

## Making the decision to donate eyes: Perspectives from the families of the deceased in Madurai, India

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**Purpose:** To identify factors affecting family members' decision whether to donate eye organs. **Methods:** A community-based case-control study based on in-home interviews with families of deceased individuals who had or had not donated eye organs, in Madurai district, Tamil Nadu, India. Data collected were knowledge and awareness of eye donations, whether the deceased individual had expressed or pledged willingness to donate, and family members' attitudes and willingness to donate their own eye organs. **Results:** Seventy-six families of donors and 256 families of non-donors completed the survey. Multivariable analysis showed that the following variables were significantly associated with a donation: age, whether the deceased had registered for eye donation, pre-expressed willingness of deceased to donate, whether family members personally know beneficiaries of eye donations, and higher score on a scale evaluating knowledge and awareness about eye donation. The majority of donors' families (71%) had been encouraged by someone to donate. Among non-donor families, a substantially larger fraction (52.8%) indicated they would have donated had someone reminded or encouraged them to do so, in comparison with those who indicated lack of awareness or knowledge (14.5%). **Conclusion:** Community programs are likely to be effective if they encourage individuals to pledge their eyes or express their willingness to donate their eyes to family members in advance of death; they increase public awareness of the value of eye donation. A friend, family member, neighbor or counselor approaching bereaved families and having a dialogue about eye donation would substantially increase the probability of a decision to donate.

**Key words:** Attitudes, case-control study, corneal transplantation, eye donations

Corneal blindness is the fourth leading cause of bilateral blindness globally<sup>[1,2]</sup> and is estimated to be the second most prevalent cause of blindness in many less developed countries. In India and Africa, the corneal disease is estimated to account for 14.6–15.4% and 8.2–30%, respectively of total bilateral blindness.<sup>[2,3]</sup> In India, approximately 6.8 million people are estimated to have vision less than 6/60 in at least one eye due to corneal diseases; of these, about a million are affected in both eyes.<sup>[4]</sup> It is expected that the number of individuals with unilateral corneal blindness in India will increase to 10.6 million by 2020.<sup>[4]</sup>

The number of cases of corneal blindness continues to grow due in part to poverty, malnutrition, lack of awareness of the need to seek immediate clinical care after trauma, and inadequate public sanitation.<sup>[3,5]</sup> At present, corneal transplantation is the primary sight-restoring solution for this condition, which relies on the donation of the eye organs of the deceased. However, a limited number of donations of usable eyes remains a major obstacle. A survey of corneal transplantation in 2012–13 estimated that 12.7 million people are waiting for transplantation globally, including 7 million in India.<sup>[6]</sup> During the year 2015–16,

only 59,810 eyes were donated in India against 6,267,685 registered deaths.<sup>[7]</sup> Additionally, utilization rates of tissues range from 33 to 49%<sup>[3]</sup> due to the poor quality of the tissue or clinical reasons. Thus, there is a huge gap between the need and availability of healthy corneas for transplantation.<sup>[8]</sup>

A recent review of 55 published studies across 13 countries<sup>[9]</sup> reports that across all included studies, 52% of respondents endorsed a willingness to donate their eyes after death, yet only 5% reported being pledged donors. Several research studies on eye donation in India have also reported that there is a high level of awareness and willingness to donate in the spectrum of communities studied.<sup>[10,11]</sup> Given this high level of awareness, it useful to focus on why conversion to actual donations is low. Most studies on eye donations include convenient study populations such as eye patients, family members of eye patients, general community populations, adolescents, university students, physicians, and medical or health science students, most of whom may be more inclined to donate organs than the general population. However, it is important to study the perspectives of family members of deceased individuals,

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since they play a central role in whether donation of the organs of the deceased actually occurs. Among the 52 studies reviewed in Williams and Muir (2018),<sup>[9]</sup> only one study<sup>[12]</sup> includes the next of kin of recently deceased potential donors who had not previously pledged to donate their corneas.

To adequately capture the perspectives of families, here we include family members of deceased individuals, some of whose eyes were donated and some of whose eyes were not donated. This case-control design allows us to contrast the perspectives of donor and non-donor families to understand the factors that influenced the donation decision.

## Methods

We conducted a community-based case-control study by gathering data from family members of deceased individuals. Aravind's ethics committee provided Institutional Review Board approval. Likewise, the Madurai District Magistrate (in Tamil Nadu, India) granted permission to access the Death Registers maintained by the vital statistics division for Madurai city.

