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Original Research Article

Awareness and attitude towards eye donation among rural population

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ABSTRACT

Background: Voluntary eye donation especially among rural areas is less and is associated with lot of myths and gaps in the knowledge.

Aim of the study was to assess the awareness and attitude towards eye donation among rural population.

Materials and Methods: Cross-sectional observational study conducted from November 2019 to February 2020, in OPD and eye camps. After written informed consent, self-designed questionnaire in the regional language with dichotomous closed ended questions was given.**Results:** Of 400 people, 47(11.75%) knew only front of the eye can be donated. 301 (75.25%) were aware that eye can be donated only after death. 253 (63.25%) mentioned that there is no age limit for eye donation. 298 (74.5%) knew diabetics could donate eyes. Majority of them had no idea about eye donation in infectious diseases such as HIV, HbsAg and were unaware as to who can give consent (111-27.75%), and place of retrieval of the eye 93(23.25%). 92(23%) answered eye should be donated within 6 hours after death. 29 (7.25%) answered that donated eyes can be used in the treatment of corneal disease. 164 (41%) were willing to donate eyes out of which nobility was the major reason for 104 (64%). 236 (59%) were not willing for donation due to fear of disfigurement.**Conclusion:** In our results we observed that awareness for eye donation is less among people of community and majority of them were unwilling to donate eyes. Hence, extensive awareness programs can change the attitude towards eye donation and motivate people to donate eyes. Community awareness is the major chain link for the success of eye donation for corneal transplantation.This is an Open Access (OA) journal, and articles are distributed under the terms of the [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License](https://creativecommons.org/licenses/by-nc-sa/4.0/), which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.For reprints contact: reprint@ipinnovative.com

1. Introduction

Blindness is a huge global concern, with at least 2.2 billion population suffer from vision impairment.¹ 90% cases of visually impairment are from the developing world. According to the World Health Organization (WHO), 80% of these cases are either preventable or treatable.² Corneal diseases are significant cause of visual impairment and blindness accounting for 12% of the world's blind population.³

Corneal diseases including keratitis or trauma resulting in corneal scarring is a major cause of bilateral or unilateral blindness and visual impairment in children and young adults. 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.⁴

Most of these diseases are preventable and treatable.⁵ Though, it is more cost effective to implement primary prevention strategies to prevent corneal blindness, yet major treatment for visual rehabilitation remains by corneal

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transplantation.⁴ As per the National Program for Control of Blindness (NPCB), prevalence of corneal blindness in India is 0.9%,⁶ cases are expected to rise from 6.8 million to 10 million by 2020.² Due to insufficient number of eye donations in India, the gap between donor and recipient keeps on growing 30,000 cases are added every year.² Thus, number of patients waiting for corneal transplantation is keeps on increasing.⁶

Eye donation is voluntary donation of one's eyes after his/her death. As per Eye Bank Association of India current corneal procurement rate is 49,000 per year,² however large number of these cornea are deemed unfit for transplantation donor corneas are unfit for corneal transplantation. According to some studies 277,000 donor eyes are needed to perform 100,000 corneal transplants in a year in India.⁴

Awareness and Attitude of the population towards eye donation is the key for successful eye donation.⁶ Lack of these maybe due various reasons. People willing to pledge their eyes for donation and their relatives to honor that pledge upon the death of the person are two important aspects of eye donations. Attitude of key family members play an important role for giving consent for eye donation. Sometimes there is a change in opinion for the donation following the death of a dear one.⁷

Hence, purpose of this study is to determine the awareness and belief regarding eye donation and to assess the attitude and reason behind the attitude especially among rural population.

2. Materials and Methods

A cross-sectional observational questionnaire based study was conducted in the ophthalmology outpatient department and medical camps arranged in villages which was conducted by a rural tertiary care hospital between the time period of July 2019 to September 2020. The considered sample size is 400 people.

In our study we included people attending Ophthalmology medical camps from nearby villages majority of them were from Bellur, Nagamangala, Javaranahalli, Bindiganavile, Govindagatta, Melkote and Yadiyur (Mandaya District). Patients and other people accompanying the patients who belonged to these areas attending the Ophthalmology OPD and the medical camps; who were willing to take part in study were included in the study.

Subjects under the age of 18 years, people who had no idea regarding eye donation and people unwilling to take part in the study were excluded from the study.

After taking approval from institutional ethical committee and written informed consent from the participants in their own language, the study was conducted with the help of questionnaire.

The questionnaire was self-made and consisted of dichotomous and closed ended multiple choice questions. It included questions regarding demographic data, educational background, source of awareness. The questionnaire was initially in English by the principal investigator translated into Kannada by language expertise.

