Analysis of motivating factors for eye donation among families of eye donors in South India – A questionnaire-based study

Josephine S Christy, Priyanka K Ramulu, Vijhaya Priya T, Megha Nair, Rengaraj Venkatesh

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

Methods: The consenting family members of 434 deceased individuals who donated eyes between April 2019 and March 2020 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.

Key words: Donation Catalyst, eye donation motivation, HCRP

Blindness due to corneal diseases is the second leading cause of blindness in most of the developing countries.\(^1\) 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.\(^2\) 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.\(^3\) 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.\(^4\) 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,\(^5\) eye donation rate is still only 0.9% of the death rate in the Indian population.\(^6\) There is a strong need for a catalyst to convert intentions into actions.\(^7\) 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.\(^8\) 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.\(^7\) 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.\(^8\) found that the overall awareness and knowledge about eye donation was better in donors’ families in comparison to non_donors’

Departments of Cornea and Refractive Services, \(^*\)General Ophthalmology, \(^*\)Glaucoma Services, Aravind Eye Hospital, Pondicherry, India, \(^*\)River Hill High School, Clarksville, Maryland, United States, \(^*\)Department of Ophthalmology, Indira Gandhi Medical College and Research Institute, Kathirkamam, Pondicherry, India

Correspondence to: Dr. Josephine S. Christy, Aravind Eye Hospital, Thiruvallukuppam, Pondicherry 605007, India. E-mail: josyfred@gmail.com

Received: 21-Dec-2021 Revised: 20-Mar-2022 Accepted: 09-Jun-2022 Published: 26-Aug-2022

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

Cite this article as: Christy JS, Ramulu PK, Priya TV, Nair M, Venkatesh R. Analysis of motivating factors for eye donation among families of eye donors in South India – A questionnaire-based study. Indian J Ophthalmol 2022;70:3284-8.
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,\[8-11\] 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.

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, 2019–March 31, 2020. 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.\[6,9,11-13\] 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. Pilot testing was done in a small set of people who had eye donations in their family and were regular patients to Aravind Eye Hospital, Pondicherry. Two study coordinators were trained to administer the telephonic questionnaire. As part of the training, they developed a simple script in the patient’s native language and practiced introducing themselves, explaining the study objectives, and strategized on how to administer each question consistently to the study subjects during the pilot phase.

Statistical analysis

The demographic details and factors associated with eye donation, which included the answers for the 15-item questionnaire, were summarized as frequencies and percentages. Factors that influenced time between death and enucleation were evaluated across variables including distance from the base hospital, type of collection, and first contact person after death. For analyses evaluating distance from the base hospital, only base hospital enucleations were analyzed as the other types of collections (like eye collection center and HCRP) involved little or no travel and enucleations were done by a local team who were not part of the base hospital. Chi-squared test and Fisher’s exact test were used to complete the above statistical comparisons. \( P \) value of <0.05 was considered as significant. STATA version 14 was used for statistical analysis.

Results

A total of 1011 eyes were received during the study period from 506 donors. Three hundred and eighty-five (76.1%) donors resulted from voluntary donations, while 121 (24%) resulted from HCRPs. Survey data was gathered from a large majority (430, 85.0%) of donor families, including 315 (73.3%) voluntary donors and 115 (26.7%) HCRP donors. There was a slight majority of male donors (55.0%), and the donors were generally older, with 70% (\( n = 301 \)) being over the age of 60 and only 13% (\( n = 56 \)) were aged 40 or less [Table 1].

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%) [Table 2]. Regarding donor occupation, only a small percentage of donors were

| Table 1: Demographics of eye donors |
|-----------------------------------|
| n (%) | n=430 |
| Age group in years | |
| ≤20 | 17 (4) |
| 21-40 | 39 (9.1) |
| 41-60 | 73 (17) |
| >60 | 301 (70) |
| Sex | |
| Male | 237 (55) |
| Female | 193 (45) |
Table 2: Attitudes and characteristics of eye donors and next of kin family members giving permission for donation