### Sample selection

We selected cases from the donor database maintained at the largest eye bank in Madurai, Tamil Nadu, India. This eye bank collects an estimated 90% of all eye organs donated in Madurai district. Madurai district is 3,741 square kilometers in size with a population of 3.1 million. There were 153 donors residing in Madurai district who had donated their eyes between July 2014 and December 2014. We followed a cluster sampling approach. We grouped the 153 donors into 70 geographical localities which are each approximately 2 to 5 square kilometers in size, randomly selected 34 localities, and sampled all donors in the selected localities. This resulted in a sample of 91 donors.

Data on non-donors to serve as controls were selected from death registers maintained by local government authorities. Within each of the 34 localities selected for cases, controls (non-donors) were chosen using simple random sampling from among all deaths listed on the register. For the selected non-donors, we collected serial number, date of death, name, age, sex, cause of death and address. For increased power, multiple controls were selected for each donor. The families were contacted 6 to 9 months after the death, as suggested by our institutional ethics committee.

### Questionnaire development

As the study design is unique, in that the subjects are families of deceased individuals, a focus group discussion among seven donor families was conducted to take their perspectives into account in developing the questionnaire. Based on insights from the focus groups, we developed a structured questionnaire in two parts: the first part captured awareness and knowledge about eye donation in general; the second part assessed the attitudes and willingness of families of the deceased to donate the eye organs of their deceased family member. The second part was designed slightly differently between donors and non-donors, to capture specific details.

Since all interviews were conducted in the local language (Tamil), the questionnaire's linguistic consistency was checked by back translation, first from English to Tamil, and then from Tamil to English. Next, we tested the questionnaire in two ways: by piloting among the family members of patients who came for an eye examination to our base hospital, and by conducting in-home interviews with members of a few donor families who reside close to the hospital (these were not in our sample of donors). The questionnaire was finalized [see Supplemental Fig. S1] after incorporating inputs from the pilot testing.

### Interviewer training

Two interviewers who had previous experience in field-work were appointed. In addition to their main tasks of interviewing and data collection, they were responsible for meeting government authorities to collect details from death registries. As part of the training, the interviewers developed a script, practiced introducing themselves and explaining the study objectives, and strategized how to administer each question consistently to study subjects. They practiced the approach during the pilot study phase and refined their scripts and flow of activities accordingly.

### Data management

#### *Data collection protocol*

The field-workers followed a standardized data collection protocol. First, they made phone calls to confirm the availability of the head of the family or the next most senior family member of a minimum age of 22 years and arranged a convenient time to meet and explain the study in person. For houses without phone access, the field workers made a visit to the family's home and either completed the interview or fixed a later time for the interview. If consent was refused, or if the door was found locked for each of three attempted visits, they selected the next family on the list. After making contact and getting informed consent, they conducted the interview.

#### *Data verification, entry, and cleaning*

All the forms handed over by the field workers were first verified for completeness and then data were entered by the experienced staff of the Department of Biostatistics, into a database that was developed using Microsoft Access 2010 (Microsoft Corporation, Redmond, Washington, USA).

#### *Grouping and scoring of questions*

In the first part of the questionnaire we asked 21 questions of which 17 were intended to ascertain knowledge and awareness about eye donation, with the answers scored as 1 if the subject knew the correct answer to a question, and 0 otherwise. These 17 questions were grouped as follows: group 1 measured awareness about eye donation in general ("General Awareness") and included ten questions: 1, 5, 7, 8, 9, 10, 11, 16, 19 and 20. Group 2 captured specific knowledge which enables a family to take timely and appropriate action to execute an eye donation ("Specific Knowledge") and included seven questions: 6, 12, 13, 14, 15, 17 and 21 [see Supplemental Fig. S1].

#### *Data analysis*

All statistical analyses were performed using Stata 11 (Stata Corporation, College Station, Texas, USA). We summarized the data by means – (standard deviation (SD)) and frequencies (%). We used logistic regression analysis to determine the factors associated with making the decision to donate. Covariates used in the model for the eye donation decision were age, sex, education, pledge status, and knowledge scores.

## Results

A list of 514 families was generated by the sampling process described previously. The field workers attempted to contact all 514 families and successfully contacted 362 families (80 donors, 282 non-donors). Of this, 332 families (76 donors: 95% of those contacted, and 256 non-donors: 91% of those contacted) both consented and completed the questionnaire [Table 1].

