl child education and less exposure of tribal women to mass media and internet .76.8% of participants with higher education i.e. above higher secondary, were willing to donate their eyes in comparison to participants with lower education status. These results were similar to studies by Ronaki et al and Marathe et al.[12,14] No such association of education status with willingness was seen by Patil et al and Bhandare et al.[6,13] In our study 88.5%(n=85) participants belonging to urban area were willing to donate their eyes, whereas only 33% (n=4) participants from rural area were willing to donate their eyes ,which is similar to the observation in studies done by Priyadarshini et al, Ronaki et al.[4,12]In our study majority population were from tribal areas and only 48%(n=421) were willing to donate their eyes.

Lack of knowledge about eye donation is a major barrier against willingness to donate eyes. Multipronged future campaigns to create awareness regarding eye donation targeting tribal population, could increase the percentage of willingness for eye donation among them. The main sources of awareness among our participants were newspapers, television, internet, information from friends, relatives, and neighbors, from wall paints, posters, pamphlets, and activities observed by eye bank.

Conclusion

Our study suggests adopting multipronged approach to create awareness for eye donation especially among tribal population by government and non-government organizations. Newspapers, television, radio, folk music, puppetry, nuked nataks, pamphlets, posters, hoardings, group discussions, observation eye

donation for night, social network posts can be used to increase awareness for eye donation among tribal population. As Internet is cheap these days and there is optical cable connectivity even to remotest tribal areas, android handsets in everyone's hands, awareness for eye donation can be created in better way now, to increase in the percentage of willingness for eye donation.

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