KNOWLEDGE ATTITUDE & PRACTICE REGARDING EYE DONATION AMONG PEOPLE ATTENDING TERTIARY CARE HOSPITAL- A SHORT REVIEW

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ABSTRACT: OBJECTIVE: To determine the knowledge, attitudes and practices regarding eye donation in selected adult population attending tertiary eye care centre. Methods: 636 interviews were successfully completed and used for analysis. A questionnaire was specially designed to know the facts about awareness and willingness for eye donation among general population attending tertiary eye care centre. Questionnaire included whether they had any knowledge of eye donation, source of information, willingness to donate eyes and also impact of eye donation on corneal blindness status. Results: Knowledge about eye donation was significantly associated with education and socioeconomic status. After counseling, 84.90% of participants agreed to motivate other family members/ friends to fill the pledge form of eye donation.

Allowance of eye donation in religion was significantly associated with the motivation to donate. Higher level of education and higher socioeconomic status were significant predictors of knowledge status of eye donation. For motivation, higher socioeconomic status, adequate knowledge and belief that eye donation is allowed in religion were significant predictors. Television emerged as the major source of information. Conclusion: Better knowledge may ultimately translate into the act of donation. Effective measures should be taken to educate people with relevant information with the involvement of media, doctors and religious scholars.

INTRODUCTION: We see the world and receive more than 90 % of our knowledge through eyes. Cornea is the most valuable part of eye. It constitutes the outer coat of the eye ball. It covers the inner contents of the eye ball, protects them from noxious insult by microbial agent and other environmental trauma. Even then if things do go wrong, it lends itself to surgical replacement by which visual acuity can be restored.

Corneal diseases constitute a significant cause of visual impairment and blindness in the developing world. With 7.8 million blind people in India, the country accounts for 20 per cent of the 39 million blind population across the globe, of which 1 per cent are on account of corneal blindness (WHO visual impairment and blindness fact sheet June 2012.)¹

Dandona R et al 2003 and S Krishnaiah et al 2004 concluded that the major causes of corneal blindness include trachoma, corneal ulceration following xerophthalmia due to vitamin A deficiency, ophthalmia neonatorum, use of harmful traditional medicines, onchocerciasis, leprosy and ocular trauma.^{2, 3}

Although strategies to prevent corneal blindness are likely to be more cost-effective, visual rehabilitation by corneal transplantation remains the major treatment for restoring sight in those who already have corneal blindness. Recognition of the fact that vision restoration through corneal

grafting is possible for a sizeable proportion of the corneal blind in India has led to a sustained multi-pronged drive to raise awareness of eye donations and corneal transplantation.

After the first successful corneal transplantation by Edward Zirm, it has now become the most successful example of organ transplantation. With the understanding of corneal anatomy and physiology especially with regard to corneal endothelium, introduction of microsurgical technique, advances in corneal preservation, the upcoming of corneal immune suppressive agents, have resulted in a high success rate of corneal grafting.

Though there has been progress in Eye Donation, only 53543 eyes were collected in year 2012-2013, whereas our target was around 60, 000 according to National program for control of blindness 2012-2013.⁴ In Madhya Pradesh, our target was 3200 whereas only 1479 eyes were collected in year 2012-2013.The purpose of this study is to spread awareness for eye donation among people attending tertiary eye care centre at Bhopal.

MATERIAL AND METHOD: This was a cross-sectional study, undertaken from Dec 2011- Dec 2013. Data collection was carried out via a face to face interview based on a pretested, questionnaire in selected participants attending tertiary eye care centre, Bhopal, after getting informed consent. Respondents for this study were randomly selected.

We used a structured questionnaire to elicit responses. We included questions regarding awareness of eye donation, source of information, awareness of corneal transplantation and religious belief.

Questions were administered in the local language. We also collected demographic details from respondents including age, gender, literacy and place of residence. Literacy was defined as a minimum ability to read or write one's name. Place of residence was categorized as either rural or urban based on existing census records. We administered the questions to randomly chosen subjects aged 18 and older. Privacy was ensured while administering the questionnaire and the time taken was approximately 10 minutes on an average.

Awareness was considered as having a realization about the fact that a dead individual's eyes can be utilized to give vision to those blind from corneal disease. Knowledge of the respondents was assessed through questions regarding meanings of the terms "eye donation", source of information for their knowledge, ideal time for retrieval of eyes, whether eye donation causes disfigurement of face and which part of donated eye is used for transplantation.

Attitudes of the respondents regarding eye donation was determined through questions regarding opinions on issues such as the willingness to donate eye in the future and influence of religion on attitude towards eye donation. Practices were admeasured by after counseling whether the subject agreed to fill the pledge form, whether the subject agreed to motivate other family members/ friends to fill the pledge form of eye donation and whether the subject agreed to spread the knowledge about eye donation to others.