### Demographic characteristics of the deceased and the respondents

We compared the sample of deceased donors and non-donors [see the upper panel of Supplemental Fig. S1]. We found that donor and control deceased subjects, on average, were not

different statistically in terms of age ( $P = 0.76$ ), sex ( $P = 0.67$ ), education ( $P = 0.15$ ), and reason for death ( $P = 0.21$ ). We also compared the samples of respondents from donor and non-donor families [lower panel of Supplemental Fig. S1] and again found that case and control samples were not statistically different in terms of age ( $P = 0.12$ ), sex ( $P = 0.77$ ), religion ( $P = 0.31$ ), education ( $P = 0.22$ ), and relationship to the deceased ( $P = 0.97$ ).

**Awareness and Knowledge about eye donation**

For each respondent, we obtained a General Awareness score by summing across the relevant 10 questions, and a Specific Knowledge score by summing across the relevant 7 questions. Larger scores indicate greater General Awareness and Specific Knowledge about eye donation, respectively. In Table 2 we show the mean (sd) scores for the two groups. Donor families were more aware than non-donors, 6.5 (1.37) vs. 5.2 (1.43);  $P < 0.001$ . Donors’ families also had more specific knowledge than non-donors about the logistics of implementing eye donation in the event of death, 5.3 (1.19) vs 1.8 (1.65);  $P < 0.001$ .

**Factors associated with the decision to donate**

In Table 3, we show the results of simple (“unadjusted”) and multivariable (“adjusted”) logistic regression analyses to identify factors that distinguish between families who donated eye organs, and those who did not. Multivariable logistic regression showed the following variables as statistically significant (all at  $P < 0.05$ ): lower age of deceased at death (age over 60 associated with lower odds of donation, adjusted odds ratio (aOR) = 0.34, 95% confidence interval (CI): 0.17–0.91), deceased had registered (aOR = 8.01, 95% (CI): 1.09, 58.92), expressed willingness of deceased to donate (aOR = 5.39, 95% CI: 1.84–15.74), family members know beneficiaries of eye donation (aOR = 7.29, 95% CI: 1.57–33.89), and higher overall knowledge and awareness score (>10 vs lower score, aOR = 13.17, 95% CI: 5.94–29.21). After adjusting for these factors, the other factors associated with the simple logistic

regression models were no longer associated with case vs. control status.

**What factors triggered the decision to donate**

In Table 4, we show an analysis of the factors that triggered donor families to make the decision to donate, separately for the cases when the deceased had versus had not pledged or expressed willingness to donate. Fifty-four (71.1%) donor families’ decisions were triggered by someone approaching and encouraging them, while 22 (28.9%) families’ decisions were simply triggered by a reminder, or recalling an earlier decision of the deceased to donate. Notably, of the 40 cases in which the deceased had not pledged or expressed willingness to donate in advance of death, 33 (82.5%) families’ decisions to donate were triggered by someone approaching and/or encouraging them.

Twelve families out of 256 (4.7%) non-donor families failed to donate even though the deceased had pledged or expressed willingness. The reasons were that the family members failed to recall the wishes of the deceased at the critical time (six families), assumed the tissue was unfit for donating due to illness of the deceased (three families), decided against the wishes of the deceased based on considerations of caste/religion (two families), or delayed making the decision until it was too late (one family).

**What could have helped non-donor families decide to donate?**

In Table 5, we show the frequency distribution of responses of non-donor families to the question about factors that would have helped them to decide in favor of donation. A simple step of someone approaching them at the right time to persuade, remind or encourage could have helped 125 (52.8%) families to make the decision to donate. Another 37 (14.5%) indicated that some form of awareness would have influenced them to donate the deceased’s eyes. Eighty-four families indicated that nothing would have helped them to make a positive decision at the time of the subject’s death, though 37 (44%) of these families expressed their willingness to donate in the future after interacting with the field worker (a form of raising awareness).

**Discussion**

Eye organ donation after death is a fundamental pre-requisite for corneal transplantation, which can potentially restore the sight of a large proportion of those who are blind from corneal diseases. The current pattern of eye donations is not sufficient in most parts of the world to clear the corneal blindness backlog. In India, there is a need to more than double the current eye donations, and improve the utilization rate of donated eyes.

