

# Analysis Of Motivating Factors For Eye Donation Among Families Of Eye Donors In East India – A Questionnaire-Based Study

Dr Smruti Priyadarsini Kar  
Dr Prasanta Kumar Nanda

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## **Abstract**

### **Purpose:**

To report the factors influencing eye donation among families of successful eye donors in India.

### **Methods:**

The consenting family members of 100 deceased individuals who donated eyes between April 2022 and March 2023 were retrospectively interviewed via a telephonic questionnaire survey. Details regarding the donors and their families, motivating factors for eye donation, and time taken for tissue recovery were collected and analyzed.

### **Results:**

The mean age of donors was 66.8 years, and only 13.9% of them had pledged to donate their eyes before death. For 62.3% of donations, children of donors were the primary consenters for eye donation. In 18.8% of donors, there was a previous history of eye donation in the family. Many donations were motivated by a non-governmental organization volunteer (40.5%) or by a grief counselor at the hospital (27.4%). Hospital-based corneal retrieval programs and donations where the first eye bank contact was made through hospital personnel had the greatest percentage of rapid enucleations (performed within 3 h after death) (48.7% and 49.1%, respectively;  $P = 0.001$  and  $P = 0.02$ , respectively).

### **Conclusion:**

Children of donors, typically in the working-age group, most often make the decision for donation, and hence, future awareness programs should focus on this specific population. All types of hospitals should advocate for eye donation as they are a common point of contact for a grieving family, and health-care professionals at all levels should be considered for training as motivators for eye donation.

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Date of Submission: 29-02-2024

Date of Acceptance: 09-03-2024

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## **I. Introduction**

Blindness due to corneal diseases is the second leading cause of blindness in most of the developing countries. In India, it is estimated that approximately 6.8 million people have unilateral blindness due to corneal diseases and 14.7% of them have bilateral involvement. A critical tool in addressing corneal blindness is corneal transplantation, which depends entirely on voluntary eye donation after a person's death. While some of the major countries in the world follow an opt-out system (anyone who has not refused is a donor) for eye donation, India still follows an opt-in system where explicit consent is mandatory before eye donation. Hence, the chances of corneal procurement are largely motivated by donors and their families' selfless act. On the other hand, because of low utilization rates for corneal transplantation, the need in India is almost 270,000 donor eyes per year to perform 100,000 transplantation surgeries. Thus, there exists a huge disparity in demand and supply of donor corneas, which is a significant challenge in the treatment of corneal blindness in India.

Several studies among various Indian populations have thrown light on the general prevalent attitude regarding eye donation. Although awareness about eye donation ranges from 28% to 35% in rural people to 100% in medical students and average willingness to donate is 59.6% among 25 different studies, eye donation rate is still only 0.9% of the death rate in the Indian population. There is a strong need for a catalyst to convert intentions into actions. Catalyst was used to promote eye donations in the Hospital Cornea Retrieval Programs (HCRPs), where trained grief counselors stationed in hospitals helped motivate potential families to donate. Although HCRPs form the backbone of most eye banks, home deaths also contribute a significant proportion of the overall donor eyes collected. For all donations that happen after death at home or via HCRP after death in a hospital, ultimately it is the decision taken by the next of kin in the first crucial hours that permits donation to occur. There are few studies in literature which examined beliefs in this important group (next of kin of the deceased) which ultimately become responsible for eye donation. A study by Sharma *et al.* evaluated attendants of critically ill

hospitalized patients and found that time taken for motivation was significantly lower in families which were partially/fully aware about eye donation, and that grief counseling had the highest influence on consenting for eye donation. Another study by Subburaman *et al.* found that the overall awareness and knowledge about eye donation was better in donors' families in comparison to non-donors' families and, most of the time, donors were motivated by an acquaintance, family, or a friend to donate.

We believe that there are potential factors that might predict successful eye donation in a family and it is worthwhile to study these factors in detail to improve our donation rates. While the existing literature has details on attributes that favor eye donation among possible donors, this study aimed to analyze the motivating factors that instigated eye donation among relatives of actual eye donors. Our findings could help the stakeholders to focus on the essential strategies to improve voluntary donations further.

