Original Article

Perception and Willingness towards Eye Donation in an urban community of West Bengal

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Abstract

Introduction: Corneal blindness, though treatable, contributes largely to the burden of blindness. With 1.2 million existing cases of corneal blindness in India, the demand for cornea collection is increasing. 69349 corneas were collected in 2018-19 but it is much less than what is needed. Faulty perceptions and unwillingness are two major hurdles against a scenario favourable towards eye donation. The objectives of the study was to assess the perception and willingness towards eye donation and the socio-demographic variables that affect such perception and willingness, in an urban community of West Bengal.

Materials and methods: In this cross-sectional study conducted among adult residents of the urban field practice area of Medical College Kolkata, data was collected from randomly selected eligible members, one each from all the available families by interviewing them using a validated pre tested schedule.

Results: Eighty nine (52.3%) among 170 interviewed participants had Secondary level education or higher, 49.4% had outdoor engagement. 128 participants reported ocular morbidity in the family but only 126 had heard about eye donation. 98 (77.8%) of these 126, had favourable perception towards eye donation. Among these 98 participants, 40 were willing to pledge for eye donation. Higher education and outdoor engagement significantly predicted favourable perception, while willingness significantly increased with participants belonging to higher socio-economic class and with higher education.

Conclusions: Compared to favourable perception, willingness of pledging eyes was lesser due to various false notions. Proper education through usage of means of mass communication and stress upon school education is needed to address these hurdles.

Key words: Eye donation, Community based, West Bengal.

Introduction

Corneal blindness appears second among the most common causes of blindness in India (Kumar & Vashist, 2020), with the country having the largest number of cases, amounting to 1.2 million (Oliva, Schottman & Gulati, 2012). Every year, 25,000–30,000 new cases are added (Gupta *et al.*, 2018).

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A large chunk of cases of corneal blindness can be treated using donor corneas. There has been an increasing demand for donor corneas, but the supply is grossly inadequate (Sharma *et al.*, 2019; Gupta *et al.*, 2018). Unfavourable perception and unwillingness are major hindrances posed towards eye donation (Saini *et al.*, 1996). Regular efforts including campaigns, are undertaken by many institutes and organizations (including Government and Private) to help overcome such hurdles, by promoting awareness and addressing the inadequacy of knowledge, that ultimately leads to perception (Kishor, 2019; The Times of India, 2016; Pioneer, 2017; Vision Mate, n.d.; National Health Portal Of India, 2019a, 2019b). In India, in the year 2018–19, 69349 corneas were collected (Ministry of Health and Family Welfare, Government of India, 2020).

The present study was conducted to assess the perception and willingness towards eye donation and also to find out the factors that were affecting such perception and willingness, in an urban community of West Bengal.

Materials and methods

This was a descriptive, community based epidemiological study of cross-sectional design. The study was conducted among residents aged more than eighteen (18) years, residing in the urban field practice area of Medical College, Kolkata, in West Bengal. In the two-month study duration (January-February 2019), 170 families out of 213 line-listed families residing in the field practice area, could be approached. The rest of the families either did not want to participate or were unavailable after two efforts of out-reach, one on two successive days of data collection. Members belonging to these 170 families, present at the time of data collection, aged more than eighteen (18) years, who gave informed consent towards participation in this study were included; those seriously ill at the time of collection of data, were excluded. One eligible member from the available families each, were chosen randomly by simple random sampling and a pre-designed and pre-tested data collection schedule was used to interview them.

There were two sections in the schedule. Questions related to socio-demographic variables were included in the first section and questions to assess perception and willingness were part of the second section. Only the participants who had heard about eye donation, were asked the questions contained in the second section. Experts of Ophthalmology and Public Health helped establish the face validity of the schedule earlier. Translation of the schedule was made into Bangla and Hindi, and it was re-translated into English to check for concordance. 20 participants from another similar community in Kolkata, who were not included in the main study, were inducted to conduct a pilot study, to make necessary modifications to the data collection schedule.

Statistical Package for the Social Science (SPSS)® (SPSS Inc, Chicago, IL, USA) version 16.0 was used for data entry and analysis. Frequency and percentages of the variables were calculated; suitable statistical operations were performed. Simple proportions were used for descriptive statistics. Relevant outcome variables for the predefined objectives were calculated and discussed. Sociodemographic variables that showed significant statistical predictability with favourable perception towards eye donation by univariate logistic regression analysis were tested further by multivariate logistic regression. Similar procedure was followed with sociodemographic variables that showed significant statistical predictability with willingness to donate eyes by univariate logistic regression.

Permission from Ethics committee of Medical College, Kolkata was taken before the study was conducted. Interview of the study participants were taken after informed consent; their identity was not disclosed.