Validity and reliability of the questionnaire was determined by sending the set of questions to two different Ophthalmologists belonging to different geographic areas and their approval was taken, after making changes suggested by them. Also, the common questions published in similar studies were taken as reference to be added in the study.

First nine questions were asked to assess the knowledge and awareness of eye donation. Questions regarding the part of the eye donated, timing, age limit, site of retrieval, medical ailments in which eye can be donated, time within which eye can be donated after death and concerned person to give consent for eye donation were included.

One question about willingness to donate eye and the reason to either donate or not to donate the eyes was included to assess the attitude of the participants towards eye donation. Participants were required to answer all the questions for the study.

Statistical analysis was done using SPSS 20.0 software. Results were tabulated and percentages were taken for each answer given by the participants.

Data presented as percentage as discussed appropriate for quantitative and qualitative variables.

Annexure-1- Sample questionnaire

Questionnaire

Name:

Age/Sex:

Place :

Questions:

1) Can eyes be donated?

a) Yes

b) No

2) If yes, which part of eyes can be donated?

a) Entire eye.

b) Only front part of eye.

c) Not sure.

3) When can eyes be donated?

a) Only after death

b) On a useless eye when the person is alive.

c) Only living adults.

4) What is the age limit of eye donation?

a) Any age

b) <50 years

c) >50 years

d) <2 years.

5) Who can donate eyes (tick multiple answers)

a Diabetics	b Hypertensive	c Glaucoma	d Cardiac disease
e Cataract post op	f Jaundice	g HIV	h Hbsag
i Alcoholics	j Smokers	k Death due to unknown causes	l Medico legal cases (suicide/ homicide/ RTA)

6) What is the time within which the eyes can be donated after death?

- a) <6 hours
 - b) <24 hours
 - c) No clear idea.
- 7) Eye transplant is applicable to:
- a) All blinds
 - b) Congenitally blind (Blind by birth)
 - c) Corneal problems only
 - d) Retina / nerve damage.
- 8) What is the site of retrieval of the eye?

- a) At home
 - b) At hospital only
 - c) Any site from body was retrieval
 - d) Not sure
- 9) Who can give consent for retrieval of eye after death?
- a) Only the person himself
 - b) Family member >18 years
 - c) Family members <18 years
 - d) Friends
 - e) Police

10) Are you willing to donate eyes? (multiple responses allowed)

If Yes	If, No
a) Noble cause	a) Fear
b) Social commitment	b) Religious reason
c) Inspiration	c) No family support
	d) Fear of disfigurement

3. Results

Among 400 participants took part in the study 298 (74.5%) were males and 102 (25.5%) were females. Out of 400, 123 participants were illiterates, 81 participants had an educational level of less than/equal to primary schooling, 144 participants had cleared their high school (10th -12th) and 52 participants were educated more than secondary school (diplomas/degrees).

Majority of them 268 (67%) answered the source of knowledge of eye donation as mass media (television serials, cinema, health talk shows), 110 (27.5%) participants heard about eye donation from nearby health care workers.

22 (5.5%) participants heard about eye donations from multiple sources.

Table 1: Questions on awareness of eye donation

Questions	Response
Part of the eye donated	Correct response 48 (11.75%) Wrong response 197 (49.5%) Not sure 155 (38.75%)
Timing of eye donation (before/after death)	Correct response 302 (75.25%) Wrong response 98 (24.25%)
Age limit for eye donation	Correct response 11 (2.75%) Wrong response 389 (97.25%)

When asked about which portion of the eye can be donated/replaced, correct response was given by 48 (11.75%) participants, wrong response by 197 (49.5%) and around 155 (38.75%) were not sure about the answer.

When asked about age limit for eye donation, majority of them give the wrong answer 389 (97.25%), only 11 (2.75%) gave the correct answer.

Table 2: Questions on awareness of eye donation

Question	Response
After death, time within which eye can be donated	Correct response 93 (23%) Wrong response 80 (19.75%) Not sure 227(56.75%)
Site of retrieval of eye (Home or hospital, site of RTA)	Correct response 51 (12.5%) Wrong response 160 (39.73%) Not sure 189(47.25%)
Person can consent for eye retrieval (The family/ friend/ doctor/ or person himself before death)	Correct response 111(27.75%) Wrong response 95 (23.75%) Not sure 194 (48.25%)

When asked about whether the eye should be donated before or after the death of the donor, 302 (75.25%) mentioned eye can be donated only after death, 98 (24.25%) people either did not know properly or mentioned that eye can be donated even before death.

Regarding the practice of eye donation, 93 (23%) participants knew eye should be donated within 6 hours of death, 80 (19.75%) participants gave the wrong response, majority of the participants, around 227 (56.75%) of them were not sure about the answer.