## II. Methods

This was a retrospective, telephonic questionnaire-based study administered to the relatives of successful eye donors of a tertiary eye hospital in South India. The study was done during the period spanning April 1, 2022–March 31, 2023. It was approved by the institutional ethics committee, and it adhered to the tenets of Declaration of Helsinki. As an institutional protocol, enucleations up to 12 h were allowed after confirmation regarding cold storage of the deceased body. Final utilization of retrieved corneas was decided after a thorough slit-lamp examination of donor tissue at the base hospital. All tissue retrieval and utilization protocols strictly adhered to the standards of eye banking in India. Details of donors and their next of kin's telephone numbers were obtained from the donor database maintained at the eye bank. Demographics of donors and details regarding time of enucleation, place and time of death were collected. Time to enucleation was stratified as within 3, 3–6, 6–8, and 8–12 h. Distance between the place of enucleation and the base hospital was also documented for all enucleations. Type of collection was classified into three categories: (1) base hospital enucleation, (2) retrieval through HCRP, and (3) eye collection center retrieval. Eye collection centers are small facilities installed in the local community beyond 100 km from the base hospital and are affiliated to the eye bank. They have a trained technician who acts as a grief counselor, harvests eyes, and is also responsible for safe storage and transportation to the eye bank.

The questionnaire used was developed by the eye bank team after focused discussion with non-governmental organization (NGO) volunteers and grief counselors who closely work among the general public to motivate them for eye donation. Additionally, two domain experts ascertained the face validity of the questions. The questionnaire consisted of 15 questions in total. The first part of the questionnaire included details regarding the donor's wish, pledge status, and occupation. The second part of the questionnaire was designed to collect details regarding the commonly perceived motivating factors in the existing literature.<sup>[69111213]</sup> It included information on family members' wishes, their relation to the deceased, their occupation, motivation by a grief counselor or NGO volunteer, and source of eye donation awareness. Additional information like previous eye donation in the family, previous history of corneal transplantation, and first contact person for eye donation (the person through which the family reached out to Aravind eye bank) were also collected. First contact persons were categorized into three groups: (1) direct contact, wherein a close family member or relative contacted the eye bank directly, (2) contact through an NGO volunteer, wherein the donor family had sought the help of a volunteer to contact the eye bank, and (3) contact through a hospital, wherein families contacted through hospital personnel (other than the base hospital where the eye bank is located). Two individual bilingual translators translated the questions into native language (Tamil), which was then approved by the ethical committee. Ten out of 15 questions had discrete choices (i.e., yes/no), while the remaining were open ended.

## III. Results

A total of 300 eyes were received during the study period from 170 donors. Seventy six(76%) donors resulted from voluntary donations, while 24 (24%) resulted from HCRPs. Survey data was gathered from a large majority of donor families, including 73.3% voluntary donors and 26.7% HCRP donors. There was a slight majority of male donors (55.0%), and the donors were generally older, with 70% being over the age of 60 and only 13% were aged 40 or less. Overall, only a small percentage of donors had formally pledged their eyes before death (13.9%), though most had expressed their wish to donate (58.8%). Regarding donor occupation, only a small percentage of donors were noted to have worked in occupations in which they are more likely to donate, such as health-care worker (2.1%) or NGO volunteer (1.2%). Although all donations were done after getting family members' consent, in most cases, the family member of the deceased stated a wish for the donation (81.9%), and many among them (18.8%) belonged to a local NGO. There was a previous eye donation in the family in a minority of cases (18.8%), and 5.1% had history of previous corneal transplantation in one of their relatives. Common sources of eye donation awareness included NGOs (42.3%), the media (31.9%), and hospitals (16.5%). At the time of death, 40.5% and 27.7% of donations were motivated by NGOs and grief counselors, respectively. Time from death to enucleation varied with the distance between the place of death and the base hospital ( $P = 0.008$ ). Highest percentage of rapid enucleations (eyes enucleated within 3 h) was found in

individuals who died 25 km within the base hospital (49.2% vs. 27% or less in all other distance groups). Time between death and enucleation also varied depending on where the corneas were collected from (base hospital, HCRP, or collection center) ( $P = 0.001$ ), with the greatest percentage of rapid enucleations noted for HCRPs and retrieval through eye collection centers (48.7% and 47.8%, respectively). Time between death and enucleation additionally differed based on the category of the first contact after death (direct contact, NGO volunteer, hospital) ( $P = 0.02$ ), with the greatest percentage of rapid enucleations found in cases where the first contact was made through hospital personnel (49.1%).