| Donor details | n (%)  n=430 |
|---------------|-------------|
| Number of donors who pledged their eyes before death | 60 (13.9) |
| Number of donors who expressed their wish to donate before death | 253 (58.8) |
| Number of donors who were health-care workers by occupation | 9 (2.1) |
| Number of donors who were NGO volunteers | 5 (1.2) |
| Number of donations where it was the family member’s wish | 352 (81.9) |
| Number of family members who were health-care workers | 14 (3.9) |
| Number of families where the members were NGO volunteers | 66 (18.8) |
| Number of families which had history of previous eye donation among the relatives | 81 (18.8) |
| Relation of the deceased to the previously donated family member | |
| Spouse | 20 (24.7) |
| Sibling | 18 (22.2) |
| Children/parent | 24 (29.6) |
| Second-line relative | 19 (23.5) |
| Number of families which had history of previous corneal transplantation among the relatives | 22 (5.1) |
| Number of families which received motivation after donor’s death | 292 (67.9) |
| NGO volunteer motivation | 174 (40.5) |
| Grief counselor motivation | 118 (27.4) |
| Source of eye donation awareness | |
| Media | 137 (31.9) |
| NGO | 182 (42.3) |
| Hospital | 71 (16.5) |
| Friends/family | 32 (7.4) |
| Others | 8 (1.9) |

NGO=nongovernmental organization. Others - local awareness programs in the community, awareness posters, teachers

Table 3 displays the characteristics of family members who stated a wish for eye donation. Most of them were children of the deceased (62.3%) and roughly one third (31.3%) belonged to an occupation related to service and sales work.

Time from death to enucleation varied with the distance between the place of death and the base hospital ($P = 0.008$) [Table 4]. 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%).

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 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. 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 fulfill 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. Indeed, families can be either a positive catalyst for or an obstacle blocking eye donation.

Similar to the study by Subburaman et al., 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.,[7] 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.

### Table 3: Summary of characteristics of family members who stated a wish for eye donation

| Relationship to the donor | n (%) n=352 |
|---------------------------|-------------|
| Children                  | 218 (62.3)  |
| Second-degree relative    | 38 (10.8)   |
| Spouse                    | 33 (9.4)    |
| Sibling                   | 27 (7.7)    |
| Parent                    | 21 (6)      |
| Grandchildren             | 15 (4.3)    |
| Occupation                |             |
| Managers and professionals| 42 (11.9)   |
| Technicians and associate professionals | 28 (8) |
| Clerical support workers  | 75 (21.3)   |
| Service and sales workers | 110 (31.3)  |
| Skilled and craft-related workers | 33 (9.4) |
| Elementary occupation     | 11 (3.1)    |
| Students                  | 13 (3.7)    |
| Religious community member| 4 (1.1)     |
| Nil/home makers           | 36 (10.2)   |

### Table 4: Factors associated with the time between death and enucleation

| Time between death and enucleation | P |
|-----------------------------------|---|
|                                  | <3 h | 3-6 h | 6-8 h | 8-12 h |
| Distance between place of death and base hospital (in km) |       |       |       |       |
| <25                               | 29 (49.2) | 25 (42.4) | 2 (3.4) | 3 (5.1) | 0.008b |
| 26-50                             | 19 (27.1) | 45 (64.3) | 1 (1.4) | 5 (7.1) |
| 51-100                            | 21 (18.0) | 84 (71.8) | 6 (5.1) | 6 (5.1) |
| >100                              | -     | 2 (100) | -     | -     |
| Type of collection                |       |       |       |       |
| Base hospital enucleation         | 69 (27.8) | 156 (62.9) | 9 (3.6) | 14 (5.7) | 0.001b |
| HCRP                              | 56 (48.7) | 54 (46.9) | 1 (0.9) | 4 (3.5) |
| Eye collection center             | 32 (47.8) | 33 (49.2) | 1 (1.5) | 1 (1.5) |
| First contact person after death  |       |       |       |       |
| Direct                            | 27 (34.2) | 49 (62.0) | -     | 3 (3.8) | 0.019h |
| NGO volunteer                     | 75 (31.4) | 142 (59.4) | 10 (4.2) | 12 (5.0) |
| Hospital                          | 55 (49.1) | 52 (46.4) | 1 (0.9) | 4 (3.6) |

HCRP=hospital corneal retrieval program, NGO=nongovernmental organization. *Includes enucleations from base hospital alone. *Chi-square test; *Fisher’s exact test.
workers to deal with the idea of donation in a professional manner.

