



WHO CARES FOR EYE DONATION?

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Abstract- The last decade has seen a major revolution in the understanding of various corneal diseases. Among 15 million blind people, 6.8 million suffer from corneal blindness with vision less than 6/60 in at least one eye. Indian government, NGOs and some private sectors are working on Eye Banking but still community does not have the gravity of this facility, resulting the decline in the corneal blindness is insignificant. Why? Who is responsible? So many eye banks are established in the country, then why the corneal blindness is still a matter of worry? To find the answers of these questions, we surveyed the eye banks working in a region (Marathwada) in Maharashtra. A ready to fill open ended questionnaire was designed for eye banks in Marathwada to know the status of cornea collection, the difficulties and views in eye banking services. Data were collected and recorded on a pre-designed proforma and managed on an excel spread sheet. Out of 19, only 9 Eye Banks /eye donation centres were reported as active or functional. There is no functional Eye Bank within 3 districts at Marathwada. Lack of public awareness and human resources is still becoming the barrier in eye banking services. Average progress in cornea collection is very slow in Marathwada region. Various sources of publicity and awareness can be adopted for strengthening the eye bank services. Additional facilities may also be provided to ease the service.

Keywords- Eye bank services, Cornea collection, Eye donation, Public awareness.

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Introduction

'Donate your eyes to help someone see'; 'Make eye donation a family tradition'; 'Your eyes after death need not perish; Help blinds to see, donate eyes after death'; The National Programme for Control of Blindness (NPCB) is continuously exploring and publishing such captions and slogans to encourage the society for eye donation to help the corneal blind persons. The last decade has seen a major revolution in the understanding of corneal diseases, as the development of more effective treatment methods for ocular surface disorders, corneal infections, immunological corneal diseases, contact lens material and corneal surgery. Without the generosity of cornea donors, many thousands would be left without sight every year. A majority of people are Cataract blind which can be treated for vision through a simple surgical technique using artificial

lenses. But a corneal blind can gain vision only when the healthy cornea received from a donor replaces the damaged cornea.

There are currently an estimated 15 million blind people in India. Among these, 6.8 million suffer from corneal blindness with vision less than 6/60 in at least one eye. The major problem in India is that eye donation has not yet become popular. Though, the studies have shown that 50% of the general population were aware of 'eye collection' in India, less than 5% knew that this should be done within the first 6 hrs of death and 20% had heard about corneal transplantation.[1] In India, thousands of people remain blind due to non-availability of donor. Loss of corneal transparency results in corneal opacity, which does not let the light rays focus on to the retina. Hence deteriorates vision. This is called corneal blindness. Majority of these persons are affected in the first and second dec-

ade of life. The major causes of this blindness are corneal ulcers due to infections, trachoma, ocular injuries and keratomalacia caused by nutritional deficiencies.[2]

Current Status of Corneal Blindness

It is unfortunate that over 1 million citizens of this country are suffering from corneal blindness. There is further addition of 40,000 to 50,000 corneal blind persons every year. Restoration of their vision is possible only through transplantation of cornea from donated eyes. Currently, in India the collection is ~22 thousand eyes a year, [3] which are negligible to the requirement.

Organ donation is a sensitive issue all over the world. Corneal transplantation is the most successful among all forms of organ transplant procedure. Corneal transplants are the most common human transplant which enjoys a 95% success rate. In the developed countries like United States about 40,000 people receives corneal transplants every year.[4] Corneal transplant is only possible through cornea donation. There is currently no substitute for human corneal tissue. Advanced medical technology has improved the success rate to approximately 95%.[5] Since the cornea has no blood supply, it is seldom subject to the rejections. Any person of any age, Cataract operated person, Diabetes, Hypertension, Mentally ill can donate eyes. Corneas are not commercially available. Hence only an eye donation made by a deceased can help restore sight for a corneal blind person. Donated corneas are transplanted only after the donor's medical and social history has been obtained.

Facts about eye donation

- Anyone can be a potential donor regardless of age, race, or medical history.
- People with short-sightedness, long -sightedness or astigmatism or even those operated for cataract, can also donate eyes.
- Eye and cornea donation can only be considered after you are deceased.
- Through the entire donation process the body is treated with care, respect and dignity.
- The eyes have to be removed within 6 hrs of death.
- There is no cost to the donor or their family for eye/cornea donation.
- The eyes cannot be removed from a living human being in spite of his/her consent and wish.
- Eye donation gives sight to two blind persons as one eye is transplanted to one blind person.
- Eyes can be actually donated to any nearest Eye Bank at the time of death.
- The corneas of people suffering from Hepatitis, Aids, Cancer or those who have died due to burns are used for research only.