Literate subjects self-administered the questionnaire; whereas we read out the questionnaire to the participants with no formal education. Those subjects not willing to participate in the study were excluded. The occupation of the participants was categorized as paramedical and nonmedical, with an understanding that individuals in paramedical occupations are likely to have a better awareness compared to nonmedical personnel. Paramedical occupation included nurses,

ward boys, and helpers working in various hospitals, while nonmedical profession included all other occupations not related to the medical field.

PROFORMA:

- 1. Name
- 2. Age/ Sex
- 3. Religion
- 4. Occupation
- 5. Rural/Urban
- 6. Address/ phone no.
- 7. Education

QUESTIONAAIRE:

- 1. Are you aware about eye donation? Yes/ No
- If yes, source of awareness Family physician Family members Friends Newspaper (media) Television Internet
- 3. Are you willing to donate your eyes? Yes/No
- 4. Do you think eye donation will be a service to mankind? Yes/No
- 5. Is eye donation against your religious belief? Yes/No
- 6. Whether eyes can be donated only after death? Yes/No
- 7. Are you aware of the ideal time to retrieve eyes after death? Yes/No
- 8. During transplantation which part of the donated eye is used for transplantation? Only cornea (layer in front of the black portion of the eye)/ whole eyeball.
- 9. Eye donation causes disfigurement of face of the donor? Yes/ No
- 10. The eyes can be removed at donor's house itself? Yes/No
- 11. After counselling whether the subject agreed to fill the pledge form?
- 12. After counselling whether the subject motivated other family members/ friends to fill the pledge form of eye donation?
- 13. After counselling whether the subject agreed to spread the knowledge about eye donation to others?

RESULT:

AGE DISTRIBUTION	NO.OF PARTICIPANTS	PERCENTAGE
18-20yrs	102	16.03%
21-30yrs	222	34.90%
31-40yrs	102	16.03%
41-50yrs	150	23.58%

51-60yrs	48	7.54%
>60yrs	12	1.88%
TABLE NO. 1. ACE DISTRIBUTION OF DADTICIDANTS		

TABLE NO. 1: AGE DISTRIBUTION OF PARTICIPANTS

636 people participated in the study. Maximum no. of participants belongs to age group 21-

30yrs.

Sex	No.	Percentage
Male	420	66.03%
Female	216	33.97%
Total	636	100%

TABLE NO. 2: SEX DISTRIBUTION OF PARTICIPANTS

There were 66.03% males and 33.97% females. 67.92% participants were educated.

Religion	No.	Percentage
Hindu	468	73.58%
Muslim	144	22.64%
Others	24	3.77%
TABLE NO. 3: DISTRIBUTION BASED ON RELIGION		

73.58% participants were Hindu, 22.64% were Muslim and 3.77% were of other religion.75% Muslim participants believed that eye donation was against their religious belief.

SOURCE OF INFORMATION	NO.OF PARTICIPANTS	PERCENTAGE
SOURCE OF INFORMATION	NU.UF PARTICIPANTS	PERCENTAGE
TELEVISION	204	46.57%
NEWSPAPER	156	35.61%
INTERNET	54	12.32%
FAMILY PHYSICIAN	12	2.73%
FAMILY MEMBER	12	2.73%
TABLE NO. 4: SOURCE OF INFORMATION		

Television was the most common source of information on eye donation in 46.57%, followed by newspaper in 35.61%, internet in 12.32%, family physician in 2.73% and family member in 2.73%.

RESPONSES	NO.	PERCENTAGE
Aware about eye donation.	438	72.64%
Willing to donate eyes.	228	52.05%
Eyes can be donated after death.	330	75.34%
Ideal time for donating eyes is within six hours after death.	36	8.21%
Participants knew that during transplantation cornea of the donated eye is used for transplantation.	210	47.94%
Knew that the eyes can be removed at donor's house itself.	132	30.13%
Believed that eye donation causes disfigurement of face of the donor.	138	31.58%
Participants agreed to motivate other family members/ friends to fill the pledge form of eye donation after counseling.	540	84.90%
TABLE NO. 5		

72.64% participants were aware about eye donation. It was observed that 75.34% participants knew that eyes can be donated after death and ideally within six hours of death was known to 8.21% of participants.

52.05% of participants were willing to donate eyes. As 198 participants were not aware of eye donation, they were not asked about willingness to donate eyes.

Everyone believed that eye donation will be a service to mankind. 30.13% participants knew that the eyes can be removed at donor's house itself. 31.50% participants believed that eye donation causes disfigurement of face of the donor. 47.94% participants knew that cornea of the donated eye is used for transplantation.

After counseling, 84.90% of participants agreed to motivate other family members/ friends to fill the pledge form of eye donation.

