



Awareness and knowledge about eye donation and the impact of counselors: A North Indian perspective

Dear Editor,

We read with great interest the article by Lal et al.¹ regarding awareness and knowledge about eye donation among students in Goa. Even though several studies^{2,3} have been reported from south India in regards to eye donation, there is paucity of literature from central and north India. Lal and associates¹ update us about the current status of eye donation trends in central India, and we would like to share our experience from north India.

From March 2017 till February 2018, we interviewed 407 people in Delhi (north India) to understand the trends, awareness, knowledge, influences, and barriers to eye donation in Indian society.

In our cohort, we found that the majority of people willing for eye donations were in the 32–52 years age group, and age did not have any correlation to willingness for eye donation ($P = 0.64$). Prior wish to donate eyes also had no effect on the family's decision for eye donation ($P = 0.09$). The socioeconomic status of the participants in terms of urban and national quintile also did not have any impact on the consent for eye donation. Socioeconomic status was evaluated using KoBoToolbox, a Harvard Humanitarian Initiative, which is an open source suite of tools for data collection and analysis in humanitarian emergencies and other challenging environments and was built to address this gap (<https://www.kobotoolbox.org/>). This equity tool was designed using the source data of Demographic and Health Survey (DHS) of 2005–06.⁴ Statistical analysis was performed using SPSS statistical software (SPSS version 21. Inc., Chicago, IL, USA). Chi-square test was used to compare categorical variables, and independent sample *t*-test was used to compare continuous variables. Statistical significance was defined at a level of 5% ($P < 0.05$). There was no significant difference in willingness for eye donation between various religious groups ($P = 0.194$). When parents were approached, they consented 50% of the time for eye donation of their child, followed by siblings (42.9%), relatives (41.6%), spouse (36.5%), and children (34.5%). The decision for eye donation was mainly self-driven (36.97%),

followed by consultations with relatives (33.52%) and parents (15.59%).

Our eye bank over the years has tried to standardize eye donation practices^{5,6} and like many other eye banks in India, has adopted the concept of Eye Donation Counselors (EDC) to approach families and proactively counsel them for eye donation. One of the highlights of our study was the positive impact of EDCs on families in deciding for eye donation ($P = 0.05$).

We found that three hundred and sixty (88.45%) participants had heard about eye donation; however, there was no statistical correlation between willingness to donate eyes and prior awareness of eye donation ($P = 0.13$).

Lastly, we noted that the foremost concern before decision-making was transparency in how the cornea would be used (32.25%). The concern with regards to whether the body would remain intact after eye donation ($P < 0.05$) significantly decreased the probability of consent for eye donation. Similarly, family becoming upset ($P < 0.05$), concerns on whether body would be treated properly ($P < 0.05$), and religious reasons ($P < 0.05$) also significantly impacted (negatively) the chance of getting consent for eye donation.

Our observations, along with Lal et al.¹ and other studies, form a platform for government and non-government agencies to work on eye donation models on a national level. These models could shape up and streamline the eye donation process in the country. Departments should be formed in the government to overlook organ donation, and satellite centers should be opened in smaller towns and cities to make tissues available to local ophthalmologists. Annual meeting should be held to discuss the performance and to share ideas and experiences. Dedicated funds should be set aside for these activities and both short and long-term goals should be determined. We wish to highlight that the barriers to eye donation are mostly due to misinformation and apprehensions about proper utilization of the donated tissue. There is a need to correct these misconceptions, which can be done by actionable nationwide strategies when devising information, education, and communication tools to boost up the eye banking movement in India. We recommend incorporating special lectures in schools and colleges on eye donation, educating the next generation, and making eye donation a culture. These can be used to target all misconceptions surrounding eye donation and addressing donor

Peer review under responsibility of the Iranian Society of Ophthalmology.

<https://doi.org/10.1016/j.joco.2018.11.001>

2452-2325/Copyright © 2018, Iranian Society of Ophthalmology. Production and hosting by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

apprehensions. Radios and televisions should be used as advocacy tools, and frequent advertisements should be shared with the public. Events like ‘eye donation fortnight’ and ‘honoring family members of donors’ should be organized at national and local levels. We would also want to emphasize the pivotal role of EDCs in facilitating the eye donation movement. Training courses for EDCs should be made available at designated training sites and youth should be encouraged to take up this as a career path. Collaborations with general hospitals should be encouraged so that any hospital or mortuary death can be traced and potential donors identified. Integrated software could be developed and incorporated in the hospitals Electronic Medical Records (EMR) tracking the functioning of the eye banks. We would also like to encourage other eye banks to share their ‘on-field’ experiences in dealing with a sensitive topic like this eye donation and ways to improve awareness, knowledge, and donation rates.

References

1. Lal B, Usgaonkar U, Narvekar H, Venugopal D. Awareness and knowledge on eye donation among Allied Health Sciences, medical, and nursing students in Goa. *J Curr Ophthalmol*. 2018;30(3):255–262.
2. Ronanki VR, Sheeladevi S, Ramachandran BP, Jalbert I. Awareness regarding eye donation among stakeholders in Srikulam district in South India. *BMC Ophthalmol*. 2014;14:25.
3. Priyadarshini B, Srinivasan M, Padmavathi A, Selvam S, Saradha R, Nirmalan PK. Awareness of eye donation in an adult population of southern India. A pilot study. *Indian J Ophthalmol*. 2003;51(1):101–104.
4. Chakraborty NM, Fry K, Behl R, Longfield K. Simplified asset indices to measure wealth and equity in Health programs: a reliability and validity analysis using Survey data from 16 countries. *Glob Health Sci Pract*. 2016;4(1):141–154.
5. Acharya M, Biswas S, Das A, et al. Quality indicators for eye bank. *Indian J Ophthalmol*. 2018;66(3):389–393.
6. Acharya M, Farooqui JH, Mathur U. Rubric for Assessment of Eye bank Professionals for Eye Retrieval: a new tool and a step towards standardizing eye retrieval process. *Indian J Ophthalmol*. 2018;66(8):1225–1227.

Javed Hussain Farooqui*

Manisha Acharya

Abhishek Dave

*Cornea, Cataract and Refractive Surgery, Dr. Shroff's Charity
Eye Hospital, New Delhi, India*

Deepali Chaku

Animesh Das

*Eye Bank Services, Dr. Shroff's Charity Eye Hospital, New
Delhi, India*

Umang Mathur

*Cornea, Cataract and Refractive Surgery, Dr. Shroff's Charity
Eye Hospital, New Delhi, India*

*Corresponding author. Cornea, Cataract and Refractive Surgery, Dr Shroff's Cahrity Eye Hospital, 5027, Kedarnath Marg, Daryaganj, New Delhi 11001, India

E-mail address: jhfarooqui@gmail.com (J.H. Farooqui).

14 September 2018