Eye Banking

Eye Bank is an organization which deals with the collection, storage and distribution of cornea for the purpose of corneal grafting, research and supply of the eye tissue for other ophthalmic purposes.

Structurally, it has administrative and medical components. The entire operation is supervised by a Medical Director, who is usually

a well qualified corneal surgeon assisted by an Administrator and other staff on the administrative aspects and trained technique. Functionally, the administrative section is responsible for public awareness programs, liaison with government, local voluntary and other health care agencies and fund raising. The medical section deals with the entire technical operation of the Eye Bank. Tissue harvesting, tissue evaluation, tissue preservation and tissue distribution represent these activities. Each of these should be carried out following medical standards of highest quality. Any deviation from accepted medical standards can result in devastating complications. By definition, only organizations with the above structure and functions are "Eye Banks" and all other are mere "Cornea Collection Centres".[6] Tony Fernandez[7] pointed that India is importing cornea from Sri Lanka. This situation should strictly overcome. He declared that the reason for the failure of such services is may be lack of leadership, financial constraints and lack of knowledge regarding the working of the eye bank.

The foremost tasks of Eye Bank are to focus on availability of trained staff round the clock to attend the calls, to evaluate and provide quality corneas to corneal surgeons, to enable corneal research using eyes unsuitable for grafts, to find newer techniques and improve preservation methods and to train doctors in eye removal procedures. Concurrently, increase in public awareness about eye donation and Eye Banking with the development and establishment of a network of eye donation centres plays the vital role in Eye Banking. To know the status of eye banking services, we conducted a study in Marathwada region of Maharashtra (India), where ~16 Eye Banks are found registered. Among them, only 4 Eye Banks are quoted in the recent Functional Eye Bank list of NPCB.[8] Very few are functional and contributing to this service. Rests of them are non-functional due to a number of reasons. Our survey reveals a number of Eye Banks which can be included in the Functional Eye Bank list. Moreover, we give an idea about the development and fluctuations within the progress of respondent Eye Banks so that Government and NGOs sectors can plan for the further task.

Methods

There are eight districts in Marathwada region of Maharashtra. This region includes Aurangabad, Jalna, Parbhani, Beed, Hingoli, Latur, Nanded and Osmanabad districts. We performed the district wise program in Marathwada.

At first, we developed a ready to fill questionnaire seeking complete information of the Eye Bank and was shared with all members of advisory group. On their inputs, a questionnaire was prepared for piloting. The questionnaire was piloted at one Eye Bank institution, The advisory group finalized the questionnaire based upon the responses obtained in the pilot study.

It was decided to have two parts (Annexure) of questionnaire. Annexure 1st contains the information of addresses and contact details of the Eye Bank and annexure 2nd consists of assessment of public awareness programs, corneal retrieval program, human resources, storage facility, equipment status, transplantation, difficulties of Eye Bank and at last suggestions from the in-charge of Eye Bank to improve corneal collection service.

Data were collected and recorded on a pre-designed performa and managed on an excel spread sheet. Graphs were generated by using MS-excel. All entries were checked for any error.

Results

General Profile

19 registered Eye Banks/eye donation centres were identified in Marathwada region of which 13 Eye Banks and 3 eye donation centres responded our questionnaire. Out of those, only 6 Eye Banks and 3 eye donation centres were reported as active or functional. More than half (58.82 %) Eye Banks were in the NGO sector while (35.29 %) Eye Banks were in the Government sector. There is no functional Eye Bank in Beed, Parbhani and Hingoli district. There was no Hospital Corneal Retrieval Program reported in any Eye Bank.

Overall, there were 28 Ophthalmologists working at 9 functional Eye Bank/eye donation centres. However, the distribution was very heterogeneous across different districts. Approximately 16 ophthalmic technicians were reported in 5 Eye Banks. Remaining 4 Eye Banks had no ophthalmic technician. All ophthalmic technicians reported were untrained. Unavailability of ophthalmic assistants or technician in every district hospital Eye Bank is worth mentioning.