#### IV. Discussion

The majority of eye donations during the study period was from voluntary donations, and nearly two-thirds of donors were >60 years of age compared to only 13% in the <40 years age group. Our findings highlight the fact that good-quality corneas from younger donors are uncommon<sup>[14]</sup> and there is a need to scale up existing donation rates to obtain enough corneal tissue to meet the demand for corneal transplantation. More than the donor's wish, it was the family members' wish to donate in 82% of donations, indicating their crucial role in donation. For 62% of donations, it was the donor's children who made the final decision to donate. So, apart from conducting awareness programs in younger student population, it is important to focus on the working population (30–50 years) who are likely to be decision-makers regarding donation in the near future.

Among our sample of successful donors, only 14% had pledged their eyes officially before death, whereas 59% had expressed their willingness to donate. This is in line with the studies in the past in which the desire to donate was high, but with a poor formal pledge rate among donors.<sup>[615]</sup> This indicates that merely promoting the act of pledging eyes during eye donation awareness programs is not sufficient. Not all pledges convert into donations and not all donations are by pledged donors. It is common in Indian culture to fulfil a dying person's wish, and the act of encouraging potential donors/pledgers to express their wish to donate their eyes to their family members should be focused on more than the act of pledging. Families play an important role in voluntary donations in India. Dissuasion by family members is one of the major reasons for not donating eyes in many of the studies done in the Indian population.<sup>[48]</sup> Indeed, families can be either a positive catalyst for or an obstacle blocking eye donation.

Similar to the study by Subburaman *et al.*,<sup>[6]</sup> where 23.7% had previous eye donation in their families, it was interesting to note that around 20% in our study population also had a previous donation in their families. This pattern of donation and altruism within families should be appreciated and encouraged by the eye banks. It can be accomplished by regularly making them feel good about their selfless act and by honoring them with certificates/medallions that showcase their selfless act to the community. As noted by Sharma *et al.*,<sup>[7]</sup> people who have witnessed prior eye donation can be easily motivated for eye donation in the future and can also serve as key facilitators in their respective community/neighborhood.

Around 5% of our donors had previous corneal transplantation among their known family members. This is another potential area for us to focus, that is, the families who benefit from eye donations, like the receivers of corneal transplantation. Similar to the concept of replacement blood donations, where a friend or family member of the recipient donates blood ensuring a consistent supply, these beneficiaries of eye donation can be motivated for pledging while they register in the eye bank and they can serve as good propagators for eye donation.

A study by Subburaman *et al.*<sup>[6]</sup> reported that 71% of donor families received positive persuasion from a second person to donate. Motivation around the time of death can play a crucial role in successful eye donations. In our study, around 40% of consenting family members were motivated by volunteers outside the family circle. At the time of extreme grief, it is difficult for the primary family members to think about eye donation unless the decision to donate eyes has been very strong in the donor family.

In the study by Subburaman *et al.*, the majority of nondonors felt that they would have donated if someone had reminded or encouraged them to do so.<sup>[6]</sup> Failure to request has been the speculated common cause of nonprocurement of eyes for donation.<sup>[16]</sup> A simple thought about eye donation to family members from a third person can stimulate a viable donation in the grieving family. This is one area where eye donation programs can focus, creating more catalysts for eye donation as opposed to encouraging pledging. Rather than a pledge card, a catalyst card can be a more direct aid in procuring donations. Target groups for potential catalysts can include religious faith leaders, emergency medical personnel, health-care workers, police officers, young student volunteers, and other non-family members who have a chance to interact with the deceased families and would not hesitate to raise the topic of eye donation.<sup>[47]</sup>

In our study population, aside from the 31.7% deaths that occurred in hospitals, an additional 27% contacted a private or government hospital for eye donation after death. Ronanki *et al.*<sup>[15]</sup> reported that except for families which had previously donated, most were not aware of the whereabouts of eye donation centers. This highlights the need for clear information boards in the vicinity of intensive care unit (ICU)/casualty in all hospitals and primary health centers to promote widespread dissemination of information related to eye donation and

nearest eye bank details. Additionally, every health-care worker can be considered as a potential advocate for donation. At some point around death, an encounter with a health-care professional will likely occur, and it is natural for health-care workers to deal with the idea of donation in a professional manner.