Results

In the present study, 170 study subjects participated, of whom, 28.8% belonged to age group 18-27 years and 38-47 years each, 28.2% were males and Bangla was the most commonly spoken mother tongue (72.9%). All were Hindus (100.0%). Most of the participants were educated up to Secondary level (35.9%) and were presently married (75.3%), 49.4% had outdoor engagement for studies or financially profitable employment; while the rest stayed or worked at home (50.6%). 36.2% of the participants were classified as belonging to Class-IV Socio-economic class, as per the Modified BG Prasad Scale (Anon, 2018). Majority of the study subjects (75.3%) suffered from an eye disease or had at least one family member having an eye related morbidity. (Table 1)

Among all, 74.1% (n=126) had heard about eye donation. Out of these 126 participants, 15.1% had known an eye-donor, while 7.9% said they knew someone who benefitted by eye transplantation. 77.8% (n=98) of these 126 subjects, had a favourable perception towards eye donation with a view that eyes should be donated, while 9.5% said donation should not be made; 12.7% did not have any clear stand.

Of these 98 participants who had favourable perception, 40.8% were willing to pledge for eye donation; 40.8% were undecided. The rest 18.4% were unwilling to donate their eyes, even though they had a favourable perception towards eye donation. Among those willing, most were 27 years old or younger (42.5%) and educated up to the secondary level (50.0%). Among the 18.4% participants who were unwilling despite of having favourable perception towards eye donation, 72.2% cited sufferance from eye morbidity behind their decision to be unwilling, as they felt, eye morbidities rendered their eyes unsuitable for eye donation; 27.7% and 22.2% respectively cited familial and religious issues as reasons behind unwillingness. However, at the same time, 60.2% of those with favourable perception, wanted their family members and relatives to donate eyes; 34.7% were undecided; the rest were against such an idea.

Each socio-demographic variable was tested for predictability towards perception and willingness for eye donation separately with univariate logistic regression. Variables showing significant results ($p<0.10$) were put together through multiple logistic regression models, separate for perception and willingness. Final results showed, higher education [Adjusted Odds Ratio, i.e. AOR=3.351 (1.319-8.514)] and outdoor study/work engagement [AOR=5.625 (2.113-14.973)] significantly predicted favourable perception (Nagelkerke's R^2=0.237), while predictability of willingness was significantly related to higher socio-economic status [AOR=13.144 (2.867-60.256)] and higher education (AOR=5.643 (1.068-29.821)] (Nagelkerke's R^2=0.399). (Table 2 and 3)

Table 1: Distribution of study participants according to socio-demographic characteristics. (n=170)

Socio-demographic characteristics	**Category/ Group**	**No. (%)**
Age (completed years) (Mean=37.02; SD: 12.75; Min=18; Max=76)	18-27	49 (28.8)
	28-37	40 (23.5)
	38-47	49 (28.8)
	48-57	21 (12.4)
	58-67	7 (4.1)
	68 and above	4 (2.4)
Gender	Male	48 (28.2)
	Female	122 (71.8)
Mother tongue	Bangla	124 (72.9)
	Hindi	46 (27.1)
Educational Qualification	Illiterate	26 (15.3)
	Just literate	11 (6.5)
	Primary	23 (13.5)
	Middle	21 (12.4)
	Secondary	61 (35.9)
	Higher secondary or above	28 (16.5)
Marital Status	Presently married	128 (75.3)
	Unmarried	32 (18.9)
	Widowed	5 (2.9)
	Separated	5 (2.9)
Family type	Nuclear	100 (58.8)
	Joint	70 (41.2)
Socioeconomic status with Per capita monthly income (INR)* **classified as per Modified B.G. Prasad Scale, July 2018.*	Class I (6871 or more)	6 (3.5)
	Class II (3435-6870)	43 (25.3)
	Class III (2061-3434)	34 (20.0)
	Class IV (1031-2060)	61 (35.9)
	Class V (1030 or less)	26 (15.3)
Occupation	Housewife	75 (44.1)
	Student	19 (11.2)
	Financially gainful employment or Business	65 (38.2)
	Unemployed	8 (4.7)
	Retired	3 (1.8)
Eye disease in family	Present	128 (75.3)
	Absent	42 (24.7)

Table 2: Socio-demographic variables predicting favourable perception about eye donation. (n=126)

Independent variable		Perception		Total	Adjusted Odds Ratio (95% Confidence Interval)	p value
		Favourable	Unfavourable/ Undecided			
Education	Middle school or less	25	15	40	Ref	*0.011*
	Secondary or more	73	13	86	3.351 (1.319-8.514)	
Occupation	At home	34	21	55	Ref	*0.001*
	Outdoor	64	7	71	5.625 (2.113-14.973)	