Status of functional Equipments

During our Eye Bank survey, we observed the variability in equipment conditions (Table 1). All functional Eye Banks had one slit lamp, operating microscope, autoclave and at least 2 sets of enucleation sets. 5 Eye Banks had Storage media for preservation of eye balls. 1 Eye Banks did not have even one functional refrigerator. All responded government owned Eye Bank reported that there was unavailability of functional vehicle especially for Eye Banks. No Eye Bank institution had reported the availability of specular microscope.

Table 1- Infrastructure facility status among respondent eye banks in Marathwada region of Maharashtra state

Sr. No. -1	-2	-3	-4	-5	-6	-7	-8	-9	-10
1 Govt. Eye bank, Aurangabad	10	X	X	√	√	√	√	√	X
2 Private eye bank, Aurangabad	2	4	X	√	√	√	√	√	√
3 Private eye bank, Aurangabad	1	X	X	√	√	√	√	√	√
4 NGO eye bank, Jalna	4	2	√	√	√	√	√	√	√
5 NGO eye bank, Jalna	1	X	√	√	√	√	√	√	√
6 NGO eye bank, Latur	1	2	√	√	√	√	√	√	√
7 NGO eye bank, Osmanabad	2	2	√	√	√	√	√	√	√
8 NGO eye bank Udgir	2	6	√	√	√	√	√	√	√
9 Govt. eye bank, Nanded	5	X	X	√	√	√	√	X	X

Column legends

(1) Name of Eye Bank/Eye donation centre (2) Ophthalmologists (3) Ophthalmic technicians (4) MK Media (5) Slit lamp (6) Operating microscope (7) Autoclave (8) Enucleating sets (9) Refrigerator (10) Vehicle.

Collection of Eyes in last eight years

Out of 8 districts of Marathwada region, we found Aurangabad, Jalna and Latur districts are leading in Eye Bank services (Figure 1A). There are 6 functional Eye Banks and 3 functional eye collection Centres found in Marathwada (Table 2) which covers Aurangabad, Jalna, Latur, Nanded and Osmanabad districts.

Moreover out of 16, 5 non functional eye banks are also seen in their respective areas. They had never shown any cornea collection within the last 8 years. The cornea collection by NGOs is more than Government sector. During our survey, we found that eyes collected in last 8 years (2003-2010) are 2210 eyes (Figure 1B and Table 3). Eyes collected in the year 2003 are 278 and eyes collect-

ed in the year 2010 are 372 indicating a mounting progress of Eye Banking

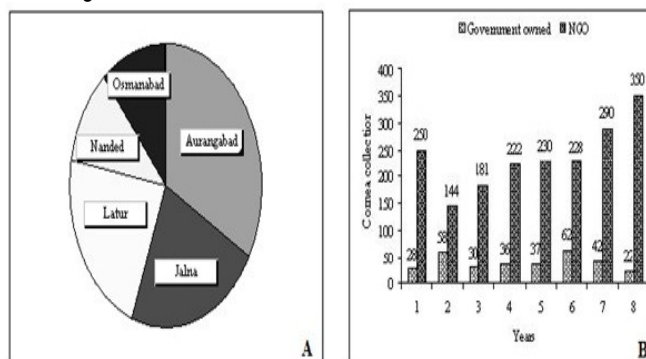


Figure 1: (A) Functional eye banks in Marathwada region and (B) Cornea collection of 16 eye banks in Marathwada region of Maharashtra in eight years (2003-2010)

Table 2- Number of eye banks in Marathwada region (Maharashtra)

Sr. No.	Name of District	No. of functional Eye Banks/eye donation centres
1	Aurangabad	3
2	Jalna	2
3	Latur	2
4	Nanded	1
5	Osmanabad	1
6	Parbhani	-
7	Beed	-
8	Hingoli	-

Table 3- Cornea collection by 9 functional Eye Banks in Marathwada region (Maharashtra) in eight years (2003-2010)

Sr. No.	Name of Eye bank	2003	2004	2005	2006	2007	2008	2009	2010	Total
1	Govt. Eye bank, Aurangabad	28	58	30	36	37	58	38	22	307
2	Private Eye bank, Aurangabad	-	-	-	7	16	19	18	14	74
3	Private Eye bank	6	6	10	12	8	2	2	2	48
4	NGO Eye bank, Jalna	136	107	150	151	173	186	238	300	1441
5	NGO Eye bank, Jalna	-	-	-	12	3	3	0	0	18
6	NGO Eye bank, Latur	108	30	18	38	22	16	14	6	252
7	NGO Eye bank, Osmanabad	-	-	-	-	-	10	2	0	12
8	Govt. Eye bank, Nanded	0	0	0	0	0	4	4	0	8
9	NGO Eye bank, Udgir	-	1	3	2	8	2	16	28	60
	Total	278	202	211	258	267	300	332	372	2220