In the study by Sharma *et al.*,<sup>[7]</sup> graduates and people in higher socioeconomic status were more aware about eye donation. On the contrary, in our study of family members who stated the wish to donate, people with higher education, like professionals/managers, were only 11.9% of the sample, and most were nonprofessional workers (65.1%). This is in line with the previous studies which found that while higher literacy and socioeconomic status had a positive impact on awareness, it did not translate to a greater willingness to donate.<sup>[8,12]</sup>

In contrast with the findings by Ronanki *et al.*<sup>[15]</sup> which found persons in social service to be less willing to donate, 18% of our donor family members belonged to an NGO and three-fifths of the voluntary donations were directly motivated by NGO volunteers. NGO volunteers are self-trained grief counselors who have a better connect with the local community as well as the eye bank. For more than half of the eye donors in our study group, such volunteers served as the primary contact person for eye donation. India, as a country that is spread across both urban and rural areas, has a varied type of population. The reach to this population is not possible without the involvement of field workers and NGO volunteers who are aligned with the goal of corneal donation. These field workers and volunteers should be actively involved in our awareness initiatives.

The main sources of eye donation awareness have been social media (TV, newspapers, and radio) and NGO volunteers. Although awareness about eye donation ranges from 28% to 35% in rural people to 100% in medical students, it does not always translate into successful eye donations.<sup>[5,17,18]</sup> Although there are studies suggesting that awareness does not strongly influence willingness to donate,<sup>[8]</sup> it still plays an important role. Sharma *et al.*<sup>[7]</sup> found that the time taken by grief counselors to motivate those who were already partially/fully aware of eye donation was significantly lower, suggesting they could be convinced easily. Hence, strategies to promote awareness among the general population should continue in parallel with the new proposed methods such as promoting catalysts over pledging and targeting working-age adults.

Limitation of this study was that it was based on telephonic interviews that were conducted many months after the actual act of eye donation. Therefore, there is a possibility of recall bias. In addition, findings of the study might be limited to the local population and cannot be generalized as India is a country with varied cultural differences. Finally, we did not compare donor and family features with a control population of nondonors.

## V. Conclusion

Family members making the primary decision to donate were most often children of the donors. Hence, this working-age population should be the focus of future eye donation awareness programs. Hospitals are a common point of contact for a grieving family. Therefore, health-care professionals at all levels should be considered as potential motivators for eye donation who can act as a catalyst during the crucial hours around death. NGOs play a major role in reaching a wider population, and future strategies by eye banks should include them to motivate the altruistic act of donation.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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## **Questionnaire**

1. Has the Donor pledged for eye donation before death?  
Yes/No
2. Did the deceased donor wish to donate his/her eyes before death?  
Yes/No
3. Was the donor a health-care worker? Yes/No
4. Was the donor involved in an NGO or an NGO volunteer? Yes/No
5. Was the eye donation the wish of any of the family member?  
Yes/No
6. If so, what is the family member's (person who wished for eye donation) relation to the donor?
  - Children
  - Spouse
  - Sibling
  - Grandchildren
  - Second-degree relative
  - Parent
7. What was the occupation of the family member who wished for eye donation? Mention.
8. Was the family member involved in an NGO or an NGO volunteer? Yes/No
9. Was there any previous eye donation in the family?  
Yes/No
10. If so, what was his/her (previous donation in family) relation to the donor?
  - Spouse
  - Sibling
  - Children/parent
  - Second-line relative
11. Was there any previous history of corneal transplantation among any of the family members?  
Yes/No
12. What was the source of eye donation awareness? (Choose the most important)
  - Media
  - NGO
  - Hospital
  - Friends/family
  - Others – mention
13. How did you communicate with the tertiary hospital for eye donation?
  - Through family/friends
  - Through hospital personnel
  - Through an NGO volunteer
14. Was there any NGO motivation at the time of donation?  
Yes/No
15. Was there any grief counselor motivation?  
Yes/No