There are various myths associated with Eye donation, in India, that may be preventing many people from donating their eyes.

MYTHS	PERCENTAGE
Donation will mutilate their body.	45.59%
Family will be charged for donating organs, tissues and eyes.	23.27%
Religion does not support donation	18.86%
Only your heart, liver and kidneys can be transplanted.	16.03%
History of medical illness is contraindication for eye donation.	63.20%
They are not of the right age for donation.	35.22%
They are of the opinion that if they donate their eyes in this life, they shall be born blind in the next life.	48.42%
Think that if they donate their eyes, it will leave holes in the place where their eyes existed.	46.22%
Person with eye problem like Cataract or Glaucoma cannot donate their eyes.	68.55%
TABLE NO. 6	

DISCUSSION: Corneal transplantation offers the potential for sight restoration to those who are blind from corneal diseases. This, however, is dependent on people willing to pledge their eyes for donation, and relatives willing to honor that pledge upon the death of the person. Data from our study suggest that additional efforts are needed to improve awareness of eye donation in the community. It is a matter of concern that only 72.65% of the persons interviewed had awareness of eye donation and only 8.21% of them knew when to donate their eyes. The timing of eye donation is important, it may not be ideal to utilize eyes for optical purposes that are donated later than 6 hours after death.

Although 72.65% of the participants had the awareness about eye donation, the willingness to donate eyes was seen in only 52.05%. This finding of better awareness than willingness to donate eyes is well observed in the study by Yew et al in 2005 in Singapore (awareness 80.7% and willingness 67%).⁵ Also, the study by Tandon R et al in 2004, showed that the prior knowledge of eye donation, literacy, and socioeconomic status had no influence on willingness for eye donation

and major reasons for not donating eyes included refusal to discuss the issue, legal problems, and religious beliefs.⁶

According to study by Sulatha Bhandary et al in 2011⁷, awareness of eye donation was observed in 69% participants. Awareness was more among females when compared to males. Only 34.42% were willing to donate eyes. Willingness was more among the Indian race. 90.3% of the participants thought that eyes could not be retrieved at the house of the deceased. Among those who were aware about eye donation, 88% knew that eyes could be donated only after death whereas according to our study 75.34% knew this fact.

No disfigurement of the face as a result of eye donation was documented by 68.55% of participants in our study. According to Sulatha Bhandary et al, no disfigurement of the face as a result of eye donation was documented by 76.2%. They also observed that the most important source of awareness was the media (55.4%) with newspapers topping the list (36.7%). According to our results, television was the most common source of information on eye donation in 46.57%, followed by newspaper in 35.61%, internet in 12.32%, family physician in 2.73% and family member in 2.73%.

In our study majority, 52.06% of participants thought that whole eye is transplanted to restore the vision and in study done by Gupta A et al, on nursing students, large number of students, 74.4% of 188 knew that the donated eye is used for corneal grafting. This is because paramedical staff has better knowledge about eye donation than non-medical.⁸

In our study, 75% of the Muslim participants felt that eye donation is against their religion. Many studies have shown that ethnicity has an important role in the willingness of organ donation. Studies show that there was poor awareness about the "Fatwa" regarding organ donation, passed by the Muslim law council in 1995. According to fatwa, it is permissible to benefit from another person's organ or tissue which has been excised for medical reasons, such as cornea. The main condition stipulated by the fatwa is that the dead person should have given his consent before death, or his heirs give theirs after his death. If neither the deceased nor heirs were identifiable, then the consent of the "Guardian of the Muslims" should be obtained. This lack of awareness has led to the fear of doing something against religion by donating organs among the population. Probably, 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.^{9, 10}

According to our results, educational status showed a positive impact on the awareness of eye donation. According to a study by Shahbazianet al¹¹, "age, sex, and occupation did not influence the attitudes; however ethnicity, educational level, economic status, and having a loved one in need of an organ, significantly increased the willingness for organ donation."

Thus, to make this dream of reducing the burden of avoidable corneal blindness, the ophthalmologists, general physicians, nongovernmental organizations (NGOs), and especially the religious leaders have to work in unison to educate and motivate people to donate eyes. There is also a great need to educate students in all fields, particularly those in the medical profession about eye donation, so as to enable the younger generation to act as future motivators for enhancing eye donation rates.

Strategies that have worked well in other parts of the world may be useful here too. For example, in 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 donate 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; the government may consider the concept of "presumed consent" to boost eye donations. Such legislation would emphasize the government's commitment to the cause of eye donation. Another area of legislation is the "required request law", wherein it becomes mandatory for all health care staff, institutions coming into contact with bereaved families to make a request for eye donation. This requires legal sanction¹².

CONCLUSION: Better knowledge may ultimately translate into the act of donation. Effective measures should be taken to educate people with relevant information with the involvement of media, doctors and religious scholars

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