When asked about the site of retrieval of the eye, whether it could be done in home or hospital setting or any other site, only 51 (12.5%) gave the correct response, 160 (39.73%) participants gave the wrong response and 189 (47.25%) of them were not sure about the correct answer

When asked about who can consent for eye retrieval (the family/ friend/ doctor/ or person himself before death), 111 (27.75%) of them gave a correct response, 95 (23.75%) of the participants gave wrong response and around 194 participants (48.25%) were not knowing the answer.

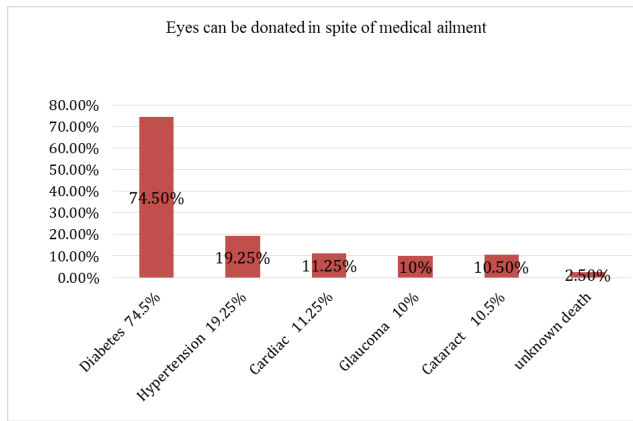


Fig. 1: Awareness on with what ailment can eye be donated

When asked about whether eye can be donated in presence of systemic diseases, 298 (74.5%) participants said that eye can be donated in presence of diabetes mellitus, 77 (19.25%) mentioned that eye could be donated by hypertensives, 45 (11.25%) in presence of cardiac disease, 40(10%) in presence of glaucoma, 42 (10.25%) mentioned eye can be donated in presence of cataract. Around 10 (2.5%) said that eye can be donated if death occurred due to unknown cause.

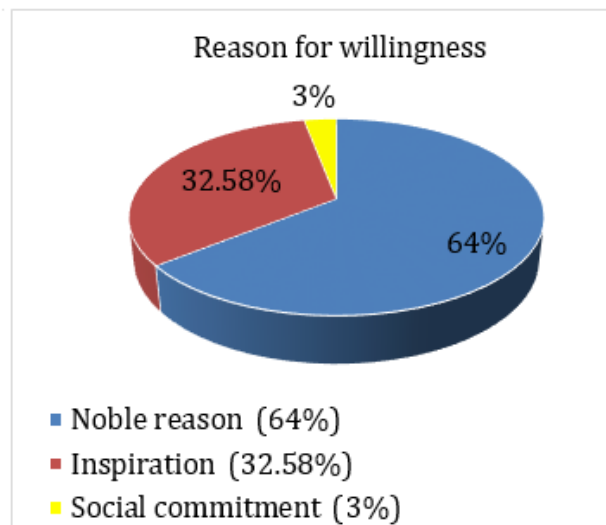


Fig. 2: Participants willing to donate eye 164 (41%)

While assessing the attitude towards eye donation, same participants were asked if they were willing to donate the eye or no, 164 (41%) participants were willing to donate eye. 104 (64%) of participants were willing to donate the eyes due to noble intentions, 53 (33%) wanted to donate the eye because they were inspired by celebrities and others who were willing to donate the eye and around 7

(3%) participants wanted to donate the eyes due to social commitment.

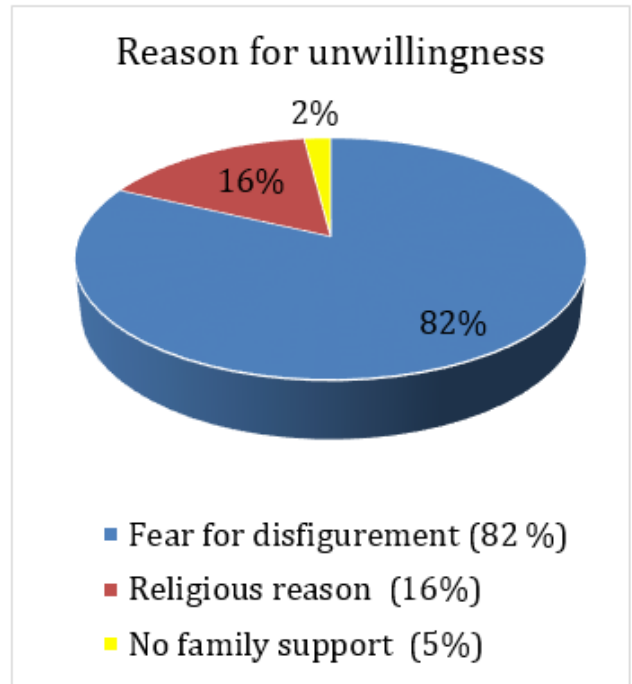


Fig. 3: Participants not willing to donate the eye 236 (59%)

236 (59%) participants were having negative attitude regarding eye donation. Majority among them 194 (82%) gave the reason as dear of disfigurement. Other reasons by 38 (16%) participants given were religious sentiments and lack of family support by 5 (2%) participants.