Our results show that eye donation is likely to occur if the deceased had pledged to donate his or her eyes, or had expressed a willingness to do so to family members. Therefore,

**Table 1: Number of respondents by group and response category (%)**

Response	Group		Total
	Donor	Non-donor	
Interviewed	76 (88)	256 (73)	332 (76)
Door locked	0 (0)	33 (9)	33 (8)
Migrated	6 (7)	37 (11)	43 (10)
Refused	4 (5)	26 (7)	30 (7)
Total	86 (100)	352 (100)	438 (100)
Wrong/incomplete address	5	71	76

**Table 2: General Awareness and Specific Knowledge about eye donation among family members of eye donors and non-donors**

General Awareness and Specific Knowledge Scores	Group		P
	Donor (n=76)	Non-Donor (n=256)	
General Awareness: (potential range: 0-10)			<0.001
Mean (SD)	6.5 (1.37)	5.2 (1.43)	
Min-Max	3-9	2-9	
Specific Knowledge: (potential range: 0-7)			<0.001
Mean (SD)	5.3 (1.19)	1.8 (1.65)	
Min-Max	2-7	0-7	
Sum of Overall Awareness and Knowledge score: (potential range: 0-17)			<0.001
Mean (SD)	11.8 (2.02)	7.0 (2.65)	
Min-Max	7-16	2-14	

SD=standard deviation; Min=minimum; Max=maximum

**Table 3: Factors associated with eye donation: Results of simple and multivariable logistic regression analyses**

Variable	Sample characteristics number (%)		Unadjusted		Adjusted	
	Donor	Non-donor	OR (95% CI)	P	OR (95% CI)	P
Age at death						
<=60	18 (23.7)	64 (25.0)	1.00	0.82	1.00	0.03
>60	58 (76.3)	192 (75.0)	1.07 (0.59-1.96)		0.34 (0.17-0.91)	
Gender						
Female	30 (39.5)	108 (42.2)	1.00	0.67	1.00	0.178
Male	46 (60.5)	148 (57.8)	1.12 (0.66-1.89)		1.69 (0.78-3.65)	
Education						
Below secondary school	45 (59.2)	175 (68.4)	1.00	0.14	1.00	0.44
Secondary school or higher	31 (40.8)	81 (31.6)	1.49 ( 0.88-2.52)		0.72 (0.32-1.63)	
Had the deceased registered for donating his/her eyes?						
No	56 (73.7)	254 (99.2)	1.00	0.00	1.00	0.04
Yes	20 (26.3)	2 (0.8)	45.36 (10.30-199.66)		8.01 (1.09-58.92)	
Had the deceased expressed his/her willingness to donate eyes?						
No	40 (52.6)	244 (95.3)	1.00	0.00	1.00	0.00
Yes	36 (47.4)	12 (4.7)	18.30 (8.78-38.12)		5.39 (1.84-15.74)	
Has anyone in your family registered for eye donation?						
No	59 (77.6)	246 (96.1)	1.00	0.00	1.00	0.40
Yes	17 (22.4)	10 (3.9)	7.09 (3.09-16.27)		0.38 (0.09-1.64)	
Has any other person in your family already donated their eyes?						
No	58 (76.3)	250 (97.7)	1.00	0.00	1.00	0.46
Yes	18 (23.7)	6 (2.3)	12.93 (4.92-34.01)		1.67 (0.43-6.44)	
Do you know anyone else who has donated his eyes?						
No	44 (57.9)	216 (84.4)	1.00	0.00	1.00	0.22
Yes	32 (42.1)	40 (15.6)	3.93 (2.23-6.92)		1.70 (0.72-3.96)	
Do you know any beneficiary of eye donation?						
No	62 (81.6)	251 (98.0)	1.00	0.00	1.00	0.01
Yes	14 (18.4)	5 (2.0)	11.33 (3.93-32.66)		7.29 (1.57-33.89)	
Overall Awareness and Knowledge score (potential score 0-17)						
<=10	22 (29.0)	225 (87.9)	1.00	0.00	1.00	0.00
>10	54 (71.0)	31 (12.1)	18.28 (9.78-34.17)		13.17 (5.94-29.21)	

**Table 4: What factors triggered the decision to donate?**

Triggers	Deceased had pledged or expressed willingness to donate		Total
	No	Yes	
Recalled deceased's intent to donate, or were reminded	7 (17.5%)	15 (41.7%)	22 (28.9%)
Encouragement or motivation by counselor, acquaintance, friend, family member, etc.	33 (82.5%)	21 (58.3%)	54 (71.1%)
Total	40 (100.0%)	36 (100.0%)	76 (100.0%)

Pearson  $\chi^2$  (1)=5.3801, P=0.020

efforts to present opportunities to make such a pledge (e.g. at the time of issuing of identification cards or driving licenses) are likely to increase eye donations. To be effective, community programs should define specific goals in terms of the number of individuals who, in advance of death, pledge their eyes or express their willingness to donate their eyes to family members.