Table 3: Socio-demographic variables predicting willingness towards eye donation. (n=98)

Independent variable		Willingness		Total	Adjusted Odds Ratio (95% Confidence Interval)	p value
		Willing	Unwilling or undecided			
Gender	Female	29	31	60	Ref	
	Male	11	27	38	0.435 (0.155-1.220)	0.114
Family type	Nuclear	30	33	63	Ref	
	Joint	10	25	35	1.792 (0.505-6.357)	0.367
Education	Middle school or less	2	23	25	Ref	*0.042*
	Secondary or more	38	35	73	5.643 (1.068-29.821)	
Socio-economic status	Class IV-V	3	31	34	Ref	*0.001*
	Class I-III	37	27	64	13.144 (2.867-60.256)	

Discussion

Corneal blindness around the world is a huge public health problem, which can be largely addressed by ensuring availability and transplantation of donor corneas. Across the world and in developing countries like India and Nepal as well, the number of donor corneas needed significantly outnumber that what is collected, resulting in a lengthening backlog.

In this study, 74.1% of the subjects had heard about eye donation. Other studies from Madhya Pradesh and Pondicherry in India reported similar findings, with 62.3% and 80.6% of their study participants aware about eye donation respectively (Tiwari *et al.*, 2017; Patil *et al.*, 2015). A study from South India revealed 50.9% of the study subjects to be aware (Priyadarshini *et al.*, 2003). Studies based in other developing countries like Malaysia, Ethiopia and Nepal showed 69%, 56.4% and 30.7% of the study subjects being aware about eye donation respectively (Bhandary *et al.*, 2011; Hussen & Belete, 2018; Joshi, 2010) A study based in Andhra Pradesh showed 30.7% participants being aware (Krishnaiah *et al.*, 2004); the difference in the findings of this study with the present one could have been due to the difference in educational status between participants of the two studies, with participants

in the present study having a better education status overall.

77.8% of participants among those who had heard about eye donation had a favourable perception towards eye donation, however, of them, 40.8% were willing to donate eyes; 60.2% wanted their family members and relatives to donate eyes. A similar study found 40.34% of its participants were willing to pledge eyes for donation (Tiwari *et al.*, 2017); as per the study done in Nepal, among those aware of eye donation, 32.9% were willing to pledge eyes (Joshi, 2010). An Ethiopian study reported 37.6% of its participants to be willing towards eye donation, 73.3% were willing to pledge eyes of their relatives (Hussen *et al.*, 2017). Like the present study, some other studies also found religious beliefs to be common hurdles against eye donation (Hussen *et al.*, 2017; Maiya, Kiran & Badiger, 2018).

In our study, higher education and outdoor study/work engagement significantly predicted favourable perception, while higher socio-economic status and higher education were significant predictors towards willingness towards eye donation. Willingness was significantly associated with age, education, religion, marital status, place of residence and source of health information according to another Indian study (Maiya, Kiran & Badiger, 2018). Another study found awareness towards eye donation, religion and educational level to be significantly associated with willingness towards donation of eyes, with subjects those who were aware about eye donation, those who were Christians and having higher education tending to be more willing (Hussen *et al.*, 2017).

Lack of adequate public awareness and the resulting poor perception and willingness towards eye donation, result in potential hurdles against every effort made towards promotion of eye donation. A crucial step towards solving this issue is to increase the general awareness towards eye donation and addressing the knowledge short-falls, that result in development of perception and willingness. Educational status was a common factor that was found by us to significantly predict favourable perception and willingness, with the less educated tending to stay away from eye donation. Hence, sensitising people in their budding years, especially in school and colleges can prove to be useful in changing the mindset of the society in future in favour of eye donation. Educational curricula can be designed in a way that helps reflect upon the generosity and humility that is associated with eye donation; taboos associated can be addressed through regular community-based campaigns. Local and religious leaders have important say in the lives of the people - they can be sensitized and asked to further educate the people they lead. Disseminating success stories to the society to motivate them to come forward for eye donation can be thought about. Participants staying at home tended to have an unfavourable perception towards eye donation, as per our study. Roping in celebrity goodwill ambassadors and publicising eye donation through mass media platforms like television and radio, which reach the drawing rooms of a majority of households, can be seen as a potential way to deliver the message of eye donation to this section of people. Therefore, a variety of approaches designed to address the knowledge insufficiency and inadequate awareness among the various sections of people based on their need is thus a call of the hour. True efforts work best if supplemented with matching tools.

We conducted our study on the residents of the urban field practice area of a Medical College, who, as a result of living so closely connected to this tertiary care institute and by virtue of frequent exposure to health campaigns, might have had a higher proportion of favourable

perception and willingness towards eye donation than others. This can be considered as a limitation to the study.

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