4. Discussion

Awareness is the key for any program to be successful. Yet in a country like India, it is lacking in most of the people. Those with awareness develop negative attitude towards donating the eye.

Hence, burden of corneal blindness is high the number of eye donations is significantly less. In our country where rural population forms a significant number, the awareness about the process of eye donation is less and the attitude regarding donation is mostly negative.

In our study 197 (49.5%) of them answered entire eye can be donated whereas only 47 (11.75%) knew that only front part of eye i.e., Cornea can be used and 314 (78.5%) participants had misconception that donated eye can be used to treat all blinds.

Similar to our study, in study by Manhas et al knew 45% of participants knew that whole eyeball is removed for donation and 23.5% participants knew only cornea is transplanted.⁶ In study by Prabhu et al 70.9% were aware retrieved tissue is utilized for corneal transplantation.⁵

In our study 301 (75.25%) participants were aware that eye can be donated only after death which is in concordance with study done by Prabhu et al in which 87.6% were aware eyes are donated after death.⁵ In comparison to study done by Qayum et al only 56% were aware.⁸

In the present study, only 92 (23%) participants were aware that ideal time for donation was within 6 hours of death. 227 (56.75%) participants were unsure about the ideal time within which eyes can be donated. In study by Gupta et al, 46.38% were aware of the ideal time.⁷ Whereas, in study done by Manhas et al awareness was high 70%.⁶ In study done by Priyadarshan et al, it was only 4.34% which denotes very less awareness.⁷

Only 50 (12.5%) participants were aware that eye can be retrieved from home or hospital, majority 189 (47.25%) participants were unaware of site of retrieval. In study by Prabhu et al., 18.3% knew that eye will be removed at site of body either home or hospital.⁵ Whereas, in study done by Gupta et al. in which 77.71% believed it was necessary to transport donor to hospital for donation.⁷

In our study 111 (27.75%) were aware that consent for retrieval of eye can be given by immediate family member, majority 190 (47.5%) were unaware who can give consent for donation due this consent issue maybe a reason people are not coming forward for eye donation of deceased family member. In the study done by, Bhandary et al. 55.6% knew that consent can be given by next kin.⁹ Whereas, Manhas et al. 100% participants believed that consent should be given by person himself.⁶

In our study, 298 (74.5%) knew that diabetics and 77 (19.25%) knew that hypertensive could donate eyes majority of participants were not sure if people with jaundice, HIV, HbsAg, alcoholic, cancer, smokers could donate eyes or not. In study done by Manhas et al. 42.5% of participants were aware that diabetic and hypertensive can donate eye.⁶

While assessing the attitude of people we found 164 (41%) population were willing to donate eye. Most important reason for willingness to donate was noble intention 104 (64%), inspiration 53 (32.58%), social commitment 7 (3%) cited as second and third reason. This is in concordance with the study by Gupta et al. where 51.50% were willing for donation.⁶ In study conducted by Prabhu et al. 71.75 were willing for donation, nobility was major reason which was 32.58%.⁵

Most of the participants who were willing to donate eye had noble intentions and were inspired by celebrities and by those who donated eyes. This shows that publishing the stories of eye donation by celebrities such as actors, sportsmen etc. can inspire more people to donate eyes. Local leaders, common people in rural areas can also share their stories in common platforms to get others into eye donations. Mass media, television advertisements play a major role in this direction.

In our study, majority 236 (59%) people were unwilling to donate eye 194 (82%) of participants

feared disfigurement. Other reason for unwillingness were religious reason given by 38 (16%) participants and lack of family support 5 (2%). Which is in concordance with study done by Kaur et al were 63.86% of subjects were unwilling to donate their eyes, as they feared disfigurement.¹⁰ In study by Prabhu et al, 28.3% were unwilling major reason being lack of awareness 17%, fear 12%, and religious reason 11%.⁵

This negative attitude can be removed by educating masses that there will be no disfigurement. Religious leaders can educate the masses and motivate them regarding eye donations. Education about the eye donation in presence of the whole family can be undertaken by local/rural health workers.

5. Conclusion

In our results we observed that awareness for eye donation is less among people of community. Hence, extensive awareness programme can change the attitude towards the eye donation. Once attitude changes more people will come forward for eye donation.

Proper motivation, giving the correct facts and eliminating myths regarding eye donation is of utmost importance. Community awareness is the major chain for success of eye donation and corneal transplantation.

6. Source of Funding

None.

7. Conflicts of Interest

None.

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