Statistical Analysis

Descriptive and inferential statistical analyses were performed to validate the findings (Table 4 and Table 5). The null hypothesis (H₀) was as no difference between the performance of Government and NGO Eye Banks for the cornea collection during 2003 – 2010. From the statistical analysis results, It is clear that, Null hypothesis rejected and Alternative hypothesis accepted.

Table 4- Descriptive statistics

Eye Donation Centre	N	Mean	Std. Deviation	Std. Error Mean
Govt.*	2	157.5	211.425	149.5
NGO**	5	356.6	614.051	274.612

*Three other Govt. eye donation centres were not functioning, so excluded from the analysis.

** Also two private eye donation centres were shown very low statistics (not significant), so excluded from analysis.

Table 5- Inferential Statistics

Z test	Significance value	95% Confidence Interval of the Difference	
		Lower	Upper
0.636	P > 0.05	-1397.694	999.494
	Not significant	-1004.081	605.881

Null Hypothesis (H₀): There is no difference between performances of Government and NGO Eye Donation Centre

Alternative Hypothesis (H₁): The NGO Eye Donation Centre showed better performance than Govt. Eye Donation Centre.

Discussion

Though shortage of cornea is a global phenomenon, it is time to access the factors influencing eye donation in different regions where number of corneal blind people are more and Eye Banking services are inadequate. Our study highlights the fact that the situation of Eye Banking services in diffident region like Marathwada is very poor. There is no much enthusiasm in people about eye donation i.e. in donors as well as in recipients also. While seeing the progress in eye donation, the last 8 years data shows that average of ~247 eyes are collected every year in Marathwada (Figure 2). This is definitely very low as compared to our need.

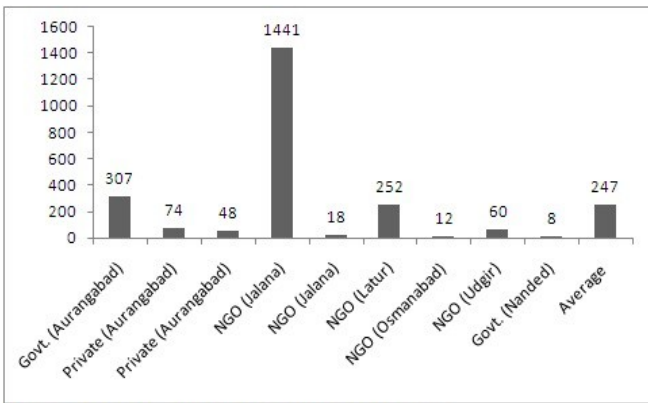


Figure 2: Performance of Eye Banks in 8 years (2003-2010)

Though the literacy rate is increasing in Marathwada, there are some misbelieves about eye donation. Lack of awareness in the general population about the concept of donation reduces the number of donors. Figure 3 indicates performance of cornea collection in Marathwada region of Maharashtra is not significant.

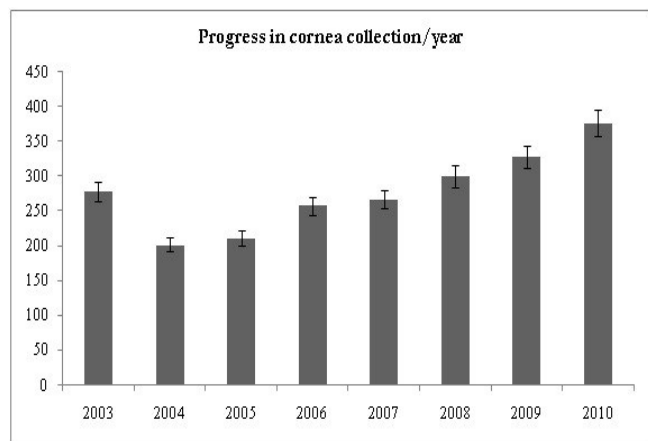


Figure 3: Year wise progress of cornea collection in Marathwada region of Maharashtra