In addition, a large minority (33 out of 76, or 43%) of donor families made the decision to donate because someone persuaded or encouraged them, even though the deceased had not pledged or expressed willingness. Further, when non-donor families were asked about factors that would have helped them make

the decision to donate, 52.8% indicated that being approached or reminded would have helped, in contrast with only 14.5% who indicated that better knowledge or awareness would have helped. The new result our current study adds is that a friend, family member, neighbor or grief counselor approaching the deceased families in the event of death to promote corneal donation is likely to be quite effective in increasing donations.

In many countries, organ donors carry an identification card or driving license with a designation "OD" (organ donor) so that the decision to donate the organ could be made and recorded in advance of death. In India and many other

**Table 5: Responses of non-donor families (n=256) to the question: What could have helped you make a favorable decision to donate eyes? Responses have been grouped by the authors**

What could have helped?	n	%
Nothing	84	32.8
Approaching, persuading, encouraging or reminding	125	52.8
If somebody had initiated the discussion in the family	3	1.2
If somebody had approached us	89	34.8
If somebody had reminded us	43	16.8
Lack of awareness/knowledge	37	14.5
If we had a common number to contact	1	0.4
If we had general awareness about eye donation	15	5.9
If deceased was healthy <sup>^</sup>	9	3.5
If deceased had normal vision <sup>^</sup>	12	4.7

<sup>^</sup>Included in awareness because these reasons indicate lack of awareness/knowledge about requirements for donation

developing or middle-income countries, this concept is new and just getting propagated. To strengthen programmatic efforts to elicit pledges to donate corneal tissue before death, we suggest that pledge forms should include a confirmation similar to "I will notify my family and loved ones of my intent to donate my organs; my family members may be contacted to provide consent in the event of an incident". To mobilize community members to act as counselors and encourage eye donations, we suggest including text such as: "I will voluntarily approach family members of the deceased to persuade and encourage them to donate in the event of an incident". Donor families also can be encouraged to act as eye donation ambassadors by visiting families of the deceased and initiating a dialogue about eye/organ donation. In our study, 22% of the donor families were already practicing this and 16% were willing to do so when the opportunity arose. Donor-mobilizers constitute an important resource that should be leveraged and developed programmatically.

While there is a need to increase the volume of eye donations, it is also important to improve the utilization rate through appropriate measures. Timely retrieval would ensure the quality and usability of tissue. Hence, collection centers with trained technicians who can reach the deceased within an hour or two of death and collect the tissues must be created and maintained. Currently, under the World Health Organization's Vision 2020 blindness alleviation program, many government and non-government eye hospitals are establishing rural primary eye centers to serve a defined community of 50 to 60 thousand population living in a radius of 5 to 7 kilometers, staffed by qualified and trained vision technicians.<sup>13</sup> These technicians potentially could be trained to reach families experiencing death in a timely manner to collect and preserve the tissues in their service region.

A limitation of this study is that since attitudes of family members were measured retrospectively, we cannot be certain that they accurately reflect the attitudes at the time of the death. Further, the very act of donating the eyes of the deceased family member may have influenced subsequent attitudes of family members, thereby potentially biasing any measured differences in attitudes between the donor and non-donor families. A strength of this study is the inclusion in the study population of family members of both, donors and non-donors.

## Conclusion

In conclusion, there is a significant gap between the need and availability of donor tissues for addressing corneal blindness

in India and other developing countries. It is important to take proactive measures to address this challenge. Approaching family members of a deceased individual in the event of death, and encouraging or reminding them regarding the option of cornea donation, increases the chance of eye donation. Currently, eye donation promotional activities help to attract more pledgers but it will take decades before these donations occur. Thus, the focus of promotional activities also should include counseling of families at the time of death, to more promptly address the current need for corneal tissue donation, as well as making the general population more aware of the benefits of eye and other organ donation. Donor families and eye donation pledgers themselves are a valuable source of volunteers who could help governmental and non-government organizations, social workers, etc., in implementing such programs.

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## Conflicts of interest

There are no conflicts of interest.

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