In the study by Sharma et al.,7 graduates and people in higher socioeconomic status were more aware of 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 previous studies which found that people with higher literacy and socioeconomic status had a positive impact on awareness, yet it did not translate to a greater willingness to donate.[8,12]

In contrast to the findings by Ronanki et al.13 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.[8,12] Although there are studies suggesting that awareness does not strongly influence willingness to donate,8 it still plays an important role. Sharma et al.7 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.

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, healthcare 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.

References
1. Oliva MS, Schottman T, Gulati M. Turning the tide of corneal blindness. Indian J Ophthalmol 2012;60:423-7.
2. Gupta N, Tandon R, Gupta SK, Sreenivas V, Vashist P. Burden of corneal blindness in India. Indian J Community Med 2013;38:198-206.
3. Gain P, Jullienne R, He Z, Aldossary M, Acquart S, Cognasse F, et al. Global survey of corneal transplantation and eye banking. JAMA Ophthalmol 2016;134:167-73.
4. Gupta N, Vashist P, Ganger A, Tandon R, Gupta SK. Eye donation and eye banking in India. Natl Med J India 2018;31:283-6.
5. William AM, Muir KW. Awareness and attitudes toward corneal donation: Challenges and opportunities. Clin Ophthalmol 2018;12:1049-59.
6. Subburaman GB, Kempen JH, Durairaj S, Balakrishnan V, Valaguru V, Namperumalsamy VP, et al. Making the decision to donate eyes: Perspectives from the families of the deceased in Madurai, India. Indian J Ophthalmol 2020;68:2094-8.
7. Sharma B, Shivastava U, Kumar K, Baghel R, Khan F, Kulkarni S. Eye donation awareness and conversion rate in hospital cornea retrieval programme in a tertiary hospital of Central India. J Clin Diagn Res 2017;11:NC12-5.
8. Tandon R, Verma K, Vanathi M, Pandey RM, Vajpayee RB. Factors affecting eye donation from postmortem cases in a tertiary care hospital. Cornea 2004;23:597-601.
9. Gupta A, Jain S, Jain T, Gupta K. Awareness and perception regarding eye donation in students of a nursing college in Bangalore. Indian J Community Med 2009;34:122-5.
10. Patil R, E RP, Boratne A, Gupta SK, Datta SS. Status of eye donation awareness and its associated factors among adults in rural pondicherry. J Clin Diagn Res 2015;9:L101-4.
11. Prabhu PB. Concerns regarding eye donation among health seekers attending a reputed eye care institution in North Kerala. Kerala J Ophthalmol 2016;28:43-7.
12. Bhandary S, Khanna R, Rao KA, Rao LG, Lingam KD, Binu V. Eye donation - awareness and willingness among attendants of patients at various clinics in Melaka, Malaysia. Indian J Ophthalmol 2011;59:41-5.
13. Kakkanatt A, Anand AF, Gopinath G. How to motivate people for donor eyes with active support and participation of NGOs. Int J Res Med Sci 2018;6:2781-4.
14. Tandon R, Singh A, Gupta N, Vanathi M, Gupta V. Upgradation and modernization of eye banking services: Integrating tradition with innovative policies and current best practices. Indian J Ophthalmol 2017;65:109-15.
15. Ronanki VR, Sheeladevi S, Ramachandran BP, Jalbert I. Awareness regarding eye donation among stakeholders in Srikakulam district in South India. BMC Ophthalmol 2014;14:25.
16. Mack RJ, Mason P, Mathers WD. Obstacles to donor eye procurement and their solutions at the University of Iowa. Cornea 1995;14:249-52.
17. Lal B, Usgaonkar U, Narvekar H, Venugopal D. Awareness and knowledge on eye donation among Allied Health Science, medical, and nursing students in Goa. J Curr Ophthalmol 2018;30:255-62.
18. Chowdhrury RK, Dora J, Das P. Awareness of eye donation among medical and nursing students: A comparative study. Indian J Ophthalmol 2021;69:1511-5.
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