Upreet Dhaliwal[9], suggested that students can be trained to be motivators for the eye banking and eye donation. With this object in view, more public awareness programs are necessary. Motivation plays an important role in 'eye donation' which can help to increase the collection of donated eyes and thus help in treatment of corneal blind persons. Priyadarshani and her co-workers[10] found that only 4.34% participants were aware that eye donation had to be done within 6 hours of death. People should know all the hidden things of eye banking services through different sources. 80% people in Marathwada live in rural area where no Eye Banks or even eye donation centre is located. 6 functional Eye Banks and 3 functional eye donation centres, all are located in urban area. Therefore, regardless of having latent desire, many people do not know where they should donate the eyes.

It was observed that the number of ophthalmologists at Govt. Hospitals is not enough. They have the workload of surgery, administrative and planning work for that they are not getting sufficient time to share for Eye Bank activities.

With regard to the infrastructure, it was observed that all Eye Banks/eye collection centres had adequate supplies of enucleation sets, one slit lamp, operating microscope and autoclave. Availability of specular microscope is not reported by any Eye Bank in Marathwada.

Conclusion

With little efforts, Eye Banks in Marathwada can be upgraded to good cornea services, as few of them already have adequate equipment and adequate human resources. However training of support personnel is needed. Our national and regional organizations can organize the workshops to train the relevant staff members of Eye Banks. The overall data implies that there is a poor improvement in the quality of service delivery. With the overcome of errors in eye bank services mentioned above, rapid progress can be achieved. From our output it is proved that there is an immediate need to restructure the functioning of Eye Banking services in government sector to increase more cornea collection in the Marathwada region. A 'Nil' report was also sought from those Eye Banks that could not collect any cornea. They should have been encouraged for cornea collection by supplying better facilities and human resources. The districts, which do not have any eye bank, yet, can be covered under eye bank services. Ophthalmologist and NGOs have better scope to spread their interest in those areas. For this noble work, human resource for Eye Banking is inadequate in Marathwada. Some Eye banks shows superior work contributing the corneal collection. These eye banks should be added in NPCB's 'list of functional eye banks.' More ophthalmic surgeons for corneal grafting and trained ophthalmic assistants especially for the post operative care of the patient should be appointed. They have the workload of surgery, administrative and planning work for that they are not getting sufficient time to share for Eye Bank activities. For motivation, active counselling can be effective even in families who do not have prior knowledge of eye donation. Unfortunately, Corneas cannot be retrieved from deceased persons whose legal next kin are not available. There should be some policy to overcome this problem. A scope of an advanced research is inviting from this end to invent a novel method or preservation medium which can preserve the cornea for longer period. Eye banks should be granted for the infrastructure

facility development to stimulate the enthusiasm in eye bank services. Unavailability of vehicle especially in Govt. Eye Bank is worth mentioning. With this study, it was observed that there is a need of Hospital Cornea Retrieval Program and trained counselors in Marathwada region. Intensive publicity of eye donation by audio visual aids (such as short video films and displaying other educational material at public places) and co-operation of government and non-government agencies is needed to enhance the voluntary eye donations. In addition, street plays on the topic 'Eye Donation' can be regulated on contract basis in rural area with the help of schools, colleges and other local drama agencies.

There is a scope to launch functional Eye Banks in Beed, Parbhani and Hingoli district. Government and certain NGOs can come together to step up this way. More Eye Banks can be established in rural area to achieve more publicity and awareness regarding eye banking services. It can also be said that Govt. Eye eye banks should improve their performance in eye donation awareness.

Also, there can be evolved, a facility to fill up the forms for eye donation in traditional banking services, along with their transaction forms. Schools, Colleges and other educational services have mandatory details of the students. Along with the admission form, an eye donation form can be provided, so that maximum registration can be achieved. Moreover, eEye Banking, An *in silico* eye banking registration services, can be developed to facilitate the easy registration for eye donation. Civil Services can organize the campaign at certain Malls and Multiplexes in metro cities. In short, co-operation of government and non-government and intensive publicity (i.e. more public awareness programs vigorously) is needed to enhance the voluntary eye donations. Eye donation is an even-handed responsibility. Proper human resources, infrastructure, increase in eye bank numbers with novel ideas of eye donation and its popularity within the society, can revolutionise the fight against corneal blindness.

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